How Costs of Health Care Affect Utilization and Financial Burden in the Childhood Cancer Survivor Study

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Background and Rationale:

Fortunately, with the continued augmentation of life-saving treatments, greater numbers of pediatric oncology patients are surviving into adulthood. More than 80% of children diagnosed today will become long term survivors.[1] There are almost 400,000 survivors of childhood cancer living in the U.S. today.[2,3] Many survivors face lifetime, ever-increasing risks for morbidity and premature mortality due to the sequelae of their primary disease or its treatment. In fact, in survivors 30 years after initial diagnosis, there is a cumulative incidence of chronic health conditions of 73%, with 42% of survivors suffering from severe, disabling, or life-threatening conditions or death due to chronic conditions.[4-6] Furthermore, when compared with their siblings, survivors have a 10-fold risk of developing a chronic disease.[5] Therefore, the importance of lifelong, close medical attention in this population cannot be overstated.

Besides being a medically vulnerable population, survivors of childhood cancer can be socioeconomically vulnerable as well. Studies have shown that the residual effects from cancer and its treatment can permeate nearly every aspect of survivors' lives, and for the entire duration of their lives. Survivors of childhood cancer, when compared to controls, are less likely to graduate from college, to be married, to be employed, and to have health insurance, while reporting more difficulty obtaining health insurance.[7-11]

The impact of these socioeconomic vulnerabilities on medical care for childhood cancer survivors, however, is less clear. There is evidence that in adult survivors of all types of cancer (not limited to childhood cancer), cost is a significant reason for decreased utilization of medical care.[12,13] Also, studies of adolescent and young adult cancer survivors demonstrate that 34% of survivors compared to 20% of population-based controls report skipping medical care due to costs in the past year.[14] However, adult survivors of childhood cancer face different medical and socioeconomic challenges than young survivors or survivors of adult cancer. For survivors of childhood cancer, their age at diagnosis, types of diagnoses and intensive treatments often lead to a larger impact on insurance, employment, and education than seen in survivors of cancers diagnosed at later ages.

While there have been studies that have investigated medical-related financial distress among adult cancer survivor populations, such as bankruptcy,[15] to our knowledge, there have been no studies of these problems among childhood cancer survivors. In addition, the impact of extreme

medical-related financial burden – such as filing for bankruptcy or mortgaging homes to pay for medical care – on survivors' adherence to health care such as taking medications or getting recommended care is unknown. We do know that for survivors of childhood cancer one of the key barriers to obtaining general and survivor-focused health care is lack of access to health insurance.[14,16,17] Also, certain clinical and demographic features such as gender and chronic conditions are associated with greater risk for long-term medical needs and/or decreased rates of employment, potentially increasing the financial stresses due to medical care.[18,19]

The current proposal will use data from an ancillary survey of insured and uninsured survivors and siblings from the Childhood Cancer Survivor Study. The objective is to examine two important and understudied areas of burden on survivors: health care utilization due to cost (e.g., skipping a recommended medical test or taking a smaller dose of medication due to costs) and financial burden due to health care costs (e.g., taking out a mortgage against a home to pay for medical expenses or filing for bankruptcy). We will investigate differences between survivors' past medical and treatment history, chronic medical conditions, insurance status, and sociodemographic features which may either be a protectant or risk factor for these outcomes. We are also interested in examining the association between those reporting financial burden and reported utilization of primary care (i.e., seeing a primary care physician) within the past year, which is a necessary health care measure for all survivors. Finally, we will examine if utilization in specific areas of needed care, such as dental, are associated with possessing insurance coverage for that specific service. The findings from this paper will provide impetus and target for reform in caring for long-term survivors.

Specific Aims:

Aim 1a: Determine the prevalence of and sociodemographic, clinical (e.g. diagnosis, type of treatment received, presence of chronic condition), and insurance status factors associated with decreased utilization of needed care due to health care cost among survivors.

Aim 1b: Determine the prevalence of and sociodemographic, clinical (e.g. diagnosis, type of treatment received, presence of chronic condition), and insurance status factors associated with extreme financial burden due to health care cost among survivors.

Hypotheses 1a and1b: Survivor factors associated with decreased utilization of needed care and extreme financial burden due to health care cost will include being female, older at time of survey, unemployed, of minority race, having a lower education level, as well as the presence of a severe chronic condition, having undergone cranial irradiation and being uninsured.

Aim 2: Determine the prevalence of and sociodemographic, clinical, and insurance status factors associated with a lack of needed medical care, lack of needed primary care, and difficulties paying medical bills among survivors.

Hypothesis 2: Survivor factors associated with a lack of needed medical care, no primary care utilization, and difficulty paying medical bills will be similar to those associated with low rates of utilization of needed care and financial burden due to medical costs.

Aim 3: Describe the association of utilization of needed care in specific types of health care due to cost, including delays in dental, vision, mental health, and prescriptions, with the presence of having insurance coverage for that specific service among survivors.

Hypothesis 3: Survivors who report having insurance for specific types of services will be less likely to report delaying those specific health care opportunities.

Methods:

Participants:
We will perform analyses using data from a supplementary questionnaire of CCSS survivors and siblings that was fielded from March 2011-March 2012. The questionnaire was sent to a random sample of CCSS participants from the United States, stratified by age (<30, 30-39, 40+). Participants could complete the questionnaire via the mail or internet. Participants received two versions of the survey: one to be completed if they were insured and one if they were uninsured. A total of 1100 survivors were sent the survey; N=698 survivors completed. Based on these completed surveys, for survivors we had a 64% response rate and 70% participation rate. Because there are two versions of the survey (insured and uninsured), for each measure of interest below, we list the variable number using the insured survey variables.

Measures of Interest:
As we are interested in factors among survivors that lead to decreased utilization of needed care and financial burden, for the current proposal our analytic sample will be limited to survivors. Dr. Elyse Park, the PI of the insurance survey project, has been working on a separate investigation using data from this same survey comparing burden of survivors to their sibling cohort. We will most likely report on the level of difference of burden between survivors and their siblings in terms of utilization of needed care and financial burden by citing Dr. Park's study to provide context to our analyses. However, as we will be generating summary measures of these items as described below, we may evaluate differences between the survivors and siblings on these summaries as a secondary analysis.

Aim 1a:
Utilization of needed care: Question 30
"In the past year, was there a time when you did any of the following because you were worried about the cost?"
Respondents were asked to respond: "Yes," "No," or "Don't know" to items a-j:

a. Skipped a medical test, treatment, or follow-up that was recommended by a health care provider
b. Had a medical problem but did not go to a health care provider or a clinic
c. Did not see a specialist when you or your health care provider thought you needed one
d. Put off or postponed preventive care
e. Put off or postponed dental care
f. Put off or postponed vision care
g. Put off or postponed mental health care
h. Had no primary care provider
i. Did not fill a prescription for a medicine
j. Took a smaller dose or fewer pills than was prescribed

Aim 1b:
Extreme financial burden: Question 31
"In the past year, have any of the following happened because of medical expenses?"
Respondents were asked to respond either: "Yes," "No," or "Don't know" to items a-i:

a. Put off major purchases, such as a new home or car
b. Been unable to pay for basic necessities like food, heat, or rent
c. Had to take money out of savings

d. Spent more than 10% of your income on medical expenses
e. Had to borrow money
f. Took on credit card debt
g. Took out a mortgage against your home or took out a loan
h. Thought about filing for bankruptcy
i. Filed for bankruptcy

For the two outcomes of interest (utilization of needed care and extreme financial burden), we will first evaluate each item individually. We will omit item a in Question 31 as we believe that putting off major purchases is not necessarily a sign of extreme financial burden (whereas bankruptcy or debt are larger burdens). Then, to evaluate which survivor characteristics are associated with the greatest burden (both in terms of decreased utilization of needed care as well as increased financial burden), we will create sums of the items in Question 30 (ranging from 0-10) and 31 (ranging from 0-8) to approximate severity. To do this, we will consider all affirmative responses to be of equal value as a threshold of severity and sum the number of responses for each question.

Based on preliminary analyses to inform this proposal, 31% of survivors reported 2 or more instances of extreme financial burden, such as filing for bankruptcy or borrowing money to pay for medical care. A total of 47% of survivors reported 2 or more events of failure to utilize needed care, such as not filling a prescription, due to medical costs. We will explore appropriate cut-points and groupings of these summaries as part of our analysis.

Aim 2:
Inability to obtain medical care: Question 24
"In the <u>past year</u>, were you able to get most of the medical care that you needed?"
Respondents were asked to respond either: "Yes," "No," or "Don't know."

Survivors who respond "No" to Question 24 will be labeled as lacking needed medical care.

Lack of primary care: Question 17
"During the <u>past year</u>, which of the following health care providers did you see or talk to for medical care? This includes routine care and sick care."
Respondents were asked to mark all that apply to a list of provider types:

- None
- Primary care physician
- Specialty care physician (e.g., cardiologist)
- Provider who sees cancer survivors for routine follow-up care (e.g., survivorship clinic)
- Nurse Practitioner/Physician's Assistant
- Nurse
- Chiropractor
- Physical therapist/Occupational therapist/Speech-language pathologist/Audiologist
- Dentist
- Eye Doctor
- Mental health care professional

Survivors who responded to *not* having seen a primary care physician in the past year will be labeled as lacking primary care. While an annual visit to a primary care physician alone is likely inadequate for most survivors, it is an important medical recommendation that applies to all survivors, and is therefore a sensitive measure of medical utilization.

Difficulty paying medical bills: Question 29
"In the past year, have you/your family had any problems paying your medical bills?"
Respondents were asked to respond either: "Yes," "No," or "Don't Know."

Survivors who respond affirmatively to Question 29 will be considered burdened by their medical bills.

Aim 3:
Specific Insurance Coverage for Care: Question 21
"Do you currently have insurance that covers most, some or none of the following types of services?"
Respondents were asked to respond either: "Most," "Some," "None" or "Don't Know" to items a-e:

a. Medical care
b. Dental care
c. Vision care
d. Mental health care
e. Prescription medication

Reponses to b-e will be associated with corresponding failure to utilize needed care (e.g., dental care coverage with postponing dental care) in Question 30 (items e, f, g, i and j) to understand whether having "some" or "most" coverage for a specific type of care is protectant against those failures to utilize needed care due to cost. An affirmative response to either item i ("Did not fill a prescription for a medicine") or item j ("Took a smaller dose or fewer pills than was prescribed"), will be considered taking prescription inappropriately due to cost. Responses to item a in Question 21 will not be used as it does not describe a specific type of coverage.

Independent Variables

Our independent variables include sociodemographic, clinical (e.g. diagnosis, type of treatment received, presence of chronic condition), and insurance status factors. These variables were chosen based on previous studies demonstrating them as either protectant or a risk factor for medical co-morbities and subsequent socioeconomic burden. We show these variables in Table 1. As needed, we will investigate different categorizations of these measures (e.g., cranial radiation cut-points) with input from the study team.

Statistical Methods:

All statistical analyses will be done using Stata version 13. Dr. Fair is currently training in biostatistics via the Master of Science in Clinical Investigation program at the University of Utah. While he will lead the analyses, he will receive weekly supervision from Dr. Kirchhoff as well as input from Dr. Leisenring and the ancillary survey study team throughout all aspects of the analyses. For all analyses, we will use sample weights to reweight the survey data to reflect the age distribution of the original sample.

- **Aim 1a and 1b:** Among survivors, we will first examine the association of our factors of interest (e.g., gender, chronic disease, insurance) with two outcomes of interest: decreased utilization of needed care due to costs and financial burden due to cost, using chi-square and t-tests as appropriate. We will investigate different potential cut-points for the outcome summary measures (e.g., 0-1 failures to utilize needed care vs. ≥2). Then, informed by these analyses, we will use multivariable generalized linear regression models using a

binomial distribution with a log-link to generate relative risks and 95% confidence intervals to examine the associations between demographic, clinical and insurance information on those two outcomes of interest (utilization of needed care due to costs and financial burden due to cost).[20] Therefore, our final models will incorporate sociodemographic and clinical factors that have been established in the literature as associated with morbidity (e.g., female gender and cranial radiation). However, we will also consider factors identified in the first part of our descriptive investigation. In addition, as a secondary analysis, we will evaluate the association between the two outcomes of interest (e.g., is a higher number of failures to utilize needed care associated with greater financial burden).

- **Aim 2:** Among survivors, we will first examine the association of our factors of interest (e.g., gender, chronic disease, insurance) with three outcomes of interest: lack of medical care, no primary care, and difficulties paying medical bills, using chi-square tests or t-tests as appropriate. Then, informed by these analyses, we will use multivariable generalized linear regression models using a binomial distribution with a log-link to generate relative risks and 95% confidence intervals to examine the associations between demographic, clinical and insurance information and the three outcomes of interest (lack of medical care, no primary care, and difficulties paying medical bills).[20]
- **Aim 3:** Among survivors, we will perform chi-squared tests (or Fischer's exact tests, if appropriate) to evaluate the association of specific failures to utilize needed care with specific insurance coverage types.

Potential Limitations:

The changing insurance landscape of the Affordable Care Act (ACA) may offer additional financial protections for survivors that were not captured in our sample due to the fielding from March 2011–March 2012. While there has been no evaluation to date of increases in insurance for childhood cancer survivors under the ACA, it is expected that there will be significant improvements in the insurance coverage for survivors of childhood cancer, warranting future studies of financial burden and utilization of needed care. Another limitation is the sample size of the ancillary survey, limiting our power to evaluate differences certain demographic and clinical information among survivors. Finally, we do not have information on the types of recommended medical services each survivor should be getting; therefore, we are assessing utilization of needed care without this context. However, all survivors should receive yearly primary care, and so by investigating this associated with our measures of interest, we can capture potential access to care issues.

Contributions and Implications:

This study has the potential to identify the financial burden imposed on survivors by their medical costs and also how medical costs impact obtaining medical care. Furthermore, the study may explicate what characteristics put survivors at greater risk. Understanding the risk factors would allow for targeted increases in medical management and/or benefits to needy survivors. Our findings should also describe the necessity and partly the adequacy of specific types of health insurance, which could identify further needs for achieving better health care utilization in this sensitive population. Somewhat timely, many of these specific types of insurance/ benefits are now covered in the ACA and this study should speak to their importance in this population. Overall, risk factors and survivor needs identified in the study should serve as potential areas for change in legislative policy and insurance coverage for survivors of childhood cancer, as well as in the way medical care is delivered to this population.

Example Tables and Figures:

Survivor Demographics/ Clinical Information		
N=698	N	%
Insurance status		
Non-insured		
Insured		
If insured, type of insurance		
Employer-sponsored		
Individual private		
Government-funded		
Age		
22-29		
30-39		
≥40		
Gender		
Male		
Female		
Race/Ethnicity		
White, non-Hispanic		
Other		
Education attained		
<High school graduate		
High school graduate, not college graduate		
Completed college and above		
Marital Status		
Unmarried		
Married		
Employment Status		
Employed (Full-time or Part-time)		
Unemployed, looking for work		
Unable to work due to illness / disability		
Other		
Chronic Condition		
None		
One condition, Grade 1-4		
≥2 conditions, Grade 1-4		
One condition, Grades 3-4		
≥2 conditions, Grades 3-4		
Cancer dx		
Bone cancer		
CNS		
HD		
Wilms		
Leukemia		

NHL		
Neuroblastoma		
Soft Tissue Sarcoma		
Age at Diagnosis		
0-4		
≥4		
Second Cancer		
No		
Yes		
Recurrence of Primary Malignancy		
No		
Yes		
Any Radiation		
No		
Yes		
Any Chemotherapy		
No		
Yes		
Any Surgery		
No		
Yes		
Amputation		
No		
Yes		
Central Nervous System Surgery		
No		
Yes		
Cranial Radiation		
None		
Scatter high/Scatter low		
<36Gy		
≥36Gy		

Aim 1a: *Determine the prevalence of and sociodemographic, clinical (e.g. diagnosis, type of treatment received, presence of chronic condition), and insurance status factors associated with decreased utilization of needed care due to health care cost among survivors.*

Aim 1b: *Determine the prevalence of and sociodemographic, clinical (e.g. diagnosis, type of treatment received, presence of chronic condition), and insurance status factors associated with extreme financial burden due to health care cost among survivors.*

Aim 1a, Example Table 1a: Demographics/ Clinical Information Among Survivors with Failures to Utilize Needed Care

										Summary		
Question: 30, Items: a-j	**Skipped test**			**Had problem but did not see provider**			**… (items c-j)**			**≥2 Delays in needed care**		
n = 698	**N**	**%**	**p-value**	**N**	**%**	**p-value**	**N**	**%**	**p-value**	**N**	**%**	**p-value**
Total survivor												
Insurance status												
Uninsured												
Insured												
Age												
22-29												
30-39												
≥40												
Gender												
Male												
Female												
… (same sociodemographic and clinical characteristics as prior Table)												

Aim 1b, Example Table 1b: Demographics/ Clinical Information Among Survivors Experiencing Financial Burden

										Summary		
Question 31, Items: b-i	**Put off major purchases**			**Been unable to pay for basic necessities**			**…(items d-i)**			**≥2 Financial burden**		
n=698	**N**	**%**	**p-value**	**N**	**%**	**p-value**	**N**	**%**	**p-value**	**N**	**%**	**p-value**
Total Survivor												
Insurance status												
Uninsured												
Insured												
Age												
22-29												
30-39												
≥40												
Gender												
Male												
Female												
… (same sociodemographic and clinical characteristics as prior Table)												

We will first do an in-depth exploration of different demographic and clinical variables associated with decreased utilization in needed care and financial burden as shown in Tables 1a and 1b. Then, based on these bivariate associations, we will select the most appropriate variables for the regression analyses. Also, Tables 1a and 1b show possible summary measures (e.g., 0-1 and ≥2 failures to utilize needed care); as discussed above, we will investigate other cut-points of these items.

As mentioned in the statistical methods, we will use multivariable generalized linear regression models to generate relative risks and 95% confidence intervals to better examine the strength of associations between demographic, clinical and insurance information on those two outcomes of interest (utilization of needed care due to costs and financial burden due to cost). For sake of space and redundancy, these tables are not shown here, but will be utilized in analysis.

Aim 2: *Determine the prevalence of and sociodemographic, clinical, and insurance status factors associated with a lack of needed medical care, lack of needed primary care, and difficulties paying medical bills among survivors.*

Aim 2, Example Table 2: Demographics/ Clinical Information Among Survivors Either Unable to Get Most of the Medical Care Needed, Did Not Obtain Primary Care, or Had Difficulty Paying Medical Bills In the Past Year						
Questions: 24, 17, 19	**Could Not Get Medical Care Needed**		**Did Not Obtain Primary Care**		**Had Difficulty Paying Medical Bills**	
n = 698	**N**	**%**	**N**	**%**	**N**	**%**
Total survivor						
Insurance status						
Uninsured						
Insured						
Age						
22-29						
30-39						
≥40						
Gender						
Male						
Female						
… (same sociodemographic and clinical characteristics as prior Table)						

We will examine the same sociodemographic, clinical, and insurance characteristics among the survivors in Aim 2 as in Aims 1a and 1b, investigating the association between these characteristics and three outcomes of interest: lack of medical care, no primary care, and difficulties paying medical bills.
As mentioned in the statistical methods, we will use multivariable generalized linear regression models to generate relative risks and 95% confidence intervals to better examine the strength of associations between demographic, clinical and insurance information and the three outcomes of interest (lack of medical care, no primary care, and difficulties paying medical bills). For sake of space and redundancy, these tables are not shown here, but will be utilized in analysis.

Aim 3: *Describe the association of specific types of failures to utilize needed care due to cost, including failures in dental, vision, mental health, and prescriptions, with the presence of having insurance coverage for that specific service among survivors.*

Aim 3, Example Table 3: Specific Missed Opportunity and Possession of Specific Insurance					
Type of Missed Opportunity	**No Coverage**		**Some or Most Coverage**		**p-value: None vs. Some/Most**
n=698	**N**	**%**	**N**	**%**	
Obtained Dental Care	**Dental Coverage**				
Yes					
No					
Obtained Vision Care	**Vision Coverage**				
Yes					
No					
Obtained Mental Health Care	**Mental Health Coverage**				
Yes					
No					

Appropriately filled Prescriptions	Prescription Coverage				
Yes					
No					

We will examine the association between utilization of needed care in specific health care domains with its corresponding insurance type.

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