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Mapping the journey of cancer patients through the health care system Part 3: An approach to staging

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Abstract

This is the third in a series of articles relating results from a line of research whose intent was to construct a complete history of patient interactions with the health care system using available data sources for all patients diagnosed in 1990 with a primary breast, colorectal, or lung tumour in Manitoba. This article presents details of the development and application of methods to produce TNM staging data on the roughly 2,000 patients in this population. The operational definitions constructed for this research can be adapted for other tumour sites and data sources. Findings include methods developed to overcome the sometimes ambiguous and inconsistent available documentation, which ultimately produced reliable TNM staging data. Survival data for this population by stage of disease are given.

In the cancer care literature, staging is a critically important covariate and prognostic for survival. Staging is included in virtually every published cancer study. A search through the CancerLit database 1991 to 1995 reveals more than 4,000 articles with the term 'staging' in the title and 324 articles with a specific focus on neoplasm staging. The objective of this manuscript is to describe how we overcame a major methodological hurdle to produce pathological staging for 2,000 cases retrospectively. Although staging data are important for comparisons of incidence and outcome, it is difficult to apply a uniform staging system in practice with consistent interpretation. A need for a comprehensive method to compile staging information became apparent during the implementation of the research. The goal of the study was to detail histories on all patients diagnosed with breast, colorectal, or lung cancer in Manitoba in the year 1990 using existing documentation and computerized data sources. Culling the staging information in an objective and reliable fashion from these sources became a major challenge and focus of the research program. This paper delineates the major problems faced and the operational procedures developed to circumvent or overcome them.

Motivation for this work on staging came from an existing gap in the recording system for cancers in Manitoba. The Manitoba Cancer Treatment and Research Foundation (MCTRF) has a legislated mandate to collect data on malignancies diagnosed in Manitoba. A special form, Form IV 'Report of Malignant Neoplasm,' is available to record all the basic information needed to construct a complete picture of a cancer patient's status and subsequent treatment. The form states that it 'should be completed at the first cancer diagnosis and again for each new primary cancer. Unfortunately, compliance is poor (Scott-Conner & Christie, 1995). The MCTRF estimates that fewer than 15% of newly diagnosed cancers in Manitoba have a Form IV completed. The study team had no other choice but to attempt to cull the required information from the retrospective chart data available and affiliated computer databases.

Staging data were gathered primarily through an abstraction process involving patient information from MCTRF patient

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records. The MCTRF Cancer Registry was used to identify the patient population. The Cancer Registry registered 6,662 new cases of cancer diagnosed in 1990. Approximately 30% of these new cancer cases have been included in this study. The portion of the 2,015 cases accorded to each type of cancer is split evenly among the three sites of breast (654), colorectal (673), and lung (688).

Staging data collection

A controversy that arose early in the development of the staging data collection system left us with an open methodological and perhaps philosophical question: Can anyone other than physicians produce accurate staging data? Several clinicians commented that, for our data to be believed, the staging data should be created by physicians, even though other health care professionals have demonstrated the capacity to stage cancer (Fehr, 1994).

It is mandatory under the Cancer Act for the MCTRF to collect data on cancer diagnoses. The reality of the present record-keeping system is that staging data are not easily obtainable from the medical chart. Although it is logical to assume that the physician involved in each cancer case is aware of the relevant case characteristics, more often than not, they do not document it in a fashion sufficient to produce a staging variable by retrospective analysis of chart notes.

It was impractical to have attending physicians stage the more than 2,000 cases, so we compromised by using physicians to train and monitor the research assistant (a registered nurse) who put the staging classification system into practice. During the abstraction process, the research assistant assigned the pathological stage for each case using the American Joint Committee on Cancer (AJCC) staging criteria (AJCC, 1988). Detailed operational rules were developed for the research assistant to apply in producing the T, N, and M classifications (tumour, nodes, metastases) on each case.

We took extra pains to ensure the data's veracity. An expert in oncology was identified for each cancer site and met with the research assistant. These oncologists instructed the research assistant on what to look for and how to classify chart information. An initial series of 10 test cases from each of the three chosen disease sites was run to check if, given the same information, the research assistant would come to the same conclusion as the clinician. An iterative process involving further test cases followed until all oncologists involved were satisfied with the research assistant's ability to abstract the required data consistently. Ultimate agreement rates between clinicians and the research assistant were in excess of 90% for the more than 60 cases reviewed initially. Any 'difficult' cases were sent to the oncologists. For some tumours, the pathologist had indicated the stage on the pathology report, in which case the staging classification was not used. Instead, the research assistant would independently stage the case, and then compare the results. If the results were different, that particular case would be given to one of the oncologists on the team for his/her determination.

Once the data collection process had been completed, three oncologists independently audited at least 10% of the staged cases and then met with the research assistant to compare staging results. Agreement in all three sites was above 90%. Discrepancies were limited to minor interpretational issues. At worst, a misclassification between the substage type would result (e.g., IIa versus IIb). Discrepancies that did exist were restricted to minor interpretational issues. Typically, this occurred when the clinician had supplementary knowledge that was not obtainable from the chart.

Staging data types

The type of staging to be implemented in the study was a major issue for discussion. Pathological staging was used based on the assumption that it would provide a more accurate and consistent description of the tumour than clinical staging. Pathological data are often available due to the substantial proportion of tumours that are resected. Another systemic difficulty is that roughly 40% of all cancer cases are treated outside the MCTRF. Together, these challenges made it difficult to obtain staging data for a large proportion of cases. Breast and colorectal cases proceeded well using pathological staging, but lung cancer was difficult because not many cases had lobectomies. Only about one-third of lung tumours are resected and no pathology report was available. The lack of information for pathological staging in lung cancer cases required clinical staging to be collected as well for cross-validation.

Staging operational definitions

In order to assess the quality and quantity of data available in the MCTRF charts, the team implemented additional measures. These guidelines deviated slightly from the criteria outlined in the American Joint Committee of Cancer Care manual (AJCC, 1988). Several operational rules had to be developed and implemented to account for the state of available data. As each disease site under study had unique challenges, different procedures were used for each.

The code "X" was only implemented if there was information available to stage either T, N, or M, but the information was ambiguous, or there was insufficient information to assign a stage. For instance, if the pathology report in a breast cancer case said there were several nodes affected, this would be indicated as "NX." If no information was available upon which to construct a T, N, or M classification, the field was left blank.

For breast cancer cases, if macroscopic residual tumour was present and the dimensions were stated, we added the dimensions together to give the maximum tumour size. If the

size of the involvement was stated in the biopsy specimen and there was residual, but the dimensions were not stated, a stage was determined based on the wording of the report. For instance, if the biopsy contained 1.8 cm of tumour and there was macroscopic residual involvement, the tumour was upstaged to T2. If the pathology report indicated that there was microscopic residual tumour, only the size of the biopsy was used to stage the cancer. If the tumour size was not given, it would be recorded as TX.

Both pathological and clinical staging mechanisms were used for determining metastatic involvement. For instance, a bone scan that indicated metastasis was sufficient for our study to discern a positive metastatic result, and a confirmatory pathological sample was not required for the metastatic categorization. In the event of any vagueness in a pathology report, the chart was forwarded to an oncologist for consultation and completion of the TNM staging process.

There were special challenges in staging breast cancer. Many women have an aspiration/biopsy first, followed by a lumpectomy/mastectomy. The structure of the pathology report does not differentiate between the amount of intraductal and invasive involvement. Thus, a 2.5 cm area of carcinoma may be 1.5 cm intraductal and 1.0 cm invasive, but is staged as a T2 tumour because the pathology report does not separate intraductal and invasive tumours. Here "over-staging" may occur because the structure of pathology reports does not facilitate following the staging rules which only use the invasive portion of the specimen for the stage. For lymph nodes, the degree of mobility was almost never mentioned in the pathology report, so the lymph nodes were assumed to be mobile. Hence, it was assumed that the lymph nodes were movable and under two centimetres unless otherwise stated.

The pathology reports for colorectal cancer were the most detailed, but terminology was varied and sometimes ambiguous. It was difficult to differentiate between T3 and T4 categories for some cases because of the vagueness in some of the pathology reports with respect to the extent of the cancer in the layers of the intestine. It was decided, in the case of a large invasive tumour, to assume a T3 classification if there was no operative report to state further organ involvement. To assess metastasis for colorectal cancer, CT scans, liver function tests, and/or chest x-rays had to have been completed. If none of these diagnostic tests were performed, "MX" was recorded. If the treatment chart indicated that the diagnostic tests had not been completed, the chart was passed on to an oncologist for further determination.

Lung cancer lymph nodes were classified ipsilateral to the affected lung unless otherwise specified. Lung cancer cases were screened a further time to obtain a clinical T, N, and M staging from the chart record due to an initial finding that the majority of lung cancers were not resected. Oncologists once again provided guidance and expertise to ensure reliability. Quality checks were again done and any questions raised during the chart abstraction were sent for review by an oncologist.

These operational definitions made possible the staging of a number of cases which would otherwise have remained

Table One: Tumour classification by cancer site

T	Breast	Colorectal	Lung	Total
Tis	23 (4%)	48 (8%)	0	71 (5%)
1	295 (47%)	41 (8%)	82 (28%)	418 (21%)
2	212 (34%)	90 (13%)	116 (39%)	418 (21%)
3	29 (5%)	335 (59%)	10 (3%)	374 (25%)
4	22 (3%)	24 (4%)	24 (8%)	70 (5%)
X	48 (8%)	28 (5%)	65 (22%)	141 (9%)
Missing	25 (4%)	107 (16%)	391 (57%)	523 (26%)
Total	654 (32%)	673 (31%)	688 (34%)	2,015

Table Two: Node classification by cancer site

N	Breast	Colorectal	Lung	Total
0	326 (61%)	299 (59%)	144 (49%)	769 (58%)
1	193 (36%)	102 (20%)	74 (25%)	369 (28%)
2	7 (1%)	58 (12%)	55 (18%)	120 (9%)
3	0 (0%)	5 (1%)	13 (4%)	18 (1%)
X	9 (1%)	34 (7%)	8 (3%)	51 (4%)
Missing	119 (18%)	175 (26%)	394 (57%)	688 (34%)
Total	654	673	688	2,015

Table Three: Metastases classification by cancer site

M	Breast	Colorectal	Lung	Total
0	171 (90%)	73 (47%)	105 (33%)	349 (53%)
1	16 (8%)	69 (44%)	194 (62%)	279 (42%)
X	4 (2%)	14 (9%)	15 (5%)	33 (5%)
Missing	463 (71%)	517 (77%)	374 (54%)	1354 (67%)
Total	654	673	688	2,015

Table Four: Staging results for 2,015 cancer cases

Stage	Breast Tumours	Colorectal Tumours	Lung Tumours	Overall Results
I	223 (40%)	85 (16%)	111 (29%)	419 (29%)
II	252 (45%)	182 (34%)	36 (9%)	470 (32%)
III	40 (7%)	148 (28%)	40 (11%)	228 (16%)
IV	16 (3%)	69 (13%)	194 (51%)	279 (19%)
Tis	23 (4%)	48 (9%)	0	71 (4%)
Missing	100 (15%)	141 (21%)	307 (45%)	548 (27%)
Total	654	673	688	2,015

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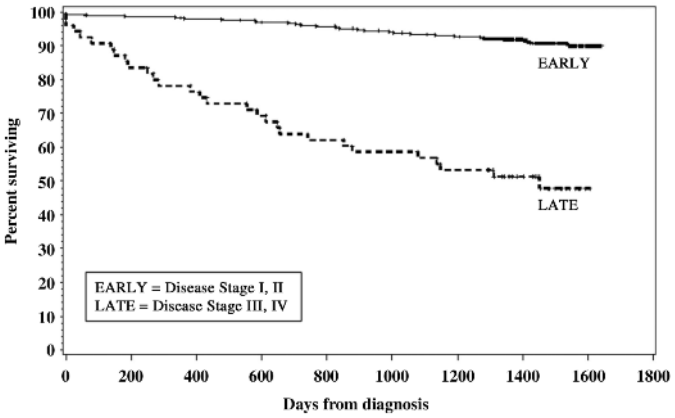
missing. We estimate the additional number of cases to be below 5% of the total cases. The main impact of the definitions, as specified above, more likely was to introduce a slight bias towards over-staging of some tumours by one level. Again, this bias is estimated to be in the order of less than 5% of all cases.

Staging results

Breakdown by site and T classification is found in Table One. Percentages for the classifiable cases are given exclusive of the missing data while the missing data percentages reflect the portion of the total number of cases. Similar results for node (N) and metastases classification (M) are given in Tables Two and Three respectively.

A computer algorithm used the rules set out in the AJCC manual (AJCC, 1988) to take the T, N, and M results from the chart abstraction process and produce a TNM classification. Even after a thorough review of the available chart records and extensive operationalizations, staging data were still unobtainable for 27% of the 2,015 breast, colorectal, and lung cancer malignancies diagnosed in 1990 (Table Four). Percentages in Table Four sum to 100% exclusive of the missing cases. For example, the 228 stage III malignancies represent 16% of the 1,467 cases for which a TNM stage was obtained. The percentage reported beside the number of missing cases is relative to the total number of 2,015 malignancies.

Figure One: Survival in breast cancer patients by disease stage. Manitobans diagnosed in 1990 (N=643)



More than 40% of breast malignancies were stage I with a further 45% being stage II. In total, four out of every five breast cancer cases were in early stage of disease. Only 3% were stage IV. Breast cancer cases had the best documentation in terms of being able to stage all but 15% of the cases. Colorectal cases were unstageable in just over one-fifth of the 673 cases. Stages II and III accounted for two-thirds of these malignancies. The 252 stage II breast tumours comprised 170 stage IIB and 82 stage IIB. The 40 stage III breast tumours equally divided into stage IIIA and stage IIIB classifications with 19 and 21 cases respectively. The 40 stage III lung tumours had 11 stage IIIA and 29 stage IIIB classifications. Lung cancer cases were unstageable 45% of the time and, in fact, accounted for 56% of the cases for which insufficient documentation was available to produce a TNM stage. Of the stageable lung cases, half were classified as stage IV, highlighting the severity of the disease at diagnosis relative to the other two cancer sites.

Grouping disease stages into an early/late dichotomy, with early defined as I, II, or Tis and late as III or IV, revealed differences in the disease site stage distributions. Almost 90% of breast tumours diagnosed were early stage, roughly half of the colorectal cases and a third of the lung cancer cases appeared in the early stage of disease.

Disease stage and survival

Figures One, Two, and Three demonstrate the difference between the early and late stage cancer patients by disease and age at death. Five-year Kaplan-Meier survival rate estimates for early/late stage breast cancer patients are above 90% and just under 50% respectively (Figure One). Late-stage breast cancer patients are at increased risk of death, especially in the first three months post-diagnosis, but the risk is small relative to other disease sites. Survival curves for early- and late-stage colorectal cancer (Figure Two) indicate the prognosis for this disease site is better than the lung cancer, but worse than breast cancer.

Lung cancer patients in late stage of disease can expect to live three times shorter from diagnosis than those in early stage cancer (Table Five). The lung cancer survival curves (Figure Three) indicate that those in early stage of disease have a better than 50% chance of surviving five years, while those in late-stage disease have only a 10% chance of survival to five years post-diagnosis. Lung cancer patients can expect to live an average of just under three years if the disease is diagnosed early (Table Five).

Figure Two: Survival in colorectal cancer patients by disease stage. Manitobans diagnosed in 1990 (N=655)

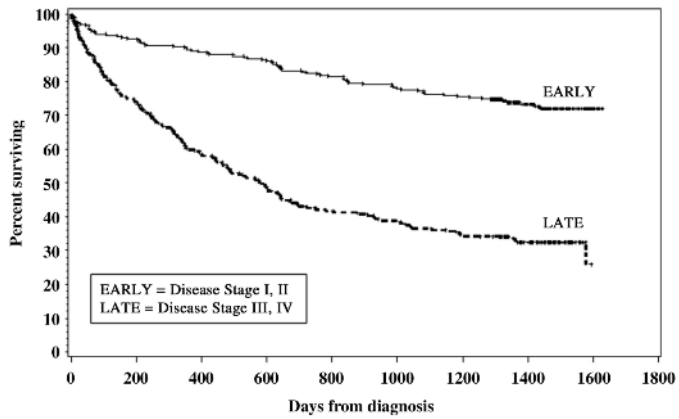
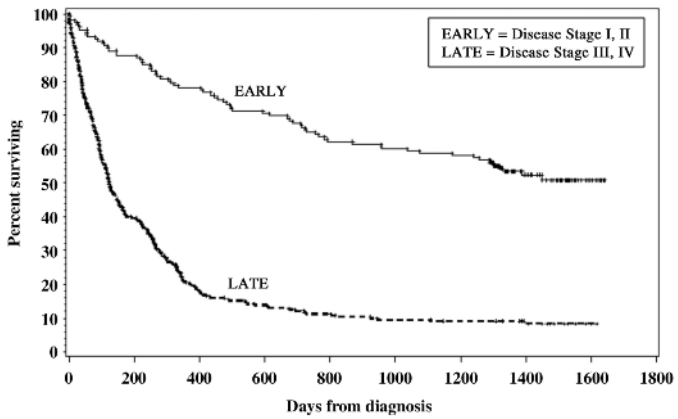


Figure Three: Survival in lung cancer patients by disease stage. Manitobans diagnosed in 1990 (N=681)



Breast cancer patients with early stage of disease can expect to live into their 90s on average (Table Six). Even those with late-stage disease averaged well into their 70s before death. Colorectal patients live a full 10 years longer than lung cancer patients if diagnosed early and six years if diagnosed in the latter stages (Table Six). Their age at death is roughly three years less than that of breast cancer patients regardless of disease stage. For lung cancer, Figure Six highlights the discrepancy between early- and late-stage disease. Late-stage cancer patients live an average of six years less than those in early stage of disease at time of presentation.

Discussion

This segment of the research into constructing complete histories of patient interactions with the Manitoba health care system represented a major hurdle. Through considerable discussion and operational definition, T, N, M staging was produced for the majority of tumours from available pathology information in a reliable and consistent manner. The approach could be adapted to other disease sites. For example, to repeat the process for prostate cancers would only involve an examination of staging peculiarities for the particular disease relative to breast, colorectal, and lung. The abstraction, validation, and amalgamation process to produce the T, N, M staging data remains the same. Ultimately, any cancer tumour could be staged from the existing data sources using our methods.

The staging system we developed will provide as reliable retrospective data as is possible to be obtained from the present charting system. While it would be desirable that every clinician enter the precise staging information so that others may use this important clinical variable, it is not reasonable to assume that it will become achievable in the near future. As such, our approach provides a means for the optimal amount of staging data to be abstracted from available information.

The approach employed in this study was to have only one person carry out the staging determination and, thereby, become as intricately aware of staging as any physician/oncologist in terms of using data available from charts. Fehr (1994) came to the conclusion that physicians are not consistent among themselves. We, thus, circumvented the issue of staging data consistency in terms of inter-rater reliability by using a single rater with reliability checks provided by clinicians auditing the results. Many meetings with oncologists were essential to produce clinically relevant and reliable information. The training program developed for the research assistant combined with the quality control checks of the clinicians formed a model that can be used by other researchers. The inter-rater consistency achieved was, in our opinion, higher than what would have been obtained if complete staging data from physicians had been available. The provincial physician variability in staging cancer is undoubtedly higher than the variability of our data due to the extensive data verification procedures.

The success of this systematic staging construction system is made more remarkable in that the databases incorporated into this project were built with a different intent in mind than building patient histories or carrying out clinical research. As such, the quality of the data for research purposes was somewhat lacking initially. There are gaps in the data with missing, incorrect, and unusable data in all sources. A large part of the challenge and success, therefore, became the separating of the wheat from the chaff to salvage usable clinical data for analysis. Even with the extensive measures taken to develop a staging collection methodology and detailed chart review to recover the information, 27% of the cases were unstageable in this population. This finding has helped create changes in the MCTRF data collection process so that staging data will be incorporated in the future. As treatment planning is based to a great degree on stage of disease, this alteration to the content of available data is an important improvement in the documentation process.

The critical nature of staging data to cancer treatment and research cannot be overstated. Results indicate that there is a need for better data collection of basic variables to be carried out at the clinician level. Complete basic data collected during the course of clinical care often reside mainly in the minds of the physicians/oncologists. The operationally defined data collection tools developed for this project provide an easily completed mechanism to ensure that the basic data are readily available. The standard data collection instrument developed in this study is convenient for clinicians to complete and for researchers to use as support for the veracity of any research study that includes staging information. With careful construction of staging information, one can put greater stock in the subsequent statistical analyses because they are based on reliable classifications.

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At the time of this study, the Manitoba Oncology Centre was called the Manitoba Cancer Treatment and Research Foundation, it is at present called CancerCare Manitoba.

Table Five: Mean (median) days censored survival from diagnosis by cancer site

Cancer Site	Early Stage	Late Stage
Breast	1,476 (1,550)	1,008 (1,451)
Colorectal	1,351 (1,638)	793 (596)
Lung	1,012 (1,240)	301 (125)
Total	1,327 (74%)	465(26%)

Table Six: Estimated mean (median) censored age at death in years by cancer site

Cancer Site	Early Stage	Late Stage
Breast	90 (93)	75 (79)
Colorectal	86 (89)	75 (76)
Lung	76 (76)	69 (70)
Total	1,327 (74%)	465 (26%)

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