# INEQUITY IN ACCESS TO COLORECTAL CANCER SERVICES ALONG THE CONINTUUM OF CARE IN NOVA SCOTIA

by

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## Abstract

**Introduction:** Despite the public and policy attention on ensuring access to health care for all Canadians, research continues to identify inequities in access to cancer care services. The objectives of this thesis are to define inequity in access to colorectal cancer (CRC), as well as to measure inequity in access to radiotherapy and end-of-life care. **Methods:** This study examined income-, geography-, sex-, and age-related inequity in access to CRC services along the continuum of care, using the Horizontal Inequity Index. Specifically, we measured and compared inequity in access CRC services in Nova Scotia using linked administrative databases. **Results:** We have identified that age- and geography-related inequity in access to radiotherapy and end-of-life care are the most consistent for CRC patients in Nova Scotia. **Discussion:** The clear distinction between inequity and inequality in this study provides indication to policy makers that the variations in access, may be of social concern.

**List of Abbreviations used**

ACCESS – Access to colorectal cancer services in Nova Scotia

CBDHA – Cape Breton District Health Authority

CDHA – Capital District Health Authority

CIHR – Canadian Institutes of Health Research

CINAHL – Cumulative Index to Nursing and Allied Health Literature

CPG – Clinical practice guidelines

CRC – Colorectal cancer

DHA – District health authority

EOL – End-of-life

ER – Emergency room

HI – Horizontal Inequity Index

HRM – Halifax Regional Municipality

LTC – Long-term care

MSIPS - Nova Scotia Medical Services Insurance Physician Services database

NSCR - Nova Scotia Cancer Registry

OPIS - Oncology Patient Information System

PCP – Palliative care program

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# Chapter 1 - Introduction

Health care is a fundamental component of the history and identity of Canada. The health care system in every Canadian province and territory strives to provide timely access to all necessary health services, regardless of location of residence, ability to navigate the health care system, or socioeconomic status, following the Canada Health Act of 1984: all "insured persons must have reasonable and uniform access to insured health services, free of financial or other barriers." (1) In essence, the Canada Health Act stipulates that health care should be provided based on an individual's need for health care. Although a clearly agreed upon definition of need does not exist, it is generally considered that those who have the most urgent condition, the most severe illness, and/or the greatest expected benefit from care should receive priority and have greater access to services. Equitable distribution of health care thus means that access to health services is determined only by the patients need for care, independent of socioeconomic, geographic, and demographic factors.

Equitable access to cancer care is of particular importance given the number of people affected by this disease, the time sensitivity of care, and the complex progression of treatment. Cancer has been within the top 2 leading causes of death in Canada since the early 1970s, and it is predicted that almost 200,000 new cases of cancer will occur in Canada in 2009, resulting in more than 75,000 deaths. (2) Ensuring timely and equitable access to cancer care is important not only because of the incidence rate of cancer, but also because of the complexity and multi-disciplinary nature of cancer care. Cancer treatment often includes several different services, provided by different health care providers, and in different locations, which opens the door to potential inequities in access along the continuum of care. In order to provide equitable access to cancer care in Canada, the first step is to accurately and comprehensively assess the current provision of cancer services throughout the population. With a clear description of equity in access to cancer care, clinical and policy interventions can be designed and current inequities reduced.

Several studies have examined variations in access to cancer care in Canada by income, education, age, sex, and geography. Research demonstrates that for many

diseases sites and points of service along the continuum of care, access is influenced by patients' socioeconomic, demographic, and geographic factors. For example, studies report that individuals with low income are less likely to be screened for CRC, while older individuals and those living greater distances from a cancer centre have less access to chemotherapy, radiotherapy, and end-of-life (EOL) care. (3,4,5) However, the current literature makes limited distinction between inequalities in access – variations in access – and inequities in access – variations in access that are of social concern; thereby rendering it difficult to identify whether access is simply unequal or is ethically problematic. In addition, current studies typically examine variations in access to a single point of service along the continuum of care and are yet to take advantage of emerging analytic techniques to measure inequity.

This thesis begins by examining the Canadian literature on inequity in access to cancer care. The purpose of the literature review is to identify what we know and what we do not know about inequity in access to cancer health services in Canada in terms of the continuum of care (i.e., screening through to follow-up or end-of-life care), cancer sites (e.g., breast cancer, colorectal cancer), and dimensions of inequity (e.g., income, age, and geographic location). Building on current literature, we investigated inequity in access to CRC services at two points along the continuum of care in Nova Scotia, Canada. Inequity is clearly defined by first incorporating clinical guidelines or benchmarks, then by adjusting for patients' need for care. Inequity is reported using the Horizontal Inequity Index (HI), the most widely used inequity index. (6)

This thesis is organized into 4 chapters. Chapters 2 and 3 are stand-alone manuscripts to be submitted to a peer-reviewed academic journal. Manuscript one, in Chapter 2, is a literature review of the current state of inequity in access to cancer care in Canada. Manuscript two, in Chapter 3, is an empirical study to investigate inequity in access to radiotherapy and end-of-life care using population-based linked databases of all individuals diagnosed with CRC in Nova Scotia between 2001 and 2005. Chapter 4 concludes with a brief summary of the main messages learned from this thesis.

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# Chapter 2 – Manuscript One

## 2.1 Introduction

Although Canada, as many industrialized countries, pledges comprehensive health care coverage for all citizens (1), access to health care in Canada varies, for example, by income, area of residence, and age. (2-4) Access to cancer care is of great interest as cancer has been within the top two leading causes of death in Canada since the early 1970s. (5) According to the Canadian Cancer Society, 40% of males and 45% of females in Canada are expected to develop cancer during their lifetime, and 24% and 29%, respectively, die from their disease. (6) Ensuring equitable access to cancer care – equal access for equal need – is important not only because of the high prevalence of cancer, but also because of the time sensitivity of care and complex progression of treatment. For some cancers, early diagnosis and referral, as well as timely access to appropriate treatments, is linked to improved outcomes. (7-11) In addition, cancer treatment is complex, often involving different services (e.g., surgery, chemotherapy, and radiotherapy), health care professionals (e.g., primary health care teams, surgeons, and oncologists), and settings (e.g., primary health clinics, surgical units, and cancer centres). Such complexity makes provision of equitable care a challenge and necessitates a clear understanding of where along the continuum of care inequity occurs. Thus, identification of inequity in cancer care is a critical step toward targeted clinical and policy interventions.

This review of the current literature on inequity in cancer care in Canada examines where inequity in access to cancer services occurs along the continuum of care for different disease sites by characteristics such as income, education, sex, and geographic location. In addition, this review examines inequities in incidence, survival, and mortality outcomes. To our knowledge, no study has offered such an overview of the Canadian literature. Previous studies typically examined a single cancer type for a specific treatment service. By providing a comprehensive picture of inequity in cancer care in Canada, we aim to 1) identify areas of greater and lesser knowledge of inequity and 2) describe methodological techniques that future studies may wish to explore. Although the focus of this review is cancer care in Canada, the framework of the review

with a particular attention to the continuum of care and multiple characteristics associated with inequity will be of interest to cancer researchers beyond Canada.

Before proceeding, clarification is necessary regarding inequity and inequality. Inequality in access to health care simply means differences in access to health care; all individuals or groups do not have identical access to services. Inequity in access to health care, on the other hand, means that variations in access to health care are ethically problematic. The distinction between inequality and inequity is often drawn based on the factors that contribute to the variation in access. Inequalities in access to cancer care are caused by both need factors – those that should influence an individual's access (e.g., health status, co-morbid conditions, tumour stage) – and non-need factors – those that should not influence an individual's access (e.g., income, education, location of residence). To measure inequity, the impact of need factors must be controlled for, thereby isolating the contributions of non-need factors towards differences in access. (12) Need adjustment acts by leveling out patients need for health care and is crucial for inequity analyses.

## 2.2 Methods

We searched PubMed, Embase, and CINAHL using Medical Subject Headings or the equivalent, as well as key terms in the 'title and abstract'. The terms 'cancer' and 'Canada' were combined with 'equity' or 'equality' or 'disparity' or 'variations' or 'delivery of health care' or 'socioeconomic factors' or 'income' or 'rural' or 'geography' or 'education' or 'sex' or 'age' or 'employment' or 'ethnicity'. The search was limited to studies published in English and between January 1990 and May 2009. After reviewing the abstracts, one of the authors (A.M.) retrieved articles if they had studied a Canadian population and examined access to any cancer service for any disease site. We then applied ISI Web of Knowledge's 'cited reference' facility to all retrieved articles and hand searched reference lists to identify further studies. We also consulted several clinical experts in the field to find unpublished papers or articles not included in the databases.

## 2.3 Results

We retrieved 51 articles. Table 1, adopted from the Cancer Disparities Grid by Bigby and Holmes (13), summarizes them. This grid presents the 51 studies by point of service and by all factors with which inequity in cancer care has been most commonly examined (hereafter, "equity stratifiers"). Some studies are included in multiple cells of Table 1 if they analyzed several points of service or equity stratifiers. Figure 1 depicts the 15 studies that examined access to cancer services by measuring wait times for care. Below we report the status of inequity in access to cancer care in Canada by point of service, equity stratifier, and disease site, as well as methods used in the literature in terms of study designs and statistical approaches.

### *2.3.1 Status of Inequity in Access to Cancer Care*

Points of service: The quantity of inequity literature varies along the continuum of care, ranging from no study examining inequity in follow-up care to 12 studies for radiotherapy and 11 studies for end-of-life care (with the latter including indicators for palliative radiotherapy, palliative care programs, physician home visits, and location of death). Evidence of inequity is most convincing in access to screening, radiotherapy, and end-of-life care services. Provision of these services is influenced by income, age, and geographic location, and identified in several disease sites and provinces after adjustment for patients' need for care (e.g., health status, co-morbidities, tumour stage). (4,14-17) Access to diagnostic services, surgery, medical and radiation oncology consultations, and systemic therapy is relatively understudied. While the literature suggests some inequities in these points of care, there are few studies and disagreements in findings.

Equity stratifiers: The most commonly examined equity stratifiers are income, geographic location, sex, age, and education. The effects of income, age, and geographic location have been studied at several points along the cancer care continuum and show the following trend. Income-related inequity is most consistently identified in access to screening and for cancer survival, while age- and geography-related inequities appear most consistent in access to treatment services, including physician consultations, curative therapies, and palliative services.

Specifically, studies suggest income-related inequity in access to screening[17] diagnosis (18), systemic therapy (19), and end-of-life care. (15) In all circumstances, individuals with lower incomes are less likely to access services and more likely to experience longer wait times for services. (19-22) Lower income has also been found to be significantly associated with lower rates of survival for cancers of the head and neck, esophagus, colon, breast, lung and cervix, even after controlling for age and year of diagnosis. (23-24) Age was examined by 34 of the 51 studies included in the review. Older patients are reported to have less access to medical and radiation oncology consultations, adjuvant and palliative radiotherapy, and to palliative care programs, even after controlling for need. (3,4,15,25-27)

Geographic location is measured as the distance to the nearest cancer centre, rural vs. urban residency, or geographic region, depending on the study. Living a greater distance from a cancer centre is associated with less access to systemic therapy and palliative radiation. (15,28) Individuals from rural areas appear to have less access to palliative care programs and increased likelihood of a cancer-related death within 6 months of diagnosis. (4,20) Comparison of geographic regions has shown that access to radiotherapy in the province of Ontario differs by city, after controlling for need. (3) Similarly, access to medical oncology consultations and systemic therapy for lung cancer patients vary by region in the provinces of Alberta and Nova Scotia, after adjustment for patients' need. (25-26)

Sex and education have been examined at several points along the continuum of care but by a limited number of studies, particularly for education (7 studies). Compared to men, women are more likely to receive surgery within two weeks of diagnosis for 12 disease sites and to have significantly shorter wait times for adjuvant chemotherapy for lung cancer. (19,29) Sex-related inequity has been examined most often in end-of-life care (6 studies). Research has identified that women in Nova Scotia are more likely to be enrolled in a palliative care program, to receive physician home visits, and to die at home than men. (4,14,30) Education has received limited research attention with only 7 studies; yet, available studies have demonstrated that breast cancer patients with higher education have greater access to screening and shorter wait times for physician referrals and

initiation of radiotherapy, compared to those with lower education. (16,31-32) Some studies also examine inequity based on employment and ethnicity, however, there are too few to discern trends.

Disease site**:** Inequity in access to care is most frequently examined for breast cancer (19 studies), colorectal cancer (10 studies), lung cancer (7 studies), gynecologic cancers (5 studies), and prostate cancer (5 studies), though no one cancer has been studied at each point of service along the continuum of care. Other disease sites have received limited research attention regarding access to services.

*2.3.2 Methods Used in The Literature*

Study design considerations: Among the 51 studies included in our review, only 10 studies examined inequities at multiple points of services along the continuum of care. (19,25-26,32,37) In addition, all studies examined inequity in access to cancer services either by receipt of a service or wait times for the service, but never both. For example, Younis *et al.* examined whether systemic therapy was received (25), while Saint Jacques *et al.* examined wait times for systemic therapy services. (32) The vast majority of studies used administrative data or a combination of administrative data and retrospective chart reviews, with the remaining few applying self-reported questionnaires (33,35), chart reviews as the primary data source (29,33,35,38-39), or population health surveys. (16,28,40)

Statistical approaches: Most studies used regression analysis to examine inequity in access to health care, where researchers investigated an independent association between the equity stratifier in question (e.g., income) and access to cancer care after adjustment for need factors (e.g., tumour stage and health status) and other confounding factors (e.g., age, education, and distance to a cancer centre). While the majority of the studies made some need adjustment, variables used for need adjustment (need factors) vary considerably. For example, in examination of access to radiotherapy based on patient income, Johnston *et al.* adjusted for age, distance to the nearest cancer centre, extent of disease, and year of diagnosis; Benk *et al.* adjusted for health region within the province,

tumour stage, and co-morbidities; and French *et al.* reported unadjusted results. (37,41-42)

## 2.4 Discussion

This review demonstrates that the quantity of research on inequity in access to cancer care in Canada varies by point of service, equity stratifier, and disease site. It also identifies that income, education, age, sex, and geographic location of residence often contribute to an individual's level of access to cancer services even after adjusting for need factors. The findings suggest that income has the most consistent influence on screening, while age and geography are most influential for accessing treatment services and end-of-life care. Taken together, this review shows that inequities in access to cancer services exist in Canada.

This review indicates that access to Canadian cancer services is most inequitable at the beginning (i.e., screening) and the end (i.e., end-of-life care) of the continuum of care. A possible explanation is that screening services and end-of-life care are often associated with both patient and primary care provider initiative (17,43), while care following a cancer diagnosis tends to follow a treatment trajectory that is often organized by cancer units. Consequently, screening and end-of-life care may be less organized compared to other cancer services, thereby increasing the potential for variation based on social or geographic factors related to the patient. (44)

The clear shortfall of research along the continuum of care is for follow-up care. No study was retrieved that examined inequity in access to follow-up care for cancer survivors in Canada. This is possibly due to the relative infancy of follow-up as part of the cancer continuum of care, yet there is an important need to evaluate access to this point of service. (45,46)

Our review also suggests that older patients have less access to surgery, systemic therapy, radiotherapy, and end-of-life care services than their younger counterparts. This corroborates recent findings that older patients are more likely to adhere to Canadian screening guidelines, yet are less likely to receive physician referrals for treatment, timely access to physician consultations, and curative therapies. (25,29,30) Such age-related

inequities in access to treatment services are not unique to Canada. Certainly, research in the US has reported declining access to cancer treatment for a number of disease sites with advancing age. (47-49) Some researchers have argued that variations in access related to age are in fact inequitable, because older age does not preclude equivalent clinical outcomes despite additional co-morbidities among the elderly. (50,51) To understand whether the variation in access by age is inequitable or not, future studies must investigate the reasons for poorer access to cancer services. For example, the variation may be attributable to increased barriers or physician recommendation, or it may be related to patient preferences for less aggressive care with advanced age.

For future research in inequity in cancer care in Canada and internationally, we make three recommendations. First, researchers studying inequity in cancer care should strive to provide a richer description of inequity in access to services along the continuum of care, either by examining, within single studies, multiple points of service or periodically conducting reviews like this study. Understanding inequities at multiple points of the care trajectory is important since access to each point of care is dependent on the preceding points and inequities appear to vary along the cancer care continuum. (19,32) For example, Saint Jacques *et al.*, examining inequities in wait times for breast cancer services in Nova Scotia from detection of disease to initiation of adjuvant therapy, identified that having a higher education was significantly associated with shorter wait times from detection to referral, but not associated with wait times from referral to first adjuvant therapy. (19) By incorporating a system perspective to studying inequity in cancer care, we can begin to address the variation in research and focus our attention across points of service. We need to ensure that no one point of service be neglected by research and that resources are used to focus on under-researched areas (such as diagnosis and follow-up care).

Second, whenever data are available, we recommend studies examining inequity in access to cancer services use a two-part access measure, by examining 1) the receipt of a service and 2) wait times for the service among the recipients. Receipt of and wait times for a service are different dimensions of care and often show different magnitudes of inequity. (19,25) Receipt of a service (e.g., adjuvant therapy) is related to the quality of

care provided and is often reflected in quality indicators (52,53), while timeliness relates more directly to access. (54) The routine use of both measures will enrich our understanding of inequity.

Finally, researchers examining inequity in cancer care can learn greatly from inequity analysis used by population-based research on inequity in health care. (3,12) Specifically, cancer researchers can benefit from making a clear distinction between need and non-need factors as a standard practice in population-based inequity analyses. Although most of the studies we reviewed employed some form of need adjustment, the choice of need and non-need factors is often implicit. Making this distinction clearly improves need adjustment, and, in turn, enhances interpretability of study results. Furthermore, cancer researchers can move beyond regression analysis by applying an inequality index, such as the Concentration Index (55), which is increasingly popular in population-based inequity analyses. (2) The use of an index increases comparability of results across populations, disease sites, points of service, and equity stratifiers.

This review is necessarily narrative as the question we asked (where does inequity exist in the continuum of cancer care in Canada?) is broad. Our search was limited to studies examining Canadian populations, which resulted in a different representation of inequity than if the international literature was examined. For example, there is extensive research in the United States that studies inequity in access to diagnostic services, but limited literature exists on diagnoses in Canada. (56) Also, Canadian studies focus primarily on income, age and geographic location, and rarely include race or ethnicity, which are commonly examined in the United States.

Equitable access to cancer care is vitally important in both the Canadian and American health systems. (57) This review provides an overview of the current state of knowledge on inequities in access to cancer care in Canada. This information is a critical first step toward appropriate policy and planning actions. However, until we improve the quantity and scope of Canadian research on equity in access to cancer services and explore more sophisticated and generalizable methods, appropriate actions will remain ambiguous, and inequities may continue to exist.

2.5 Tables and Figures

**Table 1. Canadian literature on inequity in access to cancer services**

| | Incidence (n=1) | Screening (n=6) | Diagnosis (n=3) | Surgery (n=9) | Medical oncology consultation (n=7) | Receipt of systemic therapy (n=6) | Radiation oncology consultation (n=5) | Receipt of radio-therapy (n=12) | Follow-up care (n=0) | End-of-life care (n=11) | Survival and mortality (n=10) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Income (n=35) | 58 | 16, 17, 22, 28,59, 60, | 19, 35 | 19, 29, 32, 61, 62 | 19, 25, 32 | 19, 23, 32, 35 | 32, 34 | 3, 31, 32, 34, 38, 41, 62 | | 4, 14, 15, 21, 64, | 20, 22, 23, 69, 70,71, 72, 73, 74, |
| Geographic location (n=32) | | 17, 28, 60 | 35 | 19, 26, 29, 32, 35, 55, 63 | 19, 26, 27, 32, 36 | 19, 27, 32, 35, 36 | 27, 32, 34, 36 | 3, 27, 31, 32, 34, 37, 38, 41, 42, 62, 63 | | 4, 14, 15, 21, 30, 64, 65, 66 | 20, 22, 23, 71, 75 |
| Education (n=7) | | 17, 28 | 35 | 19, 32, 35 | 19, 32 | 19, 32, 35 | 32 | 31, 32 | | | 39 |
| Sex (n=22) | | 17, 22, 28, 59 | 33, 35 | 19, 29, 33, 35 | 19, 26, 33 | 19, 35 | 34 | 3, 34, 42 | | 4,14,15, 30, 63, 66 | 20, 23, 71, 75 |
| Age (n=34) | | 17, 22, 28, 59, 60 | 33, 35 | 19, 26, 29, 32, 33, 35, 61, 62 | 19, 25, 26, 27, 32, 33, 34 | 19, 25, 26, 32, 35, 36 | 27, 32, 34, 36, 37 | 3, 27, 32, 34, 36, 37, 38, 41, 42 | | 4, 14, 15, 21, 30, 63, 66, 66, 67, 68 | 23, 71, 72, 75 |
| Ethnicity (n=3) | | 28, 58 | | | | | | | | 26 | |
| Employment (n=2) | | 28 | | | | | | | | | 39 |

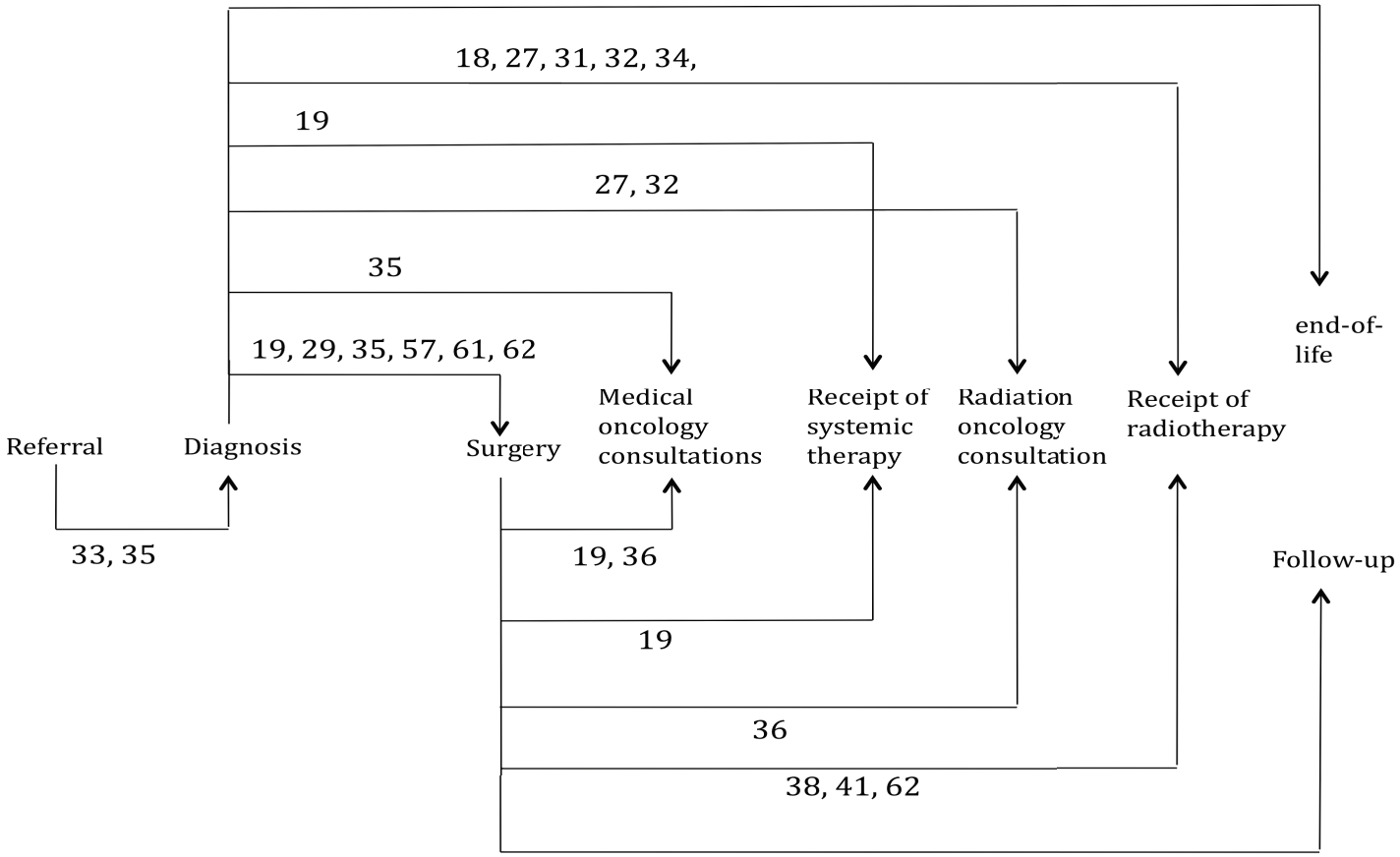


Figure 1 Canadian studies examining inequity in timely access to cancer care services across the continuum of care

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# Chapter 3 – Manuscript Two

## 3.1 Introduction

Colorectal cancer (CRC) is the third most common cancer in Canada, with an estimated 22,500 new cases in 2010. Incidence is approximately equal for men and women and 5-year survival averages 59.6%. (1) Surgery is the primary treatment for CRC, with adjuvant chemotherapy and (neo) adjuvant radiotherapy provided based on disease site and tumour stage. (2,3) Follow-up care should be provided following active treatment when there is no evidence of recurrence or new disease, while end-of-life (EOL) care is considered critical for those with advanced stage disease. (4,5)

Canada provides universal physician and hospital services for all citizens and pledges comprehensive coverage. (6) However, studies continue to identify variations in access to CRC services by, for example, patient income, geographic location, and age. (7-9) Ensuring equitable access to CRC care – equal access for equal need – is important because CRC care follows a complex and often time sensitive continuum of care. Delay in access to services along the continuum of care impact the progression of treatment and are linked to negative patient outcomes. (10-13) Identification of inequities along the continuum of care is a critical step to planning policy or clinical interventions and subsequently reducing inequity.

Although previous studies have examined variations in access to CRC care by socioeconomic, geographic, and demographic factors, they typically focus on a single point of service along the continuum of care and rarely make a clear distinction between inequality and inequity. As CRC care involves a multi-step progression of services, examining inequity at a single point of care provides a partial and inconclusive description of inequity in access to CRC care. In addition, the current literature does not clearly distinguish inequalities in access (e.g., variation in access) and inequities in access (e.g., variations in access that are of social concern), thereby rendering it difficult to identify whether access is simply unequal or is ethically problematic. Moreover, current studies examining inequity in access to cancer care are yet to take advantage of emerging analytic techniques, such as inequity indices, which have demonstrated improved

comparability between studies and populations in population-based inequity studies. (14-16) Applied to cancer studies, inequity indices can enhance comparability of inequities between points of service along the continuum of care.

The objective of this study was to examine inequity in access to CRC services at two points along the continuum of care, radiotherapy and EOL care, in Nova Scotia, Canada. We examined income-, age-, sex-, and geography-related inequity in receipt of and wait times for radiotherapy for stage II/III rectal cancer patients, as well as access to specialized palliative care programs (PCP) and community-based EOL care among patients who died of colon or rectal cancer. This study made use of population-based linked administrative data of all individuals diagnosed with CRC in Nova Scotia between 2001-2005. We made a clear distinction between inequality and inequity by distinguishing between factors that should legitimately influence an individual's access for care, need factors (e.g., tumour stage, co-morbidities) and those that should not, non-need factors (e.g., income, geographic location). We examined inequity by incorporating clinical practice guidelines (CPGs) or benchmarks, and then by adjusting for need-factors. To report the degree of inequity, we used the Horizontal Index (HI), widely used in population health inequity studies, (14) but rarely used in clinically based inequity studies.

## 3.2 Methods

### *3.2.1 Data Sources*

The Nova Scotia Cancer Registry (NSCR) identified all individuals diagnosed with CRC between January 01, 2001 – December 31, 2005 and undertook a comprehensive chart review to stage this cohort, resulting in a 5-year population-based cohort (n=3501). This cohort was anonymously linked on the patient level to 15 administrative health databases, including hospital discharge abstracts, physicians billings, and cancer centre, palliative care, and 2001 Canadian census data. (17) Together NSCR and Oncology Patient Information System (OPIS) contained information on medical and radiation oncology visits and treatments, as well as patient information and date of death. The hospital discharge abstracts included data on all hospital admissions

and discharges throughout the province. We obtained socioeconomic data from the 2001 Census of Canada at the enumeration level and linked to study individuals using the Postal Code Conversion File. (18) See Appendix 1 for a codebook of variables. These databases have been identified as highly reliable and accurate for analyses of health services utilization. (9,19) Exclusions from the cohort included: (a) individuals who were less than 20 years old, (b) individuals who had non-invasive CRC, (c) cases that were diagnosed only by death certificate or autopsy (Appendix 2 shows a complete list of exclusion criteria).

### *3.2.2 Study Populations and Variables*

#### 3.2.2.1 Radiotherapy

*Study Population and Outcomes of Interest*

We conducted the analysis of inequity in access to radiotherapy on all individuals who were diagnosed with stage II or III rectal cancer and who underwent surgical resection (n=503)(Table 2). Resected stage II/III rectal cancers were selected since CPGs recommend (neo) adjuvant treatments for these individuals. We used a two-part outcome measure (receipt and wait times). We first examined whether treatment was provided in accordance with CPGs for each patient (receipt). We then examined wait times for care for those who received the clinically recommended therapy (wait times).

The dependent variable for receipt of radiotherapy was binary: whether or not individuals received adjuvant chemotherapy and neo-adjuvant or adjuvant radiotherapy. We relied on CPGs established by Cancer Care Ontario and accepted in Nova Scotia for the years 2001-2008. The combined treatment of chemotherapy and radiotherapy has been shown to decrease local recurrence of CRC and improve five-year survival. (2) Appendix 3 shows the treatment progression and comprehensive timeline for our analysis.

The wait time analyses focused on patients who received treatment according to CPGs. The dependent variables were binary: whether or not the wait times met wait time benchmarks. Wait Time 1 examined whether the time interval from radiation oncology referral to consultation met the Canadian Association of Radiation Oncology's 14-day

benchmark and Wait Time 2 examined whether or not the time interval from ready-to-treat date to start of radiotherapy met Cancer Care Ontario's 28-day benchmark. Ready-to-treat date represents the timepoint at which the patient is considered physically able and willing to proceed with radiotherapy. See Appendix 4 for a detailed description of ready-to-treat.

*Independent Variables*

*Need factors*: We included stage at diagnosis, history of cancer diagnosis, and co-morbidity as need factors, which we would expect legitimately to influence the receipt and wait time outcomes. For example, a previous cancer diagnosis may contraindicate subsequent radiotherapy due to prior exposure to radiotherapy. In addition, multiple co-morbidities may hinder an individual's ability to receive or recover from chemotherapy or radiotherapy. We measured co-morbidities using the Elixhauser index, which includes 31 possible conditions. (20) (Appendix 5) It was used alternatively to other popular indices because it includes a more comprehensive list of co-morbid conditions. For this study, the Elixhauser score (0-28) was the sum of all recorded co-morbid conditions, excluding cancer, in the two years prior to date of diagnosis retrieved from the hospital discharge abstracts. Information regarding cancer-related conditions were included from NSCR/OPIS.

*Non-need factors*: We included income, distance to the nearest cancer centre, sex, age at diagnosis, year of diagnosis, and region of Nova Scotia as non-need factors, which should not affect access but the literature shows associations with access to cancer care. (8,21,22) For the wait time outcomes, we also included neo-adjuvant vs. adjuvant provision of radiotherapy as a non-need factor.

Radiotherapy is only provided in cancer centres in Nova Scotia, located in Halifax and Sydney. We calculated distance as the "crow flies" (i.e., the direct distance from patient location of residence to the cancer centre), irrespective of driving distance. (Appendix 6) Income was measured at the enumeration level of the 2001 census of Canada and linked to the individual using patient postal codes on the date of diagnosis.

The proxy for individual income was the average median household income from the neighbourhood of each patient.

3.2.2.2 EOL Care

*Study Population and Outcomes of Interest*

The study population for the EOL care analyses included patients diagnosed between 2001 and 2005, who died of CRC from January 1, 2001 to March 31, 2008 (Table 3). A CRC death was determined using the cause of death that was reported in vital statistics and identified through NSCR/OPIS. The sub-population of CRC deaths was inclusive to deaths from all stages of diagnosis and deaths from recurrences of CRC. The analysis of inequity in access to EOL care examined 4 binary dependent variables: (1) registration in a palliative care program (PCP) (yes / no), (2) timing of registration in a PCP (more than 60 days prior to death / equal to or less than 60 days prior to death), (3) number of ER visits in the last 30 days of life (0 / 1 or more), and (4) location of death (out of hospital / in hospital). For analyses using the PCP dependent variables, we only included patients with a location of residence in Capital District Health Authority (CDHA) or Cape Breton District Health Authority (CBDHA), as PCP data was only available in these regions (n=602). Together these two regions comprise more than 50% of the population of Nova Scotia. For analyses using the other two dependent variables, we included all CRC deaths as specified above (n=1201).

As there are no CPGs for the EOL outcome measures, we set clinical benchmarks using the pared-mean method. (23) Pared-mean benchmarks are data-driven and have been reported as accurate for predicting actual utilization of EOL services. (23-24) Specifically, separately for each outcome, we categorized the EOL sub-population by DHA, identified the top performing DHA(s) that made up at least 10% of the population, and assigned that performance as the benchmark (see Appendix 7 for detailed calculation).

*Independent Variables*

*Need factors:* We included tumour stage at diagnosis and co-morbidity (as described previously) as proxies for health status, which would legitimately influence EOL care.

*Non-need factors:* We included income, age at death, sex, geography, residence in a long-term care (LTC) facility near death, length of survival after diagnosis, and region of NS as non-need factors. Location of death and ER visits in the last 30 days of life were also included as non-need factors, excluding the models in which they were the outcomes of interest.

We measured income as explained in the radiotherapy section. We applied different measures of geography for different EOL care analyses. We used distance to the nearest PCP unit for the analysis of registration and timing of registration to PCP, and rural vs. urban residency for the analyses of ER visits and location of death. We measured distance as described in the radiotherapy analysis. The rural/urban variable was dichotomized from 7 categories derived from the Statistical Area Classifications and Metropolitan Influence Zones (Appendix 8). (25) This classification system categorizes census subdivisions based on population size and urban influence. We applied rural/urban as the geographic-indicator for ER visits in the last 30 days of life and location of death, because, for these outcomes, we were interested in access to community-based care. The indicators for community-based care differ from those for specialized care (i.e., radiotherapy or PCP) because services are distributed throughout the province.

Residing in a LTC facility has been shown to be associated with decreased likelihood of a PCP registration, yet an increased likelihood of dying outside of hospital. (9,26) We assumed having a physician visit to a LTC facility, obtained from the physician billings database, was an appropriate indicator of residing in a LTC facility and used it as a proxy for residing in LTC facility. Length of survival is associated with likelihood of dying at home and of being registered in a PCP (9,27), and was measured by subtracting the date of death from the date of diagnosis.

### *3.2.3 Measure of Inequity*

We reported the degree of inequity using the HI. (14) The HI is derived on the basis of equal access for equal need and uses the concept of the Concentration Curve. (28) Concentration Curves describe the proportion of health care use in relation to the population ranked by an equity stratifier, such as income (Appendix 9). This relationship can be summarized by the Concentration Index, which reports inequality, and the HI, which incorporates need-adjustment and reports inequity. For the example of income, a HI of zero indicates income-related equity – each individual has equal health care use regardless of income. If the HI is between 0 and -1, there is a pro-rich inequity in health care use, implying those with greater income have a higher use. The opposite case holds for an index of 0 to +1. See Appendix 10 for a complete HI direction interpretation. For both analyses of radiotherapy and EOL care, we used income, sex, age, and geography (distance to the nearest cancer centre or nearest PCP unit for radiotherapy and PCP measures, respectively; rurality for ER visits and location of death) as equity stratifiers. Calculation of the HI requires subcategories of equity stratifiers to be ranked from the disadvantaged to the advantaged; considered higher income, female, younger age groups, closer distance to the nearest cancer centre, and urban residence as the advantaged. This categorization was based on our knowledge of the literature, but nonetheless represents subjective decisions.

### *3.2.4 Analysis*

We calculated income-, age-, sex-, and geography-related inequity in access to radiotherapy and EOL care, separately for the seven outcomes (3 for radiotherapy and 4 for EOL care) described above. The analytical steps were based on van Doorslaer *et al.*'s approach (28), but modified to adjust for CPGs/benchmarks and need factors to permit our analyses to progress from an examination of inequality to one of inequity. The analysis took the following 4 steps. See Appendices 11 and 12 for analytical framework and detailed analytical steps, respectively.

First, using logistic regression, we modeled health care use for each of the seven binary dependent variables by all need and non-need factors and predicted the probability

of use for each individual. The primary purpose of this procedure was to transform each binary outcome into a continuous variable bounded between zero and one, which was necessary for the next steps of CPG/benchmark adjustments. Modeling in this first step also provided initial assessments of effects of non-need factors on access to radiotherapy and EOL care after adjustment for need factors.

Second, we identified the guideline-directed use (i.e., the use recommended by CPGs or indicated by benchmarks) for each of the seven outcomes. For the radiotherapy analysis, the guideline-directed use was 1.0 for all 3 outcomes, implying that all individuals should have received adjuvant chemotherapy and radiotherapy and all should have achieved the 14-day benchmark from radiation oncology referral to consultation and the 28-day benchmark from ready-to-treat to start of radiotherapy. Legitimate reasons for not meeting CPGs were then adjusted for in Step 3 below. For the EOL analysis, we computed benchmarks using the pared-mean method. The benchmarks were as follows: probability of 0.7 for being registered in a PCP, probability of 0.8 for being registered in a PCP greater than 60 days before death, probability of 0.5 for having no ER visits in the last 30 days of life, and probability of 0.4 for dying outside of hospital. The values of guideline-directed use for the radiotherapy analysis differed from the EOL care analysis due to the fact that there are consensus CPGs for receipt of and benchmarks for wait times for radiotherapy, yet guidelines for EOL care outcomes are less clearly defined and agreed upon. (29)

Third, we estimated the guideline-standardized use for each individual, by subtracting the probability of use from the guideline-directed use. The guideline-standardized use was the probability of use that did not achieve CPGs/benchmarks. If an individual's probability of use was equal to or greater than the guideline-directed use, we assigned zero as their guideline-standardized use.

Ideally, any variation that did not meet the CPG/benchmark would be considered inequitable. However, CPGs provide recommendations for appropriate care, of which individual patients may have legitimate reasons for not following some or all of these recommendations. To account for these legitimate reasons, the final step required need adjustment.

The final step calculated the HI of the guideline-need-standardized use separately for the seven outcome variables and four equity stratifiers. We began this step by modeling guideline-standardized use by all need and non-need factors by ordinary least squares regression. We then calculated the Concentration Index for guideline-standardized use. Following Wagstaff, van Doorslaer, and Watanabe, the Concentration Index decomposition can identify the Concentration Index for guideline-standardized use related only to need factors. (30) We subtracted this component from the Concentration Index for guideline-standardized use, resulting in a measure of inequity, the HI for guideline-need-standardized use.

Recent work has identified the HI's sensitivity to the mean of the sample population, in which the greater the mean is the smaller the bounds of the index are. (31,32) Without an adjustment for the difference in the mean, one cannot distinguish whether small inequity indicated by the HI in fact reflects small inequity or a low level of the mean. Thus, we applied the Wagstaff Normalization to the radiotherapy outcomes and EOL outcomes in order to restore comparability, (31) in which we divided each HI value by (1- $\mu$), where $\mu$ is the mean of each outcome variable.

We conducted all analyses using Stata 11. (33) Appendix 13 presents Stata code for the analysis. Our data included all Nova Scotian CRC patients in the specified study period and, thus, did not require sample weights or estimations of standard errors for statistical inference. Data access was approved by the CDHA and Dalhousie University Research Ethics Boards.

3.3 Results

Descriptive analyses indicated that access to radiotherapy is worse than access to EOL care. Less than half of those diagnosed with stage II/III rectal cancer received the clinically recommended treatment, while almost three quarters of those who died of CRC in Halifax or Cape Breton were registered in PCPs (Tables 2 and 3). Individuals from the rectal cancer sub-population averaged 67 years of age at diagnosis and two-thirds were male. Of those who received clinically recommended radiotherapy, 55.8% waited less than 2 weeks from radiation oncology referral to consultation and 52% waited less than 4

weeks from ready-to-treat to start of radiotherapy. Among the EOL sub-population, 37.3% of individuals died outside of hospital, 76.8% had no ER visits in the last 30 days of life, and 73.6% of those residing in CDHA or CBDHA were registered with a PCP. Of those who died of CRC, the mean age at death was 72 years, and 48.2% were initially diagnosed with stage IV cancer.

After controlling for all need variables, several socioeconomic, geographic, and demographic factors had independent, statistically significant associations with access to radiotherapy and EOL care in expected directions (Tables 4 and 5). In the rectal cancer sub-population, individuals with two or more co-morbidities were 0.42 times as likely to receive the clinically recommended ($p<0.05$) compared than those without co-morbidities. Individuals 75 years of age or older were 0.08 times as likely to receive the clinically recommended care than those aged 60 years or younger ($p<0.001$), and women were 41% less likely to receive it than men ($p<0.05$). Among those who received the clinically recommended care, individuals with high income ($45,000+) were 2.6 times more likely to meet the wait time benchmark from ready-to-treat to start of radiotherapy, compared to those with low income ($<30,000) ($p<0.05$). In addition, compared to HRM residents, Cape Breton residents were at least 5 times more likely to receive the clinically recommended care and to do so within both wait time benchmarks ($p<0.001$). For EOL care, greater distance to the palliative care unit and residence in a LTC facility decreased likelihood of PCP registration ($p<0.001$). Individuals from rural areas were less likely to have ER visits in the last 30 days of life ($p<0.001$), but twice as likely to die in hospital ($p<0.001$).

Comparing the degree of inequity across equity stratifiers and CRC services using the HI revealed that age-related inequity in access to services is most consistent for all outcomes (Table 6 and Figure 2). Pro-young inequity is indicated in receipt of the clinically recommended rectal cancer treatment and achieving the wait time benchmark from ready-to-treat to start of radiotherapy, as well as registration and timing of registration to a PCP. Comparing inequities in three outcomes of radiotherapy, the wait time from ready-to-treat to start of radiotherapy is of greatest concern, suggesting better access among the advantaged (pro-close, pro-young, and pro-rich). Among the four

outcomes of EOL care, access to a PCP is of greatest concern with suggestions of pro-close, pro-young, and pro-female inequity. Of note in the other two EOL outcomes is inequity by rurality, access to EOL care using the indicator ER visits is pro-rural, while access to EOL care using the indicator of dying outside of hospital is pro-urban.

### 3.4 Discussion

Using population-based linked administrative databases, this study examined income-, age-, sex-, and geography-related inequity in access to radiotherapy and EOL care among CRC patients in Nova Scotia. To our knowledge, our approach to inequity measurement by adjusting for CPGs/benchmarks and patient need is the first of its kind for cancer health services research, and we found indications of age- and distance-related inequity in access to both radiotherapy and EOL care. This study went beyond regression analyses by describing the degree of inequity by the HI, an increasingly popular inequity index in population-based inequity analyses. The use of the HI increased comparability of results between radiotherapy and EOL care and across equity stratifiers. Among the seven outcomes, inequity is most strongly indicated for receipt of the clinically recommended treatment for rectal cancer patients, achieving the wait time benchmark from ready-to-treat to start of radiotherapy, and registration to a PCP. Among the four equity stratifiers, pro-young and pro-close inequities are the most persistent.

Decreasing access to radiotherapy with increasing age has been well documented in the literature: even after controlling for health status, older individuals are significantly less likely to receive radiotherapy. (8,34-37) Our study is consistent with the literature and identified age-related inequity in receipt of the clinically recommended radiotherapy. Previous studies have demonstrated that older patients were less likely to be given radiotherapy and chemotherapy as treatment options by physicians and less likely to be referred to medical and radiation oncologists, (37,38) despite evidence demonstrating the effectiveness of these treatment modalities for elderly patients. (39,40) There may also be differences in patient wishes for care based on age; however, no available data can capture these individual choices. Further investigation is necessary to identify factors that contribute to the age-related inequity, such as lower physician referral rates, as suggested

by the literature, lower understanding of or comfort with the health system, or greater logistic challenges (e.g., transportation to a cancer centre) among older patients.

The indication of pro-male inequity in receipt of radiotherapy was unexpected and not in agreement with previous studies, (8,41,42) which identified no statistically significant association between sex and receipt of care. Reasons for this finding are unclear and require further investigation. It may be possible that there are fewer or less severe barriers for men to receive radiotherapy. Therefore, women may have greater difficulty travelling to the cancer centre repetitively to receive care or may have more constraints due to family or work commitments.

Our study suggested that inequities in wait times from radiation oncology referral to consultation are minimal, yet inequities from ready-to-treat to start of radiotherapy are of concern. Achieving the 4-week benchmark from ready-to-treat to start of radiotherapy indicated considerable pro-rich, pro-young, and pro-close inequities. The variation in degree of inequity between the two wait time intervals occurred despite similar proportions of the population achieving the benchmark (55.76% for referral to consultation vs. 52.03% for ready-to-treat to start of radiotherapy). A possible explanation for the discrepancy might be that there is greater inequity from ready-to-treat to radiotherapy because preparing for and beginning radiotherapy requires considerable planning and investment in time and money by the patient and family compared to a one-day radiation oncology consultation. Thus, additional patient barriers to starting radiotherapy might exist which leads to greater inequities in access.

Among the four EOL care outcomes, registration to a PCP demonstrated the most consistent inequity. Access to a PCP was pro-young, pro-female, and pro-close. It is known that not all individuals who are dying would like to register with a PCP, yet it is worrisome that registration be inequitably associated with age, sex, and distance to the palliative care unit. Age-related inequity in access to a PCP has been consistently identified in the literature. (9,43,44) In our analysis we considered residing in a LTC facility as a non-need factor; that is, a factor that should not influence access to a PCP. Age-related inequity in access to a PCP may be strongly influenced by this non-need factor. Our regression analysis showed that those residing in a LTC facility were 75% less

likely to register in a PCP than those residing elsewhere, and Burge et al. suggested a correlation between age and residing in LTC. (9)

Results of inequity in the number of ER visits in the last 30 days of life and location of death should be interpreted with caution. At first glance, it appears that having no ER visits near death (which presumably suggests high-quality community-based EOL care) is pro-rural, whereas the probability of dying outside of hospital (suggesting high-quality home care) is pro-urban. However, making trips to the ER near death and dying in hospital are not indications of poor care in every circumstance. For example, in some communities, patients may wish to die in hospital, as there is a sense of security from the ongoing medical attention. As well, patients who are not registered with home care may visit the ER near death, as it is the quickest means of being seen by a nurse or physician.

This study is not without limitations. First, despite our attempts to delineate inequality from inequity, our need adjustment was not perfect. For example, data on patient choices about care, physician recommendations, or unexpected patient complications were not available. Second, need factors that we included in our analyses may not have measured need optimally. For example, our co-morbidity measure likely under-reported co-morbidities. Information on co-morbidities came from the hospital discharge abstracts, which provided a measure of co-morbidities in the two years prior to date of diagnosis. This caused concerns due to the fact that the hospital discharge abstracts only includes data on individuals who were admitted to hospital. Therefore, less-severe conditions or those controlled by a family physician were not considered in our co-morbidity calculation. Furthermore, as co-morbidities were assessed for the two years prior to date of diagnosis it may have underestimated the level of co-morbidity for individuals who died of CRC: the date of diagnosis may have been several years prior to the EOL period, during which time the spectrum of co-morbidities may have changed. Also, our measure of contraindication for the clinically recommended treatment for rectal cancer was a proxy. For the rectal cancer sub-population, we adjusted for a previous cancer diagnosis, which was significantly associated with not receiving the clinically recommended treatment. A previous cancer diagnosis was used as a proxy indicator for a possible contraindication to radiotherapy due to prior exposure to radiotherapy. Because

of the variations in radiotherapy techniques and CPGs for radiotherapy, the proxy for contraindication could not be more specific.

Third, our interpretations are limited due to specific data limitations. The EOL component of the study would have benefitted if there were data on palliative care services throughout the province and more in-depth data on location of death. For this study, we were only able to study PCP registration and timing of registration for individuals residing in CDHA or CBDHA and identify whether patients' died in hospital or outside of hospital. Furthermore, the chemotherapy data do not parallel the accuracy of radiotherapy data, radiation oncology data, or EOL care data. It is assumed that chemotherapy is under-reported in NSCR/OPIS as it provided throughout the province, on an out-patient basis, and with or without a medical oncologist, thus rendering it more difficult to capture all chemotherapy services. The under-reporting of chemotherapy may have contributed to the low rates of receipt of the clinically recommended care for rectal cancer patients. Lastly, the ready-to-treat date was estimated using an algorithm based on OPIS variables and relies on face validity. The algorithm appears to error on the side of shorter wait times, therefore, in reality fewer individuals may have met the benchmarks than was reported, but should have minimal impact on the measurement of inequity.

Finally, while the use of the HI facilitates comparison between inequities at different points of care and equity stratifiers, the novelty of its use brought challenges. Horizontal Inequity values are not intuitively interpretable, and it is not clear what values we should consider clinically significant. As our study is the first to use this index in cancer health services research, we cannot compare our findings to other cancer equity studies. Comparison to studies examining inequity in use of specialist health services in Canada, however, may be useful. Both Allin and van Doorslaer et al examined income-related inequity in use of specialist visits using the HI. In accordance with our results for receipt of radiotherapy and access to PCP, Van Doorslaer et al and Allin reported pro-rich inequity values of 0.055 and 0.06, respectively. (15,16) The inequity reported by Allin and van Doorslaer et al for specialist services is greater than that reported for receipt of radiotherapy, yet less than access to PCP.

Another challenge related to the use of the HI is its sensitivity to the mean of the study population. The greater the mean is the smaller the bounds of the index. (31,32) Thus, in comparison of two populations with considerably different means, a smaller degree of inequity indicated by the HI in one population may be due to its lower mean, not smaller inequity. In our study populations, the mean probability of achieving the radiotherapy outcomes was considerably higher than that of the EOL care outcomes (Appendix 14). To adjust for the differences in the means, we applied the Wagstaff Normalization to the radiotherapy outcomes and EOL outcomes, as described in the methods section. To test this technique, we conducted a sensitivity analysis by calculating radiotherapy outcomes using the pared-mean method (as was done for the EOL outcomes) in place of clinical guidelines. This functioned by leveling out the means of the radiotherapy and EOL outcomes, and yielded similar results of those using the Wagstaff Normalization (results shown in Appendix 13).

## 3.5 Conclusion

Inequities exist in access to radiotherapy services and EOL care for CRC patients in Nova Scotia. By adjusting for CPGs/benchmarks and patient need for care and by applying the HI, we have taken a first step toward moving beyond measuring inequalities and relying only on regression analyses. For academic researchers, this study demonstrates the importance of carefully examining inequity in access to cancer care and continuing to improve methodologies and strengthen the literature. For policy makers, this study points to target areas that require further investigation, which may eventually call for design and implementation of clinical and/or policy interventions to reduce inequities in access to CRC care in Nova Scotia.

3.6 Tables and figures

| Table 2. Radiotherapy study population | | | |
|---|---|---|---|
| All individuals diagnosed with stage II/III rectal cancer who underwent surgical resection | | | |
| | | N | % |
| | | 503 | |
| Sex | | | |
| | Men | 326 | 64.8 |
| | Women | 177 | 35.2 |
| Age at diagnosis | | | |
| | <60 | 158 | 31.4 |
| | 60-74 | 199 | 39.6 |
| | 75+ | 146 | 29.0 |
| | Mean (Standard deviation) | 67.1 (12.37) | |
| Year of diagnosis | | | |
| | 2001 | 90 | 17.9 |
| | 2002 | 110 | 21.9 |
| | 2003 | 83 | 16.5 |
| | 2004 | 101 | 20.1 |
| | 2005 | 119 | 23.6 |
| Region of NS* | | | |
| | CDHA | 198 | 39.4 |
| | CBDHA | 86 | 17.1 |
| | Annapolis Valley Health, South Shore Health, and South West Health | 134 | 26.6 |
| | Colchester East Hants Health Authority, Pictou County Health Authority, and Guysborough Antigonish Straight Health Authority | 85 | 16.9 |
| Distance to the nearest cancer centre (km) | 0-14.99 | 178 | 35.4 |
| | 15-74.99 | 140 | 27.8 |
| | 75 + | 185 | 36.8 |
| Income ($) | <30,000 | 114 | 22.7 |
| | 30,000-44,999 | 232 | 46.1 |
| | 45,000+ | 145 | 28.8 |
| | Missing | 12 | 2.4 |
| Number of co-morbidities | | | |
| | 0 | 357 | 71.0 |
| | 1 | 74 | 14.7 |
| | 2+ | 72 | 14.3 |
| Stage at diagnosis | | | |
| | II | 222 | 44.1 |
| | III | 281 | 55.9 |

| Table 2. Radiotherapy study population | | | |
|---|---|---|---|
| Received clinically recommended treatment – chemotherapy in addition to neo-adjuvant or adjuvant radiotherapy | | | |
| | Yes | 246 | 48.9 |
| | No | 257 | 51.1 |
| Wait time from radiotherapy referral to consultation within 14 days** | | | |
| | Yes | 135 | 55.8 |
| | No | 107 | 44.2 |
| Wait time from ready-to-treat date to start of radiotherapy within 28 days** | | | |
| | Yes | 128 | 52.0 |
| | No | 118 | 48.0 |

*Study population excludes persons who resided in Cumberland County (n=18), as most undergo radiotherapy in New Brunswick

** Only includes those who received clinically recommended treatment – chemotherapy in addition to neo-adjuvant or adjuvant radiotherapy

| Table 3. End-of-life care study population | | | |
|---|---|---|---|
| All individuals who died of colon or rectal cancer | | | |
| | | n | % |
| | | 1201 | |
| Sex | | | |
| | Men | 643 | 53.5 |
| | Women | 558 | 46.5 |
| Age at death | | | |
| | <60 | 168 | 14.0 |
| | 60-69 | 263 | 21.9 |
| | 70-79 | 353 | 29.4 |
| | 80+ | 417 | 34.7 |
| | Mean (Standard deviation) | 72.2 (12.68) | |
| Year of death | | | |
| | 2001-2002 | 230 | 19.3 |
| | 2003 | 227 | 18.9 |
| | 2004 | 231 | 19.2 |
| | 2005 | 244 | 20.3 |
| | 2006 | 164 | 13.7 |
| | 2007- March 31, 2008 | 164 | 8.7 |
| Number of co-morbidities | | | |
| | 0 | 654 | 54.5 |
| | 1 | 255 | 21.2 |
| | 2+ | 292 | 24.3 |
| Stage at diagnosis | | | |
| | I | 49 | 4.1 |
| | II | 190 | 15.8 |
| | III | 287 | 23.9 |
| | IV | 579 | 48.2 |
| | Unknown | 96 | 8.0 |
| Rural/Urban | | | |
| | Rural | 485 | 40.4 |
| | Urban | 716 | 59.6 |
| Region of NS | | | |
| | CDHA | 416 | 34.6 |
| | CBDHA | 186 | 15.5 |
| | Annapolis Valley Health, South Shore Health, and South West Health | 318 | 26.5 |
| | Colchester East Hants Health Authority, Pictou County Health Authority, and Guysborough Antigonish Straight Health Authority | 281 | 23.4 |
| Income ($) | <30,000 | 301 | 25.1 |
| | 30,000- 44,999 | 552 | 46.0 |
| | 45,000+ | 309 | 25.7 |
| | Missing | 39 | 3.2 |

| Table 3. End-of-life care study population | | | |
|---|---|---|---|
| Length of survival after diagnosis (days) | 0-99 | 304 | 25.3 |
| | 100-299 | 262 | 21.8 |
| | 300-749 | 347 | 28.9 |
| | 750+ | 288 | 24.0 |
| Location of death | | | |
| | In hospital | 753 | 62.7 |
| | Elsewhere | 448 | 37.3 |
| Number of ER visits in the last 30 days of life | | | |
| | 0 | 922 | 76.8 |
| | 1+ | 279 | 23.2 |
| Residence in a LTC facility | | | |
| | Yes | 112 | 9.3 |
| | No | 1089 | 90.7 |
| Registration in a PCP in CDHA or CBDHA* | | | |
| | Yes | 443 | 73.6 |
| | No | 159 | 26.4 |
| Registered in a PCP in CDHA or CBDHA >60 days before death** | | | |
| | Yes | 214 | 48.31 |
| | No | 229 | 51.69 |
| Distance to the nearest PCP * (km) | 0-9.99 | 335 | 53.26 |
| | 10-19.99 | 164 | 26.07 |
| | 20+ | 130 | 20.67 |

* n = 602

** n = 443

| Table 4. Adjusted odds ratios – adjuvant therapy analyses | | | |
|---|---|---|---|
| | Receipt of care | Wait times | |
| | *Adjuvant chemotherapy and neo-adjuvant or adjuvant radiotherapy* | *Radiation oncology referral to consultation (Within 14 days)* | *Ready-to-treat to start of radiotherapy (Within 28 days)* |
| Variable | OR | OR | OR |
| **Need** | | | |
| Co-morbidities | * | | * |
| 0 | 1.00 | 1.00 | 1.00 |
| 1 | 0.74 | 2.09 | 3.55** |
| 2+ | 0.42* | 1.31 | 1.63 |
| Stage | | | |
| 2 | 1.00 | 1.00 | 1.00 |
| 3 | 1.27 | 1.17 | 1.14 |
| History of | | | |
| No | 1.00 | 1.00 | 1.00 |
| Yes | 0.33* | 0.66 | 1.67 |
| | | | |
| **Non-need** | | | |
| Timing of | | | |
| Neo-adjuvant | -- | 1.00 | 1.00 |
| Adjuvant | -- | 0.23** | 0.25** |
| Income | | | * |
| <30 k | 1.00 | 1.00 | 1.00 |
| 30 -44,999 k | 1.53 | 1.17 | 1.73 |
| 45+ | 1.10 | 1.26 | 2.61* |
| Missing | 5.29* | 0.92 | 1.96 |
| Age at | ** | | ** |
| <60 | 1.00 | 1.00 | 1.00 |
| 60-74 | 0.59* | 1.01 | 0.71 |
| 75+ | 0.08** | 1.43 | 0.72 |
| Sex | | | |
| Male | 1.00 | 1.00 | 1.00 |
| Female | 0.59* | 1.06 | 0.92 |
| Distance | | | ** |
| 0-14.99 km | 1.00 | 1.00 | 1.00 |
| 15-74.99 km | 0.48 | 1.36 | 0.72 |
| 75+ km | 0.85 | 1.33 | 0.50 |
| Region | ** | ** | ** |
| CDHA | 1.00 | 1.00 | 1.00 |
| CBDHA | 5.10** | 5.06** | 5.68** |
| **Table 4. Adjusted odds ratios – adjuvant therapy analyses** | | | |

| | | | |
|---|---|---|---|
| South shore & | 1.44* | 0.60 | 1.92 |
| Colchester/ | 2.79* | 0.79 | 1.45 |
| Year of | | | |
| 2001 | 1.00 | 1.00 | 1.00 |
| 2002 | 0.79 | 0.77 | 1.53 |
| 2003 | 1.19 | 0.79 | 0.65 |
| 2004 | 1.87 | 0.98 | 1.13 |
| 2005 | 1.50 | 0.79 | 0.86 |
| N | 503 | 242 | 276 |
| Pseudo-R | 0.2380 | 0.1394 | 0.1499 |
| Log likelihood | -265.5804 | -142.9632 | -144.78179 |

* p-value <0.05 ** p-value <0.001

Statistical significance in the row of a variable name indicates overall significance of all categories combined

[1] Annapolis Valley Health, South Shore Health, and South West Health

[2] Colchester East Hants Health Authority, Pictou County Health Authority, and Guysborough Antigonish Straight Health Authority

| Table 5. Adjusted odds ratios – End-of-life care analyses | | | | |
|---|---|---|---|---|
| | Access to PCP | Timing of registration with PCP | ER visits in the last 30 days of life | Location of death |
| | *Registered with PCP* | *Registered 60 or more days prior to death* | *No visits* | *Died outside of hospital* |
| Variables | OR | OR | OR | OR |
| **Need** | | | | |
| Co-morbidities | | | | |
| 0 | 1.00 | 1.00 | 1.00 | 1.00 |
| 1 | 1.10 | 1.49 | 1.23 | 0.90 |
| 2+ | 1.00 | 1.04 | 1.01 | 0.81 |
| Stage | * | | | |
| 1 | 0.51 | 3.09 | 0.65 | 1.79 |
| 2 | 0.46* | 0.72 | 1.30 | 0.78 |
| 3 | 0.48* | 0.97 | 0.89 | 0.85 |
| 4 | 1.00 | 1.00 | 1.00 | 1.00 |
| Unknown | 0.82 | 1.19 | 1.61 | 0.64 |
| **Non-need** | | | | |
| Income | * | | | |
| <30 k | 1.00 | 1.00 | 1.00 | 1.00 |
| 30-44,999 k | 0.76 | 1.16 | 1.24 | 0.97 |
| >45 k | 1.62 | 0.90 | 1.08 | 1.35 |
| Missing | 0.61 | 1.31 | 0.62 | 2.64* |
| Age | ** | | | |
| <60 | 1.00 | 1.00 | 1.00 | 1.00 |
| 60-69 | 1.67 | 0.45* | 1.17 | 1.01 |
| 70-79 | 0.58 | 0.37** | 1.69* | 0.92 |
| 80+ | 0.56 | 0.33** | 1.54 | 1.12 |
| Sex | | | | |
| Male | 1.00 | 1.00 | 1.00 | 1.00 |
| Female | 0.88 | 1.45 | 1.35 | 0.84 |
| LTC residency | | | | |
| No | 1.00 | 1.00 | 1.00 | 1.00 |
| Yes | 0.15** | 5.31 | 1.31 | 7.10** |
| Rural/urban | | | | |
| Rural | - - | - - | 1.00 | 1.00 |
| Urban | - - | - - | 0.31** | 2.06** |
| Distance | ** | | | |
| 0-10km | 1.00 | 1.00 | - - | - - |

| Table 5. Adjusted odds ratios – End-of-life care analyses | | | | |
|---|---|---|---|---|
| 10-20km | 0.97 | 1.01 | - - | - - |
| 20+ km | 0.26** | 0.88 | - - | - - |
| | | | | |
| Region | | | ** | * |
| CDHA | 1.00 | 1.00 | 1.00 | 1.00 |
| CBDHA | 1.03 | 0.86 | 1.70* | 0.88 |
| South shore & valley[1] | - - | - - | 0.30** | 1.78* |
| Colchester/ Pictou[2] | - - | - - | 0.62* | 1.05 |
| Year of death | | | | |
| 2001-2002 | 1.00 | 1.00 | 1.00 | 1.00 |
| 2003 | 1.59 | 1.38 | 1.49 | 0.66 |
| 2004 | 2.85** | 0.87 | 1.59 | 0.96 |
| 2005 | 2.49* | 0.78 | 2.03** | 0.90 |
| 2006 | 1.96 | 1.09 | 2.13** | 0.81 |
| 2007-2008 | 2.56 | 0.79 | 1.46 | 1.03 |
| ER visits (30 days) | | | | |
| 0 | 1.00 | 1.00 | - - | 1.00 |
| 1+ | 0.66 | 0.59 | - - | 0.24** |
| Location of death | | | | |
| Out of hospital | 1.00 | 1.00 | 1.00 | - - |
| In hospital | 0.62 | 0.55* | 4.34** | - - |
| Survival time | ** | ** | | ** |
| <100 days | 1.00 | 0.030** | 1.00 | 1.00 |
| 100-299 | 1.80 | 1.01 | 1.00 | 2.40** |
| 300-750 | 2.65** | 0.64 | 0.91 | 2.42** |
| 750+ | 2.90* | 100 | 1.03 | 2.87** |
| | | | | |
| N | 602 | 443 | 1201 | 1201 |
| Pseudo-R square | 0.2192 | 0.2230 | 0.1171 | 0.1369 |
| Log likelihood | -271.36521 | -238.39353 | -574.76734 | -684.69522 |

* p-value <0.05 ** p-value <0.001

Statistical significance in the row of a variable name indicates overall significance of all categories combined

[1] Annapolis Valley Health, South Shore Health, and South West Health

[2] Colchester East Hants Health Authority, Pictou County Health Authority, and Guysborough Antigonish Straight Health Authority

| Table 6. Horizontal Inequity Index results | | | | | | | |
|---|---|---|---|---|---|---|---|
| | **Radiotherapy** | | | **End-of-life care** | | | |
| | Receipt of clinically recommended treatment | Wait time: Radiation oncology referral to consultation | Wait time: Ready-to-treat to start of radiotherapy | Registration in a Palliative care program | Timing of Palliative care program registration | ER visits in the last 30 days of life | Location of death |
| Income-related inequity | -0.010 | -0.027 | -0.150 | -0.075 | -0.072 | 0.013 | -0.089 |
| Age-related inequity | -0.40 | 0.011 | -0.10 | -0.35 | -0.18 | 0.14 | 0.044 |
| Sex-related inequity | 0.15 | 0.018 | -0.007 | -0.12 | -0.057 | -0.040 | 0.038 |
| Distance-related inequity | -0.084 | -0.014 | -0.20 | -0.34 | -0.073 | | |
| Rurality-related inequity | | | | | | 0.17 | -0.098 |

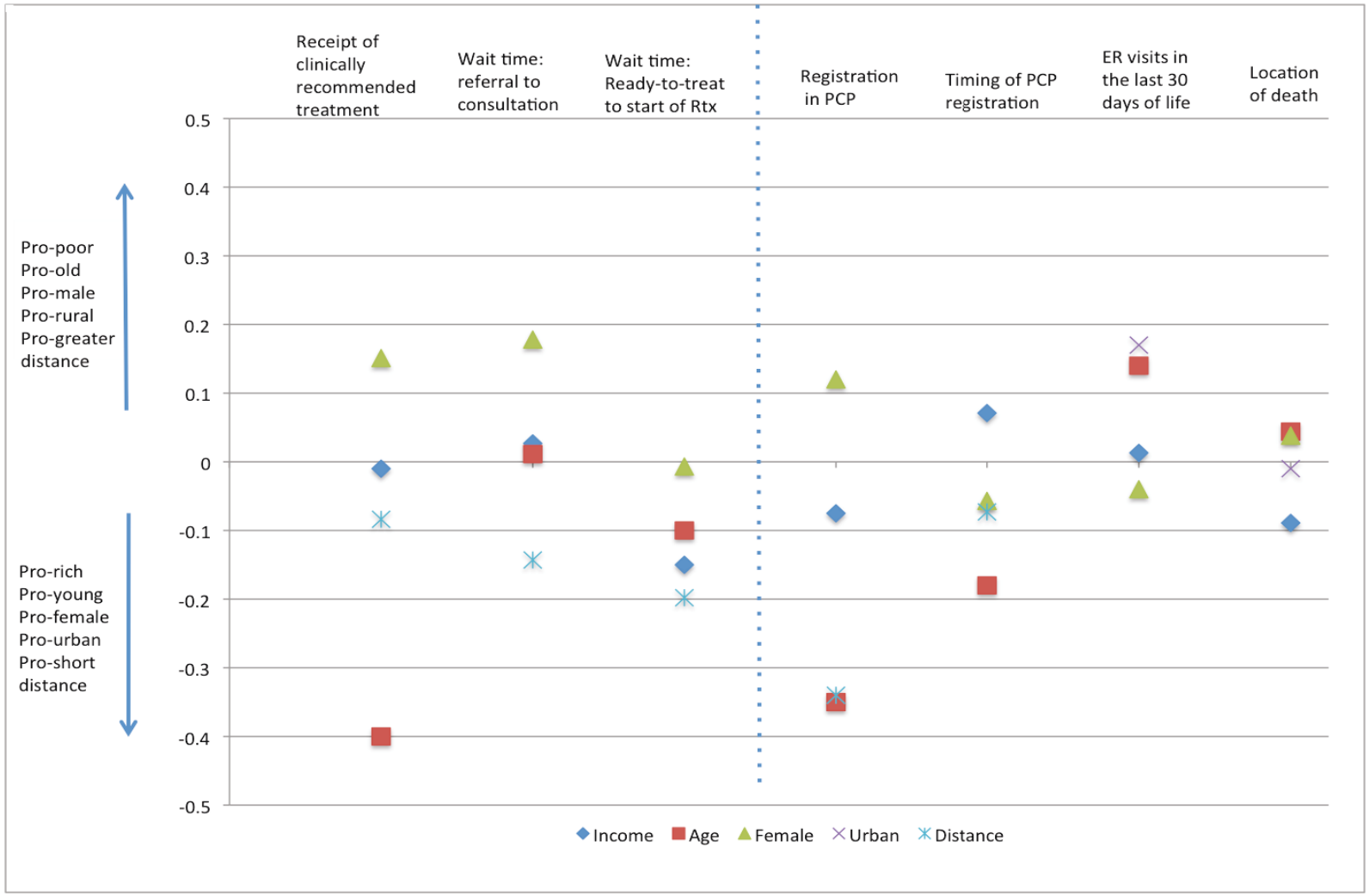


Figure 2 Horizontal Inequity in access to radiotherapy and end-of-life care service

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# Chapter 4 – Conclusion

The objectives of this Master's thesis were to clearly distinguish inequity from inequality in access to CRC services, as well as to measure income-, age-, sex-, and geography-related inequity in access to radiotherapy and EOL care. To meet the first objective, we measured inequity in access to CRC services by incorporating CPGs or benchmarks and patient need. To meet the second objective, using the HI, we calculated income-, age-, sex-, and geography-related inequity for three indicators of access to radiotherapy and four indicators of access to EOL care. Our results indicate that inequity in access to radiotherapy and EOL care exists for CRC patients in Nova Scotia. Also, we found that age- and geography-related inequities are the most consistent across radiotherapy and EOL care.

This study had a number of challenges and limitations. Below I discuss them in the following categories: Defining inequity in access to CRC services, application of need-standardization methods to clinical data, and data limitations. I conclude with suggestions for future studies.

*Defining Inequity in Access to CRC Services*

It was difficult to select specific CRC services, for which inequity could reasonably be defined. We needed to find services, for which CPGs or benchmarks existed. In consultation with clinical experts, however, we learned that CPGs or benchmarks serve as general treatment guidelines at the patient level, but not as strict treatment recommendations at the population level. CPGs are typically developed based on the best available data: from randomized controlled trials, when they exist, to expert consensus, when limited high quality studies are performed. They aim to guide health care providers in the delivery of optimal patient care. (1) Care for CRC varies considerably by disease site, tumour stage, and patient characteristics, and the task of defining equity, that is, determining who should receive which services, was complex. Through an extensive literature review and extensive communication with local experts in the field as well as consideration for data availability and sample sizes, we identified the two CRC services, radiotherapy and EOL care, for our analyses.

Our decision on examining inequity in these two CRC services and using separate sub-populations in each service was a first step towards a more comprehensive analysis of inequity along the CRC service continuum. As the first manuscript discusses, one of the limitations of the current literature examining inequity in cancer care is that studies rarely analyze multiple points of service. We acknowledged this limitation and attempted to do better in our analyses. However, the difficulty in balancing the existence of CPGs or benchmarks and reasonable data on patients' need indicates considerable challenge for future studies to examine inequity in a single population at multiple points of service in the continuum of CRC care.

In addition, we faced a question of which equity stratifiers indeed suggest inequity. Income-related inequity may reasonably be assumed to be of social concern. But we must be cautious to interpret variations by rural vs. urban or sex or age as equity stratifiers, as their interactions with access are complex. For example, as we identified in the analyses of EOL sub-population, urban residents were more likely to have 1 or more ER visits in the last 30 days of life, but more likely to die outside of hospital. However, this does not necessarily imply that patients from rural or urban areas are worse off; service provision may simply be different. Therefore, careful examination of the context and complexity is required before investigating inequity and labeling a variation as ethically problematic.

*Application of Need-Standardization Methods to Clinical Data*

As there are legitimate reasons for patients not following CPGs or achieving benchmarks, need-standardization was imperative for measuring inequity. Unfortunately, our need adjustment was limited to proxies of health status and contraindications for care. Thus, it is likely that the analysis has not completely captured patient need and that the extent of inequity calculated by the HI in fact includes some degree of unmeasured patient need. Additionally, our need-standardization could not account for patient choice regarding care. Taken together, the HI results should be interpreted with the caveat that, although we made have attempts to level out patient need for care, the remaining variation may not be entirely ethically problematic.

Although we have made considerable attempt to clearly differentiate between need factors and non-need factors, the distinction is not always or entirely discrete. In this study, certain need factors may contain attributes, which one could argue illegitimately affect patients need for care, and certain non-need factors, which contain attributes that legitimately affect patient need. For example, residing in a LTC facility was significantly inversely associated with registration in a PCP. We considered residing in a LTC facility as a non-need factor because LTC residency can be a barrier to access to EOL care due to, for example, difficulty with transportation, lack of awareness of services, poor communication between LTC facilities and PCP. However, in certain LTC facilities patients receive adequate palliative care from specially trained in house nurses or physicians, thus may receive appropriate care without PCP registration. The lack of clear distinction between need vs. non-need was also the case for tumour stage and length of survival after diagnosis. We included tumour stage as a need-factor, as a proxy for health status, for both radiotherapy and EOL. However, it can be argued that stage should not legitimately influence access to radiotherapy if the CPGs are specific for our sub-population. Moreover, for EOL care, that all patients who die of cancer eventually develop terminal cancer and should have access to EOL regardless of stage. Length of survival was included as a non-need factor for EOL care, because regardless of the time between diagnosis and death all individuals should have access. In contrast, it can be argued that individuals who die quickly may have more challenging cancers and have less time to organize EOL care. The distinction between need and non-need factors can be improved in future studies by carefully examining the context and intricacies of each variable and to apply variables that are as specific as possible.

The final challenge of the application of need-standardization for this study will be to communicate findings to decision makers, health care workers, and cancer researchers. Need-standardization is a complex approach and does not allow easy interpretation. In addition to disseminating the study results at an upcoming academic conference and in a cancer-related peer-reviewed journal, we will explore effective communication of our methods and findings to non-researchers. This work will be presented that the CDHA Grand Oncology Rounds on September 9, 2010, which will

serve as a forum to discuss our findings with the cancer care community in Halifax and other regions throughout the province.

*Data Limitations – Radiotherapy*

Chemotherapy is an important component of treatment for stage II/III rectal cancer, and CPGs recommend that individuals diagnosed with stage II or III rectal cancer received adjuvant chemotherapy and neo-adjuvant or adjuvant radiotherapy. Accordingly, in our analyses for radiotherapy, receipt of chemotherapy was an important indication of equitable care. However, receipt of chemotherapy was likely to be under-reported in our data, specifically, NSCR/OPIS, which could have led over-estimation of inequity in our analyses. Chemotherapy can be provided throughout the province as an outpatient service, and with or without a supervising physician, thus the Access database is unlikely to capture all chemotherapy visits. The NET ACCESS Team has conducted a comprehensive chart review of chemotherapy data to understand the extent of under-reporting and to update the database accordingly. Unfortunately, the result of the chart review was not available in time for the thesis analysis. I intend to include the revised chemotherapy prior to publication.

For one of the analyses of wait time for radiotherapy, we used the ready-to-treat algorithm (whether the time interval from ready-to-treat date to start of radiotherapy was within 28 days (according to Cancer Care Ontario). This algorithm needs further validation. The ready-to-treat day represents the date at which the patient is medically, physically, personally, and psychologically prepared to begin radiotherapy. Cancer Care Nova Scotia developed this algorithm to represent variations in recovery time from surgery and/or chemotherapy and personal choice, which the date of radiation oncology consultation poorly suggests, using variables in NSCR/OPIS. The algorithm has face validity but is not without limitation. In 55.4% of cases the ready-to-treat date was the date in which the radiation oncology clerk received the treatment plan from the radiation oncologist. If the patient was not ready for radiotherapy on the day of the radiation oncology consultation then the radiotherapy requisition sent to the radiation oncology clerk contained a “hold”. In this case, the “date activated” – the predicted day in which the patient would be prepared for radiotherapy – would be used as the ready-to-treat.

However, in cases that contained a hold the "date activated" was missing or incorrectly inputted in 80.5%. This may have been done appropriately (e.g., the patient was unsure when they would be ready) or inappropriately (e.g., radiation oncologist or radiation oncology clerk error). For these patients, the date they were notified of their upcoming radiotherapy date was used as an estimation for ready-to-treat. The algorithm does tend to error towards shorter wait times and does not perfectly account for legitimate (e.g., delays caused by chemotherapy) vs. illegitimate (e.g., delays caused by a shortage of radiation oncologists) waits.

*Data Limitations – EOL Care*

The EOL study population included deaths up to March 31, 2008, therefore, some individuals who were diagnosed between 2001-2005 and who had died between this cut-off date and now or will die of CRC in future were not captured in our EOL study population. The EOL study population included CRC deaths from all tumour stages and cancer recurrences. In addition, there was a 27-month window between the final date of study inclusion (December 31, 2005) and the EOL study population cut-off (March 31, 2008), and 76% of those who died of CRC died within two years. Still, it is possible that those 24% of deaths that were not captured in our EOL study population were systematically different from those who were included, and the findings of the EOL care analyses may have been biased to unknown direction. We are considering updating the EOL study population prior to submitting this thesis for publication.

Location of death (dying out of hospital vs. in hospital) is extensively used in the literature as a proxy for access to high quality community-based EOL care, and we included this variable of location of death as one of the four indicators of EOL care. However, this variable does not account for variations in patient wishes, differences in hospital characteristics, and quality of EOL care. Although the literature typically labels a hospital death as a poor outcome, this is not always the case. Patients may prefer to die in hospital, may have very successful hospital deaths, and may have poor home deaths. Moreover, there remains debate as to whether location of death accurately captures the extent of community-based EOL care that is provided, as location of death is, by definition, only measured once. (2)

*Data Limitations* – Need Variables

To adjust for health status we included patient co-morbities and tumour stage at diagnosis. However, co-morbidities were likely under-reported. Information on co-morbidities came from the hospital discharge abstracts, which provided a measure of co-morbidities in the two years prior to date of diagnosis. Because the hospital discharge abstracts only includes data on individuals who were admitted to hospital for that condition, less-severe conditions or those controlled by a family physician were not considered in our co-morbidity calculation. Furthermore, as co-morbidities were assessed for the two years prior to date of CRC diagnosis, the date of diagnosis may have been several years prior to the EOL period, during which time the spectrum of co-morbidities may have changed. The alternative to hospital discharge abstracts would have been to use physician billings data, which would have most likely captured a greater number of co-morbid conditions for patients.

We adjusted for contraindications to radiotherapy by controlling for individuals who had a previous cancer diagnosis. Ideally we would have selected only individuals who had had previous radiotherapy to the anatomical region (e.g., pelvis or rectum) that would contraindicate providing radiotherapy for rectal cancer. However, radiotherapy practices, techniques, and CPGs have changed over time rendering it difficult to identify who received previous radiotherapy and to what region. Controlling for all individuals who had a previous cancer diagnosis would probably have over-adjusted need, which may have under-estimated *inequity*.

*Data Limitations – Non-Need Variables*

Due to data limitation, measures of some of the non-need factors were not ideal. The proxy for individual income was the average median household income from the neighbourhood of each patient. Although using an ecological measure as a proxy for the individual-level measure could suffer from ecological fallacy, (3) this was the best income measure available from the databases. Distance to the cancer centre or PCP was crude, measured as the direct distance from patient neighbourhood to the nearest cancer centre or PCP. This did not take into account driving distance, road type, (e.g., country

road, provincial highway) topography, or seasonal driving conditions. In addition, the measure of rural vs. urban was also a crude proxy for characteristics of living in a rural area vs. urban area. There is no gold standard measure of rurality in studies of access to health care. We derived our rural vs. urban measure from the MIZ/SACtype, increasingly used in the literature, but it is unclear to what extent the MIZ/SACtype captures homogeneity across communities in their enabling factors and barriers to access to cancer services.

*Future Directions*

Future investigation of inequity in access to CRC services would greatly benefit from the improvement in need-adjustment and the use of a single cohort of patients along the entire continuum. As this study examined access retrospectively using administrative data, we were limited to using crude measures of need and non-need factors. Ideally, future studies would make use of more precise indicators of health status, as well as data on patient and physician motivations and wishes. Adjustment of specific contra-indications of radiotherapy, more detailed information of the severity of each co-morbidity, as well as patient and physician responses would enable much clearer distinction between legitimate and illegitimate variations, thus resulting in a more precise description of inequity. In addition, the ideal study would follow experiences of a single cohort from two years prior to diagnosis and at every point of service from diagnosis to follow-up and/or EOL care. Examining a single cohort at each point along the continuum of care would allow for increased comparability of inequity in access between points of service. This would require careful examination of what is appropriate and recommended care for each individual, and together with the improved need-adjustment, the use of a single cohort would uncover details of inequity in CRC care.

Variations in access to cancer care in Canada persist, and further evaluation is needed of how we measure these variations and the degree to which they are inequitable. This thesis has shown that the distinction between inequality and inequity that may appear simple at first sight is complex in application. Despite the difficulties, it is imperative that we continue to improve the methodologies to strengthen the literature and eventually to design clinical and policy interventions accurately and unambiguously.

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# Appendices

5.1 Variable Codebook

**Created by Martha Cox (Team ACCESS analyst) and revised by André Maddison**

**Name: RADIO**

Description: sub-population for the radiotherapy component

Structure: one record per patient

| Variable Description | Variable Name | Valid Values | Comments |
|---|---|---|---|
| **Patient identifier** | PATIENT_ID | | |
| **Age at diagnosis** | AGE | 0 – ∞ | |
| **Sex** | SEX | 'M', 'F' | |
| **Stage at diagnosis** | STAGE | Valid values for stage: 'I', 'II', 'III', 'IV', 'UNK' | 'UNK' = 'unknown' |
| **District Health Authority** | DHA | 1 = 'South Shore'<br>2 = 'South West'<br>3 = 'Annapolis Valley'<br>4 = 'Colchester - East Hants'<br>5 = 'Cumberland'<br>6 = 'Pictou County'<br>7 = 'Guysborough - Antigonish Strait'<br>8 = 'Cape Breton'<br>9 = 'Capital' | NB: Patients residing in Cumberland DHA have been excluded from the radiotherapy cohort. These patients often go to New Brunswick for chemotherapy and radiotherapy treatments. So our data for them is incomplete. |

| Variable Description | Variable Name | Valid Values | Comments |
|---|---|---|---|
| **Urban vs. Rural Residence** | SACTYPE | '1' = 'Census Metropolitan Area'<br>'2' = 'Tracted Census Agglomeration'<br>'3' = 'Non-Tracted Census Agglomeration'<br>'4' = 'Non-CMACA, Strong CMACA Influence'<br>'5' = 'Non-CMACA, Moderate CMACA Influence'<br>'6' = 'Non-CMACA, Weak CMACA Influence'<br>'7' = 'Non-CMACA, No CMACA Influence' | This variable represents *Statistical Area Classification Type*. Values of 1-3 are considered urban; 4+, rural. This is based on the MIZ methodology selected by the Team ACCESS Common Methods Group. |
| **Comorbidity** | ELIXHAUSER | 0-28<br>0 = no comorbidities. There should not be anyone with a missing value. | This variable is determined by the method selected by the Team ACCESS Common Methods Group. |
| **Co-morbid conditions** | ELIX1-ELIX17<br>ELIX21-ELIX31 | 1 = 'Yes'<br>0 = 'No' | Separate yes/no variables indicating whether the patient had each Elixhauser category of conditions.<br>NB: ELIX18-ELIX20 are cancer-related and were included below. |
| **Cancer history** | HISTORY, HIST5YS | 0 – ∞ | HISTORY =Num of cancers, any type, prior to CRC Dx (back to 1970)<br>HIST5YS =Num of cancers, any type, in 5 yrs prior to CRC Dx |
| **Median Household Income** | HHINMED | 0 – ∞ | Median Household Income for the patient's postal code, from the 2001 Canadian Census |

| Variable Description | Variable Name | Valid Values | Comments |
|---|---|---|---|
| **Date of diagnosis** | DIAGDATE, | day/month/year | DIAGDATE is the diagnosis date from the NS Cancer Registry. |
| **Date of surgery** | SURGDATE | day/month/year | Date of first surgery for CRC |
| **Last Date on Study** | LASTDATE | day/month/year | The patient's last day on study can be used for censoring. It is defined as the earliest of date of death, loss of MSI eligibility, or end of study (31MAR2008, the last date for which we have data). |
| **Distance to the nearest cancer site** | DISTCDHA<br>DISTCB<br>DIST2CC | $0 - \infty$ | Distance in km from patient's residence to:<br>• Halifax Cancer Centre<br>• Cape Breton Cancer Centre<br>• closer of the two<br>For distance analyses, DIST2CC was used |
| **Date of first chemotherapy** | CHEMOFRST | day/month/year | Date of start of patient's first chemotherapy after diagnosis date |
| **Date of first referral to radiation oncologist** | RadOncRefer | day/month/year | NB: Only kept dates within 1 year after surgery date (per Eva Grunfeld). |
| **Date of first consultation with a radiation oncologist** | RadOncConsult | day/month/year | NB: Only kept dates within 1 year after surgery date (per Eva Grunfeld). |
| **Ready to Treat date** | RTTdate | day/month/year | NB: Only kept dates within 1 year after RadOnc consultation date (per Eva). See Appendix 4 for description of "ready to treat." |
| **Date of first radiotherapy** | RTxStart | day/month/year | Date of start of patient's first adjuvant RTx. |
| **Wait time: RadOnc referral to consultation** | Ref2Cons | days<br>(0-360) | |

| Variable Description | Variable Name | Valid Values | Comments |
|---|---|---|---|
| **Wait time: Ready-to-treat to start of RTx** | RTT2RTx | days<br>(0-360) | |

**Name: EOL**

Description: sub-population for the end-of-life component

Structure: one record per patient:

| **Variable Description** | **Variable Name** | **Valid Values** | **Comments** |
|---|---|---|---|
| **Patient identifier** | PATIENT_ID | | |
| **Age at death** | AGE | 0 – ∞ | |
| **Sex** | SEX | 'M', 'F' | |
| **Stage at diagnosis** | STAGE, | Valid values for stage:<br>'I', 'II', 'III', 'IV', 'UNK' | 'UNK' = 'unknown' |
| **District Health Authority** | DHA | 1 = 'South Shore'<br>2 = 'South West'<br>3 = 'Annapolis Valley'<br>4 = 'Colchester - East Hants'<br>5 = 'Cumberland'<br>6 = 'Pictou County'<br>7 = 'Guysborough - Antigonish Strait'<br>8 = 'Cape Breton'<br>9 = 'Capital' | |
| | | | |

| Variable Description | Variable Name | Valid Values | Comments |
|---|---|---|---|
| **Urban vs. Rural Residence** | SACTYPE | '1' = 'Census Metropolitan Area'<br>'2' = 'Tracted Census Agglomeration'<br>'3' = 'Non-Tracted Census Agglomeration'<br>'4' = 'Non-CMACA, Strong CMACA Influence'<br>'5' = 'Non-CMACA, Moderate CMACA Influence'<br>'6' = 'Non-CMACA, Weak CMACA Influence'<br>'7' = 'Non-CMACA, No CMACA Influence' | This variable represents *Statistical Area Classification Type*. Values of 1-3 are considered urban; 4+, rural. This is based on the MIZ methodology selected by the Team ACCESS Common Methods Group. |
| **Comorbidity** | ELIXHAUSER | 0-28<br>0 = no comorbidities. | This variable is determined by the method selected by the Team ACCESS Common Methods Group. |
| | | | |

| Variable Description | Variable Name | Valid Values | Comments |
|---|---|---|---|
| **Comorbid Conditions** | ELIX1-ELIX17<br>ELIX21-ELIX31 | 1 = 'Yes'<br>0 = 'No' | Separate yes/no variables indicating whether the patient had each Elixhauser category of conditions.<br>NB: ELIX18-ELIX20 are cancer-related. |
| **Cancer history** | HISTORY, HIST5YS | 0 – ∞ | HISTORY =Num of cancers, any type, prior to CRC Dx (back to 1970)<br>HIST5YS =Num of cancers, any type, in 5 yrs prior to CRC Dx |
| **Median Household Income** | HHINMED | 0 – ∞ | Median Household Income for the patient's postal code, from the 2001 Canadian Census |
| **Last Date on Study** | LASTDATE | day/month/year | The patient's last day on study can be used for censoring. It is defined as the earliest of date of death, loss of MSI eligibility, or end of study (31MAR2008, the last date for which we have data). |
| **Distance to the nearest cancer site** | DISTCDHA<br>DISTCB<br>DIST2CC | 0 – ∞ | Distance in km from patient's residence to:<br>• Halifax Cancer Centre<br>• Cape Breton Cancer Centre<br>• closer of the two |
| **Date of diagnosis** | DIAGDATE | day/month/year | This is the diagnosis date from the NS Cancer Registry. |

| Variable Description | Variable Name | Valid Values | Comments |
|---|---|---|---|
| **Date of death** | DOD | day/month/year | Reflects all known deaths through 20OCT2009. |
| **Location of death** | DTHLOC | 1 = 'Hospital'<br>0 = 'Other' | |
| **ER Visits** | ERVISITS | day/month/year | This is a count of the number of visits to the emergency room within the last 30 days on study, using physician billings data where HOSPUNIT='EMCC' and [(LASTDATE – 30 days) le visit date le LASTDATE]. |
| **Registration in CDHA or CBDHA palliative care program** | PALLCARE | 1 = 'Yes'<br>0 = 'No' | Registration is considered referred to or admitted into PCP |
| **Date of palliative care program registration** | PALLDATE | day/month/year | |
| **Record of registration in a long-term care facility or nursing home** | LTCresident | 1 = 'Yes'<br>0 = 'No' | We assume that a patient was a long-term care facility resident if he/she had at least one physician visit within the last 6 months of life with location code for "nursing home. |

5.2 Exclusion Criteria from Team ACCESS Analyses

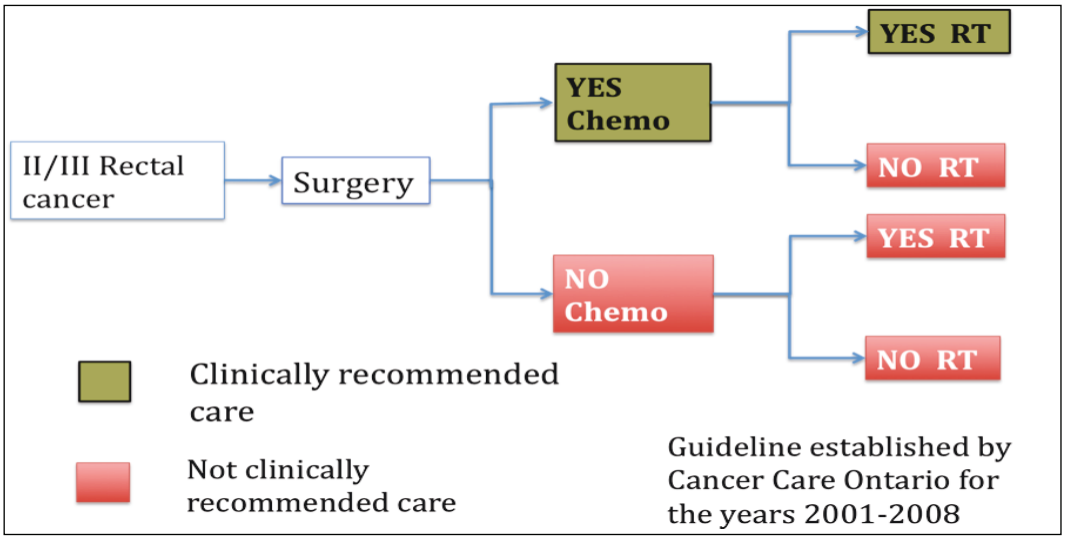
3949 colorectal cancer (CRC) cases were diagnosed in Nova Scotia from January 1, 2001 – December 31, 2005. The following exclusions were made from the study population. Where patients were diagnosed with >1 CRC in this time period, clinical rules were applied to keep the case that would most likely influence the patient's trajectory of care and health services utilization.

| **Exclusion criteria** | **n** |
|---|---|
| Patient <20 years of age | 7 |
| Patients diagnosed by death certificate only | 25 |
| Cases with collaborative stage 0 | 96 |
| Patients diagnosed by autopsy | 15 |
| Cases with non-invasive CRC | 166 |
| Lymphoma cases | 4 |
| Cases diagnosed later for multiple same stage invasive CRC | 34 |
| Cases of lower stage CRC for multiple stage cases synchronously or metachronously diagnosed within one year | 63 |
| Cases diagnosed later for metachronous invasive CRC cases diagnosed over one year apart | 20 |
| Cases diagnosed with appendix cancer | 18 |
| Total | 448 |

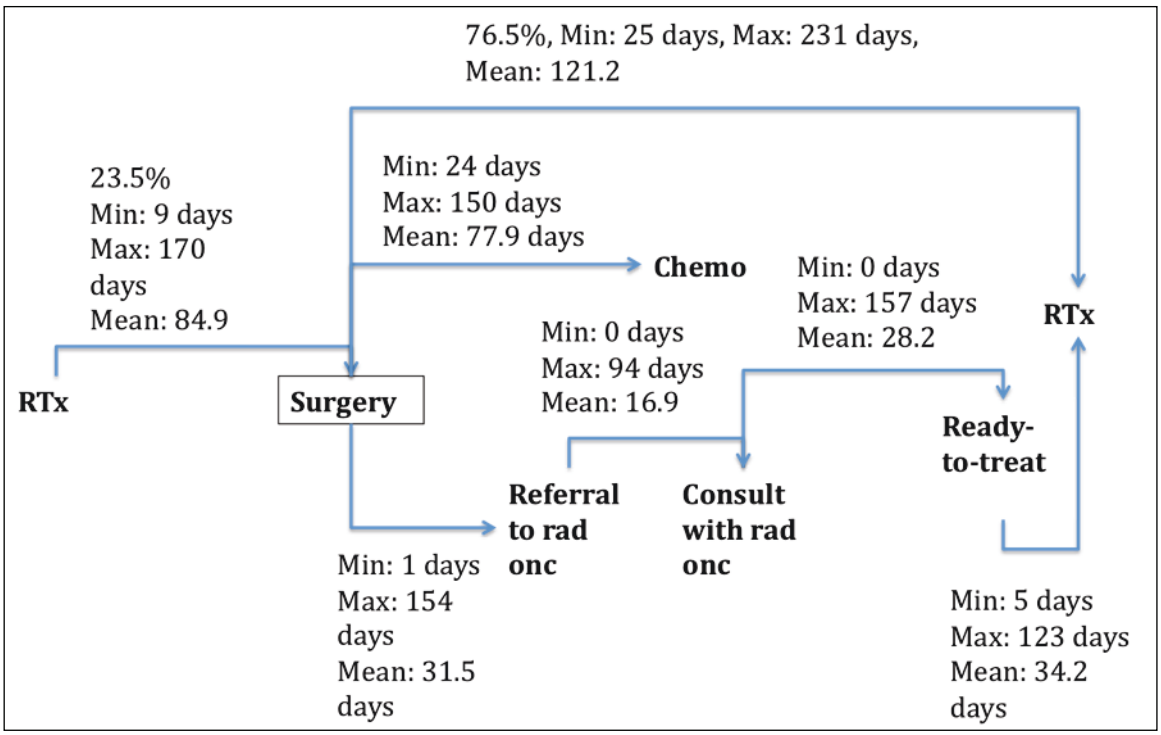
3501 patients remain in the study population after exclusions.

5.3 Radiotherapy Framework and Comprehensive Timeline

According to Cancer Care Ontario and accepted in Nova Scotia, all those diagnosed with stage II or III rectal cancer should undergo resection surgery followed by chemotherapy and radiotherapy. (1)




To provide context to the descriptive results reported in Manuscript 2, below are descriptive statistics of wait times for the 503 patients from the rectal cancer cohort. It can be seen that 23.5% of those who had radiotherapy received it prior to surgery. Also, that the mean wait time from surgery to start of chemotherapy was 77.9 days and to start of adjuvant radiotherapy was 121.2 days.



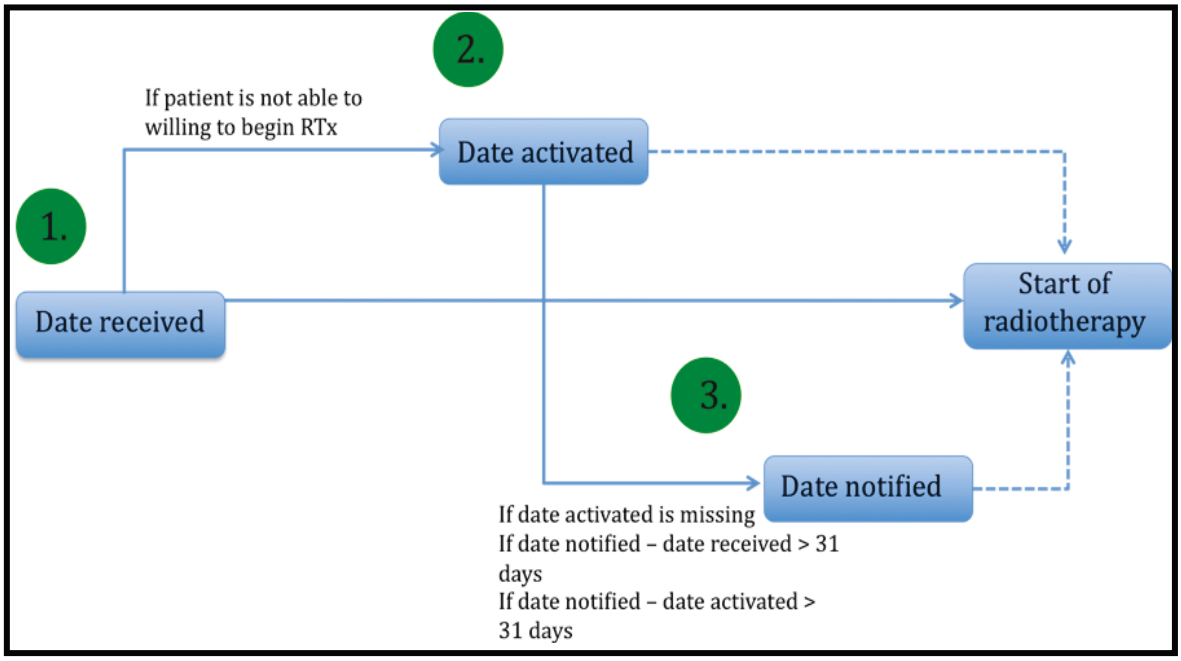

RTx = Radiotherapy

Chemo = Chemotherapy

rad onc = Radiation oncologist

5.4 Ready-to-Treat Algorithm

Ready-to-treat date is the date when the oncologist and patient have agreed that the patient is ready to begin radiotherapy. It was designed to avoid bias from variations in recovery time from surgery and/or provision of chemotherapy and patient preferences for initiating radiotherapy. Ready-to-treat date is widely applied in health services research and policy decisions but relies on face-validity. (2-3) The ready-to-treat date algorithm used for this study, shown below, was designed by Ron Dewar (Epidemiologist with Cancer Care Nova Scotia) and applied to the NET ACCESS cohort by Vickey Bu (Biostatistician with NET ACCESS).




The definitions below were retrieved from the OPIS data dictionary:

Date received - The date the requisition for Radiation therapy was received by the booking clerks, represented by year, month, day.

Date activated - The date that a requisition that has had a priority of Hold has been reactivated for treatment and the priority updated

Date notified - The date the patient was notified of the simulation appointment associated with the treatment request.

The algorithm functioned as follows: if the patient was physically able and willing to receive radiotherapy at the time of radiation oncology consultation, the radiation oncologist sent the requisition for radiotherapy to the OPIS booking clerk and the "date received" was designated as ready-to-treat. If the patient was recovering from surgery or chemotherapy or was not personally prepared to start radiotherapy at the time of radiation oncology consultation, the radiation oncologist sent the requisition for radiotherapy with a "hold". This requisition contained an estimated date at the patient would be ready for treatment, or "date activated". In this case, "date activated" was used as ready-to-treat. Lastly, if the requisition for radiotherapy contained a hold, the booking clerk notified the patient when their estimated date had arrived. To control for cases in which "date activated" is missing or not re-adjusted after further patient initiated delay, the "date notified" was used as ready-to-treat in three special cases: (1) if requisition for radiotherapy contained a hold, yet date activated was missing, (2) if date notified – date activated was greater than 31 days, or (3) if date notified – date received was greater than 31 days. For our study, of those who received radiotherapy, the date received was used in 55.4% of cases, the date activated was used in 8.7% of cases, and the date notified by 35.9% of cases.

5.5 List of Co-Mordid Conditions Included in The Elixhauser Index

The table below presents all conditions included in the Elixhauser index, as well as the prevalence among the EOL study population and percentage of all co-morbidities. (4) All co-morbidities were retrieved from the Discharge Abstract Database at the time of diagnosis, except the two cancer history variables, which were retrieved from NSCR/OPIS.

| Co-morbidity | # diagnosed with condition | | % of total population (1201) |
|---|---|---|---|
| Congestive heart failure | 75 | | 5.95 |
| Cardiac arrhythmia | 131 | | 10.40 |
| Valvular disease | 14 | | 1.11 |
| Pulmonary circulation disorder | 17 | | 1.35 |
| Peripheral vascular disorder | 29 | | 2.30 |
| Hypertension uncomplicated | 217 | | 17.22 |
| Hypertension complicated | 8 | | 0.63 |
| Paralysis | 4 | | 0.32 |
| Other neurological disorders | 18 | | 1.43 |
| Chronic pulmonary disease | 90 | | 7.14 |
| Diabetes uncomplicated | 120 | | 9.52 |
| Diabetes complicated | 22 | | 1.75 |
| Hypothyroidism | 29 | | 2.30 |
| Renal failure | 38 | | 3.02 |
| Liver disease | 21 | | 1.67 |
| Peptic ulcer | 19 | | 1.51 |
| HIV/AIDS | 0 | | |
| Rheumatoid arthritis | 10 | | 0.79 |
| Coagulopathy | 9 | | 0.71 |
| Obesity | 12 | | 0.95 |
| Weight loss | 20 | | 1.59 |
| Fluid and electrolyte disorders | 69 | | 5.48 |
| Blood loss anemia | 43 | | 3.41 |
| Deficiency anemia | 71 | | 5.63 |
| Alcohol abuse | 14 | | 1.11 |
| Drug abuse | 2 | | 0.16 |
| Psychoses | 11 | | 0.87 |
| Depression | 23 | | 1.83 |
| Cancer history (since 1970) | 0 cancers | 1067 | 84.68 |
| | 1 cancer | 167 | 13.25 |
| | 2 cancers | 22 | 1.75 |
| | 3 cancers | 4 | 0.32 |
| Cancer history (5 years prior to diagnosis) | 0 cancers | 1190 | 94.44 |
| | 1 cancer | 67 | 5.32 |
| | 2 cancers | 3 | 0.24 |

## 5.6 Description of Distance Calculation

The calculation of distance from each patient's residence to the nearest cancer centre or palliative care unit was conducted by Martha Cox (NET ACCESS database consultant). The patients' residential postal codes and the postal codes of the two cancer centres were converted to longitude and latitude using the Postal Code Conversion File (PCCF) developed by Statistics Canada. The distance between these two points was then calculated using a SAS® macro called *GEODIST*, which employs the Great Circle Distance Formula and was initially developed by Jim Warren, Department of Physiology & Biophysics, Dalhousie University.

5.7 Sample Calculation of Pared-Mean Benchmarks

The example below demonstrates the calculation of the Pared-mean benchmark for "Location of death".

Steps:

1. Compute the mean value of patients achieving the favourable outcome by DHA.

| DHA | # of patients who died outside of hospital | # of patients who died in hospital | Population size | % of Favourable outcomes | % of total population size |
|---|---|---|---|---|---|
| South Shore | 47 | 63 | 110 | 42.8% | 8.7% |
| South West | 42 | 57 | 99 | 42.4% | 7.9% |
| Annapolis Valley | 47 | 78 | 125 | 37.6% | 9.9% |
| Colchester County | 38 | 62 | 100 | 38.0% | 7.9% |
| Cumberland County | 10 | 39 | 49 | 20.4% | 3.9% |
| Pictou County | 37 | 35 | 72 | 51.4% | 5.7% |
| Guysborough | 24 | 52 | 76 | 31.6% | 6.0% |
| Cape Breton | 75 | 119 | 194 | 38.7% | 15.4% |
| Capital | 187 | 248 | 435 | 43.0% | 34.5% |
| Total | 507 | 753 | 1260 | 40.2% | 100 % |

2. Rank the DHAs in descending order based on their performance for the favourable outcome.

i. Pictou County
ii. Capital
iii. South Shore
iv. South West
v. Cape Breton
vi. Colchester County
vii. Annapolis Valley
viii. Guysborough
ix. Cumberland

3. Isolate the top performing DHA (s) to create a subset of at least 10% of the entire population. The 10% subset may be composed of only 1 DHA if the top-performing district contains at least 10% of the sample, or 2 DHAs if the top performer contains less than 10%.
   i. Pictou County – 5.71%
   ii. Capital 34.5%

4. Using only the subset, compute the following:

$$\frac{\text{Number of patients that met the outcome}}{\text{Total number of patients from the subset}}$$

$$\frac{37+187=224}{72+435=507}$$

44.18%

5. Apply this value as the benchmark for the entire sample.

Therefore, the benchmark for the dependent variable of dying outside of hospital for all those who died of CRC from our cohort is 44.18%

## 5.8 Rural/Urban Classification

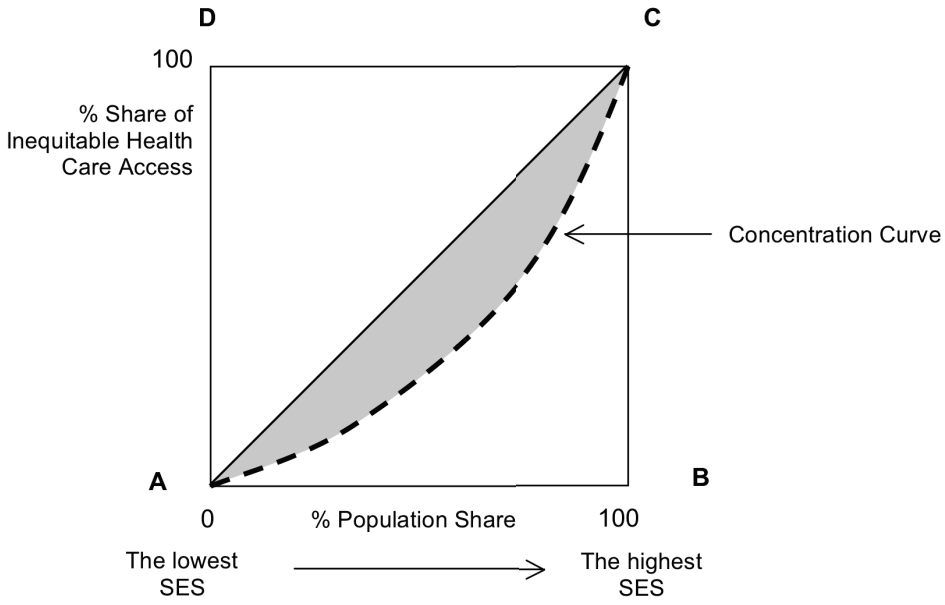
The dichotomous rural/urban variable was created using Statistical Area Classifications (SACtype) and Metropolitan Influence Zones (MIZ). SACtype groups census subdivisions based on population size and MIZ incorporates the influence of large urban areas on smaller communities. Combined, SACtype and MIZ made up 7 categories ranging from most urban to most rural: (1) Census Metropolitan Areas (CMA; large urban cities with at least 100,000 people), (2) Census Agglomerations (CA; communities with at least 10,000 people), (3) strong MIZ communities, (4) moderate MIZ communities, (5) weak MIZ communities, (6) no MIZ communities, and (7) territories. (5) Our analysis dichotomized rural/urban by grouping the 3 most urban categories and 4 most rural categories. Dichotomizing the 7 categories was appropriate because there is insufficient geographical size or population in Nova Scotia to accurately distinguish between 7 categories. We applied rural/urban as the geographic-indicator for ER visits in the last 30 days of life and location of death, because for these outcomes, we were interested in access to community-based care. The indicators for community-based care differed from those for specialized care (i.e., radiotherapy or PCP) because services are distributed throughout the province. Therefore, we were not interested in the impact of distance to a specialized service, but in the social and communal effects of residing in a rural vs. urban community.

5.9 Detailed Description of The Concentration Index

In this study, we measured the degree of inequity by the Concentration Index, a widely used measure of inequality and inequity in health care and health outcomes. (6) The Concentration Index is derived from concentration curves. Concentration curves depict the association between a selected health outcome or health care variable (e.g., likelihood of receiving clinically recommended adjuvant therapy) and an equity stratifier (e.g., income), as demonstrated below.

Individuals were rank-ordered from the lowest to the highest income along the x-axis, and the cumulative proportion of their health care was marked along the y-axis. (7) If there was perfect income-related equality in health care, the curve would be a straight diagonal from A to C in the figure below. Any departure from the diagonal depicts inequality. If the concentration curve was below the AC diagonal and the health care variable was positive (i.e., greater values for a health care variable suggest greater achievement, such as likelihood of receiving clinically recommended adjuvant therapy), then it would suggest pro-rich inequality. In contrast, if the concentration curve was above the AC diagonal and the health care variable was negative (i.e., greater values for a health care variable suggest less achievement, such as likelihood of not receiving clinically recommended adjuvant therapy), then it would suggest pro-poor inequality. The Concentration Index is twice the area between the concentration curve and the AC diagonal, and can be any value between -1 and +1. All values between -1 and 0 were pro-rich inequality and all values between 0 and +1 were pro-poor inequality. (8)

The Concentration Index applied to any variation suggests the degree of inequality. The Concentration Index applied to inequitable variation (i.e., after adjusting for clinical guidelines and patient need) suggests the degree of inequity, which is referred to as the Horizontal Inequity Index. (9)

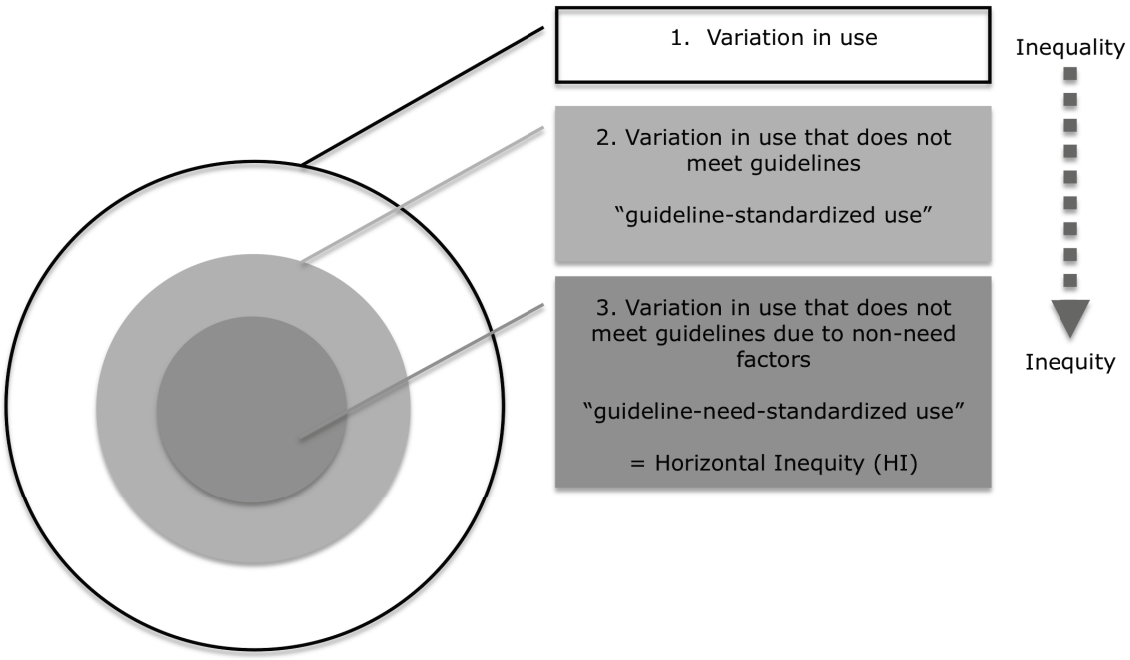

D
C
100
% Share of
Inequitable Health
Care Access
Concentration Curve
A
B
0
% Population Share
100
The lowest
SES
The highest
SES

5.10 Interpretation of Horizontal Inequity Index Results

| Equity stratifier | "Disadvantaged" | "Advantaged" |
|---|---|---|
| Income | Poor | Rich |
| Age | Old | Young |
| Sex | Male | Female |
| Distance | Far | Close |
| Rurality | Rural | Urban |
| Pro-advantaged | Worse access for: poor, old, male, far, rural | |
| $-1 \leq HI < 0$ | Better access for: rich, young, female, close, urban | |
| Pro-disadvantaged | Worse access for: rich, young, female, close, urban | |
| $0 < HI \leq 1$ | Better access for: poor, old, male, far, rural | |

## 5.11 Distinguishing Inequity From Inequality

This study attempted to distinguish inequality from inequity in access to care using clinical practice guidelines (CPGs) or benchmarks and patient need. Our approach followed the need-based approach widely used in analysis of inequity in health care in general populations and applied it to a clinical population by incorporating CPGs or benchmarks. Specifically, we began by describing the observed variation in use of cancer services, inequality (see figure below). We then moved from inequality to inequity in the following two steps. First, we identified variation in use that did not meet CPGs or benchmarks ("guideline-standardized use"). In the ideal world, CPGs or benchmarks are specific enough to solely and clearly distinguish inequity from inequality. However, in the real world, there might be legitimate reasons why patients do not receive guideline-recommended care, for example, those who have mobility problems may not be able to physically position themselves for radiotherapy. Second, we made need adjustments for the guideline-standardized use and focused only on variation in use that does not meet guidelines due to non-need factors ("guideline-need-standardized use"). We calculated the Horizontal Inequity (HI) Index of this guideline-need-standardized use. The HI is analogous to the Concentration Index after need-adjustment.


1. Variation in use
2. Variation in use that does not meet guidelines
"guideline-standardized use"
3. Variation in use that does not meet guidelines due to non-need factors
"guideline-need-standardized use"
= Horizontal Inequity (HI)
Inequality
Inequity

5.12 Detailed Analysis

For all analyses (the receipt and wait time analyses for radiotherapy and analyses for four end of life care indicators), we followed the following analytical steps. We use income-related inequity as the example below. By replacing income with age, sex, and geography, we can measure age-, sex-, and geography-related inequity in a similar manner. The analytical steps below are a modified version of the analysis steps described in van Doorslaer et al. (9)

Step 1: Calculated the degree of variation in use (inequality)

1a: Modeled health care use by all need and non-need factors

$$y_i = \alpha + \sum_j \beta_j x_{j,i} + \sum_k \gamma_k z_{k,i} + \varepsilon_i \qquad (1)$$

where $y_i$ is health care use for individual *i*, $x_j$ is a vector of need factors (clinically legitimate factors that affected health care use) for individual *i*, and $z_k$ is a vector of non-need factors (factors that should not but did affect health care use) for individual *i*. $\alpha$, $\beta$, and $\gamma$ are parameters and $\varepsilon_i$ is an error term.

1b: Estimated predicted probability of use for each individual based on model (1)

$$\hat{y}_i = \hat{\alpha} + \sum_j \hat{\beta}_j x_{j,i} + \sum_k \hat{\gamma}_k z_{k,i} \qquad (2)$$

With this procedure, the dichotomous dependent variable of health care use ( $y_i$) became a continuous variable bounded between 0 and 1 ( $\hat{y}_i$).

1c: Calculated the degree of variation in use by the Concentration Index

To compare variation in use at different points of care (e.g., radiotherapy and EOL care) and by different factor (e.g., income, age, and geography), it was convenient to express the degree of variation in use by an index. A Concentration Index of a variable $y$ was be computed as follows:

$$C = \frac{2}{y^m}\sum_{i=1}^{n}(y_i - y^m)(R_i - R^m) = \frac{2}{\mu}\mathrm{cov}(y_i, R_i) \qquad (3)$$

where $y^m$ is the sample mean of $y$, cov is the covariance, and $R_i$ is the relative fractional rank of the *i*th individual in terms of income. The Concentration Index took a value between -1 and 1, values between 0 and +1 suggesting pro-rich inequality and values between -1 and 0 suggesting pro-poor inequality. We calculated the Concentration Index of $\hat{y}_i$ from equation (2). This measured the degree of inequality rather than inequity.

Step 2: Estimated guideline-standardized use

2a: Identified guideline-directed use based on clinical practice guidelines (CPGs) or benchmarks

The first step to narrow down from any variation (inequality) to illegitimate variation (inequity) was to compare use against CPGs or benchmarks. We refered

to use recommended by CPGs or benchmarks as guideline-directed use, $y^{GD}$. For each service, we identified guideline-directed use, for example, for radiotherapy:

$$y^{GD} = 1.0 \tag{4}$$

where $y^{GD}$ is the probability of receiving radiotherapy as recommended by a clinical guideline.

2b: Estimated guideline-standardized use for each individual

For each individual in the data, we estimated guideline-standardized use, $y_i^{GS}$, as the difference between the guideline-directed probability of use the predicted probability of use. If the predicted probability of use was equal to or greater than the guideline-directed probability of use, $y_i^{GS}$ was given a value of zero.

$$y_i^{GS} = y^{GD} - \hat{y}_i \tag{5}$$

Step 3: Calculated the degree of variation in guideline-need-standardized use (inequity)

3a: Modeled guideline-standardized use by need and non-need factors

The next step to further narrow down from any variation (inequality) to illegitimate variation (inequity) was to identify variation in use that did not meet CPGs/benchmarks due to non-need factors. In other words, there may have been occasions where patients did not meet the CPG for acceptable reasons, and we needed need-adjustment for guideline-standardized use. For this, first, we modeled guideline-standardized use from equation (5) by need and non-need factors:

$$y_i^{GS} = \delta + \sum_l \zeta_l x_{l,i} + \sum_p \eta_p z_{p,i} + \varepsilon_i \qquad (6)$$

where $y_i^{GS}$ is the guideline-standardized use for individual *i*, $x_l$ is a vector of need factors (clinically legitimate factors that affected health care use) for individual *i*, and $z_p$ is a vector of non-need factors (factors that should not but did affect health care use) for individual *i*. $\delta$, $\zeta$, and $\eta$ are parameters and $\varepsilon_i$ is an error term.

3b: Calculated the Concentration Index of the guideline-standardized use

Using equation (3), we then calculated the Concentration Index of the guideline-standardized use, $C^{GS}$.

3c: Calculated the Concentration Index of the guideline-need-standardized use (inequity) by decomposing 3b

From equation (6), we estimated the contributions of need and non-need factors to the guideline-standardized use. Partial elasticities of the guideline-need-standardized use with respect to each non-need factor $p$ (the percentage change in

the guideline-need-standardized use, $y_i^{GS}$, from a percentage change in the non-need factor, $z_p$) was defined as:

$$\theta_p = \frac{\eta_p z_p^m}{y^m} \tag{7}$$

where $y^m$ is the population mean of $y$, and $z_p^m$ is the population mean of $z_p$.

Following Wagstaff, van Doorslaer, and Watanabe (2003), (10) the Concentration Index from 3b was then "decomposed" as follows:

$$C^{GS} = \sum_l \theta_l C_{x,l} + \sum_p \theta_p C_{z,p} + GC_\varepsilon \tag{8}$$

The first term was the partial contribution of the need factors to the Concentration Index of the guideline-standardized use, and the second term was the partial contribution of the non-need factors. The last term was for the error term. Our interest was the second term, the Concentration Index of the guideline-standardized use due to non-need factors or the guideline-need-standardized use. This indicated inequity.

5.13 Stata Code

```
*Inequity calculations (Started: February 1, 2010      Last updated: April 25, 2010)
*****THIS DATASET IS FOR the EOL INDICATOR - location of death in the
examination of income-related inequity

set memory 500m
set matsize 500
log using "/Users/andremaddison/desktop/Thesis/Thesis docs/Stata
code\05a_eol_dthloc.smcl", replace
use "/Users/andremaddison/desktop/Thesis/Analysis\02_eol.dta"

************************************************************
********Models for use by all need and non-need facotrs*****
************************************************************
/***Create dummy independent variables***/
char agecat [omit] 4  /* use "4"="<60 at death" as reference  */
char dxdth_cat [omit] 1  /* use "1"="<100km" as reference  */
char elixhauser [omit] 0  /* use "1"="0 conditions" as reference  */
char incomecat [omit] 1  /* use "1"="<30" as reference  */
char female [omit] 0  /* use "1"="male" as reference  */
char urban [omit] 0  /* use "1"="rural" as reference  */
char stages [omit] 4  /* use "4"="stage 4" as reference  */
char er_cat [omit] 1  /* use "1"="0 Er visits" as reference  */
char region [omit] 1 /* use "1"="CDHA" as reference  */
char ltcresident [omit] 0 /* use "0" = No ltc visit in the last 6 month as reference */
char yeardth [omit] 1 /*use "1" = died 2001-2002*/
```

```
**********************************************************************
********Logistic regression analysis of all need and non-need variables****
**********************************************************************
xi: logit dthloc i.dxdth_cat i.elixhauser i.incomecat i.agecat i.female i.urban i.stages
i.er_cat i.region i.ltcresident i.yeardth , or

rename _Iyeardth_2 year03
rename _Iyeardth_3 year04
rename _Iyeardth_4 year05
rename _Iyeardth_5 year06
rename _Iyeardth_6 year07to09
rename _Iagecat_1 age80
rename _Iagecat_2 age70
rename _Iagecat_3 age60
rename _Ifemale_1 fem
rename _Ielixhause_1 elixone
rename _Ielixhause_2 elixtwomore
rename _Iincomecat_2 income30
rename _Iincomecat_3 income45
rename _Iurban_1 urb
rename _Istages_1 stages1
rename _Istages_2 stages2
rename _Istages_3 stages3
rename _Istages_5 stagesUNK
rename _Iregion_2 CB
rename _Iregion_3 South
rename _Iregion_4 East
rename _Ier_cat_0 ER1more
rename _Idxdth_cat_2 dxdth100
rename _Idxdth_cat_3 dxdth300
rename _Idxdth_cat_4 dxdth750
```

```
rename  _Iltcreside_1 ltcvisit

*define variables
global dxdthglob "dxdth100 dxdth300 dxdth750"
global ageglob " age60 age70 age80"
global sexglob "fem"
global elixglob " elixone elixtwomore"
global incomeglob " income30 income45"
global urbanglob "urb"
global stageglob " stages2 stages3 stages1 stagesUNK"
global regionglob "CB South East"
global erglob "ER1more"
global ltcglob "ltcvisit"
global yearglob "year03 year04 year05 year06 year07to09"


**********Assigning Need and Non-need**********
global need " elixone elixtwomore  stages2 stages3 stages1 stagesUNK "
global Z " age60 age70 age80 fem income30 income45 urb South East CB ER1more
dxdth100 dxdth300 dxdth750 ltcvisit year03 year04 year05 year06 year07to09"


quietly logit dthloc $need $Z
drop if e(sample)~=1

logistic dthloc $need $Z
test elixone elixtwomore
test stages1 stages3 stages2 stagesUNK
test age60 age70 age80
test fem
test income30 income45
```

```
test CB South East
test ltcvisit
test ER1more
test dxdth100 dxdth300 dxdth750
test year03 year04 year05 year06 year07to09

**********predicting the individual probability of dying outside of hospital*******
predict dthloc_p

*************************************************************************
/*************** UNSTANDARDISED CONCENTRATION INDEX   ***********
*************************************************************************
sort incomecat, stable
gen rj=(_n-1)/_N
gen r=rj+0.5/_N
quietly sum r
sca var_r = r(Var)

egen rank = rank(incomecat), unique
tsset rank
newey dthloc_p r, lag(1)
nlcom 2*var_r*(_b[r]/(_b[_cons]+0.5*_b[r]))
mat coef=r(b)
mat var=r(V)
sca CI1=coef[1,1]
sca se1=sqrt(var[1,1])
sca t1=CI1/se1
```

```
**************************************************************************
/*************** Calculating Guideline-predicted use**********************
**************************************************************************
/* 0.4418 is the benchmark for the dying outside of hospital calculated using the Pared-
mean method    */


egen m_p= mean(dthloc_p)
gen gs_p= 0.4418-dthloc_p

recode gs_p (min/0=0)     /* To eliminate negative values*/
egen m_gs_p= mean(gs_p)
hist gs_p


**************************************************************************
/*************** GUIDELINE-STANDARDIZED CONCENTRATION INDEX*****
**************************************************************************

newey gs_p r, lag(1)
nlcom 2*var_r*(_b[r]/(_b[_cons]+0.5*_b[r]))
mat coef=r(b)
mat var=r(V)
sca CI2=coef[1,1]
sca se2=sqrt(var[1,1])
sca t2=CI2/se2

display "unstandardised CI:", CI1, "stand. error", se1, "t-ratio:", t1
di "Guideline-standardized CI:", CI2, "stand. error", se2 "t-ratio:", t2
```

```
/*****************************************************************
/**************      DECOMPOSITION OF INEQUALITY IN UTILISATION *****
/*****************************************************************

/******** DECOMPOSITION USING OLS *****/

quietly regress gs_p $need $Z

/** CONTRIBUTIONS OF NEED FACTORS **/

sca need=0
foreach incomecat of global need {
        qui {
                sca b_`incomecat' = _b[`incomecat']

                corr r `incomecat', c
                sca cov_`incomecat' = r(cov_12)
                                sum `incomecat'
                sca m_`incomecat' = r(mean)
                                sca elas_`incomecat' =
(b_`incomecat'*m_`incomecat')/m_gs_p
                sca CI_`incomecat' = 2*cov_`incomecat'/m_`incomecat'
                sca con_`incomecat' = elas_`incomecat'*CI_`incomecat'
                sca prcnt_`incomecat' = con_`incomecat'/CI2

                sca need=need+con_`incomecat'

        }
        di "`incomecat' elasticity:", elas_`incomecat'
        di "`incomecat' concentration index:", CI_`incomecat'
        di "`incomecat' contribution:", con_`incomecat'
```

```
	di "`incomecat' percentage contribution:", prcnt_`incomecat'
}


/** SPLIT NEED CONTRIBUTION INTO co-morbidities and stage **/

sca need=0
foreach incomecat of global need {
	sca need=need+con_`incomecat'
}
di "need contribution:"		need
di "percentage contribution of need factors", need/CI2

sca elixglob=0
foreach incomecat of global elixglob {
	sca elixglob=elixglob+con_`incomecat'
}
di "elixglob:"	elixglob
di "percentage contribution of elixglob", elixglob/CI2


sca stageglob=0
foreach incomecat of global stageglob {
	sca stageglob=stageglob+con_`incomecat'
}
di "stageglob contribution:"	stageglob
di "percentage contribution of stageglob", stageglob/CI2


/** CONTRIBUTIONS OF NON-NEED FACTORS **/
```

```
sca nonneed=0
foreach incomecat of global Z {
	qui {
		sca b_`incomecat' = _b[`incomecat']

		corr r `incomecat', c
		sca cov_`incomecat' = r(cov_12)

		sum `incomecat'
		sca m_`incomecat' = r(mean)

		sca elas_`incomecat' = (b_`incomecat'*m_`incomecat')/m_gs_p
		sca CI_`incomecat' = 2*cov_`incomecat'/m_`incomecat'
		sca con_`incomecat' = elas_`incomecat'*CI_`incomecat'
		sca prcnt_`incomecat' = con_`incomecat'/CI2

		sca nonneed=nonneed+con_`incomecat'
	}
	di "`incomecat' elasticity:", elas_`incomecat'
	di "`incomecat' concentration index:", CI_`incomecat'
	di "`incomecat' contribution:", con_`incomecat'
	di "`incomecat' percentage contribution:", prcnt_`incomecat'
}


/** SPLIT NON-NEED (Z) CONTRIBUTION INTO age sex urban income dha ERvisits
**/

sca Z=0
foreach incomecat of global Z {
	sca Z=Z+con_`incomecat'
```

```
}
di "Z contribution:"     Z
di "percentage contribution of Z factors", Z/CI2

sca incomeglob=0
foreach incomecat of global incomeglob {
        sca incomeglob=incomeglob+con_`incomecat'
}
di "incomeglob contribution:"incomeglob
di "percentage contribution of incomeglob", incomeglob/CI2

sca ageglob=0
foreach incomecat of global ageglob {
        sca ageglob=ageglob+con_`incomecat'
}
di "ageglob:"   ageglob
di "percentage contribution of ageglob", ageglob/CI2

sca sexglob=0
foreach incomecat of global sexglob {
        sca sexglob=sexglob+con_`incomecat'
}
di "sexglob contribution:"      sexglob
di "percentage contribution of sexglob", sexglob/CI2


sca urbanglob=0
foreach incomecat of global urbanglob {
        sca urbanglob=urbanglob+con_`incomecat'
}
di "urbanglob contribution:"   urbanglob
```

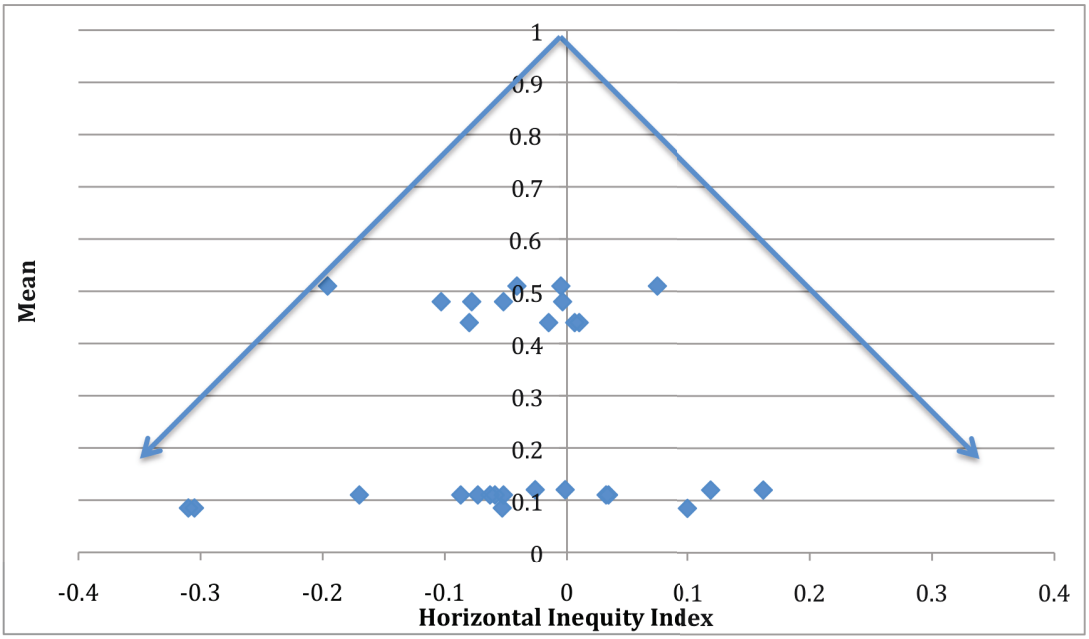
```
di "percentage contribution of urbanglob", urbanglob/CI2

sca regionglob=0
foreach incomecat of global regionglob {
        sca regionglob=regionglob+con_`incomecat'
}
di "regionlob contribution:"    regionglob
di "percentage contribution of regionglob", regionglob/CI2

sca erglob=0
foreach incomecat of global erglob {
        sca erglob=erglob+con_`incomecat'
}
di "erglob contribution:"       erglob
di "percentage contribution of erglob", erglob/CI2

sca dxdthglob=0
foreach incomecat of global dxdthglob {
        sca dxdthglob=dxdthglob+con_`incomecat'
}
di "dxdthglob contribution:"   dxdthglob
di "percentage contribution of dxdthglob", dxdthglob/CI2

sca ltcglob=0
foreach incomecat of global ltcglob {
        sca ltcglob=ltcglob+con_`incomecat'
}
di "ltcglob contribution:"      ltcglob
di "percentage contribution of ltcglob", ltcglob/CI2

sca yearglob=0
```

```
foreach incomecat of global yearglob {
        sca yearglob=yearglob+con_`incomecat'
}
di "yearglob contribution:"     yearglob
di "percentage contribution of yearglob", yearglob/CI2

di "Inequality due to need factors:", need
di "Inequality due to non-need factors:", nonneed
sca HI = CI2 - need
di "Horizontal Inequity Index:", HI

log close
```

5.14 Horizontal Inequity Index sensitivity to the mean

As discussed in Manuscript 2, during the analysis we identified the HI's sensitivity to the mean probability of achieving each access outcome. The table below presents additional details. Because we applied CPGs for the radiotherapy component, the guideline probability of use was 1.0 of all 3 outcomes. In contrast, for EOL outcomes we calculated pared-mean benchmarks for the guideline probability of use (0.73, 0.50, 0.88, 0.44). We then calculated the guideline-standardized use for each outcome, by subtracting the guideline probability of use by each individuals predicted probability of use. Due to the difference in guideline used, the mean of guideline-standardized use was systematically different between the radiotherapy analyses and EOL care analyses. The figure below demonstrates the HI values in relation to the mean of the guideline-standardized use. The cluster positioned at a mean of 0.5 at the radiotherapy HI and the cluster at 0.1 is the EOL HI. To accommodate for the variation in mean we applied the Wagstaff Normalization technique, as described in Manuscript 2. (11)

| | | Guideline probability of use | Mean guideline-standardized use |
|---|---|---|---|
| Radiotherapy | Receipt | 1.0 | 0.51 |
| | Wait time 1 | 1.0 | 0.44 |
| | Wait time 2 | 1.0 | 0.48 |
| End-of-life care | Registration to PCP | 0.73 | 0.085 |
| | Timing of PCP registration | 0.50 | 0.11 |
| | ER visits | 0.88 | 0.12 |
| | Location of death | 0.44 | 0.12 |




As discussed in manuscript 2, we conducted a sensitivity analysis to test the Wagstaff Normalization technique. Below are a subset of the results of the sensitivity analysis that compared adjusted HI values after Normalization compared to HI values when both EOL and radiotherapy benchmarks were calculated using the Pared-mean method. For simplification we report only the HI values for income-related inequity, though the results for the other equity stratifiers were also similar between the normalization and Pared-mean benchmarks.

| Access indicator | HI results – Wagstaff Normalization | HI results – Pared-mean benchmarks |
|---|---|---|
| Receipt of clinically recommended treatment for rectal cancer | -0.010 | -0.0013 |
| Wait time 1 | -0.027 | -0.029 |
| Wait time 2 | -0.150 | -0.12 |

| | | |
|---|---|---|
| Registration to a PCP | -0.075 | -0.069 |
| Timing of PCP registration | -0.072 | -0.064 |
| ER visits in the last 30 days of life | 0.013 | 0.011 |
| Location of death | -0.089 | -0.079 |

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