

IPOS Palliative Care Special Interest Group – March 31, 2023 Update

IPOS Palliative Care SIG Structure

Palliative Care SIG Chair: Gary Rodin

Education Sub-Committee Co-chairs: Dwain Fehon and Devi Nandakumar

Research Sub-Committee Co-chairs: Ashlee Loughan and Cristiane Decat Bererot

Pediatric Sub-Committee Co-chair: Lori Wiener

Breakdown of 2022 Activities, Goals, Objectives and Results

The Palliative Care SIG consisted of 3 sub-committees, which identified activities, goals, objectives, and provided an update on the results at the Palliative Care SIG meeting:

- **Education**
- **Research**
- **Pediatric**

Education Sub Committee

2022 Activities: In 2022, the IPOS Palliative Care SIG Education Subcommittee held regular meetings (1-2 times per month) that were well attended by a core group of 5-7 participants. In 2022, the subcommittee hosted one webinar and published one manuscript.

2022 Results:

One Publication:

- Willis KD, Rao SR, Normen M, de Groot J, Calman L, Bahcivan O, Centeno I, Fehon, DC. Same Storm, Different Boat: The Global Impact of COVID-19 on Palliative Care. *Psycho-Oncology*. 2022
<https://doi.org/10.1002/pon.5995>
- This invited commentary focused on the global impact of COVID-19 on the field of palliative care. The commentary summarized the main themes and lessons learned from a webinar this subcommittee hosted in October 2021.

One webinar:

- “Trauma-informed palliative care in times of humanitarian crisis: Lessons from Ukraine and Rwanda.” Held October 4, 2022. Co-Chairs: Dwain Fehon, PsyD and Janet DeGroot, MD. The webinar included four expert speakers in palliative care who addressed the need for a trauma-informed approach to palliative care practices during humanitarian crises.
- Sixty-six people registered for this webinar (37 attended). Attendees were from 20 different countries, and post-webinar ratings of the webinar were high (88% Excellent, 12% Good).

2023 Goals:

(1) Our subcommittee is currently drafting an invited commentary for Palliative Medicine. The commentary will call attention to the needs of a trauma-informed approach to palliative care and will summarize the main themes from our Trauma-Informed PC webinar.

(2) Future webinar ideas are currently being explored. Our goal is to host at least two webinars in 2023. Potential topic ideas include: a deeper dive into Trauma-Informed Palliative Care; multicultural perspectives on pain; a master class on psycho-social oncology in palliative care; pediatrics; caregivers.

Research Sub Committee

2022 Activities: Conducted a literature review of cross-cultural psycho-oncology/palliative care needs. Developed a framework for conducting research on patient dignity in the context of palliative care.

2022 Activities and Results:

- (1) Defined the main goal and study design of our research project
- (2) Obtained Dr. Chochinov's agreement to use his inventory (Patient Dignity Inventory) to perform a study
- (3) Presented this study in the Palliative Care meeting
- (4) Started writing the protocol

Pediatric Palliative Care Sub Committee

Purpose: Stimulate international communication with a diversity of clinical, research and cultural backgrounds in order to foster collaboration in clinical resources, research and education that relate to pediatric palliative care.

2022 Activities: Quarterly meetings were held, via Zoom with approximately 5-7 members present during each all. Clinical, research and programmatic topics relevant to pediatric palliative care were discussed and a topic for a collaborative research project was decided on and carried out

2022 Results:

- (1) The committed participated in the Adapted Resource and Implementation Application (ARIA) project to determine if guidelines are appropriate for resource constrained settings, with Dr. Michael McNeil at St. Jude Global
- (2) A presentation on ethical considerations in pediatric palliative care was provided by Dr. Amanda Thompson
- (3) A study examining cultural considerations in legacy planning was designed by the committee and completed. The study had 25 participants from 17 countries on 6 continents and was presented at SIOP in October, 2022 (Barcelona).

2023 Goals

- (1) Explore opportunities in competencies and training, models of care, new therapeutic tools/resources, mentoring, sharing difficult cases
- (2) Collaborate with the larger palliative care committee in planning a collaborative webinar
- (3) To publish the results of the legacy study and consider a larger study that is informed by our preliminary findings.

Challenges

Sub-committees have found limited time for groups to come together. Attendance is often limited, but enthusiasm remains high.

Goals for 2023

- (1) Develop hybrid meetings with the larger SIG, to include presentations from sub-committee leads to obtain greater engagement in sub-committee initiatives.
- (2) Pursue cross cultural understandings of the construct of dignity.

SIG Attendees

Julie Brose

Mayumi Ishida

Feng Liu

Pik Shan Chow

Dwain Fehon

Devi Nandakumar

Nele Van den Cruyce

Ekaterine Sanikidze

Mohd Yunus Khilji

Marie Solange Bernatchez

Jose Custers

Yurii Mirov

Csaba Laszlo Csaba

Victor Lasebikan

Rachel Kentor

Chung Thanh Le

Natasha Campling

foluke sarimiye

Azhani Amiruddin

saranya Sundarraju

Rifka Hanfling

Somaya Abouabdou

Revathy Sudhakar

Kristen McCarter

Qiaohong Guo

Bincy Mathew

Seema Rao

Shapir Rosenberg

Toni Lindsay

Elizabeth Akin-Odanye

Yael Ben Gal

Saranya Sundarraju

Franco Sebastian Garcia Cervera

Emily Drake

Oscar Galindo Vazquez

Lynn Calman

Kaleena Chilcote

Mary Scott

Keshav Sharma

Giedre Bulotiene

Arati Hota

Samanta Savickaitė

Ursula Sansom-Daly

Gilla Shapiro

Christian Ntizimira

Jayita Deodhar

Pnina Dorfman Etrog

Cristiane Decat Bergerot

Rodbin Campos Lobo

Ritu Rani

Lei Xu

Ging-Long Wang

Khushnuma Gandhi

Svetlana Malysheva

Suchitra Mehta

MARIA MADELINE MALLILLIN

Isabel Centeno

Nienke Zomerdijk

JACQUELINE ANDRADE AMARAL

Ray Nascimento

Kirsty Ross

Shulamith Kreitler

Diana Correia

Sravanthi Maya

Maggie Watson

Subathra Jeyaram

Christian Schulz-Quach

Shweta Chawak

Ozan Bahcivan

Giuseppe Deledda

Jairam Kamala Ramakrishnan

Shlomit Perry

Laura Siminoff

Salisu Ango Abdul-Rahim

Lori Wiener

Seema Rao

Aida Popescu

Ashlee Loughan

Naziye Ak

Claudia Tafur

Kelly McGuigan

Patricia Murphy-Kane

Andrea Benites