



Hyundai Hope on Wheels Hyundai Scholar Research

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Childhood cancer survivors suffer from late effects of therapy that can be life threatening.

Aggressive research efforts have led to advances in treatment and improvement in survival for many childhood cancers. According to recently released data from the Surveillance, Epidemiology and End Results (SEER) program of the Cancer Institute five year survival for childhood cancer increased from 58.6% in 1975 to 80% in 2003.¹ Prolonged survival for childhood cancer survivors does not come without a price. This growing population is at risk for late effects of cancer directed therapy long after their treatment is complete. Late effects are a result of the surgery, radiation and chemotherapy used to treat the initial cancer. These treatment modalities cause a wide array of chronic medical problems. Survivors have over ten fold excess mortality when compared to their siblings,² and over 3% of this population have developed a second cancer in the 20 years after initial diagnosis.³ Multi-organ system dysfunction includes cardiac, pulmonary, renal, and fertility effects among others. Survivors are also at risk for a myriad of psychosocial problems including anxiety, depression, difficulties with employment, and poor insurance coverage. In a recent study late effects were present in ~2/3 of cancer survivors and were characterized as severe or life-threatening in ~1/4 of survivors.⁴ It is clear there is a growing population of survivors who are at considerable risk for serious medical complications from the treatment they received for childhood cancer.

Excellence in pediatric cancer patient care must include survivors.

Providing quality medical care to pediatric cancer patients includes recognizing and treating the late effects of therapy. Research about the type and frequency of late effects in our population of cancer survivors is a critical component of achieving excellence along the spectrum of pediatric cancer care.

A patient database serves as the foundation of quality medical care and clinical research.

Currently our system for maintaining contact with our patients is imperfect. In order to enhance care we must establish a database of childhood cancer survivors treated at the Water's Center for Children's Cancer and Blood Disorders (Syracuse, NY) since the clinic's inception. Medical care will be improved as we identify patients in need of screening and management of late effects of cancer therapy. When new

information or clinical recommendations become available we can efficiently contact the affected patients. Research subjects can be identified and hypothesis tested utilizing demographic information and other characteristics in the database. Our research questions will address our cancer survivor population diagnoses, therapy, known late effects and survival status. Offspring outcomes will be analyzed for relation to specific treatment modalities and original diagnosis. Research questions will be designed to address survivors concerns including future health issues, employability, and insurability.

The **Hyundai Hope on Wheels Scholar Grant** will be used for clinical support while I devote time to computer training on the database program. Clinical support will allow rapid development of the database and extensive testing to maximize its usefulness in our setting. The grant will allow statistical support for the analysis of demographic and other features of our population. Working with a statistician through the development process of the database will ensure sound design needed for scientific rigor in publication of this work.

Identification of survivor characteristics that predict research participation can be used to improve clinical care.

We are currently involved in a investigation to identify characteristics of childhood cancer survivors that may be associated with their participation in research, specifically the Childhood Cancer Survivor Study (CCSS). This study includes ~30,000 childhood cancer survivors who are sent periodic questionnaires on a variety of topics related to their health and well being. The information from the CCSS is only accurate if the cancer survivors in the study represent the group at large. If there are characteristics that predict research involvement there may be bias in the study which undermines the meaningfulness of the data. We are in the process of pulling data from the charts of ~1000 childhood cancer survivors and evaluating for three characteristics: have they have maintained contact with their treating institution, were they provided a written treatment summary, and do they suffer from chronic disease. These patients have been invited to participate in the Childhood Cancer Survivor Study and we will see if there is an association between participation in the CCSS and the characteristics taken from the chart. The results of this study can be used to interpret CCSS publications as well as explore differences in health care seeking behavior among childhood cancer survivors. The support from the **Hyundai Hope on Wheels Scholar Grant** will be used to fund statistical analysis of this study and research related travel expenses. Comparisons will be made between the group who chooses to participate in the CCSS and those who do not participate. The involvement of statistician in this study will move it to the publication phase rapidly. Further at the completion of this project we will have new information on survivor characteristics that influence their follow-up medical care.

Future Research:

We are developing educational interventions to improve self advocacy for survivors as well as provide continued education on this topic to primary care providers. Our goal is to provide cancer treatment summaries and survivor care plans to survivors and their physicians. We will then evaluate if providing these documents increases survivor visits to the clinic and improves their screening for late effects. Exploratory research into communication between the oncologist and primary care physician will further enhance our knowledge of this important realm of medical care for the childhood cancer survivor.

Another area of future investigation involves fertility decisions among children and their families at different time points along their cancer continuum. We are coupling this research effort with the development of new experimental methods of fertility preservation in cooperation with local experts in this area. Part of this research will result in an organized and efficient method of addressing fertility issues with patients and their families and improve clinical care.

Currently we are undergoing an investigation into screening recommendations for thyroid cancer in childhood cancer survivors that differs from that recommended nationally. The experience in our clinic suggests that thyroid ultrasound should be used as a screening measure. Further research that documents the effectiveness of our approach is needed.

Since completion of my training in Pediatric Hematology-Oncology 10 months ago I have been busy working to improve the research capabilities of the late effects clinic. Though these efforts are still young we have had some successes: abstract presentation at a major national oncology meeting, manuscript submitted for publication, and obtained funding for technical support for a comprehensive clinical database. If selected as the **Hyundai Hope on Wheels Scholar** I will have more opportunities to continue this research that is critically necessary for children with cancer to live long, full lives. I hope to use these funds as outlined above to further the mission of providing excellent clinical care to children with cancer throughout the cancer continuum.

REFERENCES

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