2016 Moving Beyond
Cancer to Wellness:
Introduction to Cancer Survivorship

Adolescent and Young Adult Survivorship: Minding the Gaps

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Mind the Gaps:

Recognizing and Addressing Special Issues for Young Adults Transitioning to the Adult Health System

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Nancy: Seeking disability assistance and medical coverage before she turns 26.

Mark: Heading off to college in the Midwest, but will need medical care and medications while there.

Dianna: Planning for a family someday, but does she need to do something now?

Transition Project at SCCA: Minding the Gaps

Closing the Gap: Assisting Young Adult Cancer Survivors with Transition from Pediatric to Adult Health Care Systems

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Fred Hutchinson Cancer Research Center, Seattle Cancer Care Alliance, Seattle Children's

Background

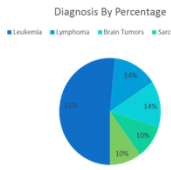
Late and long-term effects after childhood cancer treatments have been well documented by the Childhood Cancer Survivor Study since its inception in 1994. Surveillance recommendations have been available to healthcare providers through the Children's Oncology Group for over a decade. Yet, there is no consensus how best to transition our adolescent and young adult (AYA) survivors to the adult healthcare system.

Our Transition Project was designed to address a specific concern: How do we close the gap between pediatric and adult healthcare for AYA cancer survivors?

Methods

This project involved needs assessments of AYA survivors, provider collaboration across three institutions, and development of formalized referral processes and tools to promote and track the project. Tools included readiness for transition assessment, invitation letter, AYA-focused clinic brochure, and a database to track referrals, appointment completion, and general patient demographics. Feedback was solicited from patients and families after SCCA Survivorship visits were completed regarding the visit and the process. 2016 will be the 4th year of the project.

Transition Project Demographics		
Total Patients		65
Age		
	Average	22
	Range	17 - 26
Gender		
	Female	53%
	Male	47%
Diagnosis, N (%)		
	Leukemia	51%
	Lymphoma	14%
	Brain Tumors	14%
	Sarcoma	10%
	Other	10%



Results

Between January 2010 and March 2013, a total of 12 AYA patients had been referred from Seattle Children's (SC) and completed survivorship appointments at Seattle Cancer Care Alliance (SCCA). Once the project was initiated, there were 12 completed visits between April 2013 and December 2013 alone. In 2014 there were 25, and in 2015 there were 36 completed visits.

Success of this project is evidenced by completion of 73 appointments after referral from SC to SCCA's Survivorship Clinic. Of these patients, 53% have been female, with the average age of 22, and the following diagnoses: leukemia 51%, lymphoma 14%, brain tumors 14%, sarcoma 10%, other 10%. We have had a total of 8 patients who declined to schedule or were unable to be contacted, giving us an 89% positive referral to appointment completion rate. We went from an average of 5 AYA transition patients annually before the project began, to 36 in 2015, a 139% increase in AYA patients successfully transitioning the gap to adult healthcare.

Conclusions

This project had four components vital to its success:
- Collaboration between providers and staff;
- Buy-in from stakeholders, patients to hospital administration, across all three institutions;
- Tools for patients, families and care providers to easily introduce and promote transition to adult survivorship, all based on needs assessments;
- Creation and maintenance of a dynamic tracking and evaluation process to monitor change in referral patterns and visit completion.

Secondary successes of this project have been:
- Improved communication, resource development, and awareness of survivorship resources across institutions;
- Formation of a multidisciplinary, multi-institutional provider group with a special interest in the needs of AYA patients;
- Overwhelmingly positive feedback from patients;
- Encouragement for other institutions to close the gap in AYA cancer survivorship care.

Funding and Support

Supported by funds from Fred Hutch and Seattle Cancer Care Alliance.

We had assistance in designing the project through the education and mentorship of Preparing Professional Nurses for Cancer Survivorship Care, a National Institute of Health (NIH) funded educational program implemented through the City of Hope Nursing Education department.

Contact

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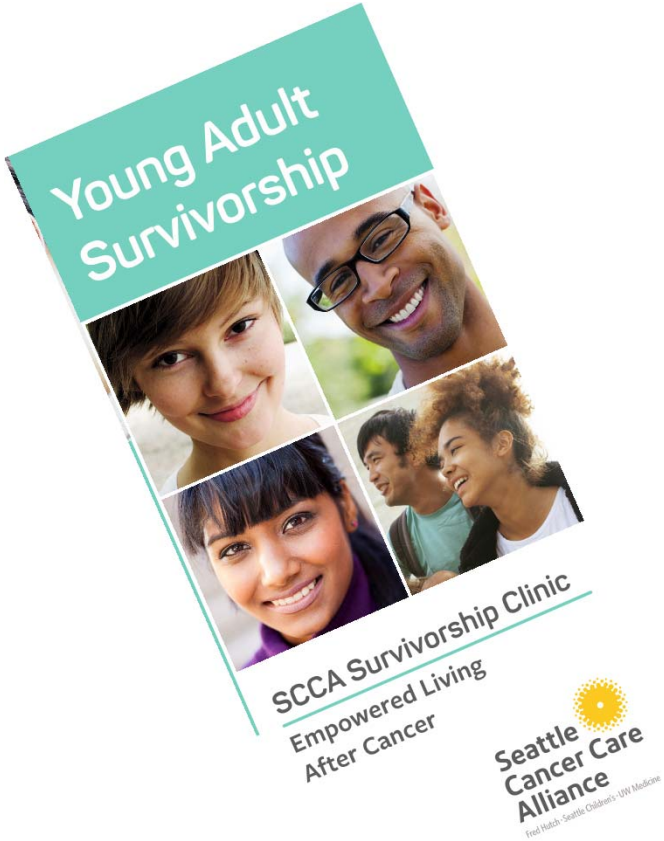
You are welcome to come to the Survivorship Clinic at SCCA!



- Call our clinic to schedule, or ask your Oncology Team to refer you
- Receive an updated Treatment Summary and Survivorship Care Plan
- *Mind the Gaps*. What would *YOU* like to address as you transition to the adult healthcare system?

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Questions?

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