



POPPI Newsletter

Pediatric Psycho-Oncology
Professionals/Providers
International

Issue 10: March, 2024

STEERING COMMITTEE

WELCOME TO THE TENTH ISSUE OF THE POPPI NEWSLETTER



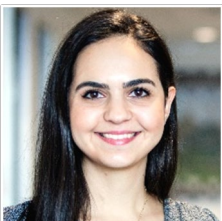
Lori Wiener,
PhD. APOS
Editor



Fiona
Schulte, PhD.
Chair IPOS
peds SIG and
SIOP



Sasja
Schepers,
PhD
Editor



Christina
Signorelli, PhD
Editor



Petra Buursma,
MSc
Secretary

A welcome note from the Chairs
by *Fiona Schulte and Lori Wiener*

Welcome to the tenth 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.

Since our last POPPI newsletter, we continue to stand with our colleagues across the globe impacted by the devastation of wars. Learning about specific steps that we can take to ameliorate suffering is part of our role as providers in our global community. We have also all been impacted by COVID-19 within our own lives and in the lives of the patients and families we care for.

Fortunately, the world is in a better place in terms of COVID at this time. We have an opportunity to see one another again in person at conferences, which is a true gift. Updates about upcoming meetings can be found on Page 5. Increasingly we are providing care in person, versus predominately through telehealth though our work settings and how we practice has changed for many of us. Thank you for all that you do to make the world a better place for those you care for and for each other.

In this issue:

- Page 1: Welcome from the Chairs
- Page 2: Research study “in the spotlight”
- Page 3: Researcher “in the spotlight”, standards of care update
- Page 4: Ukraine Collaborative update, WHO Global survey update
- Page 5: PPO conference news 2024
- Page 6: PPO theses from around the world
- Page 9: Recent PPO publications
- Page 10: APOS award recipients

Research “in the spotlight”

Study in the spotlight: Research into end-of-life care experiences of adolescents and young adults with cancer

By Jennifer W. Mack, United States

Cancer among adolescents and young adults (AYAs) is on the rise, with nearly 90,000 AYAs diagnosed in the United States each year; globally, this number exceeds 1.3 million. While most are cured, an estimated 15,000 AYAs die of cancer in the US annually, and nearly 400,000 worldwide, creating profound suffering for those whose lives are cut short and those who survive them. Research is needed to inform best care for AYAs living with advanced disease.

In response to this need, our study team has worked to understand the experiences of AYAs with advanced cancer. Here we describe work focused on care of nearly 2,000 AYAs who died between 2003-2019 after receiving care at one of three sites, Dana-Farber Cancer Institute, Kaiser Permanente Northern California, and Kaiser Permanente Southern California. We reviewed health records, including electronic records of health care utilization and medical record documentation, to understand care delivered at the end of life.

We first examined care using quality measures developed for older adults with cancer. These quality measures were designed to understand how care received matches up with best practice for older adults, even though we recognize that AYAs may have different priorities for end-of-life care. We found that end-of-life care for AYAs was frequently intensive. Many AYAs had late life emergency room visits (25% with >2 in the last month), intensive care unit admissions (31% in the last month), and hospitalizations (67% in the last month).

Notably, most AYAs also received palliative care (73%) and hospice (62%) before death, but efforts at palliation often occurred concurrently with intensive measures. In addition, just over half (59%) of AYAs received psychosocial care in the last 90 days of life, and 49% received spiritual care. We feel that psychosocial care for this vulnerable group should be nearly universal, so this finding suggests a need for improvement.

In addition, only 34% of AYAs were assessed for

symptoms of depression in the last 90 days of life, and 40% for symptoms of anxiety, again suggesting that efforts to comprehensively screen and treat mental health needs could benefit young people approaching the end of life.

<https://pubmed.ncbi.nlm.nih.gov/37890132/>

We also used medical records to examine communication about care planning and goals. Most AYAs had documented discussions about end-of-life care planning, including discussions about prognosis (86%), goals of care (83%), palliative care (79%), hospice (79%), and preferred location of death (64%) before death. However, many discussions happened near the EOL; earlier discussions were associated with fewer intensive measures near death, supporting the need for early conversations about goals and values.

<https://pubmed.ncbi.nlm.nih.gov/37625111/>

Finally, we found that racial and ethnic disparities in care were common. Black AYAs had higher odds of multiple ER visits (OR 1.66) and hospital deaths (OR 1.61). Asian AYAs had higher odds of late life hospitalizations (OR 1.53), prolonged hospitalizations (OR 1.72), and hospital deaths (OR 1.49) than Whites. Black and Hispanic patients had lower rates of goals of care discussions (81% and 77%, respectively) than Whites (86%, $P=.002$).

This work leaves many questions unanswered. Most notably, while we examined the type of care received by AYAs, we do not know what type of care patients preferred. Some patients may prefer to receive care in the hospital, for instance, especially if symptoms are challenging to address at home, or due to concerns for the well-being of siblings or children in the home. We feel that future work needs to more deeply examine patient preferences in conjunction with care received.

Nonetheless, we also feel that our findings point to some areas for improvement now, including ensuring that psychosocial and spiritual care are offered to all patients, addressing symptoms of depression and anxiety, and ensuring that conversations about care goals and preferences happen early enough for patients to make thoughtful decisions.

Researcher “in the spotlight”

Psycho-oncology researcher in the spotlight: Daniël Zwerus

By Daniël Zwerus, the Netherlands



Psychosocial outcomes and impact of hereditary screening in children with endocrine tumor predisposition syndromes and their families.

Endocrine tumor syndromes are multi-organ conditions that are dominantly

inherited, and manifest throughout childhood and adult life. In recent years predictive and surveillance testing has been introduced, with mutation carriers being identified preclinically, often in early childhood. This may have a considerable impact on the (quality of) lives of patients and families.

Multiple Endocrine Neoplasia (MEN) is a prime example of an endocrine tumor syndrome. It includes aspects such as a familial burden, screening procedures, genetic testing and the risk for both malignant and benign tumors at pediatric age and later in life. There is very limited data on the impact of MEN and the psychological wellbeing and quality of life of children and families with MEN.

The psychosocial impact of screening procedures of children and families with MEN is currently unknown. The UMC Utrecht, together with the Wilhelmina Children's Hospital and the Princess Máxima Center for Pediatric Oncology in Utrecht, the Netherlands has started a unique multicenter project funded by the renowned KIKa (Children Cancer Free Foundation) to map psychosocial outcomes in children and families with Multiple Endocrine Neoplasia. The project with the acronym KIDS&MEN started in 2023 and is currently in the data collection phase.

To collect data on psychosocial outcomes we use both quantitative and qualitative measures. In collaboration with all University Medical Centers in the Netherlands, all children aged between 5 and 18 with a mutation for MEN and their parents and siblings are asked to complete several questionnaires. Besides, a subset of the population is purposefully sampled and asked to take part in an interview. The results of this project will be used for the development of surveillance

recommendations and suggestions will be made for personalized care. Additionally, we will be working on developing / co-creating a shared decision-making tool that can be implemented in this population. We expect the results of our study to be helpful in populations of children with other predisposition syndromes as well.

As part of this larger research project, we have been working on creating a refined and distinctive overview of research on psychosocial outcomes in endocrine tumor syndromes. We reviewed all available literature on psychosocial outcomes in populations of (prevalent endocrine tumor syndromes), including Multiple Endocrine Neoplasia, Von Hippel Lindau and SDHx mutations.

Besides conducting an extensive literature search, we critically appraised the quality of the available literature. In general, studies showed a considerable impact of ETSs on psychosocial outcomes. Different underlying mechanisms found may highlight part of the psychosocial impact. Existing research covers adult populations and many different measures were used to map psychosocial outcomes.

We aim to publish full results soon in a systematic review. The team of (pediatric) endocrinologists, psychologists and scientists coordinating the KIDS&MEN project are collaborating for this review as well. Our review will be one of the first of its kind on this topic and provide a starting point in revealing the gaps, but also opportunities for future research.

In preparation: Zwerus D, Strobbe F, Verrijn Stuart AA, Van Santen HA, Valk GD, Schepers SA, Van Leeuwen RS. Psychosocial Outcomes in Endocrine Tumor Syndromes: A Systematic Review

KIDS&MEN

Part of:



Sponsored by:

Psychosocial Standards of Care Update

Implementing the Psychosocial Standards Together: Engaging Parents and Providers in Psychosocial care (iSTEPPP)

By **Lori Wiener, United States**

On behalf of the iSTEPPP Research Team: Anne Kazak, Ph.D., Michele Scialla, MSN, Kimberly Canter, Ph.D., and Emily Pariseau, Ph.D., Nemours Children’s Health; Lori Wiener, Ph.D., National Cancer Institute; Kim Buff, Momcology; Vicki Sardi-Brown, Ph.D., The Mattie Miracle Cancer Foundation.

The 15 Psychosocial Standards of Care for Childhood Cancer were published in late 2015 with evidence from systematic reviews that justify the need for comprehensive psychosocial care in pediatric cancer. However, it is not known to what extent pediatric cancer programs in the United States (U.S.) are delivering care consistent with the Standards. This information is important to assure that evidence-based care is delivered. But it is also critical to know because implementation is difficult and learning more about centers’ experiences can inform next steps. The iSTEPPP project is funded by a research grant from the Andrew McDonough B+ Foundation. We are assessing the status of pediatric cancer care consistent with the Standards, from the perspective of healthcare providers and families.

This is the first time families have been provided an opportunity to report on what Standards are most important to them. The team conducting this study represents a strong partnership between family advocacy groups (Mattie Miracle Cancer Foundation, Momcology) and researchers who are leaders in the development, testing and implementation of psychosocial care in pediatrics.

iSTEPPP is a mixed methods study that began with a national quantitative survey of 200+ cancer programs (in the Children’s Oncology Group) across the U.S. Healthcare professionals and a sample of caregivers

from families across the country will provide data on the importance of specific standards and insights into the facilitators and the challenges associated with moving towards successful implementation of the Standards. We are very pleased that a comparable study is planned for Australia this year (iSTEPPP-AU), led by Maria McCarthy, Ph.D.

The data collected will inform future research focused on implementation strategies for five of the Standards identified as most important.

STANDARDS FOR THE Psychosocial Care of Children with Cancer and their Families

- ASKING AND MONITORING**
 - Assessment of Psychosocial Needs
 - Assessment of Financial Need
 - Monitoring Neurocognitive Problems
 - Adherence: Following Treatment Recommendations
 - Screening in Long-Term Survivorship
- INTERVENTION AND SUPPORT**
 - Psychoeducation, Information, Anticipatory Guidance
 - Preparatory Information for Procedures
 - Psychosocial Support and Interventions
- FAMILY AND COMMUNITY**
 - Opportunities for Social Interaction
 - School Support
 - Parental Mental Health
 - Sibling Support
- SUPPORTIVE CARE AND BEREAVEMENT**
 - Palliative Care/End of Life Care
 - Bereavement Care

iSTEPPP
IMPLEMENTING THE STANDARDS TOGETHER
 ENGAGING PARENTS AND PROVIDERS IN PSYCHOSOCIAL CARE

The Standards for the Psychosocial Care of Children with Cancer and their Families are evidence-based and published. The iSTEPPP project is a partnership between Nemours Children’s Health, the Mattie Miracle Cancer Foundation, and Momcology, with funding from the B+ Foundation.

SAFER Ukraine Collaborative Update

Supporting Action for Emergency Response (SAFER) Ukraine

By Inna Alanbousi, United States

February 24, 2024 marks 2 years since Russia intensified its' invasion of Ukraine. This also marks the anniversary of the establishment of the Supporting Action for Emergency Response in Ukraine (SAFER Ukraine) collaborative developed to support Ukrainian children diagnosed with cancer and blood disorders who are impacted by war.

In the past two years, the SAFER Ukraine collaborative has supported the evacuation of more than 1,500 children to medical facilities across Europe and North America, and these evacuations continue. The scope of assistance has considerably expanded to meet the need of patients and families, and includes supporting repatriation, family reunification, supporting palliative care services, as well as capacity building activities to promote sustainability of pediatric cancer care services in Ukraine

([https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(23\)00577-6/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(23)00577-6/fulltext)).

The protracted nature of the conflict has also meant that psychosocial services have had to evolve from acute, emergency care to sustained support to meet

the complex needs of these children and families both in Ukraine and abroad. Patients and families continue to face many challenges. Those who traveled across Europe and North America miss their home communities. They have had to overcome obstacles, including finding work in new countries while navigating their child's medical care.

Additional challenges faced by these families include language barriers and establishing relationships with their new communities. In response, the SAFER Ukraine collaborative, alongside partners including Childhood Cancer International (<https://ccieurope.eu/ukraine-resources/>) have compiled language assistance materials and learning applications to support families and caregivers. For more information or learn how you can support our initiatives, visit: <http://stjude.org/>



St. Jude Global

SAFER Ukraine

Supporting Action For Emergency Responses in Ukraine

Lived Experience of People Living with Cancer

Update on a World Health Organization Global Survey

By Julie Cayrol, Australia

On behalf of the 'Lived Experience of People with Cancer' Study Team: Claire Wakefield, Lori Wiener, Clarissa Schilstra, and Jordana McLoone

We are excited to be finalising the second version of our WHO Global Survey on the Lived Experience of People with Cancer!

Initially launched in October 2022, this study has been adapted to respond to the feedback of previous participants and partner cancer organizations.

This second iteration will survey adults with a current cancer diagnosis, adult survivors of adult and childhood cancer, as well as family members and carers of people affected by cancer, including siblings and bereaved family members.

The study aims to understand psychosocial and financial impacts of cancer during treatment and

into survivorship, on a global scale. This online survey will be once again hosted by the World Health Organization and will be disseminated with the help of partner cancer organizations and WHO regional offices. We are hoping for a stronger representation from people living in Low-Middle Income countries, and from people with diverse educational and social backgrounds.

This version will be available in English, French, Spanish, Russian, Mandarin, Arabic and Portuguese from its launch, hoping to reach more people across the globe.

Stay tuned for the online release of this version of the global survey, capturing the voices of people with a cancer experience worldwide - and thank you for spreading the word!



PPO conference news

Recent and Upcoming Pediatric Psycho-Oncology conferences

SAVE THE DATE - 2024

- [Association of Pediatric Oncology Social Workers \(APOSW\)](#) conference: 7-10 April 2024, Chicago, United States.
- [Society of Pediatric Psychology Annual Conference \(SPPAC\)](#) 25-27 April 2024, New Orleans, United States

- [International Symposium on Late Complications After Childhood Cancer \(ISLCCC\)](#) 27-29 June 2024, Lucerne, Switzerland.
- [International Psycho-Oncology Society \(IPOS\) World Congress](#): 24-27 September 2024, Maastricht, the Netherlands.
- [The International Society of Pediatric Oncology \(SIOP\) 54th Congress](#): 17-20 October 2024, Hawaii, United States.

IPOS World Congress

By Christina Signorelli, Australia

The next International Psycho-Oncology Society World Congress will be held in Maastricht, the Netherlands from September 24 - 27, 2024. This World Congress will be hosted in conjunction with the the Dutch Psychosocial Society. Abstract submissions have now closed, although [registration](#) will open from May 1st 2024.

The overarching theme for the meeting is: "Cancer in Context". This includes a strong focus on cancer across the lifespan, including pediatric and adolescent. One of the invited speakers includes young cancer survivor Lianne Spaander, who will share her experience with attendees at the Congress.

The full abstract booklet from the 2023 World Congress (Milan, Italy) is also available to view in the official *IPOS Journal of Psychosocial Oncology Research and Practice*, which is accessible [here](#).

A reminder that IPOS invites all members to be profiled online to showcase their work.



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.

SIOP Update

By Fiona Schulte, Canada

The 2023 SIOP The Pediatric Psycho-Oncology (PPO) Education Day held in Ottawa, Canada, brought together speakers from all over the world to share their research and clinical expertise about a number of topics related to psychosocial care. Dr Nina Muriel (USA) and Professor Martha Grootenhuis (Netherlands) began the day discussing important considerations for intervention of mood and behaviour changes related to steroids.

The morning session concluded with an international panel including Dr. Lori Wiener (USA), Dr. Marina Noronha Ferraz de Arruda-Colli (Brazil), Dr. Maryland Pao (USA, on behalf of representatives from China) and Dr. Ursula Sansom-Daly (Australia) sharing their work on cultural adaptations of the Voicing My CHOICES advance care planning communication guide for use within their respective populations, with a discussion led by Dr. Michael McNeil (USA). The afternoon began with a presentation by Associate Professor Stacey Marjerrison (Canada) discussing how to build inclusive care for Indigenous and marginalised children and families in Canada. This was followed by selected presentations from a variety of speakers including Dr. Andreas Meryk (Austria), Associate Professor Lauren Daniel (USA), Dr. Elvia Grillo (Colombia), and Prof



Martha Grootenhuis (Netherlands), each sharing their research related to cancer care for children and their caregivers across diverse populations. The PPO Education Day concluded with presentations and a panel discussion including Ms. Sonia Lucchetta (Canada), Dr. Ulrike Leiss (Austria) and Ms. Veronika Kusyova (Ukraine) sharing about key learnings related to the efforts of their respective centres in supporting families displaced due to humanitarian crisis, in the context of Russia's invasion of Ukraine.

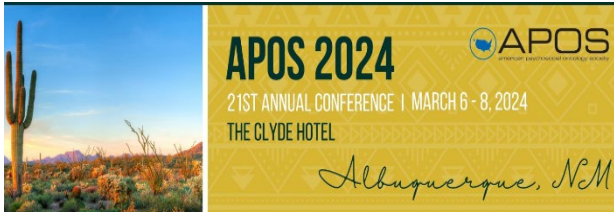
Looking ahead to 2024, the SIOP PPO is thrilled to welcome some new members to the Network Steering Group: Dr. Chiara Besani, Dr. Lori Wiener and Dr. Lisa Kahalley (Co-Chair Elect).

Also - the PPO Network is already actively working on planning the World Congress in 2024 in Honolulu, Hawaii. Stay tuned for exciting announcements regarding our next Education Day!

17th APOS Conference

By Lori Wiener, United States

APOS was founded on the belief that all individuals benefit from coming together to innovate and advance the field of psychosocial oncology through research, practice, education, and advocacy. The theme for APOS's 21st Annual Conference was 'Advancing Psychosocial Oncology within a Changing Landscape'. The changing landscape in psychosocial oncology - from evolving health systems to the intersection of complex care needs and social determinants of health for patients, families and professionals - demands adaptation, growth, and innovation. This annual meeting successfully celebrated connections with one another and with community partners, sharing novel solutions for workforce growth and professional development, clinician resilience, innovative and tailored care delivery models, and evidence-based care. In addition, all but one award recognized work in the pediatric and AYA space!



Recipients included (more information on pages 11-12):

- The Avery D Weisman & J William Worden Award for New Investigators: Anao Zhang (United States)
- The Ruth McCorkle Excellence in Research Mentorship Award: Barbara Jones (United States)
- The Outstanding Clinical Care Award: Amanda Thompson (United States)
- The Jimmie Holland Lifetime Achievement Award: Lori Wiener (United States)

Association of Pediatric Oncology Social Workers

The APOSW conference is a three-day event filled with education, networking, and meaningful connections, drawing pediatric oncology social workers and psychosocial providers from across the US, Canada, and the world. Conference speakers are nationally recognized experts in the field. Triage Cancer will be presenting a FREE pre-conference intensive on Sunday, April 7th from 8:30 am to 5:00 pm on navigating insurance and financial challenges.



PPO theses from around the globe

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

By Brooke Russell, Canada



Thesis title: Fear of cancer recurrence experienced by pediatric survivors of childhood cancer

While much is known about fear of cancer recurrence (FCR) experienced by adults, research exploring FCR experienced by children and adolescents has only begun to emerge. Importantly, children and young adolescents are a unique group characterized by dynamic and developing cognitive abilities and social worlds which may have important implications for the experience of FCR. My dissertation work aimed to 1) systematically evaluate the existing literature on FCR experienced by pediatric survivors, and 2) evaluate the psychometric properties of the Cancer Worry Scale within a pediatric sample.

I first conducted a scoping review to assess the characteristics and methods of the pediatric FCR literature, identify how pediatric FCR has been measured, and summarize the extant knowledge about pediatric FCR. Of 3902 studies screened, 19 were included (published 1991 - 2023). Studies encompassed diverse geographical locations, study designs, and measurement methods.

Few assessed FCR as a primary aim ($n = 6, 32\%$). Pediatric FCR was experienced by 43 - 90% of young survivors. FCR was often positively associated with somatic symptoms and negatively associated with quality of life and emotional functioning.

Next, I evaluated the psychometric properties of the Cancer Worry Scale (CWS; 6-item and 8-item versions) within a pediatric sample. Both CWS versions demonstrated floor effects, with no participants endorsing the highest scores. Internal consistency reliability was good for both the CWS-6 ($\alpha = .91$), and CWS-8 ($\alpha = .92$). Exploratory factor analyses produced a single factor solution for both CWS versions, accounting for 62-65% of total variance. Both CWS versions were strongly correlated with measures indicating convergent (IUSC-12, PROMIS Anxiety-8a, PROMIS Depression-8a; $r = 0.464$ to $0.535, p < .001$), and divergent validity (PedsQL; $r = -0.285$ to $-0.324, p < .05$).

In sum, this work demonstrated that FCR is a prevalent and important concern for pediatric survivors. Additional research is needed to better characterize and understand pediatric FCR. Finally, results of this work highlight the need for a pediatric FCR measure developed in collaboration with pediatric survivors themselves and using concepts and language most salient for them.

By *Pauline Holmer, Switzerland*



Thesis title: Exploring grandparents' psychosocial responses to childhood cancer: A qualitative study

A childhood cancer diagnosis is a devastating event for both patients and their families. However, the impact on grandparents has not been adequately explored in previous research. In a recent interview study, we therefore aimed to identify the negative psychosocial impacts, coping mechanisms, and positive outcomes experienced by grandparents whose grandchildren were recently diagnosed with cancer.

We found that grandparents were in shock and experienced strong feelings of fear and helplessness, especially when thinking about a possible relapse or late effects. In addition, the worst part for most grandparents was seeing their grandchild suffer, for example, when they had to take medication.

Many respondents said that their fear was always present, which could lead to tension and sleep problems. To cope with these negative experiences, grandparents in our study used internal and external strategies, such as accepting the illness or talking to their spouses and friends. Some also relied on faith and spirituality as a coping mechanism. Most grandparents also reported positive outcomes, such as becoming emotionally closer to family members and appreciating things they had previously taken for granted.

In our qualitative study, we found that grandparents suffer greatly when their grandchild is diagnosed with cancer. Encouragingly, most also reported coping strategies and positive outcomes despite the challenges. Promoting coping strategies and providing appropriate resources could reduce grandparents' psychological distress and strengthen the entire family system.

Read more:

<https://onlinelibrary.wiley.com/doi/pdf/10.1002/pon.6304>

By *Mala Joosten, The Netherlands*



Thesis title: Children with a chronic illness or cancer, their siblings and parents: psychosocial group intervention & long-term consequences

When a child is ill, all family members are impacted. They have to face stressors that are related to the illness, and can experience problems in their psychosocial wellbeing. This thesis consists of two parts that are both related to wellbeing of (family members of) children with an illness.

Part 1: The development and effect of the Op Koers intervention for different family members

The research in this part of the thesis is focused on Op Koers (in English: On Track). The Op Koers intervention program consists of group courses for children with a chronic illness or cancer, their siblings, and their parents. The aim is to teach active coping skills and prevent or reduce psychosocial problems. Peer support is an important component of the course, which is offered both in hospitals and online.

We looked at the development, evaluation and implementation of the intervention and we discussed the lessons we learned in 25 years of studying Op Koers¹⁻³. As a result of the randomized controlled trial we conducted to study the Op Koers Online for parents of children with cancer, we found a beneficial intervention effect on anxiety, depression, distress, loneliness and coping skill relaxation.

We concluded that Op Koers is an effective intervention and that parents are generally very positive about it.

Part 2: Psychosocial functioning of parents and siblings of very long-term survivors of childhood cancer

In this part, we studied the psychosocial wellbeing of adult siblings and parents of survivors of childhood cancer^{4, 5}. We found that 20 to 30 years after diagnosis of the childhood cancer in their family, both family members are doing generally well. Differences with wellbeing of reference populations were negligible and manifested in both positive and negative directions. Also, the proportion of siblings and parents with symptomatic post-traumatic stress seemed low. Cancer-related factors did not demonstrate a clear impact on wellbeing of siblings and parents on the very long-term. These findings are reassuring and can be incorporated in psycho education for families of children with cancer.

1 - [Hearing siblings' voices: exploring the \(online\) support needs of siblings of children with a chronic condition](#)

2 - [Online cognitive-behavioral group intervention for adolescents with chronic illness: A pilot study](#)

3 - [Efficacy of Op Koers Online, an online group intervention for parents of children with cancer: Results of a randomized controlled trial](#)

4 - [Psychosocial functioning of adult siblings of Dutch very long-term survivors of childhood cancer: DCCSS-LATER 2 psycho-oncology study](#)

5 - [Psychosocial functioning of parents of Dutch long-term survivors of childhood cancer](#)

By **Cristina Priboi, Switzerland**



Thesis title: Psychological Outcomes in Survivors of Childhood Cancer and Their Grandparents

Childhood cancer is a disease affecting the entire family unit, including the patients, as well as extended family members such as grandparents. The current thesis aimed to fill the knowledge gap in two overlooked areas of pediatric psycho-oncology: the sexuality of childhood cancer survivors (CCS) and the psychological health of grandparents of CCS. Two different methodologies were applied in three distinct studies for this purpose.

The [first study](#) used a cross-sectional quantitative design to describe the sexuality of CCS in comparison to a reference population and explored the determinants of survivors' sexuality. One third of CCS reported hindered sexuality due to childhood cancer, with insecure body the most often reported reason. Older age at study, lower education, surviving central nervous system cancer, poorer mental health and negative body perception were identified as determinants for delayed sexual debut, worse sexual functioning and/or sexual satisfaction.

The [second study](#) consisted in a systematic literature review investigating the psychological outcomes in

grandparents of children with severe diseases and summarizing the needed and used psychological support.

Grandparents reported experiencing a wide spectrum of feelings, with fear being the most prevalent feeling. They rarely accessed professional services due to their limited knowledge of available programs or the absence of formal services addressing their needs.

The third study assessed the psychological distress of grandparents of long-term CCS in a cross-sectional quantitative survey and compared the distress of grandparents to the general population. Our findings were encouraging, showing that grandparents of long-term CCS reported average levels of psychological distress, and their distress did not differ from the Swiss comparison sample. Having a good health perception and being in a relationship were the only factors associated with grandparents' psychological distress.

Recommendations: My research on the late effects reveals that CCS encounter challenges in various aspects of sexuality, with certain subgroups experiencing heightened difficulties. This emphasizes the importance of holistic interventions to improve survivors' sexual health, suggesting integration into standard healthcare services. Additionally, my research exposed the emotional and psychological impacts on grandparents of CCS, underscoring the necessity for tailored support services to help them effectively navigate challenging situations.

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

Ay A et al., [Prediction of family-centered care on the unmet care needs of parents of pediatric oncology patients and their psychosocial problems](#)

Dupuis LL et al., [Clinical practice guideline-inconsistent management of fever and neutropenia in pediatric oncology: A Children's Oncology Group study](#)

Greenmyer JR et al., [Consultation patterns before and after embedding pediatric palliative care into a pediatric hematology/oncology clinic](#)

Mutua D et al., [Implementation of a formalized evaluation and planning tool to improve pediatric oncology outcomes in Kenya](#)

Porter AS et al., [How we approach sharing child-caregiver PRO disagreement](#)

Hendricks M et al., [Socioeconomic status significantly impacts childhood cancer survival in South Africa](#)

Holm M et al., [Parenting a child with cancer and maintaining a healthy couple relationship: Findings from the Family Talk Intervention](#)

Lin JJ et al., [Financial assistance and other financial coping strategies after a pediatric cancer diagnosis](#)

Mallon B et al., [The feasibility of implementing Toronto childhood cancer stage guidelines and estimating the impact on outcome for childhood cancers in seven pediatric oncology units in sub-Saharan Africa. A study from the Franco-African Pediatric Oncology Group](#)

Mueller EL et al., [Perceptions of chemotherapy calendar creation among US pediatric oncologists](#)

Sisk BA et al., [Designing and validating novel communication measures for pediatric, adolescent, and young adult oncology care and research: The PedCOM measures](#)

Smith SM et al., [A qualitative study of childhood cancer families' post-treatment needs and the impact of a community-based organization in a rural, socioeconomically disadvantaged, majority Hispanic/Latino region](#)

Tamboli M et al., [Social participation of school-aged survivors of pediatric brain tumors: A daily diary report](#)

Psycho-Oncology

Baenziger J et al., [Post-traumatic growth in parents of long-term childhood cancer survivors compared to the general population: A report from the Swiss childhood cancer survivor study-Parents](#)

Choi E et al., [Psychological distress and mental health care utilization among Hispanic/Latino survivors of adolescent and young adult cancer](#)

Holmer, P et al. [Exploring grandparents' psychosocial responses to childhood cancer: A qualitative study.](#)

Joosten MMH et al., [Efficacy of Op Koers Online, an online group intervention for parents of children with cancer: Results of a randomized controlled trial](#)

Van Hoyweghen S et al., [The psychological impact of genetic testing in childhood cancer: A systematic review](#)

Merz S et al., [Changes and predictors of social support in adolescent and young adult cancer survivors-Results of a 7-year longitudinal study](#)

Perez MN et al., [Caregiver condition management and family functioning after pediatric cancer treatment: Moderation by race and ethnicity](#)

Journal of Psycho-social Oncology: Research & Practice publications

No relevant recent publications.

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



POPPI Newsletter

Our next newsletter will be circulated in mid 2024.

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.](#)

American Psychosocial Oncology Society (APOS) award recipients



THE AVERY D. WEISMAN & J. WILLIAM WORDEN AWARD FOR NEW INVESTIGATORS ANAO ZHANG, PHD, LCSW, ACSW, ACBT

ANAO ZHANG, PHD, LCSW, ACSW, ACBT, IS AN ASSISTANT PROFESSOR OF SOCIAL WORK AT THE UNIVERSITY OF MICHIGAN AND THE CLINICAL RESEARCH DIRECTOR OF THE ADOLESCENTS AND YOUNG ADULTS (AYA) ONCOLOGY PROGRAM AT MICHIGAN MEDICINE. ZHANG IS A HEALTH AND MENTAL HEALTH INTERVENTIONIST WITH A PRIMARY RESEARCH INTEREST IN PSYCHOSOCIAL-ONCOLOGY AND AYA CANCER SURVIVORSHIP. AN INTERVENTION RESEARCHER BY TRAINING, ZHANG CONTEXTUALIZES HIS WORK USING THE SOCIAL DETERMINANTS OF YOUTH HEALTH FRAMEWORK AND AIMS TO DEVELOP AND DELIVER INTEGRATED AND EMPIRICALLY SUPPORTED MENTAL HEALTH TREATMENT TO INDIVIDUALS WITH CO-MORBID PHYSICAL AND MENTAL HEALTH CONDITIONS, E.G., AYA CANCER SURVIVORS WITH DEPRESSION. TO DATE, DR. ZHANG HAS PUBLISHED 72 PEER-REVIEWED JOURNAL ARTICLES AND OBTAINED 1 MILLION IN EXTERNAL FUNDING TO SUPPORT HIS RESEARCH. ZHANG USES ADVANCED STATISTICAL METHODS TO SUPPORT HIS RESEARCH, INCLUDING META-ANALYSIS, STRUCTURAL EQUATION MODELING, CAUSAL INFERENCE, AND MACHINE LEARNING. ZHANG SERVES AS AN ASSOCIATE EDITOR FOR THE JOURNAL OF PSYCHOSOCIAL ONCOLOGY, CHAIR OF THE EDUCATION COMMITTEE AT THE AYA CANCER ALLIANCE, AND AN ASSOCIATE DIRECTOR OF THE CURTIS CENTER FOR HEALTH EQUITY RESEARCH AND TRAINING AT UNIVERSITY OF MICHIGAN.



THE RUTH MCCORKLE EXCELLENCE IN RESEARCH MENTORSHIP AWARD BARBARA JONES, PHD, MSW, FAPOS

DR. BARBARA JONES, PHD, MSW IS DEAN AND PROFESSOR AT BOSTON UNIVERSITY SCHOOL OF SOCIAL WORK. PRIOR TO JOINING BUSSW, SHE WAS A MEMBER OF THE FACULTY AND LEADERSHIP AT THE UT AUSTIN SCHOOL OF SOCIAL WORK FOR NEARLY TWENTY YEARS. AT UT AUSTIN, JONES SERVED AS UNIVERSITY DISTINGUISHED PROFESSOR, LOCKHART MEMORIAL PROFESSOR, FOUNDING DIRECTOR OF THE INSTITUTE FOR COLLABORATIVE HEALTH RESEARCH AND PRACTICE, AND ASSOCIATE DEAN FOR HEALTH AFFAIRS. SHE WAS ALSO A DISTINGUISHED PROFESSOR AND INAUGURAL CHAIR OF THE DEPARTMENT OF HEALTH SOCIAL WORK AT UT AUSTIN'S DELL MEDICAL SCHOOL.

JONES EARNED HER PHD AND MSW FROM THE UNIVERSITY AT ALBANY AND PRACTICED AS A CLINICAL SOCIAL WORKER FOR 15 YEARS. SHE IS CURRENTLY ON THE NATIONAL ADVISORY BOARDS FOR THE CAMBIA HEALTH FOUNDATION SOJOURNS SCHOLARS PROGRAM AND ACS'S CENTER FOR DIVERSITY IN RESEARCH TRAINING. HER RESEARCH, SUPPORTED BY GRANTS FROM NIH AND ACS, FOCUSES ON IMPROVING CARE FOR CHILDREN, ADOLESCENTS, AND YOUNG ADULTS WITH CANCER.

IN ADDITION TO CO-EDITING 3 BOOKS IN ONCOLOGY AND PALLIATIVE CARE AND PUBLISHING MORE THAN 130 ARTICLES IN TOP-TIER JOURNALS, JONES IS A PAST RECIPIENT OF THE APOSW SOCIAL WORKER OF THE YEAR AWARD AND IS A FELLOW OF THE AMERICAN ACADEMY OF SOCIAL WORK AND SOCIAL WELFARE. SHE WAS THE FIRST SOCIAL WORKER TO RECEIVE THE ACS PATHFINDER IN PALLIATIVE CARE AWARD. SHE IS A DISTINGUISHED SCHOLAR AND FELLOW OF THE NATIONAL ACADEMIES OF PRACTICE AND IS A 2023 FELLOW OF BOTH APOS AND AOSW. SHE HAS MENTORED DOZENS OF SCHOLARS FROM MULTIPLE DISCIPLINES IN ONCOLOGY AND PALLIATIVE CARE RESEARCH AND LEADERSHIP.



THE OUTSTANDING CLINICAL CARE AWARD AMANDA THOMPSON, PHD

FOR ALMOST TWO DECADES, DR. THOMPSON HAS DEDICATED HER CAREER AS A PEDIATRIC PSYCHOLOGIST TO IMPROVING THE LIVES OF CHILDREN, ADOLESCENTS, AND FAMILIES IMPACTED BY CANCER. SHE COMPLETED HER PH.D. IN CLINICAL-DEVELOPMENTAL PSYCHOLOGY AT THE UNIVERSITY OF PITTSBURGH, HER PREDOCTORAL RESIDENCY AT NEMOURS CHILDREN'S HOSPITAL IN WILMINGTON, DE, AND HER POST-DOCTORAL FELLOWSHIP AT NATIONWIDE CHILDREN'S HOSPITAL IN COLUMBUS, OH. DR. THOMPSON THEN SPENT A DECADE AS DIRECTOR OF PSYCHOLOGY AND PSYCHOSOCIAL SERVICES IN THE CENTER FOR CANCER AND BLOOD DISORDERS AT CHILDREN'S NATIONAL HOSPITAL IN WASHINGTON DC, BUILDING WORLD-CLASS PSYCHOSOCIAL TEAMS AND TRAINING THE NEXT GENERATION OF PEDIATRIC PSYCHOLOGISTS. SHE CURRENTLY SERVES AS CHIEF OF PEDIATRIC PSYCHOLOGY AND DIRECTOR OF PEDIATRIC PROGRAMS AT LIFE WITH CANCER, THE PSYCHOSOCIAL PROGRAM OF THE INOVA SCHAR CANCER INSTITUTE IN FAIRFAX, VA.

DR. THOMPSON HAS A NATIONAL PRESENCE AS AN AUTHOR OF THE STANDARDS OF PSYCHOSOCIAL CARE FOR CHILDREN WITH CANCER AND THEIR FAMILIES AND AS PROJECT LEAD ON DEVELOPMENT OF COMPETENCIES FOR PSYCHOLOGISTS IN PEDIATRIC PALLIATIVE CARE. SHE CURRENTLY SERVES AS CO-CHAIR OF APOS'S PEDIATRICS/AYA SPECIAL INTEREST GROUP, APA'S REPRESENTATIVE TO THE PEDIATRICS DIVISION OF THE NATIONAL COALITION OF HOSPICE AND PALLIATIVE MEDICINE, AND A BOARD MEMBER ON THE PEDIATRICS COUNCIL OF THE AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE. WITH A PASSION FOR PEDIATRIC PSYCHO-ONCOLOGY, PALLIATIVE CARE, AND PROGRAM DEVELOPMENT, DR. THOMPSON IS COMMITTED TO ENHANCING THE QUALITY OF CARE FOR ALL CHILDREN AND FAMILIES IMPACTED BY CANCER, FROM THE TIME OF DIAGNOSIS AND INTO SURVIVORSHIP OR THROUGH END-OF-LIFE, BEREAVEMENT, AND BEYOND.



THE JIMMIE HOLLAND LIFETIME ACHIEVEMENT AWARD LORI WIENER, PHD, DCSW, FAPA, FAPOS

LORI WIENER, PHD, IS CO-DIRECTOR OF THE BEHAVIORAL SCIENCE CORE AND HEAD OF THE PSYCHOSOCIAL SUPPORT AND RESEARCH PROGRAM AT THE PEDIATRIC ONCOLOGY BRANCH OF THE NATIONAL CANCER INSTITUTE (NCI). AS BOTH A CLINICIAN AND BEHAVIORAL SCIENTIST, DR. WIENER HAS DEDICATED HER CAREER TO THE FIELDS OF ONCOLOGY AND PEDIATRIC HIV/AIDS. AT THE NCI, SHE HAS DEVELOPED A ROBUST CLINICAL AND RESEARCH PROGRAM THAT HAS FOCUSED ON CRITICAL CLINICAL ISSUES SUCH AS PARENTAL COPING, LONE PARENTING, TRANSNATIONAL PARENTING, SIBLING AND SIBLING DONOR EXPERIENCES, GRAPH VERSUS HOST DISEASE, AND END-OF-LIFE PLANNING. DR. WIENER HAS ALSO DEDICATED A SUBSTANTIAL PART OF HER CAREER TO APPLYING KNOWLEDGE FROM HER CLINICAL EXPERIENCE AND PSYCHOSOCIAL STUDIES TO CREATE INNOVATIVE RESOURCES SUCH AS BOOKS, WORKBOOKS, THERAPEUTIC GAMES AND AN ADVANCE CARE PLANNING GUIDE FOR CHILDREN, ADOLESCENTS, AND YOUNG ADULTS. EACH OF THESE RESOURCES ARE DISTRIBUTED WORLDWIDE AND WIDELY UTILIZED IN PEDIATRIC CENTERS.

DR. WIENER PROUDLY LED THE TEAM THAT HAS DEVELOPED THE FIRST EVIDENCE-BASED PSYCHOSOCIAL STANDARDS OF CARE FOR CHILDREN WITH CANCER AND THEIR FAMILY MEMBERS. SHE HAS OVER 270 PUBLICATIONS SPANNING PEER-REVIEWED PAPERS AND BOOK CHAPTERS. DR. WIENER HAS CO-EDITED THE TEXTBOOKS PEDIATRIC PSYCHO-ONCOLOGY: A QUICK REFERENCE ON THE PSYCHOSOCIAL DIMENSIONS OF CANCER SYMPTOM MANAGEMENT AND PEDIATRIC PSYCHOSOCIAL ONCOLOGY: TEXTBOOK FOR MULTI-DISCIPLINARY CARE, CO-AUTHORED A STORYBOOK, THE GIFT OF GERBERT'S FEATHERS, TO HELP CHILDREN THROUGH THE PSYCHOLOGICAL AND BEHAVIORAL PROCESS OF PREPARING FOR A NATURAL END OF LIFE AND MORE RECENTLY, CO-EDITED A SPECIAL ISSUE IN CHILDREN ON PSYCHOSOCIAL ISSUES IN CHILDREN AND ADOLESCENTS LIVING WITH A RARE CONDITION.