Adolescent and Young Adult Central Nervous System Tumor Survivors: Documentation of Late Effects Risks and Screening Recommendations in British Columbia

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INTRODUCTION

- Adolescent and young adult (AYA) (ages 15-39) survivors of a central nervous system (CNS) tumor are at high risk for late effects (LE).
- LE: treatment related health problems that occur more than 5 years after the end of therapy.
- AYA CNS cancer survivors are usually discharged to be followed in the community by their primary care provider.
- The information available to primary care providers to guide risk-based follow-up care remains unclear.
- Study objective: assess the documentation of LE risks and screening recommendations in the medical records of AYA CNS tumor survivors.

METHODS & MATERIALS

- Medical records of all AYA CNS tumor patients:
- Treated 1980-2010 with radiation therapy at BC Cancer
 - Surviving 5 or more years after discharge, and alive
 - LE documentation and screening recommendations extracted and analyzed descriptively.

Patient Cancer Diagnoses (N = 132)

Patient Demographics and Treatment Data (n = 132)

		%
Sex	Male	48
	Female	52
RT treatment	Partial brain	95
	Craniospinal axis	10
	Partial spine	8
	Whole brain	4
Chemotherapy		17
	PCV	7
	VP 16	4
	Temozolomide	3
	Cisplatin/Carboplatin	4
	Adriamycin	2
Discharge status	Cyclophosphamide	1
	Discharged with dictation	50
	Lost to follow up	50

RESULTS

- Documentation of at least 1 specific LE risk increased over time $X^2(2, N = 132) = 32.257, p < .000$
- No documentation of a screening recommendation in 75% of charts

Most Commonly Specified Screening Recommendations (n = 54 instances)

	Consult %	Follow up %	Discharge %	Total %
Pituitary	11	17	7	35
Endocrine (general)	6	7	13	26
Thyroid	2	11	6	19
Cholesterol	0	4	0	4
Ophthalmology consult	2	2	7	11
Mammogram	0	2	2	4
Secondary tumor CT	0	0	2	2
Total	20	43	37	

CONCLUSIONS

- Half of patients were formally discharged from the BC Cancer.
- We found low rates of documentation of LEs risks in the charts of AYA CNS tumor survivors, though the documentation of at least one LE increased over time.
- All survivors were at high-risk for LEs, yet screening recommendations existed in only 25% of charts, and this documentation decreased over time.
- The creation of a standardized format for documentation that aligns with care processes specific to BC Cancer would improve communication with primary care providers.