

Mapping the journey of cancer patients through the health care system. Part 1: Developing the research question

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Abstract

This is the first in a series of articles relating results from research which constructed a complete history of interactions with the health care system from available data sources for all patients diagnosed in 1990 with primary breast, colorectal, or lung tumours in Manitoba from one year prior to diagnosis through to two years post-diagnosis. This article presents the motivation and genesis for this line of research. The study evolved from the question of "What happens to a person who is diagnosed with cancer?" into a major research endeavour encompassing a broad spectrum of philosophic and clinical research questions. A large interdisciplinary team collaborated on developing operational methods to combine existing data sources into unified cancer patient histories.

"What happens to a person who is diagnosed with cancer?" This simple question marked the beginning of a line of research that has caused us to examine the way in which data are collected and recorded on cancer in Manitoba, and which has produced more clinical questions than can be answered in a lifetime.

This paper is the first in a series which reports the results of a line of research initiated to investigate the basic question of the longitudinal profile of a cancer patient's experience through the Manitoba health care system. The focus of this paper will be the framing of the research question, a seemingly minor point that ultimately needed major attention and time. Subsequent publications will discuss the methodology development necessary to address the issues faced, and will present various aspects of the data involved in the patient trajectories and related analysis.

Motivation

Cancer is the second leading cause of death after cardiovascular disease, and the most expensive health problem in our society in terms of treatment costs and secondary economic loss (National Cancer Institute of Canada [NCIC], 1994). There are approximately 27,000 Manitobans surviving with a cancer diagnosis (NCIC). Each year, about 5,300 new cases are diagnosed in Manitoba (excluding non-melanoma skin cancer). Lung, breast, and colorectal cancer were estimated to comprise 40% of the cancers diagnosed in Manitoba in 1994, excluding non-melanoma skin cancer (NCIC).

The motivation for this line of research arose out of a discussion on entirely different matters. Anne Nemecek, then the director for the Community Cancer Programs Network (CCPN) within the Manitoba Cancer Treatment and Research Foundation (MCTRF), gathered

together a group of three oncologists, a data manager, a research assistant, and a statistician to brainstorm on a number of research questions targeted to evaluate the effectiveness of the CCPN program. The initial issue raised had to do with assessing the CCPN program's effectiveness at delivering cancer care, especially in comparison to care provided by the centralized cancer clinic. The CCPN program had been implemented to deliver chemotherapy and other cancer treatments in a patient's local area rather than have them travel considerable distances into Winnipeg to receive their chemotherapy.

The pursuant discussion kept stalling at the problem of finding comparative points of assessment across patients because they would all be at different points in their journey through the experience of having cancer. Making comparisons across patients was complicated because there are no well-delineated phases in the cancer experience, beyond the basic endpoints of diagnosis, treatment, response, progression, and death. Confounding variables appear at different times for different people and for different reasons so that it is difficult to hold

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these covariates constant in a statistical analysis. In terms of program evaluation and treatment assessment, it is most important from a clinical standpoint to include potentially confounding covariates such as previous treatment data and relative times to major intervention points. The point was raised that a person's path or "trajectory" through the health care system is unique in a considerable number of endpoints. Figure One depicts an example patient trajectory. We repeatedly returned to the hurdle of needing an answer to the basic question, "What happens to an individual who is diagnosed with cancer?" before we could begin to answer some of the more intricate clinical issues. The realization that this basic question had gone unanswered to a great degree was a surprise to some members of the research team and defined for the team the extent of the differences in perspective brought to the study between the clinical and non-clinical members.

The "it depends" phenomenon appeared at this point in the discussion. The type of care received, the individual delivering the care, and the mode of care delivery were, as determined from the experience of the oncologists, highly individualistic. Any analysis done on treatment evaluation would have to be constrained by the differentials in patient experience and their particular point in the disease trajectory, and their trajectory through the health care system. Restrictive assumptions necessary to completing the statistical analysis would render the representativeness of such modelling questionable. By producing a time "trajectory" for each patient, we hoped to produce further endpoints and related statistics that could be more easily compared across patients, such as time between diagnosis and first treatment or the number of treatment regimens experienced, and so produce a more complete analytical model.

Further complicating matters, there was not a singular, unified data source for all of the important endpoints. Chart data are notoriously incomplete for detailing the entire patient history and it is arduous to compile them into usable statistical data. While the MCTRF computer database is expansive and fairly comprehensive, not all cancer treatments are given through the supervision of the MCTRF. So, the MCTRF database could not contain data on events within its mandate, but delivered by other parts of the cancer care system. Given these practical restraints, it became clear why the story of what happens to the "typical" cancer patient in Manitoba had not been told, except in broad, general, and piecemeal terms.

A research study to answer the question, "What happens to the individual in Manitoba who is diagnosed with cancer?" was structured to describe the experiential trajectory of all breast, lung, and colon cancer patients who were diagnosed in 1990, from one year prior to diagnosis to two years post-diagnosis. Ethical approval for the study was obtained from the Manitoba Cancer Treatment and Research Foundation Records and Registry Access Committee, the University of Manitoba Faculty of Nursing, the University of Manitoba Faculty of Medicine, and Manitoba Health.

Literature review

There are several variables linked with the investigation of the treatment and illness trajectories of breast, lung, and colorectal cancers. An initial literature search was conducted utilizing Medline from the year 1987. The key words searched included referral delay, diagnosis delay, referral pattern, cancer trajectory, and specific

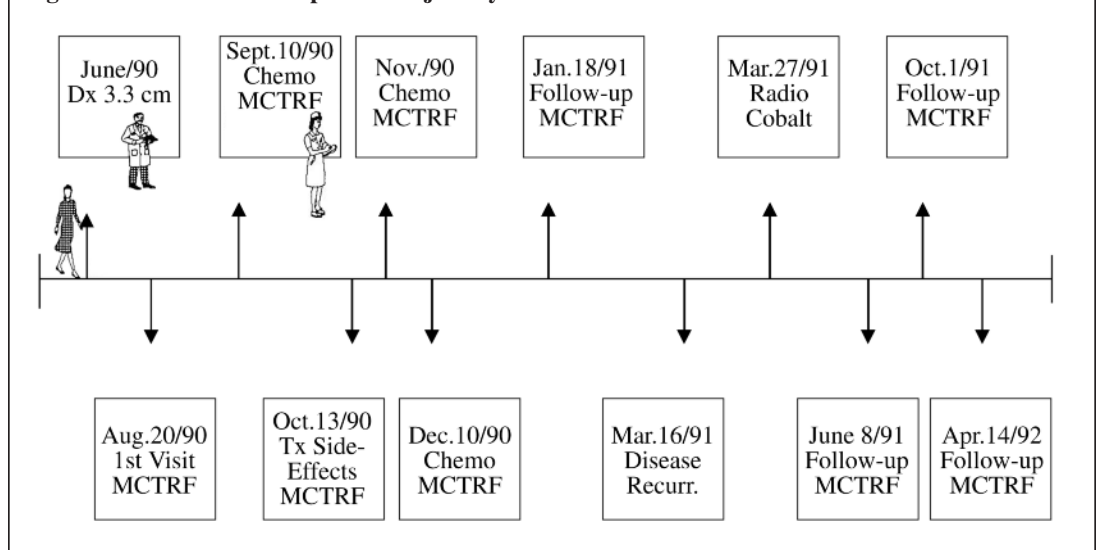
investigation of each of the cancers incorporated in the study, breast, lung, and colorectal. As the research progressed, subsequent searches were made for specific aspects of the patient trajectory using the specific databases: Cancerlit, CINAHL, Psychlit, and Health.

The literature is consistent in identifying inconsistencies with regard to the treatment process for a cancer patient. Multiple factors contribute to the process of deciding on cancer treatment for a patient (Mayer & Patterson, 1988). Dorsett applies Corbin and Strauss' illness trajectory framework on the trajectory of cancer recovery and suggests the point of origin is at diagnosis (Dorsett, 1991). Maher and colleagues (Maher, Coia, Duncan, & Lawton, 1992) found that although there was consensus as to the aims of treatment, there were apparent differences in the relationship between perceived prognosis and aims of treatment. There is also evidence that a lack of consistency in treatment process exists across geographic and prognostic groups (Silman & Evans, 1981). Greenberg pointed out that a patient's treatment course is determined not only by his or her clinical features, but also by factors that have no direct clinical relevance, such as marital status and proximity to a university hospital's cancer centre (Greenberg et al., 1988).

Although there are no published analyses describing the complete trajectory of cancer care in Canada, there are data available on certain parts of the process of care. Mackillop and colleagues (Mackillop et al., 1994a; Mackillop et al., 1994b; Mackillop, Zhou, & Quirt, 1995) in Ontario have analyzed the increase in waiting times for patients with cancer of the larynx, cervix, lung, and prostate from referral to the cancer centre to the start of their radiation treatments and have looked at variations in the management of non-small cell lung cancer patients. They have reported an alarming increase in waiting times for these four cancer types between 1982 and 1991, with the majority of the increase attributable to delay in initiation of radiotherapy.

Numerous studies worldwide have analyzed the delay in presentation of cancer patients to their doctors (Caplan & Helzlsouer, 1992-3) and have analyzed the delay in referral of patients between community physicians and specialists (MacArthur & Smith, 1984; Neugut, Timony, & Murray, 1991). While there is a consensus that access to health care contributes to variation in delay, none of the studies have analyzed delay or referral in the context of the Canadian health care system (Guilford, Petruckevitch, & Burney, 1991; Holliday & Hardcastle, 1979; Jones & Dudgeon, 1992; Tennvall, Moller, & Attewell, 1990). The data on whether delay contributes to a poorer prognosis is conflicting. The need for more study of health system delay is emphasized so that effective interventions can be designed (Caplan & Helzlsouer).

Figure One: The MCTRF patient trajectory



Availability of data, the use of registry information, and the variability in quality have been discussed extensively (Feigl, Glaefke, Ford, Diehr, & Chu, 1988; Ware, 1995). Recently, the use of hospital services by breast cancer patients has been studied in regards to utilization of resources in Finland (Kaija, Matti, & Tapani, 1996). In this study, resources were defined primarily in terms of follow-up visits and hospital days only, indicative again that the magnitude of the task of collecting, collating, and analyzing disparate health care data sources remains a barrier to the integration of information for analysis. However, as Feigl and colleagues suggest, it is essential to incorporate all available data sources in studying the patterns of cancer care due to the high rates of incomplete, variable, and silent records.

Objectives of the research line

We identified five research objectives which would collectively answer the question, "What happens to a person diagnosed with breast, colorectal, or lung cancer in Manitoba?"

1. To construct a methodology that would collect basic clinical information from existing databases in an efficient and consistent manner.
2. To evaluate the quality of existing databases in terms of documentation consistency and data completeness.
3. To merge all existing data sources into a unified case history that records all interactions with the health care system and, hence, describes the trajectory of breast, colorectal, and lung cancer patients diagnosed in 1990 through the Manitoba health care system from one year prior to diagnosis through to two years post-diagnosis.
4. To describe the patient populations in terms of demographics and survival data and draw comparisons across the three cancer site subpopulations (breast, colorectal, and lung).
5. To analyze the case histories (trajectories) in terms of patient encounters with the health care system, detailing the number, type, location and timing of encounters.

Definition of patient trajectory

A cancer patient's trajectory is defined in this study as the process of health care delivery for the time-period from a year prior to a documented diagnosis of cancer through treatment, cure, and follow-up (or death) up to two years post-diagnosis.

Our purpose of building patient trajectories was to coalesce the existing, scattered information to describe the overall care pattern. If we could detail the experiences of the Manitoba cancer patient, this would provide solid baseline data and a mechanism for process evaluation. Our intent was neither to audit physician practice, nor to critique the health care system in Manitoba.

Part of the motivation for this investigational approach is linked to the methodology used to find the Gulf Stream between Europe and North America in the 1500s (NOVA, 1989; Stommel, 1965). Observation of the course taken by discarded barrels dropped overboard from sailing ships as food larders was used to identify the Gulf Stream. The barrels were marked and their location and date of release recorded in ship captains' logs. Similarly, sightings of barrels and the ship location upon each sighting were recorded on journeys between Europe and North America. When these sighting data were collected and collated, the path or "trajectory" through the sea of each barrel could be constructed by plotting it on a map. While some barrels sailed off on eccentric and individualistic paths, a distinctive pattern emerged upon which a large proportion of barrels travelled. This path identified the Gulf Stream, which ship captains used to enable them to substantially reduce the time and difficulty of the transatlantic voyage. In similar fashion, by gathering together the available basic information for each patient within a cancer patient population in a cogent, organized format, we hoped to be able to chart the cancer patient's trajectory through the Manitoba health care system and discover a cancer care "gulf stream" which would impart

similar beneficial effects. By setting out a detailed description of a cancer patient's trajectory throughout the health care system, we would answer a simple question: "What happens to a person diagnosed with cancer in Manitoba?"

Why is this an important question and why would one go to a lot of work to answer a question that surely must be self-evident, or at least simple to answer? Why has the question not been answered already? The answers to these questions arose from recognition that there are differences in expectations around the delivery of cancer care between the patient and the oncologist, and between the general public and those within the health care system.

Public perception of the cancer care system, as gauged by the nonmedical members of the research team, revolved around a number of basic misconceptions. Surely there exists a "big book of cancer" to which all clinicians refer for a particular diagnosis, which prescribes in detail an established and validated algorithm for treating every conceivable type of cancer? This book must contain a "road map" for cancer care that will be followed. While there may be room for individual variability, the basic recipes for cancer must have been worked out by the last decade of the twentieth century and be set out for clinicians to follow. Additions to this cancer algorithm are headlined in the press almost weekly, and the amount of charitable funding that goes to cancer research must have produced solid and tangible answers to these basic questions by now. Oncologists surely must know what happens to the entire clinical population of cancer patients and must be able to readily obtain the populational data and summary statistics which describe what has happened to patients with similar disease. Clearly, for many reasons, each of these expectations may not be totally unreasonable, but are they unrealistic? In attempting to evaluate the present state of cancer care, the research team found that none of these ideas were completely tenable at present.

These gaps in knowledge of the overall systemic process led us to step away from the initial, specific, and narrowly focused research questions. The main reason this question of a standard trajectory in cancer care had not been directly addressed before is due to its broad scope, general nature and logistic realities. We came to the conclusion that, while much of the cancer care research confined itself to such specific and narrow questions, there exists a lack of an overall synthesis of available information. We decided, therefore, that it was vital to go back to basic methods to produce sound foundational data to facilitate the small (in a relative sense to our basic research question) questions that would arise as a result of the database construction. Once the foundational mechanisms were in place, we would only then be in a tenable position to address the broad spectrum of overall research questions. We would step out from within the forest of looking at individual research issues on partial histories of patient subsets to get an overall picture of all the trees (patients), their stories (trajectories), and their characteristics.

Summary

The project grew in breadth and scope because at every turn we encountered untenable assumptions regarding the present state of knowledge and available data. Gaps between expectations of the public and oncology experts were identified, pushing the researchers to further investigate the basic structure of the process of health care delivery. The result is a new perspective on the "trajectory" a patient follows through the Manitoba health care system from a year prior to diagnosis through to two years post-diagnosis.

It was important to delineate the context in which this line of research developed so the reader may understand the reasons why such a seemingly simple question has as yet remained unanswered. The project grew from the basic question of, "What happens to a person in Manitoba diagnosed with cancer?" to spawning innumerable clinical questions derived from the basic results. The nature of scientific inquiry is to break a problem into its component

pieces, fully explore each piece, and then reintegrate the solved portions into the combined solution. We discovered a lack of such integration of basic data at present in the literature pertaining to the care of cancer patients in Manitoba. While the discovery itself was notable, more important was the fact that the absence of this integration is a barrier to comprehensive cancer treatment program evaluation research. Hence, it became necessary to address this lack of integration so we could get to the questions we had identified initially. The first step was to define and collect all the basic event history data available on Manitoba cancer patients.

In constructing patient histories, many clinical, measurement and data management issues were raised and overcome. The manoeuvres required to identify, collect, and combine the various sources of data involved in constructing patient histories are laborious and time-intensive. Our having set out the framework for constructing patient histories from the available data makes subsequent application facile. The methodology can be easily applied to other cancer sites, different time periods and, ultimately, all patient populations. Uniformity of the definition of important clinical variables is essential to good scientific inquiry into the epidemiology of cancer care. Developing and defining the required operational processes is an important step forward in improving data collection and transcription methods. Details of the methodological aspects of the research will be given in the second article of this series.

A major contribution of this line of research to date has been the development of methodologies to compile and combine the varied data sources into a singular relational database that contains the entire case histories of cancer patients. We have painted a picture of the forest rather than examined only a small subset of particular aspects of each tree. This provides us with the mechanism to answer, with

relative facility, the myriad of involved clinical questions that comprise the multifaceted question of, "What happens when a person is diagnosed with cancer?" We have produced an omnibus means by which each aspect of this question can be answered. The beginnings of answering the various aspects of the question will be presented in subsequent publications in this series. In summary, the key point of this series of papers is that not only is the construction of a detailed history of cancer patients' interactions with the health care system desirable, but it is achievable. ♣

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