

Historical origins of current problems in cancer control

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Abstract

CANADA'S PROVINCES HAVE SOME OF THE MOST HIGHLY DEVELOPED CANCER control systems in the world, but the recent crisis in waiting times for radiotherapy has drawn attention to many weaknesses and inadequacies. Focusing on the province with the largest cancer control system, Ontario, this paper explores the historical origins of current problems in cancer control and shows that they are directly related to policy decisions made in the early years of the system. The development of cancer control in Ontario from the 1920s to the present is outlined, and the historical origins of 3 specific problems related to patient care are discussed: fragmentation of care, which has resulted from an emphasis on radiotherapy rather than comprehensive care and from tensions between the medical profession and government; variation in practice, which can be traced to the empirical origin of much cancer treatment and the slow implementation of research programs; and inequitable access to care, which can be attributed to the emphasis on geographic centralization of services. Attempts to reform Ontario's cancer control system are unlikely to be successful unless these fundamental issues are recognized and addressed.

Résumé

LES SYSTÈMES DE LUTTE CONTRE LE CANCER DES PROVINCES DU CANADA sont parmi les plus développés au monde, mais la crise récente soulevée par la durée de l'attente pour des traitements de radiothérapie a attiré l'attention sur de nombreuses faiblesses et lacunes. Concentrant son attention surtout sur la province qui a le plus important système de lutte contre le cancer, l'Ontario, l'auteur de ce document étudie les origines historiques des problèmes actuels de lutte contre le cancer et montrent qu'ils sont liés directement aux décisions stratégiques prises pendant les premières années du système. L'auteur décrit l'évolution de la lutte contre le cancer en Ontario des années 20 jusqu'à aujourd'hui et discute des origines historiques de trois problèmes en particulier qui ont trait au soin des patients : la fragmentation des soins, qui découle de l'importance accordée à la radiothérapie plutôt qu'aux soins complets, et de tensions entre la profession médicale et le gouvernement; les variations de la pratique, attribuables à l'origine empirique d'une grande partie des traitements contre le cancer et à la lenteur de la mise en œuvre de programmes de recherche; et l'accès inéquitable aux soins, qu'on peut attribuer à l'importance accordée à la centralisation géographique des services. Les efforts de réforme du système de lutte contre le cancer de l'Ontario ont peu de chance de réussir si l'on ne reconnaît pas ces problèmes fondamentaux et si l'on ne s'y attaque pas.

Most Canadian provinces have highly developed cancer control systems that were created in the early 20th century to address concerns about the rising rate of death from cancer and the scarcity and inaccessibility of radium for treatment. The establishment of government-sponsored cancer control programs was also stimulated by the success of public health measures in dealing with other diseases, principally tuberculosis, and by cancer control measures in other countries. Quebec became the first province to support cancer treatment when it purchased radium in 1922, but it was not until after the International Cancer Conference in 1928 that most other provinces began to take action (Table 1). In most provinces the cancer control systems have evolved along



Education

Éducation

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similar paths, which has resulted in networks of regional cancer centres; these centres have monopolized radiotherapy in this country since the 1940s.

Like other aspects of health care, Canada's cancer control systems have recently come under scrutiny. In the late 1980s their inadequacy became evident when waiting times for radiotherapy at some clinics became so long that patients were referred to other centres, some in the United States.¹ In Ontario, this crisis over waiting times was a catalyst for public concern about many aspects of the system, and in the early 1990s the government conducted a full-scale re-examination of cancer control that culminated in the publication of *Life to Gain: A Cancer Strategy for Ontario* in April 1994.² This document outlined many problems, such as poor coordination of services, lack of consistent standards of care, variations in access to care and lack of community or patient involvement in shaping cancer policy.

Because the concerns raised in Ontario are shared in other parts of Canada, this may be an appropriate time to reflect on the history of cancer control in Canada. Focusing on developments in Ontario, this paper will explore the historical roots of current problems in the cancer control system and show that several of the problems identified by patients and caregivers today can be directly related to policies established 60 years ago. The problems identified in the early 1990s are not transient phenomena but rather are deeply rooted in decisions made in the past. Almost every aspect of the cancer control system has come under scrutiny recently, but I will focus on only 3, each of which deals specifically with patient care and treatment: fragmentation of care, variation in treatment practice and inequitable access to care. I will begin with a brief overview of the origins of government involvement in cancer care and then show the roots of each of these problems. Ontario has been chosen as the focus because it has a highly developed system that has been the model for developments in other provinces. A review of the litera-

ture revealed only one study of the cancer control system in Ontario;³ that study explored the relation between government, organized medicine and unorthodox practitioners in the 1930s. Hence, this paper is based chiefly on the study of records of the Ontario Department of Health held in the Archives of Ontario and of minutes of meetings of the Ontario Medical Association (OMA).

Establishment of Ontario's cancer control system

In May 1931, at the suggestion of the OMA,⁴ the Ontario government established the Royal Commission on the Use of X-Rays and Radium in the Treatment of the Sick. This commission, chaired by Rev. Henry John Cody, president of the University of Toronto, was charged with reporting on the usefulness of radiotherapy and the advisability of the province establishing a cancer control program. Unfortunately, the members of the commission, whose recommendations had an enormous impact on shaping cancer control services in Ontario and other parts of Canada, had no particular expertise in cancer or radiotherapy. As a result, their views were strongly influenced by the head of radiology at the Toronto General Hospital, Dr. Gordon Richards, who saw the commission as a means to put into effect his idea that centralization was the best method of cancer control.

After visiting the leading cancer centres of Europe and the United States, the commission issued its report in March 1932.⁵ The commission recognized the usefulness of radiotherapy as a cancer treatment and recommended that the province purchase a supply of radium and establish a limited number of treatment centres (in the 3 cities with medical schools). It also recommended that programs of research, education and follow-up be established and that a commission or commissioner be appointed to ensure "close cooperation of all services in the treatment of cancer."

The government did not adopt a cohesive plan to implement these recommendations. Instead, action was taken on various recommendations at different times over the next 10 years. By the end of 1934 agreements had been made with local hospitals to establish 3 clinics, in Toronto, Kingston and London.⁶ These clinics were subsidized by the Ministry of Health and supplied with radium purchased by the government. A program of public education was started immediately, but the recommendation to centralize record-keeping was not implemented until 1936, when Dr. Hardisty Sellers was appointed medical statistician to the Department of Health. The delay in implementing the Cody Commission's recommendations can be explained in part by the financial hardships of the Depression.

Table 1: Early steps in cancer control in Canada

1922	Government of Quebec purchases radium
1925	Government of Nova Scotia purchases radium
1930	Saskatchewan Cancer Commission established Manitoba Cancer Relief and Research Institute established
1931-32	Study by Ontario Royal Commission on the Use of X-Rays and Radium in the Treatment of the Sick
1935	British Columbia Cancer Foundation established
1938	Canadian Society for the Control of Cancer (later the Canadian Cancer Society) established
1940	Alberta Cancer Treatment and Prevention Act becomes law
1943	Ontario Cancer Treatment and Research Foundation is established



The recommendation of the Cody Commission that an independent body be established to coordinate cancer control did not come to fruition until the establishment, in 1943, of the Ontario Cancer Treatment and Research Foundation (OCTRF), which slowly assumed responsibility for operating the regional clinics. The much-anticipated cancer institute did not come into being until the formation of the Ontario Cancer Institute (OCI), in 1952, and the opening of the Princess Margaret Hospital, in 1958.⁷ Thus by 1960 the key elements of today's cancer system — regional cancer clinics, a central coordinating body and a cancer institute, all supported by government funding — were in place.

Fragmentation of care

One of the main problems in the current system is the fragmentation of patient care. A person with cancer may see a variety of caregivers in a variety of locations, and communication among these caregivers may be limited. To quote *Life to Gain*, "People with cancer can receive radiotherapy or chemotherapy at a regional cancer centre, surgery in a community hospital, [and] chemotherapy from a family physician or through a home care program."² The way the province distributes the money it spends on cancer control contributes to this fragmentation: only 22% of the funds for cancer care are spent within the "official" OCTRF/OCI system.² The remainder is spent on surgery in community hospitals and on chemotherapy and other aspects of care given in local communities. This large "unofficial" cancer control system is entirely uncoordinated.

It is clear that this situation was not what the Cody Commission intended, because they had concluded that "since the welfare of the cancer patient should be the first consideration, there must be in all active-treatment centres, close cooperation of all services, medical, surgical, laboratory and radio-therapeutic, which deal with this malady."⁵ The concept of coordinated care originated with such authorities as Dr. Claudius Regaud of France, who met with the Cody Commission in Paris in 1931. Even before this meeting, Richards had submitted a proposal for the organization of Ontario clinics whereby multidisciplinary teams would manage the treatment of cancer patients.⁸ This philosophy of "comprehensive care" has been stated repeatedly in cancer policy in Ontario ever since.

Recent complaints and the large amount of money spent outside the organized system make it clear that this vision of comprehensive care has not been achieved. What has gone wrong? An obvious reason for the fragmentation of the system is the skewed emphasis on radiotherapy, which was built into the system from the begin-

ning. Although the Cody Commission recommended comprehensive cancer care centres for Ontario, government actions in the 1930s focused on establishing and equipping radiotherapy centres. In agreements signed by the government and the Toronto General and Kingston General hospitals, provisions were made for surgery to be performed by the referring practitioner, who might or might not have been geographically or administratively connected to the clinic.⁹ The physicians performing cancer surgery, therefore, were not expert cancer surgeons but rather staff surgeons of the local hospitals.

This was a serious error. Since the advent of anesthesia and antisepsis in the mid-19th century, surgery had become the main treatment for cancer,¹⁰ and patients were (and are) usually referred to surgeons for initial assessment, diagnosis and advice about the best form of treatment. Without surgeons dedicated to cancer clinics, Ontario could not hope to have a comprehensive cancer care system. A major component of the care of patients with cancer was absent from the system at the outset. As a result, the proportion of patients registered in the clinics who had surgery alone as their primary treatment remained low. Most significantly, the failure to formally incorporate surgery into the cancer clinic programs meant that the most important decisions about the care of patients with cancer were still made by individual surgeons in the community rather than by the multidisciplinary teams intended by the commission. Patients were referred to the clinics only if the surgeon felt that they needed radiotherapy.

The medical profession opposed the idea of centralizing cancer care, which, along with subsequent compromises in policy made by government, served to further fragment the system. From the beginning, physicians saw government involvement in cancer control as a threat to their autonomy and incomes. Even before the Cody Commission had completed its work, the Board of Directors of the OMA had to be reassured that "in whatever arrangements were made for the treatment of cancer by radium, the rights and privileges of the Doctors of the Province would not be interfered with."⁴ This concern was part of a much larger anxiety about the intrusion of government into medicine. At a meeting between the minister of health and the OMA to discuss the government's plans for cancer care, one prominent doctor said, "Perhaps the day is not too far distant when the Government will desire to establish diabetic clinics, infectious disease clinics, etc. Are we not heading into state medicine?"¹¹ The medical staff of one Ontario hospital rejected unanimously the idea of centralizing radiotherapy services.¹²

Because of this antagonism, the government turned a blind eye to the continuation of private cancer treatment. In many areas there were practitioners with established



expertise in radiotherapy. In Brantford, for example, Dr. Everett Hicks had a busy and extensive radium practice.¹³ In fact, throughout the 1930s and 40s, the Ministry of Health had a policy of distributing “radon seeds” (small quantities of radon gas encapsulated in gold tubing) to private practitioners considered competent in their use, a practice that promoted radiotherapy outside treatment centres.

With both cancer surgery and radiotherapy being provided in the community, cancer care in Ontario was fragmented from the start. Cancer clinics were quickly relegated to the role of providing radiotherapy at the behest of surgeons. Interestingly, a similar problem occurred in the early years of the cancer control system in France.¹⁴ An aggravating factor in Ontario was the early failure of the government to establish a central body with the authority to coordinate care. Although a coordinating body, the OCTRF, was finally established in 1943, its reach has never extended much beyond its clinic doors, as is shown by the 1992 statistic that only 45% of incident cancer cases are registered in the OCTRF system.¹⁵

Variation in practice

Another current concern in the treatment of cancer in Ontario is variation in practice. A lay person might expect that there would be consensus among doctors across the province and that patients suffering from similar forms of cancer would receive similar treatments regardless of where they live. In fact, recent studies have shown surprising variations in oncologic practice. In 1994 Iscoe and associates¹⁶ demonstrated large variations in surgical procedures for Ontario among women in whom breast cancer had been newly diagnosed. In spite of the fact that the survival rate for breast-conserving therapy (lumpectomy plus radiation) is the same as for mastectomy, the authors found that the rate of breast-conserving therapy ranged from 11% to 84% across counties and from 6% to 84% across hospitals. Variations have also been described within the “official” cancer control system. For example, Mackillop and colleagues¹⁷ studied radiotherapeutic practice in another common cancer, non-small-cell lung cancer, and found that between 1982 and 1991, among the 7 regional cancer centres in Ontario, there were highly statistically significant variations in the proportions of patients receiving long, intense radiotherapy treatments and the proportions of those receiving chemotherapy.

Such observations are not new. In his statistical reports on cancer in the 1930s and 40s, Sellers pointed out several areas of variation in practice in the cancer clinics. For example, in 1946 he reported differences between the proportion of cases treated with radium alone and the proportion treated with radium combined with other treatments

for different tumour sites.¹⁸ The use of radium alone to treat cervical cancer ranged from no cases in London to 28% of cases at the Ottawa General Hospital clinic.

Variation in practice thus seems to have been a feature of the cancer control system from the outset, although it has not necessarily been associated with any differences in outcome. Indeed the different radiotherapy practices in the treatment of lung cancer cannot be correlated with any difference in survival.¹⁷ However, variations in practice are associated with considerable differences in toxic effects and convenience, since longer and more intense treatments produce more side effects and necessitate more time away from home. In addition, variations in treatment cause psychological distress to patients who learn that their treatments are not the same as those being given at another centre.

This problem has arisen largely because cancer therapies have evolved on an empirical basis. The first nonsurgical therapy for cancer — radiotherapy — had its origin in the serendipitous observation that radiation caused damage to healthy tissues and the hypothesis that it might destroy diseased ones.¹⁹ Before the physics and biology of radiation were understood, physicians began using sources of radiation — x-ray machines and radium — to treat various forms of cancer. Because radiotherapy evolved from observation and practice, techniques and dosages were not standardized in the early decades of this century. When members of the Cody Commission visited the leading cancer centres in the United States and Europe in the summer of 1931, they saw a bewildering variety of practices. This was reflected in the commission’s conclusion that “There is no unanimity of opinion as to the best method of application either of radium or x-ray. While the results were most encouraging, it was apparent that individual operators were using the method to which they were most accustomed and which experience justified.”²⁵

As a result, neither the commission nor the officials who administered cancer control policy thereafter could make any firm recommendations about radiotherapeutic techniques or indeed about the value of radiotherapy in the treatment of different kinds of cancer. When the cancer clinics opened in 1933, they developed their own treatments based mostly on the experience and training of individual members of the staff. One way of resolving differences in practice might have been to recognize the lack of evidence supporting different approaches, to initiate research programs to study various treatments and to then reach firm conclusions from the results. Although the Cody Commission recommended a cancer research facility, a government-sponsored research program did not begin until 1945.⁹ Even then, the first research grants focused on basic science questions rather than clinical research. The long delay between the establishment of can-



cer clinics and the start of a clinical research program allowed variations in practice to become entrenched and, as a result, difficult to resolve.

Inequitable access to care

Another source of concern to patients and caregivers is that patients living in different parts of the province have different degrees of access to the cancer control system. To a large extent, this is a result of the disparity between the dispersion of the population and the centralization of the cancer control system. Mackillop and associates²⁰ have shown that between 1984 and 1991, the use of radiotherapy during the first year after diagnosis varied from county to county, and, not surprisingly, the highest rates of use occurred in counties closest to cancer centres. The same problem was identified nearly 60 years ago by Sellers,²¹ who pointed out that the ratio of cases treated to county population was highest in the counties where the clinics were located and lowest in the other counties.

These variations have their historical roots in the Cody Commission's recommendation that Ontario adopt a geographically centralized cancer control system similar to that in France, where regional anticancer centres were established in medical teaching centres in the early 1920s.¹⁴ The commission recommended the establishment of 3 clinics in the cities with medical schools (London, Toronto and Kingston). However, as one prominent gynecologist noted, "methods applicable to the limited and congested areas visited by the commission are not suitable to an immense, sparsely-settled province like our own."²² The fact that the French model did not apply to Ontario prompted the OMA to reject the idea of centralizing in 3 centres. Lobbying resulted in the establishment of 3 more clinics, in Ottawa, Hamilton and Windsor, by 1936.

The irony is that the commission did know which methods might be suitable to a geographically dispersed population like that in Ontario. During its work, the commission heard many opinions about the best way to organize a cancer control system. Some jurisdictions had recognized the problems inherent in centralization from the start. In Britain the National Radium Commission was the central distributor of radium to designated hospitals.²³ This solved the problem of radium supply and allowed patients to be treated in hospitals near their own homes. However, the organization in Australia was most relevant to Ontario. The Cody Commission received a detailed brief about the development of the cancer control system in Australia, where authorities recognized that the country's size and sparse population might lead to an uneven standard of care. There, in addition to main centres in state capitals, there were "a few smaller centres in more remote areas where a sufficient nucleus of population ex-

ist[ed]."²³ These smaller centres treated relatively uncomplicated forms of cancer, such as skin cancer, and provided initial assessments of more complicated cases.

Why did the commission reject these models? This is best explained by the lack of time the commission spent in Ontario and its reliance on Richards' opinions. The commission's investigation lasted approximately 5 months, but only 2 days were spent in public hearings in Ontario. Most of its time was spent touring the United States and Europe. During the Ontario hearings, the commission was advised that cancer services should be geographically accessible.⁵ However, opinions such as these were nullified by Richards' view that all cancer services should be centralized. In fact, it was Richards' personal opinion that adequate cancer treatment could only be given in Toronto.²⁴

Despite the problems and criticisms that quickly emerged, the idea of centralization had been planted firmly in Ontario cancer policy and became deeply rooted when Richards himself was appointed the first managing director of the OCTRF in 1944. The problems of geography have been partially overcome by the establishment of peripheral or outreach clinics in many smaller centres, but recent data^{16,17,20} suggest that such efforts have done little to overcome the inequities in access first pointed out by Sellers 6 decades ago.

Conclusions

As of 1997 the OCTRF has been replaced by a new organization, Cancer Care Ontario, to plan and coordinate cancer care in the province. This review of the origins of the cancer control system in Ontario has shown that current problems in patient care can be directly linked to the recommendations of the Cody Commission and to actions taken in the formative years of the system. None of the problems outlined in this paper is new; many were recognized both in the early years of the system and in 2 recent (1973 and 1984) studies of the cancer control system.^{25,26} These problems will have to be addressed when the cancer system is restructured, or history will repeat itself.

Foremost among the issues to be addressed is the degree to which the system should be centralized. A theme of this paper has been the difficulty of centralizing cancer services in a large geographic area with a dispersed population. Centralization concentrates expertise and expensive equipment in one or a few locations, but this inconveniences patients and fragments care. On a larger scale, centralization has exposed and exacerbated tensions between many communities — surgeons and radiation oncologists, generalists and specialists, university and non-university centres, and physicians and government. These tensions have undermined the vision of a comprehensive



care system. If the goal of a cancer control system is to provide comprehensive, coordinated, accessible care, then perhaps the emphasis on geographic centralization needs to give way to a new vision: cancer care as a continuum that involves both community-based caregivers, such as family doctors and surgeons, and regional cancer clinics. An initial goal might be to improve coordination and communication among existing caregivers; later, support could be given to community oncology centres.

Other important issues that need to be addressed are the role of community surgeons in the cancer control system and the development and implementation of guidelines for treatment to ensure that patients are treated consistently and in accordance with the best available evidence. Another equally important issue is the role of cancer prevention and screening, 2 areas that have been relatively neglected in the current cancer control system. Although the Cody Commission placed a great deal of emphasis on early detection and public education, the cancer control system has focused on treatment. The successful integration of education, prevention, screening, diagnosis and treatment within a fully coordinated system remains as much a challenge today as it was 60 years ago.

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