



Hyundai Hope on Wheels Hyundai Scholar Research

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Background

Today, 75 to 80 percent of children with cancer will be cured of their disease. This astonishing feat represents over 30 years of progress in the development of cancer research and treatment protocols, each built on knowledge gained from earlier studies.

Survival from childhood cancer, however, comes with unintended consequences. As many as two thirds of the survivors of childhood cancer have, or are likely to develop, treatment-related diseases and disabilities. Although children often tolerate the immediate side effects of cancer treatment better than adults, these young, growing patients are more vulnerable to problems that may emerge in subsequent years as a result of their treatment. Examples of these “late effects” include:

- Patients with radiation to the brain develop multiple and complex hormone deficits such as diminished growth, thyroid, growth and adrenal insufficiency as well as significant neuro-psychologic and learning difficulties.
- Radiation therapy can cause decreased muscle mass and diminished bone growth in areas where it is given leaving some patients needing prosthetic devices to compensate.
- Many other patients have abnormal bone density that leaves them the functional equivalent of elderly osteoporosis patients and are at high risk for fracture.
- Some very important and necessary chemotherapy drugs may cause sterility, substantial hearing loss, as well as diminished heart and lung function that limit activity.

- Many chemotherapy drugs as well as radiation therapy are also associated with an increased risk of a second malignancy later in life. The incidence of second malignancies in some groups of childhood cancer survivors is almost 20 times higher than matched healthy controls.

As knowledge of these problems grows, treatment regimens are being modified and intervention strategies developed to alleviate them. Increasingly, physicians are recognizing the need to screen and treat patients in order to protect their quality of life and to diminish the secondary economic and social implications of these problems as they progress toward adulthood, establishing long-term relationships, and entering the work force. In addition, many pediatric oncology centers are initiating specific *Late Effects Programs* to address the needs of survivors of childhood cancer.

Young Enduring Survivors

The Young Enduring Survivors (YES) Program is a multidisciplinary clinic serving all survivors of childhood cancer in New Mexico and parts of Arizona. The first YES patient was seen on February 4th, 2005. Since that time, we have screened over 300 patients between the ages of 3 and 46 years, for late effects of cancer and treatment. Dr. Linda Butros serves as the YES Clinic director and physician for the clinic; however, there are a multitude of caregivers involved in the optimal care of these patients. The YES Clinic professionals include a YES Clinic RN, a clinic coordinator, a social worker, a nutritionist, two neuropsychologists, an endocrinologist, an internist interested in late effects issues in adolescents and young adults, and a tobacco cessation counselor all of whom routinely attend to the patients in the YES Clinic.

The care and intervention available in this late effects clinic differs from that of a clinic offering active cancer therapy; yet it is no less crucial for the long-term health and well being of the young patients who visit it. Each new patient who attends the YES Clinic receives a comprehensive treatment summary which outlines each of the patient's treatment in detail as well as any significant complications during or after treatment. The YES Treatment Summary is updated with the patient's past and current medical information at their annual visit. Each new patient or patient's guardian also fills out an age appropriate questionnaire including a quality-of-life assessment. Each patient is also screened by a neuropsychologist and tobacco cessation counselor at every visit.

Research Proposal

Dr. Butros, in conjunction with the Young Enduring Survivors Clinic, proposes to develop a database for the projected 450 new patients seen in the YES Clinic between the years 2005 to 2010. To date we have seen approximately 400 new patients from the clinic's inception in February 2005. This database will allow us to monitor the incidences of long term side effects in our New Mexico population and to compare the side effects to the patients' treatments including various chemotherapies and radiation treatments and also to compare the side effects to the patients' original diagnoses. This information will contribute to the long term management and health screening for childhood cancer survivors in New Mexico and potentially nationwide.

Initially, the database will include long term side effects of treatment will be divided into categories as follows:

Psychosocial development and adaptation

1. The YES questionnaire includes a list of questions addressing how often the patients worry about the cancer returning currently and in the past. We would like to quantify and analyze these responses.
2. The YES questionnaire includes questions regarding school performance and attention deficits. Also, the neuropsychologist's evaluation in clinic annually screens for these issues and others. We would like to analyze the degree of difficulties with school performance and attention deficits in our population relative to the general population.
3. The tobacco cessation counselor screens for tobacco exposure either directly in the patient or indirectly from second hand smoke and a report is generated for each patient's visit. We would like to analyze the incidence of tobacco exposure in our population and integrate our survey results with UNM Cancer Center's epidemiology and cancer prevention programs.
4. The YES questionnaire includes a question regarding access to health insurance coverage and healthcare. The YES Clinic social worker, Yolanda Vinajeras MSW, also screens the patients for difficulties with insurance coverage and access to primary medical care. We would like to analyze our patients' access to healthcare.
5. A portion of young adult survivors in our YES Clinic have suffered from depression and post-traumatic stress disorders. We would like to analyze the numbers of patients who have attempted suicide and the psychiatric

diagnoses in these patients and compare the incidence in our population to the general population.

Physical health and well-being

1. Analyze the incidence and type of hearing loss in our population and the type of chemotherapy and radiation in the population suffering from hearing loss.
2. Analyze the incidence and type of cardiac disease in our population and the type of chemotherapy and radiation in the population suffering from cardiac disease.
3. Analyze the incidence and type of bone disease including osteopenia and osteoporosis in our population. We will also review the type of chemotherapy and radiation in the population suffering from bone disease.
4. Analyze the incidence and type of developmental delay in our population and the type of chemotherapy and radiation in the population suffering from developmental delay.
5. Analyze the incidence and type of second malignancies in our population and the type of chemotherapy and radiation in the population suffering from second malignancies.
6. Determine the five year survival rate in our YES patients who are not seen in the YES Clinic until they are disease free and two years from completion of treatment. We will also analyze causes of life-threatening morbidities and deaths in our patients and correlate their previous exposures to chemotherapy and radiation.
7. Provide follow-up on all patients registered onto therapeutic clinical trials.

Outreach

1. Develop a survey for the primary care physicians in the state of New Mexico caring for the YES patients. The survey will be used to determine the need for a statewide education and outreach initiative to the outlying communities actively caring for survivors of childhood cancer.