

## **POGO Research Unit Supported Projects (Pillar: Health Services)**

Last modified: November 26, 2009

### **The ACTION Project: Accelerating Cancer Trials Through an Internet-Based Collaborative Community in Ontario**

PI: Jadad, A.

Completed: This was an investigation of the use of the Internet to facilitate enrolment and participation in clinical trials. An interactive program identifying available trials and contact individuals was used.

### **Adolescents and Young Adults with Cancer: Improving Surveillance and Survival**

PI: Barr, R.

Ongoing: More than 50% of adolescents (15 to 17 years old) are treated outside of the POGO network. Analysis of POGONIS data suggests a progressive decrease in proportion treated by each year of age (e.g. 75% for 15 to 16 year olds, <40% for 17 to 18 year olds). There is some evidence that survival is superior in adolescents treated according to pediatric protocols by pediatric oncologists. There may be adverse outcomes from a psychosocial perspective as well. This study examines the epidemiology of adolescent cancer in Ontario, the locus of treatment, the prevalence of enrolment in clinical trials, factors influencing enrolment in clinical trials, and the survival and morbidity of treatment in this group.

### **Assessing the Impact of a Community-Based Pediatric Oncology Nursing Model**

PI: Sussman, J.

Completed: POGO retained the Supportive Cancer Care Research Unit (through McMaster University) to undertake a study to examine the perceived impact of the Pediatric Interlink Nursing Program in March 2005. The Pediatric Interlink Program is unique in a number of aspects and at the time of this project the impact of this program had not been systematically studied. The purpose of this research was to conduct a preliminary study of the Pediatric Interlink Program using qualitative methods to provide a clear understanding of the potential impacts of the Pediatric Interlink model on cancer care and service delivery, from the perspective of the Pediatric Interlink Nurses and key informants working within the pediatric cancer care system of Ontario.

## **Cancer in Young People in Canada (CYP-C)**

Co-PIs: Barr, R., Greenberg, M.L, Klein-Geltnick, J., Mery, L., and Pogony, L.

Ongoing: Cancer in Young People in Canada (CYP-C), formerly the Canadian Childhood Cancer Surveillance & Control Program (CCCSCP), was established in 1992 by Health Canada, as part of the Brighter Futures Initiative. Childhood cancer was identified as a priority domain and POGO was one of the lead organizations invited to participate in the establishment and initiation of the program. The program has four main foci:

1. Treatment and outcomes surveillance
2. Epidemiology
3. Late effects
4. Tissue banks.

The Ontario childhood cancer data required for this national initiative is completed, quality controlled, and supplied to CYP-C by POGO. The late effects study draws on a limited cohort of survivors, data for whom is supplied directly by POGO programs.

## **ChIMES: Understandability and Content Validity**

PI: Sung, L.

Ongoing: Oral mucositis is one of the most debilitating side effects of chemotherapy. The overall goal of this study is to iteratively interview parents and children in order to evaluate the understandability, content validity, and overall acceptability of ChIMES (Children's International Mucositis Evaluation Scale). The researchers will sequentially modify ChIMES based upon the comments and re-evaluate the modified instrument with a new group of parents and children. In total, three iterations are anticipated in order to achieve a satisfactory instrument, which will be ready for further evaluation.

## **Cultural Adaptation, Evaluation of Psychometric Properties of the Psychosocial Assessment Tool (PAT2.0) and Feasibility of Its Use with Families and Children Newly Diagnosed with Cancer in Ontario**

PI: Barrera, M.

Ongoing: It is well documented that the diagnosis and treatment of childhood cancer can be devastating for the child, parents, siblings, and the whole family. In order to adequately identify and intervene with the children and families who are at the greatest risk for psychosocial maladjustment, consistent assessment with well-validated instruments and evidence-based care are

required. Kazak and her colleagues (Kazak et al., 2001; Pai et al., 2008) have developed a psychosocial screen tool, the Psychosocial Assessment Tool (PAT, PAT 2.0), the only instrument of its kind that systematically assesses the psychosocial needs of families whose children are newly diagnosed with cancer.

Given the contextual diversity of cultures that form the Canadian population and the differences in health care systems across countries, one of the aims of this study is to address the external validity of this instrument with a Canadian sample. Because there are no specific health care instruments to systematically track relevant psychosocial actions the treating teams take to address the psychosocial needs of children with malignancies and their families, the investigators developed the Health Care Checklist (HCCL). Its intent is to be used as an outcome measure after its psychometric properties are tested.

### **Developing a Questionnaire to Measure Job Satisfaction and Work-Related Stress and Burnout in Pediatric Oncology Staff**

Co-PIs: Dix, D. and Klassen, A.

Ongoing: To understand more about burnout, psychiatric morbidity, and work-related sources of stress in pediatric oncology, a research team at the University of York (United Kingdom) recently completed a literature review on this topic. The York group recommended that research would benefit from the development of a questionnaire that has separate scales to measure both job satisfaction and work-related stressors. In 2009, the research team in York began a project funded by Cancer Research UK to develop just such a questionnaire.

The York team invited Drs. Klassen and Dix to collaborate in the initial phase of questionnaire development. While the York team conducts qualitative interviews with staff in the UK, Drs. Klassen and Dix will perform qualitative interviews with staff in Canada. It is envisaged that the measure developed will be a 30 to 40 item questionnaire concerned with respondents' experiences within the previous six months and cover everyday hassles, significant stressful events, and aspects of job satisfaction.

### **Developing an Assessment Framework and Indicators for Pediatric Oncology Services in Ontario**

PI: Klassen, A.

Ongoing: The goal of this project is to develop a conceptual framework and a set of health care performance indicators that will enable planners, managers,

providers, and researchers in pediatric oncology to track from a system perspective how well the services are delivered and what relationships exist between key process variables and patient and family outcomes.

### **Development of a Feasible Tool to Measure Oral Mucositis in Children with Cancer**

PI: Sung, L.

Completed: Oral mucositis is a common consequence of chemotherapy, occurring in approximately 40% of standard-dose chemotherapy regimens. It is an important consequence of cancer therapy because it is painful and affects quality of life, may lead to hospitalization for hydration or pain control, and provides a portal of entry for oral microflora.

While several options for the valid measurement of mucositis currently exist for adults undergoing chemotherapy and radiotherapy, at the time of this research there remained a lack of validated instruments for assessing mucositis in children. In order to conduct rigorous studies of mucositis prevention or treatment, appropriate instruments are urgently needed. This study represents an early step toward achieving this important goal.

### **Education, Work Experience and Employment Status of Pediatric Oncology Nurses in Ontario's POGO Network**

Completed: POGO monitors trends in Pediatric Oncology Health Human Resources on an annual basis. Aware of the increasing provincial nursing shortage, POGO's Nursing Committee agreed to participate in a formal exercise to determine the education, experience, and additional demographics of the pediatric oncology nursing workforce in Ontario.

### **Enrolment in Clinical Trials by Adolescents and Young Adults with Cancer: A Prelude to Improving Survival**

PI: Nagel, K.

Ongoing: During the last half century, important advances have been made in the treatment of cancer, with improved survival rates overall. In children (under 15 years) and in older adults (over 29 years), the improvement in survival rates has been steady, but in 15 to 29 year-olds (adolescents and young adults, or AYA) in North America the five-year survival rate has not shown the same improvement.

In recent years, the factors contributing to lack of improvement in survival of AYA in North America were explored by means of discussion groups

and workshops. One very important factor appears to be the low rate of participation by AYA in clinical trials. Most children with cancer in North America are treated in pediatric centres and enrolled in clinical trials. Such enrolment has become the standard of care. In one recent report, only 15% of adolescents with cancer in Ontario were enrolled in co-operative group clinical trials.

A feasibility study is required to refine the eligibility criteria to assemble a population-based cohort of subjects from Ontario, and to determine how best to collect data required to test the hypothesis.

### **A Feasibility Pilot Test Study of Group Therapy for Bereaved Siblings**

PI: Barrera, M.

Ongoing: The ultimate goal of this project is to develop evidence-based interventions that will improve the well-being of all children and their families affected by pediatric cancer. The research team developed a manualized group intervention that aims to foster coping with grief and psychosocial adjustment during the first year after the death of a sibling. Testing the feasibility and effectiveness of this intervention will ensure that these children receive optimal help for better reintegration into their daily lives in the community.

### **Impact of Health Human Resource Funding for Ontario Pediatric Oncology Programs: 1997-2001**

PI: Greenberg, C.

Completed: Between 1998 and 2001, the Ontario Ministry of Health and Long-Term Care (MOHLTC) invested almost \$11 million in new funding in Ontario's childhood cancer system as part of a plan to improve services. The MOHLTC wanted to determine whether this investment produced important changes to make the system more effective and whether there were areas in which further improvement/investment was necessary. The MOHLTC asked POGO, its principal advisor on childhood cancer issues, for assistance in conducting a survey of parental opinion on childhood cancer services; in conducting a survey of hospital staff on how the increased funding was used to meet the needs of children with cancer and their families; and in collecting and analyzing data on the numbers of patients and volumes of service from the five pediatric oncology programs in Ontario, in preparation for review by an expert panel.

## **Incidence and Predictors of Treatment-Related Mortality in Pediatric Acute Leukemia in El Salvador, a Low-Income Country, and Ontario, a High-Income Province**

Co-PIs: Gupta, S. and Sung, L.

- Ongoing: This project aims:
1. To describe the incidence and specific causes of treatment-related mortality (TRM) among pediatric patients with acute myeloid leukemia (AML) and acute lymphoblastic leukemia (ALL) in a low income country, namely El Salvador, and a province within a high income country, namely Ontario.
  2. To determine predictors of TRM among children with ALL and AML in El Salvador and Ontario.

## **Influence of Length of Time to Diagnosis and Treatment on the Survival of Children with Acute Lymphoblastic Leukemia and Hodgkin Disease: A Population-Based Study**

PI: Sung, L.

- Ongoing: This study describes delays in the diagnosis and treatment of pediatric acute lymphoblastic leukemia and Hodgkin's disease in Ontario. The secondary objectives are to determine whether diagnostic and treatment delays are associated with inferior event-free and overall survival and whether presentation on a Friday or Saturday are associated with inferior survival.

## **National Retinoblastoma Strategy Guidelines**

PI: Gallie, B.

- Ongoing: The full project includes:
1. The development of a national disease management program for retinoblastoma that includes: (a) comprehensive published best practice guidelines for managing care to Canadian retinoblastoma families; (b) medical school and continuing medical education modules on retinoblastoma and the best practice guidelines; (c) creation and maintenance of a secure national database to assist in the holding of regular tumour board meetings, insuring a meaningful, fully-informed, consultative process; (d) sustainable governance by a representative board that includes affected families, medical experts, and policy specialists; and (e) a mandate for transparent, accountable management for proven effectiveness and continuous improvement.

2. The establishment of simple quantitative measures for the quality of care to Canadian retinoblastoma families.
3. The implementation of certification for retinoblastoma care centres across Canada.
4. The development of a national implementation strategy.
5. The development of a campaign to increase retinoblastoma awareness in health professions.

### **Outcomes in Adolescents and Young Adults with Bone and Soft Tissue Sarcomas Treated at Pediatric Versus Adult Institutions**

PI: Gupta, A.

Ongoing: Sarcomas are treated at both pediatric and adult institutions. Experience from other tumours suggests that survival outcomes can vary depending on the treating centre. However, there are no studies comparing outcomes of AYA (adolescents and young adults) patients with sarcomas treated at adult versus pediatric cancer centres. In order to address the poor incremental survival in AYA cancer patients, the first step is to understand whether the different types of treatment centres are associated with different outcomes. Furthermore, as there are likely to be many sources of confounding factors, it also is critical to examine the specific impact of therapy, clinical trial registration, and patient-related factors on these outcomes.

### **A Population-Based Study of Medulloblastoma in Ontario**

PI: Hodgson, D.

Ongoing: This study is designed to retrospectively evaluate the impact of such variables as access to care, completeness of resection, delays in therapy, completeness and type of radiation therapy, and other variables on the event-free and overall survival of a population-based cohort of medulloblastoma patients, thereby eliminating the selection factors inherent in a clinical trial confined to select institutions and selected cases. This study draws upon the standardized POGONIS data available for the cohort, and is collecting additional information on survivors of medulloblastoma.

## **Preliminary Investigations into the Relationship Between Cyclosporine Area Under the Curve (AUC) and Acute Graft Versus Host Disease (aGVHD) in Children Undergoing Haematopoietic Stem Cell Transplant**

Co-PIs: Dupuis, L. and Schechter, T.

Ongoing: This inter-disciplinary project will begin investigations into an alternative approach to the prophylaxis of acute graft versus host disease (aGVHD), the strongest predictor of death following allogeneic haematopoietic stem cell transplantation (HSCT). It will serve as the critical foundation to subsequent multi-centre studies designed to elucidate the relationship between cyclosporine area under the curve (AUC) and important HSCT health outcomes, such as aGVHD and nephrotoxicity, as well as investigations of target cyclosporine AUC values, optimal empiric cyclosporine doses for children of different demographic sub-groups (e.g. age, underlying diagnosis), limited sampling strategy validation, and the identification of surrogate single concentrations that are appropriate surrogates for AUC. Overall, this research program will optimize the use of cyclosporine in the context of pediatric HSCT and will thereby improve pediatric HSCT outcomes in Ontario.

## **Steroids and Behaviour in Children Treated for Acute Lymphoblastic Leukemia**

PI: Maude Pound, C.

Ongoing: The purpose of this study is to determine the nature and magnitude of behavioural side effects of steroid treatment in children undergoing therapy for acute lymphoblastic leukemia (ALL), measure the proportion of children affected, and delineate specific risk factors predisposing children to the development of these side effects. Steroids have become an essential part of the successful treatment of childhood ALL. Most attention devoted to steroid toxicity has focused on physical side effects. The majority of parents note physical and behavioural changes in their child during steroid treatment. Mental disturbance induced by glucocorticoid therapy has been well documented in adults. Children receiving steroids for the treatment of ALL have also been noted to have a variety of behavioural problems, although very few objective assessments have been conducted to date.

## **A Summer Camp for Children with Cancer: Campers' Perspectives**

PI: Stevens, B.

Completed: This research contributed knowledge about children's camps from children's perspectives and was based in the concept of therapeutic landscape, described by Gesler to conceptualize how the physical and social environments can affect individuals experiences of health care.

Individual semi-structured interviews were conducted with children immediately following camp. Common themes in the children's perspectives were identified through qualitative analyses.