Second

SIOP PEDIATRIC PSYCHO ONCOLOGY

Meeting

genzyme

Dear colleagues and friends,

Welcome to the second SIOP-PPO meeting in Boston. Today we are coming together with psychologists, pediatric oncologists, and others from all over the world. We have the opportunity to update you with the current state-of-the art in Pediatric Psycho-Oncology.

This is the second PPO meeting and how far we have come! It was only in January 2007 that the SIOP Scientific Board approved the establishment of a committee dedicated to Pediatric Psycho-Oncology: SIOP PPO, an area of research which had not previously been represented. The Board gave us the opportunity to demonstrate over three conferences (2008-2010-2112) what Psycho-Oncology has to offer for all disciplines in SIOP.

In the context of research the purpose of the SIOP PPO is:
1. To facilitate the exchange of research data on pediatric psycho-oncology issues.
2. To support the integration of these data with current psychological research, theory, and practice.
3. To encourage the active incorporation of this psychological knowledge into clinical pediatric oncology practice.

Our first pre-meeting in Berlin in 2008 was very successful. Around 100 people joint the meeting. For the organization of the SIOP-PPO 2010 in Boston we fortunately invited Andrea Patenaude, an expert in the field, who works at the organizing Dana Farber Cancer Institute to join the SIOP- PPO committee. On behalf of the committee Martha thanks her for all effort she has put into the organization and helping us making this an enormous success.

We achieved several milestones. To attract psychologists, we approached the Board with a request for a non-medical psychosocial registration fee. We are happy with the Board's willingness to secure this discounted registration fee for SIOP Boston and will try to continue this achievement. We were able to mount an outstanding program. Apart from educational sessions with experts from the field, we offer discussion and sessions about traumatic stress, hardiness and resilience, neurocognitive impairment, stem cell transplantation, medical and family communication and brain tumour issues. You will be surrounded by senior and junior experts in the field of Psycho-Oncology.

Apart from today, the SIOP conference has more to offer. The SIOP-PPO symposium this year is called: *Into the Future: Computer and Internet Interventions in Pediatric Psycho-Oncology.* Furthermore we will have a joint symposium with the nurses on treatment adherence and a Keynote lecture will be given by Andrea Farkas Patenaude and Mary Jo Kupst. We are also proud that 3 free-paper sessions are scheduled for the SIOP conference in Boston.

We hope you will enjoy the meeting, and are looking forward to our next symposium in London 2012.

Martha Grootenhuis (chair) and Andrea Farkas Patenaude

Also on behalf of the SIOP-PPO Committee
Stephen Sands, John Spinetta, Gabi Calaminus, Esther Meijer- van den Bergh, Momcilo Jankovic, and Maria McCarthy

For any contact or information: siopppo@amc.nl

Overview of the Day: Room 310

7.30 Breakfast available provided by SIOP

8.15-9.00 **Opening**

Chairs: Martha Grootenhuis & Andrea Farkas Patenaude

- Robert B. Noll. The role of behavioral science in collaborative trials.

9.00-10.00 **Screening**

Chair: Esther Meijer- van den Bergh

- Anne Kazak. The feasibility and impact of screening for psychosocial risk at cancer diagnosis: The Psychosocial Assessment Tool (PAT).
- Maria McCarthy. What's behind the screen? Implications for clinical practice.
- Christopher Recklitis: Psychological distress in adult survivors of childhood cancer: Should we be screening?

10.00 – 10.30 **Preliminary research presentations (5 minutes)**

Chair: Stephen Sands

- Sima Zadeh. Perceived benefit and burden for youth and for parents from participation in psychosocial research when undergoing treatment for cancer, NF-1, or HIV.
- Marta Perez. Quality of life in pediatric patients with central nervous system tumors (CNST) and its relationship to sequelae and parental coping strategies.
- Marta Perez. Posttraumatic growth and resilience in adolescent survivors of childhood cancer.
- Alice Van Dijk. Quality of life in motion: A combined physical exercise and psychosocial intervention program for childhood cancer patients.
- Lori Wiener. Characterizing lone parenting: a multi-institutional pilot study on the perceptions of support and perceived stress of lone parents of children with cancer.
- Pam Wolters. Neuropsychological functioning in children with primary CNS Tumors after treatment with radiation therapy: preliminary results from baseline to six months post-radiation.

10.30- 10:45 Coffee break

10:45-12.00 **Morning Symposia (1a,1b,1c)**

12.00-13.00 Lunch on your own

13.00-14:00 **Plenary Discussion**

Chair: Andrea Farkas Patenaude

- Sean Phipps & Anne Kazak Traumatic stress as a model for understanding patient and parent response to childhood cancer.

14:00-14.30 **Preliminary research presentations (5 minutes)**

Chair: Martha Grootenhuis

- Kelly Ross. Health heroes. Living the cure- An innovative exercise intervention for childhood brain tumour survivors.
- Margaret Mannix. Sleep patterns in pediatric cancer patients.
- Lori Wiener. Understanding what adolescents think about participating in clinical research and how their perceptions compare to their parent's perceptions.
- Sunita Patel. Parent-directed intervention for children with cancer-related neurobehavioral late effects.
- Christina Salley. Social cognitive differences in pediatric brain tumor survivors and comparison peers.
- Eline Aukema. Feasibility of neurofeedback for reducing neurocognitve deficits after a childhood brain tumour.

14.30-14.45 Tea-break

14.45-16.15 **Afternoon Symposia (2a,2b,2c)**

16.15-16.45 **Key note lecture:**

Jimmie Holland

Role of SIOP in integrating psychosocial care into routine pediatric oncology treatment and fostering pediatric psycho-oncology research on a global level.

16:45-17:00 Closing

Morning Symposia

1a **Understanding neuro-cognitive impairment**

Room 310 *Chair: Debbie Waber*

- Kevin Krull. Genetic polymorphisms and the risk of neurocognitive impairment in survivors of childhood cancer .
- Donald Mabbott. Using neuro-imaging to understand neuro-cognitive late effects in paediatric cancer: What have we learned?
- Greta Wilkening. Amnesia is associated with germ cell tumours in adolescents and young adults.
- Sanne Schagen. Cognitive effects of non-CNS directed chemotherapy in survivors of childhood cancer.

1b **Resilience and hardiness**

Room 201 *Chair: Lutz Goldbeck*

- Bob Noll. Human Evolutionary Response to Trauma (HEART).
- Kerstin Wenninger. Psychological distress and cognitive coping in long-term survivors of childhood cancer.
- Sandra Sherman-Bien. A cross-cultural perspective of mothers of children with newly diagnoses cancer: results of a multi-institutional randomized trial of maternal problem-solving skills training.
- Robert Casey. Is survivor identity associated with physical and behavioural health? Results from Project REACH**.**

1c **Psycho-Oncology and Stem Cell Transplantation**

Room 209 *Chair: Sean Phipps*

- Susan Parsons. Caring for the caregiver: ehealth interventions for parents of pediatric hematopoietic stem cell transplant recipients.
- Stephen Sands. Long-Term quality of life for pediatric bone marrow transplant recipients: According to whom you ask.
- Christina Salley. Optimism and pessimism as predictors of children's functioning following stem cell transplantation (SCT).
- Maru Barrera. Health-related quality of life and related factors in mothers and fathers one and two years after pediatric stem cell transplantation.

Afternoon Symposia

2a **Outcome after childhood CNS tumors**

Room 201 *Chair: Colin Kennedy*

- Kathryn Vannatta. Social and behavioral adjustment of pediatric brain tumor survivors: Examination of factors that may modify risk.
- Thomas Pletschko. Assessment of neurocognitive functions in pediatric brain tumor patients based on the ICF (International Classification of Functioning, Disability and Health, WHO).
- Celiane Rey-Casserly. Neuropsychological and adaptive outcomes in children treated for medulloblastoma.
- Tonny Solveig Reimers. Parental rating of late effects in survivors of childhood brain tumors: associations with radiotherapy, health related quality of life and intelligence.

2b **Guidelines meeting** (former Psychosocial Committee)

Room 209

- With John Spinetta & Momcilo Jancovitz

2c **Communication with patients about challenging topics**

Room 310 *Chair: Gerry Koocher*

- Lori Wiener. Development and Clinical Use of an Advance Planning Document for Adolescents and Young Adults.
- Helena Kondryn. Treatment non-adherence in teenage and young adult cancer patients: a multi-informant, prospective study.
- Tim Eden. Should preadolescent children be present during consultations: qualitative interview study with parents in the months after their child's diagnosis with cancer.
- Katryn Cantrell. Introducing Zora CAMP4ALL: a virtual community to augment pediatric camping.

OPENING

THE ROLE OF BEHAVIORAL SCIENCE IN COLLABORATIVE TRIALS

Robert B. Noll [1]

[1] *University of Pittsburgh*

As the current chair of the Behavioral Science Committee (BSC) of the Children's Oncology Group (COG), Noll will describe current efforts to establish a group-wide protocol examining behavioral outcomes. In the United States, cancer is the leading cause of death by disease among children; approximately 9,500 new cases were diagnosed in 2006 in children under 19 years of age. Regardless, survival rates have sharply risen over the past 25 years (National Cancer Institute, 2008). While treatments have become increasingly successful, they are commonly intense, often requiring several years, many appointments, and invasive procedures. While success for phase III pediatric cancer trials has historically been measured by mortality rates, future work will undoubtedly need to include reliable and valid measures of what a child can do in a standard environment (level of capacity) as well as what they actually do in their usual environments (level of performance). This change in focus follows the International Classification of Functioning (ICF) with a stress on a child's health and functioning, rather than disease and disability (World Health Organization, 2002). Following this concern with health and functioning, much recent work has highlighted health related quality of life (HRQoL) as a priority. Considerable effort has been made to develop measures of HRQoL for children and parents, even developing specific measures for different diseases (e.g., cancer, juvenile arthritis, sickle cell) or sub-groups of diseases (e.g., pediatric brain tumours versus other cancers). These laudable efforts have resulted in a large inventory of available measures with variable psychometric qualities. Unfortunately, the majority of this work has failed to test validity using psychometrically sound measures with demonstrated developmental sensitivity (Noll & Fairclough, 2004). Moreover, HRQoL, by definition, is not expected to be especially stable over time or to have predictive validity. It is also extremely sensitive to contextual influences (Smith, Schwarz, Roberts, & Ubel, 2006). One measurement strategy that is typically not considered within the framework of HRQoL highlights a child's neurocognitive functioning. These patients reported outcomes often have exemplary psychometric qualities and most notably predict future functioning. While behavioural scientists have endeavoured to include comprehensive neurocognitive batteries within collaborative group studies in the past, rates of accrual have typically been < 30%. A new direction for the BSC within the cooperative group structure will be described including one open protocol; barriers to success; and recommendations for future efforts within the cooperative group structure.

Plenary Session
Screening

9.00 - 10.00 hours

Chair: Esther Meijer- van den Bergh

THE FEASIBILITY AND IMPACT OF SCREENING FOR PSYCHOSOCIAL RISK AT CANCER DIAGNOSIS: THE PSYCHOSOCIAL ASSESSMENT TOOL (PAT)

Anne E. Kazak, Ph.D., ABPP [1, 2], Lamia P. Barakat, Ph.D. [1, 2], Susan Ditaranto, RN, MHA[1], Daniel Biros, B.A. [1], Wei-Ting Hwang, Ph.D. [3], David Beele, M.S.W., L.S.W. [1], Leslie Kersun, M.D. [1, 2], Melissa A. Alderfer, Ph.D. [1, 2], Ifigenia Mougianis, A.B. [1], Matthew C. Hocking, Ph.D. [1] & Anne Reilly, M.D. [1, 2]

[1] *Division of Oncology, The Children's Hospital of Philadelphia*
[2] *Department of Pediatrics, University of Pennsylvania School of Medicine*
[3] *Center for Clinical Epidemiology and Biostatistics, The University of Pennsylvania School of Medicine*

BACKGROUND: To investigate the feasibility and impact of integrating an evidence-based screening tool of psychosocial risk in pediatric cancer care at diagnosis.

Methods: Parents of children newly diagnosed with cancer received either the Psychosocial Assessment Tool (PAT; *n* = 52) or psychosocial care as usual (*n* = 47; PAU), based on their date of diagnosis and an alternating monthly schedule. Four hypotheses were tested, including time to completion of the PAT, time to communication of PAT results to clinical care teams, distribution of PAT risk scores, and identification of psychosocial risks in the medical record.

Results: Of families receiving the PAT, 88% completed it within 48 hours. PAT was scored and results communicated to the treatment team within 48 hours in 98% of cases. The majority of families (72%) were classified as Universal risk based on the underlying Pediatric Psychosocial Preventative Health Model (PPPHM), 24% were Targeted risk, and 4% scored in the Clinical range. Significantly more psychosocial risks were recorded in the medical record during PAT intervals than during PAU.

Conclusions: An evidence-based psychosocial screener can be successfully implemented in pediatric oncology care and is associated with documentation of psychosocial risks in the medical record. While the majority of families report low levels of psychosocial risk, about one-quarter report problems that can be addressed with evidence based interventions.

This research was supported by St. Baldrick's Foundation.

WHAT'S BEHIND THE SCREEN? IMPLICATIONS FOR CLINICAL PRACTICE

Maria C. McCarthy, Ph.D.[1,2], Cinzia DeLuca ,Ph.D.[1,2]., Naomi E. Clarke, MBBS.[2]., Sarah Knight, Ph.D.[2], David M. Ashley., Ph.D.[1], Vicki E. Anderson, Ph.D.[1,2]

1. *Royal Children's Hospital, Melbourne, Australia*
2. *Murdoch Childrens Research Institute, Melbourne Australia*

Early identification of children and families vulnerable to prolonged psychosocial and psychological difficulties is an important goal for oncology healthcare teams. Screening has been advocated as a potentially efficient, cost effective and systematic approach to identifying risk and intervention needs of these families.

This presentation will focus upon 2 studies conducted in an Australian oncology centre.

Study 1 examined the validity of the Psychosocial Assessment Tool (PAT2.0) in an Australian sample. Participants were parents of 143 children newly diagnosed with cancer.

Study 2 examined the role of neurocognitive screening in a cohort of survivors and newly diagnosed children. Participants included 163 survivors 2-6 years post cancer treatment and 61 newly diagnosed patients.

Findings from these studies will be discussed in terms of the clinical utility and feasibility of using these tools within an established cancer service. Particular focus will be on the challenges of implementing screening and the potential benefits of the use of screening tools as an approach to evidence-based assessment in oncology settings.

PSYCHOLOGICAL DISTRESS IN ADULT SURVIVORS OF CHILDHOOD CANCER: SHOULD WE BE SCREENING?

Christopher J. Recklitis, PhD [1]

[1] *Dana-Farber Cancer Institute and Harvard Medical School*

As the number of childhood cancer survivors has grown, psychosocial clinicians are increasingly interested in understanding their needs as they reach adulthood. It is generally accepted that the majority of survivors will be well-adjusted and achieve expected life goals. However, cohort studies in several countries indicate that as a group they are at increased risk for psychological late-effects, and a sizable minority will develop clinically significant distress or adaptive limitations. Identifying and treating these adult survivors poses new challenges for pediatric programs and clinicians, who may have limited access to their adult survivor patients and limited resources to devote to their care. Borrowing methods and measures previously applied to adult cancer patients, many aftercare programs for cancer survivors include psychosocial screening as part of their care. This presentation will review the basic principles of screening for disease as they apply to psychosocial issues, and consider the rationale and data supporting screening adult survivors of childhood cancer. The role of the psychosocial clinician in screening, as a distinct form of assessment will be highlighted. Drawing on experiences at our center, common approaches to psychosocial screening and challenges to setting up screening programs will be presented. Limitations of screening and gaps in current research will also be discussed.

Plenary Session
Preliminary Research Presentations

10.00 - 10.30 hours

Chair: Stephen Sands

PERCEIVED BENEFIT AND BURDEN FOR YOUTH AND THEIR PARENTS FOR PARTICIPATION IN PSYCHOSOCIAL RESEARCH WHEN UNDERGOING TREATMENT FOR CANCER, NF-1, OR HIV

Lori Wiener, PhD [1], Abigail Bosk, BA [2], Haven Battles, PhD [1], Maryland Pao, MD [2]

[1] *Pediatric Oncology Branch, National Cancer Institute*
[2] *National Institute of Mental Health*

Background: Ethical concerns have been raised regarding the relative risks and benefits of conducting psychosocial research in vulnerable populations. This study assesses the benefit and burden associated with participation in psychosocial research by children, adolescents, and young adults undergoing treatment for cancer, Neurofibromatosis type 1 (NF-1), or Human Immunodeficiency Virus (HIV), and by their primary caregiver.

Methods: As part of a larger study assessing emotional distress (anxiety, depression, fatigue and pain) 17 children (7-12), 60 adolescents and young adults (AYA) (13-21) and 77 caregivers completed a self-report questionnaire assessing whether participation in psychosocial research was burdensome and/or beneficial. The specific factors contributing to their perceptions were also identified.

Results: Enrollment is underway with the goal of 220 participants. To date, few subjects found participating in a psychosocial study to be burdensome. The majority of children and AYA (86%) and their caregivers (92.5%) reported “no burden at all”. Of those who reported any burden, two caregivers felt that the questions were “confusing” and one patient found the questions “upsetting”. Over three quarters felt participation in the study was beneficial. Among caregivers, factors identified as beneficial were that participation 1) allowed them to be asked about issues affecting their lives (67%), 2) made them feel good to be helping others (64%), 3) gave them the opportunity to discuss issues they would not normally talk about (45%), 4) addressed issues the health care team doesn’t often ask about (45%), 4) helped facilitate treatment of the child’s distress (36%) and 5) helped pass the time (17%). Similar results were reported for AYA.

Conclusion: The preliminary findings suggests that children and AYA undergoing treatment for cancer, NF-1, or HIV and their primary caregivers are unlikely to experience significant burden from participation in studies examining emotional distress and, in fact, are likely to perceive benefit.

QUALITY OF LIFE IN PEDIATRIC PATIENTS WITH CENTRAL NERVOUS SYSTEM TUMORS (CNST) AND ITS RELATIONSHIP WITH SEQUELAE AND PARENTAL COPING STRATEGIES*

Marta Pérez – Campdepadrós, psycho-oncologist [1]

[1] *Onco-Hematological Pediatric Service, University Hospital Vall d'Hebron, Barcelona (Spain)*

In the last decades there has been a notable increase in childhood cancer survival rates. In spite of these, survivors are at risk of several physical and psychological late effects as a result of the tumor and their treatments. This reality has supposed an increasing number of studies on Health – Related Quality of Life (HRQoL) as well as the long – term psychological impact of pediatric cancer. As a result of this, two researches are being carried out in our Service. They are described below.

Introduction and purposes. Risk of sequelae in pediatric CNST is higher than patients with other oncological diagnosis because of the tumor location and treatments. For this reason, these children deserve special attention and an accurate follow – up. This study aims to describe HRQoL in this sample of CNST and to explore its relationship with: (1) sequelae (type and severity), (2) parental coping strategies, (3) parental stress (general perceived stress and stress related with the oncological experience), and (4) adolescent coping strategies.

Methods.
Instruments: HRQoL: *KIDSCREEN – 52* (parental version and adolescent self – report).
Sequelae: A register form developed for the current research. *Wechsler Scales.*
Coping: *COPE – generic version* (parents), *ACS – generic version* (adolescents).
Stress: *PSS* (parents), analogue numeric scale (parents).

Sample: Inclusion criteria for study participation required that: (a) participants had been diagnosed with CNST, (b) to be 12 – 19 years old at the time of the study, (c) to be 18 years old at the time of diagnosis, (d) to be off – treatment for ≥1 year, (e) to have sufficient comprehension of Spanish or Catalan language. Survivors with psychopathology diagnosed before the first oncological diagnosis were excluded from the study, as well as those with a metastatic tumor or a non – malignant tumor in the CNS.

Implications: To provide more acknowledge about the health status of CNST survivors and some related variables.To contribute with this knowledge with medical treatments. To identify risk factors that might lead to a poorer HRQoL. To be able to develop more appropriate interventions.

*Sponsored by *"Asociación Española Contra el Cáncer"* (AECC). Junta provincial de Barcelona.
**Financial support for this study was provided by the Universitat Autònoma de Barcelona (Grant FI00286UAB), DEP2006-56125-C03/PREV from "Consejo Superior de Deportes", and PSI2008-06417-C03-01/PSIC from "Ministerio de Ciencia e Innovación".

POSTTRAUMATIC GROWTH AND RESILIENCE IN ADOLESCENT SURVIVORS OF CHILDHOOD CANCER**

Marta Pérez – Campdepadrós, psycho-oncologist [1]

[1] *Onco-Hematological Pediatric Service, University Hospital Vall d'Hebron, Barcelona (Spain)*

Introduction and purposes There is still a lack of knowledge about the psychological adjustment processes and the impact of cancer on survivors. Recently, some studies suggest that to have suffered from cancer could lead to experience positive consequences. In fact, a link between benefit finding and resilience is described. For that reason, the present study focuses on understand the impact of the whole oncological experience. Specifically, this research intends to explore the association between adjustment and some variables such as: personality traits (optimism), coping strategies, healthy life styles, social support, and parental role.

Methods.
Instruments: HRQoL: *KIDSCREEN – 52* (adolescent self – report).
Sequelae: A register form developed for the current research.
Coping: *COPE* (parents), *ACS* (adolescents).
Stress: *PSS* (parents), analogue numeric scale (parents).
Optimism: *LOT-R* (parents and adolescents).
Healthy life – styles (practice of regular exercise): *AECEF*.
Social support: numeric scales (parents and adolescents).
Positive and negative consequences with regard to cancer experience: semi – structured interview.

Sample: Inclusion criteria for study participation required that: (a) participants had been diagnosed with cancer (excluding CNST), (b) to be 12 – 19 years old at the time of the study, (c) to be off – treatment for ≥1 year, (d) to have sufficient comprehension of Spanish or Catalan language. Survivors with psychopathology or mental retardation diagnosed before the first oncological diagnosis were excluded from the study.

Implications: To provide more acknowledge about the health status of childhood cancer survivors and related variables. To identify risk factors that might lead to a poorer HRQoL. To better understand the impact of cancer in survivorship. Therefore, it would be very useful for survivors follow – up and to develop more appropriate interventions.

*Sponsored by *"Asociación Española Contra el Cáncer"* (AECC). Junta provincial de Barcelona.
**Financial support for this study was provided by the Universitat Autònoma de Barcelona (Grant FI00286UAB), DEP2006-56125-C03/PREV from "Consejo Superior de Deportes", and PSI2008-06417-C03-01/PSIC from "Ministerio de Ciencia e Innovación".

QUALITY OF LIFE IN MOTION: A COMBINED PHYSICAL EXERCISE AND PSYCHOSOCIAL INTERVENTION PROGRAM FOR CHILDHOOD CANCER PATIENTS

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Purpose: Physical fitness has shown to be reduced during and after childhood cancer with physical inactivity being one of the most prominent causes. Psychosocial factors can affect the amount of physical activity. Physical inactivity ultimately leads to obesity, fatigue, a poor skeletal and/or mental health, and ultimately a compromised health-related quality of life (HrQOL). Aim of the study is to evaluate the short- and long-term effectiveness of a combined physical exercise and psychosocial intervention program, implemented during or shortly after treatment, in improving the physical fitness of childhood cancer patients (CCP). Secondary outcomes include fatigue, body composition, daily physical activity levels, depression, HrQOL, self-perception and behavior.

Method: In this multi-centre randomized clinical trial all CCP (8-18 years) on treatment with chemo- and/or radiotherapy or no longer than 12 months off treatment, are eligible. Patients requiring bone marrow transplantation and/or growth hormone treatment, those depending on a wheelchair or unable to "ride a bike", and those with mental retardation are excluded. In total, 100 consenting patients will be randomized to either the intervention or the control group after stratification according to type of malignancy, age group and moment of inclusion into the study.
The 12-week intervention consists of a combined physical exercise (2x/week; cardiorespiratory and muscle strength training) and psychosocial support program followed by a 1 day booster session. The psychosocial support program (6 child and 2 parent sessions) includes psycho-education and cognitive-behavioral therapy. The control group will receive care as usual. All participants will undergo physical performance tests and complete questionnaires prior to randomization, after 12-14 weeks and at 12 month follow-up. At 6-9 months from baseline only the questionnaires will be completed.

Results: The study started recently; until now the first 15 patients have been included.

Conclusion: Feasibility and the first results of this combined program seem promising.

Grant: Dutch Cancer Society

CHARACTERIZING LONE PARENTING: A MULTI-INSTITUTIONAL PILOT STUDY OF THE PERCEPTIONS OF SUPPORT AND PERCEIVED STRESS OF LONE PARENTS OF CHILDREN WITH CANCER

Lori Wiener[1], Sarah Friebert[2], Larry L. Mullins[3], David Elkin[4], Avi Madan-Swain[5], Sean Phipps[6], Sandra Sherman-Bien[7], Andrea Patenaude[8], Haven Battles[1], Sima Zadeh[1], Maryland Pao[9]

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6. *St. Jude Children's Research Hospital*
7. *Jonathan Jaques Children's Cancer Center, Miller Children's Hospital*
8. *Dana-Farber Cancer Institute*
9. *National Institutes of Mental Health, National Institutes of Health*

Background: The field of pediatric chronic illness has not kept pace with the demographic changes that now characterize our society; in particular, an increasing number of children grow up in single parent households. A one-day 'think tank was held at the National Institutes of Health in 2007, where a group of multidisciplinary experts in pediatric psychosocial research of chronic illness was asked to address three primary questions based on clinical experiences and programs of research pertaining to lone parents of children living with a chronic or life-limiting illness: 'What do we know?' 'What do we need to know? and 'Where do we go from here?'. The attendees were humbled by the dearth of knowledge about the complexity and diversity of the variables affecting the needs and adjustment of all parents, particularly those who care for a child with a chronic illness by themselves. There was consensus that this is an overlooked population in need of our careful attention, and the field would benefit first from a White Paper to review findings from the Think Tank with specific recommendations on the next steps of research needed (Brown et al., 2008). This would be followed by a limited multi-institutional study designed to characterize and define who should be considered a 'lone parent' and how variables such as socioeconomic status, distance from home to hospital, and presence of other children or support figures altered the potential impact on a lone parent's ability to meet the needs of a chronically ill child.

Methods: Primary caregivers of a child (ages 1 through 17 years) with a malignancy, diagnosed 6-18 months before recruitment were administered a 30-minute Lone Parent Support Questionnaire designed by the investigators for this study.

Results: The study has been IRB approved at 7 sites. To date, 50 questionnaires have been completed, with 30% of caregivers identifying themselves as a lone parent. Preliminary data analysis will take place when 75 of the anticipated 150 completed questionnaires are returned.

Conclusion: Parents who perceive themselves as parenting a child with cancer on their own, or a 'lone parent', are an overlooked population in need of targeted attention in order to develop appropriate interventions if needed. This exploratory study will begin the process of characterizing and defining what it means to be a 'lone parent', the relationship between lone parenting and social support, and whether lone parenting and perceived social support are associated with psychological distress outcomes. The goal is to identify caregivers who need more intensive support and intervention throughout the course of their child's cancer treatment course.

NEUROPSYCHOLOGICAL FUNCTIONING IN CHILDREN WITH PRIMARY CNS TUMORS AFTER TREATMENT WITH RADIATION THERAPY: PRELIMINARY RESULTS FROM BASELINE TO SIX MONTHS POST-RADIATION

Pam Wolters [1], Staci Martin [1], Katherine Walker [2], Robyn Bent [1], Kathy Warren [1]

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Background: Despite improvements in surgical techniques and an increasing role of chemotherapy, radiation therapy (RT) remains an integral part of the treatment regimen for pediatric brain tumors. However, RT is associated with significant side effects including neurotoxicity and long-term neurocognitive deficits. The purpose of this study is to explore various biologic and neurotoxic effects of RT in relation to a range of specific neurobehavioral functions in children treated for CNS tumors. The focus of this abstract is to present preliminary neuropsychological (NP) data in a variety of domains obtained from repeated assessments completed during the first six months following RT.

Methods: Children with any primary CNS tumors, ages < 21 years, referred to the NCI for RT were eligible to participate. Patients received RT as prescribed by their radiation oncologist. Children completed a comprehensive NP evaluation immediately prior to the onset of RT and again 6 months post-radiation, and a brief monitoring assessment within 2 weeks of completing RT. The evaluations consisted of measures assessing general intelligence as well as specific cognitive functions, socialemotional behavior, quality of life (QOL), and symptoms such as fatigue. Repeated measures Analysis of Variance were used to examine changes in scores over time.

Results*:* Twenty-eight children (mean age=9.8 yrs; range=3.1-16.8; 61% males) have enrolled and completed the baseline evaluation (n=23 2-week post-RT; n=16 6-months post-RT) to date. Mean parent education is 15.1 years (range=12.0-19.5). There was a range of different tumors, and a variety of treatment regimens including surgery, various types and doses of RT and chemotherapy agents, and 48% were taking steroids. All mean cognitive scores were in the Average range at baseline with no significant change over time in the mean Wechsler Abbreviated Scale of Intelligence Full Scale (105 to 109; baseline range=78-142), Verbal, or Performance IQ; Wechsler Digit Span subtest score or Processing Speed Index; California Verbal Learning Test T-score; or Delis-Kaplan Executive Function System Trails Number-Letter Switching score. All mean social-emotional and QOL parent report scores were average, and no change was found except for a significant quadratic effect of time ($F=4.88$; $p<.05$) on the energy subscale of the parent report Childhood Fatigue Scale, indicating that the children's level of energy declined immediately post-RT and then improved 6 months post-RT (-0.15 to 0.04 to -0.51). Also, on the Depression subscale of the Behavior Assessment System for Children-II parent form, mean scores declined significantly from baseline to 6-months post-RT ($n=14$; $F=5.24$, $p<.05$) indicating fewer depressive symptoms over time (52.9 to 48.4).

Conclusions: Mean cognitive and social-emotional scores were in the Average range. From baseline to 6 months post-RT, no significant change was found in any test scores indicating stable cognitive functioning in all domains. No change was found in any of the behavioral or QOL scores except for a decline and subsequent increase in energy level, and a decline in depressive symptoms, which likely are related to the acute effects of radiation therapy that dissipated over time. Future directions include analyzing the 24-month assessment scores, examining subgroup differences, and exploring relationships of biomarkers and imaging data to specific domains of neurobehavioral functioning.

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Morning Symposium
Understanding neuro-cognitive impairment

10.45 - 12.00 hours

Chair: Debby Waber

GENETIC POLYMORPHISMS AND THE RISK OF NEUROCOGNITIVE IMPAIRMENT IN SURVIVORS OF CHILDHOOD CANCER

Kevin R. Krull, Ph.D [1]

[1.] *St. Jude Children's Research Hospital*

Research suggests a significant proportion of survivors of childhood cancer experience long-term neurocognitive problems, including impaired attention, processing speed and working memory. Accurate identification of survivors at greatest risk for poor neurocognitive and/or behavioral outcomes is difficult. In addition to treatment factors and patient characteristics such as age at diagnosis or sex, potential moderators of outcome include genetic polymorphisms.

Three major classes of polymorphisms should be considered:

1. Polymorphisms in key enzyme pathways associated with pharmacokinetics or pharmacodynamics of anti-folate therapy (e.g. lower folate, higher homocysteine) and corticosteroid therapy, which may impact chemotherapy-related neurotoxicity;
2. Polymorphisms associated with oxidative stress, which may affect the biological response to a variety of central nervous system treatments;
3. Polymorphisms related to phenotypic patterns of impairment, which may identify predisposing risk factors for typical outcomes seen in long-term survivors.

Literature related to these polymorphisms will be reviewed and preliminary findings from new research data will be discussed. Accurate and reliable identification of genetic risk for neurocognitive impairment in survivors of childhood cancer would permit consideration of treatment supplementation as well as focused early preventative interventions aimed at reducing the impact on quality of life and long-term neurocognitive outcomes.

USING NEURO-IMAGING TO UNDERSTAND NEURO-COGNITIVE LATE EFFECTS IN PAEDIATRIC CANCER: WHAT HAVE WE LEARNED?

Donald J. Mabbott [1]

[1] *The Hospital for Sick Children and the University of Toronto*

Treatment with cranial radiation is required for cure of aggressive brain tumors in children, but often results in significant cognitive morbidity.The neuro-cognitive late effects of pediatric cancer, particularly brain tumors are now well known, including intellectual declines and specific deficits in attention, information processing speed, and working memory. There is considerably less information on the biological origins of this neuro-cognitive morbidity. CNS damage – particularly white matter injury - has been documented following cranial radiation.To ameliorate the neuro-cognitive morbidity of the growing number of pediatric brain tumor survivors, particularly those treated with cranial radiation, it is necessary to understand the relations between underlying CNS damage and neuro-cognitive deficits. In this talk I will focus on the neuro-imaging modalities useful in examining the effects of treatment for pediatric brain tumors on brain function, the history of neuro-imaging in research on neuro-cognitive late effects of pediatric brain tumors, and new research and approaches in using neuro-imaging in neuro-cognitive late effects research. Emphasis will be placed on relations between MRI imaging of white matter damage and neurocognitive late effects in pediatric brain tumors. New research will be presented showing that white matter injury following treatment has an impact on specific white matter pathways which in turn contributes to cognitive impairment.

AMNESIA IS ASSOCIATED WITH GERM CELL TUMORS IN ADOLESCENTS AND YOUNG ADULTS

GN Wilkening [1], NK Foreman [2], JR Madden [3]

[1] *Divisions of Neurology and Oncology*
[2] *University of Colorado*
[3] *The Children's Hospital, Denver*

Germinomas of the CNS are considered to be curable neoplasms, with survival rates reported to range from 70-90%. The prognosis for patients with nongerminomatous Germ Cell Tumors (NGGCT) of the CNS is less sanguine, but is considered to be about 70%. Germinomas and NGGCT are midline tumors, typically occurring in the pineal, or suprasellar regions, with presenting symptoms related to tumor location. Typical presenting complaints include endocrine abnormalities, headache, vomiting, and visual changes. Though memory disorders are not reported as specific to this population we have seen a large number of individuals presenting with germ cell tumors who have amnesia at the time of diagnosis or later in their course. We report on a cohort of 47 consecutively identified patients 26 of whom had complete data, including MRI, IQ and California Verbal Learning Test data. The incidence of amnesia, as defined as memory performance 2 standard deviations below measured intellectual ability, was 38%. There was no relationship between measured IQ and the likelihood of developing a profound memory disorder. There was no compelling relationship between specific diagnosis (e.g. germinoma v NGGCT) and memory outcome. When the group was confined to those who did not have involvement of the area of the third ventricle the risk for memory disorder remained high (45% of patients with pineal lesions). There is a relationship between age at diagnosis and the development of a disabling memory deficits, with those who are older at diagnosis (mean age at diagnosis = 208 months) more likely to develop amnesia than those younger at diagnosis (mean age of onset = 136 months). Current data does not suggest specific post-radiation decline in patients with germinomas or NGGCT, and radiation does not seem to be the primary source of memory morbidity, as our patients frequently presented with memory deficits. The etiology of memory deficits in individuals with tumors that do not involve the classically defined memory system is unclear, but may relate to neuro-endocrine dysfunction, or to structural abnormalities currently not able to be effectively imaged. Prospective data, perhaps using functional or metabolic imaging, is needed to further investigate the relationship between germ cell tumors and amnesia. Amnesia is a disabling condition that is hugely disruptive of the lives of patients with potentially curable neoplasms.

COGNITIVE EFFECTS OF NON-CNS DIRECTED CHEMOTHERAPY IN SURVIVORS OF CHILDHOOD CANCER.

Sanne Schagen [1], Gregory Sprenger[2], Jan-Berend Deijen[2], Cor van den Bos[3], Martha Grootenhuis[4], Annemieke Buizer [5]

[1] *Netherlands Cancer Institute/Antoni van Leeuwenhoek Hospital, Department of Psychosocial Research and Epidemiology, Amsterdam, The Netherlands*
[2] *VU University, Faculty of Psychology and Education, Amsterdam, The Netherlands*
[3] *Academic Medical Centre/Emma's Children's Hospital, Pediatric Oncology Department, Amsterdam, Netherlands*
[4] *Academic Medical Centre/Emma's Children's Hospital, Pediatric Psychosocial Department, Amsterdam, Netherlands*
[5] *VU University Medical Center, Department of Rehabilitation,Amsterdam, Netherlands*

Cognitive problems are recognized as a potential consequence of brain irradiation or localized chemotherapy for CNS disease. Historically, research on neurocognitive effects of systemtic cancer treatment has been directed more extensively to children with cancer. especially for childhood leukemia. In contrast, studies on the (late) cognitive effects of non-CNS directed chemotherapy in childhood cancer survivors (CCS) are sparse.

Up till now, the literature shows not many indications for late cognitive problems in CCS following non-CNS directed chemotherapy, but many of the studies conducted can be criticized on very small sample sizes and suboptimal reference data. We performed a study to evaluate cognitive functioning in adult CCS previously treated with non-CNS directed CT. In addition, we are currently performing a meta-analysis (including around 30 studies) in which the cognitive functioning on CSS treated with non-CNS directed chemotherapy is evaluated.

Inclusion criteria for this retrospective neuropsychological study were: treatment for Osteo Sarcoma (OS) or Ewing Sarcoma (ES) < 18 yrs: systemic chemotherapy: > 5 yrs after treatment; age > 18 yrs. Two control groups were selected. Group 1: family or friends of the CCS. Group 2: CCS, treated with surgery and / or radiotherapy only.

After asking for cognitive complaints two questionnaires aimed at quality of life (EORTC QLQ-C30) and psychological distress (HSCL-25) were applied. Thereafter 11 neuropsychological tests aimed at memory, concentration, verbal and intellectual functioning, fine motor functioning, speed of information processing and mental flexibility were done.

Respectively 34 OS and ES survivors, 34 survivors of other cancers and 45 controls were included in the study. No significant differences were found between the groups on reported cognitive complaints at the interview. On the QLQ-C30 questionnaire, the two patients groups did not differ. The CT patients reported worse physical functioning compared to controls, whereas the controls scored significantly better on cognitive, emotional and social functioning compared to the no-CT group. No significant differences in anxiety and depression symptoms were found among the groups. Neuropsychological testing showed significantly worse scores in the CT group for some memory function tests. This was also found for fine motor functioning.

This study showed that a subgroup of CT treated CCS had deviant cognitive test performance. Non-CNS directed chemotherapy is frequently applied for several forms of childhood cancer. In the light of the evidence of cognitive decline associated with the systemic delivery of cytotoxic agents in adult cancer patients with non-CNS tumors, a thorough evaluation of cognitive functioning in childhood cancer survivors treated with non-CNS directed chemotherapy is warranted.

Morning Symposium
Resilience and Hardiness

10.45 - 12.00 hours

Chair: Lutz Goldbeck

HUMAN EVOLUTIONARY RESPONSE TO TRAUMA (HEART)

Robert B. Noll [1]

[1] *University of Pittsburgh*

The commentary has two purposes:
(a) to briefly review research findings regarding psychosocial functioning of children and adolescents with cancer and other severe chronic illnesses compared to appropriate comparison peers; and
(b) to propose a theoretical rationale that could account for an increasingly compelling and consistent body of research that consistently does NOT identify psychopathology or dysfunction in these children despite exposure to major challenges and trauma. Specifically, our laboratory refined a methodology and design to examine the functioning of children with chronic illness (cancer, brain tumors, sickle cell, JRA, NF1, migraines, hemophilia) from the perspective of peers, teachers, mothers, fathers, and self reports. Our design included classmates matched one-to-one (same race/gender, closest date of birth) and utilized questionnaires and projective testing. Data were collected in classrooms without any children knowing why we visited their classroom. Data were collected in homes with an emphasis on child and family functioning, but not the hospital, clinic, disease, or trauma. With the noteable exception of children with diseases that significantly impacted their CNS, we failed to demonstrate significant differences between children with a chronic illness and matched classroom comparison peers. Since our data did not support our hypotheses and underlying stress/trauma theory, either the methodology was flawed, or the theory is not correct. Based on multiple studies showing no significant differences between children with chronic illness and comparison peers, we developed a theory to better fit our data. ***H****uman* ***E****volution****A****ry* ***R****esponse to* ***T****rauma (HEART)* is based on an evolutionary model of human behavior that asks “what is the adaptive purpose” of the behavior. We postulate that 10,000 years ago human children could not possibly grow up without exposure to randomly occurring stressful and traumatic life events. If the prototypical response was to become dysfunctional, our species would have perished. HEART posits that the linkage between chronic illness (stress/trauma) and dysfunction only occurs when the chronic illness (stressor) has a primary impact on the child’s CNS (brain tumors, NF1, CHI) or if the stressor occurs from the child’s family (abuse or neglect). The theory predicts that functional outcomes for children are not adversely affected by the occurrence of a random stressor/trauma (chronic illness).

PSYCHOLOGICAL DISTRESS AND COGNITIVE COPING IN LONG-TERM SURVIVORS OF CHILDHOOD CANCER

K. Wenninger [1], A. Helmes [2], J. Bengel [2], C. M. Niemeyer [1]

[1] *University Medical Centre, Department of* Pediatrics *and Adolescent Medicine, Division of Pediatric Hematology and Oncology, Freiburg, Germany*
[2] *University of Freiburg, Institute of Psychology, Department of Rehabilitation Psychology and Psychotherapy, Freiburg, Germany*

Background: Long-term survivors of childhood cancer may experience significant adverse late effects from their illness and treatment. While most survivors are psychologically and socially well adjusted, a significant subgroup of survivors experiences relevant levels of psychological distress.

Objective: The goal of this study was to describe the prevalence of symptoms of psychological distress in young adult childhood cancer survivors and the association of cognitive coping with this psychological distress. By examining cognitive coping in addition to the demographic and medical predictors identified in previous research, we aim at increasing the amount of explained variance in psychological distress after childhood cancer.

Methods: 168 adult childhood cancer survivors who were at least 5 years off treatment completed a follow-up questionnaire assessing demographics, health information, psychological distress and post-traumatic stress symptoms as well as illness cognitions and different ways of coping (return rate: 62%). The Brief Symptom Inventory-18 and the Posttraumatic Diagnostic Scale-8 item short form were used to measure psychological distress and post-traumatic stress symptoms.

Results: A large majority of survivors report few symptoms of psychological distress. However, 18% fit the criteria for a clinically relevant symptom level on the BSI-18. Fourteen reach the cut-off score on the Posttraumatic Diagnostic Scale indicating current posttraumatic stress disorder. As in other studies, higher levels of distress were associated with socio-demographic variables and the presence of medical late effects. These predictors explained 8% of the variance in psychological distress. When scores reflecting illness beliefs and cognitive coping strategies were entered into the prediction equation in addition to the predictors named above, the amount of explained variance increased to 47%. The following illness beliefs and cognitive coping strategies were associated with higher distress: cognitive avoidance of negative content, lower sense of predictive control, more perceived consequences of the illness, less trust in medical treatment, and a more negative emotional representation of the illness. We will also report results on perceived own risk of relapse and perceived positive consequences of the illness and their relation to psychological distress.

Conclusion: These results contribute to a better understanding of the correlates of difficulties in long-term psychosocial adjustment after childhood cancer. Cognitive strategies, which are associated with or may increase the risk for concurrent psychological distress, such as avoidance of negative thoughts, should be addressed in psychological counseling with survivors suffering from symptoms of distress.

A CROSS-CULTURAL PERSEPCTIVE OF MOTHERS OF CHILDREN WITH NEWLY DIAGNOSED CANCER: RESULTS OF A MULTI-INSTITUTIONAL RANDOMIZED TRIAL OF MATERNAL PROBLEM-SOLVING SKILLS TRAINING

Sandra Sherman-Bien, PhD; Martha Askins, PhD; Ernest Katz, PhD; Michael Dolgin, PhD; Robert Butler, PhD; Diane Fairclough, Dr PH; Robert B. Noll, PhD; OJ Sahler, MD

Statement of Purpose: Our contracting world makes international adoption of psychosocial interventions highly desirable. However, intervention strategies must consider cultural variables affecting acceptability and outcomes. A randomized trial investigating problem-solving skills training (PSST) for mothers of children newly diagnosed with cancer (Sahler et al., 2005) found that non-Hispanic and Hispanic mothers in the US and Jewish and Arab mothers in Israel all improved on problem-solving, depression, and post-traumatic stress (PTS) post-intervention. Although all mothers benefited, Spanish-speaking Hispanic mothers benefited more than Israeli and non-Hispanic mothers. Our study of mothers randomized to a usual care condition showed three distinct groups with regard to coping over time: low-stable, moderate-stable, and high-declining distress, with Hispanic and Israeli mothers represented more in the latter two groups (Dolgin et al., 2007). The current study investigated relationships among acculturation, immigrant stress, maternal distress, and problem-solving ability in the Spanish-speaking mothers.

Methods Used: Relationships among cultural measures (Bidimensional Acculturation Scale, Immigrant Stress Scale) and outcome measures (Beck Depression Inventory-II, Impact of Event Scale-Revised, Social Problem-Solving Inventory-Revised) for Spanish-speaking mothers were measured using Pearson's correlation. Hierarchical multiple regression analyses investigated whether cultural factors served as moderators.

Summary of Results: At baseline, acculturation was positively associated with problem-solving (r=.22, *p*=.047); higher Immigrant Stress predicted greater depression (r=.31, *p*=.004) and PTS (r=.29, *p*=.009). Immigrant Stress and Intervention both predicted unique variance in depression (*p'*s=.008;.011), PTS (*p'*s=.008;.018), and problem-solving (*p'*s=.032;.001) immediately post-intervention. Three months later, Immigrant Stress predicted depression (*p*=.029); Intervention predicted PTS (*p*<.001).

Conclusions: Spanish-speaking mothers in the US are at risk for distress after their child's cancer diagnosis. PSST alleviated distress and improved problem-solving. Findings from Hispanic and Israeli mothers suggest the importance of concurrent stressors (e.g., immigration, political unrest), and that having a child with cancer may not be a parent's primary stressor. Culture and concurrent stressors in coping with major illness are fertile areas for investigation.

IS SURVIVOR IDENTITY ASSOCIATED WITH PHYSICAL AND BEHAVIORAL HEALTH?: RESULTS FROM PROJECT REACH

Robert Casey [1], Eric Zwemer [2], Christopher Recklitis [2]

[1] *Dana-Farber Cancer Institute, Perini Family Survivors' Center, Boston, United states*
[2] *Dana-Farber Cancer Institute/Harvard Medical School, Perini Family Survivors' Center, Boston, United states*

Purpose: Health implications associated with cancer survivor identity are not well understood. This study examined the association of “Survivor” and “Victim” self-identification with health outcomes and health behaviors in a group of adults treated for childhood cancers.

Method: Participants were 200 survivors (52% female, median age 27) enrolled on Project REACH, a cohort study of locally-treated cancer patients. Participants responded to questions regarding the overall impact of cancer on their sense of identity and extent of identification with the terms “Cancer Survivor” and “Cancer Victim.” Responses to these two questions were dichotomized to capture strong identification for each.

Results: Survivor identification was endorsed by 68% of the sample, while only 8.5% reported Victim identification. Victim identification was associated with poor physical ($p = .044$) and emotional functioning ($p = .008$), as well as problematic health behaviors including binge drinking ($p = .031$). In contrast, those strongly identifying as survivors did not differ on physical or emotional functioning or health behaviors compared to those who did not. 38% of participants reported cancer strongly affected their identity, while 33% reported it had little or no effect. Participants who reported cancer had a strong impact on their identity were more likely to report poor emotional health outcomes ($p = .037$).

Conclusion: Surviving cancer does not guarantee adoption of a “Cancer Survivor” identity, and many childhood cancer survivors report little effect of cancer on their identity. Victim identity is uncommon, but associated with poor health outcomes and behaviors. Survivor identity is not linked with better health outcomes or health behaviors — a finding with important implications for post-treatment education and clinical care. The role of physical and emotional health outcomes in identity development and the implications for research and clinical care are explored.

Morning Symposium
Psycho-Oncology
and
Stem Cell Transplantation

10.45 - 12.00 hours

Chair: Sean Phipps

CARING FOR THE CAREGIVER: EHEALTH INTERVENTIONS FOR PARENTS OF PEDIATRIC HEMATOPOIETIC STEM CELL TRANSPLANT RECIPIENTS

Susan Parsons, Sara Ratichek, Stella Davies, Kristin Bingen, Mary jo Kupst, Lisa Schwartz, Eva Guinan, Karen Syrjala, Sunita Patel, Deborah Mayer, Fiona McTavish, David Gustafson.

Hematopoietic stem cell transplantation (HSCT) offers life-saving treatment of advanced malignancies and poor risk diseases of hematologic, metabolic, and immunologic origin. HSCT is physiologically and psychologically demanding for both the recipient and the family caregiver. The treatment is offered in specialty transplant centers, which for some families, requires geographic relocation, far from usual sources of support. Following an intensive preparative regimen, including chemotherapy and possibly, radiation, the transplant recipient faces a prolonged hospitalization, extensive follow up, and protective isolation. Initially, care is managed by the transplant center, but over time, the child's care is gradually transitioned back home to local providers. The parental caregiver serves as the vital conduit of information between providers, distant family members, and eventually, with the school, while also assuming increased responsibility as primary caretaker. Previous research has pointed to the emotional distress experienced by parental caregivers throughout the transplant process. We sought to develop an intervention that would address the geographic separation and isolation experienced by families, their many transitions across sites of care, and their changing roles over time as comforters, care enforcers, and communicators, on behalf of their child.

The intervention development process was iterative and user-centered, involving an interdisciplinary team of end users, HSCT experts and clinicians, researchers, web developers, and web designers. The first step in the process was a series of focus groups, followed by a formal needs assessment, drawn from a national sample of ~160 families. From this, we designed a web-based, health information and support program for parental caregivers of pediatric HSCT, known as HSCT-CHESS^{TM}. CHESS^{TM} (Comprehensive Health Enhancement Support System) is the umbrella name of a variety of integrated eHealth programs, developed by scientists at the University of Wisconsin, Madison (Gustafson, PI) with whom we have collaborated.

The HSCT-CHESS^{TM} program is currently being tested in a randomized controlled trial at six transplant centers national wide. The primary endpoint of the trial is change in parental emotional functioning over the first six months post transplant. To date, the 196 families who have been enrolled and randomized have completed their 3-month assessments. The trial will be completed in the Spring 2011. The presentation will include an overview of the development process, a description of the sample characteristics, and the evaluation plan of the intervention's efficacy.

LONG-TERM QUALITY OF LIFE FOR PEDIATRIC BONE MARROW TRANSPLANT RECIPIENTS: ACCORDING TO WHOM YOU ASK

Stephen A. Sands[1,2] , Rosemarie E. Feichtl [5] , Barry Rosenfeld [5] , Mitchell S. Cairo [1,3,4]

Columbia University College of Physicians and Surgeons: Departments of:
[1] *Pediatrics,*
[2] *Psychiatry*
[3] *Medicine*
[4] *Pathology*
[5] *Fordham University*

Purpose: To examine the concordance between pediatric patient's self-report and parent ratings regarding a patient's quality of life prior to and following hematopoietic stem cell transplantation (HSCT) and to identify potential medical and demographic covariates of concordance.

Patients and Methods: Utilizing the PedsQL 4.0, longitudinal QoL data was obtained from 68 pediatric HSCT patient/parent dyads prior to and up to two year post-transplantation.

Results: Reliability based on ICC indicates significantly poorer concordance in the acute phase of treatment three months post-HSCT, but returned to pre-transplant levels at subsequent assessments and continued to rise at one and two year follow-up assessments (Baseline ICC=.42; 3 months=.11; 6 months=.54). Paired T-tests further indicate that concordance was highest for observable domains of functioning (Physical and School Functioning) with greater inter-rater discrepancies on more subjective domains (Emotional and Social Functioning) at baseline and up until 6 months post transplantation (Baseline Total Score: d=.40, p=.001, Emotional: d=.45, p=.01, Social: d=.24, p=.05; Physical: d=.14, p=.24, School: d=.32, p=.10).

Conclusions: Children typically perceived and rated their QoL as being better than parents at all time points in virtually all domains. Concordance was not affected by patient age, suggesting that it is the course and severity of a child's treatment experience, as opposed to medical and demographic traits, that most greatly affect the degree to which parents and children agree on the child's QoL post-HSCT. The implications of these findings for QoL assessments in pediatric settings will be discussed.

OPTIMISM AND PESSIMISM AS PREDICTORS OF CHILDREN'S FUNCTIONING FOLLOWING STEM CELL TRANSPLANTATION (SCT)

Christina G. Salley, Kathryn Vannatta, Melissa A. Alderfer, Maru Barrera, & Sean Phipps

Purpose: Stem Cell Transplantation (SCT) is a stressful experience for children and parents. Children's functioning prior to transplant may be predictive of long term outcomes. The current study was designed to examine the extent to which children's optimism and pessimism prior to SCT predict affective functioning and quality of life 6 months later.

Method: Ninety-three children aged 6-18 (Mean age = 12.7, *SD* = 3.9) preparing to undergo SCT and their primary caregivers were recruited for a multi-site clinical trial examining the efficacy of a psychosocial intervention during SCT. Prior to randomization and preparative therapy (i.e. baseline), children completed a measure of optimism and pessimism. Parents and children also reported on child affective functioning (e.g. symptoms of depression, anxiety, PTS symptoms) and quality of life (e.g. Physical functioning, Behavioral and Mental Health) prior to randomization and 6 months later.

Results: Analyses examined associations of baseline optimism and pessimism with affective functioning and quality of life at 6 months post-transplant. We previously reported significant associations within baseline. As expected, optimism was associated with fewer symptoms of anxiety and depression and better quality of life (r = .3-.5), whereas pessimism demonstrated similar correlations in the opposite direction. However, after controlling for baseline functioning, nearly all correlations became non-significant and it appeared that this could be accounted for by relative stability in children's functioning over time. In contrast, baseline optimism or pessimism remained predictive of positive affectivity and behavioral functioning.

Conculusions: The extent to which children report being optimistic and pessimistic prior to SCT appears to predict variability in how they are functioning following SCT. However, it is possible that these associations over time are primarily accounted for by stability in children's baseline and later functioning.

DIFFERENCES IN MOTHERS' AND FATHERS' HEALTH-RELATED QUALITY OF LIFE AFTER PEDIATRIC STEM CELL TRANSPLANT: A LONGITUDINAL STUDY

Maru Barrera, PhD, Eshetu Atenafu, MSc, John Doyle, MD, Deborah Berlin-Romalis, MSW, Jennifer Pinto, MSW

Department of Psychology, Division of Hematology/Oncology, Blood & Marrow Transplant Program, The Hospital for Sick Children, Toronto, Canada

Purpose: To examine longitudinally health-related quality of life (HRQOL) and its correlates in mothers and fathers of children who undergo stem cell transplant (SCT) pre, 1 and 2 years post-SCT.

Methods: 80 parents of patients diagnosed mainly with leukemia completed a HRQOL measure pre-SCT, 46 at 1 year, and 50 parents at 2 years post-SCT. Physical and psychosocial summary scores are reported. Parents' age and gender; child's diagnosis, radiation history, age, behavior and physical health were examined as covariates. Linear mixed models for repeated measures that incorporate a covariate structure were used to assess longitudinal trends, parental differences and related factors.

Results: Physical HRQOL did not differ between mothers and fathers or over time. Maternal and paternal psychosocial HRQOL scores improved by 2 years post-SCT. Child's behavior problems and poor health, and maternal age (younger) predicted poor psychosocial HRQOL 2-years post-SCT in mothers. Child's behavior problems, diagnosis and treatment severity predicted poor psychosocial HRQOL in fathers.

Conclusions: These findings identify similar (child's poor behavior) and different (parent age, child's disease and treatment severity, and child's health status) risk factors for poor psychosocial HRQOL for mothers and fathers. These findings can guide comprehensive family care interventions after pediatric SCT.

Plenary session

Traumatic stress as a model for understanding patient and parent response to childhood cancer.

13.00 - 14.00 hours

Chair: Andrea Patenaude

TRAUMATIC STRESS AS A MODEL FOR UNDERSTANDING PATIENT AND PARENT RESPONSES TO CHILDHOOD CANCER

Anne E. Kazak, Ph.D., ABPP [1, 2] and Sean Phipps, Ph.D. [3]

[1] *Division of Oncology, The Children's Hospital of Philadelphia*
[2] *Department of Pediatrics, University of Pennsylvania School of Medicine*
[3] *Department of Psychology, St Jude Children's Research Hospital*

Drs. Kazak and Phipps, two published investigators in the area of traumatic stress in childhood cancer, will discuss several key issues related to traumatic stress in childhood cancer. The presenters will highlight common themes of their research as well as their different approaches to the associated research questions.

The session will focus on five specific questions:

1. How is having cancer, or having a child with cancer, similar to experiences of those exposed to war-related traumas that originally defined Post-Traumatic Stress Disorder (PTSD)? How is it different?
2. How does looking at childhood cancer from a traumatic stress perspective impact the treatment of distress symptoms? Are there any drawbacks to this approach?
3. What does the research evidence indicate for traumatic stress responses in patients and parents?
4. What are the operative factors to relieve traumatic stress symptoms in survivors and parents?
5. What is the current state of interventions based on traumatic stress frameworks?

The presenters will alternate in answering these questions and each will also comment on the other's responses in this structured session. Sufficient time will be allotted for attendees to ask questions of the presenters.

Plenary Session
Preliminary Research Presentations

14.00 - 14.30 hours

Chair: Martha Grootenhuis

HEALTHY HEROES: LIVING THE CURE
AN INNOVATIVE EXERCISE INTERVENTION FOR CHILDHOOD BRAIN TUMOR SURVIVORS

Kelly Ross, MA; Alexandra Walsh, MD; Margaux Barnes, MA; Lydia Futch, PhD; Josh Klapow, PhD; Drew Davis, MD; Kimberly Whelan, MD; Bobbi Jones, Avi Madan-Swain, PhD

University of Alabama at Birmingham, Children's Hospital of Alabama

Introduction: With improved survival rates in children with posterior fossa tumors, focus has shifted to addressing medical late effects that hinder physical activity and quality of life. In one study only 8% of CNS tumor survivors met recommended guidelines for physical activity. In fact, the highest prevalence of physical performance limitations in the Childhood Cancer Survivor Study (CCSS) cohort was reported among survivors of brain tumors (36.9%). Long-term documented difficulties that impede physical function include problems with balance, coordination, strength, and endurance. These physical limitations may discourage brain tumor survivors from being physically active. Few studies have investigated the efficacy of exercise interventions with survivors of brain tumors. Key methodological weaknesses in those studies include lack of behavioral reinforcement, rigidity in exercise scheduling, limited information provided on exercise regimen, and failure to account for premorbid activity level and interests. Additionally most interventions were hospital based. The current study addressed these shortcomings and included an innovative token economy system in which pre-defined compliance behaviors were reinforced by earning "chips," an online monetary unit which maximized incentive power by providing an online marketplace for the child to obtain direct reinforcers. Exercise programs for participants were individually tailored and weekly sessions were held in a local community recreation center convenient for the child's family. The present abstract reports on a preliminary subset of data from an ongoing exercise intervention for survivors of childhood brain tumors.

Methods: Posterior fossa brain tumor survivors were recruited from the neuro-oncology clinic at the Children's Hospital of Alabama. Eligible participants were at least one year off treatment and between the ages of 6-18. For all subjects pre-post measures of physical function were completed by a physical therapist. Additionally, all participants and their primary caregiver completed paper-and-pencil measures assessing quality of life. All subjects participated in a six-week standardized exercise program developed by a licensed physical therapist to increase strength, endurance, balance, and coordination. Daily exercises were designed based on the child's sports interest (e.g., marching band, cheerleading, soccer, etc.). During individual weekly sessions with a personal trainer, objective evaluation of progress in skills was conducted by having the children perform a related activity.

Results: Data on all 4 participants who completed the program indicated improvement in endurance as measured by the Pacer test. Three of the 4 participants improved in right and left knee strength, and right ankle range of motion. On average the cohort improved on parent reported quality of life including physical, emotional, social, and school functioning. Quality of life measures completed by participants revealed improvements in emotional, social, and school functioning. All participants demonstrated compliance with the exercise program prescribed by their trainer as demonstrated by their ability to successfully complete weekly physical tasks.

Conclusions: Upon completion of the six-week exercise intervention, improvements were noted in objective measures of endurance, strength, and range of motion, as well as subjective parent and child quality of life ratings. Additional participants are in the process of completing the protocol, which will strengthen findings. Results show promising trends in providing an empirically derived, community based physical activity intervention for brain tumor survivors.

SLEEP PATTERNS IN PEDIATRIC CANCER PATIENTS

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Sleep has unique importance for children's health, and has been implicated in immune function, wound healing, pain perception, and quality of life (QOL). However, the prevalence of sleep problems has rarely been studied in children on treatment for cancer, despite data that fatigue is commonly reported and persistent in this population. This study aims to delineate the sleep habits and behaviors of children being treated for cancer, to determine the prevalence of sleep disturbances and fatigue, and to explore associations between sleep and QOL.

Patients 4 - 18 years old currently being treated for any cancer diagnosis are eligible for participation. Self-report (ages 8-18) and parent-report (ages 4-18) data are collected when child is on active treatment and 6 months after completion of treatment. The assessment includes measures of sleep patterns (Children's Sleep Habits Questionnaire, Adapted School Sleep Habits Survey), fatigue (PedsQL Multidimensional Fatigue Scale), and QOL (PedsQL Generic Core Scale, PedsQL Cancer Module, Acute Version). Since March 2010, 7 patients have been enrolled; we anticipate 25 patients will be enrolled by August 2010.

Pilot data to be presented at SIOP include baseline descriptive statistics, as well as mean scores for sleep parameters (e.g. total sleep time, daytime napping, night wakings, insomnia, and bedtime anxiety). We will also examine the relationship between sleep and QOL. We hypothesize that children with cancer will have more daytime sleep, less nighttime sleep, and more sleep disturbances (insomnia, bedtime anxiety, night wakings) than expected for their age. We expect that sleep problems and fatigue will be linked to lower QOL.

Future data analysis will include longitudinal comparison of the sleep patterns of children with cancer during active treatment and 6 months after treatment is completed. Results will guide the design of future preventive clinical interventions based on specifically identified areas of need.

UNDERSTANDING WHAT ADOLESCENTS THINK ABOUT PARTICIPATING IN CLINICAL RESEARCH AND HOW THEIR PERCEPTIONS COMPARE TO THEIR PARENT'S PERCEPTIONS.

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Background: Limited data exist regarding adolescent decision making in clinical research. Little is known about how adolescents view research, what their expectations are, risks they are willing to accept in research, how they make enrollment decisions, what information they find helpful, or how closely teen's perceptions do or do not match their parents.

Objectives: To better understand how adolescents enrolled in clinical research and their parents understand study information presented, made decisions about enrolling, experienced the assent and permission processes, and perceive risks and the experience of participation.

Methods: Adolescents (13-17 years) who enrolled within the previous 6 months in a clinical study at the NIH Clinical Center or Seattle Children's Hospital and one of their parents were invited to participate. 177 teen and parent pairs were interviewed separately with a semi-structured interview designed for this study.

Results: Adolescent participants were 49% male; well distributed by age (mean 15.1); 76% had an illness and 24% were healthy research volunteers. Most (76%) of parents interviewed were teens' mothers.
Adolescents and parents were satisfied with learning about the study (95%, 98%) and the enrollment decision process (97%, 98%). Teens wanted information about what they had to do, benefits, and risks (in that order), while parents wanted information about study procedures, risks, and benefits. Teens found the consent form less easy to understand and parents felt more discussion took place with their teen prior to enrollment. Teens were more likely than their parents to feel pressure to enroll (25%, 10%), with most pressure coming from family: 57% reported the decision-making process was 'about the same as usual' regarding other family decision-making. Teens were less bothered by risks and inconveniences than their parents (temporary nausea, pain, hair loss, difficulty concentrating, night in the hospital, confidential questions). Teens and parents were similarly willing to do a skin biopsy for research. Teens became more willing if financial compensation was provided; parental willingness remained the same with/without their teen receiving money.
Eight-one percent of the teens felt "proud" to be in a research study to help others.

Conclusions: Adolescents enrolled in a range of clinical research studies and their parents were mostly satisfied with the assent and parental permission process and how their decisions were made. Overall, parent report of discussion and pressure prior to enrollment was more optimistic than the teens whereas teens are more likely to take risks, particularly when compensation is provided.

PARENT-DIRECTED INTERVENTION FOR CHILDREN WITH CANCER-RELATED NEUROBEHAVIORAL LATE EFFECTS

Sunita K Patel, Ph.D [1]

[1] *City of Hope Medical Center Duarte, California, USA.,* *Funding acknowledgment: RO3 CA130731*

Introduction: Children treated for cancer are at risk for neurocognitive late effects. While promising, studies with behavioral interventions to treat such sequelae have thus far shown mostly small effects that are not sustained. Alternative treatments remain necessary. We proposed an intervention directed at parents for the purpose of improving "pro-learning" parenting behaviors and to improve the child's cognitive outcomes.

An objective of the study was to determine the feasibility of an educational and skills training intervention directed at parents using face-to-face training sessions and phone assistance. We hypothesized that parents who received the parent intervention program (PIP) will show (a) increased knowledge of ways to facilitate their child's learning and greater frequency of "pro-learning" behaviors, and (b) decreased parenting stress, compared to parents in the usual care control (UCC) group. Finally, an objective of the study was to collect preliminary data on the indirect therapeutic impact of our parent intervention on the *child's* outcomes.

Methods: Forty-four pediatric survivors with cognitive deficits and their parents were randomized to the PIP or to the UCC arm. PIP Parents participated in 8 training sessions individually over a 3 month period (Phase 1). PIP Parents received phone support one to two times over the next 3 months (Phase 2). Parents completed self-report and parent-report questionnaires at baseline, 3 months, and 6 months. Children underwent neuropsychological testing at baseline and again at 6 months.

Preliminary Results: A parent intervention program appears feasible based on our 90% completion rate by parents in the intervention arm. We have an 84% completion rate for Time 2 neurocognitive testing in the sample, excluding the one patient who was withdrawn from the study due to disease relapse and eventual death. Satisfaction ratings of the program and its benefits effects were consistently high.

Repeated measures ANOVA found a significant interaction between Parent Knowledge and study arm ($F = 14.48$; $p=.001$) with increased knowledge in the intervention group at 3 months, which was sustained at 6 months. This interaction effect and pattern was also noted for Parent Efficacy ($F = 5.43$; $p=.009$), and for Parent's engagement in "Pro-Learning" Behaviors ($F=4.27$; $p=.023$). Parent stress also improved in PIP relative to UCC ($F = 3.90$; $p=.034$). Data analyses for measures of the child's outcomes were recently initiated and will be completed within the next 3 months.

Conclusion: The PIP intervention is effective in improving parents' knowledge, efficacy, and "pro-learning" behaviors on behalf of their children, and also appears helpful in decreasing parent stress. The effects observed at Time 2 appear to be sustained at Time 3.

SOCIAL COGNITIVE DIFFERENCES IN PEDIATRIC BRAIN TUMOR SURVIVORS AND COMPARISON PEERS

Christina G. Salley, Larissa L. Hewitt, Andrea Farkas Patenaude, Keith O. Yeates, Cynthia A. Gerhardt, & Kathryn Vannatta.

Global and specific cognitive deficits are well documented for pediatric brain tumor survivors. Recent research also indicates that survivors are at particular risk for social difficulties. Unfortunately research has yet to be directed toward understanding mechanisms for these social challenges. This study was developed in an effort to identify children at greatest risk for social difficulties and to inform efforts to design interventions that can prevent or ameliorate long term consequences of children with cancer at risk for neurocognitive late effects.

The current project was designed in response to models of social information processing models that have recently begun to integrate the influence of neurocognitive abilities and deficits. Participants in this study included 76 children and adolescents (mean age = 12.3 years, *SD* = 2.3) who completed treatment for a brain tumor at one of two pediatric care centers an average of 2.7 years (*SD* = 1.6) before study participation. Sixty-seven classmates matched for gender, age, and race were recruited to serve as a comparison group. Families participated in home visits in which data was collected from children and parents on measures of social cognition or skills (e.g. problem solving, pragmatic language, emotion recognition), child temperament (i.e. effortful control, surgency, and negative affectivity), and neurocognitive skills (e.g., executive function, processing speed, memory).

The data presented will include group differences in attention and temperament (i.e. effortful control, surgency, negative affect), variables which may potentially underlie deficits in social behavior and acceptance previously identified in this sample. In analyses completed to date, group differences have indicated that survivors demonstrate less effortful control and surgency than comparison children. Finally, the influence of treatment (i.e. radiation, chemotherapy, surgery, combination therapy) on these social cognitive and behavioral outcomes will also be considered.

FEASIBILITY OF NEUROFEEDBACK FOR REDUCING NEUROCOGNITIVE DEFICITS AFTER A CHILDHOOD BRAIN TUMOR

Eline Aukema [1], Marieke Ruiter, de [2], Bob Last [2], Netteke Schouten-van Meeteren [3], Rien Breteler [4], Jorn Hogeweg [5], Martha Grootenhuis [2]

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Purpose: Survivors of a childhood brain tumor experience neurocognitive deficits, including decreased processing speed, attention and memory, resulting in problems with learning and social functioning. Therefore, the need for effective cognitive rehabilitation possibilities in this group of survivors is high.
There is growing evidence that neurofeedback, a 'brain wave' feedback training in which the brain activity is regulated, is a valuable treatment for children with brain disorders (e.g. ADHD, epilepsy, traumatic brain injury) and could be helpful for pediatric brain tumor survivors. In this pilot study we explored the feasibility and neurocognitive impact of neurofeedback.

Method: Seventeen survivors with cognitive problems were invited to join this pilot-study. Before starting the training a quantitative electroencephalogram (QEEG) was made and a neurocognitive assessment was performed. The QEEG and assessment were repeated after 30 training sessions

Results: Neurofeedback treatment plans were generated based on each participant's QEEG profile. Nine survivors (mean age 16.96 years old, 4 female/5 male) completed the 30 training sessions. No side-effects of the training were reported, although the sessions were perceived as tiring and time-consuming. Most parents and survivors were positive towards the intervention.
Comparison of the neurocognitive assessment pre- and post Neurofeedback seems to indicate improved speed of processing. Attention scores seem to remain unaffected.

Conclusion: The pilot study indicates that neurofeedback is a feasible intervention for childhood brain tumor survivors, although the impact of the intervention is not clear yet. The effectiveness of neurofeedback is currently under investigation in a double blinded randomized controlled trial called the PRISMA study.

Afternoon Symposium
Outcome after childhood CNS tumors

14.45 - 16.15 hours

Chair: Colin Kennedy

SOCIAL AND BEHAVIORAL ADJUSTMENT OF PEDIATRIC BRAIN TUMOR SURVIVORS: EXAMINATION OF FACTORS THAT MAY MODIFY RISK

Kathryn Vannatta [1], Maru Barrera [2], Cynthia A. Gerhardt [1], Diane Fairclough [3], Mary Jo Kupst [4], Eugene A. Meyer [5], Andrea F. Patenaude [6, 7], Christopher Turner [6]

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Purpose: Earlier detection and aggressive treatment for brain tumors have led to improved survival rates; however physical and neurocognitive morbidities may compromise development for pediatric brain tumor survivors (PBTS). Difficulties with peer relationships constitute a primary concern during the early stages of survivorship and may be associated with social, emotional, and academic/occupational deficits later in life. Interventions to prevent or limit social impairment are yet to be developed and disseminated. In doing so, it will be important recognize problematic social outcomes are not universal for PBTS, and efforts should be informed by data about risk and protective factors that account for variability in outcomes. This would allow tailoring of interventions and titration of services. One aim of our research has been to identify medical, child, and family factors that may moderate the extent of social difficulties demonstrated by PBTS relative to healthy controls.

Method: We identified PBTS who were 8-15 years old and 1-5 years post-treatment using tumor registries at 5 pediatric oncology centers in the United States and Canada. Questionnaires were administered to 187 PBTS (53% male, Mage = 11.4 years) and their classmates in a primary, mainstream classroom. Overall peer acceptance and numbers of friendships within the peer group were assesed, as well as 5 dimensions of peer interaction (Victimization, Sensitive-Isolated, Aggressive-Disruptive, Leadership-Popularity, and Prosocial behavior). Medical record reviews recorded diagnositic and treatment variables. Parents of the PBTS and one classmate matched for gender, race, and age completed the Family Enviroment Scale during subsequent meetings at their homes.

Results: PBTS and control classmates differed on most dimensions of social behavior (higher Sensitive-Isolated behavior and Victimization, less Leadership-Popularity and Aggressive behavior); however the magnitude of group differences varied as a function of medical, child, and family characteristics. In particular, Isolation and Victimization in PBTS were most evident for girls and children who had undergone treatment with radiation. The magnitude of group differences in Leadership-Popularity and Sensitive-Isolated behavior varied as function if the level of Supportiveness in the family environment. We failed to find evidence of moderation by other characteristics of the family environment (e.g. Conflict or Control). Interestingly, PBTS did not demonstrate deficits in the number of reciprocated friendships identified among classmates.

Conclusion: PBTS may be at risk for multiple deficits in social behavior and relationships. However, risk of these difficulties may be moderated by specific treatment variables, child gender, and the supportiveness of the home environment.

ASSESSMENT OF NEUROCOGNITIVE FUNCTIONS IN PEDIATRIC BRAIN TUMOR PATIENTS BASED ON THE ICF (INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH, WHO)

Thomas Pletschko[1], Agathe Schwarzinger[1], Ulrike Leiss[1]

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Although studies so far have revealed the importance of single neurocognitive functions when discussing long-term outcome of pediatric brain tumor patients, the fullscale-IQ is still a commonly used measure. Few systematical approaches have been established to assess the impact of single neuropsychological domains on participation. Furthermore, the influence of the environment has been largely disregarded. In our search to approach this issue, we have found that the ICF provides a useful framework for rehabilitation and school integration of these children.
Therefore, we conducted several studies in order to gather experience about the specific nature of different neuropsychological ICF categories with respect to academic achievement and participation. The results regarding learning and memory revealed a significantly lower learning curve and a less organised recall for CNS-tumor patients. Concerning attentional functions we found that especially alertness, distractibility and processing speed were impaired in the patient group as compared to healthy controls, whereas there was no significant difference in focused attention. Since executive functions are not listed separately in the ICF, we established a special theoretical framework for this incoherent cognitive domain.
Additionally, we developed the School Participation Scales (SPS) as a tool for asking patients, parents and teachers about resources concerning participation in school and everyday life. The SPS addresses personal (neurocognitive) as well as environmental factors (social support) and is supplemented by a neurocognitive assessment of relevant domains (e.g. memory, attention, executive functions) in order to achieve a comprehensive view. The advantage of the SPS is the translation of abstractly defined functions, activities and participation possibilities – as listed in the ICF – into everyday situations.
Our findings suggest a high impact of single neurocognitive resources on participation. Patients, parents and teachers seem to have similar ideas of what the resources and deficits are. However, patients tend to rate their resources generally higher than parents and teachers do.
In conclusion, the ICF-based approach seems to be a promising method to describe participation in everyday life, even though further research has to be done especially in comparing the resources of pediatric brain tumor patients to healthy controls. Nevertheless, the SPS proved to be a reliable tool for assessing functions and activities and for including an environmental view. Furthermore, this approach enables the development of specific intervention programs at the patient-, school- and environmental level with the aim of facilitating participation.

NEUROPSYCHOLOGICAL AND ADAPTIVE OUTCOMES IN CHILDREN TREATED FOR MEDULLOBLASTOMA

Celiane Rey-Casserly[1], Tanya Diver[1], Cori Liptak[2], Christine Chordas[2], Brian Delaney[2], Peter Manley[2]

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Children treated for medulloblastoma are at substantial risk for developing deficits in neurocognitive, social, and adaptive functioning. We examined cognitive, adaptive and social outcomes of children/adolescents diagnosed with medulloblastoma between 1986 and 2008 followed clinically at DFCI/CHB. Neuropsychological data were available for 83 patients; 57 had more than one evaluation. 64% were ≤ age 7 at diagnosis (median age at diagnosis 6.6 years); 54% were male. Patients were grouped into three categories: no CSI (7); Standard Dose CSI < 30 Gy (46); High Dose CSI > 30 Gy (30). Mean follow-up from radiation was 4.9 years; median age at most recent neuropsychological evaluation was 13.6.

Full Scale IQ score at most recent evaluation ranged from 40 to 132; mean = 87. IQ score distribution was significantly different from expectations: 16% of scores were ≤ 70, 41% < 85, and only 4% ≥ 115. Mean IQ for no CSI was 84; Standard Dose 90; and High Dose 83. Mean adaptive score was 84. Both IQ and measures of executive function were significant predictors of level of adaptive function at most recent evaluation. A substantial proportion of our sample had a history of social difficulties (46%) and 64% required special educational services.

For those who completed 2 or more evaluations (N=57), we analyzed change in IQ over time. Estimate of change in IQ per year for each participant was -1.3 points per year, with 61% of the sample having a negative slope. CSI groups differed on predicted change in IQ, with those in the high dose CSI group declining more steeply relative to the other groups. For those children who received CSI only, the predicted change in IQ per year was positively correlated with age at diagnosis, with steeper IQ decline associated with younger age at diagnosis (less than 9 years of age).

Cognitive outcomes for children treated for medulloblastoma vary widely but lower IQ scores are more frequent than expected. Younger age at diagnosis and more intensive radiation treatment are associated with greater decline in IQ over time. Adaptive function and level of independence is predicted not only by cognitive level, but also by executive function abilities.

PARENTAL RATINGS OF LATE EFFECTS IN SURVIVORS OF CHILDHOOD BRAIN TUMORS: ASSOCIATIONS WITH RADIOTHERAPTY, HEALTH-RELATED QUALITY OF LIFE AND INTELLIGENCE

Tonny Solveig Reimers[1], Erik Lykke Mortensen[2], Karsten Nysom[3], Astrid Sehested[3], Kjeld Schmiegelow[4]

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[3] *The Juliane Marie Center, Rigshospitalet, Paediatric Clinic II, Copenhagen, Denmark*
[4] *The Juliane Marie Center, Rigshospitalet and Copenhagen University, Paediatric Clinic II and Faculty of Health Sciences, Copenhagen, Denmark*

Purpose: To examine the relationship between parental ratings of late effects after treatment for childhood brain tumors and radiotherapy (RT), the patient's health-related quality of life (HRQOL) and general intelligence (IQ).

Method: A consecutive sample of 123 patients aged 8 to 40 years from East Denmark, treated for a brain tumor before the age of 15 years between 1970 and 1997. Parents rated whether 15 symptoms and deficits had changed after the therapy. The patients answered an early version of the Minneapolis-Manchester Quality of Life questionnaire (MMQL) and were assessed for IQ by WISC-R or WAIS-R.

Results: The most frequently reported deficits were learning disabilities, attention and memory problems, fatigue, and motor problems, all reported by 50-59 percent of the parents. The 15 symptom ratings were intercorrelated and a scale counting the number of symptoms reported for each child had a mean score of 6.5 symptoms [range: 0-15]. For the 69 patients treated with RT, the parents rated a mean of 8.4 symptoms, while the mean rating was 4.1 symptoms for the 54 children treated without RT ($p < 0.001$). The number of symptoms rated correlated significantly with the patients' Full Scale IQ ($r = -0.62$), and with the patients' ratings of quality of life on all MMQL scales (r ranging from -0.18 to -0.55). Adjusting for IQ attenuated the correlations between parental ratings and quality of life reported by the patients, but several correlations remained significant.

Conclusion: Parental ratings of new problems after treatment for a brain tumor in childhood show a meaningful pattern of associations with treatment parameters (RT), formal cognitive testing (IQ) and the patients' reported quality of life (HRQOL). To some extent these ratings reflect information that is independent of late effects on IQ and thus parental ratings provide useful supplementary information.

Afternoon Symposium
Guidelines meeting

14.45 - 16.15 hours

GUIDELINES MEETING (FORMER PSYCHOSOCIAL COMMITTEE)

Chairs: John Spinetta & Momcilo Jancovitz

To prepare a guideline about the topic: *Behaviour of the health care team (from a medical point of view) during and after treatment.*
The chairs will generate discussion about this topic during this session. This will result in the formation of a writing committee for elaborating and preparing a manuscripts as ''guideline''. During the past 12 years, the former Psychosocial committee has prepared and published in Medical and Pediatric Oncology (now Pediatric Blood & Cancer) 11 documents addressing the promotion of psychosocial interventions in pediatric oncology as an integral part of the therapeutic trials. The audience is invited to join this session and discuss about the topic.

Afternoon Symposium
Communication with patients about challenging topics

14.45 - 16.15 hours

Chair: Gerry Koocher

DEVELOPMENT AND CLINICAL USE OF AN ADVANCE PLANNING DOCUMENT FOR ADOLESCENTS AND YOUNG ADULTS

Lori Wiener, PhD [1], Haven Battles, PhD [1], Sima Zadeh, MA [1], Maryland Pao, MD [2], Janet Osherow, LICSW [3]

[1] *Pediatric Oncology Branch, National Cancer Institute*
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[3] *Georgetown University Hospital*

Background*:* Discussing end of life (EoL) issues is difficult for adolescents and young adults (AYA) living with serious illness. Few resources exist to aid AYA in planning for their changing physical, emotional and social needs when treatment is no longer effective. Palliative care standards suggest EoL issues be discussed routinely, starting soon after diagnosis.

Methods: Phase I: Focus groups conducted with AYA with cancer or HIV (n=20) reviewed an existing advance care-planning document (ACP) (*Five Wishes®*) and explored additional topics for inclusion. With those results, a modified age-appropriate ACP tool for AYA was developed *(My Thoughts, My Wishes, My Voice)* followed by a pilot evaluation comparing *My Thoughts* to *Five Wishes®* (Phase II, N=39). Enrollment is open.

Results:
Phase I: Overall, 80% believed an ACP tool would be helpful for AYA living with serious illness. This was consistent across type of question. Additional topics for inclusion were identified.

Phase II: Participants were 54% female; averaged 20 years old (range 16-28) and were evenly divided by diagnosis (HIV vs. cancer). Just over half preferred *Five Wishes®* (51.3%) to *My Thoughts* (48.7%), however, those <21 years preferred *My Thoughts* (63%), while those >21 preferred *Five Wishes®* (65%; X^2=3.1, p=. 08). While there was no statistically significant difference by diagnosis, two-thirds of patients with HIV preferred *Five Wishes®* and two-thirds of patients with cancer preferred *My Thoughts.*
The most helpful questions were related to psychosocial issues at EoL; they included comfort, how one wants to be treated, what they would want family and friends to know and how they want to be remembered. Younger participants (<21) found the medical treatment and 'how they would want to be treated' questions more helpful than those over 21 (t=2.0, p<.05 and t=3.0, p<.01, respectively).

Questions about medical treatment and health care were rated as most stressful. There were no differences in stress associated with any of the questions by age group or diagnosis.

Five Wishes® is a legally binding document. Eighty-six percent indicated importance for an age-adapted ACP to be a legal document.

Conclusion: The study suggests that AYA living with a serious illness contemplate EoL issues, want to participate in decision-making regarding care at EoL, and would find an ACP guide helpful. The study experience so far suggests that a planning document with developmentally appropriate language would be utilized and may also facilitate discussion of EoL care between seriously ill AYA and their families.

TREATMENT NON-ADHERENCE IN TEENAGE AND YOUNG ADULT CANCER PATIENTS: A MULTI-INFORMANT, PROSPECTIVE STUDY

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Purpose: There is a definite paucity of studies examining treatment non-adherence (NA) in teenage and young adult (TYA) cancer patients. Furthermore, many of these studies have assessed NA at one time point and/or used only one source of information.

Our aims were to (1) examine the adherence difficulties encountered by TYA patients during the 4 months following diagnosis and (2) to examine the association between health professional reports of patient adherence at 2 months post-diagnosis and patient self-reported adherence at 4 months post-diagnosis.

Method: Cancer patients (16-24 years old), diagnosed and treated at a TYA cancer centre in the UK during a 30 month study period were eligible for the study. At 2 months post-diagnosis, a nurse and consultant for each patient reported upon the adherence functioning of their patient, using a scale that reflected the many treatment challenges encountered by TYA cancer patients. Patients completed a comparable adherence scale at 4 months post-diagnosis.

Results: Eighty three percent (84/101) of eligible patients participated. Results from the patient report measure (completed at 4 months post-diagnosis) showed that total NA scores ranged from 0 (100% adherent) to 19 (37% NA), mean 4.99 (10% NA), sd 4.46. Patient demographics (gender, cancer diagnosis, age at diagnosis) were not associated with patient reported adherence. However, consultant perception of patient adherence at 2 months post-diagnosis correlated with patient reported adherence obtained at 4 months ($r = .34$, $p = .002$).

Conclusion: During the first few months of treatment, NA may be a problem, with up to 37% of treatment demands not being adhered to. With the lack of consistency in the literature of factors associated with NA, the potential role of consultants in identifying patients at risk of adherence difficulties is highlighted. The authors are currently establishing the validity of these findings using an objective measure of patient adherence.

SHOULD PREADOLESCENT CHILDREN BE PRESENT DURING CONSULTATIONS: QUALITATIVE INTERVIEW STUDY WITH PARENTS IN THE MONTHS AFTER THEIR CHILD'S DIAGNOSIS WITH CANCER

Tim Eden [1], Jo Ward [2], Peter Salmon [3], Katja Gravenhorst [4], Jonathan Hill [5], Bridget Young [3]

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Purpose: To examine parents' views regarding their child's presence during consultations.

Method: Qualitative interview study which used maximum variation sampling to recruit 66 parents (39 mothers, 27 fathers) of 42 children aged 1-12 years (median 4 years). Children were receiving treatment for acute lymphoblastic leukemia at 6 UK paediatric oncology tertiary centers. The constant comparative method of analysis was used.

Results: Parents acknowledged the benefits of communicating openly with children, but only 5 of the 53 parents who spoke on this issue thought their child's presence in consultations was automatically desirable. Parents described how their child's presence restricted their own communication with doctors, made it difficult for them to concentrate on what was said and interfered with their efforts to help their child feel safe and hopeful. The child's presence was particularly difficult for parents when 'significant' issues, such as the prognosis, adverse test results and medical procedures, were discussed. Parents felt these discussions were a potential threat to their child, particularly when they had not first discussed the information with doctors separately from their child, whereas separate discussions enabled parents to absorb the information themselves and to sanction its communication to their child. Some parents experienced difficulties in accessing separate consultations with doctors.

Conclusion: The difficulties we identify are unlikely to be satisfactorily resolved by either systematically excluding children from consultations or the reverse. However, these difficulties could potentially be addressed by extending, beyond the diagnosis period, the practice of sequencing 'significant' information so that it is first communicated to parents in separate consultations, and by periodically discussing with parents what information would be in their child's interests to hear. To ensure ongoing parental access to separate consultations, consideration should be given to ways of facilitating these, including shifting the onus for initiating separate consultations from parents to doctors.

INTRODUCING ZORA CAMP4ALL: A VIRTUAL COMMUNITY TO AUGMENT PEDIATRIC CAMPING

Kathryn Cantrell [1]

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Purpose: Pediatric camping has a positive impact on adolescents with serious illnesses; in fact, camp increases hopeful attitudes by decreasing levels of anxiety related to illness (Briery & Rabian,1999; Turuk et al., 2006). Yet, the hopefulness derived from the experience may dissipate when the camper returns to the chronic stress of his/her illness (Hinds, 1988). Since May 2009, in collaboration with Camp For All (CFA), a camp for children with serious illnesses, a 3D virtual environment resembling CFA was created for campers to maintain friendships from camp and explore concepts such as hope and connectedness.

Method: The technology called Zora Camp4All was introduced to 40 adolescents with cancer (N=16), blood disorders (N=6) and their siblings (N=18) during their week at CFA in June 2009. After the weekâ€™s completion, they accessed this virtual camp through home or hospital computers. This pilot studyâ€™s goals were to discover if Zora Camp4All could: (1) sustain the campers' hopefulness after their week of camp, (2) sustain the campers feeling of connectedness after their week of camp, and (3) promote the campersâ€™ positive technological development (PTD). Hinds HSA, Lee's SCS-R, and Bersa PTD-Q were administered before and after using the program.

Results: The results from this study suggest that Zora Camp4All may contribute to sustaining social connectedness and PTD. The mean PTD increase (M=2.13, SD=4.55, N=40) demonstrates significance (t=-2.95, p=<.005) and the mean social connectedness increase (M=1.08, SD=2.27, N=40) is also significant (t=-2.99, p<.005). Increase in hopefulness did not demonstrate statistical significance. Additionally, aspects of the program that contributed to sustainability remain to be determined. Siblings and campers from urban communities scored significantly lower in each of the three areas.

Conclusion: These findings call for future exploration into the field of virtual interventions catered to the developmental needs of adolescents with chronic life-stressors.

Plenary Session
Key note Lecture

16.15 - 16.45 hours

THE **ROLE OF SIOP IN INTEGRATING PSYCHOSOCIAL CARE INTO ROUTINE PEDIATRIC ONCOLOGY TREATMENT AND FOSTERING PEDIATRIC PSYCHO-ONCOLOGY RESEARCH ON A GLOBAL LEVEL.**

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The new century has seen a wealth of research and policy changes which predict that the psychosocial care of adults and children will become better integrated into routine care at a global level. Many barriers, particularly funding, the stigma attached to psychological issues and problems, and busy overworked outpatient clinics and offices have prevented the ability to give optimal emotional support to many children and their parents. In 2007, the U.S. Institute of Medicine (IOM) of the National Academies of Science, reported the findings of a multidisciplinary panel which found that the literature contained a strong evidence base in support of the efficacy of psychosocial interventions in cancer care. Their landmark report, Cancer Care for the Whole patient: Meeting Psychosocial Health Needs led the IOM to propose that "quality (italics) cancer care today must integrate the psychosocial domain into routine cancer treatment" . The International Psycho-Oncology Society, the international body which advocates for quality psychosocial cancer care, proposed that a new international quality standard should be established stating that "psychosocial care must be integrated into routine care". Screening of new patients and following clinical practice guidelines provide a map for integration. In August, the International Union Against Cancer, the UICC, endorsed this quality standard statement which has given more credence and weight at an international level. It would be most appropriate if SIOP, through its Pediatric Psycho-Oncology group, endorsed this standard for pediatric cancer care at a global level. This international endorsement from SIOP would provide global support which could then be utilized at the national level for pediatric oncologists and psychologists to approach advocacy organizations to endorse this new standard of quality care.

ADDITIONAL INFORMATION

American Psychosocial Oncology Society

For 25 years, the American Psychosocial Oncology Society (APOS) has been actively supporting education, training and networking for and among the professionals working in the psychosocial aspects of cancer. As APOS has encouraged and facilitated multidisciplinary membership, it has also firmly established itself as the single national organization devoted solely to psychosocial care in cancer. Today, APOS members come together from the fields of oncology, psychiatry, psychology, social work, nursing, counseling, therapy and patient advocacy to improve the psychosocial care of patients and their families. The APOS 8th Annual Conference will be held 17-19 February 2011 in Anaheim, California USA.

APOS is dedicated to increasing the presence of pediatric psycho-oncology within the organization. A Pediatric Special Interest Group, chaired by Lori Wiener, PhD & Barbara Jones, PhD has been active in assuring that the annual conferences include strong pediatric speakers and content. In addition, APOS has created a Quick Reference for Pediatric Oncology Clinicians: The Psychiatric and Psychological Dimension of Pediatric Cancer Symptom Management

For more information about the Pediatric handbook, please visit the website: http://www.apos-society.org/professionals/tools-resources/handbook/pediatric/pediatrichandbook.aspx

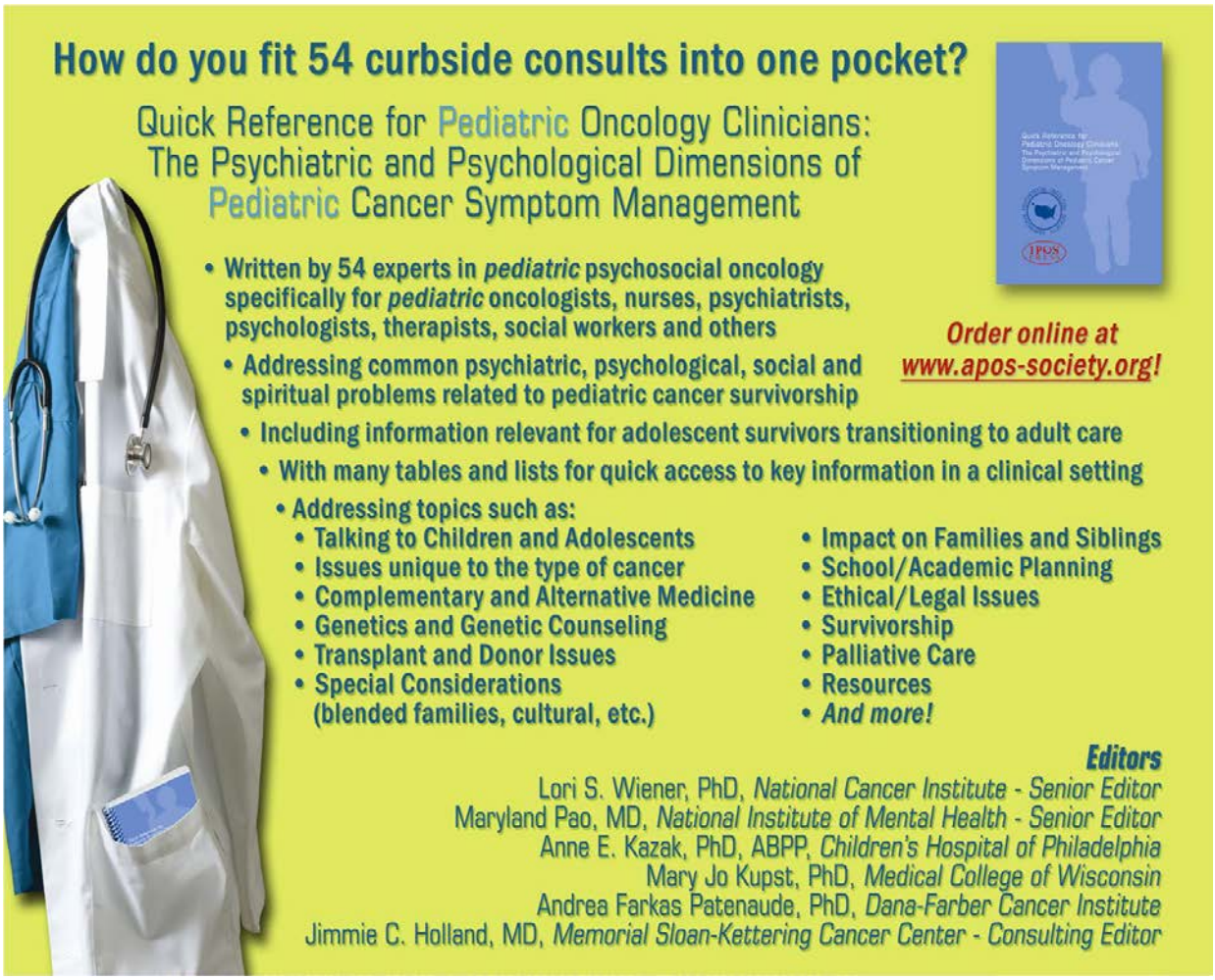
International Psycho-Oncology Society

Since 1984, the International Psycho-Oncology Society (IPOS) has fostered international multidisciplinary communication about clinical, educational and research issues that relate to the subspecialty of psycho-oncology and two primary psychosocial dimensions of cancer: 1) Response of patients, families and staff to cancer and its treatment at all stages; and 2) Psychological, social and behavioral factors that influence tumor progression and survival. IPOS is collaborating with the World Health Organization (WHO) to develop models and capacity building aimed at improving cancer patients' quality of life and their ability to cope with the disease. The collaborative educational and training programs are evidence-based and are designed to empower health professionals and other providers, in hospital and community services, in addressing cancer patients' and their families' psychosocial needs. As part of its 2010, World Cancer Congress, the International Union Against Cancer (UICC) endorsed the
IPOS International Standard of Quality Cancer Care:

1. **Quality cancer care must integrate the psychosocial domain into routine care;**

2. **Distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain.**

The IPOS-sponsored 13th World Congress of Psycho-Oncology will be held 16-20 October 2011 in Antalya, Turkey. IPOS is also dedicated to increasing the presence of pediatric psycho-oncology within the organization. A Pediatric Special Interest Group was established at the 2010 World Congress held in Quebec and is chaired by Andrea Patenaude, PhD. The Pediatric SIGs from SIOP, APOS and IPOS will be working closely to reduce redundancy and assure that the needs of pediatric psycho-oncology professionals are met worldwide.
www.ipos-society.org



Finally,

We are all thrilled to be here today to learn from one another and to network with professionals who share our goals from around the world. In an effort to increase the content in a variety of psycho-oncology society meetings to professionals who work with children with cancer, we are partnering with the IPOS and APOS to gather information about the extent and type of psychosocial services available to children, adolescents, and young adults with cancer and their families.

We hope you will complete this survey, even if you only work with youth a small portion of your time. For the purpose of this study, we define youth as children, adolescents, and young adults up to the age of 25. If you have not already completed the survey, we would really appreciate your help.

It should take you about 10-15 minutes to complete.

Thank you!

https://www.surveymonkey.com/s/68SJ8YN.