



# POPPI Newsletter

Pediatric Psycho-Oncology  
Professionals/Providers  
International

Issue 7: July, 2021

## STEERING COMMITTEE

## WELCOME TO THE SEVENTH ISSUE OF THE POPPI NEWSLETTER



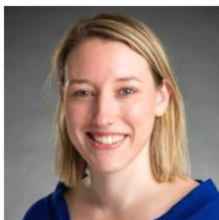
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## A welcome note from the Chairs

*by Martha Grootenhuis, Claire Wakefield, and Lori Wiener*

Welcome to the seventh 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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# Research “in the spotlight”

## Research in the spotlight: Lisa Jacola

**By Dr. Lisa M. Jacola, United States**

*Dr. Lisa M. Jacola is a neuropsychologist and psychologist at St. Jude Children’s Research Hospital. Lisa shares with us some of the research she is currently working on.*



The overarching goal of my research is to improve neurocognitive and quality of life outcomes in survivors of childhood cancer. Specific projects focus on characterizing neurocognitive outcomes and developing interventions to prevent or ameliorate problems. I am particularly enthusiastic about opportunities to translate research findings into clinical practice, as

illustrated in our recent collaboration in the Journal of Clinical Oncology special issue, “Neurocognitive Impairment in Survivors of Pediatric Cancer” (1).

### Assessment and monitoring of neurocognitive function in pediatric cancer

Survivors of childhood cancer are at risk for neurocognitive problems that negatively impact quality of life. Routine neurocognitive monitoring during therapy can facilitate early detection of patients at risk for problems and provide an opportunity for intervention to improve outcomes. However, systematic monitoring can be challenging to

implement, given variability in resources and diversity in patient populations across centers.

We developed an evidence-based framework for neurocognitive monitoring beginning during therapy and continuing into survivorship. We advocate for a risk-stratified, tiered approach to neurocognitive monitoring with the potential for application in varied settings. In addition to clinical factors (e.g., diagnosis and treatment), the contribution of preexisting conditions (e.g., Down syndrome) and persistent/late onset treatment-related complications (e.g., ototoxicity), and environmental factors (e.g., socioeconomic status) are considered. Importantly, we emphasize a developmental approach, given the longstanding impact of neurotoxic agents and treatment complications on developing brains.

Our proposed model is an important first step toward systematically integrating neurocognitive monitoring into clinical care for pediatric oncology. Although rooted in a strong evidence base, the model has yet to be systematically evaluated in a pediatric oncology population. Additional work is needed to establish the clinical utility of computerized assessment measures and the validity of assessment measures across culturally diverse groups. We look forward to learning from future investigations.

**Reference:** Jacola LM, Partanen M, Lemiere J, Hudson MM, Thomas S. Assessment and Monitoring of Neurocognitive Function in Pediatric Cancer. Journal of Clinical Oncol. 2021 Apr 22

<https://doi.org/10.1200/JCO.20.02444>

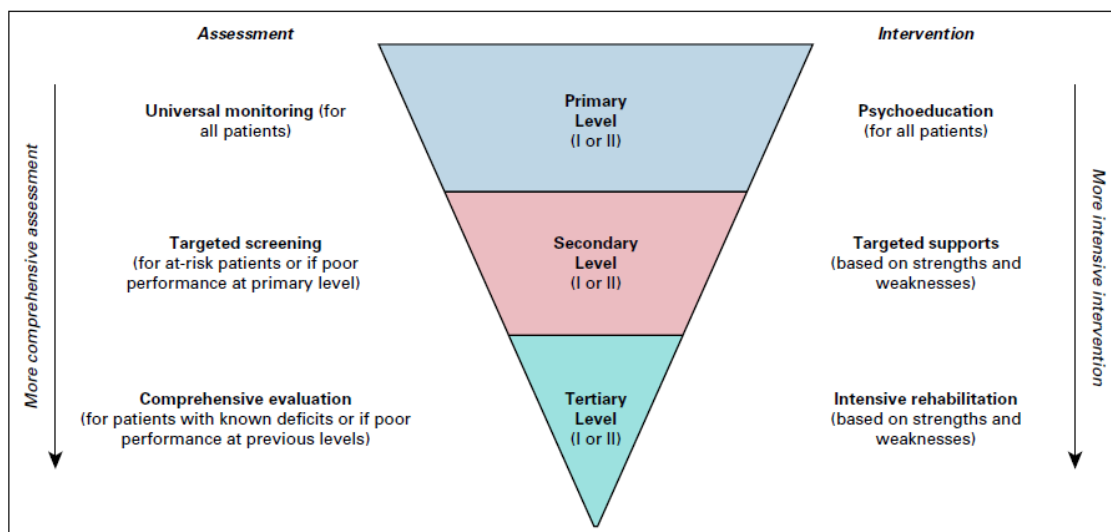


Figure: A model for neurocognitive monitoring in pediatric oncology.

# Let's team up in Europe

## Europe-wide psychosocial network

**By Liesa Weiler, Ulrike Leiss and Carina Schneider, Austria**

*Liesa Weiler, Ulrike Leiss and Carina Schneider are working on a Europe-wide psychosocial network to harmonize instruments in clinical work, trial, and collaborate on implementation of guidelines. They share with us some of their missions.*

### Let's team up in Europe

Regional and national psychosocial working groups exist in European countries. However, in order to work on overarching topics like health policy or representation in EU-funded projects, we face the missing link between working groups on regional levels and collaboration with national and international societies. Moreover, the COVID-19 pandemic brings various challenges associated with psychosocial care and research across Europe into light and aggravates structural issues even more.

### Research - Care - Structural Framework - Policy

To further improve psychosocial research and care in paediatric oncology, it needs to be an integral part of interdisciplinary teams and funding streams (project calls), structural frameworks need to be changed (or put in place) in a top down process. This can be only be possible when a joint effort is made by the health care professionals of all disciplines and patient organisations.

Our vision is the development of joint, evidence-based psychosocial standards of care, implemented across Europe.

For this, respective policies and structural frameworks need to be put in place. As clinical researchers, we want to make sure to keep equal focus on clinical practice and research.

### Our Mission!

- Harmonization and implementation of psychosocial standards of care
- Development and/or translation of practical clinical tools to support implementation
- Establish and then foster a research culture within the psychosocial field, thus also empowering the different psychosocial professions
- Raise Awareness
- Establish specialist trainings

### Share our Vision!

We aim to foster and build interdisciplinary collaboration and active networking with all stakeholders and working groups within the paediatric oncological community on the European and international level. All psychosocial professions, covering both research and/or care, are invited. At the time being we are in the process of reaching out to members to develop a structure for a network including all key positions. Interested? Contact us!

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# 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>

The Mattie Miracle Cancer Foundation once again collaborated with APOS to offer 2 early investigator grants (\$10,000 each) to study the Pediatric Psychosocial Standards of Care.

A 10-member scientific review committee reviewed the LOIs and grant proposals.

The first grant for research related to the implementation of any of the 15 pediatric psychosocial standards of care was awarded to Dr. Karen Long-Traynor for her study entitled “*Feasibility of a peer-to-peer parent mentoring program for parents of children recently diagnosed with cancer*”.

The second (new) grant on the feasibility and usefulness of the newly published Matrix and Guidelines was awarded to Dr. Stephanie Hullman for her study entitled “*SibCARE: A Comprehensive Psychosocial Support Program for Siblings of Youth with Cancer*”.

Congratulations Drs. Long-Traynor and Hullman!

# Study in the spotlight

## Development of a pediatric cGVHD symptom scale

By Abby Fry, Sandra Mitchell, and Lori Wiener




The U.S. Congress passed the 21st Century Cures Act in December 2016, funding for cancer research. This funding is referred to as the “Cancer Moonshot”. A Blue Ribbon panel was created to make recommendations for how the funding should be spent. One of the recommendations was for research on “Symptom Management.” We successfully competed to receive Cancer Moonshot funding under the Symptom Management recommendation to develop a validated symptom scale for pediatric chronic Graft Versus Host Disease (cGVHD) and an accompanying caregiver proxy measure. GVHD is one side effect of allogeneic stem cell transplantation that can cause extensive, painful, and disabling symptoms. A core outcome measure for the adult population exists (The Lee cGVHD symptom scale), however, there is no available pediatric PRO measure of cGVHD symptom bother. The first, and currently enrolling part of the study uses cognitive interviewing to assess comprehension, clarity, and ease of response of the measure for children and adolescents ages 5-17 years.

To address the considerations of conducting research with a population that is geographically dispersed and has varying mobility challenges and illness severity, we designed our study to employ remote methods. We use a three-pronged approach to data collection with children and adolescents and their caregiver: an online survey platform, phone, and a screensharing platform.

Caregivers complete the proxy version of the measure online prior to the interview. During the interview, the child participant views each symptom item on their screen, provide their verbal response, and indicate any difficulties. Animations and visual progress markers are built into the slides to facilitate child engagement for the hour-long interview. Examples of the data collection slides for 5-7-year-olds, 8-17-year-olds, and an animation shown after the completion of each symptom domain (from left to right) are shown below.

While interviews are conducted by the National Cancer Institute study team, enrollment is a collaborative process with ten study sites across the USA. Fortunately, our study was already set up for remote data collection and we were able to continue enrollment as planned despite limitations of the COVID-19 pandemic. After the completion of cognitive interviews with 60 child-caregiver dyads and subsequent refinement of the symptom scale, the planned second project of the study will evaluate the psychometric properties of the measure. We hope this research will yield a measure that can capture symptom bother and ultimately improve clinical care for children and adolescents living with cGVHD. If you have any questions about the study or if your institution may be interested in joining, please feel free to contact us at: [abigail.fry@nih.gov](mailto:abigail.fry@nih.gov) or [lori.wiener@nih.gov](mailto:lori.wiener@nih.gov).

I am bothered by...

My skin hurting			
	Not at all	Sometimes	A lot

Children with chronic GVHD can have symptoms that are bothersome to them. Please tell us how much you have been BOTHERED by the following problems during the past ONE month. There are no right or wrong answers.

ABOUT MY SKIN (I am bothered by)	Not at all	Almost never	Sometimes	Often	Almost always
My skin hurting	0	1	2	3	4

Was this question difficult to understand?  
Yes or No?



## Paper Invitation on Special Issue

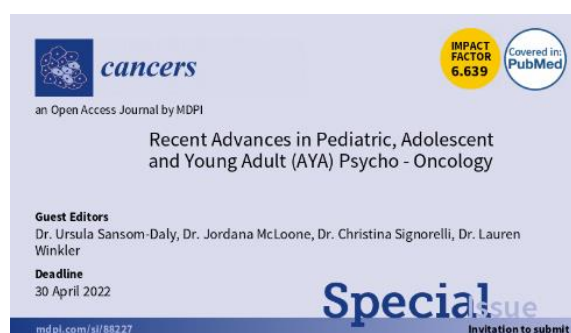
### "Recent Advances in Pediatric, Adolescent and Young Adult (AYA) Psycho-Oncology in Cancers

By Christina Signorelli, Australia

The Open Access journal Cancers (link to: <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 further reading, please follow the link to the Special Issue website at: [https://www.mdpi.com/journal/cancers/special\\_issues/RAPAYAPO](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 [c.signorelli@unsw.edu.au](mailto:c.signorelli@unsw.edu.au)



**cancers**  
an Open Access Journal by MDPI

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

[mdpi.com/si/58227](https://www.mdpi.com/si/58227)

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# PPO conference news

## Upcoming Pediatric Psycho-Oncology conferences

### SAVE THE DATE - 2021

- European Pediatric Psychology Conference: October 4-6, 2021, Virtual Conference

- The International Society of Pediatric Oncology (SIOP) 53rd Congress: October 21-24, 2021, Virtual Conference.

### IPOS World Congress

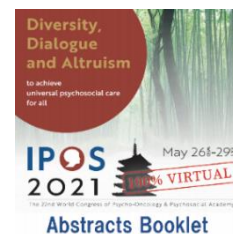
*By Claire Wakefield*

The International Psycho-Oncology World Congress was held virtually from Kyoto, Japan from the 26<sup>th</sup>-29<sup>th</sup> May 2021. The overarching theme was: 'Diversity, dialogue and altruism to achieve universal psychosocial care for all'. Childhood and adolescent cancer was well represented across the program, including a plenary on survivorship care for adolescents and young adults delivered by Professor Anja Mehnert-Theuerkauf and her team. There were a large range of presentations on the impacts of COVID-19 on cancer patients, caregivers and health professionals from around the globe. Children and adolescents were featured in multiple relevant slots alongside thematically similar adult studies (for example, within the survivorship category).

There were also specific categories focussed on children (e.g. addressing art-based models of care, acceptance and commitment therapy interventions for parents, and a focus on physical activity participation in childhood cancer survivors). There were also a range of outstanding posters focussing on posttraumatic growth in childhood cancer survivors and symptom monitoring by parents, amongst others.

You can access the full abstract book here:

[IPOS 2021 Abstracts Booklet : Journal of Psychosocial Oncology Research and Practice \(lww.com\)](#)



### 52<sup>nd</sup> SIOP Congress

*By Sasja Schepers and Martha Grootenhuis*

#### SIOP-PPO educational day 2021

The SIOP-PPO educational day will take place on **October 21, 2021**. All abstract submissions have been reviewed and the best rated abstracts were selected for either the psychosocial free paper session or the psychosocial poster discussion on the main program, or a presentation at the SIOP-PPO educational day. Notifications about the decisions have been sent out in June/July.

Considering that the conference will be completely virtual, we tried to be cautious at first about how long the educational day should be, and take into account also the time differences, especially with Europe and Australia. However, a lot of interesting work has been submitted, and with a great variety in topics we hope to build a program that is of interest to a broad audience. The SIOP platform has a function allowing you to watch back sessions, and therefore we hope that everybody will be able to attend all sessions they are interested in.

The program of the SIOP-PPO educational day is currently being finalized, but we can already share a few first teasers. There will most likely be a joint session about cross-cultural differences. A topic that is especially relevant in Hawaii, but also globally. Another session will be about PTSD in childhood cancer survivors, including attention for the new DSM-V criteria and genetic predisposition. More information about the full program will follow soon.

#### PPO on the main program

There will be a symposium on Mental health with Gisela Michel, Fiona Schultze and others: Addressing mental health across the cancer trajectory. Convener: Gisela Michel, Switzerland.

- Screening for mental health problems in childhood cancer survivorship - Gisela Michel, Switzerland
- Mental health care needs in childhood cancer patients and survivors - Jordan Gilleland Marchak, USA
- Mental health of childhood cancer patients and survivors during the COVID-19 pandemic - Fiona Schultze, Canada

Also, there will be a key note speaker on "The imperative to listen to the child's voice in pediatric oncology" by Ulrika Kreicbergs from Sweden.

#### SIOP board of directors

We are proud that Dr. Claire Wakefield was selected as the new continental president representing SIOP Oceania. As a psychologist, she is the first board member with a non-medical appointment. We would like to congratulate Dr. Wakefield with this impressive achievement!

#### Key dates

- Late Breaking Abstract Submission Period: **June 24 - August 24 2021**
- Early Registration Deadline: **July 27, 2021**
- SIOP Virtual Conference 2021: **October 21-24, 2021**



## 17<sup>th</sup> APOS Conference

By Lori Wiener, United States

### APOS Annual meeting

Pediatrics and AYA was strong at the virtual 2021 APOS annual conference with a fabulous keynote by Christine Chambers, PhD, "From Evidence to Influence: Moving Research into Practice and Policy", an invited symposium, *Psychosocial Screening in Pediatric Oncology: The Child/Adolescent Voice*, 28 talks, 25 posters, a pediatric "Noonish Education" session, the quarterly SIG, and a book club (The Gift of Gerbert's Feathers) with Meaghann Weaver and Lori Wiener.

The invited symposium included:

1. "Checking In: A new generation electronic screening tool for pediatric and adolescents in outpatient settings". Authors: Drs. Lori Wiener, Sima Bedoya, Robert Casey, Colleen Davis, Amii Steele, Alexandra Cutillo, Kathy Ruble, Devon Ciampa, and Maryland Pao
2. "Behind the Scenes" in Measure Development: Engaging Stakeholders to Develop a Psychosocial Assessment Strategy for Young Adults with Cancer". Authors: Drs. Meghan McGrady, Sarah Beal, Constance Mara, and Ahna Pai
3. "Implementation of Electronic Psychosocial Screening among AYAs with Cancer. Authors: Drs. Jordan Gilleland Marchak, Rebecca Williamson Lewis, Alison Manikowski, Tonya Bennett, Lilly Boyer, Heather Miller, Ann Mertens, and Karen Wasilewski-Masker
4. Creating Child-Friendly Cancer Treatment-Related Toxicity Items. Authors: Drs. Pamela Hinds, Deborah Tomlinson, Lei Chang, and Changrong Yuan



## New Research Topic Frontiers in Psychology

### Psychosocial Aspects of Adolescents and Young Adults with Cancer.

By Martha Grootenhuys, The Netherlands

Adolescent and young adult (AYA) oncology is typically recognized as clinical care or research focused on individuals diagnosed with cancer between the ages of 15 to 39 years old. Current evidence has shown that AYAs experience inferior outcomes compared with pediatric and older adults due to reasons such as the unique biologic features of AYA cancers and under-representation in clinical trials. Adolescence marks a unique stage in neurocognitive, emotional and psychosocial development. Being diagnosed with cancer during a period of significant physical and psychological alterations can create an overwhelming amount of stress to the affected individual, as well as their caregivers.

For this Research Topic, we invite Original Research and Review articles that focus on psychosocial and behavioral outcomes in AYAs and their caregivers throughout the cancer care continuum from diagnosis to long-term survivorship.

Full details: [Psychosocial Aspects of Adolescents and Young Adults With Cancer | Frontiers Research Topic \(frontiersin.org\)](https://www.frontiersin.org/research-topics/21332/psychosocial-aspects-of-adolescents-and-young-adults-with-cancer/participate-in-open-access-research-topic?affilaid=61ba0d1a-4958-4b15-8ddb-03bc0de3cc70)

As a leading expert in your field, we would like you to participate by submitting your research. This is a great opportunity to have your research published in Frontiers in Psychology. With an Impact Factor of 2.067 and CiteScore of 3.2, it is the largest journal in its field and brings together the psychological science community to advance understanding of human behavior.

Help to make this collection even more successful by alerting other experts in the field who could submit their own article. Simply copy and send the following link to your colleagues:

<https://www.frontiersin.org/research-topics/21332/psychosocial-aspects-of-adolescents-and-young-adults-with-cancer/participate-in-open-access-research-topic?affilaid=61ba0d1a-4958-4b15-8ddb-03bc0de3cc70>

The submission deadline for this Research Topic is 31 January 2022

#### Topic Editors

- Martha Grootenhuys, Princess Maxima Center for Pediatric Oncology Utrecht, Netherlands
- Yin Ting Cheung, Faculty of Medicine, The Chinese University of Hong Kong Hong Kong, Hong Kong, SAR China
- Ellen van der Plas, The University of Iowa Iowa City, United States
- Andreas Charalambous, Cyprus University of Technology Limassol, Cyprus



# PPO theses from around the globe

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

By Patrizia D'Olive, the Netherlands



**Thesis title:** Designing Tactful Objects for Sensitive Settings

Childhood cancer is a disruptive life event that creates high levels of stress and anxiety in families. It turns everyday routines up-side-down and can block the child's psychosocial

development when families have difficulties to emotionally cope with this potentially traumatic event. D'Olive developed three interactive objects aimed at preserving space for quality time and stimulate interpersonal communication between family members. These objects were deployed in the homes of children who are receiving cancer treatment in order to better understand how families responded to them, and whether they were appropriate to support their situation.

The broader question addressed by the work is 'how can vulnerable users be empowered by design in sensitive settings?'. Tactfulness was found to be a critical expressive design quality of such objects, leading to the idea of Tactful Objects as a design perspective on interactive artefacts that function in sensitive settings. According to this perspective, designing tactful objects for sensitive settings means to design objects that behave like sensitive partners, establish a balanced collaboration with people, resemble familiar characters and maintain a discreet presence in the context where they are introduced. The thesis discusses the practical value of Tactful Objects in healthcare as well as the methodological implications of conducting Research-through-Design in sensitive settings.

[Link Publication.](#)



Figures: three interactive objects

By Lindsay Steur, The Netherlands.



**Thesis title:** Sleep in children with acute lymphoblastic leukemia: an opportunity to improve wellbeing.

ALL is the most common type of childhood cancer. Survival rates have increased over the past years. However, both during and after treatment, patients and their families are at risk for impaired quality of life and

other adverse effects, amongst which are sleep disturbances. Sleep is essential for normal daily functioning and childhood development. Sleep disturbances are associated with many adverse physical and psychosocial health outcomes. Children with ALL are vulnerable to sleep disturbances, presumably due to treatment-related toxicities, environmental noises during hospitalization, physical and psychosocial.

This study showed that sleep disturbances around 5 months after diagnosis reported by the parent are twice more common in children with ALL compared to healthy children. Sleep disturbances do not decrease significantly over time; they continue to exist until 3 years after diagnosis. Age, co-morbidity, pain

experience, sharing a bedroom, sleeping disturbances of the parents and parenting problems are factors that are related to sleep disturbances in children with ALL. Results also showed that children with ALL experience a less robust sleep-wake rhythm compared to healthy children and are less physically active. Children with ALL and their parents report more fatigue compared to healthy children. Additionally, a disturbed sleep-wake rhythm was associated with fatigue.

## Clinical implications

Based on our research findings, monitoring of sleep disturbances in pediatric oncology is recommended in order to recognize sleep disturbances and sleep-wake rhythm problems at an early stage. This creates possibilities to start treatment early and subsequently prevent chronic sleeping disturbances. It is also important for attention to be given to parental sleep disturbances. Further, it is recommended that psycho-education is provided to increase knowledge of child and parental sleep and sleep hygiene and to stimulate physical activity to improve the sleep-wake rhythm. Effective interventions focused on preventing or treating sleep disturbances and sleep-wake rhythm, can improve the wellbeing and quality of survival in children with ALL in the future.

[Link publication.](#)

By Anat Laronne, Israel



Thesis title: Barriers and Facilitators to Implementing Palliative Care Services in Pediatric Oncology Patients in Israel.

Children diagnosed with cancer suffer greatly. Pediatric palliative care (PPC) aims to improve their quality of life.

The World Health Organization

defines PPC as the care of the child's body, mind and spirit. PPC is given throughout the disease course and includes support to the family. PPC within pediatric oncology is in different development stages around the world. While in North America, interdisciplinary specialists working on palliative care teams are common, in Israel, they are rare. To date, no research has looked at the field of pediatric palliative care in oncology in Israel.

The study aim was to evaluate barriers and facilitators to implementing palliative care in pediatric oncology patients in Israel. The project team included myself, the Principal Investigator, Leeat Granek, PhD, and co-investigators, Lori Wiener, PhD, and Hana Golan, MD.

The study was funded by the Israel Science Foundation. We chose a qualitative approach and the Grounded Theory methodology to explore clinicians' experiences. Forty-six providers from six major hospitals were interviewed.

Our findings revealed three major challenges. Our first paper, published in *Supportive Care in Cancer*, noted that palliative care among pediatric oncologists was an ill-defined, complex concept with no distinct clinical boundaries. Our second, paper accepted for publication in *Palliative Medicine*, identified barriers and facilitators to the provision of primary pediatric palliative care, relating to the organizational and clinician level. The last issue which will form the basis of the third paper, identified the vast communication challenges providers face when talking to children and their families about their disease.

The implications of our work include the need for more palliative care training for multi-professional providers, especially due to the lack of availability of specialists in Israel. Also, a consideration of the relationship between organizational and provider factors so that the resources allocated can be utilized to the greatest capacity for the benefit of children and their parents.

## 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

Afunghwi et al., [Two decades of childhood cancer care in Cameroon: 2000-2020](#)

Ananth et al., [Parent and patient perceptions of medical marijuana in the childhood cancer context](#)

Atkinson et al., [A randomized controlled trial of a structured exercise intervention after the completion of acute cancer treatment in adolescents and young adults](#)

Bava et al., [Association of language proficiency, sociodemographics, and neurocognitive functioning in dual-language Latino survivors of childhood acute lymphoblastic leukemia and lymphoma](#)

Bluebond-Langner et al., [Parents' responses to prognostic disclosure at diagnosis of a child with a high-risk brain tumor: Analysis of clinician-parent interactions and implications for clinical practice](#)

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.](#)

Child et al., [Long-term cognitive and academic outcomes among pediatric brain tumor survivors treated with proton versus photon radiotherapy](#)

Cowfer et al., [Effect of time on quality of parent-child communication in pediatric cancer](#)

Darlington et al., [COVID-19 and children with cancer: Parents' experiences, anxieties and support needs.](#)

Demers et al., [Complex behavioral interventions targeting physical activity and dietary behaviors in pediatric oncology: A scoping review](#)

Dolan et al., [Association of psychological distress and religious coping tendencies in parents of children recently diagnosed with cancer: A cross-sectional study.](#)

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Ehrhardt et al., [Cumulative burden of chronic health conditions among adolescent and young adult survivors of childhood cancer: Identification of vulnerable groups at key medical transitions](#)

van Engelen et al., [Tumor surveillance for children and adolescents with cancer predisposition syndromes: The psychosocial impact reported by adolescents and caregivers.](#)

Farooki et al., [A quality improvement project to increase palliative care team involvement in pediatric oncology patients](#)

Fisher et al., [Longitudinal understanding of prognosis among adolescents with cancer](#)

van Gorp et al., [No increase in psychosocial stress of Dutch children with cancer and their caregivers during the first months of the COVID-19 pandemic](#)

Jacola et al., [Adaptive functioning and academic achievement in survivors of childhood acute lymphoblastic leukemia: A report from the Children's Oncology Group](#)

Kenney et al., [Virtual visits as long-term follow-up care for childhood cancer survivors: Patient and provider satisfaction during the COVID-19 pandemic](#)

Khan et al., [Height, weight, and cardiovascular effects of stimulants on children with brain tumors](#)

King-Dowling et al., [Acceptability and feasibility of survivorship care plans and an accompanying mobile health intervention for adolescent and young adult survivors of childhood cancer](#)

Livingston et al., [Shared spiritual beliefs between adolescents with cancer and their families](#)

Lubas et al., [Short sleep duration and physical and psychological health outcomes among adult survivors of childhood cancer.](#)

Lyon et al., [The intersectionality of gender and poverty on symptom suffering among adolescents with cancer](#)

Madhusoodhan et al., [Characterization of COVID-19 disease in pediatric oncology patients: The New York-New Jersey regional experience](#)

Massano et al., [Hospital-based home care for children with cancer during the COVID-19 pandemic in northeastern Italy](#)

McLoone et al., [The COVID-19 pandemic: Distance-delivered care for childhood cancer survivors](#)

Moreira et al., [The Global COVID-19 Observatory and Resource Center for Childhood Cancer: A response for the pediatric oncology community by SIOP and St. Jude Global](#)

Neu et al., [Mental health and health-related quality of life in preschool-aged childhood cancer survivors. Results of the prospective cohort study ikidS-OEVA](#)

Noyd et al., [Integration of cancer registry and electronic health record data to construct a childhood cancer survivorship cohort, facilitate risk stratification for late effects, and assess appropriate follow-up care](#)

Olsavsky et al., [Family communication about fertility preservation in adolescent males newly diagnosed with cancer](#)

Palmer et al., [Late effects of radiation therapy in pediatric patients and survivorship](#)

Patel et al., [Supportive care for toxicities in children undergoing radiation therapy](#)

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

Prozora et al., [Patterns of medication use at end of life by pediatric inpatients with cancer](#)

Rensen et al., [Parental functioning during maintenance treatment for childhood acute lymphoblastic leukemia: Effects of treatment intensity and dexamethasone pulses](#)

Rouger-Gaudichon et al., [Impact of COVID-19 on cancer care: A survey from the French Society of Pediatric Oncology \(SFCE\)](#)

Roshandel et al., [Female reproductive function after treatment of childhood acute lymphoblastic leukemia](#)

sqwSalem et al., [Home-based cognitive behavioural therapy for families of young children with cancer \(FAMOS\): A nationwide randomised controlled trial](#)

Santacroce et al., [He knew more than we wanted him to know: Parent perceptions about their children's sense of pediatric cancer-related financial problems](#)

Simon et al., [Pain at home during childhood cancer treatment: Severity, prevalence, analgesic use, and interference with daily life](#)

Sisk et al., ["Don't be afraid to speak up": Communication advice from parents and clinicians of children with cancer](#)

Snaman et al., [Identification of adolescents and young adults' preferences and priorities for future cancer treatment using a novel decision-making tool](#)

Streefkerk et al., [Large variation in assessment and outcome definitions to describe the burden of long-term morbidity in childhood cancer survivors: A systematic review](#)

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***Journal of Psychosocial Oncology Research & Practice publications***

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### **HIGHLIGHTED PPO ARTICLE:** Clerici et al. *On the clinical psychologist's role in the time of COVID-19, with particular reference to experience gained in pediatric oncology.*

**By Carlo Alfredo**

During the COVID-19 pandemic pediatric oncology departments reorganized their logistics and activities, adopting restrictive measures to minimize the risks of in-hospital infections for patients and staff members. Clinical psychological support activities have had to adapt to the safety limitations and changes in settings imposed by the situation, limiting direct contact with patients (through the use of face masks and gloves), and expanding the use of communication technologies. The situation raised new problems that operators had not generally been trained to deal with:

- fewer relational resources for families at home
- less chance to socialize through schooling activities
- hospital stays with only one parent, always the same one despite long stays
- the interruption of psychosocial support group activities, such as those generally implemented for adolescents or parents due to the rules of social distancing, and of support given by the informal network of spontaneous relationships born between parents and between patients during their stay in the ward

- the rising levels of family conflicts and generalized anxiety (perception of disease, hypochondria) during the pandemic lockdown.



It was essential to find new solutions that could be promptly implemented, reconfiguring the way we humanize our hospital wards. Now in a phase in which the spread of vaccines and a reduction in infections give way to a cautious optimism, it is appropriate to evaluate what we may have learned from the pandemic. Among the most important lessons in the field of psychological support in pediatric oncology emerges the urgent need to update the training courses of psycho-oncologists providing specific programs dedicated to the new conditions of adaptation to the setting, physical distances, non-traditional methods of communication and relationships; paying attention to the value of the unique relationship between clinician and patient.

## Upcoming meeting!

The IPOS Pediatrics SIG is meeting soon to re-connect, share experiences and identify opportunities to work collaboratively at a global level. Anyone who is interested in paediatric psycho-oncology research and clinical practice is welcome to attend. The meeting will be held on the 28<sup>th</sup> July 2021 at 7am Calgary time (which will be 2pm in London, 6am in San Francisco, 11pm in Sydney).

Hopefully you can each work out your timing in your region from the above examples. The SIG will also make an effort to change the times for the next meeting too, so that others in different regions can participate too. Please contact Claire Wakefield ([c.wakefield@unsw.edu.au](mailto:c.wakefield@unsw.edu.au)) to receive the zoom invitation if you're keen you're keen to participate.

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!](#)

We would like to thank Petra Buursma for her help with the lay-out and editing in this newsletter.



## POPPI Newsletter

Our next newsletter  
will be circulated  
around the end of  
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](#).





## **Postdoctoral Fellowship in Psychiatric Oncology & Behavioral Sciences, Psychiatry, Massachusetts General Hospital/ Harvard Medical School**

The [Center for Psychiatric Oncology & Behavioral Sciences](#) in the Department of Psychiatry of Massachusetts General Hospital (MGH) / Harvard Medical School is seeking a **Clinical Psychology Postdoctoral Research Fellow** for two years. The postdoctoral fellow will also be a member of the [Cancer Outcomes Research & Education \(CORE\) Program](#) in the MGH Cancer Center. The fellow will be eligible for two years of salary (competitive) support through one MGH-funded and one NIH-funded grant. They will have an academic appointment at Harvard Medical School and should have completed the requirements for their Ph.D. This position has the potential to lead to a faculty position depending on the candidate's ability to develop their own clinical research and collaborate with existing federal or foundation-funded projects. Ideal applicants are those who plan to transition to an academic position after the fellowship period. Supervised hours for licensure are assured, as is a wealth of opportunities for research collaboration. A successful candidate will have a strong demonstrated interest and experience in clinical intervention research in psychosocial oncology and cancer outcomes, and those with experience working with people with different types of cancer, their family and/or friend caregivers, cancer survivors, or those at end-of-life are encouraged to apply.

### **Primary Responsibilities and Opportunities:**

- Devote 80- 85% of effort to psychosocial oncology/cancer outcomes research and 15-20% to clinical work and supervision in the psychiatric oncology service
- Support several NIH- and foundation funded trials in patients with cancer and their family and friend caregivers by managing study coordination, supervising study staff, and delivering study protocols
- Assist with data analyses, manuscript writing (first and co-authored publication opportunities available), scientific presentations, and grant preparation
- Attend multidisciplinary research and clinical meetings including faculty from oncology, psychiatry, palliative care, social work, and nursing to discuss innovative research and clinical care
- Receive extensive mentorship in career development and on a submission of a future NIH or foundation grant

### **Position Requirements:**

- Applicants must hold a PhD in clinical psychology (preferred) or related clinical qualification from an APA-accredited doctoral program and have completed an APA-accredited internship program
- Prior experience working on clinical research studies
- Training in quantitative and/or qualitative methods and data analysis
- Background in evidence-based treatments such as CBT and ACT

The *U.S. News & World Report* consistently ranks Mass General Psychiatry in the top among U.S hospitals, and MGH Cancer Center as one of the top cancer centers in the country. The Center for Psychiatric Oncology & Behavioral Sciences is a premier clinical and research program staffed by clinical psychologists, psychiatrists and social workers who provide comprehensive clinical services and conduct innovative research to meet the psychosocial needs of patients with cancer and their families. Massachusetts General Hospital is an Equal Opportunity Employer, and all qualified applicants will receive consideration for employment without regard to race, color, religion, sex, sexual orientation, gender identity, national origin, disability status, protected veteran status, or any other characteristic protected by law.

Contact: Interested applicants should send a cover letter and CV to Jamie Jacobs, PhD at [jjacobs@mg.harvard.edu](mailto:jjacobs@mg.harvard.edu).