

POGO Research Unit Supported Projects (Pillar: Survivor Status/Quality of Life)

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Assessing the Fertility Status of Male Hodgkin's Lymphoma Survivors and Canadian Sperm Banking Practices

PI: Nathan, P.

Ongoing: Among childhood cancer survivors and health care providers, the long-term effects of therapy are of increasing importance. Future fertility has been identified as an outcome of major concern but most published studies have looked at fertility outcomes in those treated as adults and not as children. In pubertal males, sperm banking is a practical and realistic option to preserve future fertility. However, rates of sperm banking are low, preservation practices vary across Canada, and there are no formal pediatric guidelines.

In this research project, the researchers will address some of these issues utilising two inter-related studies. The first is a descriptive study that describes the fertility outcomes of a group of men who were treated for Hodgkin's lymphoma in childhood over a 20-year period (1985 to 2004), using a specialised questionnaire and blood/semen laboratory tests. The second study is a telephone survey to gather information on the current practices and facilities for sperm banking in male adolescents with cancer across Canadian pediatric oncology centres.

Atypical Development Prior to Diagnosis of Acute Lymphoblastic Leukemia: Incidence and Neurocognitive Outcomes

PI: Janzen, L.

Ongoing: In contrast to the growing body of evidence on late effects of leukemia treatment on normally-developing children, very little is known about how children with atypical development prior to diagnosis are affected by treatment. In fact, they are frequently excluded from studies of neurocognitive outcomes.

This feasibility study is unique in that it is the first to focus on newly diagnosed children with acute lymphoblastic leukemia (ALL) who have pre-existing developmental delays and to longitudinally assess their specific neurocognitive, behavioural, and quality of life outcomes after treatment for ALL.

Autologous Transplantation Versus Conventional Chemotherapy Alone in Patients with High-Risk Neuroblastoma: The Ontario Experience, 1989-1995

PI: Klaassen, R.

Completed: Children with stage 4 neuroblastoma older than one year of age at time of diagnosis have a low probability of long-term survival. This study compared the outcome of patients who did or did not receive an autologous transplant after achieving a similar response to front-line therapy. An analysis was done of all stage 4 neuroblastoma patients diagnosed at the POGO centres from January 1, 1989 to December 31, 1995.

Childhood Cancer Survivor Study Expansion (CCSS)

PI: Greenberg, M.L.

Ongoing: The Childhood Cancer Survivor Study (CCSS) is a multi-institutional collaborative project, which has successfully established and followed a cohort of 14,370 five-year survivors of childhood cancer diagnosed between 1970 and 1986 and a sample of 3,737 sibling controls. The cohort, derived through 26 participating clinical centres, has collected detailed information on cancer diagnosis, therapy received, and outcomes encompassing over 248,000 person-years of follow-up. The study was initiated to investigate the effects of cancer treatment among the expanding population of long-term survivors of childhood cancer.

The CCSS Expansion aims to expand the existing population to include approximately 14,800 additional five-year survivors diagnosed and treated between 1987 and 1999 at one of the participating CCSS institutes.

Emotion in Music in Children with Cerebellar Tumours

PI: Dennis, M.

Completed: This project studied the emotional, behavioural, and cognitive consequences following treatment of cerebellar tumours in childhood. It is argued that children with this tumour demonstrate impairment that is typically seen in individuals with frontal lobe damage. Research suggests that this occurs because of the cerebellum's shared brain connections with the frontal lobes. Using a scientific approach, the goal of this study was to understand how children with cerebellar tumours are able to identify emotions and exert thought control over emotions.

The researchers used music to test the recognition and control of emotions; compared how thinking abilities affect the ability to control emotions; used Magnetic Resonance Imaging to test differences in

thinking abilities, emotions, and behaviour due to the location of tumour; and compared tests of emotional control to parent ratings of their children's ability to regulate their own thoughts and emotions.

End of Life Care of Children with Brain Tumours

PI: Zelcer, S.

Completed: Brain tumours are the second most common cancer in childhood and have the highest disease-related mortality of all pediatric malignancies. Yet very little is known about the symptoms and suffering these children and their families experience at the end of life. This project was the first study in the literature to explore the end of life experience of children with central nervous system malignancies as a distinct group and to describe the unique issues and challenges these families face.

Health-Related Quality of Life in Survivors of Neuroblastoma Who Have Undergone Megatherapy and Hematopoietic Reconstitution: A National Perspective

PI: Portwine, C.

Ongoing: Neuroblastoma is the most common form of malignant disease in the first year of life and the most prevalent solid tumour in childhood beyond infancy. With conventional multi-modality therapy (a combination of surgery, radiotherapy, and chemotherapy), the survival prospects for patients with advanced disease has changed very little in recent decades. Consequently, it is now common practice to recommend that children with this disease, who have poor prognostic determinants, proceed to megatherapy and hematopoietic reconstitution. However, while it appears that this results in a prolongation of median survival, the burden of morbidity among survivors has not been evaluated. In view of the short-term toxicity and late sequelae of such intensive therapy, it is important to examine the quality of survival, by measuring the comprehensive health status and health-related quality of life of the survivors of this intervention. It is possible that this "cost of cure" will be sufficiently high to prompt a re-examination of the megatherapy treatment strategy.

Health Status and Health-Related Quality of Life in Survivors of Hodgkin's Disease in Childhood and Adolescence: A Population-Based Cross-Sectional Study in Ontario

PI: Barr, R.

Ongoing: Children and adolescents who survive Hodgkin's disease may be faced with a variety of obstacles to optimal quality of life. Although Hodgkin's

disease has an excellent prognosis, the treatment is intense and can be associated with delayed problems affecting many different aspects of function. The purpose of this study is to describe the health and self-perception of a population-based sample of survivors of Hodgkin's disease several years after their treatment is over, and to determine which disease and treatment factors impact health and quality of life in these survivors.

The Impact of Adventure Therapy on the Adolescent's Perspective on Their Cancer

Co-PIs: Baruchel, S. and Stevens, B.

Completed: This study described the impact of "adventure therapy" on the self-concept, hope, social support, spirituality, and coping ability of adolescents with cancer. It was an exploratory ethnographic and qualitative study focused on both patients and caregivers. Existing recorded videotape was used to establish a methodology for evaluation of the impact of future interventions on quality of life.

Is Obesity Associated with Worse Outcome for Children Undergoing Stem Cell Transplantation?

PI: Sung, L.

Completed: Obesity is an increasing problem in Canadian children. The outcomes of obese children with acute myeloid leukemia and acute lymphoblastic leukemia are inferior to normal weight children enrolled onto recent Children's Cancer Study Group protocols. It was unknown whether these findings were valid or invalid. The researchers sought to determine whether these findings were true in another population receiving intensive chemotherapy - namely those undergoing stem cell transplantation (SCT). The objective was to determine whether overweight children undergoing SCT had different 1) 30 and 100 day ICU rates; 2) 30 and 100 day death rates; 3) event-free survival; and 4) overall survival compared to normal weight children.

Late Effects of Bone Tumours and Their Treatment in Childhood: A Comprehensive Health Outcome Study of Long-Term Survivors

Co-PIs: Barrera, M. and Greenberg, M.L.

Ongoing: Bone tumours represent 6% of pediatric malignancies. Sixty percent survival rate is attainable utilizing chemotherapy and limb-salvage surgery. There are major long-term adverse organ system effects that have been described, but this study is evaluating health outcomes, including physical

disability, psychosocial and sexual adjustment, and health-related quality of life (HRQL) in long-term survivors of childhood bone tumours.

The secondary objective of this study is to assess the validity of HRQL measures in the evaluation of long-term survivors of pediatric bone tumours.

Nausea and Vomiting After Infratentorial Surgery: Determination of Incidence, Risk, and Protective Factors

PI: Neufeld, S.

Completed: This study determined the epidemiology of postoperative nausea and vomiting (PONV) for children undergoing infratentorial surgery.

Neurocognitive Late Effects of Treatment for Acute Leukemia in Children with Down Syndrome

PI: Spiegler, B.

Completed: Because survival rates for childhood leukemia have increased dramatically over the past few decades, the neurocognitive late effects of treatment have been of growing research interest. However, outcome studies typically exclude children with pre-existing developmental risk factors, resulting in a lack of data on the health and well-being of these survivors.

The incidence of leukemia is disproportionately higher in children with Down Syndrome (DS); yet, these children had not been studied with respect to neurocognitive outcome. DS provides an ideal model for answering questions of treatment-related neurocognitive morbidity in children with pre-existing developmental risk factors. This study was designed to investigate neurocognitive outcome in DS children who were treated for acute lymphoblastic or non-lymphoblastic leukemia compared to DS children with no history of cancer, and in terms of outcome differences according to type of leukemia.

Optimal Frequency of Echocardiographic Screening for Subclinical Anthracycline-Induced Cardiotoxicity in Survivors of Childhood Cancer

Co-PIs: Abosoudah, I. and Nathan, P.

Ongoing: The optimal frequency of echocardiographic screening in asymptomatic patients who have received anthracycline chemotherapy has not been established. The purpose of this study is to generate such an algorithm based on historical echocardiographic studies performed on patients who had been treated at The Hospital for Sick Children between 1994 and

2003 with therapy including anthracyclines. Secondary outcomes include the exploration of the incidence of cardiac toxicity in this cohort, and a description of the costs associated with routine echocardiographic screening.

Publication Support for Publishing the Proceedings of the International Workshop on Quality of Life of Children with Cancer

PI: Barr, R.

Completed: A proposal was received by the POGO Research Unit and approved for the funding of publication costs related to the Proceedings of the International Workshop on Quality of Life of Children with Cancer.

Skeletal Morbidity in Acute Lymphoblastic Leukemia

PI: Pencharz, P.

Ongoing: Several have reported bone demineralization and fractures following the treatment of acute lymphoblastic leukemia (ALL). This study will determine if the bone mineral loss is disease or treatment determined, whether it is permanent, and to identify the relative risk to survivors of ALL in childhood of fractures of the weight-bearing bones, e.g. lumbar spine, hip, and femur.

Sleep and Fatigue in Children on ALL Maintenance Therapy and Their Parents

PI: Zupanec, S.

Ongoing: This research describes the sleep habits, sleep disturbance, and fatigue of children receiving cancer treatment and their parents, and the relationship of sleep habits and sleep problems to this population. Children and adolescents being treated for cancer frequently experience distressing symptoms such as pain, nausea, and fatigue. Studies have shown that fatigue is the most distressing treatment-related symptom reported by children and adolescents receiving cancer therapy. One factor contributing to fatigue in children on cancer treatment may be sleep disturbance, but more evidence to support this relationship is needed. An examination of children's sleep habits in this population could determine if poor sleep habits or sleep disturbance are contributing to increased levels of fatigue. Similarly, the impact of caring for a child with cancer on sleep and fatigue of parents has not been explored. Sleep problems for parents may contribute to their own increased fatigue levels, which could in turn affect their psychological health. As pediatric cancer care places increasing demands on caregivers, this is an important focus of research so that researchers can begin to develop strategies to improve sleep and

fatigue levels for parents, as well as children, in order to improve their well-being.

Supportive Care Priorities: What Do the Parents Say?

PI: Dupuis, L.

Ongoing: The primary focus of any effort to determine supportive care priorities in pediatric oncology must be the experiences and concerns of the children undergoing treatment. Exploration of the priorities of the children was framed by the opinions of the parents of children with cancer. This information will create the foundation for developing future tools to fully describe the supportive care priorities of the children themselves.