Oncology Care in Rural Northern New England

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Comments and suggestions on this report are welcome and can be forwarded to the Northern New England Clinical Oncology Society.

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Executive Summary

The Northern New England Clinical Oncology Society embarked on a study to assess whether there was a disparity in cancer care delivered in rural and urban areas of New Hampshire, Maine, and Vermont. The work undertaken here was to extend the findings initiated by the Maine cancer consortium. Clinical indicators of cancer care served as surrogate markers to look for discrepancies in care delivered in rural areas when compared to urban areas in colon and breast cancer patients. The three respective state cancer coalitions, registrars, hospitals, physicians, epidemiologists, and statisticians developed a working group that shared resources, streamlined data access, and developed uniform definitions so that almost 9000 patient records in 79 separate institutions could be closely evaluated. The ability to access data in such a large geographical area enabled a statistically valid comparison that would not be possible if it were confined to one state. The goal was to take a snapshot of cancer care delivered in Northern New England (NNE) during 2003 and 2004. Evaluation of differences in care offered in rural areas could be assessed to identify needs and barriers that could be addressed.

The results showed several interesting findings. Breast cancer patients in urban communities were diagnosed more often with non–invasive breast cancer than patients living in rural areas. This important finding may have several explanations including access and availability to screening, or ability to obtain or interpret biopsies in rural areas. Further studies will need to clarify this finding. Moreover, breast cancer patients in urban areas also had more sentinel lymph node (SLN) procedures than their rural counterparts. The SLN procedure was diffusing into the community from major teaching institutions in NNE and replacing the previous standard of regional lymph node dissection during this time. The ability to capture community acceptance/expertise of a new therapy, i.e. SLN, over time is also an important finding. It would be interesting to see how rapidly this (and other) new technologies are accepted and utilized in the rural community setting. Breast cancer patients undergoing SLN also received more post lumpectomy radiation therapy (RT) than patients who did not receive SLN. Even though no geographical variation between rural and urban areas was discerned, it would suggest that patients with access to a new technology also had easier access to RT. Defining variations in access to care therefore may be better measured if we looked at the difficulty patients may have in getting to the institutions where the care is delivered (i.e. driving times). The same issue was found to be true in colon cancer patients. Post operative chemotherapy is usually recommended in patients with Stage III colon cancer. A significantly higher proportion of patients received this adjuvant chemotherapy in urban rather than rural areas. The significance of these findings will require further testing and evaluation.

One difficulty the working group faced was the retrospective collection of data and callbacks. The study captured one point in time and it would be important to capture these surrogate markers (or other relevant data) again to assess whether access to care in NNE is getting better or worse. Continuing to do this work prospectively will enable us to collect data in a scientifically valid and instructive way, and hopefully would give us an ongoing tool to clarify some of the issues noted here and find strengths and weakness in the fragile care network now in place. The map shown on page 8 illustrates accessible points into the system. Are these sufficient? Do we need more resources? Where? The answer to these questions will be critical if we hope to cure more patients with cancer. The development of new technology and therapy will not save lives if patients do not have access to them. The future will only improve if important tools to measure how we do over time are developed and that is and continues to be the major goal of this study. Before we can break down barriers to care we have to see if and where they exist.

Table of Contents

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American Cancer Society
Maine CDC, *formerly Maine Bureau of Health*
Maine Cancer Consortium
Maine Cancer Registry
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NEW HAMPSHIRE

NCI/CIS Partnership Program
New Hampshire Comprehensive Cancer Collaboration
New Hampshire Department of Health and Human Services, Office of Health Statistics and Data Management
New Hampshire State Cancer Registry

VERMONT

American Cancer Society
Comprehensive Cancer Control Program
Vermont Cancer Registry
Vermont Department of Health
Vermonters Taking Action Against Cancer

Healthcare Facilities and Treatment Centers

MAINE

Blue Hill Memorial Hospital
Blue Hill, ME 04614-0823

Bridgton Hospital
Bridgton, ME 04009

Calais Regional Hospital
Calais, ME 04619-1398

Cary Medical Center
Caribou, ME 04736-2599

Central Maine Medical Center
Lewiston, ME 04240-0305

Coastal Cancer Treatment Center
Bath, ME 04530

Down East Community Hospital
Machias, ME 04654

Eastern Maine Medical Center
Bangor, ME 04401-6674

Franklin Memorial Hospital
Farmington, ME 04938-9990

Henrietta D Goodall Hospital
Sanford, ME 04073-2645

Houlton Regional Hospital
Houlton, ME 04730-9998

Inland Hospital
Waterville, ME 04901-4595

Maine Coast Memorial Hospital
Ellsworth, ME 04605-1599

Maine Medical Center
Portland, ME 04102-3175

MaineGeneral Medical Center
Augusta, ME 04330

MaineGeneral Medical Ctr
Waterville, ME 04901-4974

Mayo Regional Hospital
Dover-Foxcroft, ME 04426-1099

Mercy Hospital of Portland
Portland, ME 04101-3795

Mid Coast Hospital
Brunswick, ME 04011

Miles Memorial Hospital
Damariscotta, ME 04543-9767

Millinocket Regional Hospital
Millinocket, ME 04462-1298

Mount Desert Island Hospital
Bar Harbor, ME 04609-0008

Northern Maine Medical Center
Fort Kent, ME 04743-1497

Parkview Adventist Medical Ctr
Brunswick, ME 04011-3398

Penobscot Bay Medical Center
Rockport, ME 04856-4240

Penobscot Valley Hospital
Lincoln, ME 04457-0368

Redington-Fairview Gen Hosp
Skowhegan, ME 04976

Rumford Hospital
Rumford, ME 04276-2145

Scarborough Radiation Therapy Ctr
Scarborough, ME 04074

Sebasticook Valley Hospital
Pittsfield, ME 04967-1199

Southern Maine Medical Center
Biddeford, ME 04005-9496

St Andrews Hospital
Boothbay Harbor, ME 04538-1732

St Joseph Hospital
Bangor, ME 04401-3897

St Mary's Regional Med Center
Lewiston, ME 04240

Stephens Memorial Hospital
Norway, ME 04268-1297

The Aroostook Medical Center
Presque Isle, ME 04769-3171

Veterans Affairs Med Center
Togus, ME 04330

Waldo County General Hospital
Belfast, ME 04915-6072

York Hospital
York, ME 03909-1099

Special thanks to the healthcare facilities and treatment centers for the provision of high quality data reporting, an essential element of this project.

Healthcare Facilities and Treatment Centers

NEW HAMPSHIRE

Alice Peck Day Mem Hospital
Lebanon, NH 03766-2650

Androscoggin Valley Hospital
Berlin, NH 03570-3531

Catholic Medical Center
Manchester, NH 03102-3770

Cheshire Medical Center
Keene, NH 03431-1718

Concord Hospital
Concord, NH 03301-2598

Cottage Hospital
Woodsville, NH 03785-2001

Dartmouth-Hitchcock Med Ctr
Lebanon, NH 03756-0001

Elliot Hospital
Manchester, NH 03103-3599

Exeter Hospital
Exeter, NH 03833

Franklin Regional Hospital
Franklin, NH 03235-1299

Frisbie Memorial Hospital
Rochester, NH 03867-3297

Huggins Hospital
Wolfeboro, NH 03894-4455

Lakes Region General Hospital
Laconia, NH 03246-3298

Littleton Regional Hospital
Littleton, NH 03561-3436

Memorial Hospital
North Conway, NH 03860-5001

Monadnock Community Hospital
Peterborough, NH 03458-1295

Nashua Regional Cancer Center
Nashua, NH 03063

New London Hospital
New London, NH 03257-4570

Parkland Medical Center
Derry, NH 03038-2750

Portsmouth Regional Hospital
Portsmouth, NH 03801-7004

Southern New Hampshire Med Ctr
Nashua, NH 03060-3925

Speare Memorial Hospital
Plymouth, NH 03264-1199

St Joseph Hospital
Nashua, NH 03060-3688

Upper Connecticut Vly Hospital
Colebrook, NH 03576-9533

VA Medical Center
Manchester, NH 03104

Valley Regional Hospital
Claremont, NH 03743-2099

Weeks Medical Center
Lancaster, NH 03584-3561

Wentworth-Douglass Hospital
Dover, NH 03820-2589

Special thanks to the healthcare facilities and treatment centers for the provision of high quality data reporting, an essential element of this project.

Healthcare Facilities and Treatment Centers

VERMONT

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Brattleboro, VT 05301-3498

Central Vermont Medical Center
Barre, VT 05641-9060

Copley Hospital
Morrisville, VT 05661-9209

Fletcher Allen Health Care
Burlington, VT 05401-1429

Gifford Medical Center
Randolph, VT 05060-1381

Grace Cottage Hospital
Townshend, VT 05353-0216

Mt Ascutney Hosp and Hlth Ctr
Windsor, VT 05089-9702

Norris Cotton Cancer Center North
St. Johnsbury, VT 05819

North Country Hosp & Hlth Ctr
Newport, VT 05855-9329

Northeastern Vermont Reg Hosp
Saint Johnsbury, VT 05819-9962

Northwestern Medical Center
Saint Albans, VT 05478-1734

Porter Medical Center
Middlebury, VT 05753-8606

Rutland Regional Medical Ctr
Rutland, VT 05701-4595

Southwestern Vermont Med Cntr
Bennington, VT 05201

Springfield Hospital
Springfield, VT 05156-2003

Veterans Affairs Med Center
White River Junction, VT 05009-0001

Special thanks to the healthcare facilities and treatment centers for the provision of high quality data reporting, an essential element of this project.

Abstract

The state cancer plans of Maine, New Hampshire and Vermont have strong similarities relating to their goals of assessing access to quality care, and they include specific strategies to utilize state cancer registry data to evaluate quality of care issues in the diagnosis, staging and disease management. A tri-state epidemiological study evaluating indicators of quality care in breast cancer and colon cancer patients was conducted to assess whether limits to oncology care and access exist in rural northern New England. A total of 8,982 patient records at 79 hospitals were reviewed in Vermont, New Hampshire, and Maine during 2003 and 2004.

Cooperation by the large collaborative group of the three respective states enabled the working group to define a common methodology to collect aggregate data for comparison. Several operational differences among the three states' cancer registries were overcome in order to obtain a standardized and accurate data set. The Rural and Urban Residence Commuting Area (RUCA) classification scheme was utilized to classify residence into three types – small rural, large rural, and urban areas.

A total of 6,134 women with breast cancer were evaluated. A higher percentage of younger women (<50 years old) were diagnosed in urban areas (27.4%) than large rural areas (22.3%) or small rural areas (20.4%). More non invasive breast cancer was diagnosed in urban areas as well, but no associated increase in early Stage I breast cancer was seen in urban areas. Breast conserving surgery was performed in similar proportions in rural and urban areas, but sentinel lymph node (SLN) dissection was more common in urban areas (44.1%) than large rural (39.8%) and small rural areas (37.8%). A positive correlation between SLN dissection and post lumpectomy radiation therapy was seen. SLN patients received radiation therapy more frequently after lumpectomy than patients who underwent regional lymph node dissections without SLN (85.9% versus 75.5%). However, the rates of post lumpectomy radiation therapy in small and large rural (70.9% and 73.9% respectively) versus urban areas (72.2%) showed no significant difference. Thus, the explanation for the higher use of radiation therapy in post lumpectomy patients undergoing some form of SLN procedure is not explained by geographical differences in this study.

Colon cancer patients evaluated in the three residential classifications also showed consistencies in certain characteristics. No significant difference was noted in the distribution of stage (Stage 0,I,II,III,IV) at presentation between rural and urban areas. Similar to the results from breast cancer, patients with early Stage I colon cancer were diagnosed at a similar frequency in small rural areas (26.0%) as in urban areas (23.2%). The delivery of adjuvant therapy in Stage III colon cancer was less frequent in rural areas (57.3%) when compared to urban areas (64.7%) in this study, and this finding was statistically significant.

The ability for a patient to access care in rural areas may be limited both by patient and network/provider considerations. Providing adequate care in rural areas requires coordinated planning and resource management to limit barriers to care in cancer patients. State boundaries do not serve as an isolated barrier but differences in population density and commuting distances may play a significant role. This study illustrated areas where data were comparable in rural and urban areas of northern New England, such as the use of breast conserving surgery, proportion of positive nodes and stage at presentation for breast and colon cancer, and the utilization of post lumpectomy radiation therapy. The study did reveal differences in care offered to urban patients versus rural patients. Breast cancer patients in urban northern New England presented at a younger age and with a higher proportion of Stage 0 (i.e. non invasive disease). Colon cancer patients with Stage III disease proportionally received adjuvant chemotherapy less often in rural areas as opposed to their urban counterparts.

These differences may or may not result in overall survival differences but do point out that there are significant differences in care between rural and urban areas that should be studied further. If these disparities increase, or the fragile network in place is disrupted, then we would expect to see more glaring discrepancies than those noted here.

We hope the state cancer partnerships in northern New England will use these data to plan, implement, and evaluate activities that are targeted toward improving access to high quality oncologic care.

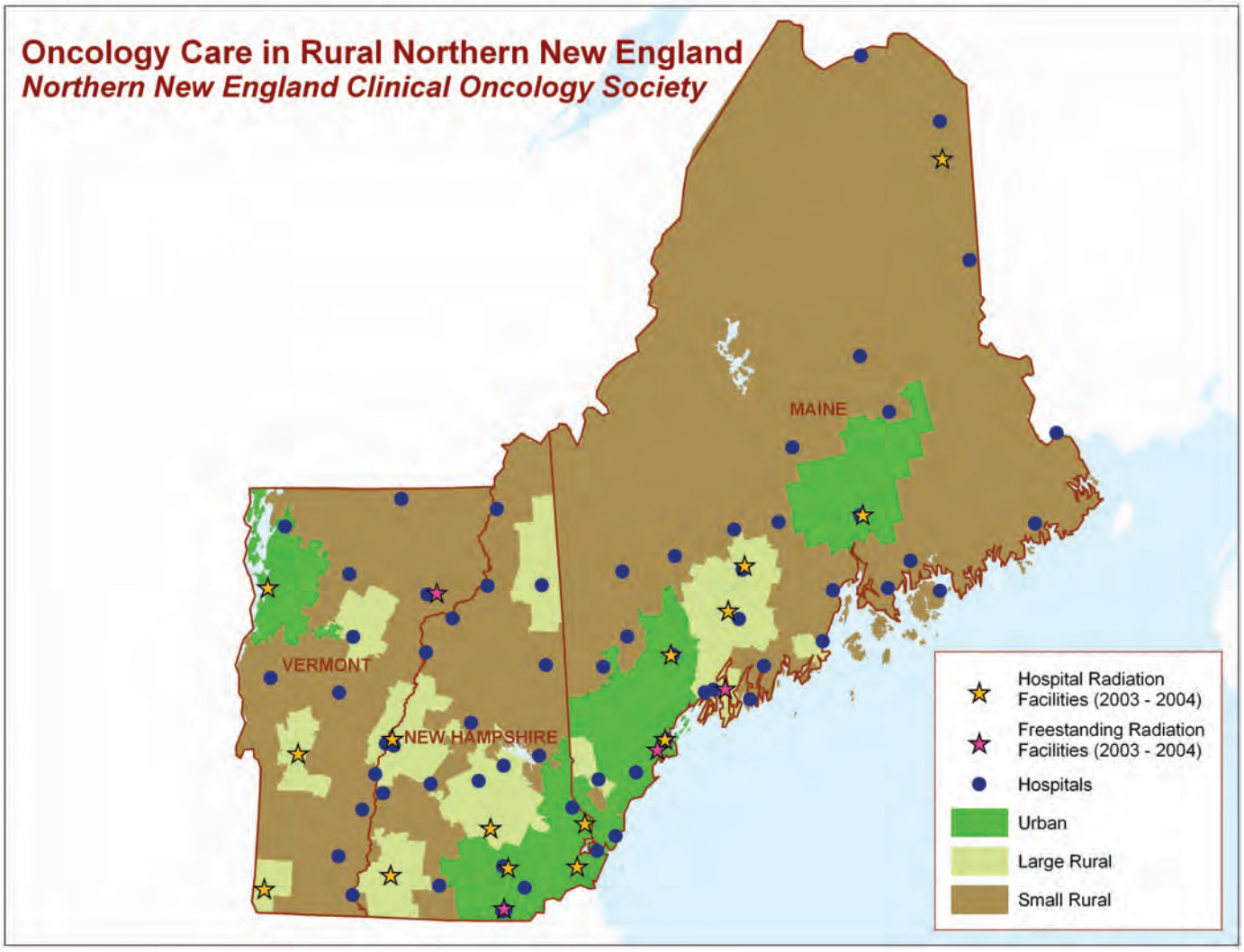
Introduction

The Northern New England Clinical Oncology Society (NNECOS) membership includes community and academic oncologists, oncology nurses, mid-level practitioners and practice managers. NNECOS' mission is to assure the availability of and access to high quality oncology care in the region.

The northern New England area of Vermont, Maine, and New Hampshire has both rural and urban areas covering a geographic area comparable to the State of New York. There are 79 hospitals in the region. Oncology services are provided in hospital based oncology practices, three large private oncology practices, two large teaching institutions, and their respective satellite clinics. These services are supplemented by 18 radiation therapy units, including hospital-based and outpatient facilities, which are illustrated in ***Figure 1***.

Of the 79 hospitals identified in northern New England, 37 are in Maine; 27 are in New Hampshire; and 15 are in Vermont. The hospitals are located in urban (25.3%), large rural (22.7%), and small rural (51.8%) locations. During 2003-2004 there were 18 radiation treatment facilities: eight in Maine, seven in New Hampshire, and four in Vermont. Fifteen (78.9%) were hospital-based while the remaining four radiation treatment facilities were freestanding. The distribution of these treatment centers in urban, large rural and small rural locations was 47.3%, 42.1% and 10.5%, respectively.

Figure 1. Study region showing type of residence and healthcare facilities.



The primary goal of the *Oncology Care in Rural Northern New England* project is to assess whether limits to oncology care access exist in rural northern New England. It is the first attempt to collaborate across state borders and to draw upon the clinical expertise of the NNECOS leadership to identify, track and report indicators of quality cancer care in order to identify gaps/needs of cancer patients in rural areas.

The project aims are threefold:

1. Conduct a unified data collection project across Maine, New Hampshire, and Vermont, thereby strengthening the collaboration among the Northern New England Clinical Oncology Society, the Maine Cancer Consortium, Vermonters Taking Action Against Cancer, and the New Hampshire Comprehensive Cancer Collaboration.

2. Evaluate colon cancer patients across the tri-state region to: a) identify the stage at initial presentation and determine if patients in rural areas present with higher stage of cancer; b) assess whether there is a difference in the rates of adjuvant chemotherapy for Stage IIB and III colorectal cancer in different geographical locations.

3. Determine the percentage of breast cancer patients who undergo sentinel lymph node dissection (SNL) and identify the percentage of women who receive post-lumpectomy radiation therapy.

A collaboration of this size and complexity requires support at the local, state, and national levels. Over the course of the year, the project team expanded to include medical and radiation oncologists, surgeons, representatives from the state departments of health, cancer registries at the state and local level, comprehensive cancer control programs, statewide cancer care consortiums, medical centers, the American Cancer Society and the National Cancer Institute.

The Centers for Disease Control and Prevention (CDC) has been committed to state cancer planning as a mechanism to promote comprehensive cancer control. Comprehensive cancer control is defined as a collaborative process through which a community and its partners pool resources and align specific tactics to promote prevention and early detection, expand access to quality cancer care services and enhance cancer survivorship. The CDC supports cancer surveillance through the National Program for Cancer Registries (NPCR). State cancer registry data are used to monitor and target cancer control activities related to access to care.

The Treatment Work Group of the Maine Cancer Consortium has previously assessed concordance with national cancer treatment guidelines for breast and colon cancer. The Consortium has used the findings to understand where adherence to clinical benchmarks could be improved. The three-state collaboration provides the opportunity to build upon Maine's analysis and investigate rural/urban differences in access to care.

The state cancer plans of Maine, New Hampshire and Vermont have strong similarities relating to their goals of assessing access to quality care, and they include specific strategies to utilize state cancer registry data to evaluate quality of care issues in the diagnosis, staging and disease management.

The Cancer Registrars Association of New England (CRANE) held their annual conference in October, 2008, in Burlington, Vermont. Because registry personnel from the tri-state area were all in one location, the project team felt this was an opportunity to garner the needed support of the registry staff; therefore, all registrars in the tri-state area were invited to a special dinner meeting. The project leader and other members of the project team presented the study to the approximately 20 registrars in attendance and requested their assistance in ensuring that high quality study data was available. At the conclusion, the registrars were excited about their role in providing data for a study that could bring about a meaningful change to the oncology care in the region.

Methods

Data Sources

Data were collected by the three central cancer registries of Maine, New Hampshire and Vermont. By law, each state is required to collect cancer incidence data for all cancers diagnosed or treated among residents of the three states. Case completeness for the three registries for diagnosis years 2003 and 2004 was estimated to be 95% or greater.[1]

Each central registry identified cases of colon and breast cancer diagnosed during the years 2003 to 2004. The variables of interest for the study were assessed for completeness and optimized by requesting updated or additional data from the reporting facilities. We used demographic data and the residence of each patient at the time of diagnosis. For colon cancer cases, data on the stage at diagnosis and surgical and chemotherapy treatments given within the first 6 months after diagnosis were collected. Similarly, for breast cancer cases, data on the stage at diagnosis, surgical and radiation therapy treatments given within the first 6 months after diagnosis were collected. Information on the use of sentinel lymph node dissection and the use of post-lumpectomy radiation therapy was collected.

For legal and logistical reasons, each state provided only aggregate data for the study, to avoid the release of identifiable personal health information outside each state. A SAS-based analysis program (SAS 9.2 Copyright 2002-2008 by SAS Institute Inc., Cary, NC, USA) was written for use by each state to extract pertinent aggregate data summaries, which were compiled and analyzed.

Definition of Rural and Urban Residence

We defined patients' residence using Rural-Urban Commuting Area (RUCA) classification scheme.[2] This classification system creates rural and urban categories at the US Census tract and ZIP code level by considering urbanization, population density, and commuting patterns. A RUCA code was assigned to each individual based on the zip code of their residence and grouped into three recommended categories: urban, large rural town and small rural town (***Figure 1***).

Derivation of Stage

For diagnosis years 2003 and 2004, the cancer registry community used two different staging systems to capture extent of disease at diagnosis. Cases diagnosed in 2003 were assigned a stage based on the American Joint Committee on Cancer (AJCC) TNM staging system. While TNM staging was also collected for cases diagnosed in 2004, it was derived through the Collaborative Stage system developed by the Collaborative Staging Task Force[3]. Collaborative staging is a coding system based on a set of data items put through algorithms that classify each case in multiple staging systems, including AJCC TNM. Because our data set included diagnosis years when stage was coded from both TNM (2003) and Collaborative Stage (2004), we developed an algorithm to generate a "best stage" based on the best available information on stage at diagnosis: 1) If the diagnosis year was 2004, collaborative stage was considered the "best stage". 2) If the diagnosis year was 2004 and collaborative stage was blank or if the diagnosis year was 2003, then AJCC TNM pathologic stage was taken. 3) If AJCC pathologic stage was blank or missing for this same group, then the AJCC TNM clinical stage was used.

Standard of Care Assumptions

The College of American Pathologists and AJCC recommend a minimum of 12 lymph nodes for adequate staging of colon cancer. For Stage IIB colon cancer, treating with adjuvant chemotherapy is controversial; however, the American Society of Clinical Oncology (ASCO) recommends consideration of adjuvant chemotherapy in a subset of Stage IIB patients, including those that are medically fit, inadequately staged (<12 nodes examined) and those with high risk features (T4 lesions, perforation, poorly differentiated histology). For Stage III colon cancers, surgical resection and adjuvant chemotherapy is recommended.[4,5]

For Stage 0, I, and II breast cancer, the recommended treatment is lumpectomy followed by radiation therapy (RT). The exceptions are patients age 70 or older, small tumor size (<1 cm), estrogen receptor antigen (ERA) positive cases, and patients with contraindications, including early pregnancy, prior radiation, and connective tissue disorders. Also recommended is sentinel lymph node surgery to provide accurate axillary staging. SLN surgery is controversial for Stage 0, but is the standard of care for Stage I and II.[6]

Data Analysis

We analyzed the data using SAS software. The total numbers and percents of cases in each category were tabulated overall by RUCA category then by stage and by treatment. To describe colon cancers by stage and by treatment, we excluded cases with unknown stage and unknown surgical and radiation treatment. To describe breast cancers by stage and by treatment, we excluded lobular carcinoma *in situ cases*. Breast cancers with unknown stage and unknown surgical and radiation treatment were also excluded. Comparisons were made using chi-squared tests. Where individual cells contained 5 or fewer cases, the case counts were suppressed.

Results

Breast Cancer

Through the three state cancer registries, we identified a total of 6,134 women diagnosed with breast cancer in the study period. For 85.4% of these women, this was a first diagnosis of cancer while 14.6% had a previous diagnosis of cancer. At the time of diagnosis, the mean age was 61 (SD: 13.9), and 87.0% had Stage 0-II disease.

We used chi-squared tests to assess the effect of residence on breast cancer diagnosis and treatment (***Table 1***). There were residence-related differences in the distribution of age categories at diagnosis ($p<0.001$), with a greater proportion of urban women diagnosed at a younger age. Tumor size at diagnosis also showed differences between rural and urban residents, with a greater proportion of patients living in a small rural area having larger tumors ($p=0.006$). The distribution of stage at diagnosis (0 through IV) also varied by residence ($p<0.001$) but without an easily interpretable pattern. In urban areas, proportionately more patients were diagnosed with non invasive breast cancer (Stage 0) than in rural areas, but fewer with Stage I. Combining the totals for Stages 0 and I shows similar proportions across the three residence categories (59.7%, 63.2% and 62.7% for small rural, large rural and urban, respectively). Metastatic disease at presentation was seen in similar proportions in both small rural and urban areas (3.4% versus 3.1%).

Table 1. Characteristics of 6,134 women in Northern New England diagnosed with breast cancer in 2003-2004.

	Small Rural		Large Rural		Urban		Total		
	No.	%	No.	%	No.	%	No.	%	p-value[a]
Age at Diagnosis									<0.001
≤ 49	363	20.4	293	22.3	835	27.4	1491	24.3	
50-64	639	36.0	482	36.7	1111	36.5	2232	36.4	
65-74	398	22.4	263	20.0	531	17.4	1192	19.4	
≥ 75	377	21.2	274	20.9	568	18.7	1219	19.9	
mean SD	*62*	*13.57*	*62*	*13.92*	*60*	*13.95*	*61*	*13.90*	
Primary Sequence									0.172
1st Primary	1535	86.4	1129	86.1	2575	84.6	5239	85.4	
Subsequent Primary	242	13.6	183	13.9	470	15.4	895	14.6	
Stage at Dx									<0.001[b,c]
0	338	19.0	251	19.1	755	24.8	1344	21.9	
I	724	40.7	579	44.1	1154	37.9	2457	40.1	
II	484	27.2	315	24.0	732	24.0	1531	25.0	
III	143	8.0	104	7.9	265	8.7	512	8.3	
IV	60	3.4	38	2.9	95	3.1	193	3.1	
NA	5	0.3	7	0.5	8	0.3	20	0.3	
Unknown	23	1.3	18	1.4	36	1.2	77	1.3	
Histology									0.021
Ductal	1108	62.4	792	60.4	1825	59.9	3725	60.7	
Lobular	192	10.8	137	10.4	302	9.9	631	10.3	
Ductal and Lobular	162	9.1	111	8.5	343	11.3	616	10.0	
Other	315	17.7	272	20.7	575	18.9	1162	18.9	
Tumor Size (cm)									0.006[c]
≤ 0.5	155	8.7	159	12.1	322	10.6	636	10.4	
0.6 to <1.0	244	13.7	192	14.6	363	11.9	799	13.0	
1 to <2	555	31.2	410	31.3	932	30.6	1897	30.9	
2 to <5	473	26.6	301	22.9	756	24.8	1530	24.9	
≥ 5	124	7.0	68	5.2	193	6.3	385	6.3	
Unknown	226	12.7	182	13.9	479	15.7	887	14.5	
Surgery									0.146
Lumpectomy	1060	59.7	819	62.4	1929	63.3	3808	62.1	
Mastectomy	614	34.6	420	32.0	947	31.1	1981	32.3	
No surgery	102	5.7	72	5.5	168	5.5	342	5.6	
Unknown, Other	1	0.1	1	0.1	1	0.0	3	0.0	
Lymph Node Dissection									<0.001[c]
Sentinel only	414	23.3	331	25.2	786	25.8	1531	25.0	
Regional only	595	33.5	428	32.6	770	25.3	1793	29.2	
Sentinel and regional	254	14.3	192	14.6	558	18.3	1004	16.4	
No dissection	507	28.5	355	27.1	924	30.3	1786	29.1	
Unknown	7	0.4	6	0.5	7	0.2	20	0.3	
Positive Lymph Nodes (LN)									0.206[d]
All negative	871	49.0	675	51.4	1461	48.0	3007	49.0	
1-3	282	15.9	190	14.5	456	15.0	928	15.1	
4-9	73	4.1	65	5.0	146	4.8	284	4.6	
≥ 10	39	2.2	23	1.8	53	1.7	115	1.9	
Pos LN, Unk #	4	0.2	1	0.1	11	0.4	16	0.3	
No LN dissection	491	27.6	342	26.1	887	29.1	1720	28.0	
Unknown if dissected	17	1.0	16	1.2	31	1.0	64	1.0	
Radiation									0.098[c]
Yes	866	48.7	682	52.0	1575	51.7	3123	50.9	
No	908	51.1	627	47.8	1470	48.3	3005	49.0	
Unknown	3	0.2	3	0.2	0	0.0	6	0.1	
ERA									0.179[e]
Positive	1138	64.0	860	65.5	1946	63.9	3944	64.3	
Negative	261	14.7	221	16.8	423	13.9	905	14.8	
Borderline	5	0.3	7	0.5	4	0.1	16	0.3	
Test not done	140	7.9	95	7.2	258	8.5	493	8.0	
Unknown	170	9.6	105	8.0	311	10.2	586	9.6	
Not collected[f]	63	3.5	24	1.8	103	3.4	190	3.1	
PRA									0.002[e]
Positive	944	53.1	708	54.0	1610	52.9	3262	53.2	
Negative	403	22.7	336	25.6	672	22.1	1411	23.0	
Borderline	29	1.6	27	2.1	8	0.3	64	1.0	
Test not done	155	8.7	102	7.8	314	10.3	571	9.3	
Unknown	182	10.2	115	8.8	338	11.1	635	10.4	
Not collected[f]	64	3.6	24	1.8	103	3.4	191	3.1	

[a]Chi-square test (Chi^2)

[b]Chi^2 excludes NA (Not Applicable).

[c]Chi^2 excludes unknown.

[d]Chi^2 compares all negative LN vs. all positive LN vs. no LN dissection, excluding unknown.

[e]Chi^2 compares positive vs. negative vs. test not done.

[f]Not collected=cases for which tumor marker was not required by a state registry.

Overall, 3,808 women (62.1%) underwent lumpectomy (59.7% small rural vs. 63.3% urban), 1,981 (32.3%) had mastectomy while 342 (5.6%) had no surgery. Of the entire cohort, 2,535 (41.3%) had sentinel lymph node sampling alone or with further axillary surgery. While there was no statistically significant difference in use of breast conserving surgery by residence, we observed differences in the use of sentinel lymph node sampling from 44.1% for urban women to 39.9% for women in large rural areas and 37.6% for women in small rural areas, respectively ($p<0.001$). The proportions of patients with any positive nodes, all negative nodes, or no dissection performed were independent of residence ($p=0.206$).

Among the 5,591 women who did undergo surgery, we evaluated the frequency of postoperative radiation therapy (RT) stratified by type of surgery (***Table 2***). Women aged ≥ 75 were significantly less likely than younger women to receive RT after lumpectomy (48.0% vs. 77.9%) or mastectomy (10.6% vs. 23.1%) ($p<0.001$) For Stage 0 (excluding LCIS), Stage I and Stage II invasive carcinoma, the use of adjuvant RT after lumpectomy varied significantly by stage (56.4%, 80.3% and 74.0% respectively) ($p<0.001$). Women with very small (≤0.5 cm) or larger (5+ cm) tumors had lower rates of RT after breast conserving surgery, (64.9% and 57.3% respectively) than women with intermediate sized tumors (76.4%).

The use of adjuvant RT after lumpectomy was positively associated with sentinel lymph node sampling ($p<0.001$). Patients with sentinel lymph node dissections (including the group that had both sentinel lymph node and regional lymph nodes dissected) had a higher rate of post lumpectomy RT utilization – 85.9% (1,517 of a total of 1,766 patients), compared to 75.5% (593 of 785 patients) who underwent regional lymph node dissection alone, and 48.0% (523 of 1090 patients) who did not undergo and lymph node sampling.

The use of adjuvant RT was also inversely associated with lymph node involvement ($p<0.001$). In the 1941 women who underwent mastectomy, there was an inverse association between post-mastectomy radiation therapy and age ($p<0.001$) and a positive association with tumor size 2cm or greater vs. <2cm ($p<0.001$), any lymph node dissection performed vs. not performed ($p<0.001$), nodal involvement vs. all negative ($p<0.001$) and late stage (III or IV) vs. early stage (0-II) disease ($p<0.001$).

Table 2. Surgery and radiation treatment among 5,591 women in Northern New England with breast cancer treated with surgery, 2003-2004.[a]

	Lumpectomy					Mastectomy					Total	
	No RT		Post-op RT		p-value[b]	No RT		Post-op RT		p-value[b]		
	No.	%	No.	%		No.	%	No.	%		No.	%
Age at Diagnosis					<0.001					<0.001		
≤ 49	188	18.5	635	24.1		379	24.6	156	38.9		1358	24.3
50-64	290	28.6	1094	41.5		515	33.4	139	34.7		2038	36.5
65-74	177	17.4	574	21.8		302	19.6	65	16.2		1118	20.0
≥ 75	360	35.5	332	12.6		344	22.3	41	10.2		1077	19.3
mean SD	*66*	*15.08*	*59*	*11.94*		*62*	*14.31*	*55*	*13.66*		*61*	*13.35*
Residence at Dx												
Small Rural	294	29.0	715	27.1		481	31.2	117	29.2		1607	28.7
Large Rural	206	20.3	582	22.1		324	21.0	87	21.7		1199	21.4
Urban	515	50.7	1338	50.8		735	47.7	197	49.1		2785	49.8
Primary Sequence												
1st Primary	831	81.9	2382	90.4		1215	78.9	364	90.8		4792	85.7
Subsequent Primary	184	18.1	253	9.6		325	21.1	37	9.2		799	14.3
Stage at Dx					<0.001[c]					<0.001[c]		
0	375	36.9	486	18.4		297	19.3	1	0.2		1159	20.7
I	355	35.0	1447	54.9		593	38.5	12	3.0		2407	43.1
II	214	21.1	608	23.1		499	32.4	152	37.9		1473	26.3
III	51	5.0	83	3.1		116	7.5	230	57.4		480	8.6
IV	20	2.0	11	0.4		35	2.3	6	1.5		72	1.3
Tumor Size (cm)					<0.001[d]					<0.001[d]		
≤ 0.5	153	15.1	283	10.7		157	10.2	5	1.2		598	10.7
0.6 to <1.0	157	15.5	475	18.0		138	9.0	6	1.5		776	13.9
1 to <2	268	26.4	1066	40.5		452	29.4	55	13.7		1841	32.9
2 to <5	218	21.5	537	20.4		492	31.9	184	45.9		1431	25.6
≥ 5	32	3.2	43	1.6		122	7.9	128	31.9		325	5.8
Unknown	187	18.4	231	8.8		179	11.6	23	5.7		620	11.1
Histology[a]												
Ductal	610	60.1	1755	66.6		946	61.4	220	54.9		3531	63.2
Lobular	56	5.5	158	6.0		147	9.5	69	17.2		430	7.7
Ductal and Lobular	95	9.4	263	10.0		162	10.5	66	16.5		586	10.5
Other	254	25.0	459	17.4		285	18.5	46	11.5		1044	18.7
Lymph Node (LN) Dissection[e]					<0.001[e]					<0.001[e]		
Sentinel only	163	16.1	995	37.8		343	22.3	18	4.5		1519	27.2
Regional only	192	18.9	593	22.5		713	46.3	262	65.3		1760	31.5
Sentinel + Regional	86	8.5	522	19.8		278	18.1	109	27.2		995	17.8
No dissection	567	55.9	523	19.8		203	13.2	10	2.5		1303	23.3
Positive Lymph Nodes (LN)					<0.001[f]					<0.001[f]		
All negative	288	28.4	1676	63.6		938	60.9	59	14.7		2961	53.0
1-3	112	11.0	357	13.5		295	19.2	147	36.7		911	16.3
4-9	31	3.1	59	2.2		63	4.1	101	25.2		254	4.5
≥ 10	10	1.0	19	0.7		34	2.2	77	19.2		140	2.5
Pos LN, Unk #	1	0.1	3	0.1		2	0.1	4	1.0		10	0.2
No LN dissection	564	55.6	517	19.6		202	13.1	9	2.2		1292	23.1
ERA[g]												
Positive	562	55.4	1886	71.6		989	64.2	294	73.3		3731	66.7
Negative	118	11.6	389	14.8		249	16.2	92	22.9		848	15.2
PRA[g]												
Positive	473	46.6	1567	59.5		809	52.5	245	61.1		3094	55.3
Negative	176	17.3	635	24.1		382	24.8	133	33.2		1326	23.7

[a]Cases excluded if stage and surgery are unknown, radiation treatment type unspecified or unknown, and histology of lobular carcinoma in situ.

[b]Chi-square test (Chi^2)

[c]Chi^2 compares Stages 0-II vs. III-IV.

[d]Chi^2 compares tumor size < 2 cm vs. ≥ 2 cm.

[e]Cases not shown if LN dissection unknown and if dissected LN unknown to be positive; Chi^2 excludes no dissection.

[f]Chi^2 compares all positive with all negative.

[g]Cases excluded if tumor marker borderline, unknown if positive or negative, or test not done or not collected.

When we analyzed only the 2,781 women with Stage I-III treated with lumpectomy (***Table 3***), we observed no differences in adjuvant RT utilization based upon residence (p=0.642) . However, residence was strongly associated with the type of lymph node sampling that was done (p<0.001).

Table 3. Characteristics of 2,781 women in Northern New England diagnosed with Stage I, II or III breast cancer, treated with lumpectomy, 2003-2004.

	Small Rural		Large Rural		Urban		Total		
	No.	%	No.	%	No.	%	No.	%	p-value[a]
Age at Diagnosis									0.003
≤ 39	22	2.8	21	3.3	55	4.1	98	3.5	
40-49	132	16.5	113	17.9	279	20.7	524	18.8	
50-64	296	37.0	234	37.0	494	36.6	1024	36.8	
65-74	203	25.4	129	20.4	243	18.0	575	20.7	
≥ 75	146	18.3	136	21.5	278	20.6	560	20.1	
mean SD	*62*	*13.02*	*62*	*13.69*	*61*	*13.71*	*61*	*13.56*	
Lymph Node (LN) Dissection									<0.001[b]
Sentinel only	299	37.4	259	40.9	551	40.8	1109	39.9	
Regional only	249	31.2	187	29.5	324	24.0	760	27.3	
Sentinel + Regional	143	17.9	118	18.6	327	24.2	588	21.1	
No dissection	104	13.0	67	10.6	147	10.9	318	11.4	
Radiation									0.642[c]
Yes	609	76.2	493	77.9	1055	78.2	2157	77.6	
No	187	23.4	139	22.0	294	21.8	620	22.3	
ERA									0.628[d]
Positive	590	73.8	486	76.8	1034	76.6	2110	75.9	
Negative	130	16.3	110	17.4	209	15.5	449	16.1	
PRA									0.633[d]
Positive	502	62.8	406	64.1	882	65.4	1790	64.4	
Negative	197	24.7	177	28.0	350	25.9	724	26.0	

[a]Chi-square test (Chi^2)

[b]Cases not shown if LN dissection unknown; Chi^2 excludes unknown if LN dissection.

[c]Cases excluded if unknown to be treated by radiation; includes cases with unspecified radiation type.

[d]Cases not shown if tumor marker borderline, unknown if positive or negative, or test not done or not collected.

Colon Cancer

The findings from 2,848 colon cancer patients diagnosed in 2003 and 2004 are illustrated in ***Table 4***. The age at diagnosis in the four categories was similar in rural and urban areas, both in terms of the mean age at diagnosis (70 years in all groups) and the distribution by age category (p=0.361).

Table 4. Characteristics of 2,848 Northern New England colon cancer patients diagnosed in 2003-2004.

	Small Rural		Large Rural		Urban		Total		
	No.	%	No.	%	No.	%	No.	%	p-value[a]
Age at Diagnosis									0.361
≤ 49	68	7.2	46	8.1	96	7.2	210	7.4	
50-64	208	21.9	140	24.6	317	23.8	665	23.3	
65-74	269	28.3	130	22.9	360	27.1	759	26.7	
≥ 75	405	42.6	252	44.4	557	41.9	1214	42.6	
mean SD	*70*	*13.10*	*70*	*13.42*	*70*	*13.10*	*70*	*13.18*	
Primary Sequence									0.284
1st Primary	792	83.4	475	83.6	1080	81.2	2347	82.4	
Subsequent Primary	158	16.6	93	16.4	250	18.8	501	17.6	
Stage at Dx									0.666[b,c]
0	99	10.4	73	12.9	162	12.2	334	11.7	
I	247	26.0	126	22.2	309	23.2	682	23.9	
II	230	24.2	137	24.1	328	24.7	695	24.4	
III	201	21.2	131	23.1	279	21.0	611	21.5	
IV	137	14.4	81	14.3	194	14.6	412	14.5	
NA	3	0.3	4	0.7	9	0.7	16	0.6	
Unknown	33	3.5	16	2.8	49	3.7	98	3.4	
Histology									0.805[c,d]
Adenocarcinoma	590	62.1	363	63.9	833	62.6	1786	62.7	
In polyp or adenoma	177	18.6	111	19.5	268	20.2	556	19.5	
Other adenomas	13	1.4	9	1.6	29	2.2	51	1.8	
Other/Unknown	170	17.9	85	15.0	200	15.0	455	16.0	
Surgery									0.625[e]
Local excision	109	11.5	70	12.3	153	11.5	332	11.7	
Segmental resection	730	76.8	413	72.7	1027	77.2	2170	76.2	<0.001[f]
Colectomy	18	1.9	15	2.6	29	2.2	62	2.2	
Other type surgery	17	1.8	17	3.0	9	0.7	43	1.5	
No surgery	75	7.9	53	9.3	112	8.4	240	8.4	
Unknown	1	0.1	0	0.0	0	0.0	1	0.0	
Nodal Sampling									0.743[g]
1-5	113	11.9	69	12.1	147	11.1	329	11.6	
6-11	194	20.4	137	24.1	283	21.3	614	21.6	
≥12	413	43.5	219	38.6	587	44.1	1219	42.8	0.079[h]
No dissection	195	20.5	125	22.0	273	20.5	593	20.8	
Examined, unk #	18	1.9	8	1.4	15	1.1	41	1.4	
Unknown	17	1.8	10	1.8	25	1.9	52	1.8	
mean, SD, median									
Chemotherapy									0.306[c]
Yes	204	21.5	135	23.8	322	24.2	661	23.2	
No	744	78.3	433	76.2	1008	75.8	2185	76.7	
Unknown	2	0.2	0	0.0	0	0.0	2	0.1	

[a]Chi-square test (Ch^2)

[b]Chi^2 excludes NA (Not Applicable).

[c]Chi^2 excludes unknown.

[d]Chi^2 compares adenocarcinoma vs. other histologies listed, excluding other/unknown.

[e]Chi^2 compares no surgery vs. any surgery, excluding unknown.

[f]Chi^2 compares segmental resection vs. other listed surgeries vs. no surgery.

[g]Chi^2 compares no dissection vs. any dissection performed, excluding unknown.

[h]Chi^2 compares ≥12 nodes dissected vs. <12, excluding no dissection and unknown.

Overall, 7.4% of patients were diagnosed before the age of 50 and 42.6% of patients were diagnosed over the age of 75.

Patients who presented with their colon cancer as their first primary represented 82.4% of patients diagnosed, and again there was no statistically significant difference between rural and urban areas (p=0.284).

Table 4 shows that the distributions of stage at diagnosis (Stages 0, I, II, III, and Stage IV) were similar in the three geographic areas studied (p=0.666). Early non invasive disease (Stage 0) was diagnosed in 11.7% of patients and metastatic (Stage IV) disease in 14.5% of cases. Stage I disease was diagnosed in 247 patients (26.0%) in small rural areas and in 309 patients (23.2%) in urban areas. Stage II and III patients represented 24.4% and 21.5% of the total, with similar distributions in the different geographical areas. The histology of the various subgroups studied also did not differ significantly between geographic areas (p=0.805).

The type of surgery performed in small rural, large rural and urban areas was evaluated closely. A comparison of the three geographical areas suggested some differences in treatment with either segmental resection, another form of surgery, or non surgical measures (p<0.001). Local excision rates represented 11.5%, 12.3%, and 11.5% in these areas respectively; segmental resection represented 76.2% of the total procedures performed, lowest in the large rural areas (72.7%) and highest in urban areas (77.2%); and a colectomy was performed in only 2.2% (62 patients).

An important component of surgery is the number of lymph nodes removed at the time of surgery. The standard of removing at least 12 lymph nodes at operation was performed in 1,219 patients, comprising 42.8% of all patients (total including non invasive disease and non surgically treated patients), 46.8% of the 2,607 treated surgically, and 55.3% of the 2,203 surgically-treated patients who had any lymph nodes removed. There was no significant difference among the three geographic areas in the proportions of patients having any lymph node dissection performed (p=0.743); but, among those who had such a dissection (n=2,203), the likelihood of having the standard of 12 or more nodes removed (55.3%) showed borderline significant differences (p=0.079) among small rural (56.0%), large rural (50.6%), or urban (56.9%) areas (as a percentage of patients who had any lymph nodes sampled).

Adjuvant chemotherapy administration is offered to patients with Stage III disease and a subset of high risk Stage II patients. We undertook this study to closely evaluate the 597 patients in this subgroup who had been treated surgically (***Table 5***).

Table 5. Receipt of adjuvant chemotherapy among 597 Stage IIB and III colon cancer patients in Northern New England treated with surgery by stage at diagnosis, 2003-2004.

	Stage IIB				Stage III				TOTAL				
	CTX given		No CTX		CTX given		No CTX		CTX given		No CTX		
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	p-value[a]
Age at Diagnosis													<0.001
≤ 49	6	15.4	2	6.1	43	13.5	5	2.4	49	13.7	7	2.9	
50-64	17	43.6	1	3.0	110	34.5	22	10.7	127	35.5	23	9.6	
65-74	9	23.1	8	24.2	96	30.1	47	22.8	105	29.3	55	23.0	
≥ 75	7	17.9	22	66.7	70	21.9	132	64.1	77	21.5	154	64.4	
mean SD	*76*	*11.11*	*62*	*11.27*	*76*	*10.57*	*64*	*12.70*	*76*	*10.64*	*63*	*12.56*	
Residence at Dx													0.195
Small rural	17	43.6	11	33.3	94	29.5	67	32.5	111	31.0	78	32.6	0.105[b]
Large rural	3	7.7	6	18.2	67	21.0	53	25.7	70	19.6	59	24.7	<0.001[c]
Urban	19	48.7	16	48.5	158	49.5	86	41.7	177	49.4	102	42.7	
Surgery													
Local excision	0	0.0	0	0.0	2	0.6	3	1.5	2	0.6	3	1.3	
Segmental resection	36	92.3	30	90.9	306	95.9	193	93.7	342	95.5	223	93.3	
Colectomy	2	5.1	0	0.0	10	3.1	7	3.4	12	3.4	7	2.9	
Other	1	2.6	3	9.1	1	0.3	3	1.5	2	0.6	6	2.5	
Nodal Sampling													0.878
1-5	8	20.5	3	9.1	34	10.7	26	12.6	42	11.7	29	12.1	
6-11	9	23.1	8	24.2	84	26.3	58	28.2	93	26.0	66	27.6	
≥12	22	56.4	22	66.7	201	63.0	122	59.2	223	62.3	144	60.3	
mean (SD)													

[a]Chi-square test (Chi^2) based on total of chemotherapy given/not given.
[b]Chi^2 compares rural (small and large) vs. urban.
[c]Chi^2 compares rural (small and large) vs. urban for Stage III cancers only.

Overall, 54.2% of Stage IIB patients received chemotherapy. Only a small proportion of elderly patients (age 75 or over) received chemotherapy after surgery for Stage IIB disease (24.1%; 7 of 29). Patients under the age of 75 received chemotherapy 74.4% of the time, but also represented a small group (43 patients total).

The 525 surgically-treated colon cancer patients with Stage III disease were assessed. Overall, 60.8% (319 of 525 patients) with Stage III disease received adjuvant chemotherapy. The majority of surgically treated Stage III patients (90.9%) were age 50 or over. In the less than 50 age group, 89.6% (43 of 48 patients) received chemotherapy. The 75 or over age group with Stage III colon cancer received adjuvant chemotherapy 34.7% of the time. A majority - 74.9% (206 of 275 patients) in the 50-75 year old age group - received chemotherapy.

Stage III patients in urban areas received adjuvant chemotherapy more often (158 of 244; 64.7%) than those in the small and large rural areas combined; (161 of 281; 57.3%) (p=0.001). Similar proportions received adjuvant chemotherapy in small rural areas (58.3%) and large rural areas (55.8%). Combining Stages IIB and III, there was no significant difference overall in the use of adjuvant chemotherapy between urban (63.4%) and combined rural regions (56.9) (p=0.105).

Limitations

Access to Care

Access to care is complex, encompassing perceptions of access (convenience, satisfaction with services, presence of a provider) as well travel time and travel distance to services.[7] Income, insurance status, and race/ethnicity can also influence a person's access to care. We used a person's zip code at time of diagnosis to categorize residence as urban, large rural, or small rural. Thus, only one aspect of access to care (residence) was considered. Furthermore, this is a proxy for distance from services, since drive time analysis between a person's residence and the treatment center was not computed. We assumed that people living in more urban areas at the time of diagnosis lived closer to services.

At best the concept of rural is complex, multifaceted, and often vague.[8] There can be significant variations in the demographics, economics, culture, and environmental characteristics of different rural places. Large rural towns that are not too distant from urban areas often have more in common with urban areas than they do with small towns.[9] We have used three residential classifications to gain a finer level of detail, and we have combined three states' data to have more power in the analysis. However, there is still a possibility that residence classifications are oversimplified and could erroneously disguise or reveal differences in access to quality oncology care. For example, Dartmouth Hitchcock Medical Center is a tertiary care center located in a large rural town (not an urban area) in New Hampshire.

We are inferring access to care from residence at a point in time because the cancer registries record residence at the time a diagnosis occurred. This may be a poor indicator of current or historic access to care because we do not know the length of time each person lived at his or her residence. People who originally lived in urban areas and were likely to have better access to care, then moved to a rural setting, and were later diagnosed with cancer, would be classified as rural. The converse is also true.

Differences in State Cancer Registration Systems

Although the state cancer registries of Maine, New Hampshire, and Vermont conform to the federal reporting standards of NPCR and the North American Association of Central Cancer Registries (NAACCR), operational differences exist among the registries. For example, each state uses a different software application for its cancer registry database.

Each cancer registry's software application has a slightly different way of creating a consolidated tumor record from multiple abstract records. For example, two states' systems merge the "best" data from abstracts into a single consolidated record at the time of export; one state's system stores a static consolidated record. This created an error in the handling of one treatment data item for one state, which was corrected in the final data set. Other idiosyncrasies like this could exist, which might affect the comparability of data across the three states.

Each state has a different set of data items that it collects from healthcare facilities and providers. For example, Vermont did not require the hormonal status of breast cancer tumors (ERA/PRA) for the diagnosis years studied, but the data were included if healthcare facilities opted to send it to the state.

The approach used to verify zip code for each patient is different in each state; this relates directly to the rural/urban residential classification used for the study. Another limitation is that zip codes can change over time. Nevertheless, the approach of using the ZIP Code RUCA approximation was preferred over other methods involving town of residence due to even more problematic differences in validation and standardization of town names among the three states' registries. We also used zip codes representing PO Boxes where residential addresses were unavailable.

Data Collection

The most significant limitation of using state cancer registry data to evaluate quality of care is that the AJCC staging scheme, also known as "TNM," is not required by CDC NPCR[10]. National cancer treatment guidelines, such as National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology™ (see http://www.nccn.org), recommend therapy based on TNM stage, which state cancer registries are not necessarily designed to collect. For the diagnosis years studied, Maine and New Hampshire required TNM staging to be reported, but Vermont did not.

In Vermont, the quality assurance process included validating previously reported TNM data, assigning TNM stage based on text in the registry, and deriving TNM from other staging variables reported.

Another limitation related to TNM stage is that the federal standards in cancer registration changed significantly from 2003 to 2004 (the two diagnosis years of the study). Data collection shifted from collecting the TNM stage group directly to deriving it from multiple data items via the Collaborative Stage Algorithm. In order to make the data from different years and different states comparable, we

standardized the data items and values (i.e., "3B" is equivalent to "IIIB"). It is possible that changes in data collection over time and differences among the three states affect the stage distribution of the breast and colon cancers studied.

It may be difficult to tell whether differences in other measures, such as number of positive lymph nodes or whether chemotherapy was administered, are due to a true difference in disease burden or oncology care, versus an artifact of data collection. Major changes in cancer registration standards occur every three years, and minor changes occur every year. When multiple years of data are used and/or the data are older, the interpretation of findings becomes more complex. We attempted to improve data quality by contacting the reporting facilities when necessary to obtain better information from the medical record for missing or unknown staging and treatment data. This may not have completely compensated for data collection issues.

Cancer incidence data are at least 95 percent complete based on evaluation by the Centers for Disease Control and Prevention (CDC) and the North American Association of Central Cancer Registries (NAACCR). However, it is possible that people diagnosed with cancer were unreported by healthcare providers or healthcare facilities. It is also possible that Northern New England residents received their diagnosis and first course of treatment in a state that does not have an interstate data exchange agreement and, therefore, would not be reported to the central cancer registries.

Data Analysis

While the three states have interstate data exchange agreements that protect the confidentiality of data shared from one state providing a person's treatment to the other state where a person resides, there are no confidentiality agreements in place to share "same-state" records. For example, if a Vermont resident is treated by a Vermont healthcare facility; this record cannot be shared with the New Hampshire State Cancer Registry. The HIPAA safe harbor method for de-identifying records would have prohibited necessary data items from being shared among the three states. Therefore, we used a standardized method for each state to extract and aggregate data in a way that could be compared with the other states' data. This meant that we could not perform multivariate analyses and were unable to examine the effects of confounding variables in the aggregated data.

Discussion

The aim of this study was to evaluate whether differences in either stage at diagnosis or standard treatment occurred in rural versus urban areas. A total of 8,982 patient records were reviewed from three different demographic regions – small rural, large rural, and urban. This required the collaboration of physicians, nurses, and provider networks which compose the Northern New England Oncology Society (NNECOS), cancer registrars from 79 different hospitals in three states and their central registries, the three state cancer coalitions (Maine Cancer Consortium, Vermonters Taking Action Against Cancer, and New Hampshire Comprehensive Cancer Collaboration) and national organizations including the American Cancer Society, the Centers for Disease Control and Prevention, and the National Cancer Institute. The data collection process itself represented a unique opportunity to compare and streamline the various methodologies in these three states. Common definitions for rural (small rural and large rural) and urban areas helped to stratify patients into separate groups that could be assessed. The development of common data sets among the three states enabled us to evaluate a large cross section of patients. Data collection and data analysis were subject to certain limitations as described earlier. Despite these limitations the data set did show marked and expected consistency in biological markers such as histology for both breast and colon cancer, and estrogen and progesterone expression for breast cancer. Similar results in these biological characteristics across different demographic areas would underscore the fact that data collection is accurate, and the population being studied is relatively similar in the three demographic areas of these three states. The endpoints chosen in this study were felt to represent reasonable collectable data points representing cancer stage at diagnosis, and reasonable standard of care assumptions.

The breast cancer results show a higher percentage of younger women (<50 years old) diagnosed in urban areas (27.4%) compared to small rural areas (20.4%) and large rural areas (22.3%). More non invasive breast cancer was also diagnosed in urban areas (24.8%) than in large or small rural areas (19.1% and 19.0%, respectively). However, within the timeframe and scope of this study, we were unable to determine whether the non invasive disease occurred preferentially among younger women in urban areas. This could be addressed in future studies.

In contrast to the pattern seen for Stage 0, no increase in Stage I breast cancer was seen in urban areas. More patients presented with Stage I disease in small rural and large rural areas (40.7% and 44.1%) compared to urban areas (37.9%). If access to screening were substantially better in urban areas, we might have expected to see an increase in Stage 1 as well as Stage 0 breast cancer. Patients in both small rural and urban areas also had similar rates of Stage IV disease at diagnosis. The data suggest that, overall, there is no significant delay in diagnosis of breast cancer patients associated with rural residence in Northern New England.

We are unable to account directly for any differences in the patterns of use of screening mammography, which might underlie regional differences in Stage 0 cancers, but this is an area for future study. Collaboration with the Behavioral Risk Factor Surveillance System in each state, as well as the New Hampshire and Vermont mammography registries of the Breast Cancer Surveillance Consortium, could help further evaluate rural/urban access to breast cancer screening.

Breast conserving surgery was performed in similar proportions among rural and urban areas with 62.1% of women undergoing lumpectomy. The stage of disease and number of lymph nodes affected at the time of diagnosis were similar in the three geographic regions. However, greater proportions of women in urban areas had either sentinel lymph node sampling (SLN) or sentinel node sampling combined with regional node dissection. The data regarding utilization of sentinel node sampling alone was still maturing in 2002 and 2003, and several major centers were actively accruing patients to studies that answered the question of whether regional lymph node dissections needed to be done in patients who had sentinel lymph nodes sampled. The best way to interpret these data is to combine the sentinel alone and sentinel and regional lymph node dissection groups. The utilization of the combined sentinel lymph group (with and without regional lymph node dissection) was more common (44.1%) in urban areas than large rural (39.8%) and small rural areas (37.8%).

Access to radiation therapy after breast conserving surgery is an important standard component of care. Certain clinical situations may preclude the use of post operative radiation therapy. These would include co morbid conditions, small non invasive breast cancer, advanced age, proceeding to mastectomy, and previous radiation therapy. Only 48.0% of elderly patients (> 75 years of age) received radiation after lumpectomy therapy (compared to 77.9% patients less than 75 years of age).

Interestingly, there was a correlation between sentinel lymph node dissection and post lumpectomy radiation therapy. SLN patients received radiation therapy more frequently after lumpectomy than patients who underwent regional lymph node dissections without SLN (85.9% versus 75.5%). The SLN alone versus SLN with concurrent regional lymph node dissection groups showed no significant difference in frequency of radiation (85.9% versus 85.8%) in 1517 patients reviewed. The use of SLN was more common in urban (44.1%) than either large or small rural areas (39.9% and 37.6% respectively). However, the rates of post lumpectomy radiation therapy in small and large rural (70.9% and 73.9% respectively) versus urban areas (72.2%) showed no significant difference. Thus, the explanation for the higher use of radiation therapy in post lumpectomy patients undergoing some form of SLN procedure is not explained by geographical differences in this study. However, patients with access to a relatively new and developing modality such as SLN sampling did receive more radiation therapy. The reason why rates of radiation therapy frequency would be lower in lumpectomy patients who had regional lymph node dissection without SLN is an area which would require further study.

Radiation therapy was also delivered more frequently in the groups where there is a perceived benefit. Groups with larger tumors, more lymph nodes involved, and Stage III disease all received more frequent radiation therapy as expected.

Colon cancer patients evaluated in the three geographical areas also showed consistencies in certain characteristics. No significant difference was noted in the distribution of stage (Stage 0, I, II, III,IV) at presentation between rural and urban areas (p=0.666). Again, similar to the results from breast cancer, patients with early Stage I colon cancer were diagnosed at a similar frequency in small rural areas (26.0%) as in urban areas (23.2%). The histology of the different subgroups was also similar in the different geographical areas studied (p=0.805).

The proportion of patients with 12 or more lymph nodes removed was also similar in small rural (56.0%) and urban (56.9%) areas. Among patients that had any lymph nodes removed, there was a borderline significant difference in the proportions having 12 or more removed (versus any number fewer than 12) (p=0.079), when all three geographical areas were compared in these 1219 patients. The likelihood of having the standard 12 or more nodes removed was 56% in small rural, 50.6% large rural and 56.9% in urban areas. The total rate of 12 or more lymph nodes (versus fewer than 12 lymph nodes) sampled in Stage IIB and III colon cancer was 62.3% in patients receiving adjuvant chemotherapy and 60.3% in patients not receiving adjuvant chemotherapy. There was no statistically significant difference between these groups, which would suggest that the surgical resection defined by this standard was similar in small rural and urban areas.

The delivery of adjuvant therapy in Stage III colon cancer was less frequent in rural areas when compared to urban areas in this study and this finding was statistically significant. Patients in small rural and large rural areas received chemotherapy less often (58.3% and 55.8% respectively) than their urban counterparts (64.7% p<0.001). We tried to account for this observation in terms of potential confounding in the data. Age for instance is inversely associated with chemotherapy use but from ***Table 4*** we see no significant differences in age or age distribution between geographical areas. We do not have information on co morbid conditions that might influence adjuvant chemotherapy use, and which potentially could vary by region. However, presumably those who are not able to receive chemotherapy because of poor performance status would likely not be able to undergo the surgery for the same reasons and so would be excluded from this analysis. Chemotherapy use may also be affected by whether this is the first primary at diagnosis – but again there was no geographical difference noted in ***Table 4***. Although we were not able to do multivariate analysis because we lack individual level data, we do not find anything obvious in our data to account for the geographical difference in adjuvant chemotherapy use. Certainly, the complexity, duration, cost, and travel for 6-12 months of adjuvant therapy could serve as a barrier to patients accessing this care. Since there is a significant overall survival advantage for adjuvant chemotherapy in Stage III colon cancer it would be important to determine why patients in rural areas received adjuvant chemotherapy less often than patients living in closer proximity to treatment (urban) areas (see ***Figure 1***).

Conclusions

The ability for a patient to access care in rural areas may be limited both by patient and network/provider considerations. Providing adequate care in rural areas requires coordinated planning and resource management to limit barriers to care in cancer patients. State boundaries do not serve as an isolated barrier but geographic differences may play a significant role. Thus, the Northern New England Clinical Oncology Society initiated this study to evaluate relevant data to establish whether there were differences in the delivery of oncologic care in small rural, large rural and urban areas of Vermont, New Hampshire, and Maine. This study is the first to actively coordinate data collection in three states to determine if there was a difference in care between rural and urban areas.

The infrastructure in place to deliver cancer care in northern New England is fragile, and the resources available to provide these services will be difficult to maintain. Thus, this coalition of partners was essential towards the success of this study. State epidemiologists, state cancer coalitions, physicians, and registrars worked seamlessly among the three states to overcome numerous hurdles. Intermediate endpoints such as those studied here merely enabled us to capture a glimpse of cancer care in northern New England in 2003 and 2004. These endpoints illustrate that similar cancer care is provided in rural and urban areas of northern New England. No evidence of stage migration was noted. Unlike Northeast

Scotland, where a higher proportion of colon and lung cancer patients with advanced disease and diminished survival presented in rural areas[11], patients in rural Northern New England presented with early stage invasive breast disease and colon cancer at a similar proportion to their urban counterparts.

This study also illustrated numerous other areas where the data were comparable in rural and urban areas of Northern New England such as the use of breast conserving surgery and proportion of any positive nodes. The utilization of post lumpectomy radiation therapy also did not differ in rural areas. The study did reveal differences between the care offered to urban patients over rural patients. Breast cancer patients in urban northern New England presented at a younger age and with a higher proportion of Stage 0 (i.e. non invasive disease). Additionally, patients undergoing sentinel lymph node sampling also received more post lumpectomy radiation than patients undergoing regional lymph node dissections, and colon cancer patients with Stage III disease proportionally received adjuvant chemotherapy less often in rural areas as opposed to their urban counterparts.

These differences may or may not result in overall survival differences but do point out that there are significant differences in care between rural and urban areas that should be studied further. If these disparities increase, or the fragile network in place is disrupted, then we would expect to see more glaring discrepancies than those noted here. The overriding goal of this study is to continue the collaboration established here so that we can prospectively collect data to measure these possible discrepancies.

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