



POPPI Newsletter

Pediatric Psycho-Oncology
Professionals/Providers
International

Issue 6: October 2nd, 2020

STEERING COMMITTEE

WELCOME TO THE SIXTH ISSUE OF THE POPPI NEWSLETTER



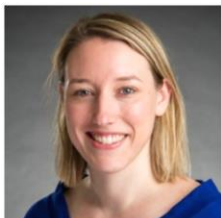
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A welcome note from the Chairs

by Martha Grootenhuis, Claire Wakefield, and Lori Wiener

Welcome to the sixth Issue of the POPPI Newsletter: Pediatric Psycho-Oncology Professionals/Providers International!

The goals of POPPI are to stimulate international communication among professionals with a diversity of clinical and research backgrounds in order to foster collaboration in clinical care, research and education that relate to pediatric psycho-oncology, and to share resources, training opportunities, ongoing research, and upcoming events in the field of pediatric psycho-oncology. Our hope is that this newsletter will provide information which will bring our field closer together and help each of us to deliver the highest quality of care to youth with cancer and their families.

Impact of COVID-19

The COVID-19 pandemic has impacted all of our lives. Many of you may be making extraordinary sacrifices to care for your patients. Some of you may have become ill, be caring for family members, quarantined from your loved ones. We are all shifting our priorities and trying to model good coping strategies, and to not spread the contagion of anxiety. We will continue to share the impact of this pandemic on the pediatric psychosocial oncology community and lessons learned. As we all bear witness during this unprecedented time, please know that our thoughts are with all of you.

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New book release

'Cancer Daily Life':

By Carola Schmidt, Germany
Twitter: @_CarolaSchmidt
W: <https://www.amazon.com/author/followingchubby>

Carola is a pediatric oncology pharmacist and author of kid's books about cancer and other books in pediatric oncology for Springer Nature, Brazil.

'Cancer Daily Life' is a bittersweet collection of single and double-frame strips that only readers who are highly involved with the C world could relate to. It's sometimes cute and sweet, sometimes acid, sometimes trivial, sometimes funny, just like daily life. 'Cancer Daily Life' is ideal for adolescents and young adults coping with cancer.

I am always asking psychologists and family members what kind of books are needed. Many people have been asking for a book for teenagers. The idea of Cancer Daily Life is to be a fun book with images and short phrases about a teen or adult's daily life. Starting with the phrase "Cancer is...", it is a book about people stalking them with green juices and bothering them with alternative "treatments" like a new diet. A neighbor who says: "I'm glad you're alive!" But it is not only about acid moments.

It is a bittersweet book. Sometimes, it is as cozy as their favorite blankets to use during the chemo. It is a book that they can relate to. They can feel truly seen and they know they are not alone. Illustrated by Rafael Antonio, a Brazilian

artist, the art includes diverse characters: diverse skin colors— including a character with vitiligo— various age rates (adolescents and adults), a character in a wheel chair, some of them without and some with hair, and diverse ethnic characteristics.

"What does it mean to have cancer?" Carola Schmidt shows all the different answers to that question in her wonderful book 'Cancer Daily Life'. Her book is full of emotional and lovely illustrations and also full of emotional and lovely words. She lets the readers know what a cancer journey means. Situations a healthy person would never think about but what for cancer patients mean the world. I was a childhood cancer patient 31 years ago and I still find myself in this book.

"While reading I could not hide my tears because finally my thoughts are shown by wonderful illustrations and told by wonderful texts. Thank you, Carola Schmidt, for this work of art you have produced. You make this world for cancer patients and cancer survivors so much more colorful. Thank you for this milestone of a cancer book." Christian Müller, Childhood Cancer Survivor and Journalist in Pediatric Oncology.

It's ideal:

- For adolescents and adults age 12 years old or older
- When you have a family member or friend coping with cancer, and you don't know what to say

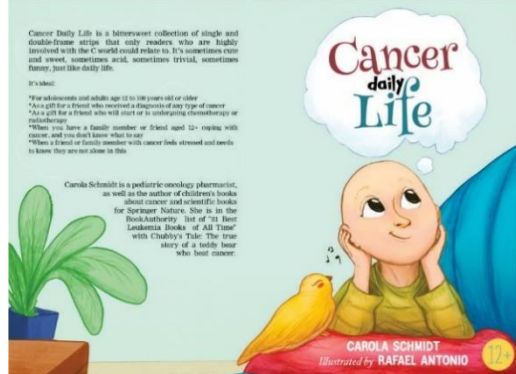
- As a gift for a friend who received a diagnosis of any type of cancer or who will start or is undergoing chemotherapy or radiotherapy
- When a friend or family member with cancer feels stressed and needs to know they are not alone in this.

Link to the book:

<https://www.amazon.com/dp/B08DSYSP3G/>

In my journey writing for kids with cancer, I realized I needed to write several different books. "Chubby's Tale: The true story of a teddy bear who beat cancer" to attend the demand of psychologists and families, to explain cancer with love and help children to understand that cancer is not their fault, why their hair can fall out during the chemotherapy and biological aspects of the disease and treatment.

"Bald is Beautiful: A letter for a fabulous girl" came to fill the demand for books about childhood cancer that does not mention the word "cancer." That book is about beauty and happiness, acceptance and love. Many friends and family members wanted a gift for a kid while they were still not prepared to accept the word "cancer." They still have a fear of that and avoidance. Bald is Beautiful is a gift book and opens the first door to talk about cancer. Since it does not mention the word "cancer," it is ideal for kids with alopecia due to other conditions.



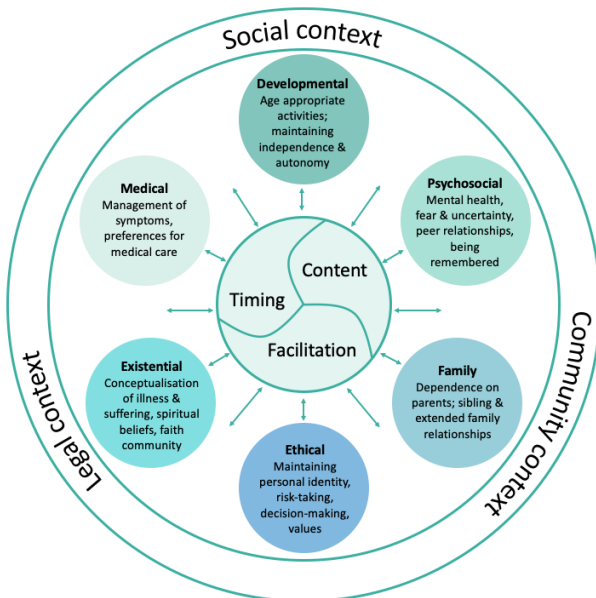
Research “in the spotlight”

Research in the spotlight: Dr Ursula Sansom-Daly’s end-of-life research

By Dr Ursula Sansom-Daly and Holly Evans, Australia

Dr Sansom-Daly is a Clinical Psychologist and Post-doctoral Research Fellow at UNSW Sydney and Sydney Children’s Hospital. Holly Evans is a PhD Student at UNSW Sydney. In this issue, they share some of their current research on end-of-life care.

Adolescents and young adults (AYAs) with cancer face developmental, psychological, and medical-related challenges. When cancer treatment is not successful and cure becomes unlikely, they can be especially at risk. In order to best meet the needs of these AYAs and their families, developmental considerations need to inform how end-of-life conversations happen.¹ This also occurs within a community, social, and legal contexts that dynamically impact on these conversations (see Figure below).



However, there is little guidance around how health professionals should navigate these factors to deliver best-practice communication with AYAs towards end-of-life. To address this gap, our team is running a two-stage study looking at healthcare professionals and end-of-life communication for AYAs with cancer, funded through a research grant from the Adolescent and Young Adult Cancer Global Accord.

Our international team aims to examine healthcare professionals’ awareness and confidence in implementing international standards of end-of-life communication with AYAs with cancer, determine training needs in this space, and develop

recommendations for evidence-based end-of-life communication training.

The first part of our research involves a survey to index the current ‘lay of the land’ in terms of current end-of-life communication practices and services internationally. Put simply, we hope to understand how end-of-life communication is currently occurring with AYA cancer patients, relative to the standard of care. The international practices survey has already been disseminated in Australia and New Zealand, with 105 health-professionals recruited.

We have just launched the UK component of this survey and are inviting any health-professionals who work with teenagers/young adults with cancer to consider participating here:

https://unsw.au1.qualtrics.com/jfe/form/SV_dbYqUA5AZ9FDkoJ

(Health-professionals based in the UK: Please get in touch if you’re interested in finding out more!).

Our research also involves a two-round Delphi survey to establish expert consensus on optimal end-of-life communication with AYAs, and training needs/preferences (including considerations around training content/format). The Delphi survey has recruited 245 healthcare professionals internationally. We will use the Delphi data to develop a model for training healthcare professionals in end-of-life communication with AYAs. We hope that this research will contribute to establishing global end-of-life communication practices and develop a training blueprint for the future. This will ultimately support delivery of gold standard care for AYAs at end-of-life.

Ursula also wrote recently about the unique challenges in end-of-life communication with AYAs for Oncology News - <https://oncologynews.com.au/tackling-taboos-can-we-agree-on-how-to-talk-about-end-of-life-with-young-people/>

Reference: Ursula M. Sansom-Daly, Claire E. Wakefield, Pandora Patterson, Richard J. Cohn, Abby R. Rosenberg, Lori Wiener, and Joanna E. Fardell. End-of-Life Communication Needs for Adolescents and Young Adults with Cancer: Recommendations for Research and Practice. *Journal of Adolescent and Young Adult Oncology*. Apr 2020.157-165. <http://doi.org/10.1089/jayao.2019.0084>

Please get in touch with Dr Ursula Sansom-Daly at ursula@unsw.edu.au if you’re interested in learning more about the study.

Psychosocial Standards of Care Update

Evidence-based standards of care updated with implementation strategies

By Lori Wiener, United States

As noted in earlier POPPI newsletters, in 2015, the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC)—a large interdisciplinary group of expert stakeholders, published 15 evidence-based standards for pediatric psychosocial care. The Standards have provided centers a blueprint on what evidence-based care should consist of.

They are available to download for free at the following link:

<https://onlinelibrary.wiley.com/doi/10.1002/pbc.28586>

Since the standards were published, there have been many requests for guidance on their implementation. In response, a **Matrix** (Institutional Scoring Measure) for each standard has been developed.

Additionally, **Guidelines** (how to implement each of the standards) has also been developed. The Guidelines include strategies and resources/tools to help sites improve their score on the Matrix and enhance their current practice.

In a published **Special Report** in *Pediatric Blood & Cancer*, the methods involved in the creation of the Matrix and Guideline templates and the development of content based on focus groups and rigorous reviews from multidisciplinary psychosocial experts are described.

The resulting Matrix and Guidelines are included as **Supplemental Information** and can be downloaded for free at:

<https://onlinelibrary.wiley.com/doi/10.1002/pbc.28586>

Funding opportunity to study the new Pediatric Psychosocial Standards of Care.

By Lori Wiener, United States

The Mattie Miracle Cancer Foundation is collaborating with APOS once again to offer 2 grants (\$10,000 each) to study the Pediatric Psychosocial Standards of Care. Letters of Intent are due 30th October 2020.

1. One grant will be awarded for research related to the implementation of any of the 15 pediatric psychosocial standards of care. Examples of the types of research funded from the last funding cycle can be found at: <https://www.mattiemiracle.com/research>
2. A second (new) grant will be awarded for research on the feasibility and usefulness of the newly published Matrix and Guidelines. This research should focus on use of the Matrix and Guidelines to implement the pediatric psychosocial standards of care. This can include ways the Matrix and Guidelines will be used to monitor changes to psychosocial practice based upon being able to identify gaps in services, build in new tools/resources/staffing, and/or achieve a more comprehensive, “next level” of service.

In order to be eligible for this funding opportunity, applicants:

1. Must hold a current APOS membership and be an early investigator (within 10 years of terminal degree).
2. A research mentor must be clearly identified, and the application should document his/her involvement in the study design and execution, as well as training and mentorship.

Components of Letter of Intent Proposal

A brief overview of the proposed project, including:

- A. Similar to an abstract, include purpose, aims, methods, and outcome measures in one page (400 words maximum).
- B. Impact Statement (2 sentences) State how this project will impact the psychosocial care of pediatric oncology patients and families and/or pediatric oncology programs and support Mattie Miracle’s psychosocial mission
- C. Innovation Statement (2 sentences) State how this project is a novel approach to childhood cancer research.
- D. Dissemination Statement (2-3 sentences) State how this work can lead to the goal of uniformity of evidence-based care (based on these Standards) for children with cancer and their families, regardless of location or size of the institution where care is provided.
- E. Identify Mentorship Team/Plan - Identify mentor(s) & describe the plan for mentorship.

Grants will be selected based on scientific merit determined by an APOS scientific review committee. There is a possibility that other smaller grants might be offered by MMCF to applicants whose projects show great promise in developing a deliverable product and/or those that directly align with the mission of their organization.

For questions, please contact **Lori Wiener** at lori.wiener@nih.gov or **Dawn Kegl** at dkeglor@parthenonmgmt.com

Psychosocial Interventions in Oncology

A Survey of Psychologist's Practices with Children with Cancer

By Ray Nascimento, Brazil



Under the supervision of Dr Lilian Maria Borges, Ray Nascimento is conducting a global survey in paediatric

psycho-oncology. Cancer is the second main cause of death among children and teenagers.

Although the chances of the disease's remission have increased in the last few decades, cancer treatment may be long, invasive, and present many side effects, which may lead to physical, cognitive, emotional, and social damages to children and teenagers.

In order to provide emotional support to children and their families, and in order to prevent or mitigate these adverse effects,

psychologists who work in pediatric oncology provide psychosocial interventions through their practice.

Our research proposes an investigation, in a quantitative and qualitative manner, of psychosocial strategies that are used by psychologists in direct assistance of children with cancer.

Our main objective is to understand the processes of the interventions that are conducted by these professionals in a hospital environment, according to their self-reports, considering the objectives and characteristics of the interventions that are used, as well as possible influences of other variables, such as child's age range, type of cancer treatment, and basic theoretical framework.

To achieve these objectives, an electronic questionnaire composed of closed questions, organized in

two parts, was created and applied online.

The first part aimed to collect sociodemographic and professional information of the participants, while the second gathered data on psychosocial interventions that are used by professionals with children with cancer. Individual semi-structured interviews were conducted with psychologists, with the aim of further investigating their professional practices in the field. We hope that this research will broaden the knowledge on how psychologists work in a context of suffering and vulnerabilities, in order to provide subsidies for interventions that aim to reduce developmental damages to children who experience cancer.

A summary of the results of the survey will be included in the next POPPI Issue.

COVID-19 and Childhood Cancer

A Survey on the health and wellbeing of families affected by childhood cancer

By Dr Fiona Schulte, Canada

With all the uncertainty surrounding the COVID-19 pandemic, it is really important to understand how this is affecting the health and wellbeing of families affected by childhood cancer treatment throughout the world. We have received IRB approval for a study to explore the impact of COVID-19 on family distress and coping over the past 7 months. The information will be used to help create specialized support, resources and

guidance to cancer centers. **You can help by sharing this opportunity with the families that you work with!** We are asking eligible patients and parents/caregivers to complete an [online questionnaire](#) that will take about 15 minutes. Participation in this study is voluntary and parents can withdraw from the study at any time.

Our findings will be shared in a future POPPI newsletter.

Children on Active Treatment

Parents/Caregivers are eligible to participate if:

- Their child is currently receiving treatment for cancer
- Their child is currently under the age of 18 years old

To participate, parents/caregivers can visit the following link or use the QC code below.

<https://is.gd/COVIDandCancer>



Survivors of Childhood Cancer

Survivors are eligible to participate if:

- They have completed their cancer treatments
- They were diagnosed before age 22
- They are at least 15 years old

Parents/Caregivers are eligible to participate if:

- Their child has completed their cancer treatment
- Their child is currently under the age of 18 years old

To participate, survivors and parents/caregivers can visit the following link or use the QC code.

<https://is.gd/COVIDandSurvivors>



Survey Opportunities

A Survey on the Use of Patient-reported Outcomes in Routine Care of Cancer Patients

By Dr Yin Ting Cheung, Hong Kong

An international team of researchers from the Multinational Association of Supportive Care in Cancer is investigating oncology practitioners' current strategies, experiences and barriers in applying or implementing Patient-reported Outcomes (PRO) in clinical practice, performance measurement and research.

Examples of PRO include patients' self-reported symptoms, physical functions, psychological and social

well-being, personal constructs, satisfaction with care, quality of life and medication adherence. The research team is looking for practicing clinicians and health care professionals involved in the care of patients with cancer to share their views in a 10-minute online survey. Please note that you do not have to be currently using PRO in routine care to participate in this survey.

This study has obtained approval from institutional review boards at the Chinese University of Hong Kong, and the Edith Cowan University in

Western Australia.

Approval has also been obtained by the professional network(s) to distribute this survey.

If you are interested in participating, please follow the link below to the full information statement and online survey:

https://cloud.itsc.cuhk.edu.hk/myc_uform/view.php?id=285387

For enquiries, please contact Dr Yin Ting Cheung (The Chinese University of Hong Kong) at yinting.cheung@cuhk.edu.hk.

PPO conference news

Upcoming Pediatric Psycho-Oncology conferences

SAVE THE DATE - 2020/2021

- International Psycho-Oncology Society (IPOS): May 26-29, 2021 in Kyoto, Japan.
- European Pediatric Psychology Conference: October 4-6, 2021 Stockholm, Sweden

- The International Society of Pediatric Oncology (SIOP) 52nd Virtual Congress: October 14-17, 2020.
- The International Society of Pediatric Oncology (SIOP) 53rd Congress: October 21-24, 2021, Honolulu, Hawaii.

Conference updates

22nd IPOS World Congress

By Christina Signorelli & Claire Wakefield, Australia

As a result of the COVID-19 pandemic, the 2020 congress has been delayed until 2021.

Preparations for the 22nd IPOS World Congress are currently underway, with a new option to participate either in person or via live webcast. More information, including pricing and registration options, will be available at a later date.

The 22nd Annual World Congress will be held on May 26-29, 2021 in Kyoto, Japan. The venue remains the same: International Conference Centre, Kyoto. The conference theme is "Diversity, Dialogue and Altruism: To achieve universal psychosocial care for all",

reflecting the IPOS mission which is to promote the psychosocial care of all people affected by cancer through collaborative efforts, awareness, research, and public policy.

The call for abstracts for symposiums, and oral and poster presentations is now open. Please note the following important dates for abstract submission and registration:

1. August 15, 2020 - [Call for Abstracts OPENS](#)
2. December 1, 2020 - Abstract submission deadline

3. February 24, 2021 - Registration early bird deadline

4. April 28, 2021 - Final Registration deadline

The IPOS 2020 Annual Members Meeting (AGM) will be held virtually on November 4, 2020 at 8am (EDT New York/Toronto). Current members of IPOS are eligible to attend and participate in the meeting.

To register for the live VIRTUAL AGM, please go to <https://ipos-society.org/event-3964875>

Please check the IPOS website for regular updates on changes to the Congress:

<https://ipos2020.com/ipos2021/>



52nd SIOP Congress 2019

By Martha Grootenhuis & Sasja Schepers, The Netherlands

Even though we will not be able to see each other in person in Ottawa this year, we believe there will still be lots of interesting networking opportunities on the virtual SIOP congress program (October 14-17 2020). We were able to compose a

high quality PPO program with cutting edge topics on research and clinical practice.

Sessions include “Sleep Interventions: Practical Knowledge”, a joint session with SIOP YI and nurses on “Breaking Bad News: Team Based Patient and Family Centered Communication”, a session on “Sexual Health: Research and Practice”, and a final session on “The psychological

impact of COVID-19 in pediatric oncology”. Please find the educational day program attached to this newsletter. There will also be lots of interesting PPO related topics on the main program. Click on the following links for [registration](#) and the [full program](#). We hope to see you all virtually this year!



17th APOS Conference

By Lori Wiener, United States

Due to coronavirus, APOS decided to go viral in 2021. Check out the website for what will be a timely, innovative, and informative virtual experience that will take place in real time and provide plenty of opportunities for interaction.

This will include a **book club** (including the authors of new books), a **career fair**, **coaching sessions**, and “office hours” with NCI Program Officers. To break up the talks, yoga and mindfulness sessions will be offered, and other

interactive activities will be provided throughout the meeting. In addition to the content that will be offered on pediatric psych-oncology, the Pediatric/Adolescent/Young Adult Special Interest Group is organizing a symposia tentatively entitled, “Psychosocial Screening in Pediatric Oncology: The Child/

Adolescent/Young Adult Voice” that will include four talks. Many exciting oral sessions will be presented and available for 90 days to registered conference attendees.

Stay tuned!

<https://apos-society.org/annual-conference/2021-annual-virtual-conference/>



PPO theses from around the globe

International PhD Candidates and recent graduates in the field share their theses

By Brooke Russell, Canada



Thesis title: Sleep Disturbances and Fatigue in Survivors of Pediatric Acute Lymphoblastic Leukemia and their Siblings

While the 5-year survival rate for acute lymphoblastic leukaemia (ALL) is now 95%, the majority of these survivors will face adverse outcomes from the treatments they received. Although broad in range, paediatric survivors have reported that fatigue and sleep disturbances are among the most distressing outcomes they associate with their cancer treatment.

Both sleep disturbances and fatigue have a significant impact on day-to-day life, including impairment to cognitive functioning, as well as social and emotional wellbeing. Despite this, little research has evaluated fatigue and sleep disturbances, particularly in the early survivorship period, using both subjective and objective measures of sleep and in-comparison with control groups. My thesis aimed to address these gaps in the literature. My primary aim was to compare fatigue and sleep in pediatric survivors of ALL, 2-7 years post-treatment, to healthy age- and sex-matched controls, as well as to siblings. My secondary aim was to evaluate survivor-only associations between treatment factors (age at diagnosis, time off treatment), fatigue, and sleep parameters. Sleep was measured via sleep diary

(subjective self-report), actigraphy (objective measure), and the Child Sleep Habits Questionnaire (parent-report). Fatigue was assessed using the PedsQL Multidimensional Fatigue Scale (self-report).

Overall, we found no statistically significant differences between groups (survivors vs. matched controls; survivors vs. siblings) on measures of fatigue, sleep diaries, or actigraphy. However, we did find that survivor siblings had significantly poorer parent-rated sleep than all other groups. In addition, we found that survivors who were diagnosed at an earlier age and those who were further off treatment had poorer actigraphy measured sleep, such that they had more wake-after-sleep-onset, poorer sleep efficiency, and shorter total sleep time.

The implications of this work suggest that regular screening for sleep disturbances in long-term survivorship is warranted. Additional research is needed to explore the possible development of sleep disturbances over time. Further, it is possible that survivor siblings may have behavioural sleep challenges. Additional research is needed to explore and characterize these findings.

Brooke's thesis is available to read:

<https://prism.ucalgary.ca/handle/1880/110749>

Publication Link:

<https://pubmed.ncbi.nlm.nih.gov/32548611/>

By **Jojanneke van Kooten, the Netherlands**



Thesis title: Improve the night, improve the day Better sleep (measurement) in pediatric oncology

Due to stress, and cancer and treatment effects, children with

cancer and their parents are at risk for sleep problems. Good sleep promotes physical and psychological recovery from illness, which makes early identifying of sleep problems important. This can be challenged by lack of valid and reliable measurement instruments. The first main aim of this thesis was therefore to improve the measurement of sleep. For sleep quality and daytime sleep-related impairment, the focus was on finding a proper patient-reported outcome measure for adolescents.

The measurement properties of the PROMIS (Patient Reported Outcomes Measurement Information System) Sleep Disturbance and Sleep-Related Impairment item banks were assessed in healthy adolescents (n = 958, age 11-19 years). For sleep quantity, the aim was to provide reference values for pediatric actigraphy-outcomes through meta-analyses (n = 83 studies, with a total of 9068 healthy children). The second main aim of this thesis was to get insight into sleep in pediatric oncology. First, the influence of infusion pump alarms on sleep was studied during hospital admissions in children, admitted for chemo or immunotherapy (n = 19

children, during 40 nights, age 2-17 years), and in their parents (n = 30 parents, during 46 nights). Secondly, the relation between sleep problems and diminished neurocognitive functioning was investigated in brain tumor survivors (n = 82, age 8-18 years) - who are at risk for both.

The results in this thesis indicate that the current PROMIS sleep item banks cannot capture sleep as one construct in children. Therefore a modular approach with a set of questions per construct (e.g. sleep onset, sleep hygiene, daytime sleep-related impairment) is proposed, with age-specific items where appropriate. When measuring sleep quantity, comparing pediatric accelerometer outcomes to a study-specific control sample - as opposed to general pediatric reference values - is currently the most valid option.

To improve sleep in pediatric oncology, a multi-system approach to make the hospital environment more suited for sleep is required, as well as a systematic approach to monitor sleep quality and daytime sleep-related impairment during treatment and into survivorship. Additionally, when children report neurocognitive complaints, taking sleep into account in addition to the standard neurocognitive test battery can be of value. Future research should focus on validating and implementing the modular monitoring of sleep in pediatric cancer patients, and assess the optimal timing for measurement and intervention.

Recent PPO publications

Recently published articles in *Psycho-Oncology* (official journal of APOS & IPOS), *Pediatric Blood & Cancer* (official journal of SIOP), and the *Journal of Psychosocial Oncology Research & Practice* (official journal of IPOS):



Pediatric Blood & Cancer



Pediatric Blood & Cancer publications

Arora et al., [Childhood cancer survivorship and late effects: The landscape in India in 2020](#)

Barr et al., [The influence of nutrition on clinical outcomes in children with cancer. \[Review\]](#)

Bouffet et al., [Early advice on managing children with cancer during the COVID-19 pandemic and a call for sharing experiences](#)

Casanova et al., [How young patients with cancer perceive the COVID-19 \(coronavirus\) epidemic in Milan, Italy: Is there room for other fears?](#)

Chardon et al., [The impact of pediatric hematopoietic stem cell transplant timing and psychosocial factors on family and caregiver adjustment.](#)

Cheung et al., [Health support to pediatric cancer survivors and their families during the COVID-19 pandemic](#)

Cohen et al., [Nutritional concerns of survivors of childhood cancer: A "First World" perspective. \[Review\]](#)

Grimshaw et al., [Physical activity for children undergoing acute cancer treatment: A qualitative study](#)

Peterson et al., [Neuropsychological impact of trametinib in pediatric low-grade glioma: a case series.](#)

Ruble et al., [Pediatric oncology provider perspectives and practices: Supporting patients and families in schooling after cancer diagnosis.](#)

Santacroce et al., [Fathers' psychological responses to pediatric cancer-induced financial distress.](#)

Santacroce et al., [Influence of pediatric cancer-related financial burden on parent distress and other stress-related symptoms.](#)

Schreiner et al., ["Living life as if I never had cancer": A study of the meaning of living well in adolescents and young adults who have experienced cancer](#)

Sharkey et al., [Psychological adjustment outcomes among pediatric brain tumor survivors: A meta-analysis](#)

Semmel et al., [Oral processing speed as a key mechanism in the relationship between neurological risk and adaptive functioning in survivors of pediatric brain tumors](#)

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<p>of parental perspectives.</p> <p>Kazak et al., Stability and change in family psychosocial risk over 6 months in pediatric cancer and its association with medical and psychosocial healthcare utilization.</p> <p>Kelada et al., Financial toxicity of childhood cancer and changes to parental employment after treatment completion.</p> <p>Livingston et al., Shared spiritual beliefs between adolescents with cancer and their families.</p> <p>Mack et al., Care experiences that foster trust between parents and physicians of children with cancer</p> <p>Mekelenkamp et al., Parental experiences in end-of-life decision-making in allogeneic pediatric stem cell transplantation: "Have I been a good parent?"</p> <p>Peterson et al., Emotional symptoms and family functioning in caregivers of children with newly diagnosed leukemia/lymphomas and solid tumours: Short term changes and related demographic factors</p>	<p>Sim et al., If only I could turn back time—Regret in bereaved parents</p> <p>Tran et al., Clinical outcomes and quality of life in children and adolescents with primary brain tumours treated with pencil beam scanning proton therapy.</p> <p>Vercasson et al., Quality of life in parents of childhood leukemia survivors. A French Childhood Cancer Survivor Study for Leukemia study</p> <p>Wiener et al., Helping parents prepare for their child's end of life: A retrospective survey of cancer-bereaved parents.</p> <p>Wiener et al., Tools to guide the identification and implementation of care consistent with the psychosocial Standards of care</p> <p>Zhou et al., Internet-delivered insomnia intervention improves sleep and quality of life for adolescent and young adult cancer survivors</p>
<p>Psycho-Oncology publications</p> <p>Andres-Jensen et al., Everyday life challenges among adolescent and young adult survivors of childhood acute lymphoblastic leukemia: an in-depth qualitative study</p> <p>Asvat et al., Substance use behaviors in adolescent and young adult cancer patients: Associations with mental and physical health</p> <p>Bitz et al., Couples coping with cancer together: Successful implementation of a caregiver program as standard of care</p> <p>Burns et al., Pediatric Psycho-Oncology in Russia: Caregiver mental health and sleep outcomes on the oncology wards.</p> <p>Chung et al., Relationships among resilience, depressive symptoms, self-esteem and quality of life in children with cancer.</p> <p>Clerici et al., On the clinical psychologist's role in the time of COVID-19, with particular reference to experience gained in pediatric oncology</p> <p>Heathcote et al., Do qualitative interviews cause distress in adolescents and young adults asked to discuss fears of cancer recurrence?</p> <p>Leclerc et al., Inconsistencies between measures of cognitive dysfunction in childhood acute lymphoblastic leukemia survivors: Description and understanding</p> <p>Mekonnen et al., Depression and associated factors among parents of children diagnosed with cancer at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia</p> <p>Michaud et al., Evaluating the Brief Parental Intake Form (BPIF) for psychosocial difficulties in childhood cancer survivors</p> <p>Peikert et al., Fear of progression in parents of childhood cancer survivors: A dyadic data analysis</p>	<p>Muriel et al., Pediatric psychosocial oncology in the COVID 19 era: Patterns of use, challenges, and lessons learned</p> <p>Pinto et al., Identifying clusters of health risk behaviors and their predictors in adult survivors of childhood cancer: A report from the French Childhood Cancer Survivor Study</p> <p>Tan et al., Colorectal cancer patients can be advocates for colorectal cancer screening for their siblings: A study on siblings' perspectives</p> <p>Tan et al., Self-reported cognitive outcomes among adolescent and young adult patients with noncentral nervous system cancers</p> <p>Walsh et al., Factors associated with social functioning among long-term cancer survivors treated with hematopoietic stem cell transplantation as adolescents or young adults</p> <p>Warner et al., Young adult cancer caregivers' use of social media for social support</p> <p>Willard et al., Profiles of perceived social functioning in adolescent and young adult survivors of childhood cancer</p> <p>Wroot et al., Fear of cancer recurrence among survivors of childhood cancer</p> <p>Yardeni et al., A three-tier process for screening depression and anxiety among children and adolescents with cancer</p> <p>Zucchetti et al., How paediatric psycho-oncology is changing during the COVID-19 epidemic in Italy: New approaches</p> <p>Journal of Psychosocial Oncology Research & Practice publications</p> <p>Shunmugasundaram et al., Caregivers' perception of psychosocial issues of pediatric patients with osteosarcoma: an exploratory study.</p>

HIGHLIGHTED PPO ARTICLE: Zucchetti, G, Bertolotti, M, Fagioli, F. How paediatric psycho-oncology is changing during the COVID-19 epidemic in Italy: New approaches. *Psycho Oncology*. 2020; 29: 1384- 1386.

By Dr Giulia Zucchetti, Italy

By March 25 2020, children in Italy younger than 18 years of age who had COVID-19 composed about 1% of the total number of patients. The pandemic, and the subsequent lockdown, have forced psycho-oncologists to change their way of approaching care, given the devastating psychological impact on patients and families.

Recent studies have highlighted the novel problems for hospitalized families, primarily hospital stays with only one parent, the suspension of all teaching and group activities on the ward, and generalized anxiety. For children and adolescent cancer survivors,

the pandemic emotional impact has been powerful: they have been forced to leave the newly reconquered “life-normality” and to experience more fear of a potential infection. Psycho-oncologists have promptly adapted to the new situation, conscious of the new needs of their patients and families who have forced to live “trauma into trauma”.

What has the pandemic taught us psycho-oncologists? In our opinion, it has taught us a lot, and enhanced our empathic abilities. We have finally experienced first-hand what it means to live in fear of getting an infection, to live behind a mask, and to keep others at a safe

feel every day. In this sense, our distance: what Covid-19 is making us all feel is what cancer patients daily attitude towards the virus becomes fundamental to caring for our patients and indirectly supporting their medical adherence. We have to fight the virus, respect the rules, use protection, and respect distances. *Isn't that what we ask our patients to do every day?*

This is a historical moment in which psycho-oncology can make even more of a difference. Now, more than ever, “our therapeutic and emotional presence” can make even more a difference for patients and families.

Have you recently published a relevant paper in *Pediatric Blood and Cancer*, *Psycho-Oncology* or the *Journal of Psychosocial Oncology Research & Practice* that you would like us to include in the next issue? [Contact us!](#)



POPPI Newsletter

Our next newsletter
will be circulated in
Spring 2021.

**All feedback and
suggestions are welcome!**

If you have any questions relating to the newsletter content, or if you would like to make a contribution to future newsletters, please contact the Editor [Sasja Schepers](#).

Program SIOP PPO 2020 - Educational Day October 14, 2020

Time slot	Topic
08.15 – 08.25 (EDT) 14.15 – 14.25 (CEST)	<i>Opening Martha Grootenhuis (the Netherlands) chair of SIOP PPO</i>
08.25 – 09.40 (EDT) 14.25 – 15.40 (CEST)	<p>Sleep interventions: Practical knowledge <i>Chair: Raphaela van Litsenburg (the Netherlands)</i></p> <ul style="list-style-type: none"> - Lauren Daniel (USA): Screening for Sleep Problems in During Cancer Treatment – - Valerie Crabtree (USA): Light Therapy is a Feasible Intervention for Fatigue in AYA with Cancer - Eric Zhou (USA): An Online Insomnia Intervention for Adolescent and Young Adult Survivors - Sarah Ellis (Australia): Supporting parents' sleep on the pediatric oncology ward
09.40 – 10.15 (EDT) 15.40 – 16.15 (CEST)	<i>Break</i>
10.15 – 11.45 (EDT) 16.15 – 17.45 (CEST)	NURSING JOINT SESSION WITH YI: BREAKING BAD NEWS
11.45 - 13.45 (EST) 17.45 – 19.45 (CEST)	<i>Break and expert lunch</i>
13.45 – 15.15 (EDT) 19.45 – 21.15 (CEST)	<p>Sexual health: Research and Practice <i>Chairs: Christopher Recklitis (USA) and Maria McCarthy (Australia)</i></p> <ul style="list-style-type: none"> - Astrid Ahler (Australia): Breaking the silence- Body image and psychosexual wellbeing in AYA Cancer - Sharon Bober (USA): Silence is not golden: Sexual health after pediatric cancer - Meghan MacMillan (Canada): Clinical case presentation
15.15 – 15.45 (EDT) 21.15 – 21.45 (CEST)	<i>Break</i>
15.45 – 17.15 (EDT) 21.45 – 23.15 (CEST)	<p>The psychological impact of COVID in pediatric oncology <i>Chair/Discussant: Lori Wiener (USA)</i></p> <ul style="list-style-type: none"> - Anne Kazak (USA) and Lamia Barakat (USA): Exposure and impact: How patients and families experience COVID-19 - Fiona Schulte (Canada) and Caitlin Forbes (Canada): "COVID-19: Information gaps and implications on mental health in adolescent and young adult survivors of childhood cancer" - Kevin Krull (USA): "The impact of the COVID-19 on psychosocial adjustment in adult survivors of childhood cancer" - Meaghann Weaver (USA) and Abby Rosenberg (USA): "Caring Together: Exploring the Impact of the Global Pandemic on Pediatric Palliative Care Clinicians"
17.15 – 17.20 (EDT) 23.15 – 23.20 (CEST)	Closing of Education Day of SIOP PPO