Cancer in Infancy
POGO Tiny Patients, Huge Challenges.

2017 Multi-Disciplinary Symposium on Childhood Cancer | November 10-11, 2017 | Westin Prince Hotel, Toronto

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Keep the Conversation Going on Twitter!

Ask questions, post comments and network with other Symposium attendees using the official Symposium hashtag:

#POGOSymp17

And don’t forget to follow POGO on Twitter @POGO4Kids
Dear Symposium delegates,

Welcome to the 2017 POGO Symposium! We are thrilled to see a diverse and multi-disciplinary audience represented here today from across Canada and the United States.

The planning committee is comprised of professionals from both tertiary hospitals and POGO Satellite Clinics across Ontario, with representation from medicine, nursing, social work, psychology and pharmacy. We are particularly proud of this year’s program, focused on the theme – Cancer in Infancy: Tiny Patients, Huge Challenges.

Although cancer occurring in infancy is a fortunately rare event, it brings medical and psychosocial problems to the child, healthcare team and the patients’ families that remain among the most challenging in modern medicine. The planning committee set out to design a program that would cover a range of topics that address these challenges in this patient population.

Throughout the symposium are lectures discussing the clinical features and new approaches to management of infants with a wide spectrum of cancers, each given by internationally renowned experts in their respective fields. These are complemented by talks that will explore pain management and supportive care, and unique aspects of drug delivery and metabolism that infants with cancer face. In addition, the program will highlight the unique psychosocial issues that caregivers experience. Further discussions of these issues will happen in the context of interactive workshops on each of the two days.

We have initiated a new aspect to the Symposium program with the inclusion of concurrent Meet-the-Expert round table breakfast sessions on Day 2 of the program. These will offer attendees the opportunity to raise specific questions in a less formal, small group setting. And we have brought back the popular rapid fire poster presentations to highlight the work of the outstanding trainees in pediatric oncology medicine. We hope this program will illuminate the issues that continue to challenge each of our respective disciplines and offer solutions that we might continue to implement to improve our care for these patients.

We would be remiss if we did not mention and thank our many sponsors and exhibitors for supporting this initiative; please be sure to visit their booths and say hello! In addition, we have over 20 posters in the ballroom foyer and surrounding area, representing what’s new in pediatric oncology research. Please be sure to visit all of the poster presenters.

It is the planning committee’s hope that the next two days will provide the opportunity for new and renewed conversations, for the exchange of ideas and for continued learning.

Thank you all for attending...we hope you enjoy the 2017 POGO Symposium!

Sincerely,

David Hodgson, MD, MPH
Co-chair, 2017 POGO Symposium Planning Committee
Medical Director and POGO Chair in Childhood Cancer Control
Pediatric Oncology Group of Ontario (POGO)
Professor, Department of Radiation Oncology
University of Toronto, and Institute for Health Policy, Management and Evaluation

David Malkin, MD, FRCPC
Co-chair, 2017 POGO Symposium Planning Committee
Past Medical Director and POGO Chair in Childhood Cancer Control
Pediatric Oncology Group of Ontario (POGO)
Professor of Pediatrics and Medical Biophysics
University of Toronto
Staff Oncologist, Division of Hematology/Oncology
Senior Scientist, Genetics & Genomic Biology Program, Research Institute
The Hospital for Sick Children
POGO gratefully acknowledges the members of the 2017 Symposium planning committee:

**SARAH ALEXANDER, MD**  
Pediatric Oncologist  
The Hospital for Sick Children, Toronto, ON

**MYLÈNE BASSAL, MDCM, FRCPC**  
Pediatric Hematologist-Oncologist  
Program Leader, Oncology AfterCare Program  
Children’s Hospital of Eastern Ontario, Ottawa, ON

**DANIELLE CATAUDELLA, PsyD, CPsych**  
Psychologist  
Children’s Hospital, London Health Sciences Centre, London, ON

**JULIE DOWLER, RN, BScN**  
Nurse Case Manager  
Children’s Hospital, London Health Sciences Centre, London, ON

**BRUNA DIMONTE, RN, BScN**  
Senior Database Administrator and Co-Privacy Officer  
Pediatric Oncology Group of Ontario (POGO), Toronto, ON

**LISA EGAN-BATES, RN, BScN**  
POGO Pediatric Oncology Satellite Nurse Coordinator  
Southlake Regional Health Centre, Newmarket, ON

**JANET GAMMON, RN, BScN**  
Volunteer  
Pediatric Oncology Group of Ontario (POGO), Toronto, ON

**PAUL GIBSON, MD, FRCPC**  
Medical Officer  
Pediatric Oncology Group of Ontario (POGO), Toronto, ON  
Pediatric Hematologist/Oncologist  
Children’s Hospital, London Health Sciences Centre, London, ON

**CORIN GREENBERG, PhD**  
Chief Executive Officer  
Pediatric Oncology Group of Ontario (POGO), Toronto, ON

**ALAN HUDAK, MD, FRCPC, FAAP**  
Pediatrician, Medical Director, POGO Satellite Program  
Orillia Soldiers’ Memorial Hospital, Orillia, ON

**DONNA JOHNSTON, MD, FRCPC, FAAP**  
Chief, Division of Pediatric Hematology/Oncology  
Children’s Hospital of Eastern Ontario, Ottawa, ON  
Professor, Department of Pediatrics  
University of Ottawa, ON

**HEATHER JONES, MN, NP - Paediatrics**  
Clinical Nurse Specialist/Nurse Practitioner, Haematology/Oncology  
The Hospital for Sick Children, Toronto, ON

**DAVID MALKIN, MD, FRCPC (Chair)**  
Co-chair, 2017 POGO Symposium Planning Committee  
Past Medical Director and POGO Chair in Childhood Cancer Control  
Pediatric Oncology Group of Ontario (POGO), Toronto, ON  
Professor of Pediatrics and Medical Biophysics  
University of Toronto, ON  
Staff Oncologist, Division of Hematology/Oncology  
Senior Scientist, Genetics & Genomic Biology Program, Research Institute  
The Hospital for Sick Children, Toronto, ON

**PAUL NATHAN, MD, MSc, FRCPC**  
Director, AfterCare Program, Division of Haematology/Oncology  
The Hospital for Sick Children, Toronto, ON

**CAROL PORTWINE, MD, FRCPC, PhD**  
Pediatric Hematologist/Oncologist  
McMaster Children’s Hospital, Hamilton, ON  
Associate Professor, Department of Pediatrics  
McMaster University, Hamilton, ON

**PAMELA WATT, RN, BScN, MHSc**  
POGO Interlink Nurse  
The Hospital for Sick Children, Toronto, ON

**JOHN T. WIERNIKOWSKI, PharmD, FiSOPP**  
Clinical Pharmacist  
McMaster Children’s Hospital, Hamilton, ON  
Clinical Assistant Professor, Department of Pediatrics  
McMaster University, Hamilton, ON
Synopsis

The 2017 POGO Multi-Disciplinary Symposium on Childhood Cancer – Cancer in Infancy: Tiny Patients, Huge Challenges – will examine clinical and scientific advances in cancer in infancy and the associated physical, psychosocial and medical issues, as well as focus on relevant resources, tools and strategies for a multi-disciplinary audience.

Pediatric oncologists, nurses, social workers, and other healthcare professionals will enhance their knowledge of cancer in infancy through a series of plenary lectures, interactive workshops, poster presentations and displays, and Meet-the-Expert sessions. The teaching faculty include nationally and internationally recognized experts across a broad range of disciplines. The overarching goal will be for participants to be able to apply what they have learned to their day-to-day practice of pediatric oncology as it applies to infants with cancer, as well as to generate novel questions to be explored in a research setting within their respective disciplines.

Learning Objectives

Participants will be able to:

1. Recognize the core principles necessary for effective identification, monitoring and management of pain in infants, particularly relevant in the context of disease or treatment-related pain in the infant with cancer.

2. Describe the clinical and genetic features of hereditary and sporadic retinoblastoma, and discuss the evolution of therapy for this disease that has occurred over the last 40 years. Participants will be able to discuss the different approaches that have been taken to manage this disease, reflecting on the use of surgery, systemic and local chemotherapy, radiation and laser therapy.

3. Identify the spectrum of malignant and benign tumours that can present prenatally, and describe the indications for fetal surgical intervention along with the potential benefits and complications.

4. Categorize the molecular and immunophenotypes of different forms of infant leukemia and apply this knowledge to defining prognostic implications and rationale for particular therapeutic opportunities through clinical trials.

5. Recognize the signs and symptoms associated with infant brain tumours, describe the common tumour types that occur in this age group, and discuss the major challenges in design and implementation of treatment plans to balance improved survival while mitigating short- and long-term toxicities.

6. Define the developmental milestones that must be monitored in infants with cancer and to recognize when these milestones are not being achieved. The participants will also be able to know what instruments can be applied to measure developmental, psychosocial, and behavioural patterns in a longitudinal manner during and after the infant’s treatment.

7. Know the signs and symptoms associated with presentation of infants with neuroblastoma and describe the molecular, clinical and pathologic tests required to appropriately classify the disease. The participants will also be able to apply this information to develop an appropriate therapy plan, and be able to discuss emerging novel treatment options.

8. Recognize behavioural and psychosocial patterns in parents and siblings of infants with cancer, as well as learn of coping mechanisms that can be applied to alleviate parent/sibling stress that develops as a result of both the diagnosis and treatment of the infant.

9. Describe different methods to maintain a good nutritional balance in infants with cancer and to apply methods to overcome challenges associated with poor nutritional intake as a result of therapy or the disease itself.

10. Recognize the unique infectious complications in infants with cancer related to commensal organisms, as well as to be able to articulate the new guidelines for blood product screening, particularly with respect to cytomegalovirus and other potential pathogen contamination.
Declaration of Potential Conflict of Interest

Speakers have been asked to disclose to the audience any real or apparent conflict(s) of interest that may have direct bearing on the subject matter of this program.

Accreditation

Royal College of Physicians and Surgeons of Canada - Section 1
This event is an Accredited Group Learning Activity (Section 1) as defined by the Maintenance of Certification (MOC) Program of the Royal College of Physicians and Surgeons of Canada, approved by Continuing Professional Development, Faculty of Medicine, University of Toronto. You may claim a maximum of 11.0 hours (credits are automatically calculated).

The American Medical Association - AMA PRA Category 1
Through an agreement between the Royal College of Physicians and Surgeons of Canada and the American Medical Association, physicians may convert Royal College MOC credits to AMA PRA Category 1 Credits™. More information on the process to convert Royal College MOC credit to AMA credit: www.ama-assn.org/go/internationalcme.

Oncology Nursing Society (ONS) - Nursing Accreditation
This continuing education activity was approved by the Oncology Nursing Society, an accredited approver by the American Nurses Credentialing Center’s Commission on Accreditation. These sessions were approved for 10.16 contact hours.

Posters

The 2017 Symposium features over 20 posters related to the care and control of malignant disease in children. Submissions cover all aspects of childhood cancer care and control. Be sure to visit each poster presenter in the Prince foyer.

Evaluations

For the 2017 Symposium evaluations will be completed online. You should have received an email with a link to the evaluation survey. Your feedback is extremely important and valuable to assisting with the planning of future symposia. Please take some time to complete the evaluation within a week after the Symposium. Upon completion of the survey, you will receive your certificate of accreditation.
Program, Day 1 - Friday, November 10, 2017

7:00 am - 8:00 am  •  **Registration & Breakfast**

8:00 am - 8:10  •  **Opening Remarks**  
*David Hodgson, MD, MPH; David Malkin, MD, FRCP*

8:10 am - 8:30  
**Tribute to Dr. Corin Greenberg, POGO's One and Only CEO: A Tale of 4 Decades**  
*Ronald Barr, MD, MPH; Sandy Nuttall, PhD; Janet Gammon, RN, BScN; Paul Gibson, MD, FRCP*

8:30 am - 9:15 am  
**The Complex Nature of Neuroblastoma in Infancy**  
*Rochelle Bagatell, MD*

9:15 am - 10:00 am  
**Infant Acute Lymphoblastic Leukemia: The Challenges and the Promise**  
*Lewis Silverman, MD*

10:00 am - 10:15 am  •  **Morning Break**

10:15 am - 11:00 am  
**Developmental Outcomes for Infants with Cancer: Understudied and Underserved?**  
*Melissa Alderfer, PhD*

11:00 am - 11:45 am  
**Retinoblastoma: An Eye to the Future**  
*Furqan Shaikh, MD, MSc, FRCP*

11:45 am - 12:15 pm  
**Poster Presentations**

1. **Emotion Recognition in Pediatric Brain Tumour Patients: Viewing Patterns and White Matter Structure**  
*Iska Moxon-Emre, MSc, MA, PhD candidate (psychology), University of Toronto, The Hospital for Sick Children, Pediatric Oncology Group of Ontario (POGO), Toronto, ON*

2. **Not Everyone Was Nice: Bullying During Pediatric Cancer Treatment**  
*Monica Molinaro, PhD Student, Western University, London, ON*

3. **“Tell It As It Is”: How Sisom Prompts Children to Discuss Their Feelings, Express Emotions, and Reflect on Their Illness Experiences**  
*Bianca Sarkis, MD, CM Candidate, McGill University, Montreal, QC*

4. **Assessment of Respiratory Disability in Adult Survivors of Childhood Cancer**  
*Mylène Bassal, MDCM, FRCP, Pediatric Hematologist-Oncologist, Program Leader, Oncology AfterCare Program, Children’s Hospital of Eastern Ontario, Ottawa, ON*

5. **Using Phone Apps to Improve Medication Adherence in an Outpatient Pediatric Oncology Clinic**  
*Rana Khafagy, PharmD, RPh, ACPR Candidate, The Hospital for Sick Children, Toronto, ON*

6. **Childhood Cancer as the First Presentation of a Cancer Predisposition Syndrome: Report from the MIPOGG Study and the SickKids Cancer Genetics Database**  
*Catherine Goudie, MD, Cancer Genetics Fellow, The Hospital for Sick Children, Toronto, ON*

7. **Hypoglyemia in Pediatric Patients Being Treated for Acute Lymphoblastic Leukemia at the Children’s Hospital of Eastern Ontario**  
*Mary-Pat Schlosser, MD, Pediatric Hematology/Oncology, Children’s Hospital of Eastern Ontario, Ottawa, ON*

8. **An Exploratory Analysis of Physical Activity and Risk-Taking Behaviours on Modifiable Aging-Related Risk**
Factors Among Survivors of Childhood Cancer  
Natalie Sloof, MD Candidate, Western University, London, ON

Giancarlo Di Giuseppe, MPH, Research Associate/Analyst, Pediatric Oncology Group of Ontario (POGO), Toronto, ON

10. Reduced Use of Parenteral Nutrition in a Paediatric Hematopoietic Stem Cell Transplant Population  
Rivanna Stuhler, BASc, RD, Clinical Dietitian, Blood and Marrow Transplant Program, The Hospital for Sick Children, Toronto, ON

12:15 pm – 1:15 pm • Lunch (Poster Boards on Display)

1:15 pm – 2:00 pm

Infant Brain Tumours: Is There a Ray of Hope?  
Maryam Fouladi, MD

2:00 pm – 3:00 pm

Concurrent Workshops

Workshop A: The Art and Science of Keeping Infants with Cancer Well-Nourished  
Laura Collins, RD; Debbie O’Connor, PhD, RD  
North York Room

Workshop B: Measuring, Managing and Mitigating Cancer and Treatment Pain in Infants  
Anna Taddio, PhD; Jason Thomas Maynes, PhD, MD  
Crown Room

Workshop C: Developmental and Psychosocial Aspects of Caring for Infants with Cancer  
Melissa Alderfer, PhD; Vanessa Burgess, MSc OT, OT Reg. (Ont.)  
Prince (Main) Room

Workshop D: A Fine Balance: Infection Control in Infants  
Michelle Science, MD, MSc; Dana Devine, PhD  
Princess Room

3:00 pm – 3:45 pm • Dedicated Poster Viewing Time / Coffee

3:45 pm – 4:30 pm

BRIGHT IDEAS: An Evidence-Based Approach to Alleviate Distress in Caregivers of Children Recently Diagnosed with Cancer  
Robert B. Noll, PhD

4:30 pm – 5:15 pm

In Utero Surgery: Exploring New Dimensions for Infants  
Jacob Langer, MD
Program, Day 2 - Saturday, November 11, 2017

7:45 am – 8:55 am  •  Registration & Continental Breakfast

8:15 am – 8:55 am

Concurrent Round Tables

Meet The Expert - Infant Brain Tumors with Maryam Fouladi, MD, Cincinnati Children’s Brain Tumor Center
Maryam Fouladi, MD
North York Room

Meet The Expert – Stress on Parents/Siblings with Robert Noll, PhD, University of Pittsburgh and Children’s Hospital of Pittsburgh
Robert Noll, PhD
Prince (Main) Room

Meet The Expert – Infant Acute Lymphoblastic Leukemia with Lewis Silverman, MD, Dana-Farber Cancer Institute/Boston Children’s Hospital
Lewis Silverman, MD
Crown Room

Meet The Expert – Chemotherapy and Infancy with Clinton Stewart, PharmD, St. Jude Children’s Research Hospital
Clinton Stewart, PharmD
Princess Room

8:55 am – 9:00 am  •  Opening Remarks

9:00 am – 9:45 am

Pain in Infants with Cancer: How Can We Do Better?
Anna Taddio, PhD

9:45 am – 10:45 am

Concurrent Workshops

Workshop A: The Art and Science of Keeping Infants with Cancer Well-Nourished
Laura Collins, RD; Debbie O’Connor, PhD, RD
North York Room

Workshop B: Measuring, Managing and Mitigating Cancer and Treatment Pain in Infants
Anna Taddio, PhD; Jason Thomas Maynes, PhD, MD
Crown Room

Workshop C: Developmental and Psychosocial Aspects of Caring for Infants with Cancer
Melissa Alderfer, PhD; Vanessa Burgess, MSc OT, OT Reg. (Ont.)
Prince (Main) Room

Workshop D: A Fine Balance: Infection Control in Infants
Michelle Science, MD, MSc; Dana Devine, PhD
Princess Room
10:45 am – 11:00 am  • Dedicated Poster Viewing / Coffee

11:00 am – 11:05 am  • Remembrance Day: Moment of Silence

11:05 am – 11:50 am
Anti-Cancer Drug Pharmacology in Infants and Very Young Children
Clinton Stewart, PharmD

11:50 pm – 12:35 pm
Rare Tumours of Infancy
Rajkumar Venkatramani, MD

12:35 pm – 1:30 pm  • Closing Remarks and Lunch
David Hodgson, MD, MPH; David Malkin, MD, FRCPC

POGO wishes to thank the Ontario Ministry of Health & Long-Term Care and our sponsors for their generous support of the 2017 POGO Multi-Disciplinary Symposium on Childhood Cancer

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Faculty

Melissa A. Alderfer, PhD
Senior Research Scientist, The Center for Healthcare Delivery Sciences
Nemours Children’s Health System/Alfred I. duPont Hospital for Children, Wilmington, DE
Associate Professor of Pediatrics
Sidney Kimmel Medical College at Thomas Jefferson University, Philadelphia, PA

Dr. Alderfer completed a doctorate degree in clinical psychology at the University of Utah and a post-doctoral fellowship in pediatric psychology in the Division of Oncology at The Children’s Hospital of Philadelphia (CHOP). After fellowship, she stayed on in the Division of Oncology at CHOP and joined the standing faculty in the Department Pediatrics at Perelman School of Medicine at the University of Pennsylvania. She rose to the level of associate professor before transitioning in 2013 to her current position as a senior research scientist in the Center for Healthcare Delivery Sciences within Nemours Children’s Health System. Under the broad umbrella of healthcare delivery science, her program of research focuses on how childhood chronic illness impacts families, how families adapt and learn to manage illness and the healthcare system, and how we can intervene to improve the experience. Her research has been funded by the National Institutes of Health, American Cancer Society, and various other cancer foundations. She currently has 92 peer-reviewed manuscripts and chapters.

Rochelle Bagatell, MD
Associate Professor of Pediatrics, Solid Tumor Section Chief, Division of Oncology
Children’s Hospital of Philadelphia, University of Pennsylvania, Philadelphia, PA

Dr. Bagatell is a pediatric oncologist with an interest in extracranial solid tumours. She is the solid tumor section chief at The Children’s Hospital of Philadelphia where she leads a multi-disciplinary team committed to improving outcomes for children with high-risk solid tumours. In addition, she leads clinical research efforts designed to critically evaluate current therapies for children with high-risk and relapsed neuroblastoma, and is committed to conducting studies of new therapies for this population. She is the vice chair of the Children’s Oncology Group (COG) Neuroblastoma Disease Committee, and is chair of the upcoming COG Phase 3 trial for children with newly diagnosed high-risk disease.

Vanessa Burgess, MSc OT, OT Reg. (Ont.)
Occupational Therapist, Pediatric Oncology
McMaster Children’s Hospital, Hamilton Health Sciences Centre, Hamilton, ON
Preceptor/Lecturer, Occupational Therapy Program
McMaster University, Hamilton, ON

Vanessa Burgess completed a Master of Science in Occupational Therapy at the University of Toronto following the completion of her undergraduate degree. She practiced at ErinoakKids Children’s Treatment Centre, conducting community rehabilitation with pediatric clients with developmental disabilities, neurological impairments, multiple disabilities, complex disabilities and sensory processing difficulties. Here she focused on oral motor and feeding skills, activities of daily living, fine motor skills and written productivity, and sensory processing. She continued her community practice experience at a private practice, focusing on oral motor and feeding skills and sensory processing with clients with a wide variety of diagnoses and undiagnosed issues. Vanessa has been practicing in oncology at McMaster Children’s Hospital for the past eight years. She is part of the multi-disciplinary team on the inpatient ward, outpatient active therapy clinic and neuro-oncology clinic. Her focus includes oral feeding and dysphagia including videofluoroscopic swallow studies, infant development, activities of daily living, functional mobility and equipment, fine motor skills and school participation. She enjoys working directly with patients and their families to empower them to overcome barriers in their everyday lives throughout their cancer journey.

Laura Collins, RD
Registered Dietitian in Pediatric Oncology
McMaster Children’s Hospital, Hamilton Health Sciences Centre, Hamilton, ON

Laura Collins graduated with concurrent degrees from the University of Western Ontario with a BSc Human Nutrition and a BA Kinesiology. She successfully completed her dietetic internship at the Hamilton Health Sciences Centre in 2000 and accepted a full-time position in pediatric oncology where she continues to practice as a clinical registered dietitian in the acute care setting. She has a particular interest in nutritional assessment, proactive enteral feeding lectures, CAM investigations and enteral
nutrition guideline development. Laura also provides education about the importance of optimizing nutrition during and after cancer therapy to learners, including dietetic interns and medical trainees.

Dana Devine, PhD  
Chief Medical & Scientific Officer  
Canadian Blood Services, Ottawa, ON  
Professor of Pathology & Laboratory Medicine  
University of British Columbia, Vancouver, BC

Dana Devine is currently the chief medical & scientific officer at Canadian Blood Services. She is also professor of pathology and laboratory medicine at the University of British Columbia, and a founding member of the university’s Centre for Blood Research. She is the editor-in-chief of the blood transfusion journal Vox Sanguinis. In service to the transfusion community, Dr. Devine is a member of numerous advisory committees and boards for such organizations as American Red Cross, Blood Systems Research Institute, Bloodworks Northwest, the New York Blood Center and the Australian Red Cross Blood Service. Dr. Devine completed her research training at Duke University in North Carolina where she obtained her PhD degree. She has a longstanding research career in blood products, transfusion medicine, platelet biology, complement biochemistry, and coagulation. Her current research is funded by the Burroughs Wellcome Fund, Canadian Blood Services, Canadian Institutes of Health Research (CIHR) and the National Science and Engineering Research Council (NSERC). She is a fellow of the Canadian Academy of Health Sciences.

Maryam Fouladi, MD, MSc, FRCP  
Marjory J. Johnson, Chair of Brain Tumor Translational Research  
Professor of Clinical Pediatrics  
Medical Director, Brain Tumor Center  
University of Cincinnati, Cincinnati, OH  
Chair, CNS Committee, Children’s Oncology Group  
Cancer and Blood Diseases Institute  
Cincinnati Children’s Hospital Medical Center, Cincinnati, OH

Maryam Fouladi joined the Cancer and Blood Diseases Institute (CBDI) in 2008 as an associate professor and medical director for Cincinnati Children’s Neuro-Oncology Program, comprising a state-of-the-art multi-disciplinary program for children and young adults with central nervous system malignancies, and a large national referral base and a tightly integrated bench, translational and clinical research enterprise with particular strengths in tumour biology, cell signaling/target identification, and the clinical development of new agents. She is currently a full professor and the Marjory J. Johnson Endowed Chair in Brain Tumor Translational Research. From 2012-2016, she chaired the Pediatric Brain Tumor Consortium. She has chaired multiple national and institutional phase I, II and III clinical trials of new agents for CNS malignancies through Children’s Oncology Group (COG), Pediatric Brain Tumor Consortium (PBTC), Collaborative Ependymoma Research Network (CERN) and local studies. In September 2016, she became Chair of the CNS Committee for the Children’s Oncology Group. She has extensive experience in the development and execution of trials, translational research and helping guide the agenda for pediatric neuro-oncology clinical trials nationally.

Jacob C. Langer, MD  
Professor of Surgery  
University of Toronto, Toronto, ON  
Attending Pediatric Surgeon  
The Hospital for Sick Children, Toronto, ON

Dr. Jacob C. Langer was educated and trained at the University of Toronto and The Hospital for Sick Children in Toronto. He did research fellowships at the University of California, San Francisco, and McMaster University, funded by the Ontario Ministry of Health, the Medical Research Council of Canada and the McLaughlin Foundation.

Dr. Langer was assistant professor of surgery and pediatrics at McMaster University and a pediatric surgeon at the Children’s Hospital at Chedoke-McMaster from 1989 to 1992. He then moved to St. Louis and became associate professor of surgery and pediatrics at Washington University and a pediatric surgeon at St. Louis Children’s Hospital from 1992 to 1999. He came back to Canada in 1999 to become professor of surgery at the University of Toronto, and chief of the division of general and thoracic surgery at The Hospital for Sick Children, a position he held until 2012. He was also the inaugural holder of the Robert M. Filler Chair in Pediatric Surgery. Dr. Langer has travelled widely to operate, and to lecture on a variety of topics in pediatric surgery. He has received many prestigious honours, is widely published in peer-reviewed journals, and has authored many book chapters on a variety of subjects.

Jason Thomas Maynes, PhD, MD  
Wasser Chair in Anesthesia and Pain Medicine  
Associate Chief of Perioperative Services, Research  
Director of Research, Anesthesia and Pain Medicine  
Scientist, Division of Molecular Medicine  
The Hospital for Sick Children, Toronto, ON

Jason Maynes, PhD, MD, is the associate chief of perioperative services (research), director of research for anesthesia and pain medicine, and an anesthesiologist at The Hospital for Sick Children. He is the holder of the Wasser Chair in Anesthesia and Pain Medicine. He has a doctorate in biophysics and completed clinical training...
Robert B. Noll, PhD
Pediatric Psychologist
Children’s Hospital of Pittsburgh, Pittsburgh, PA
Professor of Pediatrics, Psychiatry, and Psychology
University of Pittsburgh School of Medicine, Pittsburgh, PA

Robert Noll completed a doctorate in clinical psychology and did his clinical specialty training in pediatric psychology at Michigan State University following completion of his undergraduate degree and five years of military service as a naval aviator. Upon completion of his doctorate, he accepted a faculty position at Michigan State University in the Department of Pediatrics and Human Development. Dr. Noll subsequently went to Cincinnati Children’s Hospital Medical Center where he served as the director of psychosocial services in the division of hematology/oncology. From 2004-2011, he served as the medical director for behavioral health, and division director of developmental and behavioral pediatrics at Children’s Hospital of Pittsburgh. He served from 2006-2016 as chair of the Behavioral Science Committee within the Children’s Oncology Group. He has published extensively on psychosocial issues in pediatric oncology, notably documenting psychosocial difficulties for caregivers and subsequently developing evidence-based interventions. He is the author of more than 150 peer-reviewed publications and his pediatric oncology research has received funding from the National Cancer Institute, Alex’s Lemonade Stand, St. Baldrick’s Foundation and the American Cancer Society.

Deborah L. O’Connor, PhD, RD
Professor, Department of Nutritional Sciences
University of Toronto, Toronto, ON
Senior Associate Scientist
Translation Medicine Program, Research Institute
The Hospital for Sick Children, Toronto, ON
Scientific Associate Staff, Department of Pediatrics
Mount Sinai Hospital, Toronto, ON

Dr. Deborah O’Connor (PhD, RD) is a professor in the Department of Nutritional Sciences at the University of Toronto where she holds a Chair in Vitamin Research in Human Milk and Development. She also holds scientific appointments at The Hospital for Sick Children (SickKids) and Mount Sinai Hospital. Dr. O’Connor served as the Director of Clinical Dietetics and Breastfeeding Support at SickKids from 2000 to 2012 and then as associate chief of academic and professional practice until 2013. Dr. O’Connor’s research career has focused on maternal and infant nutrition and she has published extensively in the area of the nutritional requirements of pregnant and lactating women, children, and strategies to support the provision of human milk to vulnerable infants. Dr. O’Connor has received numerous awards including the 2015 Khursheed Jeejeebhoy Award for best application of research to clinical practice from the Canadian Nutrition Society. She currently serves as co-chair of the Advisory Committee for the Rogers Hixon Ontario Human Donor Milk Bank, and was co-chair of the Canadian Society of Obstetricians and Gynecologists’ Nutrition Working Group that recently published their first national female nutrition practice guidelines.

Michelle Science, MD, MSc, FRCPC
Infectious Disease Physician
Medical Advisor, Infection Prevention and Control
Medical Co-Lead, Antimicrobial Stewardship Program
The Hospital for Sick Children, Toronto, ON

Michelle Science is an academic clinician in the Division of Infectious Diseases at SickKids Hospital and an assistant professor at the University of Toronto. Since 2012, she has been the medical advisor for Infection Prevention and Control (IPAC) and the co-lead of the Antimicrobial Stewardship Program (ASP) at SickKids. More recently, she joined Public Health Ontario as a consulting IPAC physician.

Furqan Shaikh, MD, MSc, FRCP
Staff Oncologist, Solid Tumour Section, Haematology/Oncology
Project Investigator, CHES, Research Institute
Director, Fellow’s Continuity Clinic
The Hospital for Sick Children, Toronto, ON
Assistant Professor, Paediatrics
University of Toronto, Toronto, ON
Dr. Furqan Shaikh received his medical degree from Queen’s University in 2003. He completed his pediatrics residency at the Children’s Hospital of Eastern Ontario in Ottawa and a fellowship in Paediatric Haematology/Oncology at The Hospital for Sick Children in Toronto. Dr. Shaikh is a paediatric oncologist in the Solid Tumour Program within the Division of Haematology/Oncology at The Hospital for Sick Children, and an assistant professor of paediatrics at the University of Toronto. He is a member of the Germ Cell Tumor subcommittee of the Children’s Oncology Group.

Lewis B. Silverman, MD
Director, Pediatric Hematologic Malignancy Service
Dana-Farber Cancer Institute and Boston Children’s Hospital, Boston, MA
Associate Professor of Pediatrics
Harvard Medical School, Boston, MA

Lewis Silverman received his MD degree at Harvard Medical School (1991), and subsequently completed pediatric residency training at Boston Children’s Hospital (1994) and fellowship in pediatric hematology-oncology at Dana-Farber Cancer Institute/Boston Children’s Hospital (1997). After fellowship, he joined the faculty of the Pediatric Hematology Oncology Division at Boston Children's/Dana-Farber, where he has focused his clinical and research efforts on childhood leukemia.

Dr. Silverman leads the DFCI ALL Consortium, a US-Canadian collaborative group conducting clinical trials in childhood ALL. He also holds leadership positions in the Children’s Oncology Group and Therapeutic Advances in Childhood Leukemia and Lymphoma (TACL) Consortium. He is the author of over 100 original articles, as well as 20 reviews and chapters, and also serves on the editorial board of the NCI Pediatric Oncology PDQ website, which provides evidence-based online content on childhood cancers for healthcare professionals.

Clinton Stewart, PharmD
Clinical Pharmacist
Member, Pharmaceutical Department
St. Jude Children’s Research Hospital, Memphis, TN

Dr. Clinton Stewart completed his Doctor of Pharmacy at the University of Tennessee Health Science Center, Memphis. After completing a postdoctoral fellowship at St. Jude under the mentorship of Dr. William E. Evans, Dr. Stewart joined the University of Tennessee College of Pharmacy faculty as an assistant professor and was promoted to associate professor. In 1991, he joined the St. Jude faculty as an assistant member (equivalent of assistant professor) and has moved through the ranks to full member (equivalent of full professor).

He is an active member of the American Society of Clinical Oncology and the American Association of Cancer Research. His research efforts are focused in the area of pediatric clinical pharmacology, addressing clinically relevant problems of cancer therapeutics in infants and children. Current research efforts include the use of preclinical models to enhance design of clinical trials of new agents in children with cancer, and the use of pharmacokinetics (PK) and pharmacodynamics (PD) to optimize drug exposure in children with cancer. Dr. Stewart has authored or co-authored more than 275 peer-reviewed articles and book chapters. He is presently the co-chair of the Pharmacology Committee of the National Institutes of Health-funded Pediatric Brain Tumor Consortium.

Anna Taddio, PhD
Full Professor, Leslie Dan Faculty of Pharmacy
Senior Associate Scientist
The Hospital for Sick Children, Toronto, ON

Anna Taddio is a professor of pharmacy at the University of Toronto, and senior associate scientist at SickKids. Her program of research examines: (1) the short-term and long-term effects of pain in children; (2) the effectiveness and safety of pain management interventions; and (3) evidence-based practice and implementation research. Dr. Taddio currently leads a national interdisciplinary team, Help Eliminate Pain in Kids and Adults (HELPinKids&Adults), investigating and promoting evidence-based pain management during vaccination. She has authored over 200 scientific papers and book chapters, and is the recipient of numerous awards recognizing her scholarly and advocacy achievements in pediatric pain.

Rajkumar Venkatramani, MD, MS, FAAP
Associate Professor Department of Pediatrics
Baylor College of Medicine, Houston, TX
Texas Children’s Cancer Center, Texas Children’s Hospital, Houston, TX

Dr. Venkatramani completed his pediatric training at King’s College in London, and obtained membership in the Royal College of Paediatrics and Child Health. He completed a fellowship in pediatric hematology oncology at Children’s Hospital, Los Angeles. He is currently the director of the Rare Tumors Program and Thyroid Cancer Program at Texas Children's Hospital in Houston, Texas. He is the author of more than 50 original publications, multiple reviews and book chapters, and is a member of the Pediatric Blood and Cancer editorial board and PREP Hematology/Oncology editorial board.
ADDING INSULT TO INJURY: EFFECTS OF CRANIAL RADIATION TREATMENT ON STRUCTURAL VOLUMES AND ASSOCIATED MEMORY PERFORMANCE IN BRAIN TUMOUR SURVIVORS

Ayoub R\textsuperscript{1,2}, Beera K\textsuperscript{1}, Ashley Ferkul\textsuperscript{1}, Skocic J\textsuperscript{1}, de Medeiros C\textsuperscript{1}, Bouffet E\textsuperscript{1,2}, Mabbott D\textsuperscript{1,2}
\textsuperscript{1}Peter Gilgan Center for Research and Learning, Toronto, ON
\textsuperscript{2}University of Toronto, Toronto, ON

Objective: Brain and central nervous system tumours are the third most common cancers among children (Nguyen et al. 2006). Children with malignant tumours in these regions are treated with surgery, cranial radiation treatment (CRT) and/or chemotherapy (Nguyen et al. 2006). Although this combination of therapy is curative, it also results in cognitive, physical, psychological, and neurological deficits (Nguyen et al. 2006). CRT is particularly associated with insult to the brain, including decreases in volume and behavioural deficits. (Mabbott et al. 2006; Scantlebury et al. 2016). Much less is known about the relative impact of different doses and fields of CRT, including focal (FR) vs. craniospinal (CSR) radiation, and their differential impact on brain volume and cognitive outcome - including memory. The primary aim of this study is to investigate whether treatment with FR vs. CSR results in less severe volume decreases in regions of interest (ROI). The secondary aim is to analyze whether memory differences are present between treatment groups. Lastly, the exploratory aim is to observe whether there is a correlation between volume and memory performance across all participants.

Methods: 24 paediatric brain tumour survivors treated with either FR (n=7) or CSR (n=17) were scanned using a 3T/1.5T MRI scanner. T1-weighted images were processed using FreeSurfer for volume analyses. ROIs included the putamen, thalamus, hippocampus, and corpus callosum (CC). Images were processed through a cortical parcellation technique in which neuroanatomical labels were generated to each location on a cortical surface model. From there, volumes of each ROI were obtained. In addition, short and long-term memory tests were administered to participants. Using R, two linear analyses were performed to analyze differences in volume and memory performance as a function of treatment group. Both analyses were false discovery rate (FDR)-corrected for multiple comparisons. In addition, a partial least squares regression (PLS-R) model was used to examine the relations between brain volumes and memory performance.

Results: There was a trend towards significance for difference in mean volume between treatment groups in the left putamen (q = 0.0675), central CC (q = 0.0675) and mid-anterior CC (q = 0.1651). Mean volume of CC structures was higher for patients treated with FR (FR = 383.6 mm\textsuperscript{3}, CSR = 370.3 mm\textsuperscript{3}), while mean volume in the putamen was higher in patients treated with CSR (FR = 4250.5 mm\textsuperscript{3}, CSR = 4358.1 mm\textsuperscript{3}). Memory tests showed no significant differences across treatment group. Lastly, based on PLS-R analysis, individual differences in volumes across all 24 participants accounted for 91% of the variance in memory scores.

Conclusion: No significant differences in volume loss were present in the putamen, thalamus, hippocampus, and CC across treatment groups. Furthermore, memory scores were not significantly different across treatment groups, demonstrating that the cognitive capabilities of this population were similar post-treatment. Together, these findings indicate that CRT produced homogeneous effects on this patient population. It should be noted that participants treated with CSR treatment were also given a focal boost, as part of their protocol. This meant that all participants were given a localized boost, sparing significant white matter in the process. This may have caused the similarities in mean volume and memory performance metrics. Lastly, based on the PLS-R analysis, fluctuations within brain volume may be a good predictor of memory performance for patients treated with CRT.
AN EXPLORATORY ANALYSIS OF PHYSICAL ACTIVITY AND RISK-TAKING BEHAVIOURS ON MODIFIABLE AGING-RELATED RISK FACTORS AMONG SURVIVORS OF CHILDHOOD CANCER

Sloof N*¹, Hendershot E¹, Griffin M¹, Anderson L¹, Marjerrison S¹.
¹McMaster University, Hamilton, ON

Objective: By age 45, more than 80% of survivors of cancer in childhood (SCC) have serious chronic health conditions (Bhakta et al., 2017; Hudson, Ness, Gurney, & et al., 2013). The literature remains unclear whether lifestyle factors, including physical activity (PA), are related to long-term health outcomes. The objective of this study was to examine the relationship between PA and established late effects of treatment in adult survivors of childhood cancer.

Method: A retrospective chart review including all adult SCC currently enrolled in the McMaster Aftercare program was performed. Information on diagnosis, treatment, PA and other lifestyle behaviours, as well as physiologic measures was abstracted. Self-reported PA was translated into a standard Leisure Score Index for comparison (Amireault & Godin, 2015). Univariate associations were explored for all factors with physiologic plausibility. Predictors of established late effects of cancer therapy were examined using logistic regression on multivariable models built with known risk factors determined a priori, and significant predictors from univariate analyses.

Results: Of the 262 patients included, only 43% reported behaviour that met PA recommendations, and 27% indicated no PA participation whatsoever. In multivariable analysis, significant independent associations were shown between low bone density (BMD) and no PA (P=0.02), high blood pressure (P=0.02), and ideal body mass index (BMI) (P=0.01). High BMI was associated with no PA (P=0.01), cranial radiation (P=0.05), and normal BMD (P<0.01). Increased fat percentage was associated with cranial radiation (P=0.05) and female sex (P<0.01), as well as high BMI (<0.01). High blood pressure was associated with binge drinking (P=0.01) and high BMI (P=0.03), while accounting for age (<0.01). Left ventricular ejection fraction was only significantly associated with known risk factors, including age (P=0.02), doxorubicin dose >300mg/m2 (P=0.04), and chest radiotherapy (P=0.03).

Conclusion: Despite ongoing healthy active living counseling, only 43% of SCC in our clinic meet PA guidelines. We identified novel independent associations between PA and BMD and BMI shown to be more strongly associated with these markers of health than many established predictive treatment and lifestyle-related factors.

References:
ASSESSMENT OF RESPIRATORY DISABILITY IN ADULT SURVIVORS OF CHILDHOOD CANCER

Mylène Bassal MDCM*, Eden Story MD MA1, Lynn Chang MD MSc2, Vimoj Nair MBBS MD2, Nha Voduc MD2, Dhenuka Radhakrishnan MD MSc2, Joe Reisman MD MBA1
1Children’s Hospital of Eastern Ontario (CHEO), Ottawa, Ontario, Canada
2The Ottawa Hospital, Ottawa, Ontario, Canada

Objectives: As childhood cancer survival approaches 85%, it is increasingly recognized that childhood cancer survivors (CCS) are at risk for long-term therapy-related complications. Data suggest that pulmonary function test (PFT) abnormalities occur in as many as 84.1% of CCS. Our aim was to assess the prevalence and nature of respiratory abnormalities in adult CCS and to correlate these abnormalities with therapeutic exposures and health behaviors.

Methods: Patients who received pulmonary toxic therapy routinely undergo PFTs at their first visit to the POGO AfterCare clinic in Ottawa, Canada. We conducted a retrospective review of all patients seen in clinic from August 2015 until December 2016. PFT results, treatment exposures and health habits were documented. We used NHANES-III prediction equations for PFT interpretation, with expiratory flows and lung volumes of ≥80% predicted as cutoffs for normal.

Results: Of a total of 200 patients, 48 received pulmonary toxic therapy and 38 underwent PFTs. Mean age at the time of PFT was 28.8 years (18.5-57.5 years) and the mean time from diagnosis was 17.4 years (3.4-47.5 years). Although no patients reported respiratory symptoms, 42% (16/38) demonstrated a mild restrictive ventilatory defect, 11% (4/38) had mild airflow obstruction, 18% (7/38) had an isolated reduction in diffusion capacity and 1 patient had a moderate mixed obstructive/restrictive abnormality and. Only 26% (10/38) had normal lung function. Of those with restrictive defects, all received radiation and 50% were also exposed to pulmonary toxic chemotherapy. All patients with obstructive defects received radiation therapy in combination with bleomycin. Tobacco or marijuana use was reported in 26% (10/38) of the cohort, and in 29% (8/28) of those with PFT abnormalities.

Conclusion: PFT abnormalities are common among adult CCS who received pulmonary toxic therapy. Studies evaluating the change in pulmonary function abnormalities over time and their correlation to cardiopulmonary exercise testing and lung imaging are required to inform the health impact on these survivors.
BIRTH WEIGHT PREDICTS BODY MASS IN CHILDREN WHO SURVIVE BRAIN TUMORS: PRELIMINARY DATA FROM A CROSS-SECTIONAL STUDY

Kuan-Wen Wang¹,²,³, E. Danielle Sims*¹,²,³, Russell J. de Souza³,⁴, Adam Fleming¹,³,⁵, Donna L. Johnston⁶, Shayna M. Zelcer⁷, Shahrad Rod Rassekh⁸, Sarah Burrow⁹, Lehana Thabane⁴,¹⁰,¹¹,¹² and M. Constantine Samaan¹,²,³,⁴*

¹Department of Pediatrics, McMaster University, Hamilton, ON
²Division of Pediatric Endocrinology, McMaster Children’s Hospital, Hamilton, ON
³Medical Sciences Graduate Program, McMaster University, Hamilton, ON
⁴Department of Health Research Methods, Evidence and Impact, McMaster University, Hamilton, ON
⁵Division of Pediatric Hematology/Oncology, McMaster Children’s Hospital, Hamilton, ON
⁶Division of Pediatric Hematology/Oncology, Children’s Hospital of Eastern ON, Ottawa, ON
⁷Pediatric Hematology Oncology, Children's Hospital, London Health Sciences Center, London, ON
⁸Division of Pediatric Hematology/Oncology/BMT, Department of Pediatrics, British Columbia’s Children’s Hospital, Vancouver, BC
⁹Division of Orthopedic Surgery, Department of Surgery, McMaster University Medical Centre, Hamilton, ON
¹⁰Department of Anesthesia, McMaster University, Hamilton, ON, Canada
¹¹Centre for Evaluation of Medicines, St. Joseph’s Healthcare Hamilton, Hamilton, ON
¹²Biostatistics Unit, St Joseph’s Healthcare Hamilton, Hamilton, ON

Objective: Brain tumors are the most common pediatric solid tumors, and the leading cause of cancer related mortality (Miller et al. 2016). Breakthroughs in management have increased survival rates in the past four decades (Woehrer et al. 2014). However, recent evidence suggests that survivors of childhood brain tumors (SCBT) are at an increased risk of type 2 diabetes (T2D) and cardiovascular disease compared to the general population (Gurney et al. 2003, Heikens et al. 2000, Meacham et al. 2009). In the general population, birth weight is a known predictor of future obesity and cardiometabolic risk, yet this correlation has not been confirmed in SCBT (Jornayvaz et al. 2016, Rooney, Mathiason, and Schauberger 2011). The aim of this study is to determine if birth weight can predict body mass in SCBT.

Method: This is a cross-sectional study. SCBT (n=78, n=33 females) and non-cancer controls (n=133, n=60 females) were recruited into the study. Body mass index (BMI; kg/m²) and BMI z-scores were determined. In order to assess the relationship between birth weight and body mass measures, linear regression was used, adjusting for age, sex, puberty, and fat mass percentage (%FM, measured by Bioelectrical impedance). An interaction term (birth weight*brain tumor status) was introduced to investigate the relationship between birth weight and body mass in SCBT and controls.

Results: SCBT had similar age and sex distribution compared to controls. More participants were pubertal in the control group (n=116, 87.20%) compared to survivors (n=54, 69.20%). In regression analyses, birth weight was positively correlated with both BMI and BMI z-score in SCBT and controls. The interaction term (birth weight*brain tumor status) revealed that the effect of birth weight on future body mass was similar between SCBT and controls.

Conclusion: Birth weight may predict which SCBT are at risk of higher body mass and obesity, and will help prioritize those who may benefit from weight management interventions.
CARE FOR NEUROCOGNITIVE POPULATIONS: ESTIMATING THE NUMBER OF AT-RISK SURVIVORS OF CHILDHOOD CANCER AND NON-MALIGNANT BRAIN TUMOURS

Chan V*, Bradley N*, Guger S, Spiegler B, Gibson P1,3, Edelstein K4, Janzen L3

1Pediatric Oncology Group of Ontario, Toronto, ON
2Hospital for Sick Children, Toronto, ON
3Children’s Hospital, London Health Sciences Centre, London, ON
4Princess Margaret Cancer Centre, University Health Network, Toronto, ON

Objective: Treatments for childhood cancers and non-malignant brain tumours can cause irreversible neuropsychological deficits (ranging from mild to severe) that impact academic, vocational, social and emotional functioning and quality of life for patients and their families. Emerging literature suggests cognitive challenges may increase as childhood cancer survivors enter mid-to-late adulthood, resulting in earlier and/or more rapid cognitive aging (Armstrong et al, 2014; Edelstein et al, 2011). Informal reports suggest that survivors and their families in Ontario are not adequately supported in managing long-term impacts of their disease/treatments and may be left on their own to cope and navigate complex medical, mental health, educational and community service systems for help. Estimating the number of survivors at “high-risk” for neurocognitive deficits who require specialized care is an essential step toward improving access to care for this population. Our objectives were to update the provincial neurocognitive risk criteria and estimate the number of survivors at high-risk of neurocognitive impairment to inform policy development and program planning.

Methods: Data from the Pediatric Oncology Group of Ontario Networked Information System (POGONIS) were analyzed to identify residents of Ontario, diagnosed between 1985-2010, seen in a POGO partner centre, and meeting the high-risk neurocognitive criteria. Survival was defined as ≥5 years since the most recent pediatric cancer event (primary diagnosis/second neoplasm). Provincial expert-informed neurocognitive risk was defined by the POGO Care for Neurocognitive Populations Working Group of the POGO Provincial Pediatric Oncology Plan 2017–2022. This includes survivors diagnosed before age 18 years with a brain tumour, with high-risk or relapsed acute lymphoblastic leukemia (ALL), or standard risk ALL diagnosed between ages 1-4 years or between ages 5-9 years with acute neurotoxicity. Furthermore, those treated with cranial irradiation, neurosurgery or hematopoietic stem cell transplant were also included. Although many cases met more than one criterion, each case is counted once. Vital status was determined using mortality data available in POGONIS and linkage with the death record of the Ontario Registrar General to ascertain any deaths not captured in POGONIS. Attained age was calculated as of December 31, 2015.

Results: The number of estimated survivors in Ontario at high-risk of neurocognitive impairment, diagnosed between 1985 and 2010 and seen in a POGO partner tertiary centre, will be presented. The current volumes of survivors between 15-24 years of age are of particular interest, years where post-secondary education, vocational training, and career transitions occur. These data are underestimates, as they exclude survivors diagnosed prior to 1985, those not seen in a POGO partner centre, or those diagnosed with select genetic or prior developmental conditions which may increase risk.

Conclusions: There is consensus amongst neuropsychologists in pediatric and adult hematology/oncology centres in Ontario that the needs of high-risk childhood cancer survivors are not being adequately met and that these needs increase as survivors age. With improved survival rates contributing to a growing at-risk population, meeting the needs of survivors is a present challenge facing healthcare providers, planners and administrators. While cognitive impairment impacts functioning and well-being across the life span, assessing needs of the at-risk survivor population may best be approached by considering unique developmental needs within age-specific cohorts. A closer examination of health human resources and service needs within age groups is also required.
CHANGING LOCUS OF CARE: RESOURCES IMPLICATIONS

Bennett C*, Alexander S2, Clarke A3, Milks J1, Pole J1, Gibson P1,4, Greenberg M1,2
1Pediatric Oncology Group of Ontario, Toronto, ON
2Hospital for Sick Children, Toronto, ON
3Children’s Hospital of Eastern Ontario, Ottawa, ON
4Children’s Hospital, London Health Sciences Centre, ON

Background and Objectives: Over the past two decades, five tertiary hospitals and the Pediatric Oncology Group of Ontario have created a tiered system of care where children receive circumscribed components of their cancer treatment, according to best practice, in well-prepared sites with designated professional staff. This program has successfully changed locus of care from a tertiary setting; moving thousands of annual outpatient visits and hundreds of inpatient admissions/days to community hospitals located closer to home for patients and families. As advances in childhood cancer care accelerate, new opportunities must be explored to provide components of care in optimal locations while matching the distribution of human resources to locus of care. Our objective was to measure expectations, feasibility, and utility of access to outpatient care, in the tertiary and satellite setting, during non-clinic hours over evenings and weekends.

Method: Health care providers across five tertiary and seven satellite centres were surveyed to determine current practices and possibilities for improvement in access to outpatient care on weekends, holidays and evenings. All centres responded to the survey. Parents from each site were surveyed to obtain feedback regarding availability of out-of-hours outpatient care and components of care considered most important.

Results: A total of 12 programs, made up of five tertiary and seven satellite programs, provided information on hours of operation, weekend visits, and types of services by providers. Availability of physicians and nurse-practitioners was also captured. Three tertiary centres reported 8 to 9 hours with two centres operating for 12 hours a day. Among the satellites, a consistent pattern of 8 hours per day emerged. Across both tertiary and satellite centres, survey results indicated a clear trend toward the provision of care on weekends. Chemotherapy, other IV therapies, transfusion and blood work were provided as weekend services with one site reporting symptom assessment as part of the suite of services. A different service profile emerged for satellites with four sites providing symptom assessment and only one of the seven clinics indicating that they were providing weekend chemotherapy. Parent needs and expectations are important determinants of service utilization. A total of 59 parents responded to the After Hours Outpatient Care survey with 81% reporting they would make use of evening and weekend hours, if available. The majority of parents ranked transfusions and blood work as ‘very important’ components of after-hours care. Provision of chemotherapy and other IV medications followed closely. In contrast, ranking by parents for the importance of closeness to home, care over a weekend by nurses they know and face-to-face access to a physician varied greatly.

Conclusions: Based on survey results, there appears to be material benefit for after-hours clinic operations and some clinics are clearly moving in that direction with 3 tertiary and 5 satellite clinics reporting some level of care on weekends. The potential to expand operations for evening and weekend clinics is dependent upon multiple factors and in particular the availability of health human resources. Utilization by parents is also an important determinant of success for after-hours operations. Evening and weekend hours may reduce missed time at work for parents and may benefit children and adolescents by reducing time missed at school or other activities. Taken together, the survey results suggest that opportunities may exist to explore different options for after-hours services at some sites.
CHARACTERISTICS OF SURVIVORS OF INFANT CANCER IN AFTERCARE: A SINGLE CENTRE, 30-YEAR RETROSPECTIVE REVIEW

Patel S^{1,2}, Chambers A^{1}, Gibson P^{1,2,3}, Cairney, AE^{1,2}

^{1} Children’s Hospital, London Health Sciences Centre, London, ON
^{2} Western University, London, ON
^{3} Pediatric Oncology Group of Ontario, Toronto, ON

Introduction: Childhood cancer survivals have improved markedly in the past 3 decades. Increased survival has come with a substantial cost; childhood cancer survivors are at risk for multiple long term late effects to therapy. Aftercare programs allow for comprehensive follow-up of childhood cancer survivors in a systematic and evidence based manner. Survivors treated in infancy are at particular risk for late effects of therapy given the susceptibility to toxicity and the intensity of treatment required to cure infant cancers. The purpose of this study is to review the patterns of aftercare attendance and recognized toxicities of infant cancer survivors over a 30-year period at Children’s Hospital.

Methods: This is a single centre, retrospective chart review study. The Pediatric Oncology Group of Ontario (POGO) has been collecting diagnoses and treatment information in the province of Ontario since 1985 as part of the POGO Networked Information System (POGONIS). Following approval from the Research Ethics Board, a POGO data request will be submitted to provide a summary of all patients diagnosed since 1985 who were under the age of 1 year at the time of diagnosis. Furthermore, POGONIS will provide the diagnoses, date of death (if applicable) and date of referral to the Children’s Hospital Aftercare Program. Surviving patients electronic records will then be reviewed with an aim of cataloging any long term complications of therapy.

Analysis: All data will be presented using descriptive statistics. Treatment eras will be divided into 5 year intervals and referral, attendance and toxicities will be summarized with attention to evolution over time.

Conclusion: As therapy improves outcome in infant cancers, the number of survivors is expected to increase also. This group has a high potential for late effects and warrants careful management.
Background/Objectives: Cancer predisposition syndromes (CPSs) are increasingly associated with the development of malignancies in children and adolescents. The identification of CPSs is challenging for most clinicians leading to under-recognition and missed opportunities to personalize care. Variable clinical phenotypes and incomplete penetrance together with rapidly advancing knowledge and recent discoveries of novel cancer susceptibility genes contribute to the difficulties in recognizing CPSs.

In 2015, a multicenter initiative entitled the *McGill Interactive Pediatric OncoGenetic Guidelines (MIPOGG)* study, aimed at creating a clinical tool to identify children at increased likelihood of having a CPS was developed. Following the design of tumor-specific decisional algorithms, algorithm performance assessments were initiated at The Hospital for Sick Children (SickKids) involving linkage with the SickKids Cancer Genetics Database. One of the aims of this preliminary validation process is to better define the timing of primary neoplasm development relative to the recognition of the CPS. A second objective is to assess the reasons for referral to the Cancer Genetics Program.

Methods: We performed a retrospective review of all patients evaluated and/or treated at SickKids since 1999, with a primary childhood malignancy (≤18 years of age) who were diagnosed with a CPS at any time point. For each patient, we collected diagnostic information, indication for referral to the Cancer Genetics Program and the referral timeline relative to their cancer diagnosis in order to establish time to CPS recognition.

Results: Between 1999 and 2017, 171 patients met inclusion criteria (pediatric cancer and a confirmed CPS) and had available clinical information. Of these, 81 (47%), 77 (45%) and 13 (7.6%) were diagnosed with a primary cancer prior to, at the time of, and subsequent to CPS recognition, respectively. The mean age at cancer diagnosis and at CPS recognition was 5.7 years (median 3 years, range 0.1-17 years) and 15.1 years (median 7 years, range 0-54 years), respectively. Of those diagnosed with a CPS at the time of, or after the cancer diagnosis, the mean time to CPS recognition was 4.1 years, but highly variable according to tumor type. Reasons for referral to cancer genetics included suspicious personal or family history, specific cancer type, existence of multiple primary malignancies, and abnormal results of microarray studies, while being evaluated for another indication. Seventy-one percent of patients had an unremarkable family history upon referral to cancer genetics. Of those with a cancer diagnosed after the CPS, 7 (54%) were being followed with a tumor surveillance protocol at the time of their cancer diagnosis.

Conclusion: This study demonstrates that a malignancy may be the sole presenting feature of a CPS, and that family history and phenotypic features may be absent in the child at the time of the genetics referral. This study also presents an overview of the timing of cancer diagnosis relative to CPS recognition at SickKids, a tertiary care institution with a well-established Cancer Genetics Program, where there is a high index of suspicion regarding potential underlying diagnoses. We acknowledge that such programs may not be available in most pediatric centers, impacting further the ability to recognise and diagnose CPSs. The results of a larger scale study, through the MIPOGG initiative, will define patterns of CPS recognition at a national level.
EMOTION RECOGNITION IN PEDIATRIC BRAIN TUMOUR PATIENTS: VIEWING PATTERNS AND WHITE MATTER STRUCTURE

Moxon-Emre, I*1,2,3, Bouffet, E1, Laughlin, S1, Skocic, J1, de Medeiros, C1, Mabbott, D J1,2
1 Hospital for Sick Children, Toronto, ON
2 University of Toronto, Toronto, ON
3 Pediatric Oncology Group of Ontario, Toronto, ON

Objective: Pediatric brain tumour patients have previously been shown to display deficits in facial emotion recognition, which is important for successful social interactions. Eye-movement monitoring has the capacity to reveal if viewing patterns, such as inattention to emotional photographs, contribute to these deficits. The ability to identify facial emotions is thought to rely on white matter (WM) that connect posterior, limbic and frontal brain regions. The objectives of this study were to evaluate: (1) emotion recognition in healthy children and pediatric patients treated for posterior fossa (PF) brain tumours; (2) viewing patterns to emotional photographs, both overall (i.e., all trials) and on trials where emotions were judged incorrectly vs. correctly; (3) WM damage throughout the brain, and to investigate if deficits in emotion recognition are related to regional WM structure.

Method: 22 patients treated for PF brain tumours (mean age (SD) = 13.75 (2.56)) and 12 healthy children (mean age (SD) = 12.87 (2.49)) participated in the research study at the Hospital for Sick Children (Toronto, Ontario). All participants completed the Diagnostic Analysis of Nonverbal Accuracy (DANVA-2), a computerized task that measures facial emotion recognition using photographs of children and adults. Throughout the task, eye-movements were recorded with an SR Research Ltd. EyeLink 1000 plus (Mississauga, Canada) eye-tracking desktop monocular system. MRI was obtained for 30 participants from our sample (18 patients, 12 controls). Diffusion tensor imaging (DTI) was used to assess fractional anisotropy (FA), a measure thought to reflect WM structure. MRI was performed using a Siemens 3T whole-body MRI scanner. First, whole brain voxel-based analyses were conducted to compare WM between controls and patient groups. Second, regional WM was correlated with the number of incorrect responses across all participants.

Results: Patients made more emotion recognition errors than controls (mean (SD): patients = 10.95 (3.58); controls = 7.67 (4.33); t = -2.38, p = 0.02). Despite this difference, patients and controls did not differ in the number of fixations made on the photograph: (mean (SD): patients = 5.29 (0.95); controls = 5.71 (0.82); t = 1.28, p = 0.21), or in the total time (ms) spent looking at the photograph: (mean (SD): patients = 1520.94 (172.57); controls = 1593.40 (150.02); t = 1.22, p = 0.23). The number of fixations and total dwell time did not differ when viewing photographs that were judged incorrectly vs. correctly, in any group (all P > 0.05). Relative to controls, patients had lower FA in many voxels across the brain (all p < 0.05). Across all participants, FA was negatively correlated with the number of incorrect responses in the left temporal region (r = -0.503, p = 0.005).

Conclusions: We evaluated the relations between emotion recognition, viewing patterns, and WM microstructure, by comparing patients treated for brain tumours with healthy children. Our findings demonstrate that patients treated for brain tumours display emotion recognition deficits and WM damage. The emotion recognition deficits we observed do not appear to result from inattention to the photographs overall, or as function of incorrect vs. correct trials. Our results suggest that left temporal WM may be important for successful emotion recognition. We intend to further explore these findings by investigating the relations between emotion recognition and WM tracts that connect occipital brain regions to limbic and frontal brain regions (e.g., the inferior longitudinal fasciculus and inferior fronto-occipital fasciculus).
Background and Aims: Pheochromocytomas (Pheo) and Paragangliomas (PGL) are neuro-endocrine tumors rarely seen in the pediatric population. The onset of these tumors in childhood/adolescence is associated with a high likelihood (>50%) of having a germline pathogenic variant in a cancer predisposition gene (Neumann et al. 2002). The diagnosis of a Pheo / PGL in pediatric age is therefore an indication for genetic assessment and testing in view of known associations with a number of different cancer susceptibility syndromes, namely, von Hippel Lindau Disease, Multiple Endocrine Neoplasia Type 2, Hereditary Pheochromocytoma / Paraganglioma Syndromes and Neurofibromatosis Type 1, caused by pathogenic variants in the VHL, RET, SDHx and NF1 genes, respectively (Bholah and Bunchman, 2017). Similarly, other rare syndromes such as Carney triad or Carney-Stratakis syndrome have been associated with Pheo / PGLs. Diagnosis of one of these syndromes identifies a risk for other associated tumors, and provides an opportunity for initiation of appropriate surveillance strategies (Rednament et al. 2017; Druker et al. 2017). The aim of this study is to review the clinical characteristics and germline findings of children with Pheo / PGL evaluated and/or treated at The Hospital for Sick Children, a tertiary referral institution.

Methods: We performed a retrospective descriptive review of consecutive children diagnosed with Pheochromocytoma and/or Paraganglioma who were evaluated and / or treated at The Hospital for Sick Children, Toronto, over a 20-year period (1997-2016).

Results: Twenty-six patients were diagnosed with Pheo and / or PGL in this time period. Thirteen patients had Pheochromocytoma, 12 had Paraganglioma, and 1 patient had both diagnoses at presentation (age range 0.16-16 years, median 11.3 years). Seven patients had bilateral tumors and 2 had multifocal disease at diagnosis, all of whom had a family history of Pheo / PGL. Of those children with an adequately documented family history (n=24), 66% had a history suggestive of an underlying CPS. Six had a known CPS prior to development of their cancer. Twelve developed their cancer first, with subsequent diagnosis of a CPS. Of these 12 patients, 7 had family members with Pheo / PGL. All children aged <12 years at tumor development were referred for genetic assessment, with 91% having a proven germline mutation. 80% of those >12 years of age who were genetically tested had a proven CPS. Overall, 18/20 (90%) who had genetic testing performed were found to have germline mutations in the VHL or SDHx genes (VHL 61%, SDHB 17%, SDHD 22%).

Conclusions: Pheochromocytomas and Paragangliomas are rare diagnoses in the pediatric population. These disease entities are highly associated with the presence of an underlying germline pathogenic variant in a cancer predisposition gene and warrant genetic referral and testing. Despite this, one third of patients in our population had no relevant family history to suggest an underlying cancer predisposition syndrome and 15% of our population were not referred for genetic testing. Increased awareness and a high index of suspicion regarding the significant likelihood of having an underlying genetic predisposition to cancer development in the setting of these tumors is needed in order to refer patients with this diagnosis for appropriate genetic assessment.
HYPOGLYCEMIA IN PEDIATRIC PATIENTS BEING TREATED FOR ACUTE LYMPHOBLASTIC LEUKEMIA AT THE CHILDREN’S HOSPITAL OF EASTERN ONTARIO

Schlosser MP, Bassal M*, Edwards E
Children’s Hospital of Eastern Ontario, Ottawa, Canada

Background: Symptomatic fasting hypoglycemia has been reported in children undergoing treatment for acute lymphoblastic leukemia (ALL) during the maintenance or continuation phases of treatment, and has been attributed to oral 6-mercaptopurine or methotrexate. Cases of hyperinsulinism in adults being treated for ALL have been reported and attributed to PEG-L-Asparaginase.

Objectives: To review the recent cases of hypoglycemia in children being treated for ALL at the Children’s Hospital of Eastern Ontario.

Design/Method: In this case series we reviewed the 3 recent patients at our institution presenting with hypoglycemia in early phases of treatment for ALL. Basic demographic information, diagnosis, clinical features, laboratory data, treatment and outcome are reported.

Results: We observed hypoglycemia in three pediatric patients being treated for ALL. Hypoglycemia was identified incidentally on routine morning lab draw of random blood glucose. Lowest values ranged from 1.9 to 2.4 mmol/L. None of the patients were symptomatic at the time of hypoglycemia. All three patients are female. Two patients have Down syndrome. One is an infant. Each is being treated for ALL on a different protocol, but all three had had pegasparagase within 2 weeks prior to developing hypoglycemia. Other chemotherapeutics used in proximity to the episodes of hypoglycemia include vincristine, dexamethasone, cytarabine, and intrathecal methotrexate, but pegasparagase is the only chemotherapeutic in common between all 3 patients. None of the patients had IV solution with dextrose running at the time of hypoglycemia. Endocrinology was consulted in each case and critical samples, including insulin levels, were ordered. Only one critical sample was ultimately drawn and this patient was found to have hyperinsulinemia. Acute management included oral glucose or IV dextrose. Long term management included dietary modification, corn starch, and diazoxide. All patients will be monitored closely following subsequent pegasparagase.

Conclusion: Hypoglycemia in children being treated for ALL is rare. Here we report the first cases of hypoglycemia prior to maintenance therapy. Based on our cases and existing reports of hypoglycemia during treatment for ALL in adults, it is possible that the hypoglycemia observed in our patients is a result of hyperinsulinism associated with pegasparagase.
IDENTIFYING CHILDREN AT INCREASED RISK FOR A CANCER PREDISPOSITION SYNDROME: THE MCGILL INTERACTIVE PEDIATRIC ONCOGENETIC GUIDELINES (MIPOGG)

Goudie C*1, Cullinan N1, Witkowski L2, van Engelen K1, Mourad S3, Coltin H4, Villani A1, Malkin D1 and Foulkes W1
1Hospital for Sick Children, Toronto, ON
2Harvard Medical School, Boston
3Montreal Children’s Hospital, Montreal, QC
4Children’s Hospital of Eastern Ontario, Ottawa, ON

**Background:** An estimated 10-29% of children with cancer have an underlying cancer predisposition syndrome (CPS); many are unrecognized. Identifying cancer susceptibility and appropriately referring to a genetics team is vital to optimize patient care by incorporating potential preventative measures, adapting therapies, improving surveillance and counselling around family risk. Many challenges limit the likelihood of a physician identifying CPSs and technological advances in cancer genetics/genomics are rapidly outpacing the knowledge of most clinicians. To address these issues, we are developing the MIPOGG, an electronic and educational application for smart devices that include tumor-specific decisional algorithms designed to help identify those children with cancer at an increased risk of an underlying CPS.

**Methods:** For each pediatric cancer included in the International Classification of Childhood Cancers and the WHO classification of CNS tumors (2016 revision), an extensive literature review was undertaken to highlight clinical and/or molecular characteristics that increase the likelihood of a genetic predisposition. These characteristics were used to design simple algorithms following a binary tree structure with “yes / no” answers. Each algorithm ultimately advises one of two possible outcomes: ‘Referral Suggested’ or ‘No Referral Necessary’, linked with an educational module. All algorithms were critically reviewed by expert panels and validated through a multi-institutional retrospective chart review to ensure sensitivity and positive predictive value.

**Results:** Ninety tumor-specific algorithms will have been finalized and we will present examples including Osteosarcoma, Rhabdomyosarcoma and Wilms tumor, highlighting the performance of these algorithms in validation studies. We also outline the rationale for tumors requiring direct referral to a genetics service.

**Conclusion:** The MIPOGG offers a clinically targeted approach, designed to easily identify patients at risk for a CPS, without the need for extensive or sophisticated investigations. As a clinical tool, it has potential to optimize management of children with cancer, across health care systems globally.
MANAGEMENT OF THROMBOCYTOPENIA DURING ANTICOAGULATION THERAPY IN CHILDREN WITH ACUTE LYMPHOBLASTIC LEUKEMIA AND CEREBRAL SINOVENOUS THROMBOSIS

N. Parmar*, L. Brandão†, U. Athale‡

1 McMaster Children’s Hospital, Hamilton, Canada.
2 The Hospital for Sick Children, Toronto, Ontario

Objective: The management of thrombocytopenia during anticoagulation therapy (ACT) has been ill defined in relation to platelet transfusion thresholds. There are no evidence-based guidelines regarding management of anticoagulation therapy (ACT) in patients with thrombocytopenia. This study evaluates the risk of thrombocytopenia, bleeding and the reasons for platelet transfusions in children with acute lymphoblastic leukemia (ALL) receiving ACT for cerebral sinovenous thrombosis (CSVT).

Methods: This retrospective cohort study was conducted at two pediatric oncology centers (McMaster Children’s Hospital and The Hospital for Sick Children). Children (1-18 years) who developed CSVT while on ALL therapy and who were treated with ACT were included. Data regarding demographics, diagnosis of ALL and therapy, CSVT diagnosis and ACT including duration and anti-Xa levels were compiled. Information regarding platelet counts, platelet transfusions, bleeding episodes (stratification as per international criteria), and invasive procedures (lumbar puncture (LP), bone marrow (BM) examination) while receiving ACT were collected.

Results: Thirty-four patients aged 1-18 (24 boys) were diagnosed with CSVT while receiving therapy for ALL. The mean duration of ACT was 6.05 months (range 22-363 days). The mean platelet count was 263 x 10^9/L (13-994). The platelet count was <50 x 10^9/L on 63 occasions and was <20 x 10^9/L on 6 occasions. There were a total of 8 bleeding events in 7 patients (7 intracerebral hemorrhages, and 1 epidural; all major hemorrhage), in which 1 (14%) of these bleeding events had a platelet count of <20 x 10^9/L at the time of diagnosis of bleeding episode, 1 (14%) of these events occurred during a platelet count between 50 x 10^9/L and 100x10^9/L, and 5 (71%) of these episodes occurred during a platelet count greater than 100x10^9/L. There was no difference in the frequency of patients with thrombocytopenia amongst patients with (n=4) or without (n=12) bleed (p= 0.728) nor in the number of days with thrombocytopenia in patients with (mean 13 days, range 5-32) or without (mean 13 days, range 1-42) bleeding (p=0.712). In all 19 (56%) patients received 53 platelet transfusions; 3 (6%) transfusions were performed around a bleeding episode, 33 (62%) for low platelet count (<50x10^9/L), 11 (21%) platelet count between 50 to 100x10^9/L, and 4 (8%) transfusions were performed due to a procedure within 48 hours and a low platelet count. On 5 occasions, ACT was held for a platelet count of <50x10^9/L, on 3 occasions ACT was reduced to half a dose due a platelet count of <50x10^9/L and on 1 occasion ACT was reduced to half dose due to a procedure that was performed within 48 hours. There were 39 occurrences with anti-Xa levels ≥ 1.0 IU/dL in 18 patients. Only 1/7 patient had 2 occurrences of an anti-Xa level of ≥ 1 IU/dL (1.07 and 1.18) within 3 days prior to bleeding. However the anti-Xa level was <0.1 IU/dL and 0.44 IU/dL at the time of the bleed and three days after the bleed respectively.

Conclusion: Severe thrombocytopenia (platelet count ≤ 20X 10^9/L) was uncommon in our cohort of patients. The major bleeding rate was 20%. However there was no significant relationship between thrombocytopenia and bleeding episodes or duration of thrombocytopenia and risk of bleeding. Only one patient had supra-therapeutic anti-Xa level (>1 IU/dL) prior to a bleeding episode. Over half of the patients received platelet transfusions while on ACT; the majority of the transfusions were prophylactic. We recommend a larger prospective study to confirm our findings.
NOT EVERYONE WAS NICE: BULLYING DURING PEDIATRIC CANCER TREATMENT

Molinaro, M.L.*1, Fletcher, P.C.2
1University of Western Ontario, London, ON
2Wilfrid Laurier University, Waterloo, ON

Objective: Pediatric cancer is a life-altering experience for children and their families. All individuals in a family are often physically, psychologically, and socially affected. For children, some of these effects include, but are not limited to: alopecia, swelling of the face, nausea and vomiting, “chemo-brain”, aches and pains all over the body (Armenian, Meadows, & Bhatia, 2011; Monteleone & Meadows, 2007). In addition to their changed physical appearance or characteristics, children are often faced with social effects as a result of undergoing treatment; children may miss school, or experience changes in their social relationships with peers (Janes-Hodder & Keene, 2002) These particular effects have been documented in pediatric cancer literature (Miller, 2012; Monteleone & Meadows, 2007), however not to the extent of being bullied while undergoing pediatric cancer treatment. The purpose of this research was to examine the lived experiences of the perceived long-term effects of pediatric cancer on adult survivors and their primary support persons, in order to understand the multifaceted nature of the illness on adults, and how it affects others close to them.

Method: Using the qualitative theoretical orientation of interpretive phenomenology, background questionnaires were administered to all participants and subsequently used to provide context for semi-structured, one-on-one interviews conducted with ten pediatric cancer survivors and nine support persons. All interviews were transcribed verbatim and subsequently analyzed for themes that emerged from the participants’ experiences.

Results: Multiple themes and subthemes emerged from this work, however one subtheme, specifically addressing bullying the survivors experienced while undergoing treatment, will be discussed. The participants easily recalled their experiences during their cancer treatments, and some specifically remembered that they were bullied during this experience. Survivors admitted that overall, their classmates and school administrators were supportive. However, some acknowledged that many of their peers were no longer associated with them, or were making disrespectful comments about their cancer and spreading rumours. For others, the physical side effects from their treatments sparked mocking from their classmates when they were able to attend school after treatment. These survivors understood that comments and reactions of that nature were the result of immaturity from their peers, but also acknowledged these experiences made them more confident in themselves as they grew older.

Conclusion: These findings are important for school administrators and parents in order to aid in accommodating any child with health care needs atypical to his/her peers. It could aid bettering zero-tolerance bullying policies in all school systems, regardless of the conditions or characteristics of the children being bullied. Further, informational resources for school administrators, teachers, and classmates of children with cancer could be provided to school boards in order to arm them with the most appropriate accommodation plans to assist children facing pediatric cancer and their journeys through the school system.
PEDIATRIC LIVER CANCER SURVIVAL FROM 1985 TO PRESENT:
AN INTERNATIONAL COMPARISON

Jason D. Pole, PhD¹, Giancarlo Di Giuseppe, MPH¹, Danny R. Youlden, BSc², Joanne F. Aitken, PhD²
¹Pediatric Oncology Group of Ontario, Toronto, Canada
²Cancer Council Queensland, Queensland, Australia

Background: While several studies have found that overall survival from childhood cancer has been improving over the last few decades, anecdotal evidence suggests that this may not hold true for children with specific diseases like liver cancer. Given the relatively rare nature of liver cancer in pediatric patients, it is difficult to determine if the survival rate over time is due to small numbers or a true difference in survival.

Objective: To determine the survival of children diagnosed with hepatic tumours from 1985 to 2013 and compare these estimates among the three international populations including Ontario, Australia and the United States

Methods: We conducted an international retrospective population-based study of children aged 0 – 14 diagnosed between 1985 and 2011 with hepatic tumors (group VII of the International Classification of Childhood Cancer (ICCC-3)). Children were recruited from Ontario (n=136), Australia (n=216), and the Surveillance, Epidemiology, and End Results Program (SEER) in the United States (n=772). Participants were followed from their diagnosis date to the date of death, last follow-up, or censor date of December 31, 2013; whichever occurred first. Five-year relative survival rates were obtained for each individual international center and were then compared.

Results: Overall relative survival (RS) was slightly better among Australian children (RS=74.9; 95% CI, 68.4 – 80.2), compared with Ontario (RS=68.3; CI, 59.7 – 75.5) and the US (RS=68.7; CI, 65.2 – 71.8) but all locations have similar survival during the entire study period. Survival ranged from 1.62 to 2.31 times higher across all locations for young children aged 0 – 4 compared to children aged 10 – 14 at the time of diagnosis. The relative survival of liver cancers diagnosed between 1985-1992 compared to 2003-2011 increased by 14% and 25% for Ontario and the US, respectively; whereas it decreased by 9.6% in Australia.

Conclusion: Survival of pediatric liver cancer appears to be declining in Australian populations while it has been improving in North America during the past two decades. Future work should aim to include an examination of other cancer types and pediatric populations from other international centers that utilize alternate treatment regimens to determine if the reduction of survival seen in Australia is the result of random variation or due to differences in treatment.
**PROFESSIONAL AND SURVIVOR PERSPECTIVES ON THE IMPORTANCE OF COMPONENTS OF CARE FOR ADOLESCENT AND YOUNG ADULTS**

Nuttall S*, Barr R², Gupta S³

¹Pediatric Oncology Group of Ontario, Toronto, ON
²McMaster Children’s Hospital, Hamilton Health Sciences, Hamilton, ON
³Hospital for Sick Children, Toronto, ON

**Objective:** A pop-culture quote advises that “if it doesn’t challenge you, it won’t change you”. By the same token, if you don’t think it is important, you won’t act on it. As care givers and program administrators, if we don’t think a program is very important we are unlikely to argue convincingly for scarce resources in support of a particular program or service. The Pediatric Oncology Group of Ontario (POGO) is aiming to improve care delivered to adolescents and young adults (AYA) with cancer. Based on a needs assessment, we identified 4 domains: clinical trial enrollment; psychosocial care; onco-fertility; and, medical care. Once identified, we undertook to measure the importance of each domain component and feasibility of specific targets and measurements. For the purposes of this abstract, we focus on level of importance attributed to each domain and its component elements.

**Method:** Using a Delphi consensus process, we surveyed a broad group of care providers including physicians, psychosocial teams and survivors. Within our 4 domains, we solicited responses across 9 components assessing the importance of each element. Our focus was on the AYA community, ages 15 to 17 years. In all, 32 individual surveys were sent to selected individuals in the 5 POGO tertiary centres, two adult cancer centres and a survivor group. Our response rate was an acceptable 69%. The ASCO guidelines for achieving consensus were followed. Our results are reported as the percentage of respondents who rated each component as important to extremely important.

**Results:** Access to routine consultations with adult experts for specific adult-type tumours received the highest rating of importance among respondents. The availability of onco-fertility programs was also highly rated, particularly among survivors. The percentage of AYAs enrolled in therapeutic trials was also highly rated in importance. Surprisingly, psychosocial components were not ranked highly in importance. Worth noting was low importance attributed to psychosocial screening among AYA at diagnosis. By contrast, a high rating was given to the importance of age-appropriate health education materials relating to diagnosis and treatment. Within the psychosocial domain, unexpectedly low ratings of importance were reported for formal peer support groups and availability of vocational counseling. It is informative to note the divergence of perspective with respect to peer support with a high rating of importance by survivors and a low median rating by others.

**Conclusions:** The individual’s perception of importance has face validity as a variable of influence when arguing for resources and recommending program implementation. Three of the four domains measured were rated as important and are recommended as areas where appropriate programs are likely to make an important impact on health outcomes for the AYA population. In recent work, the Canadian Partnership Against Cancer reports that psychosocial care is one of the most important areas of concern for AYAs with cancer. The low rating for importance for this domain may indicate that more work needs to be done with professional and survivor communities to raise awareness of psychosocial issues. The results of the Delphi process have informed the creation of a POGO AYA strategy.
PROTOCOL TO ESTABLISH CONTENT VALIDITY OF FACE-Q KIDS FOR PEDIATRIC HEAD AND NECK CANCER

Wang Y*, Tsangaris E1, Nathan P2, Bouffet E2, Dix D3, Wong K2,4, Klassen A1

1 McMaster University, Hamilton, ON
2 The Hospital for Sick Children, Toronto, ON
3 BC Children’s Hospital, Vancouver, BC
4 University of Toronto, Toronto, ON

Objective: A facial difference can have an important impact on an individual’s quality of life. Existing patient-reported outcome (PRO) instruments used for patients with a visible or functional facial difference lack content validity, as few items address appearance and facial function issues. FACE-Q Kids is a new PRO instrument developed to measure outcomes that matter to patients aged between 8 and 29 years with ear anomalies, facial paralysis, skeletal conditions, or soft tissue conditions. Data from patient interviews were used to create a set of independently functioning scales that measure appearance, function, quality of life, and adverse effects. Since FACE-Q Kids was not developed specifically for patients with head/neck (HN) cancer, a process is needed to determine if the content is relevant to patients with a visible and/or functional facial difference caused by HN cancer or its treatment.

Methods: Cognitive interviews with patients with HN cancer aged 8 to 29 years (n=21) will be conducted and feedback from experts in pediatric oncology (n=50) will be obtained. Participants will be recruited from pediatric oncology centres in Ontario and British Colombia. Interviews will take place either face-to-face or by telephone, and will be recorded, transcribed, and coded. Input will be sought on all aspects of the FACE-Q Kids content (item wording, instructions, and response options), and to identify missing content. Analysis will involve examining participant feedback for each item to make decisions about the existing items, and to examine themes/subthemes arising from new content for item/scale development. Revised scales will be shown to experts in the field of oncology via a REDCap (Research Electronic Data Capture) survey for input and feedback. Final revisions will be shown to a sample of 10 patients to test the changes made from expert input. Final scales will form the FACE-Q Kids HN Cancer Module.

Next steps: Interviews and expert review will be coordinated at participating centers. Cognitive interviews and expert review will allow us to identify items that require re-wording, re-conceptualizing, or to be removed, as well as any missing items. Upon completion of the present study, FACE-Q Kids HN Cancer module will be field-tested on a sample of patients to determine its measurement properties.
PROVINCIAL HEALTH SYSTEM PLANNING FOR THE INCREASING PREVALENCE OF CHILDHOOD CANCER SURVIVORS: A POPULATION-BASED ANALYSIS IN ONTARIO

Chan V*1, Nathan PC2, Taccone MS3, Bradley N*1, Greenberg M1,2, Merino DM4, Bennett C1, Bassal M5

1Pediatric Oncology Group of Ontario, Toronto, ON
2The Hospital for Sick Children, Toronto, ON
3The Ottawa Hospital, University of Ottawa, Ottawa, ON
4Radiation Epidemiology Branch, Division of Cancer Epidemiology and Genetics, National Cancer Institute, Bethesda, MD, USA
5Children’s Hospital of Eastern Ontario, Ottawa, ON

Objectives: With marked improvements in survival over the last few decades, the number of childhood cancer survivors (CCS) has increased steadily. Many CCS experience long-term decrements in physical and/or psychological health due to their cancer and its treatment. A subset of survivors experience difficulties related to education, employment, social welfare and financial stability. Subgroups identified as highest risk (HR) include survivors of brain tumours and hematopoietic stem cell transplants, adolescents and young adults, survivors lost-to-follow-up, and longer-term CCS. In 1999, the Pediatric Oncology Group of Ontario (POGO) provincial AfterCare system was implemented, with support from the Ontario Ministry of Health and Long-Term Care. The system is comprised of a network of seven specialized survivorship clinics, staffed by multidisciplinary teams. Previous reports suggest that POGO AfterCare clinic attendance by CCS <18 years of age approaches 100%, but only 43% of adult CCS have attended, suggesting a loss to follow-up during transition to adulthood. The objective of this analysis is to provide current estimates on the number of CCS in Ontario to better understand the resource requirements of this population and inform future system-level survivorship care planning as part of POGO’s Provincial Pediatric Oncology Plan (2017-2022).

Methods: The POGO Networked Information System (POGONIS) and the Ontario Cancer Registry (OCR) were used to identify Ontario residents diagnosed with cancer from 1985-2010 between ages 0-19 years. Patients who survived for ≥5 years since their last cancer diagnosis were included. Vital status was determined using mortality data in POGONIS and linkage with the Ontario Registrar General death record. Attained age was calculated as of December 31, 2015. The number of survivors identified from POGONIS and OCR are underestimates, as childhood cancer diagnosed prior to 1985 is not captured in these registries. To address this limitation, SEER Cancer Statistics data were extrapolated to estimate the total number of CCS in Ontario, including those diagnosed prior to 1985, using population estimates from the US Census Bureau and Statistics Canada.

Results: As of December 31, 2015, there were 10,553 CCS in Ontario, registered in POGONIS or OCR, diagnosed since 1985. Twenty percent of survivors were eligible for pediatric AfterCare (age <18 years), and the remaining were eligible for adult AfterCare (age ≥18 years). Data extrapolated from SEER Cancer Statistics estimate approximately 18,000 total CCS in Ontario, suggesting that approximately 7,500 CCS were diagnosed pre-1985 and are eligible for adult AfterCare.

Conclusions: These data demonstrate that the majority of CCS in Ontario are now adults. Previous reports suggest that a high proportion of adult CCS are not seeking care in a specialized survivorship clinic. This highlights the need to explore potential solutions to optimize the uptake of survivorship care, particularly in adult CCS. Informal surveys have shown that existing POGO AfterCare clinics have limited capacity. As the CCS population continues to increase, there is concern that specialized survivorship clinics may be unable to meet the needs of adult survivors in the future. A closer examination of health human resources and service requirements within risk groups is needed to adequately staff provincial AfterCare clinics.
REDUCED USE OF PARENTERAL NUTRITION IN A PAEDIATRIC HEMATOPOIETIC STEM CELL TRANSPLANT POPULATION

Stuhler, R*¹
¹Sickkids Hospital, Toronto, ON

Purpose: Parenteral Nutrition (PN) is a commonly used source of nutrition in the paediatric hematopoietic stem cell transplant (HSCT) population. This is as a result of the severe side effects of myoablative conditioning regimens, as well as post-transplant complications that impact the ability to meet nutritional needs orally. Early nasogastric (NG) feeding tube insertion and initiation of enteral nutrition (EN) has been successful in some paediatric HSCT patients, reducing or alleviating the need for PN. Provision of nutrition via a nasogastric (NG) feeding tube is safer, more physiological, and less expensive than PN. In our institution, PN has been the traditional first choice for nutrition support on the HSCT unit. However, with an organizational push to decrease length of stay (LOS) coupled with perceived overuse of PN in our patient population, EN has been promoted as a superior option for first-line nutrition, with an intent to reduce the use of PN.

Methods: As PN use was thought to be a barrier to reducing LOS, the HSCT team began to wean PN early, either before engraftment in those children showing interest in oral intake, or at engraftment, with the hope of stimulating oral intake or making clear the need for EN. With coaching from the HSCT Clinical Dietitian, staff physicians began to discuss the benefits of early EN in HSCT with families in the pre-admission consult, approximately one week prior to admission. The dietitian met with patients and families on admission to discuss early initiation of EN. Data from PN Pharmacy, SickKids HSCT, and hospital databases were collected and compared. As data was only available for 18 months, statistical significance was not expected. Downward linear trends were expected.

Results: Complete PN cost data was available from January 2013-June 2015. Total PN cost for the HSCT program was compared for the first half of the calendar year for the years 2013, 2014, and 2015. There was an 11% cost reduction between 2013 and 2014, and a 25% cost reduction between 2014 and 2015. The overall cost reduction between 2013 and 2015 was 33%. In order to assess change over a continuous length of time versus three discrete time periods, PN cost from January 2013 to June 2015 was looked at in 6 month blocks. Overall, the total PN cost decreased between 2013 and 2015. Looking at cost alone is not sufficient to declare overall decreased PN use, as the amount of money spent can be affected by the number of HSCTs as well as fluctuations in patient days. Number of PN days per HSCT was compared, showing a downward trend from 2013 to 2015, with a reduction from 21 PN days/HSCT in the first half of 2013 to 18 days in the first half of 2015. A reduction of 3 days may impact LOS, and therefore be fiscally significant. PN cost/HSCT was compared, showing a downward trend, with a reduction of $258.49 per HSCT between 2013 and 2105.

Conclusions: This informal QI study shows that even small changes in the approach to nutrition during HSCT can have a positive fiscal impact. Presenting EN as a superior first-line nutrition option to patients and families over PN, and ensuring that feeding tubes are inserted early allows for a reduction in PN use and cost, and may decrease LOS. This benefits both patients and institution. Ongoing education is crucial to maintaining a positive attitude towards EN, thus minimizing the use of unnecessary PN. Data collection should continue, with the hope of showing statistical significance over time.
“TELL IT AS IT IS”: HOW SISOM PROMPTS CHILDREN TO DISCUSS THEIR FEELINGS, EXPRESS EMOTIONS, AND REFLECT ON THEIR ILLNESS EXPERIENCES

Sarkis B1*, Séguin K1, Siedlikowski M, MSc1, Rennick J RN PhD1,2, Stinson J RN-EC, PhD, CPNP3,4, Le May S RN PhD5,6,7, Choquette A RN MScN, CPON3, Ruland C RN PhD9, and Tsimicalis A, PhD, RN1,2
1Ingram School of Nursing, Faculty of Medicine, McGill University, Montreal, QC
2Shriners Hospitals for Children®-Canada, Montreal Quebec Canada
3Montreal Children’s Hospital, McGill University Health Centre, Montreal, Quebec, Canada
4The Hospital for Sick Children, Toronto, Ontario, Canada
5Lawrence S Bloomberg Faculty of Nursing, University of Toronto, Toronto, Ontario, Canada
6UHC Sainte-Justine, Montreal, Quebec, Canada
7University of Montreal, Montreal, Quebec, Canada
8Oslo University Hospital, Oslo, Norway

Background: Sisom [Norwegian acronym for the “tell it as it is”] is a computerized, interactive, communication tool shown to improve communication between children and their oncologists. Presented on a computer or tablet, Sisom prompts children to rate the severity of their symptoms on a 5-point Likert scale. In Canada, research derived from linguistically validating and testing the usability testing of Sisom, indicated children found Sisom easy to use, and was helpful in expressing their symptoms. However, what discussions unfolded from using Sisom remained unknown.

Objective: To describe if and how Sisom prompted children to express themselves, and what discussions unfolded from using Sisom.

Methods: A qualitative descriptive design was used to guide the analysis of interview transcripts derived from 39 children with varying types of cancers, and treatment trajectories, who were between the ages of 6 and 13 years. Data were coded and analyzed using thematic analysis techniques involving an iterative process of data reduction, data display, conclusion drawing and verification. Socio-demographic data were analyzed using descriptive statistics.

Results: Sisom elicited a verbal response to at least one symptom for the majority of children (n = 33). Sisom prompted children to: (1) discuss their thoughts and feelings out loud by querying for input, expressing emotions, sharing anecdotes and commenting about the logistics of Sisom; (2) express a spectrum of emotions, ranging from unpleasant to pleasant, regarding their symptoms; and (3) reflect, in varying degrees of certainty and uncertainty, regarding their illness experiences.

Conclusion: Sisom is a useful tool, which prompts children to discuss their thoughts and feelings, express emotions, and reflect on their illness experiences. Opportunity for meaningful encounters between children and their clinicians may ensue with the adoption of Sisom in practice.
THE PEDIATRIC HEMATOLOGY ONCOLOGY BESTBITS PROJECT: A JOURNAL REVIEW AND VIRTUAL JOURNAL CLUB INITIATIVE

Alexander N*, Waespe N¹, Brzezinski J¹, Bellavance F¹, Punnett A¹
¹The Hospital for Sick Children, Toronto, ON

Objectives: Keeping updated with the literature is challenging in Pediatric Hematology/Oncology. Existing journal clubs and online clinical updating tools may be limited in scope, volume and relevance to health care professionals. Following a pilot journal review initiative, online expansion was proposed to broaden educational opportunities and participation and facilitate interactive discussions. The aim of this project was to create a regularly updated virtual resource of Pediatric Hematology/Oncology literature relevant to fellows, residents, staff and allied health professionals by regularly screening a core set of journals, expand participation in periodic literature review project across Canada & facilitate an interactive virtual journal club for Pediatric Hematology Oncology. We hypothesize that participation in “BestBits” initiative will improve journal reading habits, self-efficacy in screening journals and critically appraising journal articles, and be a convenient way to keep up to date with new literature.

Methods: A needs assessment was sent to Pediatric Hematology Oncology fellows and staff across Canada and they were invited to register online to participate in journal review and other learning activities. Following initial design and development of www.bestbits.ca, the first phase of the initiative was launched. A 2-month schedule for Journal Review and Virtual journal club was developed: assigned journals are reviewed and relevant articles to read and appraise, selected using a standardized framework. Summaries with interpretation are submitted online after extensive editorial review and journal review is posted online. Selected articles from each issue are discussed online by the community.

Results: Since www.bestbits.ca was launched on March 29, 2017, over 70 registered practitioners including students, residents, fellows, staff and nurse practitioners, across Canada have registered. The website has been viewed over 4000 times and average session duration is 6 minutes. Editors have met monthly to assign journals, compile issues, discuss feedback and development. 3 BestBits Issues have been published and 75 articles relating to Pediatric Hematology Oncology were appraised and summarized by 35 reviewers. Participants reported an average of 1-hour scanning per journal and 1.5-hour critical appraisal/reviews. Journal review and submission process has been reported to be clear and educational for participants. BestBits virtual journal club was launched September 5, 2017 with registered users posting comments on the website on selected featured articles. The journal club is accredited by Royal College of Physicians and Surgeons of Canada (RCPSC) and registration has been opened to participants in associated specialities including pathology, surgery, radiology and radiation oncology.

Conclusions: Staying updated with Pediatric Hematology Oncology literature is challenging and creating an open-access relevant resource may be useful to practitioners, and promote journal reading and critical appraisal. Further development will include continuing medical education resources such as accredited self-assessment quizzes & e-learning sessions on critical appraisal and literature review. We will assess the educational impact of the initiative and encourage national, international and inter-professional participant expansion.
TRANSFUSION-RELATED IRON OVERLOAD (TRIO) IN CHILDREN WITH LEUKEMIA

Cacciotti C*,1, Millson S1, Athale U1.
1Department of Pediatrics, McMaster University, Hamilton, ON

Background: Children with cancer commonly receive red blood cell (RBC) transfusions. Transfusion-related iron overload (TRIO) is a common complication of RBC transfusion and a significant iron burden is documented after only 10 RBC transfusions (Ruccione et al., 2014). Despite heavy transfusions, few studies have evaluated TRIO in children with cancer and no guidelines for screening exist (Gurram et al., 2012).

Aims: To define the burden of RBC transfusions, evaluate the screening practices for TRIO in children (<18 years) with leukemia and study its impact on end organ function.

Methods: A retrospective, observational cohort study was performed. Inclusion (Children < 18 years of age with new diagnosis of acute leukemia) and exclusion criteria (patient with any other oncological or hematological diagnosis other than leukemia). In addition to demographic data, details surrounding diagnosis of leukemia and its therapy, ferritin values, number of RBC transfusions and organ functions at the end of therapy were extracted. Institutional research and ethics board (HiREB) approval obtained.

Results: The study cohort included 139 eligible patients, 83 (60%) had standard risk (SR) acute lymphoblastic leukemia (ALL), 44 (32%) high risk (HR) ALL, and 12 (9%) acute myeloid leukemia (AML). The mean age at diagnosis was 6 years (range 5 months- 18 years). Overall 37% (52/139) of patients received ≥10 RBC transfusions; SR-ALL median 6 (IQ range 4-9), HR-ALL median 11.5 (IQ range 7-16) and AML mean 23 (IQ range 17-44) transfusions. Patients with HR-ALL and AML were more likely to receive ≥10 transfusions (59% and 92% respectively) in comparison to those with SR-ALL (18%) (p <0.0001). Ferritin levels were measured in 94 patients (68%); and were elevated (>1,000mcg/L) in 22 (14%). Evaluation of iron overload with Ferriscan was performed in 4 patients (2%), three of which were elevated. Cardiac dysfunction in the form of cardiomyopathy was not evident in any patient who received ≥10 RBC transfusions. Hepatic dysfunction, defined as elevated AST or ALT was noted in 10% of patients with ≥10 RBC transfusions; 6% SR-ALL; 33% HR-ALL and 9% AML and consisted of autoimmune hepatitis (n=1), non alcoholic fatty liver (n=1) or hepatitis NYD (n=3). Endocrinopathies were the most common end organ abnormality and noted in 25% of patients; 6% SR-ALL, 38% HR-ALL and 18% AML, including obesity (n=7), autoimmune hypothyroidism (n=4), diabetes (n=2), delayed puberty or primary ovarian failure (n=2) and necrotizing pancreatitis (n=1).

Conclusion: Transfusion burden is highest in AML patients followed by HR-ALL. Only one patient in our study, completed therapy without transfusions. Despite the number of transfusions TRIO screening was not commonly performed. Thirty-two percent of patients did not have ferritin measurements performed. Thirty-five percent of patients who received a large number of transfusions showed evidence of end organ dysfunction. Other factors will also contribute to organ dysfunction such as chemotherapy, and infections (Jaffer et al., 2013; Ruccione et al., 2014; Reitman et al., 2015). Screening for TRIO should be incorporated into routine practice in children with leukemia.
USABILITY AND SAFETY OF A VIRTUAL REALITY PROGRAM TO REDUCE PROCEDURAL PAIN IN CHILDREN WITH CANCER

Kulandaivelu Y\textsuperscript{1}, Birnie K\textsuperscript{1}, Jibb L\textsuperscript{1}, Hroch P\textsuperscript{1}, Abla O\textsuperscript{1}, Positano K\textsuperscript{1}, Hum V\textsuperscript{*1}, Campbell F\textsuperscript{1}, Stinson J\textsuperscript{1}.

\textsuperscript{1}The Hospital for Sick Children, Toronto, ON

Objective: Subcutaneous port (SCP) needle insertions are very distressing for adolescents with cancer (AWC). Virtual reality (VR) may be an effective distraction for AWC undergoing painful SCP access. VR consists of hardware (i.e. head-mounted display) and custom software (i.e. immersive audiovisual environment). Our aim was to assess and refine usability (including acceptability, ease of use) and safety of a custom VR program in AWC undergoing SCP access in a tertiary care pediatric hospital in Toronto, Ontario, Canada.

Method: Iterative cycles of 25-minute usability sessions were conducted with AWC aged 8-18 years old undergoing SCP access. AWC used the VR program during SCP access under supervision of a trained research coordinator. AWC were asked to “think aloud” while using the program, and then responded to semi-structured questions related to usability and safety of the program. Observations and feedback were recorded, and used to refine the VR software.

Results: Over 3 cycles of testing, 17 AWC were recruited. The mean age was 11.7 years, and 12 (70%) were male. All AWC reported that the VR was easy to use, enjoyed the VR program, and understood its objective (i.e. shooting rainbow balls at underwater sea creatures). The majority of participants (16, 94%) were willing to use the virtual reality intervention during a subsequent port access or needle poke. Recommendations for changes included: (1) improving ease of aiming, (2) increasing sea life interaction, (3) increasing fish distance from screen interface, (4) preventing hardware from touching sterile areas, and (5) centrally positioning fish to avoid excess patient movement. All recommendations were implemented and no adverse events were reported.

Conclusion: AWC found the VR program to be an acceptable, easy to use, and a safe distraction activity while undergoing SCP access. Engagement of end-users is highly recommended in the development of distraction tools to ensure acceptability and effectiveness. Next steps include feasibility testing using a repeated-measures crossover pilot randomized controlled trial.
USING PHONE APPS TO IMPROVE MEDICATION ADHERENCE IN AN OUTPATIENT PEDIATRIC ONCOLOGY CLINIC

Khafagy R*, Gibson P, Reniers D, Patel S
1 The Hospital for Sick Children, Toronto, ON
2 Children’s Hospital, London, ON
3 Western University, London, ON

Background: Poor adherence in pediatric oncology leads to significant morbidity and mortality. Currently used medication reminder aids have shown little to no benefit in improving adherence. Phone applications have demonstrated improved adherence in recent studies involving adult and pediatric patients. At this time, no pediatric oncology centre is recommending a particular phone application (app).

Objectives: To determine the proportion of parents of pediatric oncology patients interested in using a phone app for medication reminders and desired features.

Methods: In this single-centre prospective observational trial, 45 questionnaires were completed by parents accompanying their child at a pediatric oncology centre. Participants had a child on active cancer treatment and were able to read and write English. Primary outcomes included number of parents currently using a phone app, number of parents interested in using a phone app, main reasons for not using a phone app, and desired phone app features.

Results: 95.6% of parents had never used a phone app to aid in medication adherence. Over 85% of these parents were highly interested in using a phone app, but most were not aware of available phone apps to use (57.1%). Desired features included: refill notifications, tracking doses administered, personalizable medication schedule, free of charge, no advertisements, ability to input special instructions, use on multiple devices, unique alarms, tracking child’s results, and privacy protection.

Conclusions: A majority of parents at an outpatient pediatric oncology clinic were interested in using a phone app to assist in medication adherence but were unaware of an available phone app. An ideal criteria list was created with ten desired features in order to evaluate available phone apps that may be recommended for this population. Further studies are needed to evaluate if phone apps recommended by this tool improve adherence.
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