

Sleepless in Cancer Land

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The long waiting times from suspicion of cancer to time of definitive treatment have bedeviled attempts to deliver the early diagnosis and treatment that Canadians expect. It is a defining characteristic of cancer that without effective treatment the vast majority of tumours will grow in an uncontrolled manner and the disease can advance past the curable stage during these delays. Knowing this, patients waiting their turn in the lineup undergo avoidable psychological suffering and spend many a sleepless night.

The problem stems in part from shortages of cancer professionals and equipment for imaging and treatment. However, the problem is also greatly complicated by disconnects in the entire health care system – entrenched silos that anxious patients have to conquer on the path to survival.

For the last six years, CACC has been tracking the progress in reducing long waiting times, analyzing the list of murky issues, which include:

- The wide array of definitions of what constitutes waiting time;
- Word games as in distinguishing “elapsed time” from “waiting time;”
- Avoiding the issues by using “ready to treat” vs. “time from referral;”
- Blaming patients for deferring appointments, thereby contributing to waiting time;
- Need for disease-specific benchmarks for waiting times;
- Differing standards for urgency of care between provinces;
- Lack of agreement regarding the effect of treatment delay on tumor progression.

There does not seem to have been any resolution of any of these issues.

CACC encouraged Dr Brent Schacter, CEO of CAPCA, to hold a pan-Canadian workshop on waiting times and he did so in February 2006. The workshop report has just been released. It is an unusually frank and accurate

description of what transpired but does not describe consensus on definitions or indicate a clear solution for resolving any of the issues listed above.

In our search for solutions, we looked outside Canada. When the egregiously high cancer mortality in the UK came to that public’s attention, the British government stepped in with the National Health Service (NHS) Cancer Plan, mandating a series of corrective steps. In a remarkably short time, the delays from suspicion to treatment (process) and the rates of cancer mortality (outcome) improved substantially. The resulting drop in UK mortality is marked but still remains higher than Canada.

The UK experience

The UK waiting times project started in 1998 under the leadership of National Cancer Director Michael Richards. A simple statement of one goal tells the story: “A long-term goal set in the NHS Cancer Plan was that no suspected cancer patient should have to wait more than a month from time of being referred by their GP, until the start of treatment.” The most recent status reports¹ are for the second quarter of 2006:

- 99.50 per cent of all patients are seen by the appropriate outpatient cancer specialist within two weeks of GP referral;
- 99.50 per cent of patients begin their cancer treatment within one month of diagnosis for any cancer;
- 95.00 per cent of patients start cancer treatment within two months of referral by the family physician;
- 99.80 per cent of breast cancer patients start treatment within 31 days of diagnosis.
- 100 per cent of children’s cancers, testicular and acute leukemia start treatment within 31 days of referral by the family physician.

How did they do that?

The NHS cancer plan was introduced with staged milestones, a support structure for advice and intervention

In the UK cancer patients are moved through the system as if their lives depend on it

THE CALGARY RAPID ACCESS CLINIC ²

When the University of Alberta Business Faculty found that prostate cancer patients were waiting 95 days from referral by the family physician to a positive diagnosis of prostate cancer, the reaction among local urologists was “this is crazy, we can do better.”

In September, 2005 the Rapid Access Clinic (RAC) opened its doors. This clinic now sees approximately 1200 patients each year. A team of urologists rotate through the clinic and every Calgary patient with a suspicion of prostate cancer is referred to the RAC.

Results

- Time from referral by family physician to seeing urologist:
just under seven days
- From urologist to biopsy:
one to two weeks
- From biopsy to results:
one to two weeks
- Total wait, from first referral to pathology result:
27 days

Dr. Bryan Donnelly, Director of the clinic, notes that if Calgary had one more pathologist to handle biopsies the process could be reduced to 20 days.

The Calgary Clinic has proposed an expansion of this service to Edmonton and is awaiting approval.

when necessary, and multiple layers of accountability that engage providers and administrators.

The first target was set in 1998, requiring that all urgent GP referrals for a suspected cancer be seen within two weeks. Compliance rates of 93.5 per cent were achieved by 2000, rising to 95 per cent nine months later, 98 per cent in 2002 and 99 per cent in 2003.

Following on this early success, the NHS Cancer Plan was published in September 2000, setting the additional four targets.

Current rates of compliance are deemed sustainable in part because the methods used to comply with the targets are monitored to avoid spikes of compliance followed by recidivism. A few weeks of wrenching change to meet the target will almost always disintegrate after the target is reached. Behaviours are watched to ensure desired long-term improvements are instituted; if not, a series of interventions are generated.

The NHS issued a directive to all regional health authorities requiring compliance with the cancer plan: screening, early detection, treatment. Failure to meet referral timelines 95 per cent of the time would affect performance ratings (and funding) and if two hospitals were involved, both hospitals were penalized.

To put this level of commitment in perspective, note a few other NHS rules:

- **General Practice:**
Patient to see doctor within two working days
- **Accident and Emergency:**
All patients must be seen, treated and discharged or admitted within four hours
- **Financial penalties if either target is missed**

These requirements apply to the every physician and hospital in the public health system.

The effect of the directive, the structure and the penalties has been to drive change at every point in the pathway, from the smallest matters (referral letters are no longer put in the mail) to the largest (rapid assessment and fast-track scheduling). Responsibility is clearly established for coordinating care from the first suspicion onward, through the tests, appointments with surgeons and other specialists so that cancer patients are moved through the system as if their lives depend on it.

A Concept for Reducing Cancer Waiting Times

It is possible to change cancer system processes in Canada but it takes courage and leadership. The concept is simple: once a person has a high suspicion of cancer that person is directed straight to a diagnostic

centre designed to determine whether the disease is or is not present and, if present, its extent (staging). For example, if a chest x-ray (taken for whatever reason) were to show a large shadow highly suggestive of lung cancer, the patient could be sent directly to a lung cancer diagnostic centre to sort out the problem, instead of having to wind through the various parts of the existing system, resulting in delays and inefficiencies, repeating expensive tests because of delays. All the while that person's primary care physician can be kept informed of results, so that if (when) referral to for treatment is necessary, it can also occur without delay.

The approach described is a derivative of the best designed breast screening centres where, when an abnormal mammogram is detected on the viewing panel, the woman is recalled to an assessment clinic within 5 working days for a multidisciplinary work-up by a surgeon, radiologist and if necessary, a pathologist. A definitive diagnosis is quickly reached and the information on how best to proceed is then relayed to her family doctor. If cancer is likely, treatment can proceed without need for any further tests.

The Manitoba Prostate Cancer Project

Using federal funds from the waiting times initiative, CancerCare Manitoba (CCM) is looking at rapid diagnosis to help family physicians efficiently investigate a suspicion of cancer.

To introduce the concept, Manitoba established a rapid assessment approach for prostate cancer by working with all the urologists to develop criteria. Any patient meeting those criteria, such as a high PSA level, moves immediately to a rapid diagnosis process rather than back through the investigative loops.

Dr. Dhaliwal, CEO of CCM, describes this approach as the logical extension of screening. Every large mass discovered on an incidental exam needs urgent attention: the patient is not sent back to the family physician but is immediately referred to a specialist unit as "high suspicion" and the family physician is informed. This intervention alone eliminates the unproductive loops that can occur as the person moves from family physician to specialist to surgeon, each one with waiting lists, each one retesting the mass.

CCM is tracking all prostate cancer patients as they go through the system to compare the speed of the rapid access group with the experience of other patients and to see if treatment outcomes are improved. Manitoba is the first and only cancer registry to have complete collaborative staging information for 2004 for all cancer patients. CCM also collects data on every contact with a service provider for six months prior to cancer diagnosis. A considerable amount of analysis has still to be done, but these data, once correlated, will create a baseline linked to outcomes. In this way, CCM will

be able to determine how much delay is safe before the disease advances.

Similar diagnostic prostate clinics have been started in BC, Alberta, and Ontario. As well, rapid assessment centres for breast cancer have long been in operation in various locations. They can be highly efficient but have largely been operated in isolation of the mainstream health care system and as a result, have served only a minority of patients.

Conclusions

Patient pathways from suspicion to diagnosis to treatment can be streamlined to reduce delays and improve outcomes. The first step is for specialists to work cooperatively toward that goal. The psychological distress of patients facing a cancer diagnosis is heightened during the period of uncertainty, waiting for answers. There is very little information about the amount of waiting time that is safe for any particular patient. Manitoba's focus on data collection and collaborative staging will provide important new insights that could guide cancer care improvements across the country.

Recommendations

- 1 Leadership by the cancer agencies is required to move rapid assessment from the rare to the routine. Cancer agencies have a responsibility to work more closely with the system outside their doors.
- 2 The concept of rapid assessment arose from screening programs but not all screening programs have a mechanism to move a patient rapidly to diagnosis. Screening programs should not be introduced without the simultaneous organization of rapid assessment centres.
- 3 The rapid assessment concept would require family physicians, surgeons and pathologists to follow algorithms that can be developed cooperatively.
- 4 Canadian pioneers in the creation of rapid assessment centres should be supported and encouraged to teach, lead and promote rapid assessment for many more cancers.
- 5 Surveillance and outcome measurement are essential to create knowledge in Canada about the effects of waiting times and process delays.

References

1. Richards, Michael: Waiting times for cancer; progress, lessons learned and next steps: A report to the Secretary of State for Health; October 2006; and UK Department of Health website, Cancer Waiting Times Statistics, <http://www.performance.doh.gov.uk/cancerwaits/index.htm>
2. CACC interviews with Dr. Bryan Donnelly, Director of the Calgary Rapid Assessment Centre, and Dr. Dhali Dhaliwal, President and CEO, CancerCare Manitoba; October, November and December 2006.

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