Achieving the Achievable in Cancer Control: Some lessons from our radiotherapy system

William J. Mackillop
(PMH RO class of 1980)

Queen’s Cancer Research Institute, Kingston
The take home message

Our best shot at reducing the burden of cancer in Canada within the next decade is to learn how to make better use of existing knowledge, technology and resources.

We need to invest more in Health Services Research aimed at identifying and exploiting opportunities for improving the performance of our cancer control systems.

Active surveillance of the performance of treatment processes is one of the keys to better outcomes.
Health Services Research is the domain of health research that seeks to improve population health by creating the knowledge required to improve the delivery of health services.

Health Policy Research seeks ways of putting that knowledge to work.

Lu Ann Aday
The WHA Declaration on Cancer Prevention and Control recommends that all nations should:

– develop comprehensive cancer control programs through the systematic, stepwise and equitable implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment, rehabilitation and palliative care;
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– develop comprehensive cancer control programs through the systematic, stepwise and equitable implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment, rehabilitation and palliative care;
Background to the WHA Declaration on cancer prevention and control:

- Recognizing that many of cases of cancer could be prevented,
- Recognizing that the technology for treatment of cancer is mature and that many cases of cancer can be cured,
- Recognizing the value of multidisciplinary management and the importance of surgery, radiotherapy, chemotherapy, and palliative care
- Mindful of the need for careful planning and priority-setting in the use of resources
The WHA recommends that national cancer control strategies should:

– frame policies for strengthening and maintaining equipment for diagnosis and treatment;

– improve access to appropriate technologies

– determine minimum standards for cancer treatment (appropriate to local situations)

– develop and strengthen health system infrastructure, particularly human resources
Thanks to many people from across Canada, but in particular to Simon Sutcliffe (PMH RO class of ’81), Canada now has a national cancer control strategy and a federal funded national agency, CPAC, charged with implementing that strategy in collaboration with many governmental and non-governmental organizations across the country.

“The engine for cancer control in Canada”
An ounce of prevention.....

What is the right balance of investment between prevention and treatment in a cancer control program?
Cancer 2020: The Potential Impact of Prevention and Screening on Cancer in Ontario, Dr. John McLaughlin, CCO

Cancer Prevention Targets
• Tobacco use
• Diet and nutrition
• Healthy body weight
• Alcohol consumption
• Occupational carcinogens
• Environmental carcinogens
• Ultraviolet exposure
• Viral infections

Cancer Screening Targets
• Cervical cancer screening
• Colorectal cancer screening
• Breast cancer


Impact of Cancer Prevention Interventions

Decreased incidence in 2020:
- females: -3.2% (1400 cases)
- males: -2.6% (1400 cases)

John McLaughlin CCO

<table>
<thead>
<tr>
<th>Cancer</th>
<th>Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>0.26</td>
</tr>
<tr>
<td>Lung</td>
<td>0.81</td>
</tr>
<tr>
<td>Colorectal</td>
<td>0.44</td>
</tr>
<tr>
<td>Uterus</td>
<td>0.10</td>
</tr>
<tr>
<td>Head &amp; Neck</td>
<td>0.23</td>
</tr>
<tr>
<td>Non-Hodgkin Lymphoma</td>
<td>0.43</td>
</tr>
<tr>
<td>Thyroid</td>
<td>0.04</td>
</tr>
<tr>
<td>Ovary</td>
<td>0.71</td>
</tr>
<tr>
<td>Melanoma</td>
<td>0.16</td>
</tr>
<tr>
<td>Pancreas</td>
<td>1.00</td>
</tr>
<tr>
<td><strong>All Cancers</strong></td>
<td><strong>0.45</strong></td>
</tr>
</tbody>
</table>

Chronic Disease Surveillance Division, CCDPC, Public Health Agency of Canada
How much does treatment contribute to the overall effectiveness of a cancer control program?

The appropriate balance of investment among the different components of a cancer control program is unknown. We need to find that out!

At present, treatment has a much greater impact on mortality than primary prevention.

Cancer-directed treatment will inevitably remain the most important element of cancer control well into the middle of this century.
How do we better?

How do we set about enhancing the effectiveness of cancer treatment programs?

Step 1 is to consider the factors that limit the effectiveness of existing programs.
The “Achievable” outcome: the best outcome we could possibly achieve within the limitations imposed by the state of scientific knowledge/technology and availability of resources.

The “Achieved” outcome: the actual outcome observed in the population, which may fall far short of the achievable…

\[ \text{Attainment factor} = \frac{\text{Achieved}}{\text{Achievable}} \quad (\text{Value} = 0 \text{ to } 1) \]

\[ \text{Achieved outcome} = \text{Achievable outcome} \times \text{Attainment factor} \]
Achieving the Achievable

Biomedical/Clinical Research

\[ \text{Achieved outcome} = \text{Achievable outcome} \times \text{Attainment factor} \]
Achieving the Achievable

\[ HSR \]

\[ \text{Achieved outcome} = \text{Achievable outcome} \times \text{Attainment factor} \]
Aspects of Health System Performance

Accessibility: Do patients get the care they need, when they need it?

Quality: Do patients get the right care, delivered in the right way?
  – Technical/personal care

Efficiency: Are we getting the best value for money in terms of the accessibility and quality?
  – Performance/allocation efficiency

These quantities are not independent of one another!
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The PMH waiting list crisis of 1989

Cancer hospital short of staff, may shut doors to new patients: Kelly Toughill Toronto Star. Sep 7, 1989


Hospital to close doors to new cancer patients; Kelly Toughill, Toronto Star. Sep 13, 1989.

*Patients are dying because their cancers have grown while they were waiting for treatment.*“ said Dr. Alon Dembo, – Toronto Star. Sept 9, 1989
1. Denial of the existence of the problem:

- “Despite media reports to the contrary, the vast majority of patients receive timely and appropriate care”  CCO, Toronto Star
Stages of acceptance of the diagnosis of "diseases of the health system"

1. Denial of the existence of the problem:
2. Denial that the problem is remediable:
   - OK, this is a problem, but it’s happening everywhere. It is beyond our control.
Waiting for radiotherapy in Ontario
Int J Rad Oncol Biol Phys, 1993

Waiting times for RT for laryngeal cancer
\( t_1 = \text{Dx to referral} \)
\( t_2 = \text{referral to consult} \)
\( t_3 = \text{consult to RT} \)
\( t_{\text{total}} = \text{Dx to RT} \)
Stages of acceptance of the diagnosis of “diseases of the health system”

1 Denial of the existence of the problem: 
2 Denial that the problem is remediable: 
   • OK, this is a problem, but it’s happening everywhere. It is beyond our control.
Waiting times from referral to RT for a patient with a T2, N0, Ca larynx at RT centres in Canada and the US

![Chart showing waiting times from referral to RT for a patient with a T2, N0, Ca larynx at RT centres in Canada and the US. The chart displays the proportion of departments with different waiting time categories. The categories are ≤1, 1-2, 2-3, 3-4, 4-5, 5-6, 6-7, and 7-8 weeks. The data is presented for Canada and the USA, with Canada in red and the USA in blue. The majority of departments fall in the 1-2 and 2-3 weeks categories for both countries.]

- Canada: 40% in ≤1, 60% in 1-2 weeks, 20% in 2-3 weeks, 40% in 3-4 weeks, 50% in 4-5 weeks, 30% in 5-6 weeks, 10% in 6-7 weeks, and 0% in 7-8 weeks.
- USA: 30% in ≤1, 60% in 1-2 weeks, 20% in 2-3 weeks, 40% in 3-4 weeks, 50% in 4-5 weeks, 30% in 5-6 weeks, 10% in 6-7 weeks, and 0% in 7-8 weeks.
Stages of acceptance of the diagnosis of “diseases of the health system”

1 Denial of the existence of the problem:
   • *This is just an anecdote: there is no evidence that this is a systemic problem!*

2 Denial that the problem is remediable:
   • *OK, this is a problem, but it’s happening everywhere. It is beyond our control and we are no worse off than anyone else!*

3 Denial that the problem is serious:
   • *There is no evidence that this affects outcomes!*
Classification of Potential Adverse Effects of Waiting Lists for RT

- Direct effects of waiting for RT
- Indirect health effects of waiting lists for RT
- Economic effects
- Other societal effects
Potential direct effects of waiting for RT

- Decreased probability of local control
- Decreased probability of survival
- Persistence or worsening of symptoms
- Anxiety
- Decreased quality of life
Predicted Decrease in Local Control with Increasing WT for RT for Cancer of the Tonsil

% Local Control Rate

Waiting Time (days)

mean $T_d = 82$ days

mean $T_d = 58$ days
Systematic review

The relationship between waiting time for radiotherapy and clinical outcomes: A systematic review of the literature

Zheng Chen\textsuperscript{a}, Will King\textsuperscript{a}, Robert Pearcey\textsuperscript{b}, Marc Kerba\textsuperscript{a}, William J. Mackillop\textsuperscript{a,*}

\textsuperscript{a}Queen's Cancer Research Institute, Queen's University, Kingston, Ont., Canada, \textsuperscript{b}Cross Cancer Institute, Edmonton, Alta., Canada
Meta-analysis of 12 studies of the association between WT and local recurrence in head and neck cancer
Conclusions

Longer WT’s are associated with a higher risk of local recurrence in head and neck cancer and breast cancer.

The RR~1.2/month of delay for head and neck cancer translates into an absolute increase in local failure rate from 25% to 30% with one month of added delay.

The observed increase in local failure rate in head and neck cancer is consistent with the estimates of risk derived from the radiobiological modes.

The magnitude of the adverse effects of delay is sufficient to outweigh the benefits of the technological advances in RT over the last 20 years.
Stages of acceptance of the diagnosis of “diseases of the health system”

1. Denial of the existence of the problem:
2. Denial that the problem is remediable:
3. Denial that the problem is serious:
4. Cautious acceptance of the problem followed by purposeful action to correct it
   - National and provincial guidelines for WT’s
   - Increased investment in RT systems
What were the lessons learned?

Bad news about health system performance may be quite unwelcome.

The evidence that the problem is serious must be carefully assembled and presented to the right people in the right way.

Don’t focus on the visible symptoms of the health system “disease” …..try to understand its “pathophysiology” or you may miss even more important underlying problems!!
The Concept of Accessibility in Health Care

- Accessibility “describes the degree of fit between the system and the patients” (Aday)

- Accessibility = utilization / need

- Accessibility embraces all factors that influence the level of use of a service, given a particular level of need....
Components of Accessibility

Availability*: total system capacity/total needs
  - Determined by total resources, efficiency, flexibility

Spatial Accessibility*
  - Distance and travel times

Accommodation* (Convenience)
  - Hours of operation; lodges; transportation services

Affordability*
  - Direct and indirect costs; ability and willingness to pay

Awareness of indications for the service among doctors and patients

* terms used by Penchansky 1981
Do patients get “the care they need”, “when they need it”?
Indicators of Access to RT

Do patients get their RT when they need it?
Waiting times for RT

Do patients get the RT they need?
Rates of use of RT
The HSR process

Define indicators of performance
The HSR process

Define indicators of performance

Describe performance
Set standards of performance

Define indicators of performance

Describe performance
Define indicators of performance

Set standards of performance

Describe performance

Evaluate performance
Define indicators of performance

Set standards of performance

Evaluate performance

Describe performance

Identify factors that affect performance
Define indicators of performance

Set standards of performance

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Design intervention(s) to enhance performance
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Define indicators of performance
**Indicators of Use of RT**

**Use of RT in initial treatment of cancer**
defined as the proportion of incident cases treated within 1 year of diagnosis

**Use of palliative RT among people dying of cancer**
defined as the proportion of cases that die of cancer who receive palliative RT in the last year of life
The HSR process

Define indicators of performance

Describe performance
Data Linkage

ONTARIO CANCER REGISTRY

Hospitals
Hospitalizations
Procedures
Co-morbidity

(thanks to Eric Holowaty and OCR)

RORU/CCE Clinical Database

Chart Review
Audit data Quality
Supplement core data

Provincial RT centres
Radiotherapy
Chemotherapy

Derived Variables
Descriptors of Diseases, Treatments, Institutions

Statistics Canada
SES
a) RT within 1 Year of Diagnosis

Northern Ontario

Southern Ontario

Quintile

- 17.5% - 24.3%
- 25.1% - 26.8%
- 27.2% - 29.1%
- 29.2% - 30.7%
- 30.8% - 35.2%
- data not available

Zhang-Salomons 2005
b) Palliative RT in the Last 2 Years of Life

Northern Ontario

Southern Ontario

Quintile

10.9% - 23.5%
23.5% - 24.5%
24.5% - 26.5%
26.5% - 29.6%
29.6% - 35.5%
data not available

Zhang-Salomons 2005
What rate is right?

Professional opinion
Evidence based approaches
Benchmarking
An Evidence-based, Epidemiological Approach

- Identify all indications for RT by systematic review
- Estimate the incidence of each indication in the cancer population
- Integrate this information to estimate overall requirement for RT
- http://www.krcc.on.ca/estimatingRT

Tyldesley et al, IJROBP, 2000
Estimating Need for RT: Lung Cancer

http://www.krcc.on.ca/estimatingRT
A Criterion-based, Benchmarking Approach

- Set criteria for identifying communities in which the rate of use of the service is most likely to be optimal
- Identify communities which fit those criteria
- Measure rates of use of the service in several such communities

*Barbera et al, Medical Care, 2003*
Initial Rate of RT for Lung Cancer in Ontario by County

Estimated Appropriate Rate = 44.6%

Estimated Shortfall = 10.6%

Overall Observed Rate = 34%

Bars (-) represent the 90% CI

Tyldesley et al, IJROBP 2001; Barbera et al, Medical Care, 2003
Define indicators of performance

Set standards of performance

Describe performance

Evaluate performance
Observed Rate of RT in the Initial Tx of Lung Cancer in relation to “Standards”

<table>
<thead>
<tr>
<th>“Standards”</th>
<th>Observed Provincial Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>✔️ Benchmark Rate</td>
<td>41.3% (39.9-42.7)</td>
</tr>
<tr>
<td>✔️ Evidence-based Rate</td>
<td>41.6% (39.2-44.1)</td>
</tr>
<tr>
<td></td>
<td>32.5% (32.0-33.0)</td>
</tr>
</tbody>
</table>

Accessibility (Attainment) = \( \frac{32.5}{41.5} = 76.1\% \)

\(^1\text{Barbera} \quad ^2\text{Tyldesley}\)
Define indicators of performance

Set standards of performance

Describe performance

Evaluate performance

Identify factors that affect performance
Factors associated with the use of RT within one year: Hierarchical Logistic Regression

<table>
<thead>
<tr>
<th>VARIABLES</th>
<th>OR (95% CI)</th>
</tr>
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<tbody>
<tr>
<td><strong>Hospital Size</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 50 cases per year</td>
<td>0.70 (0.58-0.84)</td>
</tr>
<tr>
<td>50-250 cases per year</td>
<td>1.05 (0.90-1.24)</td>
</tr>
<tr>
<td>250-500 cases per year</td>
<td>0.97 (0.82-1.14)</td>
</tr>
<tr>
<td>&gt; 500 cases per year</td>
<td>1</td>
</tr>
<tr>
<td><strong>Availability of Oncology Services</strong></td>
<td></td>
</tr>
<tr>
<td>on-site RT &amp; MO</td>
<td>1.34 (1.08-1.66)</td>
</tr>
<tr>
<td>RT visit &amp; MO</td>
<td>0.88 (0.70-1.12)</td>
</tr>
<tr>
<td>RT visit &amp; no MO</td>
<td>1.02 (0.87-1.20)</td>
</tr>
<tr>
<td>MO &amp; no RT</td>
<td>0.96 (0.81-1.14)</td>
</tr>
<tr>
<td>no RT &amp; no MO</td>
<td>1</td>
</tr>
<tr>
<td><strong>Age at Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>20-40</td>
<td>4.04 (3.71-4.40)</td>
</tr>
<tr>
<td>41-50</td>
<td>4.00 (3.73-4.29)</td>
</tr>
<tr>
<td>51-60</td>
<td>3.37 (3.16-3.59)</td>
</tr>
<tr>
<td>61-70</td>
<td>3.03 (2.85-3.22)</td>
</tr>
<tr>
<td>71-80</td>
<td>2.33 (2.19-2.48)</td>
</tr>
<tr>
<td>80+</td>
<td>1</td>
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<tr>
<td><strong>Disease Category</strong></td>
<td></td>
</tr>
<tr>
<td>with an 10% Optimal RT Rate Increase</td>
<td>1.56 (1.55-1.57)</td>
</tr>
</tbody>
</table>

The effects of all factors are significant in the model.
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Lessons learned

Active surveillance of treatment systems may reveal otherwise invisible problems that represent important opportunities for improvement.

Intervention studies are now required to learn how to exploit those opportunities.
What’s next?

Apply a similar approach to study the Quality of RT
Framework for a 1st national study of Quality of RT, from Mike Brundage (class of ’88) and the CIHR team is Access to Quality RT

Two concurrent studies of medical process (Present proposal)

Indicator Validation Study (Project 2)
- Modified Delphi Process
- Content Experts

Patterns of Care Survey (Project 1)
- survey of patterns of care
- random sample of cases
- use of clinical trials infrastructure

Utilize existing Structure/Organization information
- use existing data from CARO databases

Technical Quality Assurance in Medical Physics

Studies of Structure and Organization

Studies investigating interpersonal care

Future Structure/Organization Research

Future research projects

Improved Outcomes for Prostate Cancer Patients Receiving Radiotherapy in Canada
The take home message

Our best shot at reducing the burden of cancer in Canada within the next decade is to learn how to make better use of existing knowledge, technology and resources.

We need to invest more in Health Services Research aimed at identifying and exploiting opportunities for improving the performance of our cancer control systems.

Active surveillance of the performance of treatment processes is one of the keys to better outcomes.