



Adverse health outcomes and health concerns among survivors of various childhood cancers: Perspectives from mothers

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Introduction

Receiving a diagnosis of cancer during childhood is no longer considered fatal due to the remarkable improvement in survival rates that have been achieved with treatment (Hudson et al., 2012). Consequently, 80% of children diagnosed with cancer will survive (Kaatsch, 2010; Shepherd & Woodgate, 2010). Unfortunately however, improved prognosis has also been accompanied by treatment-related complications that leave survivors at risk of a variety of chronic health problems Kopp et al., 2012).

Therefore, following treatment, childhood cancer survivors begin a new journey during which they must face the potential challenges of late effects, defined as side effects induced by cancer treatment that can manifest months or years after treatment has ended (Pentheroudakis & Pavlidis, 2007). These late effects can involve acute or chronic, physical and/or psychological health issues (Pentheroudakis & Pavlidis, 2007). McClellan et al. (2013) described how cancer survivors experienced physical late effects of treatment and required ongoing evaluations to address these conditions. A better understanding of the incidence and differences of adverse health events in varied cancer treatments in survivors, and knowledge of their health concerns, may help healthcare teams to develop long-term follow-up care for survivors and their families.

Research Purpose

To determine the prevalence of the adverse health outcomes and health needs in survivors of childhood cancer.

Methods

Participants

- Inclusion criteria
- 1) a histologically verified diagnosis of pediatric cancer
 - 2) completion of cancer treatments at the time of assessment
 - 3) no documented mental health problems
 - 4) an ability to communicate in Mandarin or Taiwanese
 - 5) willingness to participate in the study

Measurements

Intensity of Treatment Rating 2.0 (ITR-2): It is based on treatment modality and stage/risk levels, contains two components: intensity levels and content items. Content items considered 34 different diagnostic and treatment modalities (surgery, chemotherapy, radiation, and transplant) with each item classified according to one of four intensity levels (Werba et al., 2007). It provides an objective classification of the cancer diagnosis and treatment experience, categorizing treatment intensity from least intensive (level 1) to most intensive (level 4) using dichotomous ratings, such as yes/no questions (Werba et al., 2007).

Adverse Health Event Index: It was adopted from (Oeffinger, Eshelman, Tomlinson, Tolle, & Schneider, 2000) and survivorship literatures (Aziz et al., 2006; Ginsberg et al., 2006;

M. M. Hudson et al., 2011; Meacham et al., 2012) in order to establish an Adverse Health Event Index.

Health concerns: Open-ended questions to encourage mothers or survivors to describe their feelings and thought when completing treatments.

Ethical considerations

Ethical approval was obtained from the institutional review boards of two medical center hospitals in Taiwan. Cancer survivors and mothers fully understood the research purpose and were aware of their rights. All data were de-identified.

Results

Over half of survivors' mothers had a senior high school education level, with mean age of 43.6 years (SD: 6.2 years). Of the survivors, 54.2% were male, 95% were undergoing academic training and 29.9% had a university level of education.

Table 1 Demographic Characteristics of Participants

Characteristic	N	%
Gender		
Male	114	54
Female	97	46
Education		
Elementary school	70	33.17
Junior high school	33	15.64
Senior high school	35	16.59
University	64	30.33
Other	9	4.27
Employment status		
In school	194	91.9
Working	10	4.7
Other ^a	7	3.4
No. adverse health events		
0	57	27.0
1	27	12.8
2	30	14.2
3	35	16.6
4	21	10.0
5	9	4.3
≥ 6	32	15.2

^a = includes 7 individuals with missing data and 2 individuals that had not receive an education.

Adverse health events outcomes

The frequency of adverse health events for survivors receiving radiation therapy (RT), or a bone marrow transplant (BMT) was significantly higher than those who did not receive RT or BMT. There were no differences in adverse health effects, diagnosis, treatment intensity, surgery, relapse incidence, age at diagnosis and age at interview for the compared groups. Table 2 Treatment-specific Risk factors for Adverse Health Events among Survivors

	N	Adverse health Events		H/U	P-value
		Mean	SD		
BMT					
Yes	16	4.94	4.73	2.24	0.02
No	195	2.72	3.20		
RT				3.69	< 0.001
Yes	49	4.41	4.46		
No	162	2.43	2.83		
Time from diagnosis (y)		7.79	4.60		
0–5	70	3.33	3.96	4.84	0.09
6–10	85	2.94	2.95		
> 10	56	2.27	3.13		
Age at diagnosis (y)				0.61	0.74
0–6	90	2.60	2.90		
7–12	58	2.70	2.54		
> 12	63	3.47	4.47		

Abbreviations: SD, standard error; H, the value of Kruskal-Wallis H test; U, the value of Mann-Whitney U test; SR, standard risk; HR, high risk; VHR, very high risk; BMT, bone marrow transplant; RT, radiation therapy.

Figure 1 provides an overview of the incidence of adverse health events according to the type of cancer treatment received. The top three adverse health events for brain tumor survivors were altered body image, endocrine and neurocognitive problems.

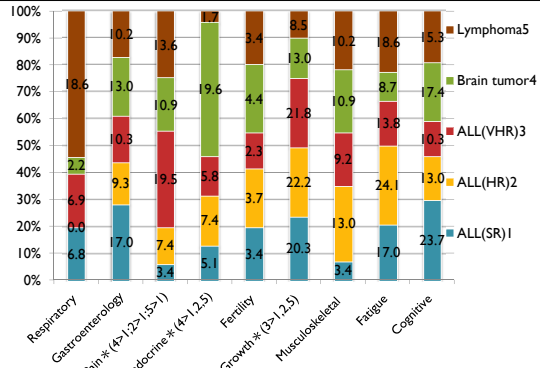


Figure 1. Overview of the prevalence of adverse health events in different types cancer

Health concerns

Table 3 reports the concerns of mothers after their child completed treatment. Relapse (32.71%), nutrition (26.33%), self-care (10.90%), caring for late effects (10.37%), and school problems (5.85%) were the top five issues for mothers after their child completed treatment. Table 3 Concerns of mothers after their child completing treatments

Concerns	N	%	Rank
School problems	21	5.85	5
Worried about the future	4	1.86	
Body image	7	2.13	
Relapse	111	32.71	1
Care for late effects	34	10.37	4
Psychological problems	16	4.26	
Nutrition	93	26.33	2
Relationship	7	1.86	
Self-care	37	10.90	3
Follow-up	6	1.60	
Social resources	7	2.13	

Conclusions

Only 29% of childhood cancer survivors surveyed for this study were free from adverse health events. Risk factors for adverse health events were found to include RT, BMT and time from diagnosis. The prevalence of altered body image, fatigue and neurocognitive problems was 31.54, 14.77 and 12.53%, respectively. Brain tumor survivors had experienced more adverse health events in terms of pain, endocrine problems and altered body image.