Fourth

SIOP PEDIATRIC PSYCHO ONCOLOGY

Meeting

SOCIÉTÉ INTERNATIONALE
D'ONCOLOGIE PÉDIATRIQUE

INTERNATIONAL SOCIETY
OF PAEDIATRIC ONCOLOGY

Dear colleagues and friends,

Welcome to the fourth SIOP-PPO meeting in Toronto.
Today we are coming together again with psychologists, pediatric oncologists, and others from all over the world, after successful meetings in Berlin (2008), Boston (2010) ad London (2012).
We have the opportunity to update you again with the current state-of-the art in Pediatric Psycho-Oncology.

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.

Through the years 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 since 2010. We have the educational day for SIOP-PPO now scheduled on the program and in the SIOP community. We have asked the Board to continue with a yearly meeting. We hope to inform you about this soon.
We will work on our terms of reference (ToR).We invite you all to participate in our committee and let us know if you are interested to be in the committee or would like to participate in working groups.

Apart from today, the SIOP conference has more to offer. The SIOP-PPO symposium this year is called: *Measuring Quality of Life during treatment: a need or a luxury?* With speakers from different disciplines: oncologist, nurse, psychologist and parents.

We hope you will enjoy the meeting, and are looking forward to the next meeting in South Africa, 2015. We will keep you updated!

Warm regards,

Martha Grootenhuis (chair)

Also on behalf of the SIOP-PPO Committee
Andrea Farkas Patenaude, Stephen Sands, Gabi Calaminus, and Maria McCarthy
With Support from Sasja Schepers and Simone Sint Nicolaas (secretary)

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Educational Day Program
&
Psycho-Oncology on the Main Program

SIOP PEDIATRIC PSYCHO ONCOLOGY

TORONTO SIOP 2014

Educational day – Wednesday, October 22nd, 2014 (8.15-17.00), *Maple East and West*

8.15-8.30	**Opening** symposium. *Martha Grootenhuis* on behalf of the committee
8.30-9.15	**Psychosocial interventions: evidence for effectiveness** Chair: Stephen Sands • Does dexamethasone induce more neuropsychological side effects than prednisone in pediatric acute lymphoblastic leukemia? a systematic review: ***L. Warris***, *M.M. van den Heuvel-Eibrink, M.A.H. den Hoed, F.K. Aarsen, R. Pieters, E.L.T. van den Akker* • Effects on quality of life of participation in a combined physical exercise and psychosocial intervention program for childhood cancer patients: ***E.M. van Dijk-Lokkart***, *K.I. Braam, G.J.L. Kaspers, M.A. Veening, M.A. Grootenhuis, I.C. Streng, T. Takken, E. van Dulmen-den Broeder, J. Huisman* • Cognitive-behavioral treatment for insomnia in adolescent and young adult survivors of childhood cancer: ***E.S. Zhou***, *L.M. Vrooman, P.E. Manley, C.J. Recklitis*
9.15 – 10.00	**Palliative treatment** Chair: Martha Grootenhuis • End-of-life decisions in Dutch pediatric cancer patients: *R.B. Van Loenhout,* ***I.M.M. van der Geest***, *A.M. Vrakking, A. van der Heide, R. Pieters, M.M. van den Heuvel-Eibrink* • A Provider Based Survey to Assess Bereavement Care Knowledge, Attitudes, and Practices in Pediatric Oncologists: *J. Jensen, C. Weng,* ***H. Spraker-Perlman*** • Why do parents not talk with their terminally ill child with cancer about death?: ***I.M.M. van der Geest***, *M.M. van den Heuvel-Eibrink, L.M. van Vliet, S.M.F. Pluijm, I.C. Streng, E.M.C. Michiels, R. Pieters, A.S.E. Darlington*
10.00-10.30	Coffee break
10.30-12.00	**Measurement: what's new and necessary/ screen or not to screen** Chair: Maria McCarthy *Screening/measurement in AYA's* • Validating the BSI-18 as Screen for Psychological Distress in Young Adult Survivors of Childhood Cancer (YASCC): Comparison with a Structured Diagnostic Interview: ***C.J. Recklitis***, *J.E. Blackmon, G. Chang* • Using the Fatigue Thermometer to Screen Adolescent and Young Adult Brain Tumor Survivors: ***S. Brand***, *C. Chordas, C. Liptak, P. Manley, C.Recklitis* • Development of a new measure of goal-based quality of life for adolescents and young adults with cancer: *L.D. Brumley, J. Deatrick, L.P. Barakat, F. Ramharrack, L. Daniel, S. Palmer, L. Pierce****, L.A. Schwartz*** *Family screening in pediatric oncology* • Caregiver distress and patient health-related quality of life: psychosocial screening during pediatric cancer treatment: *L. Pierce, J. Fleischer, M.C. Hocking, M. Alderfer, L. Schwartz, A.E. Kazak,* ***L. Barakat*** • Agreement between different coders: mothers, fathers, and psychosocial team completing the Psychosocial Assessment Tool (PAT) *S.M. Sint Nicolaas,* ***S.A. Schepers***, *M.A. Grootenhuis, C.M. Verhaak* • Health care providers' ratings of the utility of psychosocial screening tools in childhood cancer ***A. Di Battista***, *K. Hancock, D. Cataudella, D. Johnston, A. Punnett, W. Shama, U. Bartels, P.C. Nathan, M. Barrera*
12.00-13.00	Lunch provided by SIOP

Educational day – Wednesday, October 22nd, 2014 (8.15-17.00), *Maple East and West*

13-14.00	**New directions in research on pediatric cancer and family adjustment** Chair: Lynn Fainsilber Katz • Pediatric cancer and child adjustment: the role of marital and parent-child conflict: ***L. F. Katz**, J. Kawamura, I. Lavi, K. Gurtovenko, N. Stettler, B.E. Compas, D. Friedman* • Peer and family relationships that account for variability in symptoms of anxiety and depression for pediatric brain tumor survivors: ***K. Vannatta**, M. Barrera, A.F. Patenaude, C.A. Gerhardt, M.J. Kupst, D. Fairclough* • Parents and children coping with child cancer: longitudinal processes of adaptation: ***B.E. Compas**, K. Vannatta, C.A. Gerhardt* • The impact of parent distress, parent-child interactions, and coping on the adjustment of siblings after a child's death from cancer: ***C.A. Gerhardt**, L. Schwartz, M. Barrera, B.E. Compas, D.L. Fairclough, T.L. Foster, M.J. Gilmer, K. Vannatta*
14-15.00	**Functioning and interventions for siblings** Chair**:** Maru Barrera • Siblings of children with cancer: perceived changes in their place and role within the family after cancer diagnosis and throughout group treatment: **A. *Neville**, M. R. Simard, K. Hancock, A. Rokeach, L. Brister, P. Yogalingam, A. Saleh, M. Barrera* • Having a sibling with cancer: emotional experience and growth throughout an 8-week coping with cancer intervention: ***M.R. Simard,** A. Neville, A. Rockeach, K. Hancock, L. Brister, A. Saleh, P. Yogalingam, M. Barrera* • Reduction of anxiety levels in parents and siblings of children with cancer after sibling participation in a psychosocial group intervention: a randomized controlled trial: *M. Barrera, **A. Rokeach**, K. Hancock, F. Schulte, E. Atenafu, P. Nathan* • a new 1-day systemic intervention for siblings of children who have cancer and their parents: a feasibility and pilot study: ***C. Besani,** A. Higgins, C. McCusker, A. McCarthy* • Siblings: a video for brothers and sisters of pediatric oncology patients ***R. Casey**, A. Donohue, C. Hudson, C. Chen*
15.00-15.30	Tea-break
15.30-15.50	Updates on traumatic stress research in pediatric cancer- taking changes of the DSMV into consideration**:** ***Anne Kazak***
15.50-16.50	**Into the future: standards of care** Chair: Jaap Huisman • Guidelines for psychological care in children with cancer in Poland: ***M. Samardakiewicz**, J. R. Kowalczyk, E. Szweda, J. Korzeniewska, M.Grudzińska, M.Pawełczak-Szastok, J.Pilarczyk, M.Gwadera, A. Grabowska, W.Budziński* • Development of a Canadian school re-entry and educational planning guideline for children with cancer: ***J.Chung**, A. Klinck, P. Robinson* • Ethical Dilemmas Involved in Pediatric Bone Marrow Donor Evaluation: Demonstrating the Need for Standards of Care: ***S. Tarquini**, S. Ross, , N. Frumer-Styron* • The Psychosocial Standards of Care Project for Childhood Cancer: ***Anne Kazak***
16.50-17.00	**Closing**
18 00	**Opening Ceremony and Welcome Reception SIOP Meeting**

SIOP PEDIATRIC PSYCHO ONCOLOGY

PSYCHO ONCOLOGY TOPICS ON THE MAIN SIOP PROGRAM

PPO free paper session (Thursday October 23; 8.30-9.30)
Predicting and improving behavioral functioning of children and survivors
Chair: Stephen Sands

- Cerebrospinal fluid biomarkers of oxidative stress, motor dexterity and behavior during chemotherapy for childhood acute lymphoblastic leukemia, *K. Krull, USA*
- "Looking for where the wild things are": polymorphisms as predictors of late onset longterm cognitive and behavioral disability, *J. Blom, Italy*
- Effectiveness of an adventure-based training program in promoting regular physical activity among childhood cancer survivors, *O.K. Chung, China*
- Impact of posttraumatic growth on self-esteem among survivors of childhood brain tumors, *K. Kamibeppu, Japan*

Joint session nurses & PPO (Friday October 24; 14:20-15:50)
Chair: Anne Marie Maloney, Canada & Maria McCarthy, Australia

- Understanding body image, sexuality, dating, friendships, and fertility in adolescents with cancer from an adolescent and parent perspective, *L. Jibb, Canada*
- The creative box: a patient centered communication tool for use in adolescents and young adults with cancer, *V. van de Velde, Belgium*
- The development of an online psychological support intervention for teenagers and young adults (tya), *J. Chesire, UK*
- Usability testing of an online self-management program for adolescents with cancer, *J. Stinson, Canada*
- Improving quality of life of siblings of children with cancer after participation in a psychosocial group intervention: a randomized controlled trial, *M. Barrera, Canada*
- Psychosocial health-related quality of life in a cohort of childhood cancer survivors: implications for survivorship care, *K. Ruccione, USA*

Symposium (Saturday October 25; 8.00-9.30): Measuring quality of life during treatment: a need or a luxury?
Chair: Martha Grootenhuis & Corry van den Hoed-Heerschop, Netherlands

- The utility of HRQL measurement in clinical practice, *R. Barr, Canada*
- Quality of life: The sixth vital sign, *F. Gibson, UK*
- The challenge of measuring quality of life during treatment with the implementation of a webportal, *M.A. Grootenhuis, Netherlands*
- Why quality of life guides the development of the national psychosocial standard of care for childhood cancer project, *V. Brown & P. Brown, USA*
- General Discussion

Psychosocial interventions: evidence for effectiveness

8.30 – 9.15 hours

Chair: Stephen Sands, USA

DOES DEXAMETHASONE INDUCE MORE NEUROPSYCHOLOGICAL SIDE EFFECTS THAN PREDNISONE IN PEDIATRIC ACUTE LYMPHOBLASTIC LEUKEMIA? A SYSTEMATIC REVIEW

Lidewij T. Warris LT[1, 2], Marry M. van den Heuvel - Eibrink[1], Marissa A.H. den Hoed[1], Femke K. Aarsen[1], Rob Pieters[1], Erica L.T. van den Akker[2]
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Purpose/Objective

Steroid-induced neuropsychological side effects have a major impact on the quality of life in a large proportion of children treated for acute lymphoblastic leukemia (ALL). Dexamethasone is preferred over prednisone because of its higher anti-leukemic activity at the cost of a higher potency to induce metabolic side effects. To evaluate whether dexamethasone also leads to more neuropsychological side effects than prednisone, we performed a systematic review of the literature.

Materials and Methods

Articles were selected in PubMed, Embase and Cochrane on the basis of title and abstract by two independent reviewers using the following inclusion criteria: children with leukemia were receiving dexamethasone and/or prednisone; short and/or long term neuropsychological side effects (mood, cognition, behavior, sleep) were compared between both steroids; original research; written in English. We excluded case series (<10 subjects). We graded their level of evidence using the GRADE system.

Results

Of the 243 potentially relevant articles identified, we included 13 studies for review. Half of the included studies report more neuropsychological side effects with dexamethasone compared to prednisone. However, none of the randomised controlled trials with neuropsychological outcome primarily in view, showed a significant difference between dexamethasone and prednisone on mood and behavior. The randomized trials on long-term cognitive function only showed a subtle significant difference between dexamethasone and prednisone, limited to a minor decrease in word reading and a minor decrease on a IQ measure of fluid reasoning in the dexamethasone group, but both with absence of a clinically significant difference.

Conclusion

Based on this review of the literature, we conclude that the for clinical outcome valuable drug, dexamethasone, does not seem to induce more neuropsychological side effects than prednisone in children with ALL.

Acknowledgements

We would like to thank KiKa® (Kinderen Kankervrij) for funding.

EFFECTS ON QUALITY OF LIFE OF PARTICIPATION IN A COMBINED PHYSICAL EXERCISE AND PSYCHOSOCIAL INTERVENTION PROGRAM FOR CHILDHOOD CANCER PATIENTS

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Purpose/Objective

The QLIM (Quality of Life in Motion) study was designed to evaluate the effects of an intensive 12-weeks intervention program, combining physical exercise and psychosocial support. In this multi-center randomized controlled trial physiotherapist-led exercise therapy program and a psychosocial intervention aimed to enhance patient wellbeing and self-belief were offered simultaneously. Improved wellbeing and health-related quality of life (HrQoL) is hypothesized to increase the willingness and motivation to engage in sport activities and, as a result, to enhance the efficacy of the exercise program and vice versa.

Materials & Methods

Childhood cancer patients, aged 8 to 18 years and on or within the first year after treatment, were asked to participate. All participants underwent physical performance tests and completed questionnaires prior to randomization (T0) and after the 12-week intervention (T1). This abstract presents results of the HrQoL-assessments. Patients and parents filled in the PedsQoL generic core scale, cancer module and multidimensional fatigue module, both on T0 and T1.

Results

Sixty-eight patients (mean age=13.1; SD 3.1) participated. Parents in the intervention group (N=30) reported a significant improvement in HrQoL of their children compared with the parents of children in the control group (N=38) on the subscales Physical Functioning (mean ΔT1-T0= 16.0 and 6.0 respectively; p=0.02), Pain and Hurt (mean ΔT1-T0= 15.7 and -4.5; p=0.00) and Procedural Anxiety (mean ΔT1-T0= 12.0 and -1.1; p=0.04). No significant differences in improvement between the two groups were found by patient self-report.

Conclusions

In children with cancer short-term positive effects on HrQoL, as perceived by parents, were found for Physical Functioning, Pain and Hurt, and Procedural Anxiety after participation in a combined physical exercise and psychosocial intervention program. The study is continued to determine the longer-term changes.

Grant: Supported by Alpe d'Huzes/KWF (grant number ALPE-VU 2009-4305).

Cognitive-behavioral treatment for insomnia in adolescent and young adult survivors of childhood cancer

Authors:
Eric S. Zhou, PhD
Lynda M. Vrooman, MD
Peter E. Manley, MD
Christopher J. Recklitis, PhD, MPH

Purpose/Objective
Pediatric cancer survivors are at high risk for the development of insomnia due to treatment side effects, inpatient hospitalizations and medical late effects. Insomnia is linked to behavioral and emotional disturbances, substance use, and compromised school/work performance in adolescents and young adults. However, insomnia is an undertreated medical issue in pediatric survivors. Cognitive-behavioral treatment for insomnia (CBT-I) has been empirically validated in other cancer populations, but has not been adapted for use with pediatric cancer survivors, and is not offered as part of routine clinical practice even in major cancer centers delivering specialized survivorship care.

Materials & Methods
We are piloting an abbreviated CBT-I program in our regional cancer center's survivorship clinic, and evaluating whether this modified treatment (3 in-person sessions, and up to 2 telephone follow ups) would be feasible, acceptable, and effective in a cancer survivorship setting. Participants monitored their sleep using sleep logs, and completed sleep questionnaires and program evaluations.

Results
5 adolescent/young adult survivors of childhood cancer (ages 16-41 years) completed our ongoing CBT-I protocol. All reported improved sleep efficiency (pre to post-intervention: 72.9% to 88.4%), and improved Pittsburgh Sleep Quality Index (10.3 to 7.8), and Insomnia Severity Index (15.5 to 9.5) scores. Participants indicated that the abbreviated intervention was preferred to standard treatment, and were open to web/mobile interventions in the future. All indicated that the intervention was helpful, and would recommend the program.

Conclusions
There is a clinical need to incorporate effective treatment for insomnia into routine care for this at-risk population. Ongoing pilot data suggest that brief CBT-I is feasible, acceptable, and effective for improving insomnia in a pediatric oncology survivorship setting. Our findings support the potential to adapt this treatment model to a web/mobile CBT-I platform. We will discuss our plan to improve dissemination of insomnia treatment for childhood cancer survivors through technologically-enhanced intervention delivery.

Palliative treatment

9.15-10.00 hours

Chair: Martha Grootenhuis, the Netherlands

END-OF-LIFE DECISIONS IN DUTCH PAEDIATRIC CANCER PATIENTS

Rhiannon B. Van Loenhout[1,2], Ivana M.M. van der Geest[2], Astrid M. Vrakking[3], Agnes van der Heide[3], Rob Pieters[2], Marry M. van den Heuvel-Eibrink[2]

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Introduction

In care for terminally ill children with cancer, paediatric oncologists, parents and children are confronted with end-of-life decisions. These decisions range from abstaining potentially life-sustaining treatments to decisions to alleviate pain or other symptoms, using drugs with a possible life-shortening effect. It is yet not clear which end-of-life decisions (ELDs) are made in a paediatric oncology setting and how parents and oncologist perceive these ELDs.

Methods

Between 2001 and 2010, in a specified period of two years, 58 children and adolescents died from cancer. For each child, the responsible paediatric oncologist completed a retrospective questionnaire. Patient characteristics, and information on presence, characteristics, and considerations of an ELD as well as information on the communication, the dying process and evaluation after child death, were retrieved.

Results

In 63% (n=31) of all deaths, one or more ELDs were made (ELD+ cases). In 21 of the ELD+ cases (68%) potentially life-prolonging treatment were discontinued or withheld, and in 22 ELD+ cases (71%), drugs that potentially hastened death were administered to alleviate symptoms. None of the paediatric oncologists administered, supplied or prescribed drugs with the explicit primary intention of hastening death. After the child had died, the paediatric oncologist met with the child's parents in all ELD+ cases versus 12 out of the 18 ELD- cases. The paediatric oncologists were satisfied about the decision-making in 90% of the ELD+ cases versus 56% of ELD- cases.

Conclusion

In approximately two-third of all deaths, one or more end-of-life decisions were made. Paediatric oncologists were more satisfied with medical care when end-of-life decisions were made, emphasizing the importance of end-of-life decisions in care for children dying of cancer.

A Provider Based Survey to Assess Bereavement Care Knowledge, Attitudes, and Practices in Pediatric Oncologists

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Purpose

Bereavement support is a core tenant of palliative care recognized in the Clinical Practice Guidelines for Quality Palliative Care (2009). Bereavement care is difficult for clinicians as it is time consuming, emotionally charged, and not necessarily emphasized in training. This project is intended to describe practices, attitudes, and knowledge of bereavement care in pediatric oncologists in order to identify gaps in clinical practice.

Methods

A survey intended to gather data about physician's education, practice settings, attitudes and beliefs, and current practices was distributed to pediatric oncologists in the US. Data was captured in REDcap and analysis was performed using SAS 9.2.

Results

Surveys were distributed to 2,061 pediatric oncologists, 522 (25.3%) were completed. Participants were asked how often they engage in specific activities (phone calls, condolence cards, memorial attendance, family meetings, or referral for bereavement services) following a patient's death. Almost half (43.9%) reported that they sometimes do at least one activity and 18.4% rarely or never include these practices in clinical care. Lack of time was identified by 53.4% as a barrier to bereavement care. A majority indicated that resources such as communication training, standardized materials, and support from other providers are important to their efforts. Nearly all participants (96.2%) believe that bereavement care is part of good clinical care while only 8.9% indicated that they believe that bereavement is the responsibility of non-physician providers. Interestingly, a third of providers are unfamiliar with their institutions bereavement resources.

Conclusion

The majority of pediatric oncologists engage in bereavement care. Lack of time and physical resources pose barriers to clinician's efforts and many physicians are unfamiliar with the resources available within their institutions and communities. Additional supports, such as written resources and education in provision of bereavement care, should be explored to increase pediatric oncology physician uptake of bereavement care practices.

WHY DO PARENTS NOT TALK WITH THEIR TERMINALLY ILL CHILD WITH CANCER ABOUT DEATH?

I.M.M. van der Geest[1], M.M. van den Heuvel-Eibrink[1], L.M. van Vliet[2], S.M.F. Pluijm[1], I.C. Streng[1], E.M.C. Michiels[1], R. Pieters[1], A.S.E. Darlington[3]

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Introduction

Limited data is available about parents' reasons for not talking with their terminally ill child about death. This study explores parents' reasons for not having a conversation with their terminally ill child with cancer.

Methods

Parents were asked whether they had talked with their terminally ill child with cancer about death, and how they felt about this decision. Parents who did not talk were subsequently asked to indicate their reasons for not talking and parents who had talked were asked to indicate how the conversation took place. Descriptive and qualitative analyses were performed identifying emerging themes.

Results

Fifty-five parents (67%) did not talk with their child about death. The following themes were identified for not talking about death: parent-related reasons (e.g. unable to cope, not feeling confident, fearing consequences, preventing painful moments), child-related reasons (e.g. child does not want to talk, never started conversation, avoided conversation) and parental perception of child (e.g. already aware, too young). Parents who talked about death used stories or indicated simply telling the child that they would not be cured. Although the majority of parents felt good about their decision, ten parents did not, predominantly based on the subsequent negative emotional response of their child.

Conclusion

The majority of parents did not talk about death. Parental confidence and uncertainty about consequences played an important part in reasons for not talking to the child. In addition, children may avoid or not want to talk, or already be aware of their impending death. Our findings highlight the complexity of engaging in these conversations and the role for clinicians in supporting parents who will find these conversations difficult.

Measurement: what's new and necessary to screen or not to screen

10.30-12.00 hours

Chair: Maria McCarthy, Australia

Screening/measurement in AYA's

Validating the BSI-18 as Screen for Psychological Distress in Young Adult Survivors of Childhood Cancer (YASCC): Comparison with a Structured Diagnostic Interview

Recklitis, CJ[1], Blackmon, JE[1], Chang, G[2]

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Purpose/Objective

The BSI-18 is widely used to assess psychological distress in cancer survivors. However, there is limited research indicating which of several recommended cut-off scores is most accurate for identifying YASCC with clinically significant distress. This study assessed the diagnostic accuracy of several previously published BSI-18 case-rules compared to an individually administered Structured Clinical Interview for DSM-IV (SCID).

Methods

125 YASCC (age=18-40) enrolled completed the BSI-18 and the SCID interview assessing anxiety and depressive disorders in prior month. ROC analyses compared BSI-18 results to "gold standard" SCID criteria.

Results

55 survivors (44%) endorsing ≥1 critical SCID symptoms were classified as having significant symptoms; of these, 22 met criteria for ≥1 SCID diagnosis. Concordance between the BSI-18 GSI scale and SCID diagnosis was good (AUC =.88), but the standard BSI-18 case-rule (GSI or 2 subscale scores ≥63) and the widely used GSI ≥63 case-rule failed to identify 13 (59%) survivors with SCID diagnoses (sensitivity=0.41, specificity=0.97). Total Predictive Value for these case-rules was high, (87.2%) indicating overall accuracy, despite low sensitivity limiting clinical utility. Lower GSI cut-off scores missed fewer SCID diagnoses, but even the previously recommended GSI ≥ 50 cut-off missed 5 (22.7%) SCID diagnosed survivors (sensitivity=0.77, specificity =0.77). Results using the BSI-18 to identify survivors with significant SCID symptoms, rather than diagnosis were similar; previously recommended case-rules missed 40-80% of survivors with significant symptoms, though a lower GSI cut-off ≥ 47 showed promise for clinical screening (sensitivity=0.89, specificity =0.71). Overall, the BSI-18 detected YASCC with diagnoses or significant symptoms of depression more efficiently than anxiety diagnoses or symptoms.

Conclusions

The BSI-18 shows good overall concordance with a psychiatric interview, but recommended cut-off scores fail to identify a majority of YASCC with psychiatric diagnosis. Methods for developing new BSI-18 case-rules optimized for YASCC and implications for clinical screening will be presented.

Using the Fatigue Thermometer to Screen Adolescent and Young Adult Brain Tumor Survivors

Introduction

Sarah Brand[1], Christine Chordas[2], Cori Liptak[1], Peter Manley[2], Christopher Recklitis[2]

[1] Division of Pediatric Psychology, Dana-Farber Cancer Institute
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Purpose/Objective

Cancer related fatigue (CRF) is one of the most common and distressing symptom experienced by adolescent and young adult (AYA) cancer survivors and may disproportionately affect brain tumor survivors. While national guidelines recommend screening for CRF during routine follow-up, data supporting specific screening measures is limited. The objective of this study is to assess the validity of a one-item Fatigue Thermometer (FT) measure for assessing fatigue in AYA brain tumor survivors.

Materials/Methods

142 survivors (age 12-32) with a median time since diagnosis of 10.5 years (range 2.4 – 28 years) completed the 1-item Fatigue Thermometer (FT) and the 18-item Multidimensional Fatigue Scale (MFS) at a single clinic visit.

Results

57 survivors (40%) were identified as clinically fatigued on the MFS. ROC analysis indicated good concordance between the FT ratings and the MFS criterion (AUC = 0.812), but no FT cut-off score to reliably identify survivors with elevated MFS scores was identified. A low FT cut-off score of 1 had good sensitivity (93%), but poor specificity (59%), and higher FT cutoff scores of 3 had good specificity (78%), but missed too many cases of fatigue identified by the MFS (sensitivity = 65%). No FT cutoff score met study criteria for screening accuracy (sensitivity ≥ .85 & specificity ≥ .70).

Conclusions

Results from this study indicate the FT, a single-item screening measure for fatigue, is not able identify clinically significant fatigue in AYA brain tumor survivors. Results are discussed in the context of research on other “ultra-brief screening measures as well as clinical and research implications of the findings.

DEVELOPMENT OF A NEW MEASURE OF GOAL-BASED QUALITY OF LIFE FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER

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Purpose/Objective

Adolescents and young adults (AYA) with a history of cancer have significant challenges during a developmental period characterized bystruggles with setting and pursuing goals, which is a marker of poor quality of life (QOL). There are a lack of measures to track these QOL challenges across the disease trajectory or between those with cancer and other groups. A goal discrepancy model ofQOL posits that low attainability of a valued goal relates to worse QOL. We applied this model to develop theMeasure of Adolescent and Young Adult Goal-based Quality of Life (MAYA-GQOL) for AYA with a history of cancer. The measure is intended to be applicable across AYA with cancer and controls, and for those on or off treatment.

Materials and Methods

Purposeful sampling from a multi-study database,which yielded ~700 goals of 98 AYA representative across demographic (age, gender, minority status) and health variables (on treatment, survivor, healthy),was used to identify typical goals of AYA. Goals were sorted by two coders into 9 categories of an existing AYA goal taxonomy (academic, occupational, health, body/appearance, interpersonal, intrapersonal, leisure, religion, administrative). Exemplar goals of each category were identified and modified to form goal-based items on which respondents rate the value and attainability of each goal, yielding one discrepancy score (difference between the two). Focus groups andinterviews with AYA will soon be conducted to assess the comprehensiveness, relevance, and clarity of the current goal taxonomy and preliminary MAYA-GQOL items. Additional items will be created as needed.

Results

The results are a content valid, developmentally-and culturally-sensitive measure ready for pilot testing.

Conclusions

The MAYA-GQOL will enable comparison between AYA with and without cancer and tracking of adaptation and challenges across disease/treatment and developmental trajectories to inform developmentally appropriate interventions for this underserved population.

Family screening in pediatric oncology

CAREGIVER DISTRESS AND PATIENT HEALTH-RELATED QUALITY OF LIFE: PSYCHOSOCIAL SCREENING DURING PEDIATRIC CANCER TREATMENT

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Objectives

Prior research has focused on identifying family psychosocial risk factors at cancer diagnosis in order to improve pediatric cancer care. This study aimed to evaluate presence of family risk/resources and caregiver distress in the first year from diagnosis and to determine the associations of family risk/resources and caregiver distress with patient health-related quality of life (HRQOL).

Methods

Sixty-seven parents of children with cancer completed the Check-in About Recent Experiences and Strengths (CARES) protocol via iPad during clinic visits within one year of diagnosis. CARES includes: Psychosocial Assessment Tool (family risk/resources), Strengths and Difficulties Questionnaire (patient adjustment), PedsQL 4.0 (patient HRQOL), Distress Thermometer (caregiver distress), and PTSD Checklist-Civilian 6 (caregiver traumatic stress).

Results

Patients ranged in age from 3 months to 18 years (M = 9.3, SD = 5.5 years), and 49% were female. The sample was equally distributed across leukemia/lymphoma, solid tumor and brain tumor diagnoses, and mean time since diagnosis was 158.27 days (SD = 94.6 days). Distress thermometer scores indicated moderate distress (M = 4.86, SD = 2.69). Gender, age, type of cancer, and time since diagnosis were not significantly correlated with family risk/resources, caregiver distress, and caregiver traumatic stress. Reduced patient HRQOL was significantly correlated with family risk ($r=-.41$, $p < .001$), caregiver distress ($r = -.43$, $p < .001$), and caregiver traumatic stress ($r = -.33$, $p < .01$).

Conclusions

Moderate levels of distress regardless of time since diagnosis and the association of caregiver distress with reduced patient HRQOL highlights the importance of psychosocial screening and care throughout the course of pediatric cancer treatment. To target timing and focus of psychosocial interventions, our future research aims to screen psychosocial risk based on patient self- and parent report using an adapted version of CARES during and after cancer treatment.

Agreement between different coders: mothers, fathers, and psychosocial team completing the Psychosocial Assessment Tool (PAT)

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Introduction

The use of the Psychosocial Assessment Tool (PAT) makes it possible to screen families of a child with cancer for their risk of psychosocial problems. The current study describes the agreement on the PAT between mothers, fathers, and psychosocial team.

Methods

139 families (response rate 72%) of newly diagnosed children with cancer (age 0-18) from four Dutch pediatric oncology centers (AMC/RUMCN/SKZ/VUmc) agreed to participate. In 84 families, both mother and father completed the PAT. PAT total score (possible range 0.00-7.00) 0-0.99 were considered 'universal', 1.00-1.95 'targeted', and ≥1.96 'clinical'. Psychosocial team was asked to complete the PAT staff, which is an estimation of the family risk score ('universal', 'targeted', or 'clinical').

Results

Mean total PAT score was *M*=.72 [range=0-2.88] and mean difference between mothers and fathers was *M*=.055 [range=-1.44-1.17]. Agreement between different coders was: mothers and fathers *k*=.589 (p=.000), mothers and psychosocial team *k*=.121 (p=.234), fathers and psychosocial team *k*=.197 (p=.040). In 83% of the families, mothers and fathers obtained the same risk score. In 63% of the families (combined score mothers/fathers), psychosocial team and family obtained the same risk score; 25% was overestimated and 12% underestimated by the psychosocial team.

Conclusion

These results confirm that the PAT is a family questionnaire, with high agreement between mothers and fathers. The psychosocial team seems to agree with the PAT score in majority of the families, however over- and underestimation is present. Additional research is needs to be done to show which factors contribute to (dis)agreement between mothers, fathers, and psychosocial staff.

HEALTH CARE PROVIDERS' RATINGS OF THE UTILITY OF PSYCHOSOCIAL SCREENING TOOLS IN CHILDHOOD CANCER

A. Di Battista[1], K. Hancock[1], D. Cataudella[2], D. Johnston[3], A. Punnett[4], W. Shama[5], U. Bartels[4], P.C. Nathan[4], M. Barrera[1]

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Objectives

The clinical use of standardized psychosocial screening tools in pediatric oncology is rare, and how useful these tools are perceived to be by health care providers' (HCPs) is unknown. This study examined HCPs' perceived utility of two psychosocial screening tools designed for use in pediatric oncology, the Psychosocial Assessment Tool-Revised (PATrev) and (2) the Psychosocial Care Checklist (PCCL).

Methods

Pediatric oncologists (ONC), nurses (NUR) and social workers (SWK) treating patients at four pediatric cancer centres participated. Institutional approval was obtained for the study at each site and participants signed consent forms. Participants were asked to rank how useful they found: (1) psychosocial summary information derived from the parent-completed PATrev; and (2) the PCCL, an instrument completed by HCPs regarding the psychosocial needs of participating families before they received the psychosocial summary information. Usefulness was assessed using a Visual Analogue Scale (VAS). The VAS had a minimum score of 0 and a maximum score of 10; higher scores indicated greater endorsement for the utility of the measure. X^2 were used for analyses; effect sizes are reported.

Results

Seventy-three HCPs participated (32 ONC, 24 NUR, 10 SWK). Nurses reported the greatest utility endorsement of the PATrev summary compared to pediatric oncologists (d = 0.77) and social workers (d = 2.94). Similar results were found for the PCCL utility for nurses compared to pediatric oncologists (d = 0.87), and nurses compared to social workers (d = 1.94). Overall, nurses reported psychosocial screening to be more useful than the other HCPs.

Conclusions

These results suggest that there is variable belief in the utility and endorsement of these psychosocial screening tools among practitioners. Future research should examine specific barriers to uptake and implementation of these tools.

New directions in research on pediatric cancer and family adjustment

13.00-14.00 hours

Chair: Lynn Fainsilber Katz, USA

Pediatric cancer and child adjustment: The role of marital and parent-child conflict

Katz, L.F., Kawamura, J., Lavi, I., Gurtovenko, K., Stettler, N., Compas, B., & Friedman, D.

Objective

Given the stresses involved the diagnosis and treatment of cancer in a child, some families may experience considerable conflict as they renegotiate roles and make health care decisions. In normative populations, there is considerable evidence that marital and parent-child conflict predicts child maladjustment. Yet, little is known about the nature of family conflict following a diagnosis of cancer and links between family conflict and child adjustment. While studies show conflicting results on changes in marital adjustment following diagnosis of childhood cancer, there is no research on relations between marital and child functioning. Similarly, only a handful of studies have examined associations between parent-child conflict and child adjustment. In this presentation, we examine whether marital adjustment and parent-child conflict at diagnosis as rated by both primary and secondary caregivers predict changes in child adjustment six months later.

Methods

Fifty-seven children (2-15 years old, mean = 5.67) who were newly diagnosed with any form of cancer or CNS tumor were enrolled (57.9% female). Primary and secondary caregivers completed measures of parent-child conflict, marital adjustment, and child adjustment at diagnosis and at six months post-diagnosis.

Results

Primary caregiver-rated (but not secondary caregiver-rated) parent-child conflict at the time of the child's diagnosis (T1) significantly predicted changes in children's internalizing (ΔR^2 0.05, p=0.02), externalizing (ΔR^2=0.06, p=0.02), and total problems (ΔR^2=0.09, p=0.001) from T1 to 6 months post-diagnosis (T6). Primary caregivers' marital adjustment at T1 predicted children's externalizing (ΔR^2=0.04, p=0.05) and total problems (ΔR^2=0.03, p=0.07), but not internalizing problems at T6. Secondary caregivers' marital adjustment predicted children's internalizing (ΔR^2 =0.07, p=0.09), externalizing (ΔR^2=0.15, p=0.01), and total problems (ΔR^2=0.11, p =0.01) at T6.

Conclusions

Both marital adjustment and parent-child conflict at diagnosis predict child adjustment six months later. Implications for intervention will be discussed.

PEER AND FAMILY RELATIONSHPS THAT ACCOUNT FOR VARIABILITY IN SYMPTOMS OF ANXIETY AND DEPRESSION FOR PEDIATRIC BRAIN TUMOR SURVIVORS

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

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[4] *Children's Hospital Milwaukee and the Medical College of Wisconsin, Milwaukee, WI, USA;*
[5] *University of Colorado Denver, CO, USA;*

Purpose

Improved survival has led to concerns about the quality of life for pediatric brain tumor survivors (PBTS). Peer relationship difficulties and emotional distress have been reported, yet we know little about their association or family resources that account for variability. Our work examines the association of peer victimization with emotional distress and whether family supportiveness and conflict moderates this association or contributes directly to child well-being.

Method

Participants included 187 PBTS, 8-15 yoa, 1-5 years post-treatment, and 53% male at 5 oncology centers in the United States and Canada. The Revised Class Play, completed by PBTS and their classmates in mainstream, academic classrooms, assessed victimization. Primary caregivers of PBTS and comparison classmates completed the Family Environment Scale and Child Behavior Checklist during subsequent family assessments. Analysis of direct, indirect, and moderated effects were conducted using hierarchical multiple regression analysis, with cross-products of mean-centered predictors to test interactions.

Results

Overall, anxiety and depression was higher for PBTS than comparison classmates (p=.001) as well as children who experienced more peer victimization (p<.001) and family environments with less support (p=.002) and more conflict (p<.001). Within the sample of PBTS, interactions indicate that the association of victimization and child anxiety/depression is strongest when family support is low (p=.011) and conflict is high (p=.002). Within the comparison sample, support but not conflict moderated the association of victimization and anxiety/depression, and the association of victimization and symptoms of anxiety/depression were weaker when family support was low.

Conclusion

PBTS are at risk for elevations in anxiety and depressive symptoms well after treatment completion, yet risk may be partially accounted for by negative peer experiences and family environment. The relative importance and interaction of these domains have similarities and differences to patterns in typically developing children.

Parents and Children Coping with Child Cancer: Longitudinal Processes of Adaptation

Bruce E. Compas, PhD, Kathryn Vannatta, PhD, Cynthia A. Gerhardt, PhD

Objective

The diagnosis and treatment of cancer in a child is characterized by significant stress that requires the mobilization of coping efforts. The development of interventions to reduce child and parent emotional distress is predicated on prospective data that establish links between coping near the time of a child's diagnosis and emotional distress at a subsequent point in the process of treatment and recovery.

Methods

Near the time of a child's cancer diagnosis and again 12-months later, 205 children (6-17-years) and their mothers completed measures of coping and emotional distress. Three types of coping were assessed on the Responses to Stress Questionnaire--primary control engagement coping (e.g., problem solving), secondary control engagement coping (e.g., cognitive reappraisal), and disengagement coping (e.g., avoidance). Near time of diagnosis and 12-months mothers reported on their own depressive symptoms (BDI-II) and their children's symptoms of anxiety/depression (CBCL); adolescents completed the YSR.

Results

After controlling for depressive symptoms near diagnosis, mothers' primary control (β=-.55, p<.01) and secondary control coping (β=-.32, p<.01) predicted mothers' depressive symptoms at 12-months (R^2=.47). Based on mothers' reports about their children, only children's use of secondary control coping near diagnosis (β=-.17, p<.01) predicted symptoms of anxiety/depression at 12-months, controlling for symptoms near diagnosis (R^2=.35). In children's self-reports, coping near diagnosis did not predict symptoms at 12-months; however, both primary control (β=-.33, p<.01) and secondary control (β=-.21, p<.05) coping at 12-months were significantly related to 12-month symptoms of anxiety/depression symptoms after controlling for symptoms near time of diagnosis (R^2=.19).

Conclusion

These findings highlight the importance of the ways that mothers and children cope with a child's cancer and suggest that interventions designed to enhance both primary control skills such as problem solving, and secondary control skills such as reappraisal, may be beneficial in reducing distress in these children with cancer and their parents.

Siblings after a Child's Death from Cancer

Cynthia A. Gerhardt, PhD, Laura Schwartz, Maru Barrera, PhD, Bruce E. Compas, PhD, Diane L. Fairclough, DrPH, Terrah L. Foster, PhD, Mary Jo Gilmer, PhD, & Kathryn Vannatta, PhD

Objective

Parents and siblings experience significant distress after a child's death. Limited work has examined links among distress in bereaved family members and the role of coping. We examined if parent-child interactions (parenting, communication) mediated the association between parent and sibling distress in the first year after a child's death from cancer. We also tested whether mediation varied as a function of the sibling's coping (primary control, secondary control, disengagement).

Methods

After a child's death from cancer, 72 families with a surviving sibling (M_{age} = 13.2 yrs, *SD* = 2.2) were recruited from three institutions in the U.S. and Canada. Home-based assessments occurred in the first year (*M* = 12.45 months). Parents and siblings completed the Adult or Youth Self-Report (internalizing problems), as well as the Parent-Adolescent Communication Scale. Parent and sibling reports of openness and problems in communication were averaged. Siblings also completed the Child Report of Parent Behavior Inventory (parental warmth, behavioral control, psychological control) and the Responses to Stress Questionnaire (primary control, secondary control, disengagement coping).

Results

Correlations between mother and sibling internalizing problems were small (*r* = .25). Father and sibling distress were not associated (*r* = .05). Associations between mother/father and child internalizing problems were mediated by nearly all five parenting and communication subscales. Evidence of moderated mediation was found for several types of coping. Most often, associations between negative parenting/communication and sibling distress were stronger in the context of the sibling's use of less secondary control coping and more disengagement coping.

Conclusion

Negative parent-child interactions accounted for links between parent and sibling distress after a child's death from cancer. However, siblings who used more secondary control and less disengagement coping were somewhat protected from these family risk factors. Additional research and interventions to improve distress, dyadic interactions, and coping in bereaved families are needed.

Functioning and interventions for siblings

14.00 – 15.00 hours

Chair: Maru Barrera, Canada

SIBLINGS OF CHILDREN WITH CANCER: PERCEIVED CHANGES IN THEIR PLACE AND ROLE WITHIN THE FAMILY AFTER CANCER DIAGNOSIS AND THROUGHOUT GROUP TREATMENT

Neville[1], M. R. Simard[1], K. Hancock[1], A. Rokeach[1], L. Brister[2], P. Yogalingam[1], A. Saleh[1] & M. Barrera[1]

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Objective

Siblings of children with cancer have often been reported as expressing a number of social and emotional difficulties. This qualitative study aimed to examine siblings' perceptions of their place and role within the family when a brother or sister is diagnosed with cancer.

Method

Institutional approval was obtained and participants signed written informed consent. Participants included 22 siblings, aged 7-17 years, who participated in four rounds of the Siblings Coping Together (SCT) Program, an 8-week, manualized, group intervention program for siblings of children with cancer. Data consisted of materials completed by siblings during the sessions ("feelings trees" and "mind maps"), 49 in-between session homework sheets, 33 pieces of artwork/posters, and 31 logs recording events within group sessions completed by observers and group facilitators. A grounded theory framework was used for thematic data analysis.

Results

Three themes emerged regarding changes in siblings' perceptions of their place and role within the family since their brother or sister was diagnosed: Being treated differently (perceptions of being a burden in the family, ways they are included or left out of the cancer experience), perceptions of being less important than the child with cancer (seeing themselves as less loved than the affected child, having less privileges), and perception of changes in their role in the family as a whole (assisting in care giving for the ill child, a sense of increased responsibility for themselves and within the family, e.g. having to do more chores, becoming more independent). Sharing of these thoughts gradually increased over the 8-week sessions and formed the basis for the group intervention.

Conclusion

These preliminary findings provide rich insight of siblings' own views of the changes in their place and role within the family. These views emerged throughout their participation in the SCT intervention, which allowed them to improve their coping strategies.

HAVING A SIBLING WITH CANCER: EMOTIONAL EXPERIENCE AND GROWTH THROUGHOUT AN 8-WEEK COPING WITH CANCER INTERVENTION

MR Simard[1], A Neville[1], A Rockeach[1], K Hancock[1], L Brister[2], A Saleh[1], P Yogalingam[1], & M Barrera[1]

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[2]Child & Life Services and Hematology-Oncology Program, The Hospital for Sick Children, Toronto, Canada.

Objective

This qualitative study examined the emotional experiences and growth of siblings of children with cancer while participating in a manualized group intervention program: Siblings Coping Together.

Method

Participants were 22 youth partaking in four different rounds of an 8-week group intervention for siblings of patients at least three months from diagnosis. Siblings were eligible to participate if they were between 7-17 years old. Data was derived from materials (e.g., "feelings trees" and "graffiti walls") completed by siblings during the sessions, 49 in-between session homework sheets, 33 pieces of artwork/posters completed by siblings, and 31 logs recording events within group. A grounded theory framework was used for thematic analysis of data. This study was approved by the institution and participants provided signed consent.

Results

Several overarching themes emerged regarding siblings' emotional experiences during the group: feelings related to their personal experiences regarding their exposure to cancer (sense of loss, sense of being dismissed or brushed aside by their family, guilt for having negative thoughts about the ill child, and emotional confusion), feelings related to their perceptions of their brother's/sister's experiences with cancer (feeling badly for them, worry about death and their well-being, and hope for their cure), and feelings related to the family context (as stressful, emotionally labile, and dependent on the treated child's health). Siblings reported several different ways of attempting to regulate these feelings, both adaptively (e.g., "find someone to talk to") or maladaptively (e.g., avoiding difficult feelings). Sharing of these emotional experiences and how to cope with them improved over the 8 sessions of intervention.

Conclusion

These findings provide rich evidence capturing siblings' views about themselves, the ill child's and family's experience, progressively emerging throughout a group intervention. This information is critical for treatment planning and ultimately helping siblings to navigate the experience of having a brother or sister with cancer.

REDUCTION OF ANXIETY LEVELS IN PARENTS AND SIBLINGS OF CHILDREN WITH CANCER AFTER SIBLING PARTICIPATION IN A PSYCHOSOCIAL GROUP INTERVENTION: A RANDOMIZED CONTROLLED TRIAL

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Background

Childhood cancer diagnosis and treatment can result in major psychological distress in the family.. Programs targeting the specific psychosocial needs of siblings are rare and examination of the effects of these interventions on sibling and parental distress has not been previously investigated.

Objective

To determine if a manualized group intervention program for siblings, Siblings Coping Together (SCT), (Experimental Group, EG), improves anxiety in siblings' (directly) and parents' (indirectly) compared to a Control Group (CG).

Methods

Institutional approval was obtained and participants signed consent forms. Methods: A multi-site randomized controlled trial (RCT) with repeated measures. Inclusion criteria: Siblings, ages 7 to 16 years, and one parent, of patients at least three months from diagnosis. Both groups completed 8 two-hour weekly group sessions and three assessments (T1, pre-; T2, immediately post-intervention; and T3, three months later). EG sessions followed SCT's educational, social, and therapeutic problem-solving plan through games and crafts; CG sessions focused on socializing through games and crafts. Parents and siblings completed standardized self-report measures of Anxiety (Multidimensional Anxiety Questionnaire and Multidimensional Anxiety Scale for Children). Repeated-measures ANOVAs were conducted with partial eta-squared as indices of effect size.

Results

Preliminary analyses were based on 53 participants at T1 and 26 at all 3 assessment points. Parent Self-Report. Two significant group x time interactions were found: physiological panic reactions ($\eta 2=0.30$) and social phobia ($\eta 2=0.20$), suggesting improvements for parents in the EG compared to CG across time. Significant effects of time suggested both groups improved on measures of total anxiety, worry-fears, and negative affectivity ($\eta 2=0.36$, 0.29, and 0.43, respectively). Child Self-Report. A significant group x time interaction in panic/separation suggests improvement in the EG relative to CG, maintained over time ($\eta 2=0.24$).

Conclusions

Preliminary findings suggest major improvements in siblings' and their parents' anxiety, sustained over time, following participation in the manualized group intervention program.

A NEW 1-DAY SYSTEMIC INTERVENTION FOR SIBLINGS OF CHILDREN WHO HAVE CANCER AND THEIR PARENTS: A FEASIBILITY AND PILOT STUDY

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Objective:
The aim of this study was to determine the feasibility and acceptability of a new 1-day systemic intervention for siblings of children with cancer and their parents, and to examine outcomes of a pilot study. Preliminary evidence was gathered to assess whether the current intervention promoted psychological adjustment in siblings in terms of mood, self-esteem, coping, and resilience, reduced psychosocial risk in the family and improved family functioning and communication.

Materials and methods:
This study recruited siblings of children who were being treated for all cancer types at a regional pediatric oncology and hematology centre in the UK over a period of 12 months. Twelve families (17 children and 19 parents) participated in the 1-day systemic therapeutic intervention. The intervention was developed combining three therapeutic components: systemic, narrative and problem solving strategies. The study used a longitudinal repeated measure design and included pre- and post-intervention assessments (4 and 12 weeks follow-up) and a qualitative assessment of participants' experience (8 weeks follow-up).

Results:
Enrolment, retention, attrition and satisfaction data support feasibility and acceptability of the intervention, but also highlight challenges. Outcome data showed changes in the desired directions: at 4 and 12 weeks follow-up, siblings in the intervention groups showed improved scores on the self-esteem, psychological competences, resilience and coping scales, and parents showed improvement on the scales of family functioning and communication and a reduction on the psychosocial risk scale (with Effect Sizes from small to large).

Conclusion:
The current study filled a gap in the current literature proving the feasibility and acceptability of delivering 1-day systemic intervention study for siblings of children with cancer and their parents in a regional centre in the UK. The authors developed a manual of the current intervention that allows for the replication of the current study in different oncology centres.

SIBLINGS: A VIDEO FOR BROTHERS AND SISTERS OF PEDIATRIC ONCOLOGY PATIENTS

Casey, R.; Donohue, A., Hudson, C., & Chen, C.
Children's Hospital Colorado/University of Colorado, Aurora, CO

Background/Problem

Siblings of pediatric cancer patients are confronted with unique challenges from the moment a brother or sister is diagnosed. Siblings must learn to cope with the chaos of the initial diagnosis, the disruption to daily life, and the intense emotions that inevitably follow. Research findings suggest that most siblings experience some level of stress associated with the treatment of the ill child. Despite this understanding, formal interventions for siblings are limited.

Project Description

The Siblings video, produced by academy award winner Donna Dewey, highlights some of the most common thoughts and feelings that siblings encounter as they accompany a brother or sister through cancer treatment. This 25 minute video is designed to be previewed by a parent and then viewed by the sibling and parent together, or by the sibling and a member of the medical team experienced in psychosocial intervention. The video may be viewed in its entirety or by choosing relevant segments.

Project Goals

Use of the video and accompanying manual is intended to normalize the experiences and emotions of siblings, and to provide a developmentally appropriate context for ongoing discussion of coping strategies and illness related education.

Evaluation/Results

Initial pilot data suggests that that the video identifies key emotions experienced by siblings and provides a catalyst for families to recognize and acknowledge the challenges that siblings face. Data collection is ongoing and additional data will be presented.

Implications for Treatment

Members of the medical team (e.g. psychologists, social workers, child life specialists, nurses) experienced in psychosocial intervention can provide direct intervention using the video and manual. More broadly, the video can be an educational tool increasing awareness of sibling adjustment, thereby increasing the likelihood of appropriate intervention.

Updates on traumatic stress research in pediatric cancer: taking changes of the DSM-V into consideration

15.30 - 15.50 hours

Presenter: Anne Kazak, USA

Into the future: standards of care

15.50 – 16.50 hours

Chair: Jaap Huisman, the Netherlands

Guidelines for psychological care in children with cancer in Poland.

Samardakiewicz M. [1, 9], Kowalczyk J. R. [1], Szweda E. [2, 9], Korzeniewska J. [3, 9], Grudzińska M. [3 ,9], Pawełczak-Szastok M. [4, 9], Pilarczyk J. [5, 9], Gwadera M. [6, 9], Grabowska A. [7, 9], Budziński W. [8, 9]

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9. Polish Pediatric Psychooncology Group, PPPG

Introduction

Significant progress has been made in treatment results of children with cancer in Poland. This progress was achieved due to the close collaboration within reference onco-hematology centers (POH units) in Poland. During cancer treatment it is recommended not only to monitor somatic functioning of patient but also to give well-planed bio-psychosocial support.

Aim of the study

Introduction of bio-psychosocial support programme of children with cancer in Poland, with place emphasis of psychological care.

Material and Methods

Programme of bio-psychosocial support in Polish POH units was based on the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology recommendations. The implementation of the programme was started in1998 and elaborated during regular, twice a year meetings of clinical psychologists, initially within 7 POH. In part of psychological care, the support programme include a few rules: 1. providing parents and child with cancer with comprehensive information on the diagnosis and treatment by trained in communication skills staff members; 2. each child with cancer should be offered psychological support; 3. planned psychological care include diagnostic and therapeutic relations with child and adolescents with cancer due to their developmental and individual needs; 4. monitoring the level of adaptation to the treatment across the treatment course and at the critical moments.

Results

Between 1998-2012, the PPPG hold 29 meetings, gathered most POH psychologist and focused on solving different psychological issues concerning children with cancer in Poland. During this time it was possible to elaborate the unified model of disclosure of cancer diagnosis, establish set of diagnostic methods, and undertake efforts to do adaptation of disease-specific tools.

16 years of experience of polish POH in improving planned biopsychosocial support was noticed during the first EU Conference in Warsaw, and was taken advantage in guidelines entitled “European Standards of Care for Children with Cancer’.

DEVELOPMENT OF A CANADIAN SCHOOL RE-ENTRY AND EDUCATIONAL PLANNING GUIDELINE FOR CHILDREN WITH CANCER

Joanna Chung, Department of Psychology, Oncology/Hematology/BMT Program, BC Children's Hospital, Vancouver, BC, Canada

Ann Klinck, Psychology, Children's Hospital, London Health Sciences Centre, London, ON, Canada

Paula Robinson, C17 and the Pediatric Oncology Group of Ontario, Toronto, ON, Canada

On behalf of C17 Inter-Disciplinary School Re-Entry and Educational Planning Guideline Panel

Objective

To describe the development of a School Re-entry and Educational Planning Guideline for Children with Cancer. This guideline aims to provide pediatric oncology health care providers, children, families, and the school community with recommendations for educational planning for children with cancer.

Method

A pan-Canadian, inter-disciplinary panel of experts was convened to develop the health questions addressed in the guideline, identify a source guideline for adaptation, synthesize the available evidence and develop recommendations. Established guideline methods (CAN-IMPLEMENT, AGREE-II) were used. Librarian-scientist assisted systematic literature searches were undertaken to identify possible source guidelines and existing literature related to school re-entry and educational planning. The quality of evidence was assessed and the strength of each recommendation was determined using GRADE methodology. The draft guideline will undergo an extensive external review by international content experts and by stakeholders (Canadian pediatric oncology physicians, psychologists, social workers, nurses, community educators, parents). The guideline will be revised based on this feedback.

Results

No source guideline was identified; a de novo guideline was developed based on a systematic review of the primary literature. The guideline provides recommendations to facilitate the process of children continuing with their education after a cancer diagnosis including: service coordination, psychosocial needs assessment, patient/family support, education of school staff and peers, and ongoing monitoring/follow-up for the children. Research gaps are identified.

Conclusions

The evidence-based guideline recommendations apply to all school-aged patients to 18 years of age with cancer. The scope of the guideline is limited to the psychosocial aspects of school re-entry. Patient and family needs and preferences, available resources, organizational and governmental policies will determine the extent of implementation of the recommendations in each jurisdiction. The impact of these recommendations on the quality of life of children with cancer requires prospective evaluation.

Ethical Dilemmas Involved in Pediatric Bone Marrow Donor Evaluation: Demonstrating the Need for Standards of Care

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Stem cell transplantation has become standard treatment for a variety of diseases in children and adults. Children often serve as hematopoietic stem cell donors, most commonly for their siblings. Although a general outline of recommended criteria to be met in order for a child to serve as a donor was presented in a 2010 policy statement by the American Academy of Pediatrics, there is currently no established standard of care in regards to the psychological assessment of child donors. The purpose of this presentation is to discuss a variety of ethical dilemmas that may be present during the pediatric donor evaluation process in order to demonstrate the need for standards of care.

We have completed sibling donor evaluations for a large pediatric hospital in the Northeast. Evaluations include a variety of components centered on providing psychoeducation, ruling out contraindications to participation, and ultimately obtaining child assent. Based on extensive clinical experience, we have compiled a list of ethical dilemmas faced while completing these evaluations, each illustrated by a brief case summary. These dilemmas are rooted in areas of development, culture, language, psychological functioning, and family dynamics.

Ultimately, we aim to demonstrate the need for standards of care for pediatric bone marrow donors in an effort to provide guidance to clinicians and ensure the psychological well-being of these children. Challenges associated with establishing such guidelines will be discussed. It is our hope that a standard evaluation procedure for pediatric bone marrow donors would lead to an improvement in the quality of care provided to pediatric donors, increased collaboration among psychosocial providers, and an improved ability to conduct psychosocial research across hospital sites. This may ultimately lead to multi-site studies that examine outcomes for pediatric donors.