An Integrated Approach to Relapse

POGO 2015 Multi-Disciplinary Symposium on Childhood Cancer
October 30-31, 2015 at the Westin Prince Hotel, Toronto

program + abstracts
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Keep the Conversation Going on Twitter!

Whether you would like to ask a question, share a comment or a photo or network with other Symposium attendees, connect by using the official Symposium hashtag: #POGOSymp15

And don’t forget to follow POGO on Twitter at @POGO4Kids!

An Integrated Approach to Relapse

2015 Multi-Disciplinary Symposium on Childhood Cancer
Welcome
A message from the Chair of the Symposium Planning Committee

Dear Symposium delegates,

Welcome to the 2015 POGO Symposium! As always, the group assembled here reflects the diversity of our community and the unwavering commitment of its many multi-disciplinary practitioners. The planning committee is comprised of professionals from both tertiary and satellite clinics, with representation from medicine, nursing, social work, psychology and pharmacy and has, we believe, created a program of interest to all concerned. This committee unanimously decided on the 2015 POGO Symposium theme – An Integrated Approach to Relapse.

Though the five year survival rate for childhood cancers is high, we in the pediatric oncology community remain all too aware that relapse does happen and brings with it unique and intensified challenges for healthcare providers, patients and family members alike. This program has been designed to explore the impact of relapse on the patient, family and healthcare team and to encourage new conversations and in-depth thinking about providing optimal care for relapsed disease. The theme of integration – of Phase 1 treatment with palliative measures, of the different roles of the whole healthcare team and of medical with psychosocial and ethical concerns – is revisited in lectures, panel presentations and interactive workshops throughout the two days of the Symposium.

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… I hope you enjoy the 2015 POGO Symposium!

Sincerely,

David Malkin, MD, FRCPC
Chair, 2015 POGO Symposium Planning Committee
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
Synopsis

The 2015 POGO Multi-Disciplinary Symposium on Childhood Cancer – An Integrated Approach to Relapse – will examine what happens to the child, family and health-care team at the time of, and following relapse, the associated physical, psychosocial and medical issues that arise, and the resources, tools and strategies that may be harnessed to address these unique challenges. Pediatric oncologists, nurses, social workers, and other health care professionals will enhance their knowledge of management options for patients at the time of relapse toward an ultimate goal of integrated care.

Learning Objectives

1. List the differences and similarities in palliative and aggressive treatment approaches for patients with relapsed cancer and describe how these approaches can improve care.
2. List the signs and symptoms of grief and loss experienced by the professional caregiver and describe approaches to minimize or alleviate these.
3. Describe the differences between primary and relapsed tumors at the molecular level and understand the techniques by which these molecular differences can be identified.
4. List and describe the benefits and risks for patients in the use of complementary therapies in the context of end-of-life care.
5. Quantify the economic impact of different end-of-life care options.
6. Summarize the qualitative, quantitative, religious, ethno-cultural, legal and ethical principles required to guide families through difficult decisions at the time of relapse.

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

The 2015 Symposium is an Accredited Group Learning Activity (Section 1) as defined by the Maintenance of Certification program of the Royal College of Physicians and Surgeons of Canada, approved by the University of Toronto (9.5 credits). 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™.

ONCC for ONC-PRO – Points for renewal of CPON certification:
The accredited continuing education is in the category of Continuing Medical Education, and may be used for points toward renewal by ONCC (Oncology Nursing Certification Corporation).

Posters

The 2015 Symposium features 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 to get your poster passport stamped. Hand in your completed passport (including your vote for best overall poster) at the registration desk for a chance to win your registration to next year’s Symposium!
Program, Day 1 - Friday, October 30

8:00 am – 8:55 am • Registration & Continental Breakfast

8:55 am – 9:00 am Opening Remarks
David Malkin, MD, FRCP (C)

9:00 am – 9:45 am
Care of the Relapsed Patient: The Current State of Affairs
Adam Rapoport, MD, FRCP, MHS; Brenda Weigel, MD, MSc

9:45 am – 10:30 am
Care for the Professional Caregiver
Leeat Granek, PhD

10:30 am – 10:45 am • Morning Break (Poster Boards on display)

10:45 am – 11:30 am
Delving Deep: The Biology of Relapsed Tumours
Michael Taylor, MD, PhD, FRCSC

11:30 am – 12:30 pm • Dedicated Poster Viewing and Judging (coffee & tea available)

12:30 pm – 1:30 pm • Lunch (Poster Boards on Display)

1:30 pm – 2:45 pm
Workshop A – Quality or Quantity: Guiding Families through Difficult Decisions (Prince Ballroom)
Andrea Frolic, PhD; Pamela Hinds, PhD, RN, FAAN; Shayna Zelcer, MD, FRCP

Workshop B – How Religion and Culture Affect Advanced Care Medical Decision Making (Princess Room)
Pamela Mosher, MD, MDiv; Gerardo Quintanar, BA (PH), PhD (Th); Randi Zlotnik Shaul, JD, LLM, PhD

Workshop C – Canada on Capacity: Legal and Ethical Implications (Crown Room)
Rose Geist, BSc, MD, FRCP(C); Hon. Stephen Goudge, O.C.; Lawrence Jardine, MD, FRCP

Workshop D – Bridging the Divide: The Role of Complementary Therapies in End of Life Care (North York Room)
Lynda Balneaves, PhD, RN; Elena Ladas, PhD, RD

2:45 pm – 3:00 pm • Afternoon Break (Poster Boards on Display)

3:00 pm – 3:45 pm
Optimizing Treatment, Integrating Care: Palliative and Aggressive Approaches
Jaclyn Beca, MSc; Pamela Hinds, PhD, RN, FAAN; Adam Rapoport, MD, FRCP, MHS; Brenda Weigel, MD, MSc

3:45 pm – 4:30 pm
Toward Integrated Care
Donna Johnston, MD, FRCP, FAAP
Program, Day 2 - Saturday, October 31

7:30 am – 7:55 am • Continental Breakfast

7:55 am – 8:00 am
Opening Remarks
David Malkin, MD, FRCP (C)

8:00 am – 8:45 am
A Fine Balance: The Economics of Drug Therapy
Jaclyn Beca, MSc; Suzanne McGunn, RN, BScN, MPA; Judy Van Cleavef, RN, BScN, MN

8:45 am – 9:30 am
Select Poster Presentations and Updates
Post-Chemotherapy Measles, Mumps and Rubella (MMR) Titters in a Pediatric Population – Lauren Friedman
An In-Progress Mixed Methods Study to Test the Usability of an Interactive Communication Tool to Help English- and French-Speaking Children Express their Cancer Symptoms – Rachel Hamilton
Impact of a Manualized Group Intervention for Bereaved Parents with Complicated Grief Symptoms: 3-Month Follow-Up – Kyleigh Schraeder
POGO Mucositis Practice Guidelines – Paul Gibson

9:30 am – 10:00 am • Morning Break & Poster Viewing

10:00 am – 11:15 am
Workshop A – Quality or Quantity: Guiding Families through Difficult Decisions (Prince Ballroom)
Andrea Frolic, PhD; Pamela Hinds, PhD, RN, FAAN; Shayna Zelcer, MD, FRCP(C)

Workshop B – How Religion and Culture Affect Advanced Care Medical Decision Making (Princess Room)
Pamela Mosher, MD, MDiv; Gerardo Quintanar, BA (PH); PhD (TH); Randi Zlotnik Shaul, JD, LLM, PhD

Workshop C – Canada on Capacity: Legal and Ethical Implications (Crown Room)
Rose Geist, BSc, MD, FRCP(C); Hon. Stephen Goudge, O.C.; Lawrence Jardine, MD, FRCP(C)

Workshop D – Bridging the Divide: The Role of Complementary Therapies in End of Life Care (North York Room)
Lynda Balneaves, PhD, RN; Elena Ladas, PhD, RD

11:15 am – 11:30 am • Lunch is served for Lunch and Learn Session

11:30 am – 12:15 pm • Lunch and Learn:
Radiation, Palliation, Communication – Discussing Recurrent Malignancies and the Role of Radiotherapy
Normand Laperriere, MD, FRCP(C), FRANZCR(Hon)

12:15 pm – 12:30 pm • Closing Remarks & Goodbye

Time for Q&A has been built into every session:
Plenary sessions – 5-10 minutes of Q&A
Workshops – 30-35 minutes of Q&A and interactive discussion
Faculty

Lynda Balneaves, RN, PhD
Director, Centre for Integrative Medicine
KY and Betty Ho Chair in Integrative Medicine
Associate Professor, Faculty of Medicine and Leslie Dan Faculty of Pharmacy
Scientist, Princess Margaret Cancer Centre

Dr. Lynda Balneaves is an Associate Professor in the Leslie Dan Faculty of Pharmacy and the Department of Psychiatry, Faculty of Medicine, University of Toronto. She is the inaugural Director of the Centre of Integrative Medicine, a collaboration of the Faculty of Medicine and the Leslie Dan Faculty of Pharmacy, as well as The Scarborough Hospital. She holds the Kwok Yuen and Betty Ho Chair in Integrative Medicine at the University of Toronto and is a Scientist in the Department of Psychosocial Oncology and Palliative Care at the Princess Margaret Cancer Centre.

Dr. Balneaves’ research program is focused on knowledge translation and supporting informed treatment decisions in people interested in using complementary therapies. Since 2007, she has been the principal investigator of the Complementary Medicine Education and Outcomes (CAMEO) research program, which has focused on the development and evaluation of education and decision support strategies for people living with cancer who are using complementary therapies. Dr. Balneaves has been active on a variety of intervention studies on select complementary therapies and lifestyle interventions in cancer care. She is also involved in health services and policy research related to medical cannabis in Canada.

Jaclyn Beca, MSc, Manager, Pharmaeconomics Research Unit
Cancer Care Ontario

Jaclyn completed her MSc in Health Services Research with a focus on Health Economics at the University of Toronto’s Institute for Health Policy, Management and Evaluation (IHPME). As Manager of the Pharmaeconomics Research Unit at Cancer Care Ontario, she works with policy-makers, clinicians and researchers to develop and evaluate analyses assessing the cost-effectiveness of new therapies for cancer drug policy and reimbursement. Her research interests include economic evaluation of cancer screening and treatment interventions, the role of pharmaeconomic evidence in reimbursement decision-making, and knowledge translation and exchange (KTE) for health economic methods and findings.

Andrea Frolic, PhD
Director, Office of Clinical & Organizational Ethics, Hamilton Health Sciences, Hamilton
Assistant Professor, Department of Family Medicine, McMaster University, Hamilton

Andrea is currently the Director of the Office of Clinical & Organizational Ethics at Hamilton Health Sciences, and Assistant Professor in the Department of Family Medicine at McMaster University. She has a Ph.D. in Anthropology from Rice University in Houston, Texas, including a two-year fellowship in Clinical Ethics at the University of Texas, MD Anderson Cancer Center. Since her appointment at HHS in 2004, Andrea has focused her efforts on developing an integrated ethics program including: clinical ethics consultation; end of life care infrastructure; a regional ethics network to connect hospital and community care; and mindfulness-based interventions for healthcare professionals designed to enhance resilience and reflective practice. Andrea has published on a wide range of topics, including: pandemic triage; narrative ethics; health policy and the intersection of nationalism and bioethics discourses. Andrea is a freelance choreographer and dancer whose work focuses on the unspoken, embodied dimensions of healthcare practice. Andrea’s extracurricular passions include her two kids, singing, yoga and chocolate.

Rose Geist, BSc., MD, FRCPC
Chief and Medical Director, Mental Health Program
Trillium Health Partners; University of Toronto
Medical Psychiatrist, Hospital for Sick Children

Dr. Geist is the Chief and Medical Director of the Mental Health Program at Trillium Health Partners University of Toronto and a medical psychiatrist at the Hospital for Sick Children. She had been the Inaugural Director of the Medical Psychiatry Program in Pediatrics, University of Toronto until 2009. She has provided support for medical/surgical and psychiatric teams working with youth whose capacity to consent to treatment requires assessment and understanding. She has published and lectured widely in the area of an understanding assessment and guidelines of capacity of youth to consent to treatment in both medical and psychiatric settings.
Hon. Stephen Goudge, O.C.,
Counsel, Paliare Roland Rosenberg Rothstein LLP, Toronto

Leeat Granek, PhD
Head, Gerontology Department; Assistant Professor of Psychology
Department of Public Health, Faculty of Health Sciences
Ben-Gurion University of the Negev, Beer Sheva, Israel
Leeat Granek, PhD is the head of the gerontology department and an assistant professor of psychology in the Department of Public Health, Faculty of Health Sciences at Ben-Gurion University of the Negev. Dr. Granek’s expertise and research areas are in grief and loss, psycho-oncology, women’s mental health, and qualitative methods. She is currently the Principal Investigator on several mixed-methods studies examining among other topics: oncologists experiences of patient death; how oncologists, nurses and social workers identify suicide risk in cancer patients; and barriers and facilitators to mental health care among Jewish and Arab women with breast cancer. Her academic published works focus on the emotional lives of healthcare professionals, the pathologization of grief and mourning, qualitative methodologies, and how families of cancer patients cope with caregiving. She frequently presents her work at oncology centers around the globe including Memorial Sloan Kettering Cancer Cancer in New York, and Princess Margaret Hospital in Toronto. She has published about her work extensively in academic journals and in the popular press including in the New York Times, The Huffington Post, and Slate Magazine.

Pamela Hinds, PhD, RN, FAAN
Director, Department of Nursing Research and Quality Outcomes
Children’s National Medical Center, Washington

Lawrence F. Jardine, MD, FRCP(C)
Section Head, Pediatric Hematology Oncology
Children’s Hospital, London Health Sciences Centre
Dr. Lawrence Jardine is the Medical Director of the Bleeding Disorders Program, Pediatrics. Dr. Jardine is the head of the section of Paediatric Haematology and Oncology and Associate Professor at the University of Western Ontario (UWO).
Dr. Jardine studied at the Memorial University of Newfoundland earning his Bachelor of Medical Science and his Doctor of Medicine. In 1987 he entered his paediatric residency training at Janeway Child Health Centre also in Newfoundland and then undertook a one year clinical fellowship at the CHWO. He completed his fellowship in haematology and oncology at the Manitoba Cancer Treatment Centre before returning to the Janeway Child Health Centre where he was appointed section head and principal investigator for the Children’s Cancer Group.
He is a member of the Association of Haemophilia Clinic Directors of Canada (AHCDC) and is on the Board of Directors of the Paediatric Oncology Group of Ontario (POGO). He holds membership in the American Society of Paediatric Haematology Oncology, the American Society of Haematology and the American Society of Clinical Oncology. He is an investigator with the US National Cancer Institute.

Donna Johnston, MD, FRCP(C), FAAP
Pediatric Hematologist/Oncologist, Children’s Hospital of Eastern Ontario
Professor of Pediatrics, University of Ottawa
Dr. Donna Johnston completed her pediatric training at the University of Ottawa and her fellowship at the Fred Hutchinson Cancer Research Center in Seattle. She joined the staff at the Children’s Hospital of Eastern Ontario as a Pediatric Hematologist/Oncologist in 2001 and became the Chief of the Division of Hematology/Oncology in 2012. She is a Professor of Pediatrics at the University of Ottawa.
Dr. Johnston is a researcher at the Children’s Hospital of Eastern Ontario Research Institute and is the Principal Investigator on a melatonin phase 1 study and the Vice Chair of a Children’s Oncology Group phase 2 study on Nilotinib in chronic myeloid leukemia. She is the Chair of the COG Palliative Care and Quality of Life Committee, a member of the Cancer Control Steering Committee and a member of the Acute Myeloid Leukemia steering committees at COG. Her current research focuses included melatonin in oncology patients, extramedullary AML, neuro-oncology, oncology supportive care and palliative care in oncology patients.
Elena J. Ladas, PhD, RD
Assistant Professor of Nutrition in Pediatrics and in the Institute of Human Nutrition
Columbia University Medical Center
Co-Director, Center for Comprehensive Wellness
Division of Pediatric Hematology/Oncology/Stem Cell Transplant
Dr. Ladas joined the Integrative Therapies Program at its inception in 1998 and now serves as Co-Director Center for Comprehensive Wellness, Columbia University. She is also Assistant Professor of Nutrition in Pediatrics, and at the Institute of Human Nutrition in Columbia University Medical Center.
Dr. Ladas is an internationally known researcher focusing on supportive care for children with cancer. She co-chairs the Nutrition Committee of Children’s Oncology Group, a national organization investigating nutritional interventions to alleviate short and long term toxicities of cancer treatments. She is also co-author of Integrative Strategies for Cancer Patients: A Practical Resource for Managing the Side Effects of Cancer Therapy.
Dr. Ladas is Co-Chair of the International Society of Pediatric Oncology, PODC Nutrition Working Group, developing research and educational programs to enhance nutritional care for young cancer patients in developing countries.

Normand Laperriere, MD FRCPC FRANZCRI(Hon)
Division of Hematology/Oncology
Hospital for Sick Children
Department of Radiation Oncology
Princess Margaret Cancer Centre
Professor, Radiation Oncology, University of Toronto
Norm Laperriere completed his undergraduate and Radiation Oncology training at the University of Toronto in 1984. He soon after joined the Princess Margaret Cancer Centre and currently leads the programs in Tumours of the Central Nervous System and Eyes. In 1998 he joined the Hospital for Sick Children where he has since been involved in the management of children with cancer.
He is the author of more than 130 original publications and 28 reviews and chapters and has lectured extensively on the clinical management of children and adults with tumours of the brain and eyes.

Suzanne McGurn, RN, BScN, MPA
Assistant Deputy Minister and Executive Officer
Ontario Public Drug Programs
Suzanne McGurn was recently appointed as the Assistant Deputy Minister and Executive Officer of Ontario’s Public Drug Programs, a program that provides access to over 3.3 million Ontarians and over 4200 drugs. Suzanne’s previous role was Assistant Deputy Minister for Health Human Resource Strategy Division.
Suzanne’s background is nursing and she has worked in the health-care environment for over 25 years. The first half of her career was in a variety of clinical roles - spanning acute care, chronic care, corrections, industry and home care. In 2000, she joined the Ministry of Health and Long-Term Care where she has been, through a variety of positions, engaged with health care in a differently rewarding way. Her career has provided the opportunity to see the value and difference that our healthcare system makes every day – touching the lives of patients and their families often at times when they are at their most vulnerable.
Suzanne is a graduate of Queen’s University with both a Bachelor or Nursing Sciences and a Masters of Public Administration.
When not working, Suzanne heads home to Tamworth, a tiny community north of Napanee.

Pamela J. Mosher, M.D., M.Div.
Staff Psychiatrist
Pediatric Psychiatry Consultation-Liaison Service
Hospital for Sick Children
Pamela Mosher is originally from the United States (Boston), and received her education at Duke University (B.Sc.), Harvard University (M.Div.), and Stanford University School of Medicine (M.D.). She completed her combined residency training in pediatrics, adult psychiatry and child/adolescent psychiatry fellowship at Brown University (2011). She is currently Assistant Professor in the Department of Psychiatry at the University of Toronto and a staff psychiatrist with the Consultation-Liaison Psychiatry service at The Hospital for Sick Children in Toronto. From 2012-2015 she was an Assistant Professor in the Departments of Psychiatry and Pediatrics at Dalhousie University, and worked at the IWK Health Centre, initially as a pediatric palliative care physician and then as a child/adolescent psychiatrist. Her interests include child and adolescent grief; the emotional and psychological experiences of children and youth with life-limiting illness; the medical education of physicians in end of life communication, difficult conversations, and grief; and clinician/trainee wellness. She was a 2011 recipient of the Laughlin Fellowship from the American College of Psychiatrists.

Gerardo Quintanar, BA (Ph), PhD (Th)
Manager Spiritual Support Services, Children’s Hospital of Eastern Ontario
Dr. Gerardo Quintanar was born in Mexico and moved to Canada in 1981. Gerardo holds a Bachelor’s degree in Philosophy from Dominican College in Ottawa, Canada, a Masters in Divinity from St. Thomas Aquinas in Rome, Italy and a Doctorate in Theology from the Dominican College. Gerardo worked as an Outreach Coordinator and Community Developer for the Catholic Immigration Centre in Ottawa. In 1999 he joined CHEO (Children’s Hospital of Eastern Ontario) as the Manager of Spiritual Support Services. In addition, Gerardo is the Consultant for Spiritual Care at Roger’s House (pediatric palliative hospice of Ottawa) and leads Cultural Competency and Interpretation at CHEO.
Adam Rapoport, MD, FRCPC, MHSc
Medical Director, Paediatric Advanced Care Team (PACT)
Hospital for Sick Children
Medical Director, Emily’s House Children’s Hospice
Assistant Professor, Departments of Pediatrics and Family & Community Medicine, University of Toronto

Adam Rapoport is a general pediatrician with a Masters in bioethics. His palliative care career began in 2009 when he joined the Temmy Latner Centre for Palliative Care at Mount Sinai Hospital, as their pediatric consultant. In July 2011 Adam became the first Medical Director of the Paediatric Advanced Care Team (PACT), the palliative care service at SickKids. PACT provides both inpatient and outpatient palliative care to children with life-threatening illnesses, and their families, including grief and bereavement support. In 2013 Adam became Medical Director at Toronto’s first pediatric residential hospice – Emily’s House. Adam’s academic work focuses on the intersection of his 3 primary interests: pediatrics, palliative care and ethics.

Michael Taylor, MD, PhD, FRCSC
Neurosurgeon
The Hospital for Sick Children
Principal Investigator
The Arthur and Sonia Labatt Brain Tumour Research Centre
Associate Professor, Departments of Surgery and of Laboratory Medicine and Pathobiology
University of Toronto

Dr. Taylor was born in Calgary, Alberta and was educated at The University of Western Ontario where he obtained his MD in 1994. He entered the University of Toronto Neurosurgery residency program in 1994. He then did a PhD in Molecular Pathology at the University of Toronto (1998-2002), and completed his residency training in 2003. In 2003 Michael was awarded a Detweiler Travelling Fellowship from the Royal College of Physicians and Surgeons of Canada for fellowship training in paediatric neurosurgery and paediatric neuro-oncology at St. Jude Children’s Research Hospital in Memphis, Tennessee. Dr. Taylor also did a post-doctoral fellowship in the Department of Developmental Neurobiology at SJCRH.

Dr. Taylor joined The Hospital for Sick Children (SickKids), Division of Neurosurgery in 2004. He has an appointment in the Developmental & Stem Cell Biology Program at the SickKids Research Institute. He is a principal investigator at the Arthur and Sonia Labatt Brain Tumour Research Centre. He also has cross-appointments to the Departments of Surgery & Laboratory Medicine and Pathobiology at the University of Toronto. His research is supported by the Canadian Institutes of Health Research (CIHR), Genome Canada, National Cancer Institute of Canada, National Institutes of Health (USA), American Brain Tumor Association and SickKids Foundation. He has published close to 100 peer reviewed publications. Dr. Taylor’s laboratory focuses on the genetics of paediatric medulloblastoma and ependymoma. Clinically, he has a special interest in paediatric neuro-oncology.

Judy Van Clieaf, RN, BScN, MN
Vice President, Clinical
The Hospital for Sick Children, Toronto

Judy Van Clieaf is Vice-President, Clinical, at The Hospital for Sick Children, where she provides strategic and operational leadership to several clinical programs and services including the Cancer Centre, Solid Organ and Bone Marrow Transplant Programs, Dialysis Unit, Genetics’ Centre, Psychology Department, Operating Room, and Surgical Inpatient Units. Van Clieaf has held a variety of leadership positions with 28 years of experience in paediatric and tertiary health care. She played a key role in a $39 million capital expansion and redesign of oncology ambulatory facilities, provided leadership oversight across several departments to attain and maintain accreditation and regulatory compliance for the hospitals transplant programs, and led the establishment of a centralized Newborn Screening Program at SickKids. Van Clieaf currently sits on the Provincial Steering Committee for Solid Organ Transplant and serves on the Boards of Directors of the Pediatric Oncology Group of Ontario (POGO) and Ronald McDonald House Toronto.

Ms. Van Clieaf was recognized for her leadership by SickKids in 1992 with an Excellence in Nursing Practice Award and in 2012 with the President Award. She holds a Bachelor of Science from Ryerson University and a Master of Nursing from the University of Toronto.

Brenda Weigel, MD, MSc
Associate Professor, Department of Pediatrics; Director, Division of Pediatric Hematology/Oncology
Lehman/Children’s Cancer Research Fund Endowed Chair in Pediatric Cancer; Chair, Children’s Oncology Group Developmental Therapeutics Committee
University of Minnesota, Minneapolis

Dr. Brenda Weigel is a Pediatric Hematologist/Oncologist at the University of Minnesota Masonic Children’s Hospital. Dr. Weigel received her medical degree from McMaster University in Hamilton, Ontario. She came to the University of Minnesota in 1996 to do her fellowship. During her fellowship, Dr. Weigel worked in the lab of Dr. Bruce Blazar and developed a mouse model in which to study a rare cancer called rhabdomyosarcoma. Dr. Weigel is currently the Director of the Division of Pediatric Hematology/Oncology. She is an associate professor cross-appointed at the University of Minnesota’s Cancer Center and the Department of Pediatrics, and the recipient of the Lehman/Children’s Cancer Research Fund Endowed Chair in Pediatric Cancer. She is also the Co-Director of the Sarcoma Program in Pediatric Oncology in the Masonic Cancer Center, Chair of the Sarcoma Translational Working Group Executive Committee in the Masonic Cancer Center, and Medical Director of the Clinical Trials Office of the Masonic Cancer Center. Dr. Weigel’s translational research interests are centered in her extensive involvement with the Children’s Oncology Group (COG) leading the development of new therapies for children with cancer nationally.
Shayna Zelcer, MD, FRCPC
Staff Physician, Paediatric Hematology/Oncology
Children’s Hospital, London Health Sciences Centre
Associate Professor, Department of Paediatrics
Schulich School of Medicine and Dentistry
Dr. Zelcer is a staff physician in Paediatric Hematology/Oncology at Children’s Hospital, London Health Sciences Center (LHSC). She has an academic appointment at the University of Western Ontario, Schulich School of Medicine and Dentistry as an Associate Professor in the Department of Paediatrics. She is the local Principal Investigator for Children’s Oncology Group (COG). Dr. Zelcer’s current research interests are in the areas of paediatric palliative care, neurooncology, and survivorship. She is the principal investigator of the current national project entitled: Development of a quality of life instrument for children with advanced cancer: the pediatric advanced care quality of life scale (PAC-QoL).

Randi Zlotnik Shaul, JD, LLM, PhD
Director, Bioethics Department
The Hospital for Sick Children
Dr. Randi Zlotnik Shaul is Director of the Bioethics Department at The Hospital for Sick Children. In that role she provides ethics consultation, bioethics education and policy support and conducts bioethics research. Randi is an assistant professor in the Department of Paediatrics, has an appointment in the Department of Surgery and is a member of the University of Toronto’s Joint Centre for Bioethics. Randi has a degree in political science from McGill University, a law degree from Osgoode Hall, and a Master of Laws degree and a Ph.D. in bioethics from the University of Toronto. Before graduate school Randi practiced law at the Ontario Ministry of Health. Her current research interests include accountability and the interface of law and ethics, the introduction of innovative therapies and tensions and synergies between models of patient and family centred care.
ACTIVITIES OF DAILY LIVING AND QUALITY OF LIFE IN SURVIVORS OF CHILDHOOD BRAIN TUMOUR

Demers C*1,2, Gélinas I1,3, Carret AS2
1 McGill University, Montreal, Qc
2 CHU Sainte-Justine, Montreal, Qc
3 Montreal Center for Interdisciplinary Research in Rehabilitation, Laval, Qc

Objective: Innovations in medical technology have led to earlier diagnoses and improved treatment of cancers, increasing the survival rate to nearly 70% for children with brain tumours (BT) in North America (American Cancer Society, 2009; Canadian Cancer Society, 2011). Nevertheless, survivors are left to struggle with a host of issues that often leave them unnecessarily disabled or, at the very least, only able to function at a level that is not optimal. The impact of late effects on function and daily living activities are poorly documented and quantified; existing research that measured performance in activities of daily living (ADL), from an objective perspective using standardized evaluation tools, are rare in the literature (Parks et al., 2009). The aim of this research is to address the functional outcomes and health-related quality of life (HRQoL) of adolescent and young adult survivors of childhood BT. The focus is on performance in ADL and HRQoL as they reflect the everyday life of survivors beyond the acute diagnosis and treatment phases. The primary objective is to estimate the extent to which survivors of childhood BT achieve a level of performance in ADL that is comparable to their peers 5 years after diagnosis. The secondary objectives are: 1) to explore the association between observed limitations in motor and process skills and the HRQoL of BT survivors; 2) to determine which factors are likely to be associated with performance limitations.

Method: A cross-sectional study was conducted with a convenience sample of 36 survivors of childhood BT recruited from a long-term follow-up clinic at CHU Ste-Justine in Montreal. The Assessment of Motor and Process Skills (AMPS), a standardized objective measure, was used to evaluate the quality of ADL task performance, and a generic instrument, the SF-12 questionnaire, to measure HRQoL.

Results: Survivors of childhood BT had significantly lower performance in ADL compared to age-norms (p<0.05). Furthermore, their functional level was found to be positively associated with the physical component scale ($r^2=0.5$) and the mental component scale ($r^2=0.3$) of the SF-12. Lower level of functioning was associated with age at diagnosis for process skills; and gender, tumour location, time since treatment and chronic health conditions for motor skills.

Conclusion: Understanding the impact of cancer and its treatment on the life of childhood cancer survivors emphasizes the importance of the long-term follow-up. It also provides foundation for the creation of specialised rehabilitation programs aiming at improving the functional level and HRQoL of survivors.
Background: Developed in Norway, Sisom is an interactive, rigorously tested, computerized, communication tool designed to help children with cancer express their perceived symptoms. Children travel virtually from island to island rating their symptoms on a 5-point Likert scale. While Sisom has been found to significantly improve communication in patient consultations in Norway (Ruland, 2012), usability testing is warranted with children in Canada prior to further use. The objective of this in-progress study is to test the usability of Sisom in terms of ease of use, usefulness, aesthetics, and item comprehension from the perspective of English- and French-speaking children diagnosed with cancer.

Methods: A multi-site, mixed-methods, two-phase, usability study is currently in-progress with a purposive sample of children with cancer aged 6 to 12 years. Participants complete 8 Sisom usability tasks captured with Morae 3.3 usability software, which includes creating an avatar, selecting the first island, travelling to the five islands (About Managing Things; My Body; Thoughts and Feelings; Things One Might Be Afraid Of; At the Hospital) to rate their symptom severity, and generating a symptom report. Morae is being used for automatic recording and analysis of all verbalizations and screen shots. After completing Sisom, children discuss their Sisom experience in an audiotaped, semi-structured interview which includes questions about what they liked and disliked about the software, and whether they would like to use Sisom again. Parents are offered the choice to remain by their child’s side but requested not to interrupt the testing. Data are transcribed and analyzed descriptively.

Results: To date, 26 children have participated in this study. The majority of participants liked using Sisom and able to complete the 8 tasks. The majority of children (n = 24, 92%) found Sisom easy to use although 11 children (42%) needed support using the Likert scale. Twenty-two (85%) children thought Sisom was useful and would like to use it again at the hospital. In terms of aesthetics, the children enjoyed the graphics, and indicated their favorite island was ‘At the Hospital’. Some symptoms were not understood by at least one child requiring clarification by the interviewer such as “Tired of talking and nagging”, “Treatment is uncomfortable”, and “Central line dressing hurts”.

Conclusion: English- and French-speaking children enjoyed using Sisom and were able to complete the 8 usability tasks. They found Sisom easy to use, useful, and aesthetically pleasing. Suggestions for improvement and adjustment may optimize the use of Sisom for children in Canada, and help clinicians overcome the challenges assessing children’s symptoms in a child-friendly manner. Future research includes testing feasibility via pilot randomized controlled trial.

References:

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ARE PEDIATRIC ONCOLOGY PATIENTS AND CAREGIVERS RECEIVING THE INFLUENZA VACCINE? A QUALITY ASSURANCE STUDY

Grace Lee*, Vicky Rowena Breakey1,2
1McMaster University, Hamilton, ON
2McMaster Children’s Hospital, Hamilton, ON

Objective: Although immunocompromised patients are at higher risk of influenza, children with cancer are particularly vulnerable to both the infection and to secondary bacteria infections (Kersun et al., 2013). Data indicates that the influenza vaccine can protect pediatric oncology patients from influenza-related morbidity and mortality (Kersun et al., 2013; Centers for Disease Control and Prevention, 2013; Ontario Government, 2015). In addition, patients’ caregivers, other immediate household contacts and healthcare professionals should also be vaccinated as an adjunct strategy to limit exposure (Lessin et al., 2012). The purpose of this study was to determine vaccination rates in the 2014-15 season for pediatric oncology patients, their caregivers and healthcare providers at McMaster Children’s Hospital, and to determine any potential barriers to the influenza vaccination.

Method: A cross-sectional study using a novel questionnaire surveyed 42 caregivers of children with cancer and 56 healthcare professionals in both inpatient and outpatient Hematology/Oncology clinics at McMaster Children’s Hospital in February 2015.

Results: The response rate was 71% (30/42) for caregivers and 70% (39/56) for healthcare providers. Family members reported that 13/30 (43%) pediatric oncology patients undergoing active chemotherapy received their influenza vaccine in 2014-15. Families reported low vaccination rates of 43% for at least one parent and 40% for siblings of children with cancer. Of the healthcare providers surveyed, 30/39 (77%) reported receiving their influenza vaccine. 70% of parents surveyed felt that the vaccination was easily accessible for their child to receive, whereas all of the healthcare professionals felt it was easily accessible. Several barriers were identified amongst the caregivers, including a lack of time, difficulty attending a community vaccination clinic, etc.

Conclusion: Many McMaster pediatric oncology patients and their immediate household contacts were not vaccinated against influenza. Staff vaccination rates were also sub-optimal. Additional education may assist in informing families of the importance of influenza vaccination. Additional system-based changes, including the administration of vaccines in the outpatient clinic, may improve vaccination rates and protect children from influenza and its sequelae.
“BY PARENTS, FOR PARENTS”: THE PROCESS OF GENERATING AN INFORMATION TOOL TO SUPPORT PARENTS OF CHILDREN NEWLY DIAGNOSED WITH CANCER

Rands-Flanagan C*1, Dilay L*1, Moloney J1,2, Alexander S1,2
1Haematology Oncology Family Advisory Council, Hospital for Sick Children, Toronto
2Division of Haematology Oncology, Hospital for Sick Children, Toronto

Objective: Parents of children newly diagnosed with cancer need information regarding the disease, their child’s treatment plan as well as information about practical aspects of navigating hospital systems and resources for support. Paucity of easily accessible and consistent information regarding practical aspects of hospital navigation and supportive care resources were identified as a target for improvement by members of The Hospital for Sick Children’s Haematology Oncology Family Advisory Council (FAC).

Method: The Hospital for Sick Children Haematology Oncology Family Advisory Council (FAC) consists of twelve parents of children with cancer or serious blood disorders and ten staff members representing various disciplines including nursing, social work, systems quality, and medicine. Parent members of the FAC created a list of information needs (unrelated to specific cancer diagnosis or their specific treatments) that they felt were likely important to most parents of children newly diagnosed with cancer. The list was discussed and refined over several FAC meetings. A parent survey aimed at gathering broader feedback was generated and was approved as a formal quality improvement project by the Sick Kids Quality and Risk Management committee. The survey was administered to 54 parents in the haematology oncology clinic to gather input on perceptions of importance of various types of information and feedback regarding best timing post diagnosis for the provision of information. A clinic map was generated by a nurse intern. Based on the survey data and FAC member input, an information pamphlet was generated. A prolonged process of approvals was undertaken and completed within Sick Kids and with each community based agency included in the pamphlet.

Results: Version one of the “Resource Guide for Families Facing Childhood Cancer developed by Oncology Families for Families” has been completed. The document is being provided to new oncology families to supplement other written information sources including the COG family handbook and disease and drug specific tools. Contents of the resource guide include information on financial resources, in hospital and community based support services, practical tips in navigating care at the hospital and suggestions for other information sources. Feedback on the utility of the booklet and suggestions for modifications are being sought. In addition to a paper version, the guide will be made available to families on the Garron Cancer Center web page and the Haematology / Oncology section of the SickKids website.

Conclusion: Experienced parents of children with cancer have unique and important insights into the needs of new families. The FAC provides an opportunity to gather parent input and generate solutions in attempts to improve care. A systematic approach to identifying information needs and a substantial and sustained effort by members of the FAC has lead to the creation of a unique resource. A similar guide for families with serious blood disorders is near completion.
Objective: Approximately 1500 cases of childhood cancer are diagnosed each year in Canada (Childhood Cancer Canada Foundation, 2011). In 2014, there were 160 cancer deaths in individuals between the ages of 0 to 19 (Canadian Cancer Society, 2014). Family dynamics are shifted after a pediatric cancer diagnosis, with mothers often assuming much of the extra caregiving demands (Fletcher, 2010, Fletcher, 2011). As such, the objective of this research was to further explore the lived experiences of mothers of children with pediatric cancer during diagnosis, treatment, and the period thereafter.

Method: Nine mothers (aged 32 to 47) from Southern Ontario who had children treated for cancer were recruited for participation. Participants were given consent forms and background questionnaires, and then participated in a one-on-one, semi-structured interview that was recorded. In order to ensure credibility, each participant was given a copy of their transcript. Phenomenology was the theoretical orientation used to guide the research.

Results: The overarching theme of the research was caregiving for a child with cancer, particularly mothers of those children. Three sub-themes emerged from the data, being (1) providing medical care, (2) dedication of time, and (3) support from others. Each of these sub-themes will be discussed. Mothers expressed that they tried to provide as much medical care to their children as possible, in order to spend more time with them as well as to comfort them. Some of these responsibilities included attending all appointments and administering medications. Additionally, mothers stated that they gave up or lessened the amount of work done outside the home in order to care for their ill children, as they wanted to be present for anything regarding their children’s condition. Further, in some cases, their children requested for them to stay for comfort. Lastly, mothers stated that they received support from their spouses, family, friends, and children's school while undergoing the cancer journey with their children. In many cases, this support was a silver lining to these mothers, as it was difficult at times to maintain balance and normalcy for their families.

Conclusion: Overall, all of the mothers conveyed that a pediatric cancer diagnosis is daunting not only to children, but to their families as well. Mothers are often more likely to take time off work to care for their children, while their spouse continues to work. In many cases, this becomes overwhelming for mothers. On top of previously established parenting roles, mothers are now faced with increased responsibilities that accompany caring for their children with cancer. Further studies should examine the role of fathers and siblings when faced with a pediatric cancer diagnosis in order to determine how cancer affected their lives. As well, further research could extend into the lives of mothers whose children have died, and compare differences across family dynamics with mothers whose children survived their cancer diagnosis.
COST-UTILITY ANALYSIS OF THERAPEUTIC DRUG MONITORING FOR ASPARAGINASE IN PEDIATRIC LEUKEMIA

Rayar M1,2*, Penner M2,3, Sander B2,4,5, Wijeysundera H2,6,7,8

1Division of Paediatric Haematology/Oncology, Department of Paediatrics, The Hospital for Sick Children. 2Institute of Health Policy, Management and Evaluation, University of Toronto. 3Child Development Program, Holland Bloorview Kids Rehabilitation Hospital 4Toronto Health Economics and Technology, University of Toronto. 5Public Health Ontario. 6Division of Cardiology, Sunnybrook Health Sciences Centre 7Institute for Clinical Evaluative Sciences, University of Toronto. 8Evaluative Clinical Sciences, Schulich Health Research Program, Sunnybrook Research Institute

Objective: Asparaginase is a chemotherapeutic agent used for pediatric acute lymphoblastic leukemia(ALL). Therapeutic drug monitoring(TDM) is used to detect patients with clinically silent inactivation of this drug. These patients experience inferior outcomes if their therapy is not changed. This project aimed to determine the costs and quality adjusted life years(QALYs) generated by asparaginase TDM compared to the current standard treatment, no TDM.

Methods: This cost-utility analysis took a government health-care payer perspective and lifelong time horizon. Probabilities for the development of silent inactivation and other clinical outcomes were derived from published literature. For each identified health state, a health utility(from published literature) and cost per person in 2014 Canadian dollars(from government publications) were assigned. All parameters were inputted into a Markov decision model to determine the incremental cost-effectiveness ratio(ICER). One-way sensitivity analyses were performed for all variables to assess the impact of parameter uncertainty, and two-way analysis was performed for those variables with threshold values causing the ICER to pass above/below $50,000/QALY.

Results: TDM is associated with an increase in life expectancy of 3.4 years, from 55.6 years to 60 years. The use of TDM produces 14.4 QALYs at a lifetime cost of $319,500. Current standard treatment(without TDM) generates 14.3 QALYs at a cost of $312,500. The resulting ICER is $94,000/QALY. Using a willingness to pay(WTP) threshold of $50,000/QALY, only variation in stem cell transplant treatment costs for relapsed patients and the discounting rate are associated with a threshold where TDM becomes the preferred strategy. The ICER was also very sensitive to small decreases in specificity and thus the detection of false positive cases. In contrast, the same magnitude changes in cost-effectiveness are only seen if the sensitivity of TDM falls below 0.4.

Conclusions: The use of asparaginase TDM for pediatric ALL is associated with a small increase in life expectancy and QALYs as well as an increase in health care costs. Consideration of other societal and ethical factors must be made prior to implementation of this technology.
DEVELOPING A STORYBOOK OF CHILDREN’S CANCER NARRATIVES: A FEASIBILITY STUDY

Sabanayagam M1, Punnett A2
1 University of Toronto Faculty of Medicine, Toronto, ON
2 The Hospital for Sick Children, Toronto, ON

Objective: Since the 1970s, a growing body of literature has explored the potential of storytelling and narrative in the pediatric cancer population (Woodgate, 2006; Bearison, 1991; Bluebond-Langner, 1978). While such studies have provided valuable insight into the childhood cancer experience, they are mainly targeted to an academic audience. To date, there are no published anthologies or storybooks written for children and families themselves about the experience of living with childhood cancer. Rarely have children had the opportunity to voice their stories in their own words, share their stories with a broader audience, and read the stories of other children living with cancer (DasGupta, 2007). The goals of this pilot project are to 1) assess the feasibility of developing a storybook of personal narratives written by and for children with cancer, 2) identify motivators and challenges to this process and 3) understand how a storybook intervention may help gauge children’s health literacy about their condition.

Method: Semi-structured, in-depth interviews were conducted with five children, aged 7-10 years, from the pediatric oncology unit at The Hospital for Sick Children, Toronto, about the subjective experience of living with cancer. Transcripts were re-written as coherent stories and compiled into a book draft. Ethnographic field notes and personal reflections were recorded post-interview. Thematic analysis of stories was done around health literacy and a feasibility assessment made as to motivators and challenges to the storybook-making process. Feedback from families was solicited during interviews and through an online survey. Ethics approval for this project was obtained through the SickKids Quality Risk and Management Board.

Results: Three themes were identified under informational health literacy: dichotomous understanding of cancer biology (“good cells” and “bad cells”), gap between actual and perceived knowledge (children often underestimated their understanding of cancer biology and treatment), and “getting poked” (identified commonly as the toughest part of their illness). Under experiential health literacy, four themes were identified: strong insight into one's personal transformation, use of passive voice, interest in helping others, and tendency to describe troubling experiences in a positive light. Motivators to the storybook-making process included enthusiasm of children and families and the niche for such an initiative given the lack of story-based resources. Challenges included variability in children’s storytelling styles, variability in their publishing preferences, and the subjectivity of translating interviews into story format.

Conclusion: Based on the feasibility assessment and feedback from families, it appears that a storybook of personal narratives from children living with cancer would be an important resource. Children displayed a remarkable degree of “health literacy” on both the biomedical and experiential fronts, showing a strong grasp of cancer biology and registering the transformations in one’s inner self and emotions. This suggests the need to consider both branches of health literacy in future qualitative health research studies, as health literacy has traditionally been defined in a purely informational way. Ongoing evaluation and feedback from families will help refine the storybook and ensure it is a repertoire of candid and realistic narratives about what it is like to live with cancer.

References
DEVELOPMENT OF A CANADIAN SCHOOL REINTEGRATION GUIDELINE FOR CHILDREN WITH CANCER

Chung J*1, Klinck A2, Robinson P3,4, Seelisch J5, Drybrough K4,5, Howitt MJ6, Johnson B7, Pryor R8, Rassekh R1,9, Taylor L1, Tims A10, Witol, A11, Dupuis LL5

1Department of Psychology, Oncology/Hematology/BMT Program, Children’s & Women’s Health Centre of British Columbia, Vancouver, BC
2Psychology, Children’s Hospital, London Health Sciences Centre, London, ON
3C17, Toronto, ON
4Pediatric Oncology Group of Ontario, Toronto, ON
5The Hospital for Sick Children, Toronto, ON
6IWK Health Center, Halifax, NS
7Candlelighters Simcoe Parents of Children with Cancer, Simcoe, ON
8Saskatoon Cancer Centre, Saskatoon, SK
9University of British Columbia, Vancouver, BC
10Thames Valley District School Board, London, ON
11Stollery Children’s Hospital, Edmonton, AB

Objective: To describe the development of the Canadian C17 School Reintegration Guideline for Children with Cancer. This guideline aims to provide pediatric oncology health care providers, children, families, and the school community with recommendations for school reintegration planning for children with cancer.

Method: A pan-Canadian, inter-disciplinary panel of experts was convened to develop the health questions addressed in the guideline, synthesize the available evidence and develop recommendations using established guideline methods. Librarian-scientist assisted systematic literature searches were undertaken. The quality of evidence was assessed and the strength of each recommendation was determined using GRADE methodology. The draft guideline has undergone an extensive external review by international content experts. It will also be reviewed by stakeholders (Canadian pediatric oncology physicians, psychologists, social workers, nurses, child life specialists, community educators and parents). The guideline will be revised based on this feedback.

Results: A de novo guideline was developed based on a systematic review of the primary literature. The guideline provides recommendations to facilitate the process of children continuing with their education after a cancer diagnosis including: service coordination, psychosocial needs assessment, patient/family support, education of school staff and peers, and ongoing monitoring/follow-up for the children. Research gaps are identified.

Conclusions: The evidence-based guideline recommendations apply to all school-aged patients (Junior Kindergarten through Grade 12) with cancer. The scope of the guideline is limited to the psychosocial aspects of school re-entry. Patient and family needs and preferences, available resources, organizational and governmental policies will determine the extent of implementation of the recommendations in each jurisdiction. The impact of these recommendations on the quality of life of children with cancer requires prospective evaluation.
Objective: Despite the development of numerous cancer-specific, youth quality of life (QoL) measures, no single measure comprehensively captures the areas of concern for youth with poor prognosis cancers (Solans, 2008). Unfortunately, 20% to 30% of youth will not be cured of their disease (Tomlinson et al., 2011). For these individuals it is important to aim to improve cure rates, but also to ensure effective integration of palliative care to improve QoL. The Pediatric Advanced Care Quality of Life Scale (PAC-QoL) has been developed for this purpose. Previously, item generation, content validation, and assessment of item comprehension have been conducted (Cataudella et al., 2014; Morley et al., 2014). The current study describes the fourth of five stages in scale development, scale administration and the evaluation of face and structural validity.

Method: Four versions of the PAC-QoL are examined; two self-reports (child, ages 8–12; adolescent, ages 13–18) and two parent reports (toddlers, ages 2–4; children and adolescents, ages 5–18). Across eight Canadian pediatric oncology centres, 157 youth with poor prognosis cancers (as evidenced by disease relapse or progression on front line therapy, predicted two year event-free survival <50%, or a malignancy for which the oncologist believed there was no realistic chance of cure) and/or their parent completed the suitable version of the PAC-QoL and the corresponding validity questionnaire (yes/no; “Do you think this is an important question to ask children with cancer?”). Researchers and experts in the field reviewed responses with the aim of modifying or removing items to improve face validity and condense the scale for use in a clinical setting. A confirmatory factor analysis of the a priori five-factor QoL framework used in the PAC-QoL development will be conducted on the remaining items.

Results: Across all versions (170 items total), 54 items were left unchanged, 48 were removed and 68 were modified following researcher and expert consensus. The resulting versions of the PAC-QoL contain 26-29 items each. Reasons for item modification or removal include: low validity rating, low endorsement of occurrence, lack of item clarity or appropriateness, and item redundancy. Data suggested parents were unable to accurately answer questions about children younger than four. Similarly, children younger than nine experienced difficulties with self-report items and parents often felt unable to act as a proxy in such cases. Accordingly, age ranges associated with each version were adjusted as follows: parent report on “young children” ages 4-8, parent report on “older children” ages 9-18, child self-report for ages 9-12 and adolescent self-report for ages 13-18. A confirmatory factor analysis, using principal factors as the extraction method, will be presented on the poster to determine if the five-factor priori QoL framework used in the development of the PAC-QoL is supported.

Conclusion: Items on all versions of the PAC-QoL were modified to ensure face validity, and the structural validity of the scale will be assessed. Changes to age ranges and length of each version improve the practicality of the scale for clinical use. The PAC-QoL is ready for large-scale distribution for psychometric evaluation. This scale is a valuable tool for objectively assessing QoL and the efficacy of supportive care interventions for children with poor prognosis cancers, which cannot be captured by existing approaches.
FEVER CARDS: A TOOL TO IMPROVE IDENTIFICATION OF ONCOLOGY PATIENTS AND AID IN MORE TIMELY AND APPROPRIATE ANTIBIOTIC ADMINISTRATION

Decourcy, Mary Jo¹, Martin, Colleen², Gibson P¹,³
¹ Children's Hospital, London Health Sciences Centre
² Chatham – Kent Community Health Centres
³ Department of Pediatrics, Western University

Introduction: Febrile Neutropenia remains an important cause of morbidity and mortality in pediatric cancer care (Castagnola et al., 2007). Prompt administration of antibiotics has been shown to be associated with decreased morbidity and improved outcomes (Fletcher et al., 2013). Nevertheless, several barriers to timely antibiotic administration exist, particularly in after hour settings outside of an oncology specific clinic setting.

Methods: We evaluated a variety of potential barriers to timely administration of antibiotics in pediatric oncology patients presenting to our pediatric emergency department. Amongst these barriers, we noted that it was at times challenging for patients to be properly identified as oncology patients, timing of antibiotics (before or after a CBC result) and proper antibiotic selection were thought to be of high priority. Our section therefore instituted a Fever Card system for all on treatment patients. These cards are provided to families with the instruction to bring them to all Emergency Department visits. The cards provide basic diagnosis and treatment information and suggested empiric antibiotic coverage. The card allows personalizing the empiric coverage for patients with issues such as allergy, renal dysfunction or a history of resistant organisms.

Results: Three different Fever Card templates have been created and implemented. These include specific cards for patients on induction therapy for leukemia, post bone marrow transplant and general oncology patients. All patients at Children's Hospital have been provided with a card.

Conclusions: Fever cards have proven to be a valuable tool to address some identified barriers in prompt antibiotic therapy in oncology patients. Future work will look to address the additional barriers to prompt therapy such as physician and nurse education, medical directives and optimized patient flow.
Impact of a Manualized Group Intervention for Bereaved Parents with Complicated Grief Symptoms: 3-Month Follow-Up

Schraeder, K.¹*, Cataudella, D.¹,²
¹The University of Western Ontario, London, ON
²Children’s Hospital at London Health Sciences Centre, London, ON

Objective: Due to the unique bond shared between a parent and child, bereaved parents present an increased risk for developing significant psychological problems such as anxiety and depression, and prolonged or complicated grief (Kreicbergs et al., 2004; Zetumer et al., 2015). Healthcare professionals provide a range of bereavement services and interventions, including support groups and psychotherapy (Donovan et al., 2015). There is very limited research, however, on the efficacy of such interventions. Consistency in outcome measures used across studies and assessment of specific grief-related symptoms are lacking. Heterogeneity among treatment groups and small sample sizes also complicate interpretation of findings (Endo et al., 2015). The aims of this research are: (1) to describe the clinical presentation of a targeted self-referred sample of bereaved parents who participated in group-based complicated grief treatment (CGT) and (2) to assess parents’ grief-related symptoms before, after, and 3-months following the intervention.

Method: The CGT manual developed for this study uses a cognitive behavioral model that incorporates education about typical grief reactions and CG symptoms, with coping strategies for addressing both loss-oriented grief stressors (e.g., processing the loss, dealing with intrusions, etc.) and restoration-oriented stressors (e.g., revisions to life roles, goals, priorities, etc.) (Shear et al., 2005; Strobe & Schut, 2010). A total of 38 parents (21 mothers, 17 fathers; M= 43 years of age) whose children died from a medical condition 3 months to 2 years earlier participated in four separate groups, held between 2011 and 2015. Among the deceased children (n=22; ages 2-18 years), cancer was the most common medical condition (n=8). Parents completed self-report measures of overall psychological functioning, grief symptoms, and post-traumatic growth (PTG) at 3 time points: baseline, post-, and 3-months after group completion. Clinically meaningful and reliable change was assessed using specified measure cut-offs and the Standard Error of Measurement method (Eisen et al., 2007).

Results: At baseline, 75% of parents (N=36) fell in the clinical range (T-score ≥65) for depression. Of those who had clinically significant depression scores at baseline, 48% showed reliable improvement at 3-month follow-up; 52% remained stable. A repeated measures ANOVA (n=20) showed statistically significant change between depression scores at pre- and both post-assessment and 3-month follow-up (F(2,38)= 4.77, p=.01). Parents’ grief and PTG scores at follow-up assessments indicated no significant change. Parents consistently reported most PTG in how they relate to others and their appreciation of life, and least growth in spiritual change and viewing new possibilities (e.g., developing new interests, establishing new paths in life). Of the parents (n=13) whose children died from cancer, almost all (92%) had clinically significant depression scores at baseline and one third had clinically significant anxiety. At 3-month follow-up (n=9), 37% showed clinically reliable improvements for depression; grief and PTG were similar to rest of group.

Conclusion: About half of bereaved parents with clinically significant depressive symptoms at baseline showed reliable clinical improvement after receiving CGT, which was maintained 3-month follow-up. During the first two years since their child’s death, many bereaved parents continued to exhibit significant CG symptoms and showed limited PTG. This might explain why some parents continued to have depressive symptoms. Despite modest clinical improvements, the majority of parents reported high satisfaction with the group and would recommend it to other bereaved parents. Larger sample sizes and a longer follow-up period are needed to better understand the recovery trajectory, treatment effects, and other important factors (e.g., culture, spouse’s/family functioning) on outcomes.
INTELLECTUAL OUTCOME IN MOLECULAR SUBGROUPS OF MEDULLOBLASTOMA

Moxon-Emre I*1,2,3, Taylor M D1,2, Bouffet E1, Hardy K4, Campen C5, Malkin D1,2,3, Hawkins C1,2, Laperriere N2,6, Ramaswamy V1, Scantlebury N1, Spiegler B1, Janzen L1, Law N1,2, Walsh K S4, and Mabbott D1,2

1 Hospital for Sick Children, Toronto, ON
2 University of Toronto, Toronto, ON
3 Pediatric Oncology Group of Ontario, Toronto, ON
4 Children’s National Medical Center, Washington, DC
5 Lucile Packard Children’s Hospital, Palo Alto, CA
6 Princess Margaret Hospital, Toronto, ON

Objective: Medulloblastoma is a heterogeneous disease comprised of at least four molecular subgroups: WNT, SHH, Group 3 and Group 4. These subgroups have distinct demographic, genetic and clinical features, yet their respective intellectual outcomes are unknown. With the advent of subgroup-specific therapy de-escalation strategies, the goal of the present study was to characterize intellectual functioning in each subgroup, and to evaluate the implications of reducing treatment.

Methods: One hundred and twenty one patients with medulloblastoma (51 Group 4; 25 Group 3; 28 SHH; 17 WNT), treated between 1991 and 2013 at the Hospital for Sick Children (Toronto, Canada), Children’s National Medical Center (Washington, DC) or the Lucile Packard Children’s Hospital (Palo Alto, CA), had longitudinal intellectual functioning evaluations. First, we compared IQ measures between subgroups, controlling for demographic and clinical variables that differed between them: sex, age at diagnosis, craniospinal radiation (CSR), chemotherapy and mutism. Next, we evaluated the effect of: a) radiation intensity (i.e. reduced-dose radiation with a focal tumor bed (TB) boost vs. treatments that deliver higher radiation doses and/or larger boost volumes to the brain), and b) mutism, on full scale IQ (FSIQ) in each subgroup. Growth curve analysis was used to determine the stability or change in IQ scores over time.

Results: Subgroups declined comparably in all IQ measures except processing speed (PS). SHH had lower baseline PS, and declined less, than Groups 3 and 4 (all P<0.05). Mutism was a significant covariate for all IQ measures (all P<0.05). Across all subgroups, patients treated with higher intensity protocols declined in FSIQ (all P<0.01). In WNT and Group 4, reduced-dose CSR with a TB boost was associated with improved (P=0.005) and stable (i.e. a non-significant increase) FSIQ (P=0.28), respectively. In contrast, Group 3 and SHH patients treated with reduced dose CSR and a TB boost showed non-significant declines in FSIQ (all P>0.05). Although FSIQ decline did not differ according to mutism status for any subgroup (all P>0.05), Group 3 patients with mutism had lower baseline FSIQ (P=0.014).

Conclusion: Despite displaying similar intellectual functioning trajectories, subgroups may not benefit equally from treatment reduction. Namely, therapy de-escalation appears to be a suitable way to achieve optimal intellectual functioning in patients with WNT and Group 4 medulloblastoma only.

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INTRACRANIAL HAEMORRHAGE IN PAEDIATRIC ONCOLOGY PATIENTS

Betcherman L*, Pole J, Estcourt L, Stanworth S, Sung S, Lieberman L

1 University of Toronto, Toronto, ON
2 Paediatric Oncology Group of Ontario, Toronto, ON
3 University of Oxford, Oxford, UK
4 Hospital for Sick Children, Toronto, ON
5 University Health Network, Toronto, ON

Background: Intracranial haemorrhage (ICH) is a rare but serious complication seen in paediatric oncology patients. ICH is recognized both as a result of the malignancy itself, and of its treatment. Furthermore, it is associated with significant long-term morbidity and mortality. Studies have shown that ICH risk factors differ between the general population and those with cancer, and vary with the type of malignancy. In adults, several factors have been shown to increase the risk of ICH in cancer patients including hypertension, tumor invasion or compression of blood vessels, sepsis, DIC and thrombocytopenia. However, few studies have directly examined the incidence, risk factors and clinical outcomes for ICH in the paediatric oncology population.

Objectives: (1) To assess the incidence and risk factors for the development of ICH in paediatric oncology patients and (2) To assess morbidity and mortality 24 hours and 30 days following the event.

Methods: A retrospective chart review of oncology patients <18 years of age treated between 1995-2014 at the Hospital for Sick Children (HSC) was conducted. Patients were identified in two ways: 1) The Paediatric Oncology Group of Ontario (POGO) identified ICH cases from their database and (2) the entire POGO database was cross-linked with ICD-9 and ICD-10 coded ICH from Health Records at HSC. Controls were selected via a case-crossover design. The first admission prior to the ICH was chosen as the control admission with the discharge date >14 prior to the ICH. Data regarding demographics, cancer diagnosis and treatment, risk factors, clinical outcome post-ICH, vital signs and laboratory data, and infectious history were collected.

Interim Results: Methods 1 and 2 independently identified 63 and 136 cases, respectively. 61 were excluded based on no radiological documented ICH or cancer diagnosis, traumatic ICH, or lack of available data. The remaining 138 cases were described in terms of number of bleeding episodes (200 episodes), and by diagnosis: group 1 (non-brain tumor, 23 cases, 25 bleeds), group 2 (brain tumor, 25 cases, 38 bleeds). 96 bleeds occurred within two weeks of neurosurgery, and were also excluded. Primary descriptive statistics were applied to the first 48 patients (63 bleeding episodes), without analysis performed on the controls. For group 1 bleeds, risk factors included: IV beta-lactams (80%), IV antifungals (32%), L-asparaginase (32%), bone marrow transplants (4%). 68% of group 1 intracranial haemorrhages were preceded by a suspected or proven infection. Within 48 hours of the ICH, the majority of patients were transfused (68%), and transferred to the ICU (68%). A smaller proportion received ICH medications (24%), and 68% had their chemotherapy treatment suspended (20%). 30 days following the event, 28% remained in hospital (8% in ICU). 24% experienced neurological sequelae, 20% required surgical intervention, and 12% died. Logistic regression models will be used to assess the risk factors and their association with the development of ICH.

Future Directions: This pilot study assessed risk factors for paediatric oncology patients who develop ICH. Future research will be undertaken in other paediatric centers across Ontario to further investigate these risk factors and to identify any differences between treatment sites.
“IT’S A BIG DEAL, BUT IT ISN’T”: BALANCING GRIEF AND SURVIVAL WHEN A CHILD HAS A BRAIN TUMOUR

Eaton Russell C\(^1,2\), Bouffet E\(^1,3\), Beaton J\(^2\)
\(^1\) The Hospital for Sick Children, Toronto, Ontario
\(^2\) University of Guelph, Guelph, Ontario
\(^3\) University of Toronto, Toronto, Ontario

**Objective:** While researchers have explored many important aspects of living with childhood cancer, including the multitude of strains on family members and their reactions, very little is known about the experiences of children with brain tumours and their parents (Forinder & Norberg, 2010). Despite being the second most common form of childhood cancer and the leading cause of solid tumour deaths (Canadian Cancer Society, 2013), these children have been underrepresented in psychosocial research because of their varied abilities, protocols and prognoses (Jackson et al., 2009). Researchers have explored the impact of diagnosis and treatment on families, and how families react (Bhat et al., 2005; Hildenbrand, Clawson, Alderfer & Marsac, 2011; Patterson, Holm & Gurney, 2004). This research team sought to explore the experiences of childhood brain tumours from the perspectives of children and their parents.

**Method:** Using a qualitative approach, this research team employed grounded theory methods to explore the unique and shared elements of the experiences of childhood brain tumours, from the perspectives of these children and their parents. Semi-structured interviews were conducted with twelve children between the ages of 6 and 14, and one of each of their parents for a total of 24 participants.

**Results:** Woven throughout their stories were expressions of grief and uncertainty related to the tumour and its effects on their lives. Children and parents described efforts and strategies that they used to try to maintain a positive outlook and a sense of normalcy, in order to cope and to adapt to the struggles and the changes in their lives.

**Conclusion:** A substantive theory of Balancing Grief and Survival was developed, offering a lens through which to view the children’s and parents’ complex experiences, struggles and coping strategies as integrated, dynamic processes. This presentation will introduce participants to this theory, illustrated by quotes and insights shared by the children and their parents. Elements of their experiences that were common, and those that varied for children and their parents' will be explored, as well as their important implications for future research and clinical practice.

**References:**


LINGUISTIC VALIDATION OF AN INTERACTIVE COMMUNICATION TOOL TO HELP FRENCH-SPEAKING CHILDREN EXPRESS THEIR CANCER SYMPTOMS

Louli J1,2, Tsimicalis A3, Le May S4,5, Stinson J6,7, Rennick J1,2, Vachon MF3, Berube S3,7, Treherne S1,2, Yoon S8, Nordby Bøe T9, and Ruland C9

1 Ingram School of Nursing, Faculty of Medicine, McGill University, Montreal, QC
2 Montreal Children’s Hospital, McGill University Health Centre, Montreal, QC
3 UHC Sainte-Justine, Montreal, QC
4 Faculty of Nursing, University of Montreal, Montreal, QC
5 The Hospital for Sick Children, Toronto, ON
6 Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, ON
7 Department of Psychology, University of Montreal, Montreal, QC
8 School of Nursing, Columbia University, New York, United States
9 Oslo University Hospital, Oslo, Norway

Background: Sisom is an interactive, computerized tool designed to help children with cancer communicate their perceived symptoms (Ruland, Starren, & Vatne, 2008). Despite rigorous testing in Norway, important design issues relevant to other childhood cancer populations remain unexplored, including: (a) the need to identify a methodological approach for linguistically validating Sisom and (b) linguistic validation of a French version of the tool. The purpose of this study was to adapt a methodological approach (Varni, 2002) to linguistically validate Sisom with a group of French-speaking children with cancer, their parents, and health care professionals.

Methods: A single-site descriptive qualitative study was conducted at a university-affiliated hospital in Montreal, Canada. The linguistic validation process entailed the following steps: (1) forward translation to French, (2) backward translation to English, (3) patient testing, (4) production of a Sisom French of the tool, (5) patient testing of the prototype, and (6) production of the final Sisom French prototype. A panel of experts (i.e. recruited health care professionals and members of the research team) oversaw each of the 6 steps and produced reconciled Sisom French versions and summary reports after each meeting. Descriptive content analysis was used to analyze the data derived from the audio-recorded expert panel meetings and patient testing interviews.

Results: Four independent translators were hired for steps 1 and 2. Five healthcare professionals and ten children and their parents participated in the study. Health care professionals actively oversaw the translation process (steps 1 to 6) and provided clinically meaningful suggestions derived from their practice. Two rounds of patient testing (steps 3 and 6), which included parental participation, resulted in the emergence of the following themes: (a) comprehension, (b) suggestions for improving the translations, (c) usability, (d) parental engagement, and (e) overall impression.

Conclusion: Overall, Sisom was well received by participants who were forthcoming with input and suggestions for improving the French translations and linguistically validating Sisom. Our proposed methodology may be replicated for the linguistic validation of other e-health tools. Future research includes testing the usability of Sisom with French-speaking children with cancer.

References:

MAINTENANCE OF COMPETENCY OF VENOUS PORT ACCESSING IN INFREQUENT USERS: AN EDUCATIONAL INITIATIVE

Kidd C.*, Card K.*, Gibson M.
South Eastern Ontario Cancer Center at KGH, Kingston, Ontario

Introduction: Vascular access devices (VADs) are becoming essential to support patients requiring acute and chronic treatment of illnesses (Douglas, Aspin, Jimmeson, & Lawrance, 2009). Pediatric oncology patients require frequent vascular access for blood sampling chemotherapy and other intravenous medications, transfusions, etc. Pediatric patients rely on their venous access devices and nurses are at the forefront of central line care. Studies have shown that increasing self-efficacy will reduce the number of vascular access device complications and delay in patient treatment (Ngo & Murphy, 2005; Tian, Zhu, Qi, Guo, & Xu, 2010; Yap, Karapetis, Lerose, Iyer, & Koczwar, 2006). Increasing self-efficacy and knowledge is important for the healthcare team but also for patients and their family. We must form a partnership with our patients as defined by a patient-centered approach (Poochikian-Sarkissian, Sidani, Ferguson-Pare, & Doran, 2010). Maintaining competency of added skills can be challenging for healthcare providers in both adult/pediatric settings. Accessing venous ports in an area that has a low pediatric population can create barriers to maintaining skill proficiency. With a lack of competency, pediatric oncology patients are at an increased risk for potential infection, delay in initiation of antibiotic therapy, and added fear/anxiety both patients and their healthcare provider.

Method: Data collection via surveys given to healthcare providers at 2 time points: prior to implementing teaching tools and six months after. A teaching poster will provide helpful tips, illustrations and a YouTube video site to assist with troubleshooting. The teaching posters will be displayed in targeted areas of our institution. Surveys would be provided to nurses in those areas with key questions related to their comfort level and frequency of accessing ports. After six months, follow up surveys to evaluate outcomes for healthcare providers will be evaluated. This may also include a pre and post chart audit, if approved, to be included within our research results. The health care providers will be provided with a wallet card, to refer to if needed, with bullet points on the accessing process. The importance of patient/family education is also emphasized, and therefore wallet flash cards will be provided, covering proper techniques in accessing venous ports.

Conclusion: The patient experience is important. We hope to encourage patients/family members to advocate for a protocol driven access procedure. The goal is to enhance the competency and confidence of the healthcare providers when accessing venous ports. Lower anxiety levels among patients and an improved healthcare provider/patient/family relationship is also anticipated.

NAUSEA AND VOMITING FOLLOWING INTRAVENOUS ADMINISTRATION OF ERWINIA ASPARAGINASE IN PEDIATRIC PATIENTS UNDERGOING TREATMENT FOR ACUTE LYMPHOBLASTIC LEUKEMIA: A SINGLE-CENTRE CASE SERIES

Reniers D\textsuperscript{1}, Orr C\textsuperscript{1}, Gibson P\textsuperscript{1,2}

\textsuperscript{1} Children’s Hospital, London Health Sciences Centre
\textsuperscript{2} Department of Pediatrics, Western University

Introduction: Asparaginase is a crucial element of paediatric acute lymphoblastic leukemia (ALL) and lymphoblastic lymphoma (LL) therapy. Up to 30\% of patients who receive \textit{E.coli} derived products will develop hypersensitivity reactions requiring a change to the antigenically distinct product, \textit{Erwinia} asparaginase (EA) (Wang et al., 2003; Vrooman et al., 2010). EA in addition to all other asparaginase products have been classified previously as being minimally emetogenic, regardless of route of administration (Dupuis et al., 2011). Our early experience with delivering EA by IV has suggested nausea and vomiting is far more common when administered IV. We report our institution’s experience thus far.

Methods: Our series involves seven children between the ages of 8 months to 13 years receiving IV EA; data was collected over a 14-month period. Most patients received IV EA 25,000 units/m\textsuperscript{2} on a Monday, Wednesday, Friday schedule for six doses. Five of these patients had also received intramuscular (IM) EA doses at some time in their treatment course. Two patients received only IV EA doses.

Results: Six of seven children experienced nausea during the IV EA infusion and five experienced vomiting. Four patients had nausea and vomiting persisting well after the infusion, lasting up to 24 hours. All patients received 5-HT3 antagonists as an anti-emetic prior to IV EA administration with little effect. None of the patients who received IM EA required anti-emetic prior to therapy and there was no reported nausea or vomiting in any patients.

Conclusions: In our limited experience we have found the IV delivery of EA to be significantly emetogenic. We suggest that clinicians provide antiemetic prophylaxis as they would for agents classified as having moderate to high emetic risk (Dupuis et al., 2013).
We present a case of a girl who was diagnosed at 11 months of age with an atypical teratoid/rhabdoid tumour of the posterior fossa with a synchronous metastatic lesion in the right frontal area. She was treated with surgery, high-dose chemotherapy, stem-cell rescue, and tamoxifen maintenance. She was identified to have a partial deletion of exons 1-5 of the *SMARCB1* gene at five years of age confirming her diagnosis of Rhabdoid Tumour Syndrome. She followed the SickKids surveillance protocol and underwent imaging of her brain by MRI and of her abdomen and pelvis by ultrasound every six months until the age of eight. She continued annual imaging of her brain by MRI thereafter. She remained cancer-free for eight years. At nine years of age, she presented with a malignant rhabdoid tumour of her left thigh. This extra-cranial and extra-renal lesion has required revisiting surveillance protocols.

Rhabdoid Tumour Syndrome is caused by a germline pathogenic variant in the *SMARCB1* tumour suppressor gene. Classically, young children with a germline pathogenic variant have a high risk for developing aggressive atypical teratoid/rhabdoid tumours of the central nervous system as well as renal and extra-renal rhabdoid tumours. Rhabdoid tumours occur predominantly in infants younger than one year of age with an incidence of five per million in the first year of life, 0.6 case per million from ages 1-4, 0.1 from ages 5-9 and 0.04 from ages 10-14 (Stiller 2007).

In a study of 106 children who were diagnosed with extra-cranial rhabdoid tumours, the most common site was the kidney, accounting for 48% of cases. 14% of tumours arose in the head and neck, 13% in the liver, and 25% in a wide range of other sites in the trunk and arms, but no cases of rhabdoid tumour of the lower limbs were recorded. The tumour site tended to change with increasing age with an increased number of extra-cranial and extra-renal rhabdoid tumours being diagnosed after the age of five (Brennan 2013).

AT/RT and rhabdoid tumours have traditionally had a very poor prognosis. Most patients with either tumour have a high mortality rate and poor prognosis. As treatment continues to improve, there will be more long-term survivors. Secondary tumours are likely to arise with increasing age. Our surveillance protocols, therefore, must be modified accordingly. Consensus amongst team members at SickKids and in consultation with other international experts is that our patient and other paediatric survivors with *SMARCB1* pathogenic variants should undergo a dedicated MRI of the brain and abdominal and pelvic ultrasound every six months until the age of eight in addition to a rapid full-body MRI to be done on an annual basis until discharged. Future studies will be required to determine the efficacy of this new surveillance protocol.
POST-CHEMOTHERAPY MEASLES, MUMPS AND RUBELLA (MMR) TITERS IN A PEDIATRIC POPULATION

Friedman L¹, McLean H², Silva M¹²
¹Queen’s University, Kingston, ON
²Kingston General Hospital, Kingston, ON

Introduction: As a result of chemotherapy, many pediatric oncology patients lose immunity to vaccine-preventable illnesses, such as measles, mumps and rubella (Kosmidis et al., 2008). Ontario is experiencing higher than normal measles activity in 2015, with 20 incident cases as of June 3rd, compared to 22 cases in 2014 (Public Health Ontario, 2015). As such, it is critical to identify which children lose protective titers to vaccines that they have previously received, and to determine the most effective re-immunization protocol.

At Kingston General Hospital (KGH), MMR titers are checked 6 months post-chemotherapy. If non-protective, the patient receives an MMR vaccine and titers are re-checked in 6 months. This continues for a maximum of three vaccines, at which point patients are informed of their incomplete immune status but not vaccinated further.

Objectives: To establish rates of immunity to MMR in post-chemotherapy pediatric patients, and to determine the immune response to re-immunization.

Methods: Retrospective chart review of KGH pediatric oncology patients diagnosed between January 2001 and December 2014. Selected patients were over one year of age at diagnosis, had finished chemotherapy and had at least one set of MMR titers drawn.

Results: 74 patients were included in the main group analysis. Post-chemotherapy, 29/74 patients (39%) were immune to all three viruses. After three MMR vaccines, 46/74 patients (62%) were fully immune and 2/74 patients (3%) were non-immune. The remaining 26/74 patients (35%) did not have a complete set of titers, either due to relapse, clinical error or an insufficient amount of time elapsed since the last vaccine. Overall, 46/48 patients (96%) with a complete titer set were immune to MMR.

Patients had a higher likelihood of losing immunity to mumps, as opposed to measles or rubella (p=0.002). No statistically significant differences were found between sex, age group or cancer type.

Conclusions: The results of this study support our re-immunization protocol, in demonstrating that simply vaccinating children with MMR once after treatment is insufficient; up to three vaccines may be required to achieve immunity rates similar to the general population. A fixed re-immunization schedule, as recommended by Zengin & Sarper, would lead to unnecessary vaccination in some and insufficient vaccination in others (Zengin & Sarper, 2009).

Further research is required to clarify trends that, albeit not statistically significant, have been noted between age groups and cancer types.

Works Cited:
RETROSPECTIVE EVIDENCE FOR GENETIC ANTICIPATION IN VON HIPPEL-LINDAU SYNDROME

Laura Aronoff, Bailey Gallinger, Stephen Meyn, David Malkin, Jonathan Wasserman and Harriet Druker.

1 Clinical and Metabolic Genetics, SickKids, Toronto, Ontario
2 Department of Molecular Genetics, University of Toronto, Toronto, Ontario
3 Program in Genetics and Genome Biology, SickKids Research Institute, Toronto, Ontario
4 Department of Pediatrics, University of Toronto, Toronto, Ontario
5 Haematology/Oncology, SickKids, Toronto, Ontario
6 Endocrinology, SickKids, Toronto, Ontario

Background
Von Hippel-Lindau (VHL) is a rare hereditary tumour predisposition syndrome inherited in an autosomal dominant pattern. Patients are susceptible to benign and malignant tumour growth in various visceral organs and the central nervous system. Management of VHL involves frequent, lifelong surveillance for tumour growth and treatment of symptoms when they arise.

Objective/hypothesis
This study will assess if genetic anticipation exists in VHL through comparison of the age of onset (AOO) over multiple generations in familial cases. The results will aid in a review of the current surveillance recommendations for VHL patients.

Methods
A retrospective review of all VHL families (n= 27) at Sick-Kids was undertaken. Only patients with familial VHL and sufficient information to confirm a diagnosis and AOO for a minimum of two generations were included in the study (n=14 unrelated families, n=76 patients). A paired Wilcoxon Signed Rank test was used to determine if the AOO varied significantly between generations (n=60 parent-child pairs). AOO was defined as either: the age at which a VHL tumour was diagnosed, or the age at death if confirmed to have VHL.

Results
There was a significant difference in the AOO between the children and parents (p<0.001) and parents and grandparents (p=0.009).

Conclusions
Genetic anticipation is apparent in VHL as the AOO was significantly different between generations concluding that subsequent generations have an earlier age at which symptoms first arise. These results indicate a need to review current surveillance protocol recommendations for children with familial VHL.
SAFE HANDLING OF HAZARDOUS MEDICATIONS: BRIDGING THE GAP BETWEEN CURRENT STATE AND BEST PRACTICES

Costantini S*, Pinheiro-Maltez M, Hollis K, Children’s Hospital of Eastern Ontario, Ottawa, ON

**Background:** Ministry of Labour requires the institution to have policies and procedures related to safe handling of hazardous medications and materials. Following the Quality Initiative of the Program in Evidence-Based Care, Cancer Care Ontario released a guideline document on the safe handling of cytoxics in December 2013.

**Objectives:** Develop a policy and standard work that documents the trajectory of the hazardous medication, from receipt through preparation, administration and disposal. The ultimate goal of the Safe Handling of Hazardous Medication Program is to minimize the risk of occupational exposure to all employees and physicians at the hospital.

**Methods:** Using lean methodology and process maps, a student was employed to perform observation of select employees from all disciplines involved in handling hazardous medications and its waste. Process maps were developed and a gap analysis performed to best practices. The nursing discipline was tasked with the development of standard work in order to bridge the gaps between current practices and best-practices using a rapid improvement process. The working group included: Nurse Educators, frontline nurses, Pharmacist and a member of the Quality Team.

**Results:** The gap analysis identified the following inconsistent/varying nursing practices that increase the risk for exposure: set-up for administration, use of PPE when in contact with the medication or its waste, use and placement of our closed system device during line set-up, areas/surfaces used to place medication during the independent double check process and spiking of medication bag, disposal of waste (i.e lines, supplies, soiled linen, PPE, etc.) in containers not indicated for cytotoxic waste.

**Conclusion:** The Safe Handling of Hazardous Medications Program is essentially a large quality improvement project. In hopes to change practice, sustain the changes and ensure the safest work environment for staff and physicians we have ensured that frontline staff are involved in the development of standard work documents that pertain to their practice. Sustaining these changes by adhering to the policy, standard work documents and best practice guidelines will also require continuous assessment and adjustment of these processes. Through process observation, we hope to ensure a sustained change and gather feedback allowing us to continue to improve and refine our processes. Thus, ensuring we continuously provide a safe work environment.
**THE CLINICAL SIGNIFICANCE OF SUBTLE FINDINGS ON STAGING SPINAL MRI IN CHILDREN WITH MEDULLOBLASTOMA**

*Bennett JM*, *Ashmawy R*, *Stephens D*, *Laperriere N*, *Bouffet E*, *Shroff M*, *Bartels U*

1. The Hospital for Sick Children, Toronto, ON
2. Princess Margaret Hospital, Toronto ON

**Background:** Medulloblastoma is the most common malignant brain tumor of childhood, with cerebrospinal spread being the most common site of metastasis. Traditionally, treatment has been risk-stratified grouping those with visible metastatic spinal lesions on magnetic resonance imaging (MRI) as high risk medulloblastoma with subsequent increased dose of craniospinal radiation (CSI) (Gerber et al., 2014; Packer et al., 2012). With evolving MRI techniques, more detail is detected and the distinction between metastatic disease and abnormal findings without clinical relevance can be difficult. This report reviewed subtle abnormal findings such as nerve root clumping, linear vascular enhancement, nerve root enhancement and/or other vague findings on spinal MRI to elucidate their prognostic significance and aid in appropriate risk stratification.

**Methods:** This retrospective cohort study identified children (≥3 years) consecutively diagnosed and treated with medulloblastoma from the comprehensive neuro-oncology database between 1998-2012. Only children treated with upfront CSI were included, and staging MRI of the spine must have been done either pre-operatively or within 72 hours of primary tumor resection. Initial staging MRI of the spine was assessed by 2 independent reviewers blinded to patient outcome to evaluate for subtle findings. Survival analysis was done to determine if subtle findings impacted overall survival (OS).

**Results:** One hundred of 150 patients were eligible for final analysis. MRI revealed subtle findings in 48 (48%) patients. Of those 48 patients, spinal MRI was done pre-operatively in 45 (94%) patients. OS in children with subtle findings on staging MRI compared to those without any abnormal findings was not different, 81% vs. 84% respectively, while OS in M+ patients was significantly worse at 53%, *p = 0.04*.

**Conclusion:** Subtle findings are commonly seen on staging spinal MRI. This institutional review suggests that clumping or enhancement of the nerve roots, linear vascular enhancement or other vague findings were not associated with decreased OS. These findings should not prompt increased dose of CSI.

**References:**


THE EFFECTS OF EXERCISE TRAINING ON FUNCTIONAL CONNECTIVITY IN BRAIN TUMOUR SURVIVORS

Gauvreau S*1,8, Dockstader C6, Harasym D1, Piscione J3,4, Laughlin S5, Timmons B6, Bartels U3,7, Skocic J1, de Medeiros C1, Scheineman K8, Bouffet E3,7, Doesburg S10 and Mabbott D1,2,8

1Neurosciences and Mental Health, Hospital for Sick Children, Toronto, Ontario
2Department of Psychology, Hospital for Sick Children, Toronto, Ontario
3Division of Haematology/Oncology, Hospital for Sick Children, Toronto, Ontario
4Department of Rehabilitation Services, Hospital for Sick Children, Toronto, Ontario
5Diagnostic Imaging, Hospital for Sick Children, Toronto, Ontario
6Department of Paediatrics, McMaster University, Hamilton, Ontario
7Department of Paediatrics, University of Toronto, Toronto, Ontario
8Department of Psychology, University of Toronto, Toronto, Ontario
9Human Biology Program, University of Toronto, Toronto, Ontario
10Biomedical Physiology and Kinesiology, Simon Fraser University, Burnaby, British Columbia

Objective: Without treatment, many paediatric brain tumours are fatal. Recent advances in medical treatment have dramatically improved survival rates, but at a considerable cost (Louis et al., 2007). Children treated with radiation for brain tumours consistently suffer from altered brain structure and function leading to long-term cognitive impairments (Mabbott et al., 2006; Mabbott et al., 2009; Dockstader et al., 2013; Dockstader et al., 2014). Given these alterations, we would infer that there are also changes in communication between brain regions, which can be measured using functional connectivity. Exercise training has been reported to induce neural plasticity, indexed by brain structure, and improve cognitive function (Hillman, 2008; Chaddock-Heyman et al., 2013), making it a potential recovery intervention for children treated with radiation for paediatric brain tumours. This present research aims to investigate whether physical exercise can promote functional connectivity recovery in paediatric brain tumour survivors.

Methods: In a randomized crossover study, 27 patients (12F; 11.64yrs +/- 3.05SD) participated in a three-month exercise condition and a three-month non-intervention condition (Figure 1). Resting-state data was obtained at each assessment using magnetoencephalography. Time-series were reconstructed for all cortical, subcortical and cerebellar sources in the Automated Anatomical Labeling (AAL) atlas and filtered into delta (2-3Hz), theta (4-7Hz), alpha (8-12Hz), beta (13-29Hz), low gamma (30-59Hz) and high gamma (60-100Hz) frequency bandwidths. Weighted phase lag index (wPLI) values were computed to index functional connectivity among brain regions. Functional connectivity strength was calculated for all brain tumour patients before and after the study.

Results: Upon completing the study, patients in the immediate exercise group demonstrated increased theta (4-7Hz) connectivity between left inferior temporal and left prefrontal regions. This change in average theta network strength, calculated using wPLI, was 0.048 (p<0.05). In contrast, patients in the delayed exercise group showed a widespread increase in high gamma connectivity (60-100Hz) predominantly within the left hemisphere. This change in average high gamma network strength was 0.019 (p<0.05).

Conclusions: In patients, exercise intervention facilitates long-term increases in theta connectivity and potential short-term increases in high gamma connectivity. These frequencies have been previously identified as pertinent for network integration supporting high-level cognitive processes, such as cognitive control and information processing (Cavanagh and Frank, 2014; Dockstader et al., 2014). Future research will identify the effects of maturation and investigate whether functional connectivity changes are associated with structural and cognitive improvements.
THE IMPACT OF SCHOOL VISITS ON SIBLINGS OF CHILDREN WITH CANCER; A FEASIBILITY PILOT PROJECT

Sjoberg I*, Pole JD, Cassidy M, Boilard C, Costantini S, Johnston DL

1Children’s Hospital of Eastern Ontario, Ottawa, ON Canada
2Pediatric Oncology Group of Ontario, Toronto, ON Canada

Objective: It is well known that a diagnosis of childhood cancer affects not only the patient, but the entire family. Siblings can be affected by their brother or sister’s illness and live through similar stress and anxiety (Wilkins et al, 2005). The goal of this pilot study was to examine the feasibility of studying the impact of the Ontario Oncology Nurse School Visitation Program on the wellbeing and school adjustment of siblings of pediatric cancer patients. The specific objectives of this pilot study were to assess; (1) the ability to enroll patients; (2) subject retention; (3) feasibility of collecting demographic and other data elements including the reliability and validity of measures; (4) feasibility of mode of questionnaire delivery; (5) the proportion of families that have multiple siblings that are eligible for school; and (6) the logistics of study procedures.

Method: Fourteen siblings (aged 5-13 years) of children diagnosed with cancer were enrolled over a period of 18 months. The siblings were interviewed and asked to complete the PedsQL® (Varni, 1998) before and after the class visit. School attendance 3 months pre and post intervention was examined as well. Data collection was done in person or by telephone. Families with more than one eligible sibling were included but only one sibling, chosen at random, participated.

Results: All eligible siblings agreed to participate. It took 6 months longer than anticipated due to many siblings not fitting the eligibility criteria for age and distance from the hospital. The mode of data collection was agreeable to all and easy to plan and execute. School attendance showed a reduction of days missed (from a mean of 1.9 to 0.6 days missed, p=0.03) but there was not remarkable impact on PedsQL® results (p=0.62). The interviews yielded positive feedback regarding the class visit.

Conclusion: Overall, the class visits had a positive effect on the siblings as was reflected in school attendance and interviews. The data collected will help plan a future similar study.
TO EMPOWER THE SURVIVORS OF CHILDHOOD CANCER AND THEIR PARENTS BY MEETING THEIR INFORMATION NEED

Wong A *1, Teh R 1,2, Williams D 1
1 Cambridge University Hospitals NHS Trust, UK
2 Lister Hospital, Stevenage, UK

Objective: It is well recognised that survivors of childhood cancer are at considerable risk of late effects (Oeffinger et al 2006). Knowledge about the cancer diagnosis, the consequences of having the cancer treatment, the risk of late effects will all empower the parents and the cancer survivors to have better understanding, be more reassured and participate more actively in the appropriate individualised long-term follow-up care plan. Various studies have shown that there is an information need for the above in both parents and survivors (Knijnenburg et al 2010, Gianinazzi et al 2013 & Vetsch et al 2015). We have often received similar requests from our parents for more information on late effects. We aim to meet this information need by providing a personalised care plan with treatment summary when our patients have finished their cancer treatment. We are also providing them with late effects patient information - in the form of written leaflets and video clips.

Method: We check what information is available out there for various late effects. Where information is too general, too simplistic or non-existent, we start writing our own patient information after researching on the various subjects, which is then checked by our experts. Where information is already comprehensive and appropriate, we gather the materials or website links for use in our clinic area. We plan to have ipads available specifically for late effects look-up.

Results: This is an ongoing project. We have so far produced a series of “how to look after your ... after cancer treatment” written information, focussing on kidney(s), heart, lungs, eyes and hearing. These give a simple introduction to the various organs, highlighting which cancer treatments would have put the patients at risk and in what way, explain the common tests we use in follow-up, and give tips on how to keep the organs healthy. We have also written information on general healthy lifestyle tips, for example “what to do if your child gains too much weight after cancer treatment” and “healthy snack options”. These are all written in easy-to-read and understand language with attractive illustrations or pictures. Two video clips have been made, “how to look after your teeth after cancer treatment”, one targeting the younger age group and the other for teenagers. We have collected other important patient information and made them available to our patients, such as ‘Aftercure’ booklets from Children’s Cancer and Leukaemia Group, sun care information from Karen Clifford Skin Cancer Charity. The above have all been well received by our patients and their parents.

Conclusion: By providing appropriate and personalised information to our patients and their parents, they are empowered to understand better the cancer itself, the treatment and potential late effects so that they can look after themselves more effectively, enabling them to lead as healthy a life as possible after their cancer.

USABILITY TESTING OF THE PAINSQUAD+ SMARTPHONE-BASED REAL-TIME CANCER PAIN MANAGEMENT APP FOR ADOLESCENTS WITH CANCER

Jibb LA*1,2,3, Nguyen C1, Cafazzo JA2,4, Nathan PC1,2, Seto E2,4, Stevens BJ1,2, Stinson JN1,2
1Hospital for Sick Children, Toronto, ON
2University of Toronto, Toronto, ON
3Pediatric Oncology Group of Ontario, Toronto, ON
4University Health Network, Toronto, ON

Objective: This study utilized a user-centered design approach to develop and test the usability (defined as being acceptable, easy to understand, easy to navigate, and not prone to error-making) of a gamified smartphone-based real-time cancer pain management app (“Pain Squad+”) for adolescents.

Method: Three iterative cycles of qualitative usability testing involving user observation and interview were used to refine the Pain Squad+ app. Sixteen adolescents (14.8±2.0 [M±SD] years) with a variety of cancer diagnoses and pain at least once in the previous week were recruited from 1 large pediatric tertiary care center. A brief app demonstration was provided and the entire usability testing session was audio-recorded. Participants used the app while “thinking aloud” about issues encountered with the interface and content while 2 trained observers recorded difficulties and navigation errors. Participants then answered open-ended questions addressing their experience and recommendations for app improvement. Using a rapid-analysis approach, the 2 observers discussed the content of the session and developed consensus on emerging themes related to app usability and refinements were made. Audio-recordings were referred to as necessary.

Results: Overall, adolescents liked Pain Squad+ aesthetics and content, endorsed the app as a potentially clinically useful tool to manage pain, and made few errors while using the app. Cycle 1 usability issues related to: (1) streamlining navigation (recommendation for fewer taps needed to navigate the app), and (2) improving access to gamification elements (ability to review inspirational videos, which encourage compliance). Changes were made to address these recommendations. Cycle 2 issues related to the need to clearly: (1) distinguish the meaning of pain assessment questions from one another, and (2) present information related to the dose and timing of recommended pain advice. Changes were made and no new issues were identified following Iterative Cycle 3.

Conclusion: The multifaceted usability approach utilized provided insight into how a real-time pain management app can be made amenable to adolescents with cancer. Clinical feasibility testing of the app is currently ongoing and will be completed before ultimately testing intervention effectiveness in a multicenter randomized controlled trial. It is expected that an acceptable and usable app will improve pain outcomes for adolescents with cancer.
Objective: In the pediatric brain tumor population, cranial radiation therapy (CRT) is associated with volumetric reductions in the hippocampus and long-term deficits in declarative memory (Riggs et al., 2014). Studies with adult rodents report differential vulnerability of hippocampal subfields to radiation injury and ablated neurogenesis in the hippocampal dentate gyrus (T M Madsen, 2003), but the distribution of CRT-induced volumetric reductions across hippocampal subfields in humans remains unknown. Hippocampal subfields have unique cytoarchitecture and mediate distinct aspects of memory processing (Lee, Ekstrom, & Ghetti, 2014) making them an important target in understanding CRT-induced memory decline. This study examines the impact of CRT and neurological complications (hydrocephalus requiring treatment) on the distribution of volume loss across hippocampal subfields and amygdala in paediatric brain tumor survivors.

Methods: Children and adolescents treated with CRT for brain tumours (n=17) and healthy controls (n=20) were scanned at the Hospital for Sick Children (SickKids, Toronto, Canada). The patient sample includes survivors of medulloblastoma (n=14), ependymoma (n=2) and pineoblastoma (n=1). MRI images were acquired using a GE LX 1.5T and Siemens 3T MRI scanner. The multi-atlas based automatic segmentation algorithm Multiple Automatically Generated Templates (MAGeT) (Pipitone et al., 2014) was used to segment the hippocampus and proximal anatomy into the CA1, CA2/3, CA4/DG, stratum radiatum (SR)/lacunosum (SL)/moleculaire (SM), subiculum and amygdala (fig 1) and volumetric data was extracted. Raw volumes were corrected for intracranial volume using a regression based technique (Free et al., 1995). T-tests were used to assess group differences for each region in each hemisphere. A subset of patients developed hydrocephalus requiring cerebrospinal fluid diversion (n=10). Given the previously reported relationship of this condition to intellectual decline (Hardy, Bonner, Willard, Watral, & Gururangan, 2008; Moxon-Emre et al., 2014), we also assessed the impact of hydrocephalus requiring treatment on regional volumes using analysis of variance (ANOVA).

Results: The CRT group had smaller right CA2/3 (p = 0.02, mean difference = 28.6 µm³), right amygdala (p = 0.04, mean difference = 83.6µm³), left subiculum (p = 0.05, mean difference = 23.5 µm³) and marginally reduced left CA4/DG (p = 0.09, mean difference = 46.5µm³). Despite regional effects, there were no significant group differences in total hippocampal volume for either hemisphere. Compared to controls, patients with hydrocephalus requiring treatment had smaller left CA4/DG (p=0.02, mean difference = 83.3µm³), and marginally smaller left hippocampus (p=0.07, mean difference = 220.7µm³).

Discussion and Conclusion: This study is among the first to quantify the distribution of hippocampal subfield volume loss following CRT. Our results suggest that right CA2/3, right amygdala and left subiculum are especially vulnerable to the neurotoxic effects of CRT, and CA4/DG to injury sustained from hydrocephalus treatment. Volumetric reductions may reflect reduced neuron number, size or fewer connections between and within regions. Given the link between hippocampal volume loss and memory decline, alternative hippocampal-sparing radiation protocols are important to consider whenever possible to improve quality of life for survivors. Future work will examine the impact of radiation field and dose on hippocampal subfield volume and memory impairment in this population.
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