

Case report

Waiting Lists for Radiation Therapy: A Case Study

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Abstract

Background: Why waiting lists arise and how to address them remains unclear, and an improved understanding of these waiting list "dynamics" could lead to better management. The purpose of this study is to understand how the current shortage in radiation therapy in Ontario developed; the implications of prolonged waits; who is held accountable for managing such delays; and short, intermediate, and long-term solutions.

Methods: A case study of the radiation therapy shortage in 1998-99 at Princess Margaret Hospital, Toronto, Ontario, Canada. Relevant documents were collected; semi-structured, face-to-face interviews with ten administrators, health care workers, and patients were conducted, audio-taped and transcribed; and relevant meetings were observed.

Results: The radiation therapy shortage arose from a complex interplay of factors including: rising cancer incidence rates; broadening indications for radiation therapy; human resources management issues; government funding decisions; and responsiveness to previous planning recommendations. Implications of delays include poorer cancer control rates; patient suffering; and strained doctor-patient relationships. An incompatible relationship exists between moral responsibility, borne by government, and legal liability, borne by physicians. Short-term solutions include re-referral to centers with available resources; long-term solutions include training and recruiting health care workers, improving workload standards, increasing compensation, and making changes to the funding formula.

Conclusion: Human resource planning plays a critical role in the causes and solutions of waiting lists. Waiting lists have harsh implications for patients. Accountability relationships require realignment.

Introduction

In early 1999 waiting lists for radiation therapy in Ontario reached a crisis point. Newspaper articles described

the waiting lists as "agonizingly long" and "medically" unacceptable [1], cited possible explanations of why they developed ("Cancer experts 'ignored' over waiting lists"

[2]), and possible solutions ("U.S. cities to treat Ontario's cancer victims") [3].

Defined as "a roster of patients awaiting a particular service," [4] waiting lists are a feature of public health systems like those in the United Kingdom, New Zealand and Canada. For example, waiting times for cancer treatment in England were recently described [5]. Outstanding initiatives, such as those of Naylor and Hadorn, have focused on use of clinical data in managing waiting lists [6,7]. However, why waiting lists arise and how to address them remains unclear, and an improved understanding of these waiting list "dynamics" could lead to better management [4]. Waiting lists are also an issue in health care ethics since they relate to the underlying ethical principle of justice.

The waiting list for radiation therapy in Toronto is a good model in which to explore waiting list "dynamics." Evidence for improved clinical outcomes including survival, organ preservation, and quality of life with radiation treatment is available for many tumor sites [8,9,10]. Oncologists in Ontario are actively involved in an evidence-based practice guideline initiative [11] that provides up to date systematic reviews on the specific cancer treatment recommendations. These practice guidelines are widely available [12] and influence practice. A goal of treating 45% of all incident cases of cancer was adopted in Ontario [13]; although radiation therapy utilization rates in Toronto were found to be significantly lower [14].

We studied the waiting list for radiation therapy at a major Canadian cancer center. Our objectives were to understand the "dynamics" of the waiting list - how the current radiation therapy shortage developed; the implications of prolonged waits to receive radiation therapy; who is held accountable for managing such delays; and short, intermediate, and long-term solutions.

Methods

Design

We used the case study method, which "investigates a contemporary phenomenon within its real-life context." [15] The case is the radiation therapy shortage in 1998/99 at Princess Margaret Hospital (PMH), Toronto. PMH is one of nine institutions that deliver radiation therapy in Ontario and is Canada's largest center for cancer treatment, research, and education.

Data Collection

Data were collected from documents, interviews and observations of meetings, which were identified using theoretical sampling. Theoretical sampling is "sampling on the basis of emerging concepts." [16] For example, if a

particular person were mentioned as influential in an aspect of waiting lists, we sought to interview that person. [17] Documents included current memos, articles, reports including those referred to by participants in the context of interviews or meetings, and the agenda of relevant meetings. Face-to-face interviews were conducted, using a semi-structured interview guide based on the research questions, audiotaped and transcribed with 10 individuals including two physicians, one radiation therapist, four senior administrators (from radiation therapy, physics, radiation oncology and a senior administrator at CCO), and three patients awaiting radiotherapy. The 10 people selected were felt to be knowledgeable about the current situation through first-hand experience. Of the three patients interviewed, one had breast and the other prostate cancer, which represented the two most prevalent types of cancer on the waiting list. Six relevant meetings were observed during which detailed 'field notes' were made.

Data Analysis

These data sources generated more than 500 pages of data that were analyzed using a modified thematic analysis. Data segments that pertained to the study objectives were identified and coded. Coded units were compared for similarities and differences. Related issues were grouped into common themes (e.g. "human resource planning", "inadequate salary", "job dissatisfaction", "restructuring") and then under larger domain labels (e.g. "why waiting lists arose"). The data were then recoded using the domain labels. This process was conducted by one analyst (D.P.D.) in consultation with a second analyst (D.K.M.). To address validity, we conducted a "member check" by giving a draft of this paper to three interview participants for review and correction.

Research Ethics

The study was approved by University of Toronto Committee on Research with Human Subjects. Written consent was obtained from interview participants and individual participants are not identified.

Results

In 1998, over 6,000 new patients were seen in consultation in the Department of Radiation Oncology at PMH, representing a 16% increase over 1997. In February 1999, the time from referral to consultation was as much as seven weeks. The time from deciding to administer a course of radiation to starting curative treatment was 24-63 days. Delays of more than two weeks from referral to consultation or consultation to starting treatment, increased from 80% of cases in October 1998 to 88% in February 1999. These delays exceed the recommendations of the Canadian Association of Radiation Oncologists (maximum two weeks from referral to consultation

with a radiation oncologist, and two weeks from consultation to start of radiation).[18] The number of patients with various tumor sites who were waiting to start radiation treatment in February 1999 is shown in Table 1. Almost two-thirds of the waiting patients had breast or genito-urinary tumors for which there is good evidence for the role of radiation therapy in improving outcomes [9,19,20,21].

Table 1: Number of Patients Waiting to Start Treatment Radiation Medicine Program - PMH on February 5, 1999

Site Group	Number of Patients	Number of Patients
	<i>Radical</i>	<i>Palliative</i>
Breast	115	4
Central Nervous System	7	1
Endocrine	1	2
Head & Neck	28	0
Eye	0	1
Gastrointestinal	30	8
Genito-urinary	77	5
Gynaecological	12	2
Lung	15	15
Lymphoma	20	2
Myeloma	0	1
Paediatric	3	0
Sarcoma	7	0
Skin	1	2
Unknown	1	0
TOTALS	317	44

Radical - given with intent to provide eradication of tumor, a high quality of life and prolongation of survival **Palliative** - given to control or prevent symptoms of disease

How the current radiation therapy shortage developed

The radiation therapy shortage developed as a result of several factors. First, the incidence of cancer continues to rise by 4% per year. Many types of cancer, like prostate cancer, increase with age and are becoming more common with an aging population.

Second, there is greater use of radiation for certain tumors such as ductal carcinoma in -situ (DCIS) of the breast and longer courses of radiation have shown improved relapse-free rates for prostate cancer [20,21, 22]. The increased utilization is reflected by an 86% increase in the number of curative courses of radiation in Ontario over a 10-year period [23].

Third, human resource shortages involving radiation therapists, medical physicists, and radiation oncologists developed. Radiation therapists' salaries are lower in

Ontario than in some other areas in Canada and the U.S. A worldwide shortage of radiation therapists has led to recruitment by other centers. Training positions have been decreased and the provincial radiation therapy training program was closed for one year (1997). A lack of employment prospects lead to declining numbers of Canadian radiation oncology residents.

Finally, the Ministry of Health was slow to respond to funding requests for additional staff and equipment. This has limited treatment capacity and prevented hiring of staff. Funding to operate cancer treatment facilities have not accounted for changes in indirect services (e.g. support staff), depreciation of equipment, or increased numbers of patients. During prolonged waits for radiation treatment in 1989, PMH closed its doors to new patient referrals, and many were sent to other Canadian centers. In 1991, the Cancer Manpower Committee, appointed by the Ministry of Health, issued a report with recommendations regarding human resource issues [24]. Participants felt the current situation was a "frightening replay" of the previous delays, and that prior recommendations had not been followed.

Implications of waiting lists

Participants identified three main implications of the waiting list. First, local control of the cancer may become compromised, with increased toxicity of treatment (e.g. larger fields) or lower rates of organ preservation (e.g. larynx).

Second, the psychological effect on patients waiting to start radiation can be devastating - as one participant commented, "soul-destroying." Patients feel powerless about their situation: one patient interviewed reported his cancer visibly enlarging while he waited to start treatment. Prolongation of symptoms can lead to unnecessary suffering or requires interventions that have adverse effects. Daily activities and work can be disrupted. One participant felt unable to "move on to the next step in her life" while she waited.

Finally, radiation oncologists interviewed felt the patient-physician relationship was strained. The implicit trust that the physician is providing optimal care for the patient was lost. A heavier workload resulted in less time spent with patients.

Accountability for waiting lists

Participants felt that government and administrators of cancer services should be accountable for waiting lists. However, the physician may be legally liable. Hospital legal counsel advised radiation oncologists that they were responsible for patient outcomes on waiting lists. The Canadian Medical Protective Association, in response to

a letter written by a concerned physician, advised that "sound medical judgement within the accepted standards of practice for similar communities must always guide the physician's treatment and care of patients and take priority over cost restraints." In response to a patient's letter on delays to starting radiation, a Ministry of Health official indicated that responsibility for timeliness of treatment rests with the individual physician. While no action has been taken against a radiation oncologist for delayed treatment, in a mock legal case involving the cardiac surgery waiting list, a judge concluded that the physician was liable and the government was not [25].

Short- and long-term solutions

In March 1999, the Task Force on Human Resources for Radiation Services concluded that the current situation could not be addressed by "quick fixes." Recommendations were made on improving training programs, recruiting out-of-province workers, improving workload standards, adding staff, increasing salary, ensuring greater availability of continuing education and academic programs, and changing the funding formula to a per case basis. The Minister of Health accepted these recommendations [26]. With respect to short-term solutions, participants endorsed re-referral of patients to other facilities, likely in the United States since there are waiting lists for radiation therapy in most Ontario radiation treatment centers [27]. The re-referral process was postponed several times pending a final detailed analysis of radiation capacity in Ontario. Many logistical issues arose from sending patients out of province for treatment, including criteria for patients sent, resources required to assess patients for re-referral, follow-up care, and legal liability.

Discussion

Although we did not conduct a detailed analysis of clinical outcomes of patients on the waiting list, our study describes the "dynamics" of an actual waiting list. The findings underscore the unexamined and unintended moral implications of administrative decisions.

The waiting list for radiation therapy arose from an interplay of factors, including: rising cancer incidence rates; increasing indications for radiation therapy; human resource management, training and planning; government funding decisions; and responsiveness to previous planning recommendations. Models proposed to assess waiting lists for radiation do not allow for the complexities identified in our case study [28,29,30]. The importance of human resource management, planning and training issues in this case study was striking.

The implications of delays for radiation include perceived lower cancer control rates, patient suffering, and strained patient-doctor relationships. While the emotional consequences for patients of delays in diagnosis and treatment may be acknowledged by the media, the moral dimensions of this emotional burden are rarely acknowledged in policy making. Current delays, and the burdens they impose on patients, are ethically unjustifiable.

An incompatible relationship exists between moral and legal responsibility - government is viewed as morally responsible but physicians may bear legal liability. Physicians are given the responsibility without power to change the waiting list situation. Although liability can likely be reduced through disclosure of waiting times and alternatives such as treatment elsewhere, this responsibility paradox is morally untenable. Physicians ought not to be held liable for administering treatment schedules that are beyond their control. Moral and legal accountabilitys for waiting lists require realignment.

A short-term solution is re-referral, although this presents logistical difficulties. Increased "supply" of human resources cannot necessarily be rectified quickly by an infusion of money, and delayed corrective action may never solve a growing problem [31]. This may explain the mixed results of increasing resources to ameliorate waiting lists. A sustained commitment to human resource planning is required.

Our study has four main limitations. First, it focussed on waiting list "dynamics" rather than clinical outcomes. Second, it examined waiting lists at a single radiation treatment center and may not be generalizable. However, some of the findings, such as the importance of human resource management, will likely be generalizable to other settings and health systems. Others, such as the trade-off between moral and legal responsibility, will require assessment in other health systems. Third, we interviewed only 10 individuals. However, this information was triangulated with data from documents and observation of meetings. Finally, our participants may each have seen the problem from their own "biased" perspective. We interviewed patients, health care providers, and administrators. Unfortunately, government officials declined our requests for an interview, so their perspective was reflected only through public statements in the media and in planning documents.

In conclusion, human resource planning plays a critical role in the causes and solutions of waiting lists. Waiting lists have harsh implications for patients. Accountability relationships require realignment.

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