

Misaligned Responsibilities: Health Services for Long-Term Childhood Cancer Survivors

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CARE + RESEARCH

An agency of the Provincial Health Services Authority

Adult Childhood Cancer Survivors (CCS): cost of cure

- > 80% survive a childhood cancer
- Higher risk for chronic illness and late effects in adulthood
 - By 40 years of age:
 - 75% of survivors will develop a chronic disease
 - 40% of survivors will develop a life threatening, or fatal condition
- Physical
 - second malignancy, endocrinopathies, cardiovascular disease,
- Neurocognitive
 - communication, attention, memory
- Psychological
 - anxiety, depression, PTSD, suicidal ideation
- Social
 - lower educational attainment, unemployment, social isolation

Long-Term Follow-Up (LTFU)

- Leading associations **recommend LTFU for CCS at high risk for late effects**



**CHILDREN'S
ONCOLOGY
GROUP**

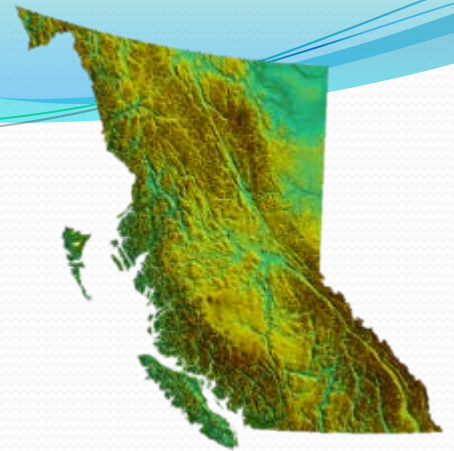
The world's childhood cancer experts



Long-Term Follow-Up (LTFU)

- LTFU should include:
 - screening for second primary cancers
 - surveillance and management of the physical and psychosocial late effects of cancer
 - promotion of psychosocial adjustment
- British Columbia:
 - At least 3,000 adult CCS
 - Each year 120 or more CCS “graduate” from pediatric oncology
 - There is a lack of information on the state of LTFU for CCS as well as patient and provider experiences of these services
- Research purpose:
 - Examine patient and provider experiences of health care for adult CCS in British Columbia, Canada

Methods



- Qualitative Research
 - Embedded in a larger study investigating CCS medical and psychosocial challenges and needs
 - Data Collection: In-depth, open-ended interviews with:
 - 30 adult CCS
 - Diagnosed with cancer prior to 19 years of age
 - Currently ages 17 to 45 years
 - Convenience sample: 2 BC clinics
 - 13 key health care professionals
 - Data Analysis: Qualitative constant comparative methods
- Environmental Scan
 - Identified available health services for CCS in BC
 - Online and print sources, correspondence with key stakeholders, site visits
 - Data capture form used to document information

Demographic Characteristics		n = 30
Age	20-24	16%
	25-29	27%
	30-34	30%
	35+	27%
Gender	Women	60%
	Men	40%
Place residency	GVRD	70%
	Other	30%
Marital status	Single	73%
	Married	27%
Level of education	Did not complete high school	7%
	High school	23%
	University/college	70%
Employment status	Unemployed	13%
	Student	10%
	Employed	77%

CCS characteristics

Medical Characteristics		n = 30
Age diagnosis	0-4	27%
	5-9	33%
	10+	40%
Type of cancer	Leukemia / Lymphoma	53%
	Brain tumour	20%
	Sarcoma (not including brain tumour)	20%
	Other solid tumour	7%
Treatment	Radiation therapy	90%
	Chemotherapy	97%
	Surgery	30%

HCP characteristics

HCP characteristics		n = 13
Type of HCP	Oncologist	3
	Other Specialist	2
	Family Physician	1
	Nurse	1
	Program Manager	3
	Counselor/Social worker/Advocate	3
Place of practice	GVRD	11
	BC other	2

Findings

- Recognition among CCS, HCP, and BC organizations that LTFU is essential
- BUT the current structure of health services does not adequately support LTFU
 - CCS: challenges accessing appropriate care
 - HCP: challenges providing care
 - Health services: no one's priority, no one's responsibility

CCS: challenges accessing appropriate care

- Transition from pediatric to adult services
 - CCS need help to learn how to:
 - access and navigate the adult health care system
 - talk with adult HCP
- HCP do not have adequate knowledge
 - *“It’s futile to see a regular dentist because they really have no clue as to the cause of what’s going on. The last time I saw a dentist I explained it to him in great detail that my problems are from the radiation, but he was still convinced that my dental problems were a result of eating too much sugar or citrus.”*
 - Laughed at or dismissed by HCP
- CCS selectively engage with HCP
 - GP ONLY for issues unrelated to cancer
 - Specialists for issues related to cancer

CCS: challenges accessing appropriate care

- LTFU takes significant time, energy and money
- De-centralization of services burdensome
 - Financial costs and difficulty taking time off work to attend multiple appointments, in different locations, on different days
 - *“I have to come down [to Vancouver] 3 times in a month or 2 times in a month and then the bills add up from there. It’s very frustrating.”*
 - Taking public transportation or relying on others difficult
- Substantial costs of medications, dental work, hearing aids
 - Pay out of pocket
 - Forgo medications, procedures or medical aids

Health care professionals (HCP): challenges providing care

- Difficult to find physicians to assume LTFU
 - *“The whole thing about transition is it’s fine to transition if there’s a program to transition to. And this is really the whole problem of transition across all chronic healthcare disciplines. People here and there and so none of those are coordinated care.”*
- CCS are often complex patients whose service provision can be difficult and time consuming
 - In-depth knowledge of CCS medical history required
 - Specialized knowledge of late effects required
- Lack of time, resources and compensation barriers
 - Specialists have limited time and access to multidisciplinary resources
 - GPs can not bill for the comprehensive services that CCS require

Health care professionals (HCP): challenges providing care

- HCP site an ethical imperative to ensure services are available
- Cohort of adult CCS “lost to follow-up”
 - Unaware of high health risks
 - Not receiving adequate LTFU
 - *“And they’re not aware of the problem, that they may develop a problem and it’s not going to be for ten years or fifteen years down the line. So then it’s not until they actually get very sick that somebody recognizes oh, they maybe should have been followed.”*
- Limited formal linkages between specialists, primary care providers and multidisciplinary teams

Health services: no one's priority or responsibility

- Health services for CCS not seen as the priority or responsibility for any one HCP, program, institution, or health authority
- HCP prioritize care according to:
 - What they are paid and trained to do
 - *“We’re busy enough with complex cases that I’m afraid the oncologists have to take a step back and look at their practice and say ‘what am I really trained for?’”*
- Health service programs rarely inclusive of CCS
 - *“The brain cancer survivors don’t get services. They don’t really fall under mental health because their primary problem is brain injury. But they don’t really fall under brain injury because they didn’t have a traumatic brain injury. From a classification point of view we don’t have an organization that looks after survivors of childhood cancer.”*

Health services: no one's priority or responsibility

- The priority for pediatric service centres is the management of pediatric patients
- Adult centres do not see CCS, who were treated as children at another centre, as their responsibility
- The health authority funding structure is a barrier to the provision of adequate services for CCS
 - *“The problem is also with funding agencies. The Cancer Agency is in PHSA and so is Children’s Hospital. So the Vancouver Coastal part wants PHSA to put in some money because they assume that it’s their problem because PHSA is provincial, Vancouver Coastal is only Vancouver. So they say well then we’re not going to see anybody who lives outside of Vancouver Coastal. So who’s going to put in what dollars so Vancouver Coastal doesn’t get saddled because half the population comes from Fraser Health.”*

Conclusions

- Adult CCS face significant barriers to accessing appropriate LTFU
- HCP face multiple structural barriers to providing LTFU
- LTFU is neither the primary priority or responsibility of HCP, programs, institutions, or health authorities
- Aligning the primary responsibilities of health system stakeholders and including LTFU as a priority might improve experiences for patients and providers and lead to better patient outcomes

Questions and Comments

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