



POPPI Newsletter

Pediatric Psycho-Oncology
Professionals/Providers
International

Issue 8: March, 2022

STEERING COMMITTEE

WELCOME TO THE SEVENTH 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 eighth 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.

At the time of this POPPI newsletter coming out, we are called to acknowledge the invasion of Ukraine and devastation of war. IPOS, SIOP and APOS are committed to the human right to cancer treatment and psychosocial care, and we stand with our colleagues across the globe impacted by this war. Learning about specific steps that we can take to ameliorate suffering is part of our role as providers in our global community. With our unique lens as pediatric oncology healthcare professionals, we will keep you informed, through these organizations on ways that we might be able to share our knowledge, expertise, compassion, and time with our local and international communities in need. If you are interested helping, SIOP has created a webpage summarizing opportunities for people to contribute. In particular, there is a need for Ukrainian and Polish speaking health professionals who might be able to translate medical documents into English. Even translating just one document would be highly valued. You can find the webpage and details about how to volunteer here: <https://siop-online.org/ukraine-how-you-can-help/>

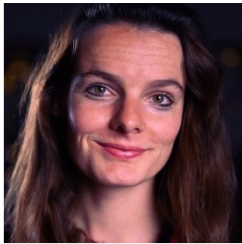
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Research “in the spotlight”

Study in the spotlight: Anne van Driessche on “BOOST pACP”

By Anne van Driessche, Belgium



Anne van Driessche is a doctoral researcher at the End-of-Life Care Research Group at the Vrije Universiteit Brussel & Ghent University in Belgium. She has a Master’s degree in Health Education and Promotion and a Master’s degree in Global Health. Anne

shares some information on the main project she is working on, under the guidance of Prof. Dr. Kim Beernaert.

Advance care planning (ACP) has been widely advocated to support patient and family engagement in understanding the patient’s values, preferences, and goals of care. ACP can provide an opportunity to address misconceptions, improve understanding of prognosis and prepare families for future situations. From earlier research in pediatrics, we know that healthcare professionals often find it difficult to explore the adolescent patients’ and parents’ perspectives on current and future care preferences on a regular basis, among other factors because of perceived parental unreadiness to talk about ACP themes and insecurity about their own communication skills.

Therefore, we developed the structured BOOST pACP (Benefits of Obtaining Ownership Systematically Together in pediatric Advance Care Planning) intervention. This intervention aims to facilitate and improve ACP communication among adolescents with cancer (between 10 - 18 years old), parents and pediatric oncologists, considering ACP as a broad concept to be initiated early in the illness trajectory.

Through normalization of thinking and talking about ACP themes, we hope to increase the adolescents’ involvement in their own care and treatment.

The core components of the BOOST pACP intervention include: 4 ACP conversation sessions with the adolescent and/or parent(s) provided by a trained facilitator, structured by interactive conversation cards covering different ACP themes, followed by a transfer of information from the intervention facilitator to the pediatric oncologist. We applied an iterative step-by-step approach during which adolescent patients, their parents, healthcare professionals and pACP experts were involved to develop and test the acceptability and feasibility of the intervention.

The intervention is now being tested in a multi-centre parallel-group randomised controlled trial, with an embedded mixed-methods process evaluation in pediatric oncology in Belgium. This will result in increased knowledge of the effectiveness of improving ACP communication between adolescents, parents, and paediatric oncologists and on other potentially positive or negative effects. We will gain insight into how adolescents with different types of cancer in various stages and parents value advance care planning and shape this communication process in the semi-structured BOOST pACP format, leading to a better understanding of ways to facilitate a tailored ACP approach.

Read more: van Driessche A, et al. [Advance care planning for adolescents with cancer and their parents: study protocol of the BOOST pACP multi-centre randomised controlled trial and process evaluation.](#) *BMC Pediatrics.* 2021;21:376:1-16.

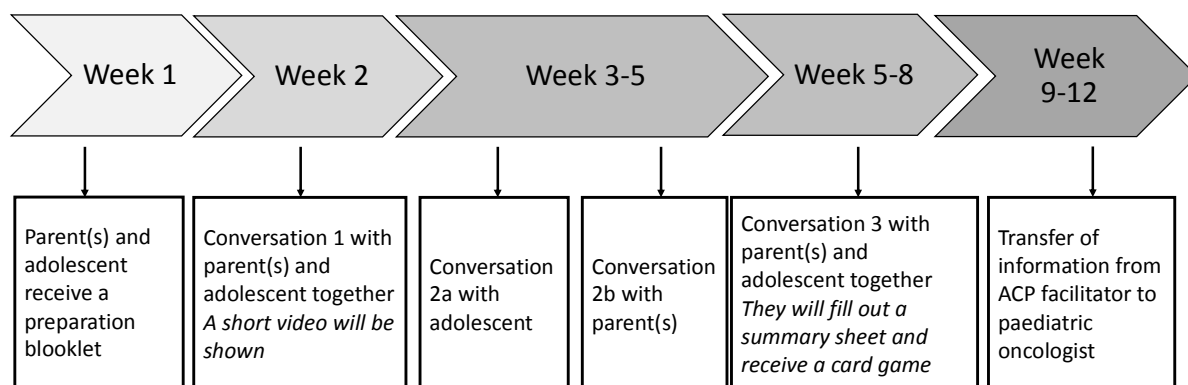


Figure: Timeline of the BOOST pACP intervention

Psychosocial Standards of Care Update

Evidence-based standards of care updated with implementation strategies

By Lori Wiener, United States

Research examining the impact of the Standards continues. Recently, a study that many readers of the POPPI newsletter participated in was published:

<https://europepmc.org/article/MED/34828757>

This study examined the psychosocial interventions and services provided to children with cancer and their family members, whether there are differences in

the interventions provided by age of the patient and by treatment, and barriers to psychosocial service provision. We thank each of you who participated in this study.

We have been so fortunate that the Mattie Miracle Cancer Foundation collaborated with APOS to offer new early investigator grants (\$10,000 each) to study the Pediatric Psychosocial Standards of Care. Below, you will learn about two of these funded grants.

Feasibility of a Peer-To-Peer Parent Mentoring Program for Parents of Children Recently Diagnosed With Cancer

by Dr. Karen Long-Traynor

The diagnosis of childhood cancer is potentially one of the most intense, disruptive, and enduring experiences a parent can have and it is typical for parents to experience significant psychological distress, particularly during the early months following diagnosis. Poor social support is one identified factor that contributes to higher levels of parent distress. We hypothesize that increasing support through a parent-to-parent mentoring program may alleviate some of the distress. As such, we designed a study which aims to create and test the feasibility of a 3-month virtual parent-to-parent mentoring program in which parents of children newly diagnosed with cancer receive support from a parent with shared lived experience (i.e., whose child was also diagnosed with cancer and is now at least one year post treatment completion). A secondary aim is to explore the preliminary effectiveness on mentor and parent outcomes using qualitative interviews and quantitative questionnaires measuring listening and empathy skills, parental distress, and the quality of connection between the mentor and mentee.

To date, 10 parent mentors (8 mothers and 2 fathers) completed training, including a self-guided workbook and live virtual workshop. All participants rated the workbook and training as acceptable or very acceptable, and not surprisingly, scored above average on listening and empathy skills compared to the normative population. Eight parents of children who were newly diagnosed with cancer (5 mothers and 3 fathers) were approached to participate; three mothers agreed to participate. Of those who declined, two were not interested and three indicated they already had a lot of community or family support. Preliminary descriptive analyses of the enrolled mentees at baseline indicated similar levels of parental distress compared to a normative population of parents of newly diagnosed children and an average amount of perceived support compared to a general normative population. This work is ongoing and the intent is to enroll a total of 30 mentees.

SibCARE: A Comprehensive Psychosocial Support Program for Siblings of Youth with Cancer

By Dr. Stephanie Hullmann

We are in the process of developing, implementing, and evaluating a SibCARE (Comprehensive Assessment, Resources, and Education) program, following the Guidelines for Implementing the Pediatric Psychosocial Standard for Sibling Support (Standard 10). The SibCARE program is designed to align with each component of the Standard. SibCARE includes: 1) assessing psychosocial difficulties in siblings of youth with cancer and providing siblings with tailored interventions and resources, 2) educating parents and community professionals about how to support siblings, and 3) educating cancer center staff about the psychosocial needs of siblings.

To date, we have developed a screening program for parents to complete about siblings. Parents complete the psychosocial screening questionnaires within 3 months of diagnosis, and they are given feedback about the sibling's scores. Those siblings whose results suggest that they are "at risk" are offered a virtual consultation with our Psycho-Oncology team and triaged to appropriate mental health resources. We have also developed a binder with resources and education about sibling support. We provide all parents with information about local and national sibling support resources/programs. Through funding from our hospital and community partners, we have been able to purchase developmentally appropriate books about having a sibling with cancer and the Cellie Coping Kit for Siblings, which we provide to all families. We have also developed education for parents and community professionals about how to support siblings, which is included in the parent binder. We are currently in the process of getting family feedback on the education and resources provided. Our next step is to develop our CME training for our cancer center staff about psychosocial needs of siblings. We have already received informal feedback from parents and staff members expressing their appreciation and excitement for a way to support siblings of children with cancer.

New funding opportunities! Mattie Miracle Cancer Foundation/American Psychosocial Oncology Society Pediatric Psychosocial Standards of Care Research Grants

By Lori Wiener, United States

Two grant types will be offered (anticipated funding one of each). Stakeholder engagement is encouraged for both, as appropriate for the proposed project. This can include the perspectives of patients, parents/caregivers, administrators, and/or payors. Each award is \$10,000. Payments for stakeholder involvement should be included in the award budget. Applicants should justify if additional funds in excess of the \$10,000 budget is needed for stakeholder compensation.

1. **Implementation of the Standards.** These applications should focus on research that advances the implementation of any of the 15 Standards and can document improved care provided to children with cancer and their family members. The standards can be found at: <http://onlinelibrary.wiley.com/doi/10.1002/psc.25675/full>
2. **The feasibility, application and utilization of the Matrix and Guidelines.** This research should focus on use of the Matrix and Guidelines to implement the pediatric psychosocial Standards of care in practice. We are looking for evidence of how the Standards can be introduced into practice and/or how the Matrix and Guidelines can be applied to monitor/track changes in psychosocial practice. This may include identifying gaps in services and building new tools/resources/staffing. Quality Improvement/Improvement Science methodologies may be included. <https://onlinelibrary.wiley.com/doi/10.1002/psc.28586>

Eligibility:

1. Current APOS membership and an early investigator (within 10 years of terminal degree).
2. A research mentor must be clearly identified, and the application must document his/her

involvement in the study design and execution, as well as training and mentorship.

Expectations:

1. Funded grant results are expected to be presented at the APOS annual meeting.
2. Researchers are expected to publish the results of their funded grant research.
3. Grant recipients are expected to acknowledge the Mattie Miracle Cancer Foundation (funding agency) in presentations and in publications and share a brief summary of the research for a MMCF newsletter.

The Letter of Intent is Due May 20, 2022 (11:59 PM ET).

Components of Letter of Intent (LOI) Proposal (400 words maximum)

Include a brief overview of the proposed project.

- A. Abstract (400 words maximum) with purpose, aims, methods, and outcome measures
- 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
- 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) and describe general plan for mentorship.

For specific questions, please contact Susanne Tomlinson at: stomlinson@parthenonmgmt.com or Lori Wiener at: lori.wiener@nih.gov

PPO conference news

Upcoming Pediatric Psycho-Oncology conferences

SAVE THE DATE - 2021

- [The American Psychosocial Oncology Society annual conference](#): March 9th - 11th 2022, Barcelona, Spain.
- [SIOP Europe 3rd Annual Meeting of the European Society for Paediatric Oncology](#), 23-25 March 2022, (virtual conference)
- [International Symposium on Late Complications after Childhood Cancer \(ISLCCC\)](#), 8th - 9th of July 2022 Utrecht, Netherlands (hybrid conference)
- [International Psycho-Oncology Society \(IPOS\)/Canadian Association of Psychosocial Oncology \(CAPO\) World Congress](#): August 29th to September 1st, 2022, Canada. (hybrid conference)
- [The International Society of Pediatric Oncology \(SIOP\) 54th Congress](#): September 28 - October 1, 2022 | Barcelona, Spain.

17th APOS Conference

By *Lori Wiener, United States*

APOS Annual meeting

Pediatric and AYA psychosocial oncology was strong again at the 2022 conference, which transitioned from in-person to virtual. Abstracts will be published in an upcoming Pediatric Blood & Cancer issue.



Highlighted Oral Presentations

- Feasibility and Preliminary Efficacy of a Novel Computer-CBT Treatment for AYA Cancer Survivors' Depression: A Pilot Randomized Control Trial - *Anao Zhang, PhD, LCSW, MSW*
- Turning Points in Fertility Preservation Decision-Making Among AYAs with Cancer from Diverse Racial and Ethnic Backgrounds - *Mollie Canzona, PhD*
- Medication Self-Management Behaviors in Adolescents and Young Adults with Cancer - *Kristin Bingen, PhD*
- The Role of Social Support in Adolescent/Young Adults Coping with Cancer Treatment - *Julie Germann, PhD*
- Best Practices for Conducting and Reporting Digitally-Supported Remote Cognitive Interviews: Feasibility and Acceptability in Pediatric Cancer Survivors of Stem Cell Transplantation - *Abigail Fry, BA*
- "They Didn't Know How to React at All": Normative Social Support in Young Adults Cancer Survivors - *Nick Iannarino, PhD*
- Daily Text Message Assessments of Oral Chemotherapy Adherence among Adolescents and Young Adults with Cancer: A Pilot Study and Next Steps for Implementation - *Alexandra Psihogios, PhD*
- Feasibility of a Peer-to-Peer Parent Mentoring Program for Parents of Children Recently Diagnosed with Cancer Community-Focused Pilot Test of the Electronic Surviving Cancer Competently Intervention Program (eSCCIP): Results and Lessons Learned - *Karen Long-Traynor, PhD*
- Elephants and Tea: Using Storytelling to Build Community - *Nicholas Giallourakis, MS*
- Pediatric End of Life Care and Bereavement during COVID-19: The Experiences of Moral Distress - *Lori Wiener, PhD*
- SibCARE: A Comprehensive Psychosocial Support Program for Siblings of Youth with Cancer - *Stephanie Hullmann, PhD*
- Development of a Blueprint for Psychosocial Services for Siblings of Youth with Cancer: A Nationwide Study - *Kathryn Davis*
- Lessons Learned from the Development and Improvement of a Smartphone Application for Young Adults with Cancer - *Annelise Ryan, MPH*
- Online Cancer Misinformation Experiences and Suggested Interventions among Adolescent and Young Adult Cancer Patients and Caregivers - *Echo Warner, PhD, MPH*
- PhotoVoice: An Innovative Virtual Support Group for Young Adults Undergoing Hematopoietic Stem Cell Transplantation (HSCT) - *Lori Wiener, PhD*
- Connecting Peers to Improve Survivorship Care Self-Management: Acceptability of an Online Peer Mentoring Intervention for Adolescent and Young Adult Survivors of Childhood Cancer - *Katie Devine, PhD*
- Bereavement via Zoom during COVID-19 - *Sue Morris, PsyD*
- The Hint Project: Utilizing an Intervention Adaptation Framework to Inform a Health Insurance Navigation Program for Childhood Cancer Survivors - *Elyse Park, PhD*
- Oncohealth - *Karen Fasciano, PsyD*
- Health Insurance Literacy and Adolescent and Young Adult Cancer Patients - *Anne Kirchoff, PhD*
- Lessons Learned from the Other Side of the Bed: How My Child's Cancer Treatment Changed My Clinical and Research Practice - *Sarah McCarthy, PhD*



IPOS World Congress

By Christina Signorelli & Claire Wakefield

The next International Psycho-Oncology Society World Congress is being delivered in conjunction with the Canadian Association of Psychosocial Oncology (CAPO).

Abstract submissions for presentations and symposia closed in February, although registrations for the conference is [now open!](#) This year, there are two options for attendance at the conference: in-person, or virtually. The full abstract book from the 2021 World Congress is still also available to view [here](#).

In other IPOS news, IPOS recently launched a new initiative to profile their members, and their work, online. This is a wonderful way to highlight the incredible and diverse members of the growing and vibrant IPOS community! You can read member profiles at this [link](#). If you are interested in being profiled, email ed@ipos-society.org.

The meeting will be held in Toronto, Canada from August 29th to September 1st, 2022. The overarching theme for the meeting is: “Reimagining psychosocial oncology: embracing voices from around the world”.



SIOP Update

By Martha Grootenhuis

Conference

- The SIOP conference will be from **September 28 - October 1, 2022** in **Barcelona, Spain**.
- Up to date information about the conference can be found at: <https://siop-congress.org/>.

We look forward to seeing you in Barcelona at SIOP 2022!



SIOP-PPO

- Our PPO Educational Day will be on **Wednesday September 28, 2022**.
- Abstract submission is open, and we encourage you to [submit your work for SIOP 2022](#) as soon as possible. The deadline is **April 4th, 2022**. All abstract submissions (also for the Educational Day) will be handled by SIOP, so please submit your abstract in the main system under the category “Psychosocial (PPO)”. Your abstracts will be reviewed and the best rated abstracts will be chosen to be presented at the SIOP-PPO Educational Day or at the Main Program in one of the Psychosocial Free Paper Sessions. Abstract submission guidelines can be found [here](#).

Educational Day: Call for experts and work on Pain

- We are happy that Marta Perez Campedados, a psychologist from Spain, has joined our Steering Group this year as a local representative.

- We are in the middle of planning our Educational Day, and excited to announce that **pain** will be a central topic. If you have suggestions for speakers or recent achievements in the area of pain, or if have any other interesting work you would like to share, please contact us at siop-ppo@prinsesmaximacentrum.nl.

Show your support to #throughyourhands for International Childhood Cancer Day

Together, the CCI and SIOP kindly ask for your support in an online campaign for International Childhood Cancer Day (ICCD) 2022. The campaign involves leaving a message and creating an electronic handprint on the Tree of Life website (<https://www.iccd.care/en-us/handprint>), which is open until **31st March 2022**.

The 2022 edition is dedicated to the role of the healthcare team in providing the best possible care and improving the lives of children with cancer. The aim is to maximize the visibility of the diverse disciplines involved as well as the different countries affected by childhood cancer as a truly global issue.

We are hoping for a big “wave” of hands to show the widespread support for health care professionals caring for children and adolescents with cancer. For queries, contact olga.kozhaeva@siope.eu

Warm regards, Dr. Martha Grootenhuis (chair), also on behalf of the SIOP-PPO Steering Group: Dr. Maria McCarthy (member), Dr. Christopher Recklitis (member), Dr. Stephen Sands (member), Dr. Fiona Schulte (member), & Kelly van Bindsbergen (secretary).

3rd Annual Meeting of the European Society for Paediatric Oncology

By *Ulrike Leiss*

The Virtual SIOP Europe Annual Meeting (23-25 March 2022) will provide a distinct opportunity for participants to share their knowledge, collaborate on cutting-edge research, debate the outcomes of the high quality clinical and basic research carried out in Europe, as well as provide mentoring and training for young doctors and fellows.

The programme includes:

- ✓ Open, joint and operational meetings of 14 European Clinical Trial Groups
- ✓ Open and operational meetings of 7 SIOPE Working Groups
- ✓ 3 Plenary Sessions on important cross-tumour topics and best practice

[Access the Programme here](#)

Sessions of interest to psychosocial community:

- ✓ SIOP Europe Psychosocial Working Group: Psychosocial Care - more than an emergency service: The working group will present its goals and visions. This will be followed by a panel discussion on key psychosocial services, the need for joint European standards, ways to implement them, and shared visions for psychosocial care and research, among other topics.
- ✓ We are INVolved - PPIE is more than just a box to tick
- ✓ Disentangling the Epidemiology of Childhood Cancer in the European countries
- ✓ Artificial intelligence: The Game-Changer in the Future?
- ✓ SIOPE Palliative Working Group Session
- ✓ Show me the way! A new tool to better understand leukaemia protocols

- ✓ SIOP Europe AYA Committee: Developing European multidisciplinary excellence for AYA with cancer

A Virtual Meeting: What does it mean?

All open and joint sessions will be recorded and available for viewing 'on demand' until **25 May 2022**. Moreover, a **Virtual Networking Lounge** will be accessible to all participants who are willing to meet and network outside of the scientific programme.

We invite you to register soon to book your place at the SIOP Europe Virtual Annual Meeting!

Reduced registration fees are guaranteed for SIOP Europe, CCI Europe and the Young SIOPE Group members.

[Register now](#)

We are also happy to inform you that the SIOP Europe Virtual Annual Meeting 23/03/2022-25/03/2022 has been accredited by the European Accreditation Council for Continuing Medical Education (EACCME®) with 16 European CME credits (ECMEC®s).

To find out more, please visit the [SIOP Europe Annual Meeting website](#). SIOP Europe is fully committed to keep this meeting as engaging and interactive as possible, to keep the spirit of the SIOP Europe Annual Meeting, regardless of the event format. We are looking forward to creating this Virtual Meeting with you!



Society of Pediatric Psychology: Caregiver Wellbeing SIG

By *Chrissy Salley, & Dana Bakula, United States*

The Society of Pediatric Psychology (SPP; Division 54 of the American Psychological Association) hosts several Special Interest Groups (SIGs) where pediatric psychologists with common clinical and research interests come together. In August 2021 a new SIG, the Caregiver Wellbeing SIG became the first to focus solely on parents and caregivers of children with special healthcare needs. Led by Co-Chairs Dana Bakula, Ph.D. and Chrissy Salley, Ph.D., eight board members, and two trainee representatives, the SIG has grown to over 100 members. Many members work with families in pediatric oncology and want to work toward innovative and meaningful ways to support caregivers of children with cancer.

The Caregiver Wellbeing SIG has four active subcommittees which are working on short and long-term projects. Currently, the Research Subcommittee has taken the lead on submissions to the Society of Pediatric Psychology Annual Conference (SPPAC), is developing a journal review mentorship program, and will soon be starting work on a repository of resources for researchers such as measures used to capture caregiver functioning. The Education Subcommittee is

committed to identifying educational and training needs for pediatric psychologists who are working with caregivers. This will span from reaching undergraduate students and introducing these topics to them, to understanding the training provided to graduate students on caregiver mental health, to providing continuing education opportunities to practicing psychologists. The Clinical Practice subcommittee is working on understanding how clinicians deliver care to caregivers across a variety of settings, examining areas such as billing and documentation practices to name a few.

One major component of our mission is to disseminate "public facing" information to caregivers and other stakeholders working with caregivers (e.g., pediatricians). These activities fall within our Outreach Subcommittee which is publishing blog posts for caregivers and running our Twitter and Instagram accounts. This subcommittee is also working on an exciting project, including caregivers, to provide them an outlet for sharing their lived experiences through a video series.

To date, more than one-third of the SIG's members identify as students or trainees. Thus, in collaboration with our two trainee representatives, we actively encourage student involvement and create

opportunities for them to contribute in meaningful ways in line with their personal and career goals. We gladly welcome new members and ideas! You must be a member of the Society of Pediatric Psychology to join the SIG. If you are a member of SPP and are interested in becoming involved, please email Dana Bakula (dmbakula@cmh.edu) and/or Chrissy Salley (Christina.Salley@nyulangone.org). To stay connected with the SIG on social media, follow us on Twitter [@CaregiverSIGSPP](https://twitter.com/CaregiverSIGSPP) and Instagram [@caregiverwellbeingspp](https://www.instagram.com/caregiverwellbeingspp).



You can also find us on our website here: <https://div54cwsig.wixsite.com/caregiverwellbeing>

Special Issues on advances in Psycho-Oncology

Call for papers in advances in psychosocial research in cancer and other rare diseases

By Christina Signorelli, Australia

The Open Access journal [Cancers](https://www.mdpi.com/journal/cancers) invites contributions for full research paper or review articles to the upcoming Special Issue “Recent Advances in Pediatric, Adolescent and Young Adult (AYA) Psycho-Oncology”. Articles should focus on any aspect related to the theme pediatric, adolescent and young adult (AYA) psycho-oncology.

For more information, or to read the papers already published in this Special Issue, please follow the link to the Special Issue website at:

https://www.mdpi.com/journal/cancers/special_issues/RAPAYAPO

Manuscripts can be submitted any time now or up until the deadline; 30 April 2022. Submitted papers should

not be under consideration for publication elsewhere. Please direct any enquiries about the Special Issue to Christina: c.signorelli@unsw.edu.au

cancers
an Open Access Journal by MDPI

IMPACT FACTOR 6.639
Covered in PubMed

Recent Advances in Pediatric, Adolescent and Young Adult (AYA) Psycho - Oncology

Guest Editors
Dr. Ursula Sansom-Daly, Dr. Jordana McLoone, Dr. Christina Signorelli, Dr. Lauren Winkler

Deadline
30 April 2022

Special Issue
Invitation to submit

[mdpi.com/si/88227](https://www.mdpi.com/si/88227)

By Lori Wiener, United States

The Open Access journal [Children](https://www.mdpi.com/journal/children) invites contributions for full research paper or review articles to the upcoming Special Issue “Psychosocial Considerations for Children and Adolescents Living with Rare Diseases”. Articles should focus on the psychosocial needs of children and adolescents living with a rare condition and interventions that have been developed to address their needs.

For more information, or to read the papers already published in this Special Issue, please follow the link to the Special Issue website at:

https://www.mdpi.com/journal/children/special_issue/psychosocial_considerations

The Special Issue Deadline has now been extended to April 15th, 2022.

Submitted papers should not be under consideration for publication elsewhere. Please direct any inquiries about the Special Issue to Lori: lori.wiener@nih.gov

children
an Open Access Journal by MDPI

IMPACT FACTOR 2.863
Covered in PubMed

Psychosocial Considerations for Children and Adolescents Living with Rare Diseases

Guest Editors
Dr. Lori Wiener, Dr. Maureen E. Lyon

Deadline
28 February 2022

Special Issue
Invitation to submit

[mdpi.com/si/93318](https://www.mdpi.com/si/93318)

Psycho-Oncology Professionals website

Join the NCI webpage for Pediatric Psycho-Oncology Professionals

The Pediatric Oncology Branch of the National Cancer Institute has developed a webpage specifically for Pediatric Psycho-Oncology Professionals (PPOP): <https://ccr.cancer.gov/pediatric-psycho-oncology>

The site has two main goals:

- 1) to stimulate international communication among professionals with a diversity of clinical and research backgrounds in order to foster collaboration in

The hope is that this website will provide information which will guide professionals in providing the highest quality of care to youth with cancer and their families.

If you are not yet a member, please [CREATE YOUR PROFILE](#) and join! If you are already a member, we are working improve the site and update its content.



clinical care, research and education that relate to pediatric psycho-oncology, and

- 2) to develop a comprehensive list of resources, training opportunities, ongoing research, and upcoming events in the field of pediatric psycho-oncology.

Please contact Sima Bedoya (sima.bedoya@nih.gov) with any questions, or:

1. If you would like to continue to be listed
2. If any information on your profile needs to be updated (please check your position, relevant publications, etc);
3. If your profile photo is now blurry and you are able to submit a higher resolution photo (our apologies, this occurred as a consequence of the platform switch);
4. If you are aware of helpful resources which are not included on the website already ([see current resources](#)); or
5. If you have any other comments or suggestions for us.

PPO theses from around the globe

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

By Perri Tutelman, Canada



Thesis title: A Multimethod, Patient-Oriented Examination of Pain in Childhood Cancer Survivors

Emerging theory and empirical work suggest that pain may be a significant late effect of childhood cancer and trigger of fear of cancer

recurrence (FCR). The present dissertation aimed to provide a comprehensive understanding of pain after childhood cancer and its relationship with FCR. This was accomplished through four interrelated studies using a range of qualitative and quantitative approaches.

The [first study](#) qualitatively explored the experience and meaning of pain in 10 childhood cancer survivors (ages 8-18 years) and their parents using an Interpretive Phenomenological approach. Three superordinate themes were generated: (a) pain is a changed experience after cancer; (b) pain may be interpreted as a threat; and (c) pain interpretation occurs within the context of how the cancer experience is appraised.

In the [second study](#), a laboratory-based experimental pain protocol was used to characterize generalized differences in pain and sensory functioning in childhood cancer survivors (ages 8-17 years) compared to reference values. Results revealed pervasive sensory

differences present years after treatment completion. Demographic, clinical, and psychosocial risk factors for differences in sensory processing were identified.

In the [third study](#), the first self-report measures of FCR for childhood cancer survivors and parents were developed based on the established Fear of Cancer Recurrence Inventory (FCRI). Psychometric properties of the adapted child (FCRI-Child) and parent (FCRI-Parent) measures were examined and demonstrated strong internal consistency, construct validity, and criterion validity.

The fourth and final study examined the contributions of pain, anxiety and pain catastrophizing to FCR in childhood cancer survivors and their parents. For survivors, greater anxiety symptoms were associated with increased pain intensity, pain catastrophizing, and FCR. For parents, greater anxiety symptoms and pain catastrophizing, but not child pain intensity, were associated with FCR. Pain catastrophizing predicted unique variance in parent and child FCR.

Taken together, this dissertation contributes to the understanding of pain after childhood cancer and its relationship with FCR. Findings point to potential targets for intervention for this complex population.

Thesis link:

<https://dalspace.library.dal.ca/handle/10222/81069>

By **Brittany McGill, Australia**



Thesis title: Genetics, genomics and precision medicine: Innovations in childhood cancer care through the eyes of families and oncology professionals

Precision medicine, including genetic and genomic testing for cancer predisposition syndromes,

promises to enhance the targeted and individualised prevention, diagnosis, treatment and long-term management of childhood cancer. The diagnosis of a cancer predisposition syndrome in a child with cancer also offers opportunities for cascade testing, and then proactive management of cancer risk, in the wider family.

At the same time, precision medicine presents new psychosocial challenges for families, and new professional challenges for oncology professionals and cancer genetics services. As a clinical psychologist, I have long been interested in the ways families cope

with the stress and upheaval of a childhood cancer diagnosis and then, as a later-developing research interest, how families manage the ‘double whammy’ of navigating genomics and precision medicine at an already unbearable moment of their lives. Taking a multi-perspective, mixed-methods approach, I conducted an in-depth investigation of the experiences of young patients, parents, and oncology professionals in the Australian healthcare context.

In identifying the information and support needs of key stakeholders, my next priority is to work with a multidisciplinary team, including paediatric oncologists, genetics professionals, and implementation scientists to devise and evaluate precision medicine resources to support and empower families and oncology professionals. The development of tailored psychosocial support for children and adolescents affected by cancer predisposition syndromes is also a critical area of need.

McGill BC, et al 2019 [“I remember how I felt, but I don’t remember the gene”: Families’ experiences of cancer-related genetic testing in childhood.](#)

By **Sarah Ellis, Australia**



Thesis title: Sleep in parents of children and adolescents with cancer

Following their child’s cancer diagnosis, parents often experience a period of rapid adjustment, during which many attempt to maintain their everyday roles and

routines with the added responsibility of caring for a sick child. Whilst sleep is an essential component of physical and psychological health and wellbeing, very few studies have investigated sleep amongst parents of children and adolescents with cancer, particularly during the acute, on-treatment phase. This thesis utilised a mixed-methods multi-perspective approach to examine the prevalence, predictors, and consequences of sleep difficulties among parents, to determine how we can best support their sleep, during this vulnerable time.

We identified a range of factors influencing parents’ sleep across both home and hospital settings, including: (1) Child characteristics; (2) Medical/treatment; (3) Environmental; (4) Parenting role and supports; (5) Sleep-related behaviours; and (6) Psychological factors (cognitive/emotional). Poor sleep was found to affect parents’ cognition, mood, levels of fatigue, daytime

functioning, relationships, and capacity to provide optimal care for their unwell child. Both parents and healthcare professionals (HCP) strongly endorsed the need for personalised interventions to improve parents’ sleep.

This thesis also documents the consumer-driven development and pilot evaluation of a brief, multi-component intervention *CatNap: Carers at Night in Paediatrics*. CatNap was based on the principals of cognitive behavioural therapy for insomnia (CBT-I), and specifically tailored to support parents’ sleep in the hospital setting. The CatNap intervention was found to be both feasible and acceptable to deliver. Most participants reported benefiting from the intervention and said they would recommend CatNap to others.

Implications: A multitude of factors contribute to inadequate/disturbed sleep for parents of a child diagnosed with cancer. As such, a comprehensive approach including tailored interventions for parents (e.g. CatNap), hospital/environmental adaptations, improved education for HCP around sleep promoting practices, and changes to healthcare policy may be implemented to better support parents’ sleep and overall wellbeing.

Thesis link:

<https://ses.library.usyd.edu.au/handle/2123/25851>

By Elin Irestorm, the Netherlands



Thesis title: Sad, shattered or slow? Fatigue in survivors of childhood cancer.

Fatigue has consistently been found to be one of the most prevalent and distressing symptoms in childhood cancer survivors. Despite this, fatigue is

frequently overlooked as a long-term sequela of paediatric cancer diagnosis and treatment and is currently not included in the Swedish follow-up programme for survivors of childhood cancer. The overall aim of this doctoral thesis was to contribute to the ongoing development of systematic follow-up protocols for survivors of childhood cancer. The main objectives were to investigate the overlap between fatigue, depression, and cognitive deficits.

The assessment of fatigue at follow-up revealed that

cognitive fatigue was the fatigue domain most affected in survivors, but also that survivors of brain tumours suffered more from fatigue than survivors of acute lymphoblastic leukaemia. The results also indicated that cognitive fatigue should not be assessed on its own, but that depressive symptoms and cognitive processing speed should be considered as well.

A decrease in cognitive processing speed from the pre-treatment assessment to the follow-up was also associated with experiencing more cognitive fatigue. Overall, the results suggest that more research is needed concerning the development of fatigue over time, to see if it decreases or if there instead is a risk of increasing symptoms. Future studies should also focus on finding medical predictors and developing a biopsychosocial model of fatigue in survivors of childhood cancer.

Thesis link:

<https://portal.research.lu.se/sv/publications/sad-shattered-or-slow-fatigue-after-childhood-cancer>

By Merel van der Vlist, the Netherlands



Thesis title: Fatigue, daily life participation, and health-related quality of life in paediatric chronic disease

More than one in five children with a chronic disease, such as cystic fibrosis, an autoimmune

disease, or children after the treatment of childhood cancer, reports severe fatigue. This is four times as much as children in the Dutch population. This study found that fatigue was more related to a number of potentially modifiable factors such as physical fitness, depressive symptoms, social support and certain parental factors (such as parental load) than to which diagnosis a child was diagnosed with.

We investigated the perspective of children and parents on the child's daily life participation through in-depth interviews. From the child's perspective, participation was considered more than merely engaging in activities

rather, they view having a sense of belonging, the ability to affect social interactions and the capacity to keep up with peers as key elements of full participation. Parents predominantly focused on securing their child's well-being instead of focusing on participation. The friction between parents and children was based on the level of agreement on who takes the lead regarding the child's participation. The dialogue regarding who makes decisions regarding the child's participation, is important.

To help the child take directorship over his/her fatigue and daily life participation, we investigated PROfeel; a combination of personalized assessment and feedback via an app. During six weeks, we daily assessed fatigue and associated symptoms via ecological momentary assessments in fatigued children. This led to a personalized report and tailored advice. PROfeel was feasible and useful and children were enthusiastic about the tool.

Link to thesis: <https://nolk-s3-bucket.s3.eu-west-1.amazonaws.com/wp-content/uploads/2019/12/28171936/Beyond-the-diagnosis.pdf>

By Holly Evans, Australia

Talking about dying can be distressing, but for young people with incurable diseases like cancer, talking about their needs and wishes at end-of-life can be critical for achieving the best possible outcomes for patients and their families.

There is a gap in the literature on factors influencing individual differences in how young people talk about death. To address this gap, this thesis looks at the relevance of attachment theory in this context.

Attachment theory concerns how people interact with those closest to them, in particular how close relationships are used as an emotional support in difficult situations. Across five experiments using healthy AYAs, our research increased awareness of attachment figures prior to imagining end-of-life scenarios to examine the impacts of attachments on how end-of-life conversations are approached.

Several of these experiments found that an attachment prime did not influence willingness to engage in end-of-life conversations, but we did find that avoidantly

attached participants (a form of attachment where a person is less likely to depend on others for emotional support) were less likely to want to have end-of-life conversations.

Further, participants receiving an attachment prime were more likely to talk about relationship issues. We also found that while avoidantly attached individuals did not seem to find the talking task more difficult, they did talk less about emotional issues. Across experiments, priming attachment awareness did not appear to play a role in young people's engagement with end-of-life conversations.

However, attachment style seemed to influence the engagement with and content of these simulated end-of-life conversations among young people. These results give early evidence that consideration of attachment theory may have an important role to play in outcomes around end-of-life for young people and their families. Individual differences in openness to discussing difficult topics such as death based on individual attachment style should be expected and worked around.

Read more:

<https://spcare.bmj.com/content/early/2020/02/24/bmjspcare-2019-001963.full>

By Niki Rensen, the Netherlands

Each year in the Netherlands, about 600 parents learn that their child has cancer, which profoundly impacts their lives. Major predictors of adverse health-related quality of life (HRQoL) outcomes in parents of children with cancer include

psychosocial factors (e.g., distress) and sleep problems. Prior to this thesis, the prevalence and course of sleep problems were not well elucidated. Additionally, the extent to which the vicious cycle of sleep and distress affects parents of children with cancer had not yet been investigated. Similarly, risk factors for the concurrence of sleep problems and distress, and its impact on HRQoL were not known.

In order to contribute to this knowledge, I included parents from two different study cohorts: the cross-sectional Amsterdam Parent Project and the longitudinal ALL11 add-on SLAAP-study. Parents completed questionnaires on their sleep, distress and quality of life. Rensen demonstrates that sleep problems are common, tend to persist over time, and are closely related to distress. More than a third of the parents of children with cancer still report sleep

problems years after their child's diagnosis. The combination of sleep problems and distress cumulatively affects HRQoL. Major risk factors for reporting both sleep problems and high distress are experiencing little social support, parenting problems, or having a chronic illness.

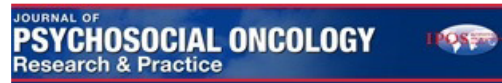
This thesis demonstrates the necessity of assessing family's psychosocial risk profile as soon after diagnosis as possible in order to identify parents at risk of greater distress and sleep problems at a later stage. Furthermore, parental functioning, including sleep, should be monitored consequently both throughout and after treatment. Improving parental sleep might simultaneously improve distress and HRQoL, as well as benefit the child's development and adjustment. A stepped care approach could be useful, with the provision of psychoeducation on sleep hygiene, and evidence-based interventions such as cognitive behavioral therapy for insomnia (CBT-i) delivered to parents with persistent sleep problems. Future research must explore which interventions are most effective to break the vicious cycle of sleep problems and distress, as well as improve HRQoL in parents of children with cancer.

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):

NEWS! We would like to congratulate Dr. Kelly Trevino for her new role as Associate Editor for North America for the *Psycho-Oncology* journal! Dr. Trevino is an Associate Professor of Psychology in Clinical Psychiatry, at the Weill Cornell Medical College in New York, United States.

Pediatric Blood & Cancer



Pediatric Blood & Cancer publications

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Bates C et al., [Psychosocial functioning of caregivers of pediatric brain tumor survivors.](#)

Bisogno G et al., [Role of centers with different patient volumes in the management of rhabdomyosarcoma. An analysis by the Italian Pediatric Soft Tissue Sarcoma Committee.](#)

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HIGHLIGHTED PPO ARTICLE: *Eche I., et al A systematic review and meta-analytic evaluation of psychosocial interventions in parents of children with cancer with an exploratory focus on minority outcomes.*

By **Ijeoma Julie Eche, United States**



Parents of children with cancer face substantial psychological distress throughout the cancer care trajectory. However, the medical literature is fraught with studies that examined psychosocial intervention responses of White, non-Hispanic families of children diagnosed with cancer. Yet, we know that minority families have disparate sources of stress such as concrete material needs, single parent households, and income poverty that may make them especially vulnerable to increased psychological distress during their children's cancer care.

Further, minority families are also less likely to receive mental health services compared to White, non-Hispanic families even when they display psychosocial distress symptoms. In our systematic review and meta-analysis, we examined the efficacy of psychosocial

interventions among parents of children with cancer with an exploratory focus on racial and ethnic minorities. We learned generally that parents reported lower distress levels following parent-level psychosocial interventions; however, the gross underrepresentation of minority families across included studies made it challenging to examine their intervention response.

Guided by a middle-range theory (**Figure 1**, below) of remediable psychosocial needs of families facing childhood cancer, I am currently exploring perspectives of African Americans - a historically disadvantaged group whose cancer-related psychosocial needs have gone unrecognized in pediatric psychosocial research - related to their psychosocial needs.

My overarching goal is to improve cancer-related palliative care disparities and psychosocial outcomes through developing and testing culturally congruent psychosocial interventions for parents of children with cancer from historically disadvantaged backgrounds.

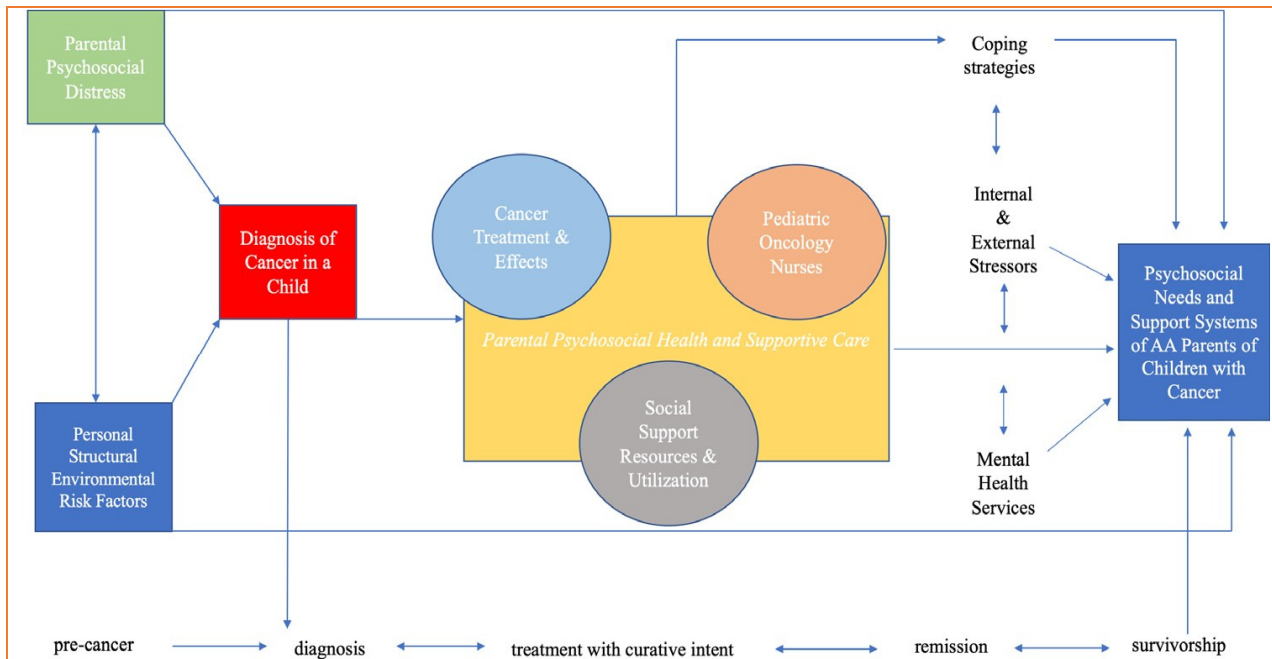


Figure 1. A conceptual framework adapted from Erdman et al. (2019) to understand psychosocial needs of African American (AA) parents of children with cancer

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