Reducing inequalities in cancer survival for Ontario First Nations: From surveillance to action

Lorraine Marrett, Diane Nishri, Amanda Sheppard, Anna Chiarelli, Alethea Kewayosh
Prevention & Cancer Control, Cancer Care Ontario

NAACCR Meeting
June 25, 2014
Objectives

• To outline disparities in cancer burden, especially survival, in registered First Nations in Ontario

• To demonstrate the trajectory from surveillance data to research to cancer control action
Outline

- Aboriginal people in Ontario
- Cancer burden in Registered First Nations in Ontario
- Explaining disparities in survival
- Moving from knowledge to action
- Going forward
Aboriginal People in Ontario

• In Canada,
  • 1,400,685 Aboriginal people (~4% of total population)
    • First Nations (FN): 851,560 (60%)
    • Métis: 451,795 (32%)
    • Inuit: 59,445 (4%)
  • Collectively referred to as ‘FNIM’

• Ontario has 201,100 (24%) of Canada’s First Nations people
  • 62% are “Registered” as Indians under the Indian Act
  • 37% of those with Registered status live on reserve*

*37% is probably an underestimate since a number of reserves were under- or non-enumerated

Outline

• Aboriginal people in Ontario
• Surveillance: Cancer burden in Registered First Nations in Ontario
• Explaining disparities in survival for one cancer
• Moving from knowledge to action
• Going forward
What do we know about cancer burden in Ontario’s FN population?

- Population-wide estimates of cancer burden in Ontario typically come from the Ontario Cancer Registry (OCR)
  - The OCR records data on cancer diagnoses for all Ontarians, 1964-2010
  - All cases are followed up for vital status and date of death, so survival times from diagnosis can be calculated
- Cannot routinely estimate cancer burden for ethnic/racial subgroups, including FNIM
  - Race/ethnicity not systematically recorded in administrative health records upon which the OCR is based
Cancer burden in Registered First Nations in Ontario: Methods

• The ‘Indian Registry System’ (IRS) is maintained by Aboriginal Affairs & Northern Development Canada (AANDC)
  • 140,000 Registered First Nations (1968-91)
• Used probabilistic record linkage to link IRS, OCR and Ontario mortality file
All cancer incidence, Ontario, 1968-2001, ages 15-74

- Historically lower cancer incidence rates
- Incidence rates rose faster than in Ontario as a whole

Rates age-standardized to the 1991 Canadian population.
Horizontal bars around First Nations rates indicate 95% confidence limits.
Source: Marrett & Chaudhry, Cancer Causes Control 2003; Marrett et al. unpublished data.

Females

Males

Year of diagnosis

Age-standardized rate/100,000

0 10 20 30 40 50 60 70 80 90


First Nations

All Ontario

Rates age-standardized to the 1991 Canadian population
Horizontal bars around First Nations rates indicate 95% confidence limits
Source: Marrett & Chaudhry, Cancer Causes Control 2003; Marrett et al. unpublished data.

Females

Males

High smoking rates in off- and especially on-reserve FN

Year of diagnosis

Year of diagnosis

Rates age-standardized to the 1991 Canadian population
Horizontal bars around First Nations rates indicate 95% confidence limits
Source: Marrett & Chaudhry, Cancer Causes Control 2003; Marrett et al. unpublished data.
Five-year age-standardized observed survival (%) by cancer site and sex comparing the First Nations population to other Ontarians for cancers diagnosed between 1992-2001 with follow-up to December 31st, 2007 and censoring at age 75.

Outline

• Aboriginal people in Ontario
• Cancer burden in Registered First Nations in Ontario
• Research: Explaining disparities in survival
• Moving from knowledge to action
• Going forward
Stage at Diagnosis and Comorbidity Influence Breast Cancer Survival in First Nations Women in Ontario, Canada

Amanda J. Sheppard¹,²,³, Anna M. Chiarelli¹,², Loraine D. Marrett¹,², E. Diane Nishri¹, and Maureen E. Trudeau⁴

• Purpose: To further examine survival disparity between Ontario FN and non-FN women diagnosed with breast cancer between 1995-2004
  • Reviewed charts for stage and other important prognostic factors (comorbidity, treatment, smoking, etc) not in the OCR
Key findings

• FN women 50% more likely to be diagnosed at stages II+
• % with appropriate treatment-for-stage and -age same
• Only stage 1 survival worse for FN women
  • More comorbidity, especially diabetes, in FN women explained this
  • No other prognostic factors significantly different

• Caveats
  • Full assessment of impact of distance not possible since matched on cancer centre
  • No data on socioeconomic status
  • Only breast cancer
Outline

• Aboriginal people in Ontario
• Cancer survival in Registered First Nations in Ontario
• Explaining disparities in survival
• Cancer control: Moving from knowledge to action
• Going forward
**Aboriginal Cancer Strategy (ACS II) 2012-15**

- Cancer Care Ontario’s roadmap to address FNIM cancer control needs in Ontario
- Led by CCO’s Aboriginal Cancer Control Unit
- ACS III is under development

**Vision**

“To improve the performance of the cancer system with and for FNIM peoples in Ontario in a way that honours the Aboriginal Path of Well-being”

“The ACS II sets out a clear plan for reducing risk & preventing cancer...”
ACS II: Strategic Priorities

**Strategic Priority 1:**
Build productive relationships

Work with FNIM groups to formalize relationships based on trust and mutual respect

**Strategic Priority 2:**
Research and surveillance

Data to inform programming initiatives will be compiled/developed

**Strategic Priority 3:**
Prevention

Smoking cessation efforts will be a key focus but we will begin looking at other modifiable risk areas

**Strategic Priority 4:**
Screening

Increasing participation to cancer screening across the Province

**Strategic Priority 5:**
Palliative and Supportive care

Help address the Palliative and Supportive care needs of FNIM with cancer

**Strategic Priority 6:**
Education

Increase the knowledge and awareness of cancer through cancer education and awareness initiatives
Outline

• Aboriginal people in Ontario
• Cancer burden in Registered First Nations in Ontario
• Explaining disparities in survival
• Moving from knowledge to action
• Going forward...more to be done...
Updating and completing the picture: continuing surveillance

- Linkage of Indian Registry System 1991-present & Ontario Cancer Registry to estimate current cancer burden (collaboration with the Chiefs of Ontario and ICES)
- Access data from linking 1991 Canadian Census (long form) and the Canadian Cancer Registry to estimate cancer burden in FN and Métis, nationally (and large provinces)
- Novel ways to identify non-Status FN, Métis and Inuit are necessary in order to complete the FNIM picture
Conclusions

- Having cancer surveillance data for Ontario FN was foundational to establishing the strategic priorities and specific priority activities and securing funding to implement.
- ACSI I focuses on both system level change as well as programmatic activities.
- Ongoing surveillance and research is important to monitor and understand changes and to assess and adjust strategy.
Thank you!
Questions?

Lorraine.marrett@cancercare.on.ca