

# BOOK OF ABSTRACTS

## PALLIATIVE CARE CONFERENCE 2023



A COLLABORATION BY



CAPE TOWN | SOUTH AFRICA | 26-29 APRIL 2023

PALLIATIVE CARE IS EVERYONE'S BUSINESS

## A Palliative Counselling and Communication Service in the ICU Setting During the Covid-19 Pandemic.

SUB-THEME: RELEVANCE | ORAL PRESENTATION

Denise Huxham (Private practice)

Yolande Riekert (Private practice)

The Covid-19 pandemic necessitated an increase in the practise of palliative care to support impeccable symptom control, provide appropriate end-of-life care in any setting and facilitate holistic supportive care for patients and their families. Due to the restrictions put in place for infection control, the flow of information between patients and their families was affected, compromising their psycho social and spiritual health and putting further pressure on healthcare workers.

CareConnect was a counselling service which was established at Life Vincent Pallotti Hospital during the Covid-19 pandemic and used primarily in the ICU setting. It operated throughout the various Covid-19 waves of 2020-2022 and provided families with multifaceted support during a period of high stress. Medical personnel were better able to focus on clinical work, knowing that the socio-emotional aspects of patient care were being attended to.

CareConnect consisted of a multi-disciplinary team of healthcare workers with PC and counselling experience. The team included nurses, doctors, social workers, counsellors, an OT and a speech therapist. Hospital physicians provided daily medical updates which were recorded on an online webpage by coordinators and then accessed remotely by the counsellors and conveyed to the families. Counselling was also provided and, where indicated, video/voice calls, as well as family visits, were facilitated by a counsellor within the hospital.

This team transformed the way medicine was practiced within the hospital. Testimonials from grateful families were overwhelmingly positive. Both counsellors and physicians saw clear benefits in this service which resulted in reduced family trauma, improved patient/ family satisfaction and a reduced burden on hospital staff. It put a more caring, compassionate face to high quality hospital-based patient care. This service is highly applicable to the ICU and EC settings outside the context of Covid-19. We are currently working on ways to implement it in an acute care setting.

# A Reflection on the Hidden Curriculum in a Multi-disciplinary Paediatric Palliative Care Course.

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

Rika Swanzen (Independent Institute of Education (IIEMSA))

Nicolette Brown (Private practice)

Angidi Mauree (Private practice)

Kirsten Jane Sylvester (Private practice)

Mehnaaz Patel (Private practice)

Thaanayah Gydien (Private practice)

The University of Cape Town's Postgraduate Diploma in Paediatric Palliative Care class of 2022 had students coming from more diverse specialties than before, since its introduction as a fully separate stream in 2017. The one-year contact course requires a significant number of application-based assessments and is offered in a way that heightens the peer-to-peer multi-disciplinary learning.

The programme outcomes are aligned with the competency areas recommended by the European Association of Palliative Care. The hidden curriculum is defined "as the unofficial (and informal) channels of genuine and useful learning that can be acquired within or outwith both the physical and metaphorical walls of academia"<sup>[1]</sup>.

Students from various disciplines and cultures will reflect on their lessons learned, from the intended and unintended curriculum. To frame the reflection on the learning generated from the hidden curriculum, the framework of the four stages of competence were used. Palliative care (PC) is not a common topic taught in medical school nor in the social service profession degrees; even less so when it is paediatric related. One is under the misinterpretation that PC kicks in when someone is about to die (unconscious incompetence). Due to the broad range of professions within the class and their diverse perspectives, the scope of learning from both personal and professional experiences was increased. Areas such as communication and teamwork between professions, navigating loss, spiritual assessment, and recognising the vital role of each discipline in the PC team, emerged as new consciously competent areas.

It is believed that the experiential lessons reflected on, both clinical and psychosocial, can assist with not only strengthening the multi-disciplinary needs of students, but also to align the hidden and formal curricula.

[1] Dely L. Elliot, Soren S. E. Bengtsen, Kay Guccione and Sofie Kobayashi, 2020. The Hidden Curriculum in Doctoral Education. Palgrave MacMillan.

## A Rural Palliative Care Programme in the Western Cape province of South Africa - a Four-year Review.

### SUB-THEME: SUSTAINABILITY | ORAL PRESENTATION

Agnes Hamilton-Baillie (Improving Global Health, Thames Valley and Wessex Leadership Academy, United Kingdom)

Louis Jenkins (George Hospital, Western Cape)

Margie Munnings (George Hospital, Western Cape)

Ernestine Bruinders (George Hospital, Western Cape)

Annemarie Bekker (George Hospital, Western Cape)

Karin Steenkamp (George Hospital, Western Cape)

Annelie van Niekerk (Bethesda Medical and Relief Services NPC)

Zilla North (George Subdistrict, Western Cape Dept. Of Health)

#### Background and description

There is increased recognition in South Africa and globally about the importance of integrating palliative care into public health service delivery. George subdistrict in the Garden Route District launched a pilot rural palliative care model in 2018. The model is now well established, with multi-disciplinary palliative care being offered from community home-based services, non governmental organisations, primary health care clinics, and from the regional and local tuberculosis hospitals.

#### Outcomes and lessons learned

The model is implemented by a core palliative care team with community, clinic and hospital representation, including a sessional palliative care doctor. To date, 109 health professionals have received palliative care training and 119 multidisciplinary palliative care hospital ward rounds have taken place. Weekly rounds also occur at Bethesda intermediary care facility. Patients are referred to the palliative team via a centralised system. To date, 735 palliative care referrals have been made, with patients accessed by community teams in their homes. ICD-10 coding of palliative diagnoses in the Emergency Centre takes place. Ongoing data collection details patient demographics, diagnoses and care provided.

#### Conclusions and next steps

There is district wide recognition of the shared importance of integrated palliative care. Contribution and buy-in from dedicated multidisciplinary stakeholders, simple and centralised referrals, and training about palliative care principles contribute to the success of the programme. Challenges have included the limited capacity of community teams to provide palliative care alongside their other responsibilities. Capturing accurate data about the extent of community palliative care is ongoing.

Work is ongoing to quantify the numbers and outcomes of home visits. A dedicated palliative care nurse will be appointed soon. Discussions are ongoing regarding a telephone support line for patients and families.

# A Study to Identify the Burden of Chronic Disease on a Private Emergency Medical Service in the Southern Sub District of Cape Town, and if there is a Need for Palliative Care Provision in the Pre-Hospital Healthcare Sector.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Linley Holmes (University of Cape Town)

### Introduction

Paramedics often provide initial contact and care to patients with exacerbation of their chronic, non communicable disease. Many of these patients may benefit from early access to a palliative care program. Currently, paramedics are not trained nor provided access to palliative care consultation, resulting in many patients being transported to hospital unnecessarily.

### Aim

This study aims to assess how many patients with non-communicable disease symptoms were transported to a medical facility by EMS versus remaining at home, what clinical management they received, and whether there is a need for education, inter-disciplinary consultation, and provision of palliative care, by EMS in the pre-hospital environment.

### Methods

This was a retrospective descriptive analysis of de-identified patient PRFs of adult patients, attended to by a private Emergency Medical Service (EMS) between January 1st, 2019, up until 30th April 2019.

### Results

Of the 283 patients included in the study, many had more than one NCO, often experiencing more than one of the primary symptoms of pain, SOB, cognitive changes, and N&V simultaneously. The majority of these patients were likely to go to hospital with ambulance transport and frequently there was no appropriate clinical intervention by paramedics. Clinical advice was seldom sought by paramedics for patients with NCDs (cancer, chronic heart disease, chronic lung disease, dementia, and chronic kidney disease) experiencing symptoms of pain, SOB, cognitive changes and N&V, and it was evident that palliative care access, and availability, for patients was minimal.

### Conclusion

Palliative care is a necessary approach to patient-centred care, with specifically trained EMS and paramedics being an available resource to assist with this approach. EMS can facilitate access to available palliative/ home care networks for patients that have a need for palliative care support in the out of hospital context, limiting the inappropriate transport of patients to already over-burdened Emergency Departments.

# A Study to Understand the Experiences of Adolescents and Young Adults Living with Cancer in a Northern Cape Public Health Setting.

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

Leana Spies (Private practice)  
Prof Liz Gwyther (UCT)  
Dalene van Jaarsveld (UFS)

### Introduction

The challenges and holistic care needs of adolescents and young adults (AYAs) with cancer in low and middle-income countries are under-researched. This limits evidence-based information regarding their experiences.

### Aim

To explore the challenges experienced by AYAs with cancer in a Northern Cape public health setting.

### Objectives

To describe the key concerns and priorities experienced by AYAs with cancer in the Northern Cape, to determine their holistic care needs and identify the current limitations of healthcare resources that influence the provision of appropriate palliative care for this group.

### Methodology

In this qualitative study, purposive sampling was utilized to select AYAs with cancer and between the ages of 18 and 39 years who received curative or non-curative cancer treatment at either Robert Mangaliso Sobukwe Hospital or Harry Surtie Hospital oncology centres. Individual, open-ended semi-structured interviews were conducted. Data were analyzed using thematic analysis.

### Results

A total of twelve participants between the ages of 22 and 39 were identified. Six key themes emerged that provided insight into the challenges experienced by AYAs with cancer. These challenges were interrelated on a physical, psychosocial, spiritual and healthcare level. Apart from similar challenges experienced by AYAs with cancer in developed countries, such as overwhelming emotional responses, threatened dreams and hopes, a need for emotional counselling and better support systems, participants from this study also reported the impact of socio-cultural influences such as stigmatization, cultural beliefs, socio-demographics, poverty, unemployment, and a lack of cancer awareness and education within communities.

### Conclusion

AYAs with cancer experience complex, multidimensional, interrelated challenges that include many health system issues. In a middle-income country, these challenges are amplified by additional factors such as communicable diseases, sociocultural influences, and poverty. Consequently, their holistic care needs are largely unmet. Further research is necessary in order to acknowledge and address their total pain.

# An Observational Study of Understanding of Spirituality and Spiritual Care in Palliative Care in Five Countries.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Joan Marston (Elisabeth Kubler-Ross Foundation)

### Background

Objective of the study- to understand the impact of nationality, culture and religion on perceived ability to provide spiritual care in palliative care (PC). Review of 9 teaching presentations, 6 workshops to a total of 370 palliative care team (PCT) members on spirituality and spiritual care (SSC) for PCT in South Africa, India/Bangladesh/Nepal and Singapore between January-November 2022. Reviewed SSC teaching of the past 5 years and completed the ISPEC Interdisciplinary Spiritual Care Education Curriculum presented by George Washington Institute for Spirituality in Health Care (GWiSH). Participants were from a variety of cultural, language and religious groups; predominantly Christian, Hindu and Buddhist. Eight on children's spirituality, and seven across all ages.

### Description

Reviewing recordings and post presentation reports from previous years similar problems to understanding SSC appeared. In 2022 after each teaching session reported challenges to understanding and practicing spiritual screening, history-taking, planning and assessment identified by participants were documented. Definition used is the international consensus definition (C. Puchalski et al).

### Lessons learned

Despite differences in countries, culture, language, and beliefs as well as focus on different age groups the challenges were similar. Common themes were poor understanding of the meaning of spirituality and presence; lack of differentiation between spirituality and religion; inability to use and adapt screening questions and tools for spiritual history-taking; concern when patients were non-verbal, very young, had dementia or severe disabilities. Discomfort with different cultures, religious beliefs, own spirituality; and lack of spiritual self-care and development. Spirituality difficult to assess, feels ephemeral. Many rituals were similar.

### Conclusions

Spirituality's focus on meaning, purpose, connection, mystery, and transcendence. Recommend use of the international consensus definition and validated tool such as FICA; training of all PC and PPC practitioners; trained specialist pastoral counselors.

## Assessing the Success of a Uniquely South African Online Learning Platform for Paediatric Palliative Care.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Suzanne Boucher (PatchSA)  
Tracy Rawlins (PatchSA)

It is a priority to increase knowledge of PPC through affordable & accessible education relevant for SA healthcare providers. In 2020 funding to provide in-person PPC training was redirected to develop an e-learning platform of courses on key aspects of PPC & launched in Feb 21. Effective learning requires interaction between the learner and the material. While online learning has the advantage of delivering information in a creative way to a large number of people, skill is needed to create e learning materials, with little evidence of impact of online learning on patient care.

PatchSA aimed to deliver a valuable, interactive, meaningful online educational experience and gather data on impact of learning on practice & patient care.

#### Methods

Two content experts studied e-learning instructional design to create relevant & interactive CPC courses. To assess value, interactivity levels & needs met, students completed a survey immediately after completing a course and another 1 - 10 months later where they rated the course value & impact on practice/patient care. Rating was on a scale of 1 - 5, with 5 = excellent/most and 1 = poor/least.

#### Results

12 CPD accredited online courses; 1200+ registrations with >50% completed; course included in curricula of 2 SA universities and sold to hospitals and NGOs.

Survey results show 95% rated courses as Very Good (VG) or Excellent, 91% rated interactivity with learning material as VG/excellent and 86% rated improvement to practice/patient care as VG/Excellent. There were no responses that rated a 1 (Poor/least) Written examples of improvement to practice were provided by respondents.

Conclusions Using content experts to learn instructional design and create CPC e-learning courses improves the product, increases interactivity with learning material and completing good online courses can lead to significant improvement in practice and patient care.



# Caring for Children with Life Limiting Conditions in the Community through improving their access to Palliative Care.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

**Yvette Andrews** (Metro Health Services)

**Audrey Gourrah** (St Joseph's Home)

**Manda Kanka** (Paeds Pal)

Palliative care cannot just be provided by specialist services but should be integrated into primary health care to ensure equitable access for children.

It was this idea that brought the authors together to look at how they could combine their skills to further paediatric palliative care and enhance the service provided to their clients and family. The authors represent different sections of the health system namely Tertiary hospital support through Paeds Pal, Intermediate Care support through St Josephs and community support via the contracted NPO (Non-Profit Organisation) TBHIV Care. This partnership also showcases the relationship government has with NPO partners to provide health services and in this case paediatric palliative care

The objective of this partnership is to provide children and their families in need of palliative care a seamless service from RXH/Paeds Pal to St Josephs to their Community with Community Based Care Support and back again as required.

### **Allowing for**

Ongoing care for the child and their family at all the levels of the health care system with Health Care Workers being able to communicate with each other across the system.

Comprehensive advance care planning with an MDT team.

Opportunities for learning /mentorship / support for all the staff involved in the program

Opportunity to showcase how practically the service can be implemented.

## Changing the Ending.

### SUB-THEME: SUSTAINABILITY | ORAL PRESENTATION

Dawn Garish (Life Righting Collective)

Two submissions for the Palliative Care Conference 2023 from the life righting collective - a talk

**Changing the Ending** - Writing as a tool for agency and witnessing.

'You can't go back to the beginning and change what happened, but you can start from where you are and change the ending.' CS Lewis

Our lives are riven through with both beauty and pain. Few of us are unmarked by suffering. We need resources to help us meet and process our challenges, and thereby come to terms with what has happened. Patients, carers and health care workers in the field of terminal care require support, courage and insight. Writing as a regular creative practice can assist us to expand our capacities, to debrief, to reimagine our lives, and to act as advocacy in this important yet concealed sphere.

Dawn Garisch is a GP, an award-winning author and poet, and a founder member of the Life Righting Collective [www.liferighting.com](http://www.liferighting.com).

### Workshop

#### Changing the Ending

Writing as a tool for agency and witnessing

'You can't go back to the beginning and change what happened, but you can start from where you are and change the ending.' CS Lewis

Those who prefer an embodied experience of how writing can transform our relationship with ourselves and others, are welcome to come on a writing workshop facilitated by Dawn Garisch.

# Community Participation in Establishing an Integrated Palliative Care Program.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Jennie Morgan (WCDOHW)  
 Rene Krause (UCT)  
 Katya Evans (WCDOHW)  
 Maggie De Swardt (UCT)  
 Porcia Williams (WCDOHW)

In 2021 the Western Cape Department of Health and Wellness (WCDOHW), in collaboration with the University of Cape Town (UCT), identified a geographic area where a model of integrated palliative care could be established with the dual aim of improving care for community members and training health care workers in palliative care.

The aim of this presentation is to describe how Palliative care has been integrated in the Heideveld/Manenberg area by developing strategic partnerships, community involvement, education, and research. The objectives were to develop strategic partnerships, to ensure community involvement and to use education and research as methods of integration.

Strategic partnerships between the National department of Health, the WCDOHW, CANSA, UCT and the Heideveld/Manenberg community were initiated by means of a workshop to establish and strengthen existing partnerships. A successful application was made to Discovery Health to finance this project.

Community Partnership was established by involving key community members from the beginning and meeting regularly with them.

### Education and research

Community Health Workers were trained in the introductory course in Palliative Care and a Professional Nurse was identified to be trained in the certificate course. Medical students are being taught Palliative Care at the Clinic and in the Emergency Centre. Research was conducted to identify the gaps in knowledge of when to initiate a Palliative Care approach.

### Results

Community participation has identified gaps in the service that were able to be addressed. Research showed the gaps in the education of existing staff, with the result that further goal-directed training can take place.

### Lessons learned

The community is an integral part of integration of any new health service

### Conclusion

Palliative Care has become an integral part of the care in Heideveld/Manenberg and this project will continue to strengthen this service.

# Correlation of Survival with Two Palliative Needs Assessment Tools in Cancer Patients in a South African Surgical Emergency Center.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Henriette Burger (Stellenbosch University and Tygerberg Hospital)

Dennis Dogbey (University of Cape Town)

### Background

Advanced cancer is associated with a significant symptom burden, and timely identification of palliative care (PC) needs, and provision of appropriate PC can improve treatment outcomes, reduce healthcare costs, and enhance patient and family satisfaction with care. Several tools have been used to identify PC needs in different clinical settings and patient groups.

### Design

This cross-sectional observational study included all patients with known malignancy admitted through the surgical emergency center (SEC) of a large academic hospital in South Africa (SA) for acute surgical emergencies. The validated Supportive and Palliative Care Indicators Tool (SPICT™) was applied to patients' files on admission to the SEC to determine the prevalence and associated characteristics of PC needs. In addition, attending physicians were asked to estimate the 1-year survival probability of these patients by answering The Surprise Question (SQ). The association between PC needs and overall survival was explored as a secondary outcome.

### Results

112 Admissions were included with a median age of 58 years. Just under half (46.4%) of the admissions were for metastatic patients and 60.7% were known with palliative treatment intent. The prevalence of SPICT™- and SQ-defined PC needs was 46.4% and 54.7% respectively. Median OS for patients indicated to be SPICT-positive was 1 month, and for SPICT-negative 7.5 months. Further statistical analysis will be performed to determine the correlation of SPICT and SQ positivity with survival at one year.

### Conclusions

SPICT and SQ positivity was significantly associated with 1-year mortality in this cohort. However, clinicians appear to have underestimated the risk of 1-year mortality, which represents an obstacle to the early integration of palliative care.

## Expansion of Palliative Care (PC) Training to Online Platform during COVID-19 Pandemic.

### SUB-THEME: SUSTAINABILITY | ORAL PRESENTATION

Ewa Skowronska (HPCA), Leonore Haley (HPCA)

#### Background

HPCA has been the main developer and provider of short courses in PC for the last three decades in South Africa, provided face-to-face, impacting the number of HCWs trained.

#### Context

COVID-19 pandemic motivated HPCA to expand the way we offer our courses. Additionally, online delivery is particularly relevant in rural areas, where trainers are not available or have to travel long distances.

#### Aims

- Increase number of Health Care Professionals trained in Palliative Care.  
Courses included: Introduction to PC for Professionals, Certificate Course in Palliative Nursing, and HPCA Palliative Care Psychosocial Course.
- Increase portfolio of courses offered online: next will be HPCA Bereavement and Support Course.
- Assisted government with the implementation of the National Policy Framework and Strategy for Palliative Care in SA.

#### Methodology

The use of a Learning Management System was where the content of 8 modules was available. The delivery was adapted to a blended method of asynchronous and synchronised weekly Zoom discussions, participant Forums and group discussions. Expert PC Facilitators were engaged in the relevant modules. As this was an accredited and CPD bearing course, assessment criteria included a pre and post-test, group communications role play and case study presentations.

#### Programme Interventions

Transformation of face-to-face courses into online courses and increase the number of trained HCWs in PC.

#### Results/lessons

Using online platform HPCA trained 957 HCW during the period July 2020 - February 2023 capacitating them to increase referral pathways and provide PC appropriately. Online platform proved to be reliable, flexible, user friendly, and professional.

#### Conclusion

In today's fast paced and unpredictable environment, provision of online PC Courses is an often preferred, and an adjunct to conventional delivery. The experiences suggest that mixing technology in training can lead to substantial progress for access PC training.

# Exploring the Importance, Meaning and Experience of Hope for Adult Patients with Advanced Cancer and their Family Caregivers in KwaZulu-Natal.

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

Colleen Cox (IALCH)

Klaus von Pressentin (Dept Fam Med, UCT)

Martin Chasen (Dept Community and Fam Med, University of Toronto)

### Background

The importance of hope for patients with life-threatening illness, in enhancing QoL and facilitating coping, has been widely reported in international literature. Patients and their family members reportedly look to healthcare professionals to give them hope. There is however not a clear understanding of what hope means in South African healthcare, particularly around issues such as “hope for a cure” and “false hope”. Also, the benefits of internationally-validated interventions in South Africa are unknown.

### Aim

To describe the importance, meaning and experience of hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal (KZN)

### Method

A qualitative descriptive cross-sectional design was followed, involving semi-structured interviews with patients with advanced cancer and their family caregivers around the importance, meaning and experience of hope. Data was analysed thematically and related to the clinical and demographic contexts of the participants.

### Results

Eleven patients and 11 family caregivers were included. All participants affirmed that hope was important to them, particularly when facing cancer or in caregiving. Thematic analysis of both the meaning and experience of hope revealed strong correlation with spirituality, human connection/support and physical/psychological comfort. Hope was also associated with psychological fortitude, having a goal and purpose, and living well while being ready to die. The tension of oscillating between hoping for a cure and accepting poor prognosis was demonstrated. Overcoming previous adversity as a source of hope for most participants was an unexpected finding. Almost all participants expressed a preference for truthful communication regarding their diagnosis/prognosis and described how hope assisted in coping with bad news and reaching acceptance. Participants described how doctors and nurses can give hope.

### Conclusion

The importance of hope in assisting oncology patients and their family caregivers to cope and live well in the face of life-threatening illness was confirmed. Hope-fostering interventions were suggested.

# Factors Influencing Paediatric Oncologists' Decision making When Balancing Curative and Non-curative Treatment Options at Diagnosis in Low- and Middle Income Countries (LMICs)

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

Amy Porter (Boston Children's Hospital/Dana-Farber Cancer Institute)

Marta Salek (St. Jude Children's Research Hospital)

Nickhill Bhakta (St. Jude Children's Research Hospital)

Erica Kaye (St. Jude Children's Research Hospital), CATALYST Study Group (Multiple institutions)

### Background & Aims

The global burden of childhood cancer lies predominantly in LMICs (low- and middle-income countries), where outcomes are inextricably linked to local and regional economic and social contexts, including available healthcare infrastructure and psychosocial support. Many children present with advanced or incurable disease, and access to palliative care is scarce. In this study, we sought to identify factors considered by LMIC physicians when deciding how to balance curative and non-curative treatment options for children presenting with advanced or incurable cancer at the time of diagnosis.

### Methods

Using a community-engaged research approach, we invited a global panel of paediatric oncologists to participate in four sequential focus groups. In two initial focus groups, participants were asked to identify factors related to the disease, decision-maker, and contextual factors impacting care. Content analysis informed the development of a visual model and semi-structured interview guide to further probe these topics with LMIC physicians, which the working group reviewed together in the subsequent two focus groups.

### Results

Eleven paediatric oncologists representing all WHO regions participated. Participants identified numerous factors influencing decision-making unique to LMICs, including the ability to access diagnostic tools and treatment interventions, lack of established referral pathways, and financial compromises to treat a child at expense of family health, and confirmed these major categories. Participants recognized that intensive treatment often resulted in toxicities and poor outcomes, yet they defaulted to offering curative therapy due to perceived lack of palliative alternatives and lack of direction from available guidelines. Member-checking with the working group yielded consensus on semi-structured interview prompts for future work.

### Conclusions

Oncologists in LMICs face unique challenges that influence treatment decision-making. Future interview findings will inform development of clinical practice guidelines and educational interventions that leverage core palliative care concepts to better support LMIC oncologists balancing curative and non-curative treatment approaches.

# Gastrointestinal Ostomies in Paediatric Palliative Care Surgical Perspectives.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Marion Arnold (University of Cape Town Division of Paediatric Surgery/ Red Cross War Memorial Children's Hospital)  
Yentl Gamiet (University of Cape Town Division of Paediatric Surgery/ Red Cross War Memorial Children's Hospital)

### Background

Surgically or endoscopically placed stomas for feeding or gastrointestinal drainage are frequently employed in children with life-limiting and life-threatening conditions. Complications and socio economic implications of these procedures are under-appreciated and there is limited support in the South African healthcare system for managing ostomies.

### Methods

A literature review and local experience of complications and other sequelae is presented of gastrostomies, feeding jejunostomies, drainage jejunostomies, ileostomies, appendicostomies, "button" tube colostomies and colostomies within a palliative care context.

### Results

Prevalence of gastrostomy placement in children with cerebral palsy ranges widely, with gastrostomy devices placement in over a fifth of children in some countries; South African prevalence is unclear but use is widespread. Major and minor complications are extremely common and may bring significant healthcare burden, despite improving ease of feeding and nutritional status for many.

Similarly, ileostomies and colostomies carry a significant healthcare burden, and have major socioeconomic impact on families, both due to prolonged associated hospitalization and stigma impacting home-based care. Antegrade colonic enema devices such as appendicostomies and tube colostomies are possibly under-utilized from a medical care perspective, but this may be due to social attitudes towards medical devices in our context as well as limited medical support for their care.

### Conclusion

Healthcare workers outside surgical contexts require more training and exposure to gastrointestinal ostomy care, both to provide support for patients with them, as well as to refer patients appropriately for their placement and subsequent complications. Families and patients with ostomies should be more extensively counselled and supported regarding decision-making about indication for ostomies as well as post-operative care.



## In conversation with Death: Riding on the Death Train.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Pierre Matthee (Private practice)

In the palliative care space, patients and their families are confronted with death on a regular basis. This can be very frightening and as a therapist, one often needs to think out the box to make it more comfortable to talk about. In conversation with death: riding on the death train, relies heavily on real life experiences and patients interactions with the death concept. Incorporating, analogies and metaphors during the therapeutic process allows patients and or their families to make use of “pictures” they can relate to, thus removing some of the uncertainty from the conversation. The conversation focuses the listeners attention on the concept of Narrative therapy, which is a therapeutic technique where the person receiving “therapy” is the expert and it is a collaborative approach between client and therapist. The listeners will learn that the person is not the problem, but the problem is the problem.

Concepts such as externalisation, re-membling and reauthoring will be introduced. The conversation encourages health care practitioners to assist the client to make use of existing skills and strengths when working with the problem.

## Measuring Quality of Care: Data Analysis in Palliative Care.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Wayne Oxford-Huggett (Msunduzi Hospice)

Marcelle Joubert (HPCA)

Using the World Health Organisation's palliative care framework, we discuss and demonstrate how the World Health Organisation framework aligns with the palliative care indicators used by the Hospice Palliative Care Association of South Africa. We cover what data is and its life cycle. We examine some of the tools available for exploring data. We discuss what the advantages and disadvantages of flat files versus a database application are. How data analysis can be used to help understand your data, how it is used to measure quality of care, manage patient care and make data driven decisions.

# Occupational Engagement in the Face of Death. An Occupational Therapy Perspective in Palliative Care.

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

Madelein Kritzinger (Madelein Kritzinger Occupational Therapy)

Occupational Therapists (OT) are skilled rehabilitation professionals that provide client-centred interventions aimed at improving quality of life through enabling participation in meaningful activities, promoting functional independence and managing symptoms while adjusting to deterioration and death. An OT theory of doing-being-becoming-belonging relates to a person's physical, emotional, psychosocial and spiritual well-being and is a natural fit with the philosophy of palliative care (PC).

There is currently a significant lack of OT involvement in the treatment of PC patients in the private care setting. Patients are mainly managed by treating physicians or oncologists together with in patient nursing staff. OT intervention in the PC setting is aimed at improving or maintaining independence in activities of daily living (ADL), engagement in meaningful activities including final wish activities, living as actively as possible for as long as possible, and managing distressing symptoms with non-pharmacological treatment methods. Furthermore, end-of-life planning and realistic goal setting is done in order to give the patients and their families a sense of control and reduced anxiety.

A recent research study discussed the establishment of an Occupational Therapy Palliative Care programme in a private hospital setting where patients with life-threatening illnesses were included in an individualised PC rehabilitation program. Patients enrolled in the program had diagnoses of cancer, chronic obstructive pulmonary disorder (COPD), and cardiac failure and received intervention from an OT. The program is generating positive results and allowing for PC patients to receive holistic care according to their own goals and needs, and incorporating their doing-being-becoming belonging to prepare for a positive end-of-life experience. Patients and their families report less anxiety around death, better control of distressing symptoms, and less suffering throughout the journey of their life-threatening illness. Further research in, and inclusion of, OT in PC could contribute significantly to patient welfare and should be prioritised.

# Organ Donation after Circulatory Death - Are we offering Donation in all Appropriate Circumstances - Positive kidney Transplant Outcomes in a South African DCD Experience.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Tinus Du Toit (UCT)  
David Thomson (UCT)  
Kathryn Manning (UCT)  
Elmi Muller (Stellenbosch University)

### Introduction

At Groote Schuur Hospital, the number of deceased donors have declined over the last two decades. In 2007, measures to expand the deceased kidney donor pool were implemented: an HIV positive to positive program, utilisation of Extended Criteria Donors (ECD) and a Donation after Circulatory Death (DCD) program.

South Africa (SA) has one of the lowest deceased organ donor rates in the world (1.4 donors per million population), with thousands of patients awaiting solid-organ transplantation. The aim of this study was to report on our institutional experience with DCD kidney transplants outcomes and prove good outcomes from this donor source.

### Materials and methods

This was a retrospective descriptive study of consecutive deceased donor referrals at Groote Schuur Hospital, Cape Town, SA (from January 2007 to December 2016), utilising a regional donor referral registry and consecutive DCD renal transplants at Groote Schuur Hospital over a 10 year period (1 January 2007 to 31 December 2016).

Results:

Over the 10-year study period, 861 possible organ donors were referred, with a steady increase in the number of referrals over time. Of the referrals, 514 (59.7%) were eligible for donation of at least one solid organ. Of the 508 families that were approached for consent to donation, 342 declined consent for a variety of reasons, resulting in a consent rate of 32.7%. 13 DCD procurements were performed, with no kidneys discarded. 26 Renal transplants were performed with a mean cold ischaemic time of 11 hours (IQR 8-14). 30-Day morbidity (other than DGF) was 19.2% (Figure 2). Graft survival at 1, 2 and 5 years were 100%, 95.8% (95% CI 73.9% - 99.4%) and 83.6% (95% CI 56.1%-94.8%) respectively (Figure 3).

### Conclusion

Results from this study reaffirm the potential of DCD to expand deceased donation throughout Africa, in a religiously and culturally sensitive way.

## Palliative Care After Surviving Life Threatening Stroke.

### SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Clint Cupido (Abundant Life Palliative Care Victoria Hospital Wynberg)

Palliative Care after a Stroke is very challenging, primarily because strokes are sudden onset, in a patient who may have been previously well with risk factors or may have been chronically unwell. The challenge lies within multiple layers of complexity of an acute catastrophic event, unexpected nature of the event, difficulty of decision making in a very short period of time. It is unlike a Cancer, or Chronic Organ Failure and seldom thought of as a Palliative Care Case. It is a classic medical case requiring Multi-disciplinary Team approach which has illustrated the need for Palliative Care Training for all members of the MDT Team.

This has been an excellent example of “infusing palliative care into Internal Medicine”

Post Stroke the number of possible trajectories are many, from improvement with no neurology, weakness with independence and ability to function, significant weakness and bedbound state, difficulty swallowing with artificial feeding required and depressed level of consciousness with rapid or slow progression to death. The time period of these trajectories are difficult to predict and some may have a fluctuating functional state.

The role for Palliative Care in Stroke Care is important in dealing with Difficult conversations about Goals of Care, Management of Symptoms, Family Support, Advance Care Planning and End of Life Care.

Palliative Care is not an Alternative to Stroke Care and Rehabilitative Care but needs to be provided together with all other care. Most important is the Team Based, Shared Decision-Making Process that includes all MDT Members and Family and Patient if possible. Extremely challenging process which we hope to share our experience at Victoria Hospital.

## Palliative Care for a Child with Hollow Visceral Myopathy: Challenges and Lessons.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Lyndal Gibbs (Paedspal)

Marion Arnold (Red Cross War Memorial Children's Hospital)

Anisa Bhattay (Red Cross War Memorial Children's Hospital)

Degenerative leiomyopathy, a form of hollow visceral myopathy, is a rare condition which causes chronic progressive intestinal pseudo-obstruction. Management strategies where there is no access to long-term home parenteral nutrition and intestinal transplant focus on symptom relief, as particularly ACTG2-related cases are otherwise fatal, typically during childhood.

This presentation, based on a case study of a 14-year-old girl managed by our team, focuses on the relief of the patient's physical pain during the last four months of her life. We explore surgical, pharmacological and non-pharmacological interventions employed to manage our patient's severe gastrointestinal pain, as well as strategies to relieve her total pain. We acknowledge the burden of care on the nursing team and family, the many challenges that needed to be overcome, and the value of team-work in providing patient-centred care for children with complex palliative care needs.

Having learned many valuable lessons while caring for our patient, we hope to enhance the future management of children with hollow visceral myopathy in South Africa.

## Palliative Care in Peripheral Vascular and Arterial Disease.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

SR Krause (UCT)

Magdaleen De Swardt (UCT)

Peripheral vascular and arterial disease have not traditionally been identified as conditions requiring palliative care. On the SPICT SA, vascular disease is recognized as requiring palliative care when we can label it as “severe inoperable disease”

However, evidence demonstrates that palliative care is underused within patients with PAD/PVD. The evidence also supports better outcomes when palliative care is integrated early. Barriers to early integration will be explored as possible interventions on how we can advocate for early integration. This talk will discuss identifying patients with PAD and PVD who require a palliative care approach, exploring their unique palliative care needs, management and how to identify co-morbid conditions that need to be managed. This lecture will explore what service delivery can be included across the continuum of care, how to support the family and what needs to be done at home for these patients and families. The comprehensive approach to care will be discussed as the possible gaps in the research within the area.

## Parents' Perceptions of their Children Participating in Paediatric Palliative Treatment and Care.

SUB-THEME: RELEVANCE | ORAL PRESENTATION

Penelope Mathe (Hospice Wits)

According to the South African Children's Act 38 of 2005, children have the right to participate in decision making regarding their lives. Parents' stance towards children's participation in decision making in the context of paediatric palliative care could, however, undermine this right. The right is borne from the notion that children with terminal illness deserve to be treated in accordance with human dignity.

The General Medical Council (2007:7-14) identified the elements that constitute child participation in the health care context as: assessing the best interest of the child; open communication, that is, not talking about the child but talking to the child; involving the child in discussions about his or her treatment and care; informing the child in a child-friendly manner what is going on; purpose of the treatments and what they involve; risks, benefits and other social implications.



## Practical Application of Psychotherapeutic Interventions that Empirically Improved Dignity in South African Palliative Care patients.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Raksha Balbadhur (Private/Verulam Hospice)

Liz Gwyther (UCT)

The concept of dignity underpins palliative care, yet healthcare practitioners (HCPs) struggle to practically improve the dignity experience of dying patients. Dignity Therapy (DT) and Guided Imagery (GI) have been shown internationally to benefit patients. This study explored the impact of DT and GI on the dignity of SA patients from diverse socio-economic and cultural backgrounds.

Method: DT is an appreciative enquiry into the lives of patients to allow them to discuss aspects of their life that matter most, and their words of advice to produce a legacy document. GI was implemented to affirm the experience of patients' intrinsic dignity and worth. A patient feedback questionnaire was used to explore the impact of these interventions. The qualitative feedback was analysed using content analysis.

Results: This study illustrated the beneficial impact of DT and GI on dignity with confirmations on measures of helpfulness (100%), satisfaction (100%), a heightened sense of dignity (75%), purpose (100%) and meaning in life (92%). 83% shared that it lessened their sense of suffering, feelings of anxiety and depression (92%) and improved their will to live (83%). The benefit spread beyond themselves to help their families (92%) and their relationship with their HCPs (92%). Qualitatively there was a beneficial impact on the bio-psycho-socio-spiritual domains of their lives with various sub-themes.

Conclusion: DT and GI are shown to be relevant, feasible and acceptable, and GI focused on intrinsic dignity proved to be a short novel 5-minute intervention that can be conducted at the bedside by HCPs to affirm the intrinsic worth of patients. To add to the knowledge on dignity research, this study highlighted the need to affirm intrinsic dignity and personal worth of dying patients.

In this workshop (20min x 2 parallel sessions), both interventions will be discussed. A workshop on GI will enable practitioners to experience and practice using this novel South African tool to enhance dignity

# Reframing Guilt and Blame: A Tool for Pediatric Palliative Care teams Guiding Debrief Discussions Following Patient Deaths.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Amy Porter (Boston Children's Hospital/Dana-Farber Cancer Institute),  
 Chelsea Heneghan (Boston Children's Hospital/Dana-Farber Cancer Institute)  
 Eleanor Frechette (Boston Children's Hospital/Dana-Farber Cancer Institute)  
 Jennifer Snaman (Boston Children's Hospital/Dana-Farber Cancer Institute)  
 Sarah Halix (Boston Children's Hospital/Dana-Farber Cancer Institute)

### Background

When children die, clinicians may feel a sense of failure or guilt. Paediatric palliative care (PPC) teams play a crucial role in multidisciplinary team reflection on patient deaths. Holding space for distress and supporting other clinical teams' grief processing risks burnout for PPC teams.

### Case Description

JP is a 19-year-old young man with refractory leukemia who died following intensive chemotherapy complicated by an invasive fungal infection. JP's family believed his survival was "in God's hands" and hoped to extend his life however medically possible to allow for miraculous intervention. To maintain their deep faith, they framed JP's death as a failure of biomedicine and blamed the clinical teams. While the Oncology team recognized the inevitability of his death, they felt guilt at not prolonging his survival. Further, they expressed distress that the PPC team had not optimally managed emotion and communication with JP's family around end-of-life care.

Talking points to guide debriefs around JP's death were distilled into a clinical tool that centers on three conceptual tasks:

1. recognizing clinical teams' patient-centered work supporting families and optimizing their experience,
2. acknowledging the emotional burden of caring for a dying patient
3. illuminating the explanatory model that has driven the family to express blame toward the clinical team and/or the framework that has led the team to feel blame.

In JP's case, our talking points emphasized how hard team members worked to manage his symptoms and allow for memorable shared experiences, while ensuring goal-concordant care.

Finally, they framed that for JP's family to "prepare" for his death would have directly undermined their strong faith in a miracle.

### Conclusion

A clinical debrief tool has the potential to mitigate burnout among PPC teams whose role often includes guiding clinical teams through difficult patient deaths complicated by feelings of guilt and/or blame.

# Review of a Comprehensive Model of Paediatric Palliative Care Delivery in Cape Town.

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

Dr Michelle Meiring [Paedspal]

Dr Lyndal Gibbs [Paedspal]

### Background

Paedspal was started as a project of UCT in July 2015 and became a fully-fledged independent NGO in January 2016. The Cape Town based NGO sees children and families referred from both public and private sectors.

### Description

This presentation reviews Paedspal's statistics since its inception and links this to its changing models of care encompassing support in different settings: hospital, out-patient clinic and in the community. The pro's and cons of the organization's stages and models of implementation are described and sustainability issues as well as model changes to support longevity, are discussed.

### Lessons learnt

Modelling NGO funded specialist paediatric palliative care services requires:

1. An understanding of team members' own developmental stages in palliative care practice
2. Ongoing engagement in policy and advocacy to increase government support in the public sector
3. An understanding of the barriers to care and remuneration for services in the private sector
4. A balance between providing services and building capacity amongst primary care teams
5. Networking with other organizations
6. Annual strategic planning and review of services, equity and efficiency
7. Buy in from funders, board and team members
8. Patience, flexibility and resilience!

### Conclusions/next steps.

With the slow implementation of the National Palliative Care Strategy and Policy Framework, NGO's working in this arena need to explore models that provide the best "bang for the donor's buck" and maximize impact. Models of care that strengthen health care systems and build capacity need to be balanced with the fact that palliative care is person and family centered and that we develop deep relationships with our patients during difficult times in their lives. Whilst Palliative Care is everyone's business there will always be a need for a specialist team who make this their main business!

## Rural Experience of End Stage Renal Disease.

### SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Hilary Grey (Knysna Sedgefield Hospice)

Rural Experience of End Stage Renal Disease (Ethics and Advance Care Planning)

#### Background

This presentation is about a young female with ESRD, requiring dialysis but not currently eligible. We look at the ethical decision process, symptom management by the whole palliative care team.

#### Description

Bianca is 30-years-old, a single mother who works a community care worker in a retirement home. Bianca has always been overweight and with a BMI>25. She developed hypertension in 2016 and started treatment which she was compliant with. She developed glaucoma and her eyesight deteriorated to the point she was unable to see.

In September she developed oedema and was admitted in the district hospital she was treated and referred for a workup. She has ESRD, in need of dialysis and while she meets most criteria, she at 120kgs she has been told she needs to lose at least 40kg to become eligible.

Bianca is not looking at the potential of cure or even transplant, her focus is getting dialysis. Dialysis in rural areas requires patients travel from Knysna to George twice weekly, their day starts at 05:30 and sometimes they only get home 12 hours later.

Bianca is working with dietician and has lost 12kgs since in 3 months

#### Lessons learned

Ethical decision making is the cornerstone of every decision, Advanced care planning is a crucial step in the way forward Peer support, which was difficult because of age was essential.

#### Next Steps

Bianca is one of 5 patients with ESRD on our register, her young age the primary reason that any options other than end of life care is put forward, developing tools to introduce a care pathway that empowers patients and Healthcare Providers to make helpful choices earlier on.

## Sherry's Quality of Life Plan; Living Optimally with MND.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Elizabeth Scrimgeour (Drakenstein Palliative Hospice)  
Sherry Dwyer (Private practice)

Sherry is a passionate palliative nurse who was diagnosed with Motor Neuron Disease (MND) in April 2022. Since her diagnosis, Sherry's mission has been to live optimally with MND.

The palliative hospice care approach is to establish an Interdisciplinary Care Plan, with the patient as the head of the treatment team to provide quality of life and dignity in death. Are we not also in a unique position to support our patients' personal quality of life goals? Elizabeth and Sherry spent time together developing an Advanced Care and holistic Quality of Life Plan establishing the fundamental principles of Sherry's hopes and wishes for her future.

Sherry said of the process: 'If I by some miracle got well again, I would like to spend my time developing an Advanced Care and Quality of Life Plan with my patients. Having a person listen to my story in a structured planned way and documenting my ideas and wishes without judgment and without being the expert on my life, has brought some form of control and value to my chaotic uncontrolled world, I feel empowered. Instead of each day being a blank page, I now have control.'

As a Pastoral Narrative Therapist and palliative care nurse, Elizabeth used intentional respectful questioning to co-search and co-create Sherry's meaning through a non-judgmental and non-expert approach. Documenting the holistic Quality of Life Plan has assisted Sherry to find her 'best companion story' and has provided a lifeline of hope to approach her future physical deterioration with courage... and a plan.

## Spiritual Care within Palliative Care: Perspectives from Soul Carers in South Africa.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Mary Ryan (Soul Carer Network)

Cheryl Hodgkinson-Williams (Soul Carer Network)

Carol Scrooby (Soul Carer Network)

Rafaela Peerutin (Soul Carer Network)

Although well known that effective palliative care requires a broad multidisciplinary approach, inclusive of spiritual care, the latter is often marginalized or undeveloped within palliative environments. In other non-palliative end of life environments, aside from the provision of specific religious or chaplaincy care, which may not be appropriate for all, spiritual care is mostly unrecognized. The absence of spiritual care is a deficit within a holistic model of end-of-life care.

The purpose of this small-scale study was to elicit information from a group of people providing spiritual care to people at the end of life (designated Soul Carers) as to how they understood their role and practice in the field, as well as to 'map' the extent of the work being done in different areas. Its intention is to make visible what is often invisible in the end-of-life communities of practice.

We chose a grounded theory approach, drawing from the reflections and experiences of people who have worked in the field in different places in South Africa, for periods ranging from 10 years to more recently. Our sample comprised over 34 spiritual carers from a diversity of cultural, spiritual/religious backgrounds and locations, and who have wide-ranging skill sets. They were drawn from the cohort of participants in Soul Care training courses between 2019-2022.

Data generation occurred via a series of facilitated Zoom workshops during which participants were guided through a series of questions captured in the Chat tool and through the recording.

The thematic analysis of the data provided some key insights into the impact Soul Carers are making on the field of spiritual care at the end of life, and how Soul Carers themselves are being impacted by this work. The findings also point to new questions and areas for further research or action.

# Supporting Optimal End of Life Care: A Funder's Perspective.

## SUB-THEME: SUSTAINABILITY | ORAL PRESENTATION

Jane Ball (Discovery Health)

Kim Cardwell (Discovery Health)

Lizelle Steenkamp (Discovery Health)

Sian Da Silva (Discovery Health)

### Background

The value of early access to palliative care is well documented with benefits to patients, their families, healthcare teams and funders. Discovery Health Medical Scheme (OHMS), the largest open medical scheme in South Africa, provides comprehensive cover for palliative care through the Advanced Illness Benefit (AIB).

### Description

OHMS data demonstrates that members enrolled onto AIB at least 3 months before death have improved outcomes; reflected in reduced hospital admissions, days in ICU, comprehensive use of palliative care and positive member feedback. The financial sustainability of the healthcare fund is also positively impacted as costs for members enrolled on AIB are 30% lower.

A combination of (1) Advanced Machine Learning to identify members likely to benefit from end-of-life care, (2) supporting growth and sustainability of palliative teams, (3) value-based contracting and (4) creation of a member support programme has increased enrolment.

OHMS members enrolled on AIB increased by 82% between 2016 and 2021 with 1,798 members enrolled in 2021. A key driver is the increasing proportion of oncology claimants with metastatic disease enrolling (14% in 2016, 17% in 2021).

While good progress has been made, more work is required to optimize early access to end-of-life care. In 2021, 22,865 adult OHMS members deceased, of which 5,585 were oncology related. 68% of oncology-related deaths were not enrolled on AIB. In addition, many members enroll too late with 29% of enrolments within the last month of life.

### Lessons learned

Members on end-of-life programmes have improved outcomes and lower overall healthcare costs. Predictive analytics, value-based contracts and member support programmes positively impacted on enrolment.

### Conclusions

Focused initiatives result in increased enrolment on end-of-life programmes and improved outcomes. More work is required to build on these gains and ensure timely access to high-quality palliative care for all members who require it.

# TeleHospice as a Component of a Hub and Spoke Palliative Care Service in Western Kenya.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Kenneth Cornetta (Indiana University)

Sarah Nyariki (AMPATH)

Imran Manji (Mai Teaching and Referral Hospital)

Esther Muinga (KEHPCA), Naftali Busakhala (Mai University School of Medicine)

Hussein Elias (Mai University School of Medicine)

### Background

Patients living in rural Kenya often lack access to palliative care services. Our research addressed whether hospice-eligible cancer patients would accept phone monitoring of symptoms and use of medications provided preemptively for non-pain symptoms.

### Methods

The study was conducted at Mai Teaching and Referral Hospital, a public hospital in Eldoret, Kenya. Eligibility included adult cancer patients discharged home who were no longer eligible for cancer treatment; requiring opioid therapy, and Palliative Care Performance Status of 30-60. Symptoms were assessed at enrollment then weekly for 8 weeks. Based on the assessment, the research nurse could refer participants to a palliative care provider. Use of a 24-hour hotline was also available. Participants were given a "comfort kit" with 30 doses of six medications commonly required at end-of-life and 100 KSh (approximately \$1) telephone credit.

### Results

The enrollment goal of 30 patients was met. Participants were aged 20 to 93, 73.3% women and returned to 15 counties in Western Kenya. Our feasibility goal of obtaining 80% participation was exceeded with 100% participation in weekly calls. Symptom assessment questions and mean scores are shown in Table 1. Changes in medication occurred after 12% of follow-up calls and 38 calls were made to the hotline. Eight participants were alive at 8 weeks, 10 died at home, and 12 were admitted to an in-patient facility. Comfort kit used increased with the length of time patients remained on-study; over 75% of participants alive at eight weeks used the majority of the bisacodyl, paracetamol, omeprazole, and metoclopramide. Loperamide was rarely utilized.

### Conclusions

We noted strong engagement in phone monitoring of symptoms and use of certain medication by hospice-eligible patients. Our findings suggest palliative care providers at tertiary care hospitals can use Telehospice to provide symptom management to those lacking access to home based hospice.



# Tempo and Touch, Sound and Smell: an Integrative Approach to Complementary Therapies in Paediatric Palliative Care.

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

Fiona McLennan (Paedspal)  
Mari Stevens (Paedspal)

### Background

A child with a life-threatening or life-limiting illness endures painful and invasive procedures, often takes chronic medication and is subject to other uncomfortable experiences and interventions. With regular and often long hospital admissions these children are also uniquely separated from their peers and friends, their family, their home space, and everything that feels safe and familiar. A life threatening or life-limiting diagnosis has a severe impact on family-life and family-focus and changes a child's social world experiences. Hospital admissions, medical procedures, pain, isolation, loneliness and the sounds, smells and sensations that accompany severe illness alter the world of a child.

### Description

Music psychotherapy and Aromatherapy massage are uniquely positioned modalities that help children cope better in these situations by providing non-invasive, non-threatening, individualised therapeutic experiences that address holistic needs by means of social, emotional, and sensory input. Both therapy modalities offer a space for emotional expression and regulation, social connection, and physical stimulation which can alter pain experiences, lift mood, and encourage play. This is offered in outpatient and in-patient settings within a multi-disciplinary specialist palliative care team.

### Learnings & Conclusion

Music - and Aromatherapy as collaborative and individual interventions in a paediatric outpatient unit and hospital setting with children diagnosed with life-threatening or life-limiting conditions will be discussed by considering the nature of each therapy modality and their impact on isolation, communication, responsiveness, pain relief, and humanising highly medical environments. Besides for the individual child, these therapeutic interventions also transfer to and impacts on the broader context such as other families and hospital staff. The value and importance of the systemic transference of Music- and Aromatherapy will also be considere

# The Aligned Palliative Care Programme Strategies to Increase Early initiation of Palliative Care in Patients with Advanced Cancer & Related Outcomes.

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

Linda Holding (Aligned)  
Jesne Kitsan (Private practice)  
Ursula Torr (Aligned)  
Lungi Nyathi (Aligned)

Aligned has developed a solution to increase access to palliative care by unlocking funding through a value based care solution. The Aligned Palliative Care Programme has to date enabled access to palliative care for over 1,100 patients and their families. The current strategies used by Aligned have proved to be successful in improving quality of life, improving the remuneration to the involved palliative care multi-disciplinary team and reducing health related costs.

Early integration of palliative care (PC) into standard care services has been found to reduce symptom burden, lower health costs and improve quality of life for patients and their families. For example, early engagement with palliative practitioners allows for re-discussion of the goals of care. Later integration of PC would miss this opportunity of aligning care to patient desires.

Aligned use various strategies to increase the number of referrals and specifically earlier referrals for patients with advanced stage or metastatic cancer for optimal PC. These strategies including specific elements of the Aligned Palliative Care Programme design and the use of a PC clinical algorithm which identifies potentially eligible patients using medical scheme claims data.

This presentation will describe these strategies in more detail and will also outline both cost and quality outcomes achieved thus far, including a reduction in non-beneficial care (such as surgery and chemotherapy) in the last month of life, as well as the latest results from our next of kin quality survey.

# The Biology of Grief

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

Lanise Shortell (RN CHPPN CPLPC)

### Overview:

Grief is a process of complex organic disruption. Whereas emotional and psychosocial effects are well known and described, physical manifestations are not commonly characterized. We present novel information on the biology of grief that explains the multifaceted impact of loss.

My presentation emphasizes 4 key concepts: the distinction between grief and mourning; common manifestations of grief, psychoneuroimmunology, allostasis, and ways to mitigate the impact of acute and chronic grief and loss on the tissues of the body.

### Results:

1. Grief is the presence of emotions expected from loss. Mourning is the expression(s) of loss.
2. Manifestations of acute and chronic grief include constriction and inflammation within the tissues of the physical body caused by psychoneuroimmunology, the study of the relationship between emotions and their physical expressions.
3. Allostasis is the body's internal mechanism of reaction to stress that can be diminished with acute and chronic grief.
4. Avenues to enhance allostasis to neutralize the chemical reactions to the impact of grief and loss on the body enhancing the long term wellness of grievers.

**Resources:** Books, online articles, and reports from foundations are provided to aid the journey to wholeness that accompanies grief.

### These include:

- When the Body Says No by Gabor Mate, MD
- Biology of Belief by Bruce Lipton, PhD
- The Wild Edge of Sorrow by Grace Weller
- The Rosette Story: An Anatomy of Health by John Bruhn and Stewart Wolf

### Online Resources:

Insight Timer - a complementary meditation APP

### Foundations:

MISS Foundation led by Joanna Cacciatore, PhD

## The Clinical Complexities of Palliative Sedation.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Mike Brown (Chariot Health)

Palliative Sedation, formerly also known as Terminal Sedation, is a contentious issue in today's world, where there are increasing calls for euthanasia on demand.

This presentation is aimed at the practical aspects of palliative sedation, while a separate presentation deals with the legal, ethical and moral aspects of palliative sedation.

We will address the What, When, Who, Where and How aspects of providing palliative sedation to those patients where there is intractable distress and who are terminally ill or dying, with a life expectancy of days to a week or two. Standard protocols for palliative sedation exist, and we will review the Waterloo Wellington Palliative Sedation Protocol and its applicability in the South African context.

#### Topics include

Definitions of palliative sedation, refractory or intractable symptoms, existential suffering

Indications for palliative sedation.

Role of the interdisciplinary team

Criteria for initiation of palliative sedation, the doctrine of "Double Effect" Process, documentation and monitoring of palliative sedation

Review of the pharmacological agents available for palliative sedation

The role of the family, support for the family, and support for the clinical team

The identification of terminally ill patients with refractory symptoms and the timely initiation of goals-of-care discussions can contribute significantly to patient care. The provision of multi/interdisciplinary care and family meetings has been shown to improve the bond between the patient/family and their caregivers. It has also been demonstrated to relieve stress, anxiety, and frustration. The use of palliative sedation continues to be controversial, however studies have demonstrated that palliative sedation has significant benefits in patients beyond just pain control.

## The Ethical Complexities of Palliative Sedation.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Shannon Odell (PALPRAC)

Susan Hall (Stellenbosch University)

Within the continuum of palliative care at the end-of-life is the last-resort practice of palliative sedation. Palliative sedation is the intentional lowering of an imminently dying patient's consciousness to relieve their suffering, when despite all attempts at reprieve, the patient's intolerable symptoms remain refractory. This study probes whether palliative sedation can be justified sufficiently for the reasons set out in the literature, including existential suffering, and whether these reasons are relevant in the South African context. Initially, it was necessary to establish the conceptual boundaries of palliative sedation by reviewing the definitions and guidelines available in the literature, and clarifying concepts such as refractoriness, tolerability, pain, suffering, proportionality, terminality and consciousness.

Next, the arguments pertaining to the application of palliative sedation to existential suffering were presented. Reviewing the available evidence regarding palliative sedation not hastening death, and other types of sedation and practices such as voluntary euthanasia, physician-assisted suicide and the withholding and withdrawal of nutrition and hydration, helped define the conceptual framework for palliative sedation further. Subsequently, the doctrine of double effect was analysed for its moral justification of palliative sedation. In addition, analysis of other relevant moral frameworks - namely principlism, utilitarianism, Kantianism and virtue ethics - provided a broader framework for ethical discernment of the complexities inherent to palliative sedation. Finally, the tentative suggestion was made to consider Aristotle's "golden mean", and the concepts of tolerability and compassion being represented on a spectrum, with the healthcare practitioner and multidisciplinary team pursuing the intermediate between the extremes.

This seems reasonable to equip healthcare practitioners to strengthen their moral reasoning regarding palliative sedation. Further research is required to increase empirical knowledge relating to the practical aspects of palliative sedation implementation and South African guideline development; and to clarify ethical constructs pertaining to palliative sedation to reduce moral distress.

# The Golden Thread through MND/ALS Care.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Mitchell Scott (UKZN)

### Background

MND is a group of motor neuron disorders that includes Amyotrophic Lateral Sclerosis (ALS), Parkinson's Disease, Primary Lateral Sclerosis, and Progressive Muscular Dystrophy. ALS is traditionally often referred to as motor neuron disease (MND) in Australia, the United Kingdom, and in SA. In the United States of America, it is termed ALS or Lou Gehrig's disease.

The rationale for this talk originates from my own clinical observations of a number of challenges, regarding wishes for care at the EOL. These were also noted by several of the patients themselves, their carers (including family), and the professional health care workers (HCWs).

The potential challenges faced by ALS patients include physical, psychological, social, and spiritual issues, namely: if and when to commence or withdraw various physical life-sustaining therapies, and requests by patients and carers for the hastening of termination of the patient's life which may have been influenced by psychological, social, and spiritual factors.

Ethics plays a cardinal role in the decision-making in managing ALS patients. Within medical discourse, ethical decisions are largely based on four pillars/principles of ethics, namely: autonomy; beneficence; non-maleficence; justice. Superimposed on this are other ethical principles considerations, such as the ethical decision-making theoretical framework of Van den Bulcke, which considers three domains, interdisciplinary communication, and collaboration, leadership in physicians, and an ethical environment.

### Objectives

Strengthening the role-players' fibres of the invisible Golden Thread enabling the 'seamless' care of MND/ALS by all.

Method: Educational presentation considering ethical care of MND/ALS.

### Conclusion

Early palliative care with impeccable communication, including serious illness and difficult conversations, and Advanced Care Planning (ACP) is paramount to providing ethical care to this cognitively vulnerable population.

## The Impact of Cultural Beliefs in Relation to Osteosarcomas in Children.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

**Tracey Brand** (Umduduzi - Hospice Care for Children)

**Julia Ambler** (Umduduzi - Hospice Care for Children)

The province of KwaZulu-Natal is steeped in tradition and many people celebrate both their cultural/traditional beliefs as well as their religious ones. This often leads to a conflict between families and treating teams when it comes to amputation.

This paper will explore 4 cases where cultural beliefs have led to conflicts in treatment, dissatisfaction and fear from the families and the patient, and in some cases an unnecessary death. It will also explore the spiritual crises experienced by some of the patients when their belief system has “failed” them.

Each case will be presented in terms of the families’ and patients’ response to the diagnosis, the treatment plan and their eventual decisions. We will explore the difficult decisions that the treating team has had to make in terms of following legal routes to fulfil, in their definition, the “best interests of the child”.

The balance between respect, duty and emotion is a difficult one to maintain. In each of these cases difficult decisions have had to be made and ones that have not always been easy to live with.

# The impact of Palliative Care on the Quality of Life of Patients with Cancer in Johannesburg, South Africa.

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

Mpho Ratshikana (University of the Witwatersrand)  
 Oluwatosin Ayeni (University of the Witwatersrand)  
 Sabelo Msomi (University of the Witwatersrand)  
 Rofhima Mathiba (University of the Witwatersrand)  
 Jacob Tsitsi (University of the Witwatersrand)

### Background

Healthcare providers strive to understand the impact of healthcare interventions on patients' lives. Quality of life (QOL) is a core outcome of palliative care (PC), in sub-Saharan Africa there is a dearth of evidence on the impact of PC on QOL. We aimed to assess the impact of PC on the QOL among patients on treatment for cancer in Johannesburg.

### Methods

From September 2021-September 2022, a prospective PC service was initiated for patients in Gauteng province with referrals mainly from three tertiary hospitals. Multidisciplinary teams provided comprehensive PC services to the patients. The QOL of the patient was assessed at each PC visit using the WHOQOL-100 tool. We compared the baseline QOL with the QOL at the 2nd PC assessment reporting means  $\pm$  standard deviation (SD) for each question, and domain, and the paired t-test was used for comparison between means.

### Results

A total of 1558 were diagnosed with cancer during the study period. Among these patients, 1170 (75.1%) had a baseline QOL assessment and of these, 194 (16.6%) had a second QOL assessment. The mean  $\pm$  SD was 54.6  $\pm$  14.4 years and breast cancer (26.2%) was the most common cancer. With a median (interquartile range) of 14 (6-43) days between the baseline and second QOL assessment, patients had improvement in their QOL assessment for domains: psychological (49.54 vs. 56.02,  $p < 0.001$ ), social (40.70 vs. 48.62,  $p < 0.001$ ), and environmental (54.14 vs. 59.94,  $p < 0.001$ ) except for the physical domain (36.73 vs. 36.84,  $p = 0.925$ ).

### Conclusions

Palliative care interventions lead to improvement in the QOL of patients with a cancer diagnosis. Our finding that patients had no improvement in their QOL in the physical domain requires further exploration.



# The Long Road to Palliative Care for Cancer Patients.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Zodwa Sithole (Cancer Association of South Africa)

### The long road to Palliative Care Introduction

Statistics show that one in four South Africans is diagnosed with cancer in his or her lifetime with more than 100 000 South Africans being diagnosed with cancer each year. CANSA is determined to use its influence to help fight cancer and protect the dignity of cancer patients.

### Background

Palliative care is important for cancer patients because it gives patients an option for pain and symptom management and higher quality of life while still pursuing curative measures.

Barriers experience by cancer patients:

In South Africa access depends on geographic location, socioeconomic status, and health insurance. Lack primary health care level awareness and education remains an issue, especially in rural population.

### Issues

Reports of diagnostic and treatment delays, emotional and physical suffering, disruption to family life, difficulty maintaining employment, information, and travel needs, all illustrate the complex nature of physical and treatment challenges.

### Description

Barriers, weak referral pathways and inadequate diagnostic modalities result in late -stage diagnosis for many patients with cancer. Cancer patients often involves a series of losses, such as the loss of good health, temporary or permanent changes to appearance, not being able to work or do your normal activities, changed finances, a loss of independence, and a shift in how you see yourself. Pain management is one of the problems the patients is experiencing.

### Results

CANSA and our partners advocate to educate decision-makers on the necessary changes needed to protect the rights of cancer patients.

### Lessons learned

Low cancer awareness and Palliative Care for Health Care Workers is a serious obstacle to cancer care for the patients.

### Recommendations

Holistic Care for cancer patients: physical, emotional, psychosocial, and spiritual should be a standard of oncology care and standards of patient-centered care in oncology should be improve through training and professional development.

## The Management of Depression & Anxiety in Palliative Care.

### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Michelle Beukes-King (Private practice)

Depression and anxiety frequently go undiagnosed and as a result untreated in patients with life limiting illnesses. There are several reasons for this including: the diagnosis may be difficult to make; a lack of awareness of the increased risk of depression; and patients may not report that they are feeling depressed or anxious. Not treating depression and anxiety can have significant treatment implications, which includes both decreased patient compliance and increased mortality and morbidity. As a result, having effective tools to screen patients in a busy practice and being able to assess and make a diagnosis becomes important. With the shortage of specialists in South Africa, getting an appointment to see a psychiatrist may take time, and this may be time that the patient does not have. Having the knowledge about what treatment and medications will be most beneficial for your patient is needed to overcome this barrier. Managing depression and anxiety in palliative care looks at this in detail and will discuss: effective screening tools; how to assess and diagnose depression and anxiety; and what treatments and medications can be prescribed; as well as when to refer. With this knowledge you may be better equipped at managing this group of patients in your practice.

# The Plight of Abandoned Children with Life-Limiting Conditions in South Africa.

## SUB-THEME: RELEVANCE | ORAL PRESENTATION

**Tarryn Bell** (Butterfly Palliative Home)

South Africa has one of the highest child abandonment populations in the world. Annually 3500 children in SA survive abandonment. For every one child that survives, two children are found deceased. Since the first COVID-19 lockdown there has been a massive surge in cases of abandonment. Children with life-limiting conditions are the most vulnerable of these as they need specialised palliative placements which South Africa, due to a lack of children's hospices and limited paediatric palliative care services, simply cannot provide.

In 2022 the researcher undertook an informal study with the aim of describing and quantifying the plight of abandoned children with life-limiting conditions in South Africa.

This research aims to draw attention to the unique needs of abandoned children with palliative conditions in South Africa.

To quantify and describe the problem a mixed-method research design was used. Persons involved in the placement and care of the target population were identified for sampling. Interviews and open ended questionnaires were the major methods of data collection.

Results indicated high numbers of abandoned children with palliative needs, most within their first year of life. Abandoned children with significant life-limiting conditions do not receive adequate palliative care services and more than 70% are not placed in children's palliative care facilities. A substantial number of the research population end up as long-term hospital admissions due to the scarcity of long-term placement options.

### Conclusion

South Africa is failing to address the needs of abandoned children with life-limiting conditions. Professionals at the forefront of service-rendering show limited insight into the unique needs of children with palliative conditions, resulting in unsuitable placements and secondary neglect. Awareness around the plight of this extremely vulnerable child population is of paramount importance and an increased number of palliative care in-patient units are essential if the problem is to be addressed.

# The use of Storytelling and Forums as a Teaching Strategy: Creatively Incorporating the Art of Nursing into Paediatric Palliative Care (PPC) education.

## SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Tracy Rawlins (PatchSA)

### Introduction

Stories have been used as learning tools from the beginning of time. A story engages our curiosity, emotions, and imaginations, and allows for self-reflection. Stories are a way to understand and make sense of our world and describe feelings, attitudes, values, and experiences. Life stories speak directly to the art of nursing, caring for patients and their families and managing the symptoms of their diseases and conditions.

This presentation will explore the value of including storytelling as a teaching strategy in paediatric palliative care education and cover topics such as case studies, biogs and forums.

It will focus on the domains through which we acquire knowledge and skills and how these impact on the science and art of nursing. It will describe the correlation between PPC, a story and holistic thinking. An interactive approach will be used to look at the differences between a PPC case study and a PPC story and will conclude with helpful resources and examples of when and how to use storytelling, both in and out of the classroom situation.

### Conclusion

Research reveals that when a child is dying one of their biggest concerns is whether they will be remembered. This confirms that their lives, however short, are a story waiting to be told and shared. A story transforms important information from an academic experience to a human lived experience.

## The Various Roles of Art Therapy in Palliative Care.

### SUB-THEME: INCLUSIVITY | ORAL PRESENTATION

Angela Rackstraw (Paedspal)

#### The various roles of Art Therapy in Palliative Care

Making art is a universal way of communicating something non-verbally, where words or language are hard to find or not accessible. This has been evident throughout ages, and across all cultures. In South Africa we have our beautiful San paintings to remind us of this, some of these being between 3000 and 5000 years old.

In this presentation we look at how Art therapy can contribute to a whole range of the different facets of palliative care. One does not need to be “good at art” to participate in this way of working, but the therapist needs to know how to help facilitate this process with the patient or family member. Art Psychotherapy is an HPCSA registered profession, and until 2022, training for this was not available in South Africa.

We will be looking at the Art therapy service at Paedspal in Cape Town, which offers support to ill or dying children, their siblings, and families. This takes place both in hospitals, as well as the out-patient clinic at Paedspal. Slides of various artworks will be shown, which illustrate a variety of interventions, as well as the use of different art forms. These will include both individual and group work with our patients, the bereavement groups offered to mothers, and the individual bereavement and support work done with siblings and mothers. All resulting art works tell a precious and individual story.

Legacy work is also encouraged, and children are assisted to tell or write their individual stories. They are also encouraged to express their fears and find their voice, either verbally or non-verbally.

## We can always do Something: Expanding Access to Palliative Care Through a Hybrid Multidisciplinary Team.

### SUB-THEME: SUSTAINABILITY | ORAL PRESENTATION

Barbara Matthews (Private practice)

Jesne Kistan (Alignd)

Linda Holding (Alignd)

A private sector network organization embarked on a pilot project to increase access to palliative care to patients enrolled on their palliative care program who live in areas where access to palliative care services was limited i.e., where palliative trained health professionals are sparse. The network organization contracted palliatively trained doctors to provide expert advice and care to patients directly via the use of telehealth and to coordinate care between nurses, general practitioners, and hospices (without a doctor) and patients in the form of a hybrid MDT.

This case report demonstrates the findings and experiences of the palliative practitioner champion who participated in the hybrid model of care.

# Why Palliative Care is MY Business: Recounting the Lived Experiences of Health Care Providers in a Hospice Setting and Exploring Ways of Retaining them in our Organisations to provide this Critical Area of Health Care.

## SUB-THEME: SUSTAINABILITY | ORAL PRESENTATION

Francesca Tong (Overstrand Hospice)

### Issue

Providing palliative care to patients (and their families) diagnosed with a life-threatening illness can be deeply satisfying and fulfilling, although within a hospice setting equally challenging and exhausting on personal, professional, and organisational level. Yet despite the multi-layered challenges that confront health care providers, such as over-burdened staff, under-resourced organisations, unrealistic expectations from beneficiaries, they continue to provide excellent quality care within our organisations; some have for many years.

### What this presentation will attempt to address:

What sustains our health care providers within our member organisations?

How can we strengthen those areas which help to sustain them and realistically reduce or minimize those challenges which threaten their exodus from our organisations.

### Description

A questionnaire will be circulated to members of the multidisciplinary/interdisciplinary teams to organisations across the country. The questionnaire will include reflective questions that cover personal, professional, and organisational aspects of their work, including the challenges and obstacles.

### Lessons Learnt

Based on the results of the survey, issues will be highlighted which have served to strengthen and encourage our palliative care team members, as well as those which have made their working environment challenging and difficult, and how, in their view, these might be minimised or reduced. The way forward and recommendations:

Recommendations will be put forward as to how member organisations, with the ubiquitous socio economic challenges that confront us, can strengthen, and build upon organisational systems and structures which will be helpful in sustaining and retaining our health care providers who make it their business to provide quality palliative care.

## “I won’t consent to the ICU!”

### The role of Pediatric Palliative Care Teams in Interpreting Emotional Expression Disguised as Goals of Care.

#### SUB-THEME: RELEVANCE | ORAL PRESENTATION

Chelsea Heneghan (Boston Children’s Hospital/Dana-Farber Cancer Institute)

Amy Porter (Boston Children’s Hospital/Dana-Farber Cancer Institute)

Sarah Halix (Boston Children’s Hospital/Dana Farber Cancer Institute)

Eleanor Frechette (Boston Children’s Hospital/Dana-Farber Cancer Institute)

Jennifer Snaman (Boston Children’s Hospital/Dana-Farber Cancer Institute)

#### Background

Parents may articulate emotional statements that sound like statements of preference while witnessing their child’s suffering in a medical emergency. Clinical teams may mistake such externalized emotion as expressions of goals of care. This confusion risks muddling goals and misses opportunities for validating parental emotion in urgent or emergent clinical contexts, when understanding goals of care matters most.

#### Case Description

ND was a 5-year-old boy with relapsed acute leukemia undergoing CAR-T therapy. Both the patient and his mother feared the ICU due to traumatic experiences earlier in his illness trajectory. When he became acutely ill due to the CAR-T-generated inflammatory response, his mother declared, “I won’t consent to the ICU!” The oncology team expressed distress regarding whether to assume altered goals of care (no escalation in cardiorespiratory support) and allow him to stay on the floor or use legal policies to force his mother to consent to ICU transfer.

Given our longitudinal relationship with this patient and family, our paediatric palliative care (PPC) team recognized the mother’s statement as externalized emotion - a vociferous wish that he was not so sick to require ICU-level care. We responded to her emotional exclamation and clarified her deeply held goals to receive the necessary care that would provide the best chance of survival. He was transferred to the ICU, even as she continued to wish that his clinical status would improve enough for him to return to the floor.

#### Conclusion

PPC teams influence parental decision-making by using their longitudinal relationships and deep understandings of parental goals of care to support bidirectional communication between parents and clinical teams. By holding and interpreting parental distress, PPC teams can assist primary clinical teams in discerning externalized emotion from re-definition of goals. The collaboration can promote better alignment of parental goals with clinical plans of care.



# A Global Compassionate Community Response for Ukraine.

## SUB-THEME: INCLUSIVITY | POSTER PRESENTATION

Joan Marston (PallCHASE)

Mariya Vynnytska (The Soul Centre)

### Background

Palliative care as a child's right must be available in humanitarian settings. Ukraine had a country wide network of government -funded services that were severely affected by invasion. Palliative care services reduced, and staff deployed. The international Paediatric Palliative Care (PPC) community was not prepared but responded with a unique, evolving cross-border programme.

### Description

Collaborative, rapid cross-border action assisted PPC in Ukraine.

Trauma counsellors received training and Circles of Support Collaborative channels helped children be transported to safer countries. A cross-border initiative mapped services, educated, and supported practitioners. Virtual training, online learning and webinars were initiated. An international Statement of Support was developed.

### Lessons Learned

War affects access to PPC. Collaborative action was rapid and innovative. PPC practitioners in Ukraine reported they felt supported. Funding assisted programmes.

### Conclusions:

The global PPC Community acted as a compassionate community, but lessons learned must advise national, regional, and international interventions. PPC education should include humanitarian crises.

# Factors Influencing Consent Rate to Organ Donation - Problems in Communication at End-Of-Life.

## SUB-THEME: INCLUSIVITY | POSTER PRESENTATION

Hloni Bookholane (UCT)  
David Thomson (UCT)  
Alexia Michaelides (Netcare)  
Fiona McCurdie (Groote Schuur)  
Babalwa Gili (Red Cross Children's Hospital)  
Elmi Muller (University of Stellenbosch)

### Background

South Africa (SA) has very low and unchanging organ donation rates. A key point in the pathway of organ donation is obtaining informed consent from the family, which is necessary before organ donation can proceed. Best practice is for this to be a shared responsibility between the treating team and the trained requester who is brought in from the transplant team to assist.

### Methods

A prospective descriptive study was performed of all requests to families for organ donation in Western Cape Province, SA, by Groote Schuur Hospital (state sector), Red Cross War Memorial Children's Hospital (state sector) and Netcare (private sector) transplant co-ordinators from 1 May 2017 to 1 May 2018 to describe factors influencing consent rates.

### Results

The 6 co-ordinators (3 state sector and 3 private sector) recorded data of 83 consecutive families approached in 16 hospitals over the 1-year period. Consent to organ donation was granted for 23 family requests (n=18 (state sector); n=5 (private sector)). The majority of referrals came from trauma and emergency units (n=55; 66.3%) and very few from intensive care units (n=25; 30.1%). Immediate fluid resuscitation was required in 56 (67.5%) potential donors. In 42% of state sector families approached for consent the family was not aware of the poor prognosis when the transplant coordinator was asked to request consent. The majority of families (n=74; 89.2%) were receptive to the organ donation request, independent of their ultimate decision regarding donation.

### Conclusion

This study showed that the number of families approached for consent to organ donation were low in the Western Cape (lower in the private sector), with a low consent rate (lower in the state sector).

End-of-life care must include a best practice approach for consent.

# Health Care Workers Knowledge of when to Initiate a Palliative Care Approach.

## SUB-THEME: SUSTAINABILITY | POSTER PRESENTATION

Jennie Morgan (University of Cape Town)  
Rene Krause (University of Cape Town)  
Katya Evans (University of Cape Town)  
Ruth Amore (University of Cape Town)  
Sadiya Patel (University of Cape Town)

When looking to implement a palliative care service we need to start at the entry point to palliative care, identifying which of our patients needs a palliative care approach.

This study surveyed 55 staff at a community health centre and an adjoining emergency unit to determine health care workers knowledge of when to initiate palliative care and further to determine if prior training or palliative care experience impacted on this knowledge. A survey of 15 cases was provided, staff were asked to identify if each patient required palliative care or not.

The cohort was too small to find any statistical significance, but trends are noticed. All junior doctors were able to identify the renal failure and cancer patients correctly. Over 75% of the senior doctors were able to correctly identify the renal failure, cardiac failure, dementia, and cancer patients. Overall, nurses and doctors were not able to identify which patients needed palliative care based on the patients' functional status.

When looking at average scores out of 15 the doctors scored 8.2 compared to the nurses who scored 5.5. Basic training received an average score of 8.1 while no training scored 5.6. There was minimal difference between the groups with different palliative care experience.

Although there seems to be reasonable ability to identify cancer and renal failure patients in need of palliative care, other disease specific indicators are not well translated into practice. It is clear from all the results that functional status is poorly used to initiate pall care. We can see that basic pall care training does impact on knowledge of when to initiate pall care.

These results can be used to encourage training in our institution and to guide further training and discussion to address the gaps in knowledge of our health care workers.

# Holistic Care.

## SUB-THEME: RELEVANCE | POSTER PRESENTATION

Ruth Lerato Rangaka

### Background

Are we doing enough as organizations that we provide Holistic Care? What are we doing with Palliative Care as Hospices. Is our government acknowledging our services?

### QUESTIONARES CONDUCTING SURVEY ON HOW HOSPICES CONDUCT HOLISTIC CARE

Hospices makes holistic care a priority for every patient and family from an interdisciplinary medical to emotional counselling to spiritual services, every aspect of patient's life is taken seriously.

How do you address the following in terms of holistic care?

1. Social Needs
2. Spiritual Needs
3. Physical Needs

How does hospices help people to make informed decision about treatment in collaboration with health professionals.?

In end-of-life care, who must understand the fundamentals about the grief, loss and bereavement on the part of patient and families, and also within themselves?

Vulnerable population are individuals who are at greater risks of poor physical and health status. They include the economically disadvantaged, racial and ethnic minorities, the uninsured, low- income children, the elderly, the homeless, those with immunodeficiency virus (HIV) and those with other chronic health condition including severe mental illness.

- The needs of these population are serious, are we providing enough intervention?

In Palliative Care cultural consideration is essential around issues such as decision making and symptom management. Culture basically describes the characteristics of individuals and group identity. Palliative Care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illnesses, through the prevention and relief of suffering by means of assessment and treatment of pain and other problem, physically, psychologically and spiritual.

- How can you provide culturally appropriate palliative care?
- How does culture affect end of life care?

# Impact Of A 3-Day Community Based Palliative Care Training On Community Health Volunteer's Knowledge, Confidence And Practices.

## SUB-THEME: SUSTAINABILITY | POSTER PRESENTATION

Hussein Elias (Mai University)  
Evelyne Kisémbé (Mai University)  
Sarah Nyariki (AMPATH)  
Ivan Kiplimo (AMPATH)  
Juli Bait (Livingroom International)  
Allison Tarus (Livingroom International)  
Naseem Mohamed (Webuye County Hospital)  
Kenneth Cornetta (Indiana University)

### Background

There are limited palliative care (PC) services in rural communities where the majority of Kenyans live. In an effort to bring PC services closer to the communities in need, the Academic Model Providing Access to Healthcare (AMPATH) trained 105 community health volunteers (CHVs) using a novel knowledge and skill-based community PC curriculum.

### Methods

The training involved a 3-day in person training followed by a 1-month observation period. CHVs were provided with a training manual, assessment tools, and airtime to facilitate communication with PC providers within their region. Structured questionnaires were used pre- and post-training to assess knowledge acquisition, impact on practice, and content delivery. A mixed method study design was conducted 12-month post training that included structured questionnaires and focus group discussions (FGDs).

### Results

Immediately after training, CHV provided very positive ratings on relevance and content delivery. In the month following training, CHVs evaluated 1,443 patients, referred 154, and conducted 110 and 129 tele consults with the patients and PC providers respectively. At approximately 12 months later, 79 out of the 105 CHVs participated in the follow-up survey. The analysis revealed improved knowledge and confidence in various domains of palliative care including symptom and spiritual assessment and provision of basic nursing and bereavement care. FGDs revealed the CHVs ability to interpret symptoms, make referrals, improved communication/ interpersonal relationships, spiritual intervention, patient comfort skills and health care practices as newly learned and practiced skills.

### Conclusions

We noted improved knowledge, new skills and change in practice after CHVs participation in a novel training curriculum. We feel through training, mentorship, and linkage, CHVs can make important contributions to the PC work force and be first line PC providers in the community as part of larger hub and spoke care model.

# Inclusive Pedagogy: An Interprofessional Training Program Model for Paediatric Palliative Care.

## SUB-THEME: INCLUSIVITY | POSTER PRESENTATION

Jennifer Snaman (Boston Children's Hospital/Dana-Farber Cancer Institute)

Sarah Halix (Boston Children's Hospital/Dana-Farber Cancer Institute)

Chelsea Heneghan (Boston Children's Hospital/Dana-Farber Cancer Institute)

Eleanor Frechette (Boston Children's Hospital/Dana-Farber Cancer Institute)

Amy Porter (Boston Children's Hospital/Dana-Farber Cancer Institute)

### Background

Palliative care teams historically are comprised of interprofessional team members, including nurses, advanced practice clinicians, social workers, chaplains, child life specialists, and others. Yet palliative care training is often separated by discipline, with each professional group educating their own trainees. Siloed training experiences present a missed opportunity for collaborative thinking and learning, paving the way for a future integrated, interprofessional approach.

### Educational Innovation

Our interprofessional paediatric palliative care training program intentionally selects cohorts of physician, nurse practitioner, and social worker fellows to learn alongside each other. All patient and family consultations happen as an interprofessional team with both experienced practitioners and trainees representing each of the three professions. Debriefs following clinical encounters also include all three professions, facilitating learning among disciplines about how pathophysiology influences prognosis and palliative care approach, how to interpret family dynamics, and how best to interface with the clinical team in support of patient and family goals of care.

Didactics are designed to be relevant to all three professions. This differs from other models of interprofessional palliative care education that offer workshops or short-course intensives bringing professions together in that the entire curriculum is founded upon collaborative interprofessional learning, processing/reflection, and skills development.

### Conclusion

There are clear benefits to interprofessional training in paediatric palliative care. When designing training programs in palliative care, educators should consider interprofessional pedagogy that includes physicians, advanced practice clinicians, and social workers, as well as other professions, including but not limited to nurses, chaplains, child life specialists, psychologists, and pharmacists.

# Inter-Institutional and Multidisciplinary Collaborative Interventions Towards Improving Palliative Care Services for Patients Living With Cancer In Kwazulu-Natal, South Africa.

## SUB-THEME: RELEVANCE | POSTER PRESENTATION

Sthabile Mtolo (CIDERU MLCCP)  
Mpho Motlana (CIDERU MLCCP)

### Background

Palliative care is an integral part of cancer care requiring organizational and multidisciplinary collaborations for optimal health outcomes. Innovative strategies to collaborate are emerging as essential building blocks to packaging cancer care services, including learning, documentation, psychosocial support, coordination of care and survivorship care services. These methods are anticipated to optimise advances in the delivery of cancer care services.

### Objective

To implement the inter-institutional and multidisciplinary collaborative package of palliative care services for patients living with cancer and their families, in KwaZulu-Natal (KZN).

### Methods

A collaboration between Multinational Lung Cancer Control Program (MLCCP), Inkosi Albert Luthuli Central Hospital (IALCH) and Cancer Association of South Africa (CANSA) was formed to strengthen palliative care services offered to cancer patients in KZN. Patients were identified in the lung and palliative care clinics; and linked to services. The collaboration flow of services starts from institution where cancer patients are identified, assessed, while receiving treatment and palliative care and linked with psychosocial services available in their communities as part of the collaboration.

### Results/Interventions

Patient navigation has identified, assessed, referred 48 lung cancer patients to access various support systems including hospice, support groups, counselling collaboratively rendered by social workers at CANSA and MLCCP. Quality of life check-up services were rendered, 16 more patients with cancer and eligible for palliative care were identified and supported. Eighteen cancer patients and their families received palliative care services provided by CANSA. This total is made up of 13 patients receiving continuous palliative care and support and 5 families provided bereavement supportive services. CANSA-MLCCP volunteers continue to provide care and support services to identified patients in their communities.

### Conclusion

While this study is ongoing, preliminary results hold promise that inter-institutional and multidisciplinary collaborative interventions to palliative care may yield better outcomes, both for patients living with cancer and their families.

# Ketamine Infusion - The Bio, Psycho, Spiritual Role in Palliative and EOL Care.

## SUB-THEME: INCLUSIVITY | POSTER PRESENTATION

Alan Howard (KetaMIND / SOKePSA)

The NMDA antagonist, ketamine, is best known as a dissociative anaesthetic with an established safety record in adults and children spanning more than half a century. Ketamine's usefulness does not end here:

Mediated by the surge of glutamate (the most ubiquitous neurotransmitter in the nervous system), infusion of subanaesthetic doses of racemic ketamine has proved to be a remarkable antidepressant in patients where traditional agents have failed to produce remission. Ketamine infusion therapy (KIT) can reverse suicidal ideation in 70-80% of patients within hours.

McInnes et al examined outcomes of KIT in 537-depressed patients and found that over 53% reduced their PHQ-9 depression-rating score by over 50%, almost 30% remitted, and 73% reduced suicidal ideation.

Besides its role as a rapidly acting antidepressant (now endorsed by the South African Society of Psychiatrists (SASOP), there is good evidence for KIT's efficacy in lowering pain scores in patients with neuropathic pain, and alleviating anxiety.

Apart from stimulating neuroplasticity, the KIT experience itself can be profoundly therapeutic. Spiritual themes, positive affirmations and emotional security are frequently described by patients, and valuable benefits of KIT at end-of-life.

It cannot be disputed that patients (and family members) in the palliative and end-of-life space constitute a cohort of individuals where depression, anxiety and pain are prevalent bedfellows. Amongst such individuals are those for whom traditional antidepressants, anxiolytics and analgesics have not delivered adequate remission, and who deserve a trial of a safe, effective, and emerging treatment.

The KetaMIND Clinic Group, founded in 2019, now has four accredited outpatient clinics in three provinces in South Africa. Over five-thousand ketamine infusions have been safely administered.

KIT has been of significant benefit to patients of all ages, and none (appropriately selected) are more deserving of these benefits than those with incurable illness reaching the end of their lives.



# Models of Integrated Palliative Care in Low and Middle Income Countries: A Systematic Review.

## SUB-THEME: SUSTAINABILITY | POSTER PRESENTATION

Lindsay Farrant (University of Cape Town)  
Richard Harding (King's College London)  
Richard van Zyl-Smit (University of Cape Town)  
Liz Gwyther (University of Cape Town)

### Background

The evidence for the benefit of the integration of palliative care into standard care is predominantly from high income countries. The burden of diseases requiring palliative care predominates in low- and middle-income countries (LMICs) where access to palliative care is limited. In low resources settings there is a need to understand the evidence for the effectiveness of models of integration of palliative care into standard care.

### Methods

A systematic review of the evidence for the effectiveness of models of integration of palliative care in LMIC settings involving a systematic search of ten electronic databases and grey literature databases. Four sets of terms are used: 1) defining the population; 2) describing Palliative Care as the intervention; 3) the presence of integration; 4) low- and middle-income countries or settings. Adult and paediatric populations in any setting are included for studies exploring the integration of palliative care into standard care for experimental and non-experimental designs.

Quantitative, qualitative and mixed-methods studies are included methodologies.

### Results

Included studies will be graded and a narrative synthesis will be presented. The levels of integration of palliative care for each study will be described according to frameworks of integration.

### Conclusions

The description of potential models of integration of palliative care in low and middle income countries, including potential barriers and facilitators, can guide the discourse on and implementation of integrated palliative care in these settings.

# Palliative Care in Uganda: Quantitative Descriptive Study of Key Palliative Care Indicators 2018-2022.

## SUB-THEME: SUSTAINABILITY | POSTER PRESENTATION

Mark Donald Mwesiga (Palliative Care Association of Uganda (PCAU))

Ahern Lacey N. (Global Partners in Care, Mishawaka, IN, USA)

Kagarmanova Ainur (Eck Institute for Global Health, University of Notre Dame, Notre Dame, IN, USA)

### Background

Parents may articulate emotional statements that sound like statements of preference while witnessing their child's suffering in a medical emergency. Clinical teams may mistake such externalized emotion as expressions of goals of care. This confusion risks muddling goals and misses opportunities for validating parental emotion in urgent or emergent clinical contexts, when understanding goals of care matters most.

### Case Description

ND was a 5-year-old boy with relapsed acute leukemia undergoing CAR-T therapy. Both the patient and his mother feared the ICU due to traumatic experiences earlier in his illness trajectory. When he became acutely ill due to the CAR-T-generated inflammatory response, his mother declared, "I won't consent to the ICU!" The oncology team expressed distress regarding whether to assume altered goals of care (no escalation in cardiorespiratory support) and allow him to stay on the floor or use legal policies to force his mother to consent to ICU transfer.

Given our longitudinal relationship with this patient and family, our paediatric palliative care (PPC) team recognized the mother's statement as externalized emotion - a vociferous wish that he was not so sick to require ICU-level care. We responded to her emotional exclamation and clarified her deeply held goals to receive the necessary care that would provide the best chance of survival. He was transferred to the ICU, even as she continued to wish that his clinical status would improve enough for him to return to the floor.

### Conclusion

PPC teams influence parental decision-making by using their longitudinal relationships and deep understandings of parental goals of care to support bidirectional communication between parents and clinical teams. By holding and interpreting parental distress, PPC teams can assist primary clinical teams in discerning externalized emotion from re-definition of goals. The collaboration can promote better alignment of parental goals with clinical plans of care.

# Patients Requiring Palliative Care Attending a Regional Hospital Emergency Centre in South Africa: A Descriptive Study.

## SUB-THEME: INCLUSIVITY | POSTER PRESENTATION

Christopher Straeuli (University of Cape Town)

Louis Jenkins (University of Stellenbosch)

Nardus Droomer (University of Cape Town)

### Background

Globally, emergency centres (ECs) face increasing patients with palliative care (PC) needs. This is also true for South Africa, with an increasingly older population and rising rates of non-communicable and infectious diseases. A paucity of data exists on local rates and reasons for patients with life limiting conditions presenting to ECs. PC and emergency medicine are established specialties, but little is known how they interface in clinical practice. This study describes the contribution of patients with life limiting conditions to the case load of an EC in a regional hospital in the Western Cape.

### Methods

This was a prospective, descriptive study. Ethical clearance was obtained from Stellenbosch University and the Western Cape government. The setting was a 266-bed rural regional hospital in the Garden Route district. The EC manages 4000 patients monthly and serves 10 clinics. All patients entering the EC over 3 months were assessed using a validated PC identification tool, developed for low-and-middle-income countries. All patients entering the EC were captured in an electronic database. Those identified to have life limiting illnesses and potential PC needs received an ICD-10 code. These files were extracted and statistically analysed. Variables included diagnosis, demographics, reason for visit, and disposition.

### Results

A total of 426 patient visits (4.24%) were identified. Cancer (25.8%), neurological (19.7%) and HIV (17.4%) were the most frequent diagnoses. Patients with HIV and TB were significantly younger. Physical symptoms were the most common reasons for attendance (87%), followed by social (11%) and system issues (10%). Most patients were discharged home (55%), 26% were admitted, and 13% died in the EC.

### Conclusion

Patients requiring PC make up a significant percentage of EC visits. Optimizing health systems and community home-based care could alleviate EC pressures and improve the illness experience of patients with life limiting conditions.

# Quality Of Life of Lung Cancer Patients In Kwazulu-Natal: A Study Using The WHOQOL-BREF.

## SUB-THEME: RELEVANCE | POSTER PRESENTATION

Mpho Motlana (Cancer and Infectious Diseases Epidemiology Research Unit (CIDERU))  
Themba Ginindza (Cancer and Infectious Diseases Epidemiology Research Unit (CIDERU))  
Nkosana Jafta (Cancer and Infectious Diseases Epidemiology Research Unit (CIDERU))

### Background

Quality of life is subjective, determined by the patients' individual feelings and needs, beliefs, values and attitudes which may change over time.

### Objective

The aim of the study was to assess the quality of life of patients living with lung cancer in KwaZulu Natal, South Africa seen in tertiary health facilities.

### Methods

**Study Design:** A longitudinal study was conducted amongst patients who were diagnosed with lung cancer (2020-2021).

**Data Collection:** Twenty-six (26) patients living with cancer were assessed at least once using the World Health Organization Quality of Life Assessment (WHOQOL-BREF) tool that was administered telephonically. The tool is divided into four domains namely:

1. physical,
2. psychological,
3. social and
4. environmental.

### Analysis

The reliability and validity of the questionnaire were assessed by coefficient and factor analysis respectively. Socio-demographics of the participants were described using proportions and multinomial logistic regressions identified predictors of the outcome domains.

### Results

A total of 26 patients living with cancer were assessed and 17 (65%) patients of them were available for the second quality of life interview and 9 (35%) patients were interviewed three times. The study had male preponderance (69%). The mean age 59 CI 98% (54-65). Common symptoms reported by patients living with lung cancer were cough (31%), pain (27%), weight loss (27%), loss of appetite (23%) and fatigue (19%). Eleven (42%) patients living with lung cancer rated their quality of life as average that is neither poor nor good. The majority of participants indicated that they are satisfied with the support they receive from personal relationships and friends. However, 46% reported that they quite often get negative feelings such as blue mood, despair, anxiety and depression.

### Conclusion

This study demonstrates that lung cancer significantly affected patient's quality of life, especially the physical and psychological aspects. Moreover, patients seemed to be satisfied with their environment and social relationships.

## Reflections on a Paediatric Palliative Care Service.

### SUB-THEME: SUSTAINABILITY | POSTER PRESENTATION

Alex Daniels (ICPCN)

#### Background

The establishment of a donor funded Paediatric Palliative Care service within a government funded facility in the Western Cape, coincided with the roll out of a new Intermediate Care Policy Framework, that included palliative care. For the first time palliative care for children was considered at an Intermediate Care Facility (ICF) in the province/country.

#### Description

A novel service was established within an ICF with a section of the 60 bedded hospital refurbished to accommodate a 10 bedded palliative care unit. The In-Patient Palliative Care Unit offered symptom management, respite & terminal care to children & their families.

#### Lessons Learned

The demand for transitional care confirmed the need for care provision between acute hospital care services & the patient's home with a significant proportion of children with chronic conditions e.g.: HIV and severe cerebral palsy (ACT 2 & 4), requiring care and support. Primary caregivers are key role players in their child's care & all efforts to support their endeavours to provide the best care for their children must be prioritised. A diverse group of healthcare workers, equipped with appropriate skills & knowledge is recommended to care for the complex needs of children living with LL and LTC's & their families. Resources must be secured for this to happen & it is unfortunate the service could not be sustained.

#### Conclusion

Subsequently, a South African National Policy Framework for Palliative Care has been developed that includes children. Implementation of PPC has been slow with the vast majority of PPC still being provided by NGO's. However, a donor funded post was created in the National Dept of Health, a set of National Guidelines for Palliative Care is being developed, PPC has been integrated in undergraduate curricula at some universities, the Bettercare books on PPC are available & various NGO's offer training opportunities.

# Review Protocols for Palliative and Elderly Patients with Diabetes Mellitus.

## SUB-THEME: RELEVANCE | POSTER PRESENTATION

Mandy Swart

Patients with Diabetes Mellitus (DM) have a limited life expectancy and a high incidence of death due to DM complications. In South Africa, there is a particular need for a protocol for elderly and end-of-life care for patients living with DM. Patients' needs differ in different phases of their life and this is particularly true for the elderly or end-of-life patients with DM.

The focus of this research is to highlight the additional complications and risks involved when these vulnerable patients are living with DM. The importance of this research is to provide guidance to HCPs that will assist them to effectively manage these patients living with DM. The goal of diabetes management for these patients should be symptom management, maintenance of independence for as long as possible, pain management, quality of life, minimisation of symptomatic hyperglycaemic and hypoglycaemic events and minimisation of drug side effects.

The main conclusions drawn from this study are that as end of life approaches, a review of treatment and goals must be undertaken to ensure that an individualised drug regimen and glycaemic target is incorporated into the care plan for the patient. The IDT includes Healthcare Practitioners (HCPs), family/carers and the patient; it is important that the entire team make all decisions regarding the care plan.

Symptom management might require both non-pharmacological and/or pharmacological interventions as holistic care addresses the spiritual and psychological needs of the patient.

# Teaching End of Life Care - A 5-year Experience from a Massive Open Online Course: Organ Donation from Death to Life.

## SUB-THEME: INCLUSIVITY | POSTER PRESENTATION

David Thomson (UCT)  
Tinus Du Tait (UCT)  
Lori Bocchino (Wits)  
Martin Brand (UP)  
Kiera Noel (UFS)

### Introduction

Comprehensive education is needed of all doctors who might one day be relied upon to identify, refer, and manage potential donors while comforting a grieving family. Online education platforms offer a method of teaching medical professionals and the public on a large scale about deceased organ donation best practices. We describe the 5-year demographic and geographic profile and perceptions of participants who completed a MOOC on organ donation offered by an African university via a global platform.

### Methods

5-year review of the massive open online course Organ Donation: From Death to Life since its launch in July 2017 was done using the Coursera analytics platform. Local uptake in South African Universities was also reviewed.

### Results

A total of 8675 people enrolled in the course over the 5-year period. Of these 5803 started the course and 3461 completed the course. An average star rating of 4.8 / 5 was attained from 617 reviews with 84% giving the course a 5-star rating. The majority of students 52% were between the ages of 25-34 with 60% being female. The majority of participants were from Africa (45.9%) followed by Asia (23.9%), North America (13.9%) and Europe (11.7%). Average monthly learners hit a peak of 433 learners in the 3rd month of the COVID-19 pandemic. Only 2% of enrolments paid the optional course fee.

Only 4 South African universities (University of Cape Town, University of the Free State, University of the Witwatersrand, and University of Pretoria) had formally included the online educational resource into their undergraduate curricula, all with an individual local educator driving the course.

### Conclusion

Online education resources on aspects around end-of-life care and donation are well received. Local champions are needed at universities to run such a course and ensure we educate all our graduates on these important skills.

# The Challenges faced by the Most vulnerable palliative care patients during COVID-19 in Soweto, South Africa

## SUB-THEME: RELEVANCE | POSTER PRESENTATION

Penelope Mathe (Hospice Wits)

### Abstract

The challenges faced by the most vulnerable palliative care patients during COVID-19 in Soweto, South Africa.

The impact of COVID-19 on people living with life limiting illnesses has caused great havoc to the patients who are indigent with no proper housing and health care plans. As a social worker in palliative care, I felt a great urge to assist my patients in some way though I was also anxious and fearful of contracting the virus. What kept me going are my patients who were in dire situation than I was. This was the opportunity for me as a social worker to really assist my patients in their time of need. This paper paints a picture of what we went through as the country in the past two year.

My opinion is that psychosocial initiatives to address the different needs of vulnerable palliative care patients during the COVID-19 pandemic should be developed. Those initiatives should examine the issue of supporting palliative care patients who come from poor communities. The Association of Palliative Care Practitioners of South Africa (2020) compiled an evolving document created to provide guidance during COVID-19 pandemic. This guidance is important for all health care workers to learn about integrating palliative care into standard care in intensive care units, hospital wards, emergency departments, out-patient clinics, intermediate care facilities, care homes and private homes. Most of these initiatives focus primarily on clinical actions. As a result, the very important component of psychosocial intervention during a crisis situation like COVID-19 pandemic is often overlooked. The COVID-19 pandemic has had major psychological and social consequences for the population (Saladino et al., 2020). However, my country has access to little research that addresses the impact of COVID-19 on people living with life threatening illnesses.



# The Global Prevalence of Palliative Care Needs in Hospitals: A Systematic Review

## SUB-THEME: SUSTAINABILITY | POSTER PRESENTATION

Emily Potgieter (Victoria Hospital Internal Medicine Research Initiative (VIMRI), Victoria Hospital)  
Laylah Ryklief (VIMRI, Department of Medicine, University of Cape Town)  
Keisha De Gouveia (VIMRI, Department of Public Health, Brown University)  
Ameer Hohlfeld (VIMRI, South African Medical Research Council)  
Franco Fong (Department of Medicine, University of Cape Town)  
Clint Cupido (Abundant Life Palliative Care, VIMRI, Department of Internal Medicine Victoria Hospital)  
Mark Engel (Department of Medicine, VIMRI, Cape Heart Institute, University of Cape Town)

### Background

The World Health Organisation estimates that 40 million people are in need of palliative care (PC), yet only 14% receive it. An assessment of the demand for PC amongst inpatients is essential so as to allow for adequate resource allocation for appropriate end-of-life care.

### Aim

To estimate, from published studies, the prevalence of palliative care needs amongst adult hospital inpatients.

### Method

We identified, using appropriate keywords, relevant studies via a search of the literature in PubMed and Scopus databases, complemented by a hand-search of grey literature and conference proceedings. We used the Hoy tool to assess the risk of bias of included articles. Procedures were done in duplicate by two independent reviewers. Stata® was used to obtain prevalence estimates, using a random effects model. Subgroup analysis was done on available data using R software.

### Results

The search strategy yielded 757 unique results, of which 27 articles were included. Globally, 28% of inpatients require palliative care, ranging from 7% in Germany to 90% in Norway. Low- and middle-income countries have higher PC requirements (39%) - two thirds of the patients have malignancies or infectious diagnoses. In high income countries the predominant diagnoses were malignancies and cardiorespiratory illnesses. 16% of patients with PC needs had been appropriately referred for PC services. The definition of PC varied considerably across the studies.

### Conclusions

This systematic review, the first of its kind, highlights the large proportion of general inpatients requiring palliative care, with a higher burden of needs found in low-resourced countries. Further high-quality studies with a consensus on the definition of palliative care and standardised palliative care need identification tools are needed to ensure that appropriate palliative care can be provided worldwide.

# The Impact of Dignity Experience on Wanting to Live or Die in South African Patients with Advanced Disease.

## SUB-THEME: RELEVANCE | POSTER PRESENTATION

Raksha Balbadhur (Private/Verulam Hospice)  
Liz Gwyther (UCT)

### Background

A qualitative study was conducted to understand the dignity experience of SA'n patients with advanced disease from diverse socioeconomic and cultural backgrounds.

### Method

A semi-structured interview guide of 8 questions was used in the exploration of the dignity experience of patients receiving home care from two hospices in the North of Durban, KwaZulu Natal. Patients' responses to question 7, "Some people feel life without dignity is a life not worth living, how do you feel about that?", provided qualitative data illustrating the impact of dignity on patients' wanting to die or live. Interviews were audiotaped and transcribed verbatim. Data was analysed using thematic analysis.

### Results

Pendulum of Wanting to Live (good symptom control, respect, compassionate care, social support, affirmed intrinsic worth, strong psycho-existential coping mechanisms) vs Wanting to Die (symptom burden, disrespected, devalued by society, burden on others, loss of identity/role, psycho existential distress)

### Conclusion

Participants were ambivalent about the wish to die and seemed to swing from moment to moment with the pendulum of wanting to die and wanting to live depending on their experience of dignity from moment to moment in keeping with international studies. Unfortunately, 'dignity in dying' has been used to describe euthanasia, suggesting that people who are ill and dying cannot have dignity. However, with dignity interventions, dignity is a construct that is possible even in illness.

Wanting to die is often a transient thought which participants feel safe to express without acting on. At other times when they felt cared for, loved, respected, valued, with good symptom control and strong in feelings of self-worth, finding meaning in their situations, they want to live. This evidence suggests that wanting to die is a reflection of underlying psychological, physical, and socially mediated distress - wanting to die is a litmus test for providing quality end-of-life care.

# The Importance of Aromatherapy Massage in Paediatric Palliative Care.

## SUB-THEME: RELEVANCE | POSTER PRESENTATION

Fiona McLennan (Paedspal)

### Background

The comfort of touch is essential to the survival of mammal babies, and 'skin hunger'/ touch deprivation is a very real problem when children are seriously ill. Complementary therapies such as aromatherapy and reflexology both use hands-on touch in different ways.

### Description

A child in hospital especially is faced with invasive and painful procedures. In an outpatient setting, the child often still is afraid of touch from professionals from having undergone many procedures. A child can be massaged in hospital or in an outpatient setting. If necessary, they can even sit on their mother's lap while a gentle massage is done on their feet and lower legs. The massage takes place with little disturbance to the child. Clothes may be removed as needed and the child is otherwise kept warm and covered.

### Aromatherapy massage offers the sick child:

The chance to take back control of their space by deciding to accept massage.

The child benefits from stimulation of the senses of smell and touch

A parent can be taught basic massage skills and use those on their child. This gives the parent a sense of agency.

The medical team will also benefit from the observations of a skilled therapist.

### Lessons Learned

The vast majority of children enjoy their massages and request them again.

The therapy is more than a 'nice-to-have' and can truly benefit the child's mental and physical Health.

### Conclusions

Massage is a gentle and safe adjunct to traditional medical treatment;

Massage should be widely available in hospitals and outpatient units;

The oils are expensive, and ways need to be devised to include touch therapy in palliative care.

More research needs to be done.

# The Prevalence of Compassion Fatigue Among Oncology Healthcare Professionals in Three Public Healthcare Facilities in Kwazulu-Natal, South Africa.

## SUB-THEME: SUSTAINABILITY | POSTER PRESENTATION

Phindile Mlaba (University of KwaZulu-Natal - CIDERU - MLCCP)

Khumbulani Hlongwana (University of KwaZulu-Natal - CIDERU - MLCCP)

Themba Ginindza (University of KwaZulu-Natal - CIDERU - MLCCP)

### Background

Compassion fatigue (CF), a concept defined as a secondary traumatic response resulting from the close contact with the pain and suffering of others, is a serious global challenge among healthcare professionals dealing with diseases with poor health outcomes in clinical settings. Chronic exposure to the suffering of others is inevitable in the oncology setting and remains one of the main contributors to CF. This study determined the prevalence of CF among oncology healthcare professionals (OHPs) in the three public healthcare facilities that offer oncology services in KwaZulu Natal, South Africa.

### Methods

This cross-sectional descriptive study was conducted among 73 OHPs working in the three public healthcare facilities that offer oncology services in KwaZulu-Natal, using the Professional Quality of Life Scale version five questionnaire. The Statistical Package for Social Sciences was used to analyse data and to determine the frequencies of high, average and low CF scores across demographic categories.

### Results

More than half (56.2%) of the participants had average scores for CF, with 43.8% and 56.2% of OHPs scoring low and average, respectively. OHPs from Inkosi Albert Luthuli Central Hospital had the highest CF mean score (26.8) compared to Addington Hospital (21.2) and Greys Hospital (22.9). Female OHPs had a marginally higher mean score of 24.3 for CF compared to their male counterparts (20.6). CF scores were positively correlated with older OHPs and longer work experience.

### Conclusion

Despite the study coinciding with the COVID-19 pandemic, the prevalence of CF among OHPs, was average, compared to other studies. Nevertheless, these results cannot be taken lightly, given the straining effects of unmanaged CF on the healthcare system generally and patient care in particular. This study has provided essential information, that can contribute to policy development and planning of intervention strategies towards the management of CF among OHPs.

## The Red Thread: Arts-Based Groups with Nursing / Medical Staff

### SUB-THEME: RELEVANCE | POSTER PRESENTATION

Angela Rackstraw (Paedspal)

So many studies on the efficacy of arts-based groups for medical staff have shown that art making helps reduce burnout and stress, and promotes resilience. Literature has shown that this has specifically been the case with medical staff working in palliative care settings.

This presentation shows art and textile (crochet and stitching) work that has taken place in three Cape Town settings, and mainly focuses on work with nursing staff.

Persuading medical staff to participate in creative endeavours has sometimes proved challenging, and we explore various ways to address this.

# The Use of Local Therapeutic Rituals And Disease Discourses by Cancer Patients in Palliative Care Centres in Kwazulu-Natal, South Africa.

## SUB-THEME: SUSTAINABILITY | POSTER PRESENTATION

Nkosinathi Mncwabe (University of KwaZulu- Natal)

### Background

Health and healing are at the heart of the socio-moral, political and cosmological order in African societies across the generations. Traditional/alternative medicine continues to be used by cancer patients globally, with a rapidly growing economic importance.

### Methods

This ethnographic study explored cancer patients' use of local therapeutic rituals and illness discourses by cancer patients attending palliative care centres in eThekweni and uMsunduzi municipalities. Cancer patients were recruited within the palliative care settings, using the ethnographic approach. Data was generated through participant observation and interviews over the period of three months.

### Results

Three themes were identified emerging from the analyses, 1. Informed Health Decisions, 2. Use of local therapeutic rituals, and 3. Discourses about the sickness of the body. The findings pointed out that patients are knowledgeable about cancer and have adopted different mechanisms of dealing with it. Likewise, the use of local therapeutic rituals- the reality that even though most people rely on the mainstream western medicine for healing, local therapeutic rituals are regarded as effective by cancer patients. This study also revealed that participants in palliative care centres have adopted discourses about the sickness of the body. Participants adopted these discourses as ways to understand and manage the illness. In these discourses, the participants attributed power, in the form of the power to interpret illness in a manner that is relevant and sensible to them.

### Conclusions

There is a need to develop strategies that amalgamate different healing methods. Successful linking of the different health systems will form the basis for improving cancer care, including pain management. Likewise, systematic efforts to institutionalise change are needed, beginning at the health policy level.

## Zhimkita's Doll

### SUB-THEME: INCLUSIVITY | POSTER PRESENTATION

Angela Rackstraw (Paedspal)

#### Zimkhita's Doll:

Many of the children with whom we work, inform and shape our practice, not only with them, but far beyond. Zimkhita was one such patient. A 14 year old girl still so full of life, instructed me to make her a doll.

And so it began. Stitching became part of my work as an Art Psychotherapist. In this presentation we follow the thread by looking at a few case examples, where individuals have made and worked with dolls and storycloths, and where groups of bereaved mothers have made heirloom pieces to honour their children, and lastly, where staff have used textile work as a way to de-stress and in some cases, reconnect to themselves and each other.

Stitching, and work with textiles in a broader context, has traditionally been considered to be "women's work". Women were often elected to sit quietly and sew while men sought to solve the problems in the world. However, what transpired, is that stitching became a way for groups of women to make political statements where speech was forbidden during times of war and political turmoil, and more generally as a way for them to communicate something where finding the words was just too difficult. These (stitching) groups are where women will listen to and support each other, and in their own way seek to solve the problems in the world around them.

More recently, research has shown how therapeutic stitching is. We will briefly look at how a short stitching experience was for a group of medical / nursing staff in Cape Town. We will also look at other case examples by looking at photographic slides.