Childhood Cancer Survivor
Concept Proposal

Project title:
Mental Healthcare Insurance Coverage, Service Availability and Utilization Among Childhood Cancer Survivors

Working Group:
Psychology

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Background:

Improvements in cancer therapies have revolutionized the treatment of childhood cancers. Decades of research have revealed significant declines in cancer mortality in the context of increased incidence rates, leading to a rapidly expanding number of childhood cancer survivors (CCS)[1,2]. In fact, it is estimated that approximately 328,000 CCS are currently living in the U.S (National Cancer Institute (NCI), 2012), and survival rates continue to rise with current 5-year and 10-year estimates approaching 80% (NCI, 2012).

Although mortality rates associated with primary diagnoses continue to decline, CCS are faced with an array of acute and chronic physical sequealae related to their diagnosis and treatment. For example, CCS are confronted with a lifetime risk of treatment-related late effects, including cancer recurrence, secondary neoplasms, cardiac complications[3,4], osteoporosis, reproductive difficulties[5,6], sexual problems[7], neurocognitive deficits[8,9], and liver dysfunction[10]. In fact, more than half of survivors have been found to suffer from at least one late effect of cancer therapy[11]. Knowledge of their inherent vulnerability for chronic health problems and quality of life impairments has been posited to make survivors particularly susceptible to experiencing a myriad of adverse psychosocial outcomes, especially in their endeavors to reintegrate into society and adjust to life after treatment[12,13]. Adolescent survivors may not only grapple with typical, developmentally appropriate struggles related to their identity and social development, but they may also contend with other socioemotional challenges associated with cancer-related bodily changes or disfigurement[14,15]. The transition into adulthood may incite additional fears, including worries about possible infertility, starting a family, and establishing a professional identity[7,14,16]. Physical and cognitive impairments related to invasive treatments may render some individuals underemployed[17] or unable to work, leading to high rates of unemployment and underinsurance[7,18,19]. Overall, adjusting to life after cancer can leave CCS feeling encumbered in their endeavors to attain normalcy while enduring continual fear of recurrence or consequential health conditions.

Despite their elevated risk for psychological distress, rates of psychiatric disorders have been documented to be relatively low[20]. In fact, most studies have found that CCS are generally well adjusted; however, there remains a proportion of survivors who are prone to developing negative psychosocial effects related to their survivorship status[3,21,22,23,24]. Particularly, researchers have found that survivors who underwent intense and invasive treatments and who presented with more cognitive deficits were more likely to exhibit psychological symptoms[23]. In contrast, other studies document higher rates of mental health symptoms in survivors as a whole when compared to siblings or other peers[25]. One recent study by Schwartz & Drotar[26] examined rates of post-traumatic stress symptoms in healthy peers and CCS who were five years post-treatment. Compared to a healthy, age concordant control group, the researchers found that survivors were nearly 5 times more likely to report PTSD symptoms. Importantly, there are studies that suggest CCS may be prone to minimizing or underreporting negative symptoms[27]; in fact, one recent study of adult survivors of childhood cancer determined that survivors were more likely to report later instances of suicidal ideation[28]. Similarly, there is evidence that survivors may be more likely to receive psychoactive medications in comparison to sibling controls[29]. Accordingly, although rates of psychiatric symptoms may be lower than presumed, the implications associated with being a cancer survivor leaves CCS at risk for negative mental health outcomes and poorer quality of life[26].

Significance:

Understanding the mental health implications of survivorship is warranted, as studies have documented a strong relationship between depressed mood, anxiety, and negative health behaviors among CCS. For example, studies have found a strong link between distress and drinking behavior[30], obesity, lack of physical activity, and other maladaptive health behaviors[31,32]. Engaging in risky or maladaptive behaviors can have very harmful consequences for a former cancer patient, placing this already vulnerable population at greater risk of cancer-related morbidity, greater impairment, and early mortality. Despite these concerns, there is a dearth of research exploring survivors' uptake of mental health services; equally important, even fewer studies have identified potential barriers to mental health care utilization. Understanding some of the psychosocial, disease, and treatment-related factors predicting mental health service use can help identify individuals who are in need of, but do not access services and are therefore at risk of negative psychosocial and physical health outcomes.

Methods

Project Aims:

Aim 1: a) Describe rates of mental health care insurance coverage for CCS compared to siblings and b) Identify sociodemographic and cancer-related factors that are associated with mental health coverage among CCS.

Specifically, are there differences in mental health service coverage between survivors and siblings? Furthermore, do survivors and siblings differ in terms of their preferences for mental health care coverage? Does mental health care utilization in CCS vary based on sociodemographic background, mental health symptoms (i.e., baseline, 2003, and 2007 BSI score, the 2003 post-traumatic stress inventory and the emotional health scales from the 2003 SF36), insurance type cancer diagnosis, age at diagnosis, length of time post-treatment, medical history?

Aim 2: a) Describe rates of mental health care utilization for CCS compared to siblings and b) Identify sociodemographic and cancer-related factors that are associated with mental health utilization among CCS. Specifically, are there differences in mental health service utilization between survivors and siblings? Does mental health care utilization in CCS vary based on sociodemographic background, mental health history (BSI scores from 2007 survey), insurance type, cancer diagnosis, age at diagnosis, length of time post-treatment, medical history? Furthermore, do survivors and siblings differ in terms of their preferences for mental health care coverage?

Aim 3: a) Describe the rate of unmet mental health care needs for survivors compared to siblings and b) Identify sociodemographic and cancer-related factors associated with unmet mental health care needs (defined as postponing mental health services due to cost concerns) among CCS who endorsed clinical level of distress. Specifically, among those who endorsed a clinical level of distress **(**based on 2007 BSI score cutoff = T-score score ≥ 63) how many survivors postponed mental health services due to cost concerns? How do these rates compare with those of siblings? Are there medical, psychological, or sociodemographic factors that are associated with increased likelihood of CCS with mental health needs delaying mental health services due to cost?

Hypothesis:

Compared to siblings, CCS will have less mental health care coverage and will utilize mental health care services at a lower rate. These disparities will be particularly marked among survivors with clinically elevated distress.

Participants:

Study participants include a cohort of childhood cancer survivors who were diagnosed between 1970 and 1986 with Leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma, central nervous system (CNS) malignancies, Wilms Tumor, neuroblastoma, soft tissue carcinoma, or bone tumors before age 21, received treatment at 1of 26 U.S. hospitals, and were at least 5 years post-diagnosis. Eligible participants included CCS (N = 698) and siblings (N = 210) who completed both the 2007 childhood cancer survivor study (CCSS) survey and the Health Insurance Ancillary survey. For the purposes of aim 3, given the low rates of distress reported in the literature for both siblings and survivors (e.g., 10% survivors and 7% in siblings), it is anticipated that eligible participants will include approximately N = 70 for survivors and N = 14 for siblings when distress is defined by the BSI in 2007.

Variables:

Outcome variables (specific survey questions explored):

Aim 1 (categorical outcomes):

- Do you currently have insurance that covers most, some, or no mental health care services? (Insured q21d)
- In the past year, did a health care provider or hospital not accept insurance that covers your mental health care? (Insured q25)

Aim 2 (categorical outcomes):

- During the past year, did you visit a mental health care provider? (Insured q17 and Uninsured q18)
- In the past year, was there a time when you put off or postponed mental health care because you were worried about the cost? (Insured q30 and Uninsured q28)
- Thinking about your ideal health insurance plan, how important is mental health care coverage? (Insured q36d and Uninsured q34d)

Aim 3 (categorical outcomes):

- In the past year, was there a time when you put off or postponed mental health care because you were worried about the cost? (Insured q30 and Uninsured q28)

Independent Variables (Aims 1b, 2b, 3b):

- Insurance status (e.g., Insured vs. uninsured, Insurance Type, SSI/SSDI receipt), age at survey, sex, race/ethnicity, education, marital status, employment status, income, cancer diagnosis, age at diagnosis, surgery status, chemotherapy status, cranial radiation, recurrence, Length of time post-treatment.

Statistical Analyses:

A CCSS statistician will help with the proposed study analyses. SAS will be used for all statistical analyses. Descriptive statistics including frequencies, means, and ranges will be performed to describe the sample. Since sampling for the Health Insurance Ancillary study was carried out stratified on age, we will account for survey weights in all analyses so that the data summarized and reported will reflect the overall CCSS eligible population. Also, analyses including both survivors and siblings will be formulated as regression analyses to incorporate robust variance estimates that account for the intra-family correlation between survivor and siblings that account for the intra-family correlation between survivor and siblings.

Aim 1: a) Statistical differences in mental health service coverage between survivors and siblings will be examined within the framework of a log-binomial regression model adjusted for age, gender, and race, with generalized estimating equations and robust variances; **b)** Among CCS, predictors of mental health care service coverage will be examined using multivariable log-binomial regression analyses. The explanatory variables indicated above will be examined as predictors of mental health coverage, including the baseline, 2003, and 2007 BSI score, the 2003 post-traumatic stress inventory and the emotional health scales from the 2003 SF36. Because they will likely be correlated, they will be examined separately and as a composite variable.

Aim 2: a) Statistical differences in mental health service utilization between survivors and siblings will be examined within the framework of log-binomial regression adjusted for age, gender and race, with generalized estimating equations and robust variances; **b)** Among CCS, predictors of mental health care utilization will be examined using multivariable log-binomial regression analyses. To determine predictors of mental health services utilized in the past year (dichotomous outcome), the explanatory variables delineated under "Independent Variables" will be examined in addition to the BSI, PTSI, and SF-36 scale scores. To decrease the impact of multicollinearity on our regression model, BSI scores and history of CRT will be examined independently (as they are often highly correlated).

Aim 3: a) Similar to the above analyses, either log-binomial, or logistic regression models (depending on prevalence of the outcome), with generalized estimating equations and robust variance estimates will be used to examine the difference between the proportion of siblings and survivors with mental health needs (clinical level of distress based on 2007 BSI scores) who report postponing mental health care services. Ideally, these would be adjusted comparisons, but due to the small numbers of siblings available for this analysis, this may be primarily a descriptive comparison; **b)** Among CCSS, the following explanatory variables will be examined using log-binomial or logistic regression models (to account for the intrafamilial correlation) as factors that may be related to delaying mental health services (dichotomous outcome) within this subset of subjects: Insurance status, insurance type, SSDI & SSI status, age at survey, sex, race, educational attainment, marital status, income, employment status, cancer diagnosis, age at diagnosis, recurrence status. Care will be taken not to overfit the model, examining age, gender, race adjusted univariate models first before selecting for a multivariable model, since numbers are still relatively small among the CCS.

Special Considerations:

This study has some limitations. Because the measures are based on self-report, they may not be an accurate depiction of actual health insurance coverage amongst this population of survivors and siblings. There may be some general confusion regarding what is or is not covered in terms of mental health care.

Results

Table 1: Demographics

	Survivors (N = 698)		Siblings (N = 210)		p Value
	N	Weighted %	N	Weighted %	
Age at survey Years					
18 - 29					
30 - 39					
40 - 49					
> 50					
Gender					
Male					
Female					
Race					
White					
Black					
Hispanic/Latino					
Other					
Education					
< High school graduate or High school graduate					
Some post-graduate college					
Completed college and above					
Marital Status					
Married or living with partner as married					
Single, never married					
Divorced or separated					
Widowed					
Employment status					
Employed (Full-time or Part-time)					
Caregiver (not looking for paid work)					
Unemployed and looking for work					
Unable to work due to illness or disability					
Retired					
Student					
Household income					
less than 20,000					
20,000 - 39,999					
40,000 - 59,999					
60,000 - 79,999					
80,000 - 99,999					
100,000 and over					
Cancer Diagnosis					
Leukemia					
Cenral Nervous System					
Hodgkins Lymphoma					
Neuroblastoma					
Wilms Tumor					
Soft tissue sarcoma					
Bone					
Non-Hodgkins Lymphoma					
Age at diagnosis					
0-5					
6-10					
11-15					
16-20					

Table 2: Comparison of mental health care service coverage and utilization between survivors and siblings

	Survivors (N = 698)	Siblings (N = 210)	
	N (%)	N (%)	p*
Mental health coverage offered by insurance plan			
Yes (most or some)	392 (56.1)	123 (58.6)	
No	114 (16.3)	53 (15.2)	
Don't know	175 (25.2)	51 (24.3)	
Mental health services utilized in past year			
Yes	80 (11.4)	24 (11.4)	
No	613 (87.8)	186 (88.6)	
Postpone mental health care due to cost concerns			
Yes	72 (10.)	22 (10.5)	
No	587 (84.1)	173 (82.4)	
Don't know	14 (2.0)	7 (3.3)	
Provider not accept insurance for mental health care			
Yes	20 (2.8)	4 (1.9)	
No	436 (62.5)	120 (57.1)	
Don't know	69 (9.9)	29 (13.8)	
N/A; no coverage over past year	149 (21.3)	50 (23.8)	
Perceived importance of mental health care coverage			
Very important	271 (38.8)	73 (34.8)	
Somewhat important	220 (31.5)	67 (31.9)	
Not too important	138 (19.8)	54 (25.7)	
Not at all important	44 (6.3)	8 (3.8)	

Note: percents will be weighted
*Adjusted for age, race and gender

Table 3: Predictors of mental health care service availability and utilization

	Services Available (Insured q21D)	**Service Used (Insured q17)**
	OR (95% CI)	**OR (95% CI)**
Insurance Status Insured Uninsured		
Insurance Type Employer Sponsored/Military Individual insurance Medicaid/state Medicare Don’t know		
Receive SSI Yes - current No - past only No - never Don’t know		
Receive SSDI Yes - current No - past only No - never Don’t know		
Age (at survey) 18 - 29 30 - 39 40 - 49 > 50		
Sex Male Female		
Race/Ethnicity White Black Hispanic Other Unknown		
Education < High school graduate or High school graduate Some post-graduate college Completed college and above		

Marital Status Married or living with partner as married Single, never married Divorced or separated Widowed		
Employment status Employed (Full-time or Part-time) Caregiver (not looking for paid work) Unemployed and looking for work Unable to work due to illness or disability Retired Student		
Household income less than 20,000 20,000 - 39,999 40,000 - 59,999 60,000 - 79,999 80,000 - 99,999 100,000 and over		
Cancer Diagnosis Leukemia Cenral Nervous System Hodgkins Lymphoma Neuroblastoma Wilms Tumor Soft tissue sarcoma Bone Non-Hodgkins Lymphoma		
Age at diagnosis 0-5 6-10 11-15 16-20		
Surgery Status Amputation Other None		
Chemotherapy status Anthracyclines Other chemo None		
Radiation Cranial Chest Other None		

Second cancer/recurrence None Second cancer Recurrence		
BSI scores from 2007 survey		

Table 4: Predictors of unmet mental health services needs

	Services Postponed (Iq30)	**Coverage Declined (Iq25)**
	OR (95% CI)	**OR (95% CI)**
Insurance Status Insured Uninsured		
Insurance Type Employer Sponsored/Military Individual insurance Medicaid/state Medicare Don't know		
Receive SSI Yes - current No - past only No - never Don't know		
Receive SSDI Yes - current No - past only No - never Don't know		
Age (at survey) 18 - 29 30 - 39 40 - 49 > 50		
Sex Male Female		
Race/Ethnicity White Black Hispanic Other Unknown		
Education < High school graduate or High school graduate Some post-graduate college Completed college and above		
Marital Status Married or living with partner as married Single, never married Divorced or separated Widowed		

Employment status Employed (Full-time or Part-time) Caregiver (not looking for paid work) Unemployed and looking for work Unable to work due to illness or disability Retired Student		
Household income less than 20,000 20,000 - 39,999 40,000 - 59,999 60,000 - 79,999 80,000 - 99,999 100,000 and over		
Cancer Diagnosis Leukemia Cenral Nervous System Hodgkins Lymphoma Neuroblastoma Wilms Tumor Soft tissue sarcoma Bone Non-Hodgkins Lymphoma		
Age at diagnosis 0-5 6-10 11-15 16-20		
Surgery Status Amputation Other None		
Chemotherapy status Anthracyclines Other chemo None		
Radiation Cranial Chest Other None		
Second cancer/recurrence None Second cancer Recurrence		

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