

# Transition From Pediatric to Adult Care for Survivors of Childhood Cancer

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# Outline

1. Review some of the academic literature around the transfer of pediatric oncology patients into adult care.
2. Present our research program examining transitions to adult care for pediatric oncology patients.

# Why is transition to adult care an issue?

- One of the most important health services issues for children and youth with chronic medical conditions is transitioning to adult care.
- Late adolescence is a tumultuous period for people, which is more complicated for youth with chronic or ongoing medical conditions.

# Survivors of childhood cancer

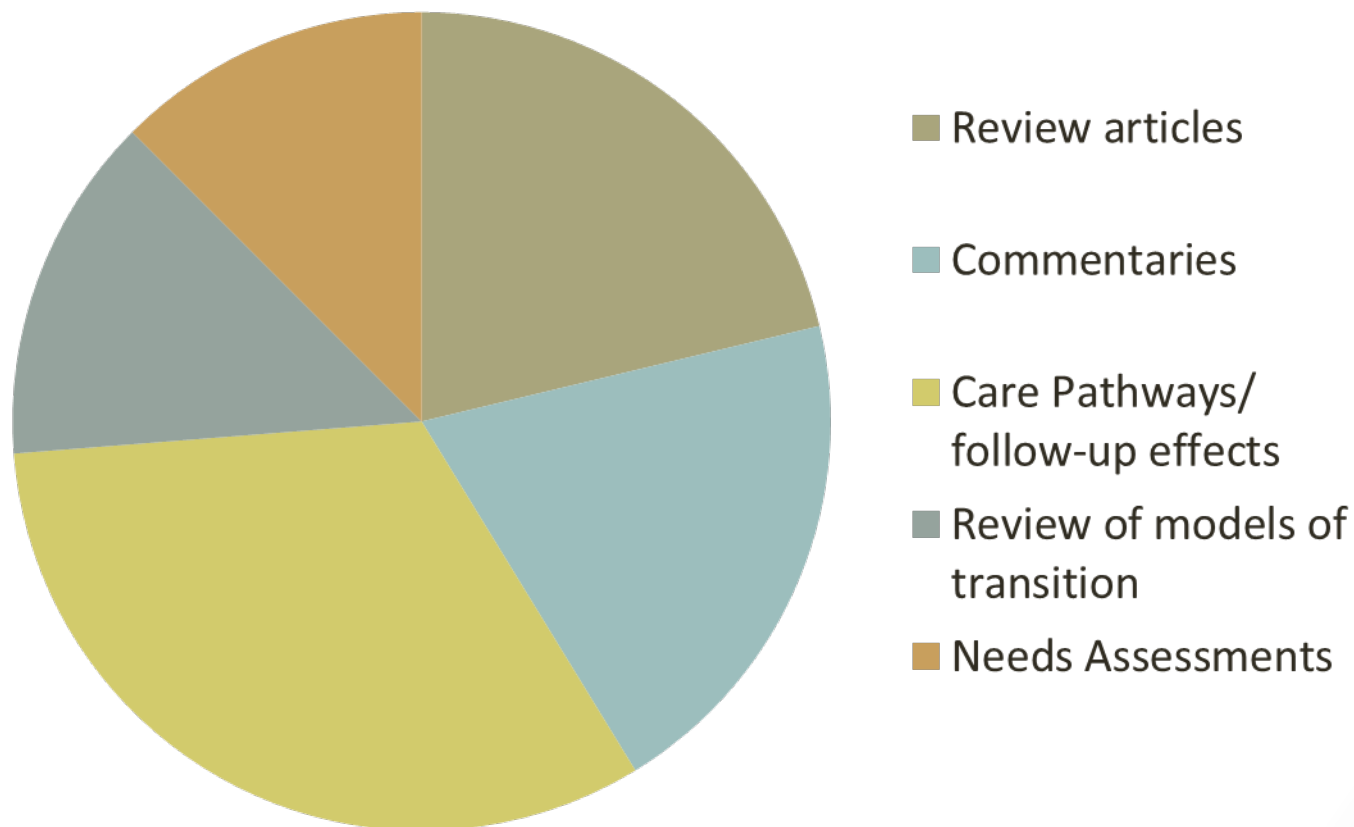
- Increasing in number due to improvements in clinical outcomes.
- Changing information needs as patients age (e.g., fertility issues).
- Treatment phase complete.
- Late effects of chemotherapy, which have been estimated to be as high as affecting 2/3 of childhood cancer survivors.
- Increased potential for second cancers.
- There appears to be a good deal of variation in transition experiences across the country.

# Results of literature scan

- The initial search on pediatric oncology transitions yielded over 230 results from PubMed, EBSCO, EMBASE, and the Cochrane Library;
- 80 articles reviewed to date;
- International scope, with 5 Canadian articles reviewed so far.

# Findings of literature scan

## Breakdown of findings



# Transitions for survivors of childhood cancer

- Eshelman-Kent et al. reported on a survey of 179 pediatric oncology programs in the US.
- 35% of pediatric oncologists sees adult survivors indefinitely at the pediatric centre.
- 31% say they transfer the patient when he or she is ready.
- Others transfer when the child is 18 (5%), 21 (17%), 25 (4%) or 30 years old (1%).

# Transitions for survivors of childhood cancer

- 44% of survivors are kept at the treating institution for cancer-related care;
- 38% transferred to adult providers within the same health care system with collaboration between adult and pediatric care team;
- 21% transferred to primary care for all care.
- 3% transferred with only mail or phone follow-up.
- 2% transferred to an adult oncologist.

# Canadian literature

- Ristovski-Slijepcevic, S., Barr, R., Bernstein, M., & Nathan, P. C. (2009) studied follow-up care at 17 pediatric programs across Canada
  - 12 of 17 programs had adolescent program
  - Only 6 of 17 centres had a formal adulthood program
  - Still a need for formal, integrated follow-up care

# Canadian literature

- Rosenberg-Yunger, Z. R. S., Klassen, A. F., Amin, L., Granek, L., D'Agostino, N. M., Boydell, K. M., ... Nathan, P. C. (2013) identify major facilitators/barriers to follow-up
  - micro-level patient factors (e.g., due diligence, anxiety)
  - meso-level support factors (e.g., family, friends)
  - macro-level system factors (e.g., appointments, communication, healthcare providers)

# Improving the transition from pediatric to adult care for childhood cancer survivors

# Team

## Newfoundland

- Co-PI - Dr. Roger Chafe
- Dr. Lynette Bowes
- Dr. Paul Moorehead
- Dr. Kevin Chan
- Dr. Katherine Stringer
- Jeanne Robinson
- Peter Wilton

# Team

## Ontario

- Co-PI Dr. Jennifer L. Gibson
- Dr. Paul Nathan
- Dr. Jonathan Sussman
- Maria Grant
- Esti Heale
- Dr. Ross Upshur

# Team

## British Columbia

- Co-PI Mary McBride
- Kelly McQuillen
- Cathy Ulrich
- Dr. Sheila Pritchard
- Dr. Karen Goddard
- Dr. Phil White

# World Health Organization's Quality Care Strategy

- Phase 1: Situational Analysis
- Phase 2: Choosing Interventions for Quality
- Phase 3: Implementing

# Situational Analysis

1. Quantitative analysis: Use of existing health care administration databases and data already collected to evaluate care transitions for survivors of childhood cancer who have transferred into adult care in the last 10 years.
2. Qualitative analysis: Care transitions for adult survivors of pediatric cancer.
3. Ethical Analysis of data, to make explicit the underlying values embedded in the different models of transition.

# Key Informant Interviews

- How transition occurs
- Experiences of transitions to adult care
- Identify available services and gaps in services for survivors of childhood cancer
- Barriers and facilitators of quality care through transition
- Innovative practices and suggestions for improvements

# Interesting differences across provinces

- NL – Patients transferred usually at the age of 25, but only once an ongoing connection is made with an appropriate primary care provider.
- ON – All patients enrolled in a survivorship program run by the adult cancer program.
- BC – Patients usually transferred into primary care at the age of 18.

# Initial Pilot Projects

- ON – Determining which patients need to be enrolled in an after care program.
- BC – Standardizing care plans for family physicians / primary care electronic access to oncology program patient records.
- NL - Standardizing care plans for family physicians

# Timeline – NL Situational Analysis

Step 1	Step 2	Step 3	Step 4	Step 4
Liaison with care providers and oncology team	Recruitment of interview participants (patients, healthcare providers, administrators)	Completion of analysis of existing health databases	Ethical Analysis of Data	Completion of situational analysis / Confirm pilot intervention
June 2014	July-October 2014	July -October 2014	Sept – Dec 2014	December 2014

# Questions and Suggestions