HEALTH AND HEALTH CARE CHALLENGES AMONG YOUNG ADULT CANCER SURVIVORS

Mary McBride, Distinguished Scientist
Cancer Control Research, BC Cancer Agency

BCCA Survivorship Day
November 1, 2013
Issues for young adult cancer survivors

- Young adult cancers are transitional between childhood and adult cancer patterns
- Young adults are a distinct developmental phase, both biologically and psychologically.
- Survival gains have not been as dramatic as for childhood cancer patients.
- Young adults would be expected to experience late effects of their cancer and its treatment

There is little evidence available on risks of late physical and cognitive effects of cancer among young adults.
Characteristics of Young Adult Cancers

Common Types of Cancer Afflicting AYAs (% cases/disease)

*Includes melanoma, colorectal, cervical, and other less prevalent cancers.

CAYACS Study objectives for YACS

For those diagnosed between age 20 and 24 years in British Columbia from 1970, and surviving at least 5 years post-diagnosis, using de-identified linked registries, clinical and administrative data, we examined:

▪ the risk of late mortality among YACS and the impact of factors affecting these risks

▪ the risk of SMN among YACS and the effect of factors on risk

▪ the risk of late morbidity leading to hospitalization among YACS and the effects of risk factors

▪ health care utilization and factors affecting utilization
Study population (N=1248)
- diagnosed with cancer between 20-24 yrs old (excluding non-melanoma skin)
- Resident in BC at the time of diagnosis
- Survived at least 5-yrs after diagnosis

Death Identification
- From death records at the Vital Statistics Agency (VSA)
- Participants without death records are considered as alive

Modifying variables
- Type of original cancer diagnosis
- Clinical factors (disease-related, treatment)
- Socio-demographic factors
Male survivors had higher cumulative mortality over time than females.
Late Mortality: Results

- 117 deceased cases
  - 62 due to recurrence or progression of original cancer
  - 23 due to another cancer
  - Rest attributed to non-cancer causes
    - Circulatory
    - Infections

- Groups at increased risk:
  - Survivors of CNS and leukemia
  - Males
  - Those who received radiation
Study population
- Young Adult Survivor Cohort (N=1248)

Second malignant neoplasm (SMN)
- A neoplasm that occurred between 5 years after the index diagnosis and December 31, 2007

Modifying variables
- Type of original cancer diagnosis
- Clinical factors (disease-related, treatment)
- Socio-demographic factors
- There was no significant difference in cumulative incidence of SMNs by sex over time.
62 (5.0%) developed an SMN

Average latency period: 20 years

Risk decreased over time

Groups with increased risk
- Those with radiation
  - Half of the survivors with RT and a SMN had SMN in the radiation field (mostly Hodgkins)
- Survivors of lymphoma and germ cell tumour
- Males
Study population (N=902)
- Young Adult Survivor Cohort diagnosed from 1986-2007
- Compared to age-gender-matched sample of BC population (N=9020)

Outcome measure-- Late morbidity leading to hospitalization
- Conditions that were most responsible for the hospitalization

Modifying variables
- Type of original cancer diagnosis
- Disease- and treatment-related factors
- Socio-demographic factors
- Health system factors
Risks of Late Morbidity Leading to Hospitalization

Survivors vs. Comparison

Whole Cohort
Leukemia
Lymphoma
CNS
Bone
Soft Tissue Sarcoma
Germ Cell
Melanoma
Carcinomas
Others
Risk of Late Morbidity Leading to Hospitalization

Survivors vs. Comparison

- All types of late morbidity
- Infective and Parasitic Diseases
- Neoplasms
- Endocrine, Nutritional, and Metabolic Disorders
- Diseases of the Blood
- Mental Disorders
- Diseases of the Nervous System
- Diseases of the Circulatory System
- Diseases of the Respiratory System
- Diseases of the Digestive System
- Diseases of the Genitourinary System
- Complications of Pregnancy
- Diseases of the Skin
- Diseases of the Musculoskeletal System
- Signs and Symptoms
- Injury and Poisoning
- Supplementary Classifications

Hazard Ratio
50% of survivors had at least one type of late morbidity leading to hospitalization (vs 38% of general population sample)
- 68% among CNS survivors
- 41% among germ cell survivors

Highest incidence
- Neoplasms
- Digestive system problems

Highest relative risk
- Neoplasms
- Blood diseases

Groups at highest risk
- Combination of radiation, chemotherapy and surgery
- Survivors of CNS tumours and bone cancer
Health Care Utilization: Overview

- **Study population**
  - Young Adult Survivor Cohort (N=888) diagnosed from 1986
  - Followed 2002-2003

- **Outcomes:**
  - Physician visits
    - GP visits
    - Specialist visits
  - Hospitalization
    - Yes/No, days in hospital
    - Overall, and by type of hospitalization
  - High use of primary care services (physician services, prescription drugs)
    - In top 10% of total cost, based on the general population
Health Care Utilization: Results

Physician visits
- No difference in likelihood to see a GP in 2-year period than peers
  - More likely to have 10+ visits
  - Higher likelihood of a specialist visit
    - Dermatologist
    - Urologist
    - Neurologist
- Females more likely to have more visits (true also for peers)

Hospitalization
- 1.6 times more likely to have a hospitalization (excl pregnancy) than peers
- Groups at highest risk
  - Those with a relapse
  - Those living in rural areas and/or in Interior or Northern HA
  - Female (similar to peers)
High users of Primary Care Services

- Those with high levels of health problems (comorbidity)
- No overall difference between YA survivors and peers with similar levels of comorbidity
- Sociodemographic factors did not affect level of use

Groups most likely to be high users
- Those with a SMN
- Those in metropolitan areas
- Those with high levels of comorbidity
  - Particularly combinations of chronic conditions and psychosocial conditions
- No differences by treatment after taking comorbidity into account
Among survivors of young adult cancers,

- **Late mortality among young adult cancer survivors**
  - ongoing increased risks of late mortality in the survivors
  - Factors with increased risk of mortality: exposure to RT, recurrence and SMN

- **SMN among young adult cancer survivors**
  - Increased risks of SMN in the survivors; lower risk over time
  - Factors with increased risk of SMN: lymphoma, exposure to RT

- **Late morbidity leading to hospitalization among young adult cancer survivors**
  - ongoing increased risks of having hospital-related morbidity
  - Factors with increased risk of late morbidity: CNS or bone cancer, radiation

-> **those with high ongoing comorbidity need and use health care more**
Acknowledgements

FUNDERS
Canadian Cancer Society (CCS) Research Institute
CCS BC & Yukon
Canadian Centre for Applied Research in Cancer Control

DATA SOURCES
BC Cancer Registry
BC Cancer Agency
BC Children’s Hospital
BC College of Pharmacists
Ministry of Health
Statistics Canada

CAYACS TEAM
Shebnum Devji  Laura Game
Nelson Ha  Maria Lorenzi
Sharon Relova  Yang Zhang
Rita Parmar  Dongdong Li
Shannon Vogels

CO-INVESTIGATORS
Dr. Paul Rogers, BCCH
Dr. Sam Sheps, UBC
Dr. Victor Glickman, UBC
Dr. Karen Goddard, BCCA
Dr. Joan Hu, SFU
Dr. Stuart Peacock, BCCA
Dr. Sheila Pritchard, BCCH
Dr. Rod Rassekh, BCCH
Dr. Linda Siegel, UBC
Dr. John Spinelli, BCCA
Dr. Paulos Teckle, BCCA
Thank you!
QUALITY CARE FOR YOUNG ADULT CANCER SURVIVORS

Mary McBride, Distinguished Scientist
Cancer Control Research, BC Cancer Agency

BCCA Survivorship Day
November 1, 2013
Our work demonstrates that survivors of young adult cancer in British Columbia may face increased health risks for many years after diagnosis related to:

- Initial diagnosis (particularly CNS, bone, and lymphoma)
- Treatment (radiation, alone or in combination)
- Other comorbid conditions (particularly chronic medical or psychosocial) that may arise independently of either the cancer or its treatment
  - Adds to overall health burden and can complicate care
Quality follow-up care consists of:

- Ongoing monitoring for cancer recurrence and new primary cancers
- Surveillance and treatment of late effects of cancer
- Management of other health problems
- Support for healthy lifestyle, psychosocial and functional issues (e.g. independent living, relationships)
Quality follow-up care involves:

- Individualized, risk-based care
- Multidisciplinary, coordinated care
- Continuity of care
- Equitable access to appropriate, acceptable care
- Sustainable care
Study I: Method – CAYACS research program

- CANCER CENTRES, CHILDREN’S HOSPITAL: Cancer Treatment Data
- VITAL STATISTICS: Sibling Cohort
- CANCER REGISTRY: Survivor Cohort, Patient ID, Diagnosis, Death Follow-up
- EDUCATION MINISTRIES: Education Data, Student Sample
- MEDICAL INSURANCE PLAN: Health Utilization Data, General Population Sample
- BC CANCER AGENCY: Oncology Scheduling, Screening Data
- STATCAN: Income and Employment Taxfiler Sample
- PHARMANET: Prescription Drug Info

CAYACS SURVIVOR RESEARCH RESOURCE

Development of outcome indicators, analysis files

I. Health Outcomes
II. Health Care Outcomes
III. Education Outcomes
IV. Income and Employment
V. Knowledge Translation