EXSPANSE

A REPORT FROM THE CANCER SURVIVAL & PREVALENCE ANALYTIC NETWORK

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To get the full story, proper consultation and comparisons are necessary.

Quality matters

Ancient Greek philosopher, scientist and physician Aristotle said "Quality is not an act, it is a habit" and Canada's cancer registries are doing an excellent job of living up to that mindset.

Data quality, which includes completeness, accuracy, timeliness and comparability, really does matter in health care because it can affect the statistics produced from the data, and the statistics are the basis of health policies and programs that in turn have implications for the population. We are fortunate in the cancer world because attention to quality has a major focus right at the beginning of the process – data collection. Cancer registrars record details on who gets cancer, what kind of cancer they have, and what their outcome is. They examine information as it comes in, examining it closely for reasonableness and resolving contradictions in personal data and diagnoses.

Standards are well-known and quality audits occur annually through the North American Association of Central Cancer Registries (NAACCR). For survivorship statistics, it is critical to understand data quality and the potential for its impact on interpretation. Two areas are particular concerning: the quality of tumour registration and the quality of death registration. In each case we are very concerned about completeness, accuracy and timeliness, and that the practice is consistent enough to enable comparability.

As readers of this newsletter are aware, survivorship statistics are important to many people: patients, health care providers and policymakers in particular. We have built a cancer system that relies on such information: cancer control policies use numbers as their foundation, and increasingly the cancer system's performance is being assessed through a host of measures including survival statistics.

But what are the statistics made of? The building bricks are, of course, data – and it's important to understand the potential potholes and speedbumps in our data. Hence we are spending a little extra time in this issue speaking about data quality.

As driven as we are for results, society tends to take numbers at face value – no questions asked. To maintain quality and provide reliable data, cancer registrars work diligently to ensure the collection and organization practices meet or exceed current standards and coding classification systems. With dependable data at hand, analysts can provide information to advocates and policy makers who in turn can feel confident about planning the best decisions possible. By collaborating and improving how the information is presented, everyone will be able to proceed easily and know where to step with caution.

In addition, readers will see that we are providing a sneak preview of C-SPAN's first major survival report to the policymakers, due out shortly. This work would not have been possible without the collective effort of all members of C-SPAN, users and analysts alike. Thank you all for helping us to achieve this milestone! And we're not finished – as seen in the analyst column by senior methodologist Ron Dewar, the analytic group is beginning to address additional survival measures, notably conditional survival.

Stay tuned to this newsletter – more on "what's next for survival statistics" in our next issue!

Dr. Donna Turner
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Table 1.1 Five-year cancer survival in Canada: an overview
Age-standardized relative survival for patients diagnosed with cancer (1992-1994 vs. 2004-2006) by type of cancer, all Canada (excludes Quebec)

	Cancer Diagnosis Year		Trend	Range Lowest to Highest Province (2004-2006)
	1992-1994	2004-2006		
All cancers	55.5 %	61.7%	⬆	58.0-64.1%[4]
Lung	14.5%	16.6%	⬆	14.1-18.2%
Colorectal	56.2%	64.0%	⬆	60.3-65.8%
Colon	56.6%	63.9%	⬆	59.1-66.0%[4]
Rectum	54.9%	63.8%	⬆	61.5-65.1%
Breast	82.0%	87.3%	➡	82.8-88.4%
Prostate	86.1%	95.2%	➡	90.4-98.3%

⇨ Trend arrow is based on + or − 10% of the past value. Colour indicates if the trend is good (green), neutral (yellow) or needs to improve (red).

Important notes for interpreting survival data:
1. Survival statistics shown here are relative survival ratios, which show survival for patients diagnosed with cancer compared to people of the same age who do not have cancer.
2. The period approach was used to estimate survival for 2001-2003 and 2004-2006; the cohort method was used for 1995-1997 and 1998-2000.
3. If a patient has more than one cancer diagnosed, all were used (not just the first primary).
4. Newfoundland and Labrador's survival may be overestimated due to under reporting of cases to the cancer registry. The missed cases have poorer survival, so the survival statistics presented must be interpreted with caution.
5. Due to differences in defining the date of diagnosis and issues in ascertaining the vital status of Quebec cases in the Canadian Cancer Registry, the estimate for Canada excludes Quebec.

Increasing survivorship has made survivor issues a significant topic in cancer control. However, while registries regularly report on cancer incidence and mortality, survival and prevalence are not produced routinely or uniformly which makes quantifying the burden of cancer in Canada difficult.

User engagement was a big part of the process of improving how information is communicated and in the development of cohesive, standard ways to calculate survivorship measures. Based on these valuable sessions and conversations, C-SPAN's has released a first draft of what cancer survival information could look like to all of our partners. Overall, early reaction has been positive. All the comments will be reviewed and changes will incorporated into the final version.

"We recognize that the style is quite new for cancer surveillance reports, however, these profiles are reflective of what users were telling us," said Dr. Donna Turner, principal investigator for the C-SPAN project, adding that very detailed appendices will be included in the report as a web-based document to satisfy those looking for confidence intervals, stability (standard error) flags, as well as first vs multiple primary approaches.

With two main chapter styles - a province-specific report and a cancer type-specific report – these profiles address issues users shared with the C-SPAN team, including attention to titling, telling the story and highlighting what is important, and showing real numbers. 'Audience' was also frequent topic. Users clearly expressed the fact that reports need to be written it to fit a particular audience which is why the profiles feature a user-oriented format. Practicality was also noted so the graphs were designed to show well in both colour and black and white should the document be photocopied.

Policy on 2

This section is designed to engage, educate and learn from the end-users of cancer surveillance information so that we can create products that work for you.

Spring 2011 topic:

Reporting Survival

C-SPAN's Methodology Working Group

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C-SPAN Member Biosketch

Lorraine Shack

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Job title/Position
Research Program Leader, Health Promotion Disease and Injury Prevention

Associate Professor, Department of Preventative Oncology and Community Health Sciences (joint appointment), University of Calgary

Education & Training
Biology and Psychology, University of Victoria
Masters in epidemiology and doctoral degree in inequalities in cancer survival, London School of Hygiene and Tropical Medicine

Area of interest
Lorraine's research focuses on inequalities in cancer survival, cure and access to treatment. She has worked mainly on population-based cancer registry data with linkage to hospital data in England and Scotland. However, the focus of her work is currently shifting towards research on cancer risk factors, particularly weight management.

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From page 1 ...

Let's consider how death information is captured in the cancer registries. Most registries have good relationships with their provincial vital statistics departments and can acquire death data regularly for everyone in the cancer registry (called "death clearance" in registry-speak). Further, there is a national death clearance provided by Statistics Canada on a regular basis. However, there are some exceptions, and incomplete recording of deaths falsely inflate survival statistics – for example, these cancer patients may appear to be 130 years old today! In the past, there have been concerns about the completeness of death information in two areas – Newfoundland and Labrador, due to local incomplete death clearance, and Quebec, as there are difficulties in ascertaining the vital status of Quebec cases in the Canadian Cancer Registry.

For Quebec data, the missing death information in the national registry and some unique differences in the way diagnosis data are collected, have led to the exclusion of Quebec from the overall national statistic and many national survival analysis reports – but note that there is a provincial report available for Quebec at http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2010/10-202-04W.pdf . Improvements in Newfoundland and Labrador's death clearance has led to their inclusion in more recent reports, but with cautions.

Tuning the head

Pickin' and reckoning with Ron Dewar, who puts down his banjo to write:

Our work on the cancer survival experience is changing how we do business and has given us pause for thought. Extensions of traditional survival approaches are providing concepts and methods that can give new insight into what survival might mean for the patient and for the cancer system.

One intriguing concept is that of conditional survival - the likelihood that an individual, having already survived for a certain time after diagnosis of cancer, survives for at least some further specified time. Since the measure is rather novel in the Canadian context (aside from the International Cancer Benchmarking Partnership), at the very least we have to carefully describe alternative formulations, give clear interpretations, and perhaps indications of which methods best fit which questions.

Our analysis plan includes investigating several approaches, but exactly how we present the data will be determined following discussions with our user groups.

Modeling relative survival to partition mortality into that due to cancer, and that due to general population mortality (formally, a competing risks framework), may provide new ways of thinking about the burden of cancer in a group of survivors.

In addition to the recent focus on survival, questions related to prevalence are also on the table. A common question often asked is "can we count cancer patients and survivors that migrate into our province?" Our registries are incidence-focused, and may only capture new diagnoses. Most registries do not have a way to estimate how many cancer survivors who were originally treated in another province, are now living in their region.

We also know there is some out migration of cancer patients, but is the net impact on prevalence really zero? We may be over estimating prevalence by counting as alive in the province all patients not known to be deceased.

Can census estimates of migration patterns in healthy people be applied to cancer patients? Are there tabulations of place of death by place of diagnosis that could assist? Some of this might be fine tuning of the prevalence picture; I welcome thoughts on tracking this type of counting.

Ron Dewar
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Items under Discussion

This regular feature highlights topics that have come up for discussion and require further action or updates.

1. Conditional survival: In thinking about what's next for survival analysis, there is interest in conditional survival. Essentially, this addresses, "if someone survives a year after diagnosis, what is the likelihood they will survive five years?" It turns out there may be different definitions of this measure and the merits of each are currently being debated.

2. Suppression rules: When data are published, sometimes the numbers are small and yield unstable results. When should survival and prevalence statistics be suppressed? The merits of different approaches are being considered.

We want to hear from you. Please contact *exSPANse* with your comments or story ideas by emailing roberta.koscielny@cancercare.mb.ca.