



POPPI

Newsletter

Pediatric Psycho-Oncology
Professionals/Providers International

Issue 9: June, 2023

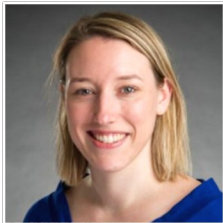
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WELCOME TO THE NINTH ISSUE OF THE POPPI NEWSLETTER

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

Welcome to the ninth 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 invasion of Ukraine and the devastation of war. 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 deaths. Increasingly we are once again providing care in person, versus predominately through telehealth.

A final message from Martha Grootenhuis: After many years of representing the PPO as a chair in this newsletter, it was time to step down which happened at SIOP Barcelona (2022). My chairmanship was passed to Dr Maria McCarthy and Dr Christopher Recklitus. I am happy Dr. Fiona Schulte, also a committee member of the PPO and representing social media, will be the new representative editor for this newsletter. I am proud we have launched this newsletter years ago and the opportunity to provide all of you in the field with information from our wonderful area of work. So much is happening and it is always exciting to read and learn in the POPPI newsletter about all your clinical and research activities. I hope whenever you have projects or initiatives that you would like shared, you will let the editors know!



Claire Wakefield stepping down as POPPI newsletter committee member: Congratulations to Professor Claire Wakefield who has commenced with Minderoo Foundation as Director, Collaborate Against Cancer. In this role, Claire will lead the strategic direction and philanthropic efforts of the Collaborate Against Cancer initiative and team. With a particular strategic focus on childhood cancer, the Collaborate Against Cancer initiative partners and shares information globally to reduce the incidence of cancer, accelerate development of breakthrough therapies, and empower patients, scientists, and clinicians to strive for a world where cancer is a treatable, non-fatal disease. We congratulate Dr. Wakefield with this exciting career opportunity - she will be missed in the POPPI newsletter!



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Research “in the spotlight”

Study in the spotlight: Julia Simon

By Julia Simon, the Netherlands



In September 2023, I will defend my thesis entitled: *“From research to relief: improving children’s cancer pain management at home using digital health”*. Over the past years, we have developed, tested, and started implementation of a digital health tool (the *KLIK Pijnmonitor app*) aimed at

improving pain-related education and communication for children with cancer at home. Implementation has been a top priority throughout the project. For the scoping review presented below, we combined quantitative (literature review) and qualitative data (interviews) to identify existing digital health tools for pain in children with cancer, and to assess common barriers and facilitators of implementation of these tools in clinical practice.

Digital health tools for pain monitoring in pediatric oncology: a scoping review and qualitative assessment of barriers and facilitators of implementation

Pain has been identified as one of the most common symptoms during all phases of childhood cancer treatment. Relative to other pediatric diagnoses, pediatric cancer treatment is particularly intense and toxic. And with new treatment regimens allowing patients to spend more time at home, the responsibility of managing pain lies with families themselves more than ever. Therefore, we felt there was a need to identify existing digital health tools for pain management in children with cancer. In addition, the rapid development and rise of these, often very costly, tools raise the urgency of implementation science.

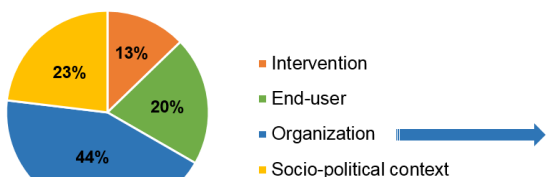
It generally takes approximately 15-20 years to successfully implement a new intervention in healthcare settings, and as a result many interventions end up unused. Thus, we aimed to identify existing digital health tools for pain in children with cancer, and to assess common barriers and facilitators.

Of 121 potential publications, 33 met inclusion criteria, describing 14 tools. Two methods of delivery were used: apps (n=13), and a wearable wristband (n=1). Most publications focused on feasibility and acceptability. Results of interviews with project leaders (100% response rate), reveal that most barriers to implementation were identified in the organizational context (47% of barriers), with financial resources and insufficient time available mentioned most often. Most factors that facilitated implementation related to end users (56% of facilitators), with end-user cooperation and end-user satisfaction mentioned most often (see figure).

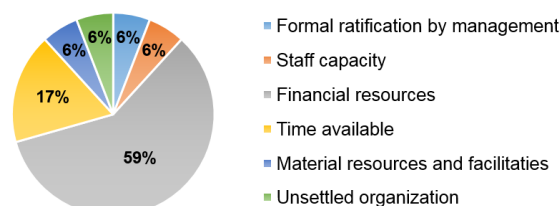
Existing digital tools for pain in children with cancer were mostly apps directed at pain severity monitoring and little is still known about their effectiveness. Paying attention to common barriers and facilitators, especially taking into account realistic funding expectations and involving end users during early stages of new projects, might prevent evidence based interventions from becoming ‘research waste’.

Reference: Simon JDHP, Hooijman IS, Van Gorp M, Schepers SA, Michiels EMC, Tissing WJE, Grootenhuys MA. Digital health tools for pain monitoring in pediatric oncology: a scoping review and qualitative assessment of barriers and facilitators of implementation. Support Care Cancer. 2023 Feb 21;31(3). <https://doi.org/10.1007/s00520-023-07629-2>

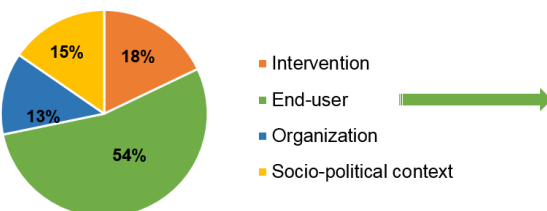
Key barriers (main themes)



Organizational barriers (sub-themes)



Key facilitators (main themes)



End-user facilitators (sub-themes)

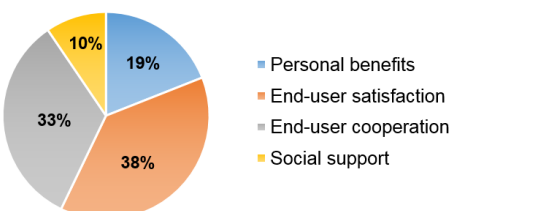


Figure: Identified key barriers and facilitators categorized in MIDI (Measurement Instrument for Determinants of Innovations) themes and sub-themes

Psychosocial Standards of Care Update

Evidence-based standards of care updated with implementation strategies

By Alexandra Neenan, United States

The Psychosocial Standards would not exist without the dedication of Vicki and Peter Brown, caregivers to their son Mattie throughout his cancer treatment and founders of the Mattie Miracle Cancer Foundation.

Given their unique insight at both caregivers and champions for evidence-based psychosocial care, it feels particularly fitting to have partnered with the Mattie Miracle Cancer Foundation alongside the Caregiver Wellbeing SIG of the Society of Pediatric Psychology (Division 54 of the American Psychological Association) to promote the Standards of Care through a social media initiative.

Throughout Childhood Cancer month, we sought to empower parents and caregivers to advocate for

implementation of the Standards by raising awareness of what they entail. In service of this goal, we developed 18 multimedia posts that were shared via Facebook, Twitter, and Instagram to educate parents and caregivers about the Standards and offer authors' perspectives on their importance. Nearly 20 authors of the Standards contributed quotes to these social media posts, which have now been shared over 100 times by caregivers and other stakeholders across platforms.

The images disseminated through our social media initiative will be available indefinitely as a resource for professionals and caregivers alike to promote the Standards in an organic, digestible manner. You can see some examples of these images below - we hope that you may share them as well.

Mattie Miracle
CANCER FOUNDATION

Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation.

Psychosocial Standard of Care #7

Caregiver Wellbeing
SOCIETY OF PEDIATRIC PSYCHOLOGISTS
SPECIAL INTEREST GROUP

Amanda Thompson, PhD
Inova Schar Cancer Institute
Author of Psychoeducation Standard

"The Psychosocial Standard recommends that children and families receive psychoeducation and guidance at all stages of illness that accounts for individual preferences and needs (e.g., coping and learning styles, age and development, language and culture)- there is no one size fits all!"

Mattie Miracle
CANCER FOUNDATION

Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status.

Psychosocial Standard of Care #13

Caregiver Wellbeing
SOCIETY OF PEDIATRIC PSYCHOLOGISTS
SPECIAL INTEREST GROUP

Cynthia Bell, PhD
Spectrum Health West Michigan
Hematology/Oncology
Author of Palliative Care Standard

"Palliative Care as a Standard of Care in Pediatric Oncology focuses on reducing suffering from cancer diagnosis to cure. When cure is not possible this compassionate care extends to the end of life, including bereavement."

PPO conference news

Recent and Upcoming Pediatric Psycho-Oncology conferences

SAVE THE DATE - 2023

- [International Psycho-Oncology Society \(IPOS\) World Congress](#): August 31 to September 3, 2023, in Milan, Italy.
- [European Pediatric Psychology Conference \(EPPC\)](#), August 30th - September 1st, 2023, in Stirling, Scotland, UK.
- [The International Society of Pediatric Oncology \(SIOP\) 54th Congress](#): October 11-14, 2023, in Ottawa, Canada.
Pediatric Psychosocial Oncology (PPO) day will be on October 11th. Early bird registration ends mid-July
- [Association of Pediatric Oncology Social Workers \(APOSW\)](#) conference, March 5th to 8th (location to be announced shortly)

IPOS/CAPO World Congress

By Christina Signorelli, Australia

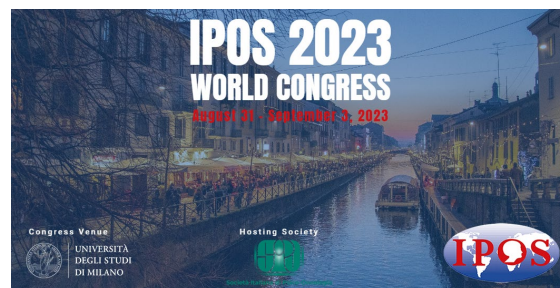
The International Psycho-Oncology World Congress was held at the end of last year in conjunction with the Canadian Association of Psychosocial Oncology (CAPO) in Toronto, Canada from August 29th to September 1st, 2022. The overarching theme for the meeting was: "Reimagining psychosocial oncology: embracing voices from around the world".

The full abstract booklet from the 2022 World Congress is available to view in the official IPOS *Journal of Psychosocial Oncology Research and Practice*, which is accessible [here](#).

Childhood and adolescent cancer was well represented across the program, including a specific topic on 'Cancer care across the lifespan (children, adolescent and young adults, adults, and older adults)', which featured presentations on fear of cancer recurrence, educational and social outcomes, psychological and peer support interventions, coping, and patient reported outcomes.

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.

The 2023 IPOS World Congress will be hosted in Milan, Italy, from 31st August to 3rd September. The theme of the meeting will be "working together towards innovation in psycho-oncology for the future of our patients". Moreover, 5 goals have been defined: innovation, education, equity, measuring efficacy, and sustainable psychology. Abstract submissions have now closed, but [registration](#) is now open.



SIOP Update

By Fiona Schulte, Canada

2022 was a very big year for The Pediatric Psycho-Oncology (PPO) Network at SIOP. To begin, we saw the transition of our founder and Chair, Dr. Martha Grootenhuis off the network Steering Committee. Martha has led the SIOP PPO for the last 15 years and we have been so grateful for her exceptional leadership. As Chair, Martha developed the PPO, introduced the PPO education days and has advocated for the critical importance of PPO within the larger umbrella of SIOP. Thank you Martha! In her place, we are thrilled to welcome Dr. Christopher Recklitis and Dr. Maria McCarthy as our new network co-chairs who will work hard to maintain the strength of the network Martha created. We also welcomed 3 new members to our Network Steering committee including: Dr. Victoria Willard (USA), Dr. Jurgen Lemiere (Belgium) and Dr. Matt Bisset (Australia). We are looking forward to

working with our new committee!

The SIOP World Congress in Barcelona marked our return to in-person meetings. As always, our educational day was a highlight which featured multiple presentations on Pain including aspects of pain during treatment, as well as into survivorship, and highlighted both behavioral and pharmacological approaches. We welcomed 2 exceptional speakers who reflected pain from different perspectives: Maarten Mensink (pediatric anesthesiologist from the Netherlands), and Michelle Fortier (clinical psychologist from the USA) as well as many other invited talks from trainees, researchers and clinicians from around the globe sharing their work and insights into the experience of pain for children diagnosed with cancer.



17th APOS Conference

By Lori Wiener, United States

The 17th APOS Conference was held in Portland, Oregon on March 15-17, 2023. The first plenary talk by Devon Still, a previous NFL player and father of a child treated for neuroblastoma was outstanding and set the tone for the rest of the conference.

Pediatric, adolescent and young adult sessions were presented throughout the 3 days, where our colleagues shared exciting novel clinical interventions, hot-off-the press research findings, and future opportunities.

Mark your calendars for APOS 2024 to be held on March 5-8, with the location to be announced shortly.

Special Issue on cancer and rare diseases

Advances in psychosocial research in cancer and other rare diseases now published!

By Lori Wiener, United States

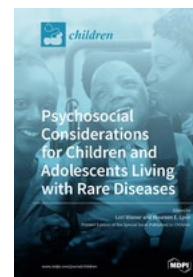
The Special Issue "*Psychosocial Considerations for Children and Adolescents Living with Rare Diseases*" has now been published in the Open Access journal *Children*. The Issue included 14 peer-reviewed articles that focus on the psychosocial needs of children and adolescents living with a rare condition and interventions that have been developed to address their needs. Some of the articles are listed below:

- [Psychosocial Characteristics and Experiences in Patients with Multiple Endocrine Neoplasia Type 2 \(MEN2\) and Medullary Thyroid Carcinoma \(MTC\)](#)
- [Documentation of Psychosocial Distress and Its Antecedents in Children with Rare or Life-Limiting Chronic Conditions](#)
- [Using Communication Tools to Explore Young Siblings' Experiences of Having a Brother or Sister with Pediatric Palliative Care Needs](#)
- [The Needs of Adolescents and Young Adults with Chronic Illness: Results of a Quality Improvement Survey](#)
- [Family-Centered Advance Care Planning: What Matters Most for Parents of Children with Rare Diseases](#)

- ["It Is a Whole Different Life from the Life I Used to Live": Assessing Parents' Support Needs in Paediatric Palliative Care](#)
- [The Social Networks and Social Support of Siblings of Children with Cancer](#)
- [Psychosocial Considerations for the Child with Rare Disease: A Review with Recommendations and Calls to Action](#)
- [The Transition to Adulthood for Youth Living with Rare Diseases](#)

To access all of the papers published in this Special Issue, including an Editorial, please follow this link to the website:

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



By Christina Signorelli, Australia

The Special Issue "*Recent Advances in Pediatric, Adolescent and Young Adult (AYA) Psycho-Oncology*" has now been published in the Open Access journal *Cancers*. The Issue included 18 peer-reviewed articles that focus on various advances in pediatric, adolescent and young adult (AYA) psycho-oncology. Some of the articles are listed below:

- [Adapting the Voicing My CHOICES Advance Care Planning Communication Guide for Australian Adolescents and Young Adults with Cancer: Appropriateness, Acceptability, and Considerations for Clinical Practice](#)
- [Using Intervention Mapping to Develop an Education and Career Support Service for Adolescents and Young Adults Diagnosed with Cancer: Identification of the Contextual Factors That Influence Participation in Education and Employment](#)

- [Interactive Education on Sleep Hygiene with a Social Robot at a Pediatric Oncology Outpatient Clinic: Feasibility, Experiences, and Preliminary Effectiveness](#)
- [Feasibility and Acceptability of Bright IDEAS-Young Adults: A Problem-Solving Skills Training Intervention](#)

Guest Editors Drs Ursula Sansom-Daly, Jordana McLoone, Christina Signorelli and Lauren Winkler wrote an Editorial featuring some of these articles in a broader commentary on the changing landscape of pediatric psych-oncology and key challenges and opportunities, which can be accessed here:

[New Frontiers in Child, Adolescent and Young Adult Psycho-Oncology Survivorship Care](#)

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

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

PPO theses from around the globe

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

By Lauren Ha, Australia



Thesis title: A patient-centred approach to engage childhood cancer survivors in health behaviours using novel digital technologies.

Childhood cancer survivors are at increased risk of developing treatment-related health complications including secondary cancers, obesity, and cardiovascular disease. Engaging in protective health behaviours, such as regular physical activity, may reduce survivors' risk of late effects. Benefits of living a physically active lifestyle for survivors also extend to improvements in cardiorespiratory fitness, muscular strength, fatigue, and health-related quality of life.

Despite these benefits, many survivors do not meet the recommended physical activity guidelines and have low fitness levels. Many survivors are also faced with additional challenges to physical activity adherence including insufficient age-appropriate exercise information or education, uncertainty regarding what exercise to do, or barriers accessing specialist exercise services particularly for families living in regional or remote areas. These factors make it difficult for survivors to achieve optimal physical activity levels in survivorship and may exacerbate their already increased risk of late effects. As an exercise physiologist, I have been interested in

understanding the factors that may influence survivors' health behaviours and the role of digital health interventions to overcome common challenges experienced by survivors and their families.

My thesis used a mixed methods and multi-perspective approach to guide the development and pilot testing of 'iBounce', a patient-centred digital health education program that aimed to foster health behaviours and reduce cardiometabolic complications among childhood cancer survivors. iBounce was found to be feasible to deliver and acceptable among survivors. Many survivors reported iBounce to be enjoyable and easy to use, however reported low satisfaction with the activity tracker, potentially due to the technical difficulties which disjointed the program.

The digital design of iBounce ensured that this model of health behaviour education and engagement was accessible to survivors and families, regardless of their location. To ensure that iBounce will result in high user engagement, uptake, adherence, and acceptability, my next priority will be to address participant feedback and incorporate co-design methods involving users and stakeholders in the development and improvement of iBounce, including survivors who are culturally and linguistically diverse. I also aim to use a hybrid effectiveness-implementation trial design to concurrently evaluate the effectiveness of iBounce and develop a rigorous implementation plan to fast-track the uptake of iBounce in clinical practice.

By Loes van Erp, the Netherlands



Thesis title: Psychosocial challenges of childhood cancer survivorship

Childhood cancer survivors (CCS) are a growing population facing unique challenges. This thesis aimed to increase the understanding of psychosocial challenges of childhood cancer survivorship.

The first part of this thesis contains two reports of large nation-wide cohort studies of HRQOL in Dutch adult childhood cancer survivors. From both studies, we concluded that adult CCS are at a higher risk of worse HRQOL compared to peers from the general population.

The studies stress the need for attention for vitality and cognition. Furthermore, female CCS seem to be impacted more severely by childhood cancer survivorship than their male counterparts.

The second part of this thesis describes the need for attention for young adult childhood cancer survivors (YACCS) as a distinct group. We conclude that YACCS are a vulnerable population who, as a group, report worse psychosocial well-being than the general population. YACCS reported more anxiety and depression than the norm, lower HRQOL, and more fatigue. Despite this vulnerability, many YACCS have normal psychosocial development, and also experience positive impact of cancer besides negative impact. Nevertheless, over 80% of YACCS reported a need for support, especially for information and counseling related to late effects of childhood cancer and lifestyle.

To support optimal quality of life, we developed and evaluated Op Koers Online for YACCS. The study of this e-health intervention provided a first indication of the feasibility and potential effectiveness in improving psychosocial outcomes.

Our research shows the need of specialized survivorship care throughout the lifespan.

By *Clarissa Schilstra, Australia*



Thesis title: Assessing and addressing social well-being and social anxiety among adolescents and young adults with cancer in Australia

Approximately 1,750 Australians aged 15-25 are diagnosed with cancer annually. Adolescent and young adult (AYA) cancer survivors continue to report poor social well-being both during and after cancer treatment. There is evidence to suggest social anxiety disorder (SAD) is an under-recognised yet highly treatable concern for AYAs with cancer. However, no studies have investigated the experience of clinically significant symptoms of SAD among AYAs with cancer. This thesis aimed to define the prevalence, course, and characteristics of SAD among Australian AYAs with cancer and use these findings to improve models of care for their social well-being.

Study 1 was a systematic review identifying the ways social well-being has been defined in the context of AYA cancer, measures used to assess social well-being in this context, and modifiable factors, including SAD, that are associated with poor social well-being and

could be targeted by intervention. **Study 2** was a research priority-setting workshop with AYA cancer survivors that confirmed social well-being as a research priority area.

Through **Study 3**, a cross-sectional/mixed methods study involving AYA-aged long-term survivors of childhood and adolescent cancer, and Study 4, a prospective/longitudinal study involving AYAs recently diagnosed with cancer, ~30% of AYAs reported clinically significant symptoms of SAD. This is more than double the prevalence of SAD (5-15%) seen in the general AYA population. For AYAs ever diagnosed with cancer, SAD symptoms increased in severity over time, and were characterised by fear of embarrassment, avoidant behaviour, and negative self-evaluation. Interviews indicated SAD symptoms were often driven by physical and psychosocial consequences of AYAs' cancer experience (e.g., hair loss, social isolation).

No international recommendations exist for assessment of SAD in AYA cancer care. Therefore, my final study presents expert- and evidence-based clinical guidelines for caring for the social well-being of Australian AYAs with cancer, including assessment and intervention for SAD.

Thesis link:

<https://unsworks.unsw.edu.au/entities/publication/24a27ece-333a-4878-ac94-03abc9ae8ed3>

By *Kelly van Bindsbergen, The Netherlands*



Innovations in pediatric oncology care: Interactive tools for psychosocial support for children with cancer and their families during treatment

In my dissertation we developed and scientifically evaluated several interactive tools for psychosocial support during pediatric cancer treatment. The thesis is divided into two parts: support for children at the hospital and support for families at home.

Support at the hospital: A social robot

In the first part, we examined the introduction of a social robot (which was named Hero) into pediatric oncology care. We used existing hardware (the NAO6 robot) for which we developed new additional software. This software enabled the robot to interact with children autonomously (i.e., without the help of a human controlling the robot via a laptop) and attuned (i.e., personalized) to the responses of children, whereby also using earlier answers of the child (i.e., it had a memory). Hero was developed with two different functionalities: (1) A buddy to reduce stress and anxiety (including multiple interactions: getting acquainted, co-creating a story, and storytelling), and (2) a professor for sleep hygiene education. Using multiple qualitative and quantitative methods, three prospective clinical studies were conducted to examine: (1) The feasibility of using a social robot in the pediatric oncology setting, (2) the experiences of children, families and health care providers with the social robot, and (3) the potential effectiveness of the social robot.

Support at home: AscoltaMe and Mr.V

In the second part, we examined the introduction of two newly developed tools (which were named AscoltaMe and Mr.V) to families with a child with cancer in the home context. For both tools, hardware and software were developed. AscoltaMe was designed based on the tin-can-telephone game whereby family members could leave voice messages for each other to enhance family communication. Mr.V (later redesigned into Mr.V the Spaceman) was designed based on a gumball vending machine whereby the machine was filled by family members themselves with activities and messages which were randomly distributed to families as surprises to support family functioning. Using multiple qualitative and quantitative methods, two prospective clinical studies were conducted to examine: (1) The feasibility and acceptability of families with a child with cancer of using the interactive tools at home, (2) the experiences of children and families with the interactive tools, and (3) the potential effectiveness of the interactive tools.

Overall, the dissertation concludes that the developed interactive interventions have the potential to reduce medical traumatic stress and to support families in coping with childhood cancer treatment. However, further research and technological development are needed, as well as the involvement of child life specialists. The dissertation aimed to contribute to future psychosocial care in pediatric oncology, incorporating technological innovations to support children with cancer and families during treatment both at the hospital and at home.

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

Albee M et al., [A prospective study of social competence in survivors of pediatric brain and solid tumours](#)

Athale U et al., [Healthcare utilization and costs associated with acute lymphoblastic leukemia in children with and without Down syndrome](#)

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

Belle FN et al., [Body image in adolescent survivors of childhood cancer: The role of chronic health conditions](#)

Benedetti DJ et al., [The role of ethicists in pediatric hematology/oncology: Current status and future needs](#)

Bouchard EG et al., [An initial investigation of using smartphone-enabled micro-temporal data collection to increase acceptability, feasibility, and validity of research on cancer caregiving](#)

Cotache-Condor C et al., [Determinants of delayed childhood cancer care in low- and middle-income countries: A systematic review](#)

Davis ES et al., [Financial hardships and psychosocial outcomes among parents of children who die of cancer](#)

Davis KA et al., [Inconsistent, uncoordinated, and reactive: The current state of sibling psychosocial care](#)

De Clercq E et al., [No wrong decisions in an all-wrong situation. A qualitative study on the lived experiences of families of children with diffuse intrinsic pontine glioma.](#)

Dee E et al., [Adolescents and young adults with cancer: Considerations from the South East Asian perspective.](#)

Ebelhar J et al., [Differences in palliative opportunities across diagnosis groups in children with cancer](#)

Fay-McClymont T et al., [Neuropsychological, behavioral, and quality-of-life outcomes in children and adolescents with sickle cell disease treated with nonmyeloablative matched sibling donor hematopoietic cell transplantation: A case series](#)

Greenzang KA et al., [“There's no playbook for when your kid has cancer”: Desired elements of an electronic resource to support pediatric cancer communication](#)

Götte M et al., [Multidisciplinary Network ActiveOncoKids guidelines for providing movement and exercise in pediatric oncology: Consensus-based recommendations](#)

Hehr A et al., [Meditation reduces brain activity in the default mode network in children with active cancer and survivors](#)

Jacobs SS et al., [Longitudinal use of patient reported outcomes in pediatric leukemia and lymphoma reveals clinically relevant symptomatic adverse events](#)

Jurbergs N et al., [How I approach: Defining the scope of psychosocial care across disciplines in pediatric hematology-oncology](#)

Klages K et al., [Pain, depressive symptoms, and health-related quality of life among survivors of pediatric hematopoietic stem cell transplant](#)

Larsen EH et al., [Perceived barriers and facilitators to physical activity in childhood cancer survivors and their parents: A large-scale interview study from the International PACCS Study](#)

Ludemann J et al., [The evolution of fertility preservation care models in a large pediatric cancer and blood disorders center](#)

Lundgren J et al., [Concerns experienced by parents of children treated for cancer: A qualitative study to inform adaptations to an internet-administered, low-intensity cognitive behavioral therapy intervention](#)

Ma C et al., [Provision of a personalized survivorship care plan and its impact on cancer-related health literacy among childhood cancer survivors in Hong Kong](#)

Mader L et al., [Social, emotional, and behavioral functioning in young childhood cancer survivors with chronic health conditions](#)

Marks IR et al., [Ethical challenges faced by healthcare workers in pediatric oncology care during the COVID-19 pandemic in Australia](#)

Merkel E et al., [Quality measures in end of life care among pediatric cancer patients: a lever for optimizing comfort and improving equity](#)

Merz A et al., [Adaptation of the Day100 Talk communication intervention for Spanish-speaking families of children with cancer](#)

Morse M et al., [Psychosocial outcomes and quality of life among school-age survivors of retinoblastoma](#)

Nelson AT et al., [Health-related quality of life in children and adolescents with pleuropulmonary blastoma: A report from the International PPB/DICER1 Registry](#)

Phillips C et al., [Implementation science in pediatric oncology: A narrative review and future directions.](#)

Porter AS et al., [Navigating prognostic communication when children with poor-prognosis cancer experience prolonged disease stability](#)

Rabinowicz R et al., [How essential are in-person clinic visits during maintenance treatment of children with acute lymphoblastic leukemia?](#)

Reuman H et al., [Living in an online world: Social media experiences of adolescents and young adults with cancer](#)

Roberts HJ et al., [The impact of clinical trial enrollment on specialty palliative care utilization in pediatric patients with high-grade gliomas](#)

Ruble K et al., [Strategies to improve communication about neurocognitive impacts in pediatric oncology: Quality improvement findings](#)

Schwartz LF et al., [Adverse childhood experiences and resilience in childhood and adolescent and young adult cancer patients](#)

Sisk B et al., [Co-management of communication and care in adolescent and young adult oncology.](#)

Steineck A et al., [Seeking virtual support: Digital technology use in adolescent and young adults with advanced cancer](#)

Tanner L et al., [CREATE Childhood Cancer Rehabilitation Program development: Increase access through inter-professional collaboration](#)

Thomas S et al., [Transatlantic progress in measurement of cognitive outcomes in paediatric oncology trials](#)

Umaretiya PJ et al., [“The simple life experiences that every other human gets”: Desire for normalcy among adolescents and young adults with advanced cancer](#)

Van Zyl A et al., [Psychological distress of adolescent and young adult childhood cancer survivors in a South African cohort](#)

Vishwa C et al., [Neurocognitive outcomes in survivors of childhood acute lymphoblastic leukemia: experience from a tertiary care center in india](#)

Voll M et al., [Dissemination of an evidence-based behavioral intervention to alleviate distress in caregivers of children recently diagnosed with cancer: Bright IDEAS](#)

Warren EAH et al., [Cognitive predictors of social adjustment in pediatric brain tumor survivors treated with photon versus proton radiation therapy.](#) Weaver M et al., [How I approach the use of bibliotherapy in caring for children with oncologic and hematologic conditions.](#)

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HIGHLIGHTED PPO ARTICLE: *Philips, CA. et al. Implementation science in pediatric oncology: A narrative review and future directions*

By Charles Phillips, United States



Implementation science (IS) has arguably been underused in pediatric oncology with substantially more work having been done within the adult oncology population. In our narrative review, we attempted to characterize prior IS work within pediatric oncology. This is important because IS informs delivery of evidence-based care and addresses key facets of care delivery including healthcare structures, patient and provider behaviors, health disparities and patient outcomes.

We analyzed studies published prior to January 2021 for their relation to IS and pediatric oncology. Of 216 articles initially reviewed, nine were selected as specific to IS and pediatric oncology. All nine examined oncologic supportive care including psychosocial best practices, cancer prevention, or cancer control. Based on these findings, we concluded not only were there

few examples of IS in pediatric oncology, but also that the field appears underdeveloped. It is noteworthy that within supportive care, over half of the studies included pertained to psychosocial supportive care, and psychosocial researchers are playing a leading role in IS for pediatric oncology.

This study did not examine the reasons for the supportive care focus. We hypothesized it may be due to the presence of cooperative study groups such as the Children's Oncology Group (COG). As a field, we are so lucky to have a strong cooperative group infrastructure that efficiently drives cancer-directed therapy changes through clinical trials. For example, the vast majority of children with cancer in the United States are treated at a COG center and by updating their chemotherapy protocols, COG functionally implements the best practice chemotherapy for a significant number of patients.

Future IS within pediatric oncology should embrace this ecosystem and focus on cancer control interventions that benefit patients across multiple cancer types and patients treated outside cooperative group studies.

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!](#)



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