

GIPPEC

Global Institute of Psychosocial,
Palliative & End-of-Life Care

Africa Symposium *Proceedings Report*

Advancing Psychosocial, Palliative, and End-of-Life Care in Africa

February 18-19, 2025

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Background



Across the globe, families and patients living with advanced disease face complex and often overwhelming challenges at the end of life. As populations age and the burden of non-communicable diseases, such as cancer and dementia grows there is a growing need for integrated models of care that address the physical, psychological, social, and spiritual dimensions of suffering. Despite growing recognition of its importance, access to high-quality psychosocial and palliative care remains limited for most of the world's population in need.

The World Health Organization (WHO) estimates that almost 57 million people globally require palliative care, with the vast majority living in low- and middle-income countries (L-MICs). For children, 98% of those in need of palliative care reside in these countries, nearly half of them in Africa (WHO, 2013). Health systems across this continent have limited availability of essential medications for symptom relief, and a severe shortage of trained providers in psychosocial and palliative care. These challenges are compounded by the frequent exclusion of psychosocial and palliative care in national health policies, and the lack of education for health professionals in end-of-life care. According to the report of the 2019 WHO Global Survey, 68% of countries reported some level of funding for palliative care, but only 40% indicated that services reached even half of the patients in need (WHO, 2020).



It is estimated that almost 10 million people in Africa require palliative care, representing approximately one percent of the continent's population (WHO, 2020). In some regions of Africa, there are as few as two to three doctors and less than 40 nurses per 100,000 people. Even in countries with relatively more developed healthcare systems, the gap between patient need and provider availability is vast. For example, South Africa has only one specialist palliative care nurse for every 39,400 cancer patients (Rawlinson et. al, 2014). These workforce challenges are compounded by systemic barriers, such as limited training in palliative care, insufficient integration of palliative care into national health strategies, and poor access to essential medicines for symptom relief.

The need for coordinated, culturally responsive, and evidence-based care approaches has never been more urgent. Inspired by the vision of Dr. Eve Namisango of the African Palliative Care Association, the Africa Symposium on Psychosocial, Palliative and End-of-Life Care was developed to address this critical gap in psychosocial and palliative care for patients with life threatening disease and their families. This event was predicated on the assumption that sustainable transformation within African healthcare systems must be grounded in shared knowledge, collaborative research, and the strengthening of both clinical and educational capacity. The symposium aimed to amplify local expertise, showcase innovations in practice and research, and foster cross-continental dialogue on the best ways to meet the psychosocial and end-of-life needs of individuals and families living with advanced illness across Africa and in the rest of the world.



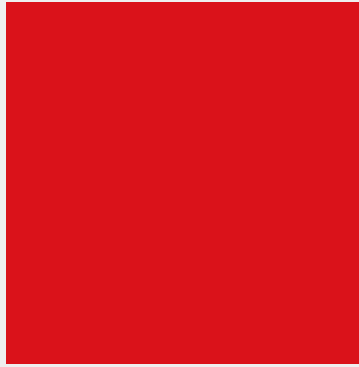
Executive Summary

The Africa Symposium on Psychosocial, Palliative and End-of-Life Care, held virtually via Zoom on February 18-19, 2025, was convened through a collaboration with the African Palliative Care Association (APCA) and Global Institute of Psychosocial and Palliative Care (GIPPEC) at the University of Toronto. The symposium addressed the urgent and evolving needs of individuals with advanced illness and their families across the African continent. This event was inspired by the growing need for coordinated, culturally responsive, and evidence-based psychosocial and palliative care, particularly in resource-constrained settings. The symposium provided a platform for clinicians, researchers, and policymakers to discuss practical solutions and explore innovations in research and practice. It aimed to foster cross-continental dialogue, enhance research collaborations, and build clinical capacity to meet the psychosocial and end-of-life care needs of individuals and families affected by advanced illness in Africa.

The symposium focused on six (6) key topics:

- Managing Cancer and Living Meaningfully (CALM): Extending the Boundaries
- Quality of Dying and Death Research and International Implementation
- Development and Implementation of the Malawi Symptom Toolkit for Symptom Management
- Dementia and Advanced Disease in Africa
- Grief and Bereavement Care in Africa
- End-of-Life and Advanced Care Planning

The event attracted 168 registrants, with 24 speakers from across Africa and beyond. Participants hailed from countries such as Uganda, Cameroon, Eswatini, Sudan, Seychelles, Nigeria, Canada, U.S., and other regions. It concluded with a strong call for continued international collaboration, the mobilization of resources, and the advancement of culturally adapted care models. These outcomes aim to address the unmet palliative care needs in Africa and support the expansion of services to improve the quality of life for individuals facing advanced illness.



Agenda

Day 1 - February 18, 2025

Welcome and Overview of Symposium Objectives

Dr. Gary Rodin, Dr. Eve Namisango

Managing Cancer and Living Meaningfully: Extending the Boundaries

Dr. Gary Rodin, Mr. John Lule, Mr. John Bosco Kafuuma, Dr. Eve Namisango (Moderator)

This session explores the theoretical framework and clinical application of CALM therapy, featuring case presentations from Uganda's Kitovu Hospice and St. Francis Naggalama Hospital.

Break

Quality of Dying and Death Research and International Implementation

Dr. Eve Namisango, Dr. Gary Rodin, Dr. Alyssa Tilly, Ms. Mary Goombs, Ms. Maria Chikasema, Dr. Jared Lowe (Moderator)

This session explores the Quality of Dying and Death (QODD) across diverse contexts, highlighting research from Canada, Kenya, Uganda, and Malawi, the validation of the RGV measure in Africa, and its potential application in other regions.

Development and Implementation of the Malawi Symptom Toolkit for Symptom Management

Dr. Alyssa Tilly, Ms. Maria Chikasema, Dr. Christian Nitzimira (Moderator)

This session introduces a novel Symptom Toolkit designed to optimize cancer symptom management, including key medications for addressing the most common patient experiences.

Agenda

Day 2 - February 19, 2025

Welcome

Dr. Gary Rodin, Dr. Eve Namisango

Dementia and Advanced Disease in Africa

Prof. Noeline Nakasujja, Dr. Janet Nakiggude, Prof. Seggane Musisi, Dr. Racheal Alinaitwe, Dr. Paul Kiwanuka-Mukiibi, Prof. Celestino Obua, Dr. Edith Wakida, Dr. Ronald Kamoga, Dr. Kennedy Nkhoma (Moderator)

This session examines dementia care in Uganda, covering diagnosis, challenges, caregiver experiences, community outreach, and palliative training, with insights from research and the Uganda Alzheimer's Association.

Break

Grief and Bereavement Care in Africa

Dr. Eve Namisango, Dr. Gary Rodin, Dr. Alyssa Tilly, Ms. Mary Goombs, Ms. Maria Chikasema, Dr. Kennedy Nkhoma (Moderator)

This session examines approaches to grief and bereavement support in Africa, featuring measurement tools, a community-led intervention in Uganda, and Zimbabwe's Island Hospice model.

Multimorbid Ageing Primary Palliative Care in Ghana, Malawi and Zimbabwe

Dr. Kennedy Nkhoma

This session explores multimorbid aging populations, highlighting challenges and strategies for improved care in Africa.

End-of-Life and Advanced Care Planning

Dr. Layne Heller, Dr. Eve Namisango, Dr. Craig Sinclair, Dr. Breffni Hannon (Moderator)

This session discusses end-of-life care priorities for advanced disease in Mozambique, the context of advance care planning in Africa, and training for health professionals.

Working Session: Research on End-of-Life Care, Death, and Dying in Africa

Moderators: Dr. Gary Rodin, Dr. Eve Namisango, Dr. Alyssa Tilly

This interactive working session will synthesize key insights from the symposium, identify gaps in end-of-life care research and practice in Africa, and develop a toolkit to guide future psychosocial and palliative care priorities.

Symposium Summary

Managing Cancer and Living Meaningfully: Extending the Boundaries

Featured Speakers

Dr. Gary Rodin

Director of GIPPEC, Princess Margaret Cancer Centre

Mr. John Lule

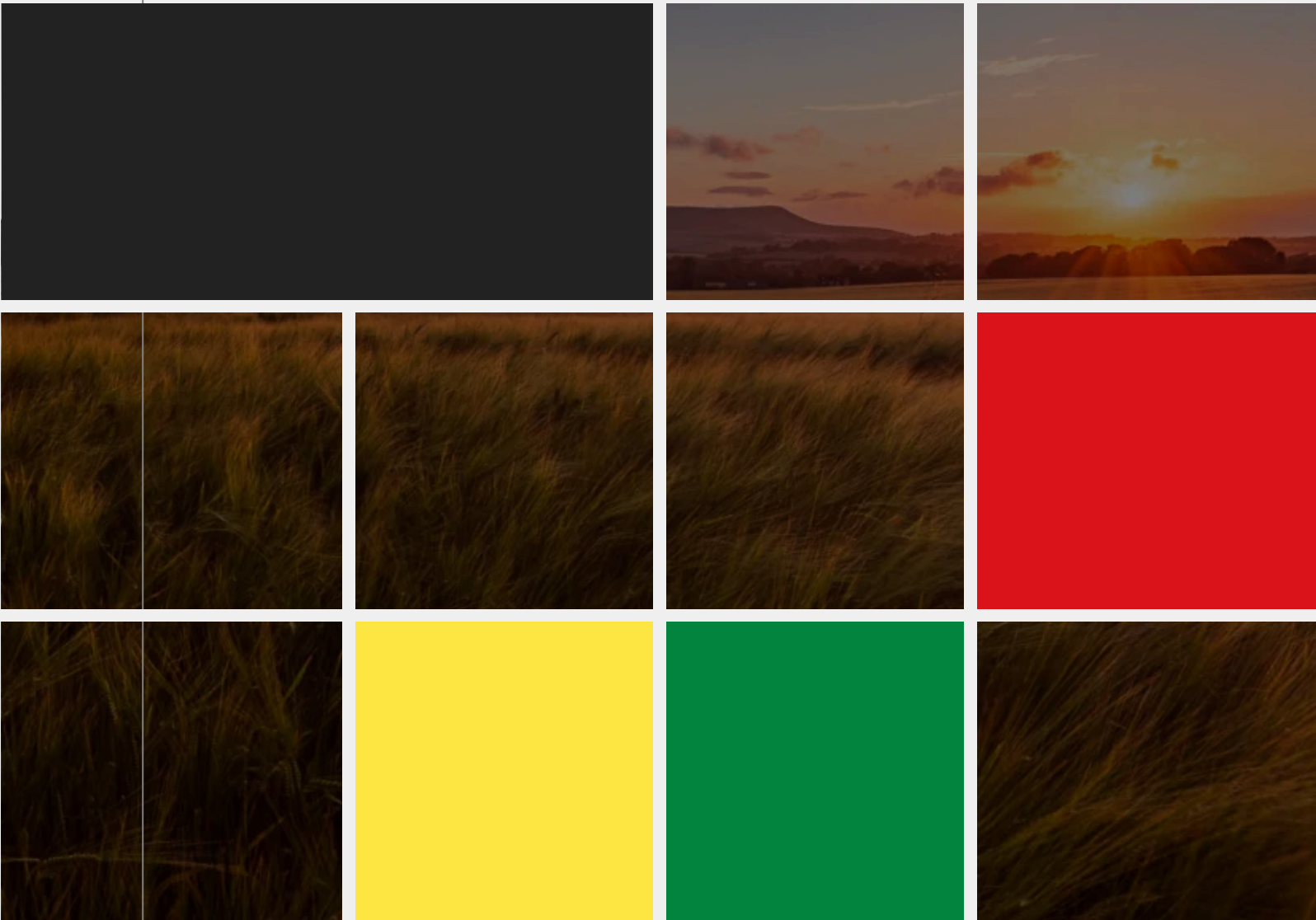
Medical Clinical Officer and CALM Therapist, Kitovu Mobile Hospice

Mr. John Bosco Kafuuma

CALM Therapist, St. Francis Hospital Naggalama

Dr. Eve Namisango (Moderator)

Programmes and Research Manager, African Palliative Care Association



Symposium Summary


Managing Cancer and Living Meaningfully: Extending the Boundaries

The first session of the Africa Symposium on Psychosocial, Palliative and End-of-Life Care focused on Managing Cancer and Living Meaningfully (CALM), a framework designed to address the psychological, relational, and existential challenges faced by individuals living with advanced or life-threatening cancer. CALM is a systematized psychotherapeutic intervention that integrates early palliative care, offering supportive-expressive therapy to help patients and caregivers manage distress and improve their quality of life. Originally developed in Canada, CALM has been adapted and disseminated in more than twenty countries globally, successfully addressing the universal challenges that patients with advanced cancer face.

Dr. Gary Rodin, co-developer of CALM, spoke about the application of CALM in Africa and emphasized the universal challenges faced by patients with advanced cancer. CALM provides a tailored therapeutic approach that helps patients navigate the "tipping point" — the critical moment when they perceive their time is short, and the psychological burden of their diagnosis becomes overwhelming. This moment creates an opportunity for CALM to offer much-needed support, allowing patients to reflect on their experiences and cope with existential concerns.



Figure 1. *The CALM Global Network.* Map illustrating the international reach of the CALM intervention, which is currently delivered in over 20 countries worldwide, reflecting its adaptability and global relevance in psychosocial oncology.



CALM addresses four (4) core domains that guide the therapeutic conversation:

1) Disease Management and Relationship with Healthcare Providers

Helping patients navigate treatment and communicate effectively with their healthcare team.

2) Changes in Self and Relationships with Close Others

Supporting patients in renegotiating their relationships, as they deal with the emotional and physical changes caused by advanced cancer.

3) Sense of Meaning and Purpose

Assisting patients in finding meaning in their lives, whether through spiritual reflection or redefinition of their goals.

4) Mortality and Future-Oriented Concerns

Addressing fears and anxieties about death, enabling patients to confront their mortality and make meaningful decisions.

CALM's framework incorporates key therapeutic elements such as mentalization, which helps patients reflect on their illness and emotional experiences from multiple perspectives. In a brief intervention—delivered in just three to six sessions—but provides patients with a structured, reflective space to explore their fears, feelings, and hopes. Evidence supports its effectiveness, with studies demonstrating reductions in depressive symptoms, death anxiety, and distress, alongside improved communication with healthcare providers and greater preparedness for the end of life (Rodin et al., 2018). The session highlighted the importance of integrating CALM into early palliative care in Africa and encouraged participants to adapt its flexible framework to meet local needs and resources.

The session concluded with real applications of CALM in patient cases (found in Appendix D), showcasing how the framework was used with patients in their care. These case studies highlighted the transformative impact of CALM in supporting patients through their emotional and existential struggles.

Symposium Summary

Quality of Dying and Death Research and International Implementation

Featured Speakers

Dr. Alyssa Tilly

Assistant Professor, University of North Carolina (UNC) School of Medicine

Ms. Mary Goombs

*Clinical Research Analyst, Department of Supportive Care,
Princess Margaret Cancer Centre*

Ms. Maria Chikasema

Nurse Coordinator and Lead Research Nurse, UNC Project, Malawi Cancer Program

Dr. Eve Namisango

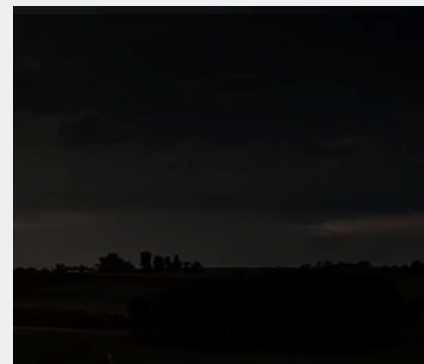
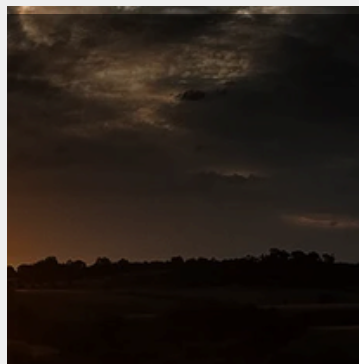
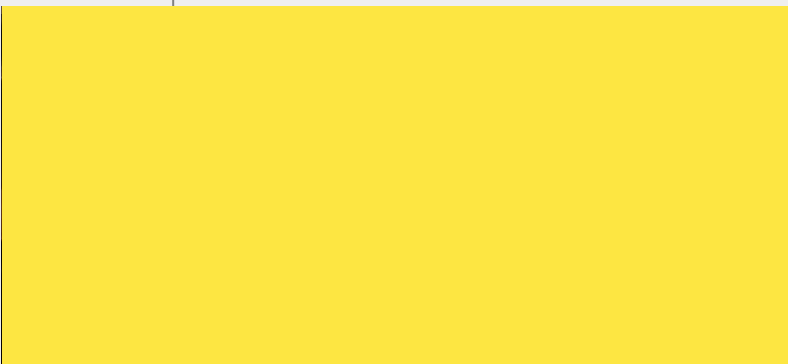
Programmes and Research Manager, African Palliative Care Association

Dr. Gary Rodin

Director of GIPPEC, Princess Margaret Cancer Centre

Dr. Jared Lowe (Moderator)

Medical Director & Assistant Professor, University of North Carolina (UNC) Hospice



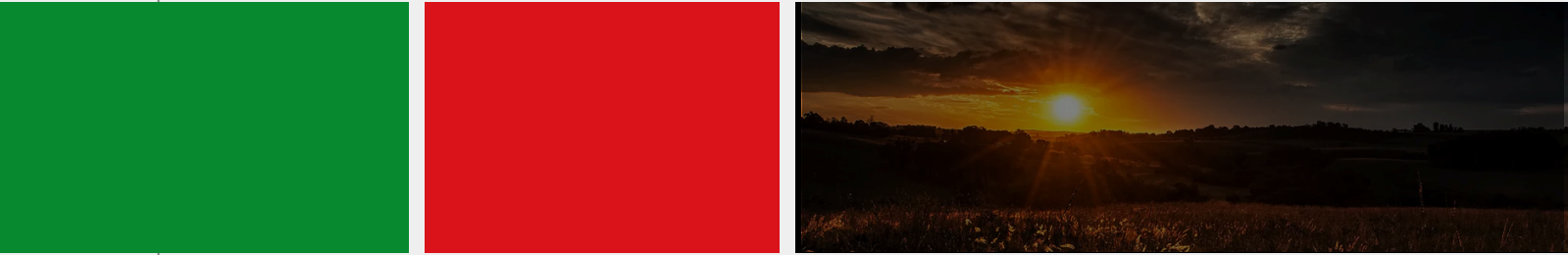
Symposium Summary

Quality of Dying and Death Research and International Implementation

Dr. Eve Namisango provided an African perspective on death and dying, sharing her experiences from working with patients and their families in Uganda. Dr. Namisango emphasized that a good death is not only about managing physical symptoms but also about addressing the emotional, social, and spiritual needs of the patient. She highlighted the importance of reconciliation, forgiveness, and the presence of loved ones in improving the quality of the dying experience. Dr. Namisango pointed out that these aspects of death not only help the patient transition peacefully but also aid the grieving process for the family members left behind.

Following this, Dr. Gary Rodin provided an overview of the Quality of Dying and Death (QODD) measurement tool. He explained that the QODD was initially developed in the United States and its application in diverse cultural contexts, particularly in Africa, presented challenges related to the length and burden of the questionnaire and the inclusion of items that lack cultural relevance in many settings. The original QODD was found to be too lengthy and culturally irrelevant in some settings. This led to the creation of the QODD-RGV, a revised version designed to be more universally applicable and culturally sensitive, while also simplifying the rating system to ensure broader use across different healthcare settings (An et. al, 2022).

Dr. Alyssa Tilly then shared insights into the ongoing research involving the QODD-RGV, focusing on its use in North America and Malawi. She highlighted the efforts to validate the tool in both high-resource settings (HRSs) and low-resource settings (LRSs), emphasizing the need for culturally relevant instruments in palliative care. Dr. Tilly discussed the challenges of measuring the quality of dying and death, given that much of the data comes from proxy ratings but also pointed out that proxy ratings can provide valuable insight into the dying experience, especially when direct patient responses are not feasible.



Next, Ms. Mary Goombs presented findings from her research on the QODD-RGV, focusing on its validation in North American hospices. She detailed the study's design, which involved caregiver proxy ratings of patients who had passed away, and shared preliminary findings that demonstrated promising reliability and validity. Ms. Goombs also discussed the modifications made to the QODD-RGV during the revision process, including the simplification of questions and the elimination of culturally irrelevant items, which improved the tool's usability (Goombs, 2024).

The session also featured insights from Ms. Maria Chikasema, a senior research nurse and palliative care specialist from Malawi, who presented her experiences conducting cognitive interviews with bereaved caregivers in Malawi. She shared how the QODD-RGV was adapted for use in Malawi, including a translation process into the local language (Chichewa) (An et. al, 2022) and the challenges associated with cultural nuances in end-of-life care. Ms. Chikasema emphasized the importance of understanding caregivers' emotional and psychological needs during the dying process, noting that communication, both with healthcare providers and within the family, was often a key concern for caregivers.

The session concluded with a discussion on the future directions for the QODD-RGV, including further validation studies in different cultural contexts, particularly in LRSs, and its potential application in clinical trials and palliative care interventions. The panel agreed that while there are challenges in developing a universal measure of quality of dying and death, the QODD-RGV represents a step forward in providing a reliable, culturally sensitive tool for improving palliative care outcomes globally.

Symposium Summary

Development and Implementation of the Malawi Symptom Toolkit for Symptom Management

Featured Speakers

Dr. Alyssa Tilly

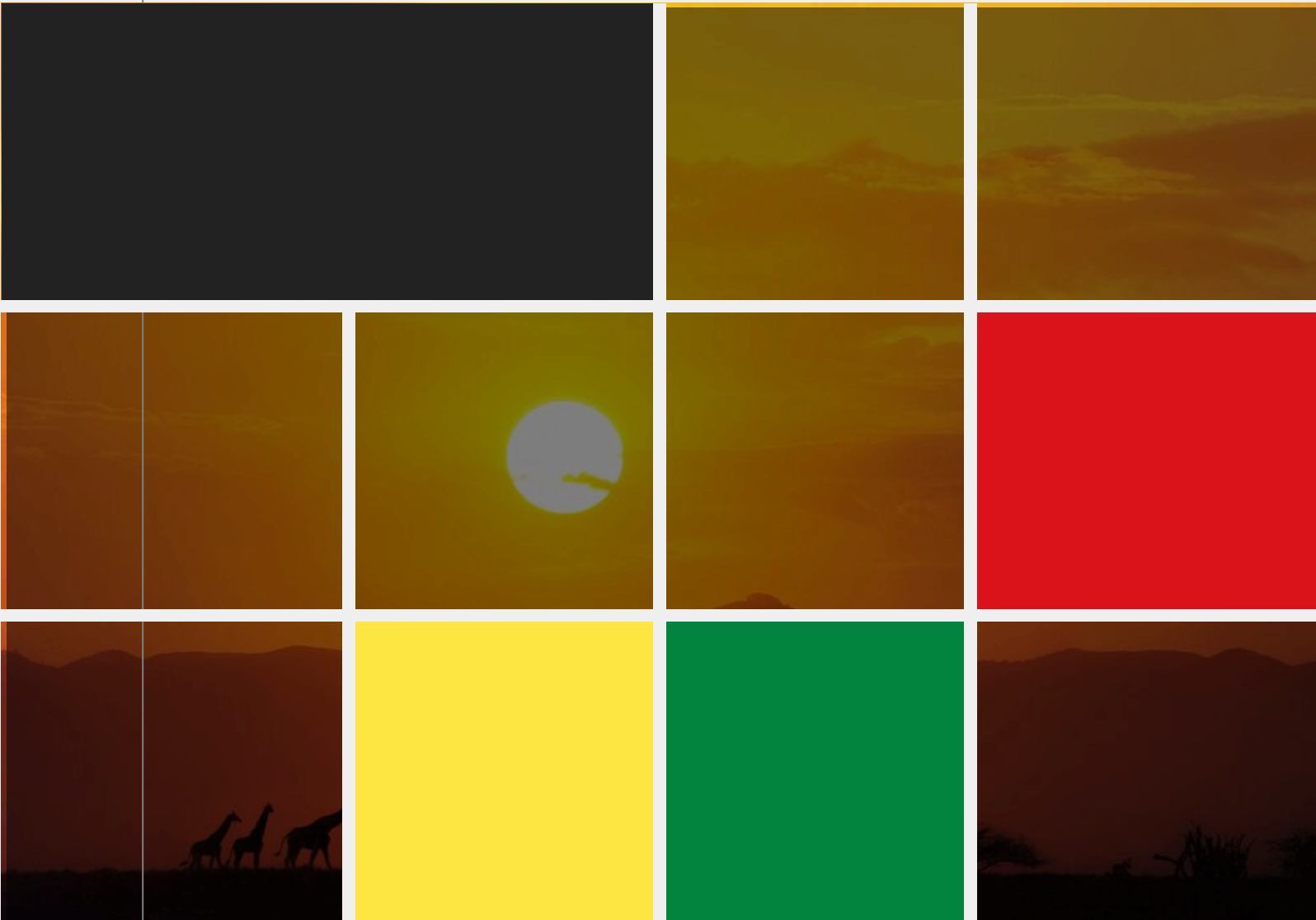
Assistant Professor, University of North Carolina (UNC) School of Medicine


Ms. Maria Chikasema

Nurse Coordinator and Lead Research Nurse, UNC Project-Malawi Cancer Program

Dr. Gary Rodin (Moderator)

Director of GIPPEC, Princess Margaret Cancer Centre





Symposium Summary


Development and Implementation of the Malawi Symptom Toolkit for Symptom Management

The Development and Implementation of the Malawi Symptom Toolkit for Symptom Management session at the Africa Symposium on Psychosocial, Palliative and End-of-Life Care showcased an innovative intervention designed to address the symptom management needs of cancer patients in Malawi, particularly those receiving treatment for lymphoma. This session, presented by Dr. Alyssa Tilly and Ms. Maria Chikasema, focused on the creation and preliminary evaluation of a symptom toolkit tailored for LRSs, aimed at improving the quality of care and reducing symptom-related suffering among cancer patients in rural areas.

The session began with Ms. Maria Chikasema, a senior research nurse and palliative care specialist in Malawi, providing a comprehensive overview of the state of palliative care in Malawi. She highlighted that while the country faces a significant burden of cancer, with an estimated 25,000 Malawians living with the disease, the availability of palliative care services remains limited, particularly in rural areas. Despite these challenges, Malawi has made significant strides, with the government recognizing palliative care as a critical component of its healthcare system since 2002 and establishing the first palliative care centre at Queen Elizabeth Central Hospital. However, much work remains to ensure equitable access to symptom management and end-of-life care across the country.

Dr. Alyssa Tilly then discussed the rationale behind the development of the symptom toolkit. The toolkit was designed to address common symptoms experienced by cancer patients undergoing chemotherapy, particularly those in remote and underserved areas where access to healthcare facilities and medications is limited. The toolkit includes a combination of educational materials, symptom management guidance, and a symptom diary to help patients manage their symptoms at home between chemotherapy cycles.

Figure 2. Components of the Malawi Symptom Toolkit. Pictorial Symptom Representations (1) and Patient Symptom Tracking Card (2) Used to Support Home-Based Symptom Management Among Cancer Patients Receiving Chemotherapy



The initial feasibility assessment of the symptom toolkit showed promising results. Of the 65 patients enrolled in the study, a significant majority reported using the symptom toolkit and medications as needed, with a high level of adherence to the treatment regimen. The toolkit was found to be user-friendly and well-received by patients, with many reporting symptom relief and improved quality of life. Notably, the toolkit helped reduce stigma by empowering patients to manage their symptoms independently at the community level, thus promoting socialization and improving overall well-being. Additionally, the intervention led to greater accessibility and reduced the financial burden of traveling to healthcare facilities for symptom management.

Dr. Tilly and Ms. Chikasema also outlined future plans for the toolkit. The next steps include expanding the toolkit's application beyond the lymphoma cohort to include a broader range of cancer patients in Malawi. This expansion will involve adapting the toolkit based on feedback from patients, caregivers, and healthcare providers, including oncologists, nurses, and palliative care clinicians. The goal is to pilot the toolkit with a broader patient population and ultimately to conduct a full-scale clinical trial to assess its feasibility and effectiveness in improving symptom management and quality of life.

Future research on the Malawi Symptom Toolkit will focus on integrating it into national healthcare systems and training local healthcare providers, including village health workers, to implement it in remote communities. This approach is aimed at improving palliative care delivery in regions with limited access to specialized services. The session underscored the importance of developing culturally appropriate, low-cost, and scalable interventions to address the symptom management needs of cancer patients in resource-constrained settings. The toolkit represents a significant advancement in improving quality of life for patients in Malawi, with promising potential for broader application across Sub-Saharan Africa.

Symposium Summary

Dementia and Advanced Disease in Africa

Featured Speakers

Prof. Seggane Musisi

Professor of Psychiatry, Makerere University College of Health Sciences

Dr. Janet Nakiggude

Lecturer and Clinical Psychologist, Makerere University, Uganda

Dr. Racheal Alinaitwe

Consultant Psychiatrist, Jinja Regional Referral Hospital

PhD Fellow, CREATE PhD Program

Dr. Paul Kiwanuka-Mukiibi

Executive Director and Founding Board Member, Uganda Alzheimer Association

Dr. F. Akosua Agyemang

Senior Lecturer at the University of Ghana, Legon

Department of Social Work/Centre for Ageing Studies

Dr. Jane Frank Nalubega

Counselling Psychologist, Staff Representative on the Governing Council,

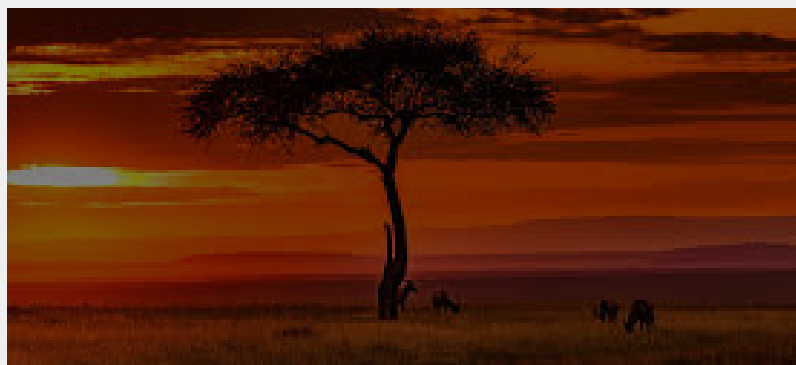
Chairperson MIHS Staff Association, Dean School of Applied Sciences

Mr. Michael Jjemba

Nutritionist & President of the Allied Nutritionists' Association of Uganda

Dr. Kennedy Nkhoma (Moderator)

Research Fellow in Global Health, King's College London, Cicely Saunders Institute





Symposium Summary

Dementia and Advanced Disease in Africa

The Dementia and Advanced Disease in Africa session featured nine insightful presentations that examined the multidimensional challenges of dementia care in Uganda. These presentations explored a variety of themes, including diagnostic practices, caregiving experiences, and the integration of mobile and community-based interventions to improve the quality of life for individuals living with dementia. The presentations highlighted the growing need for enhanced healthcare infrastructure and specialized training in dementia care in Africa. With an estimated 2.13 million people in sub-Saharan Africa living with dementia in 2015—and projections that this number will more than triple by 2050—the urgency for developing culturally appropriate, scalable models of care has never been greater.

Overview of Dementia in Uganda

Prof. Seggane Musisi provided a critical overview of dementia in Uganda, illustrating its increasing prevalence and the associated gaps in diagnosis, treatment, and care. He underscored the challenges that arise from the stigma surrounding mental health, lack of public awareness, and the absence of specialized healthcare services for dementia patients. Prof. Musisi highlighted the necessity for urgent attention to dementia within public health initiatives.

Neurocognitive Testing for Dementia in Uganda

Dr. Janet Nakiggude shared results from a cross-sectional study in central Uganda of how dementia symptoms affect caregiver burden. The study involved 113 patient-caregiver dyads and used standardized tools—including the Addenbrooke's Cognitive Examination, the Neuropsychiatric Inventory, and a culturally adapted Zarit Burden Interview—to evaluate cognitive, behavioural, and psychological symptoms in patients with Alzheimer's and related dementias. Findings showed that symptoms such as delusions, hallucinations, and aggression were significantly associated with caregiver distress. Dr. Nakiggude highlighted the importance of integrating neurocognitive testing into routine care to support early diagnosis and guide targeted interventions for both patients and caregivers.



Challenges of Dementia Care in Uganda

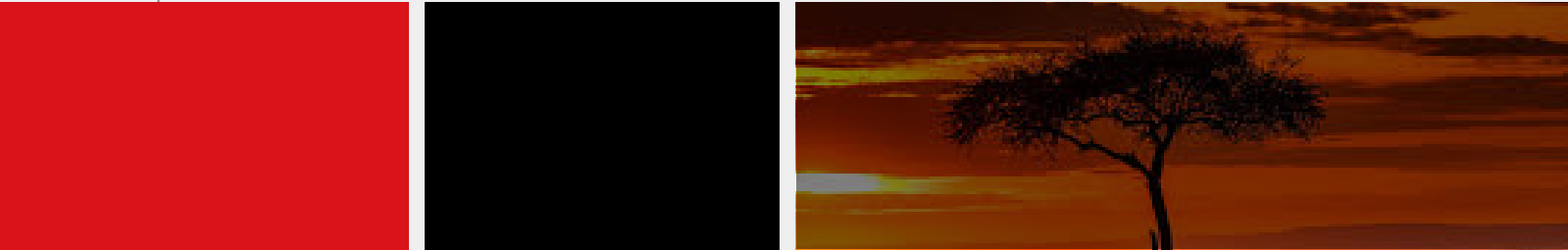
Professor Seggane Musisi presented on the systemic challenges facing dementia care in Uganda, emphasizing delayed diagnosis due to stigma, low public awareness, and misattribution of symptoms to normal aging. He outlined barriers across the care continuum, including a shortage of trained professionals, limited access to affordable diagnostic tools, and the absence of culturally adapted screening instruments. Drawing from a cross-sectional study conducted in Wakiso District, he reported a dementia prevalence of nearly 30% among adults over 60. The findings of this study highlighted gaps in early detection, especially in rural areas, and underscored the urgent need for national strategies to strengthen workforce training, community education, and access to geriatric mental health services.

Screening and Referral for Dementia Care in Uganda

Dr. Racheal Alinaitwe shared findings from a mixed-methods study evaluating the feasibility of using community health workers (CHWs) to screen and refer older adults with cognitive impairment in rural Uganda. Conducted in Wakiso District, the study involved 385 older adults and 12 CHWs trained in the use of the AD8 dementia screening tool. The results showed a 96.4% agreement between CHWs and psychiatric clinical officers in identifying cognitive impairment, with CHWs successfully referring over 90% of suspected cases for further assessment. Qualitative findings revealed that CHWs were trusted by their communities, felt motivated to support older adults, and were well-positioned to provide psychosocial support. However, participants highlighted the need for ongoing training, expanded mental health education, and resource support to sustain their role. Dr. Alinaitwe concluded that CHWs represent a promising workforce for bridging the dementia care gap in LRSs.

Informal Caregiver Experiences for Dementia in Uganda

Dr. Paul Kiwanuka-Mukiibi, Executive Director of the Uganda Alzheimer's Association, provided an in-depth exploration of the challenges faced by informal caregivers of people living with dementia in Uganda. Based on his extensive engagement with families and communities, he illuminated the multifaceted burdens borne by caregivers and compounded by pervasive stigma, limited public understanding of dementia, and delays in diagnosis, often rooted in traditional



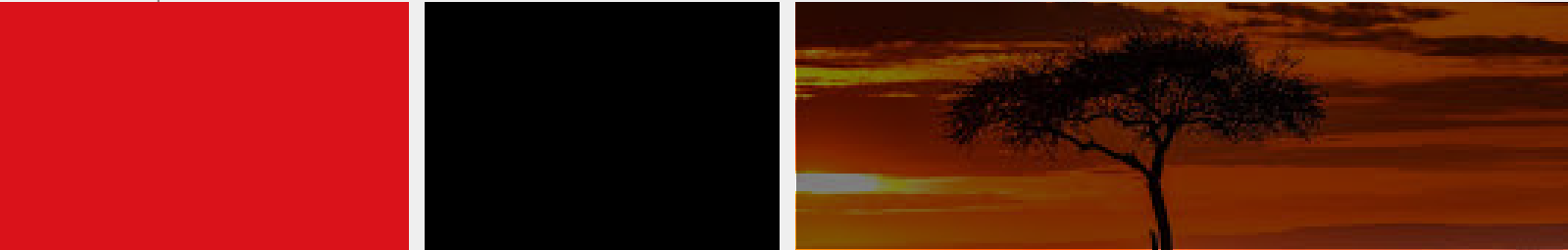
beliefs and insufficient health system infrastructure. Many caregivers are left to manage complex care responsibilities with little formal support or legal recognition. Dr. Kiwanuka-Mukiibi underscored the urgent need for enhanced community education, psychosocial support services, and the development of strong caregiver networks. He also presented the work of the Uganda Alzheimer's Association, which plays a critical role in advocacy, caregiver coordination, and public awareness initiatives aimed at reducing stigma and advancing equitable access to dementia care across Uganda.

Aging

Dr. F. Akosua Agyemang delivered a comprehensive overview of the aging landscape in Ghana and its implications for dementia care, situating the issue within broader demographic and socio-cultural shifts. She noted the rapid rise in the older adult population across sub-Saharan Africa, with Ghana experiencing a notable increase in individuals aged 60 and above. This demographic transition, she argued, is occurring amid the erosion of traditional extended family support systems due to urbanization, migration, and modernization. As a result, many older Ghanaians—particularly those in rural areas—face heightened vulnerability, including poverty, poor healthcare access, and social isolation. Dr. Agyemang drew attention to dementia and other mental health conditions, and misinterpretation of their symptoms, often dismissed due to normal aging or attributed to spiritual causes. She underscored the need for integrated, culturally sensitive healthcare models that bridge geriatric and palliative care with social support systems. Her presentation also spotlighted the University of Ghana's Centre for Aging Studies as a leading institution in advancing aging research, professional training, and policy advocacy to improve the lives of older adults in the country.

Using Mobile Outreach Psychosocial Services to Improve Elderly Quality of Life in Wakiso District, Uganda: A Randomized Controlled Trial

Presented by Professor Seggane Musisi on behalf of Dr. Jane Frank Nalubega, this presentation highlighted the outcomes of a randomized controlled trial evaluating the effectiveness of Mobile Outreach Psychosocial Services (MOPS) in improving the quality of life for older adults in Wakiso District, Uganda. The study compared the MOPS intervention to standard care, using both quantitative methods (including



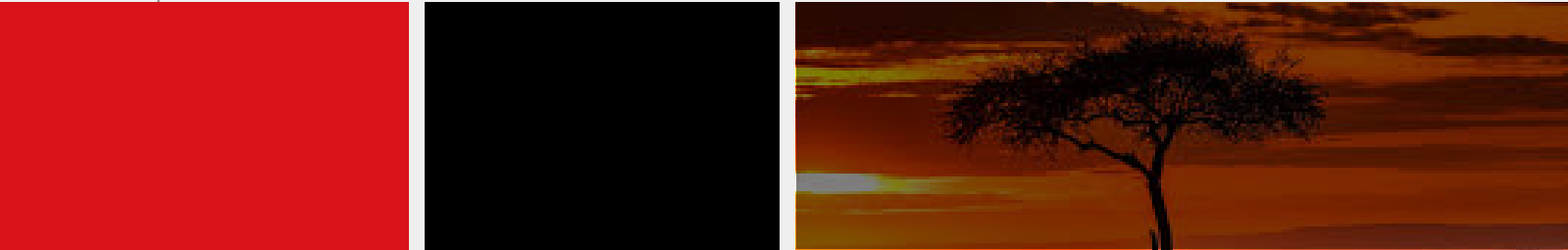
the WHOQOL-BREF scale) and qualitative approaches, such as focus groups and key informant interviews. The intervention trained community geriatric volunteers to provide home-based psychosocial support, engage in community sensitization, and facilitate social and economic activities aimed at enhancing well-being. Findings indicated significant improvements across all domains of quality of life, particularly in environmental well-being. Qualitative results underscored increased self-worth, empowerment, and social engagement among participants. Reminiscence therapy, especially through spiritual music, emerged as a culturally meaningful strategy. Some participants did not find this intervention to be valuable due to differing expectations and limited mental health training for volunteers, but the study demonstrated the potential of community-led outreach models to strengthen psychosocial care and support for aging populations, including those affected by dementia.

Training for Palliative Care for Dementia in Africa

Prof. Musisi returned to discuss the critical need for specialized training in palliative care for dementia patients across Africa. He outlined the lack of formal training programs for healthcare providers and the challenges this poses in delivering quality care. Prof. Musisi argued that training clinicians in palliative care principles tailored to dementia would significantly improve the quality of life for patients and ensure a more compassionate approach to care.

Diet, Nutrition, and Dementia in Western Uganda

Mr. Michael Jjemba delivered a comprehensive presentation on the role of diet and nutrition in the management and potential prevention of dementia in Western Uganda. Drawing from both scientific literature and regional observations, he emphasized that although Western Uganda is a national food basket, malnutrition with childhood growth stunting remains prevalent and has long-term implications for cognitive health. He explored how deficiencies in key nutrients, such as omega-3 fatty acids, folate, vitamin B12, calcium, and polyphenols can impair hippocampal neurogenesis and contribute to neurodegeneration. Mr. Jjemba also highlighted the gut-brain axis, underscoring the importance of probiotics and the gut microbiota in producing neurotransmitters and supporting memory and mood regulation. In addition, he addressed how poor sleep, inadequate dietary habits, and lack of nutrition education further exacerbate dementia risk. His presentation called for targeted, culturally sensitive nutrition



interventions and community-based education programs to improve brain health outcomes and address the growing burden of dementia in aging Ugandan populations.

Key Takeaways: Dementia and Advanced Disease in Africa

The Dementia and Advanced Disease in Africa session underscored the urgent need for comprehensive and culturally sensitive strategies to address dementia care in Uganda and other African countries. Key themes that emerged from the session included the importance of early diagnosis through neurocognitive testing, the necessity of specialized training for healthcare providers in dementia palliative care, and the invaluable role of caregivers, particularly informal ones. The session also highlighted the potential of mobile and community-based interventions, such as mobile psychosocial services, in reaching underserved populations and improving access to care.

One of the most pressing challenges discussed was the lack of infrastructure and resources dedicated to dementia care, particularly in rural areas. The integration of dementia care into primary healthcare settings, supported by mobile technology and community health workers, was presented as a viable solution to bridge these gaps. Furthermore, the session emphasized the need for more research on the dietary and psychosocial aspects of dementia care, as well as the development of robust screening and referral systems.

As dementia continues to affect an increasing number of individuals in Africa, particularly in low resource regions, the session highlighted that a multi-faceted approach, combining improved diagnostic tools, caregiver support, palliative care education, and innovative healthcare delivery models, is needed to address this growing health crisis. The collaborative efforts presented during this session offered a hopeful outlook for improving dementia care in Uganda and can serve as a model for other African nations facing similar challenges.

Symposium Summary

Grief and Bereavement Care in Africa

Featured Speakers

Dr. Iddi Matovu

Programs Director and Deputy Executive Director, Kitovu Mobile Hospice, Uganda

Dr. Wendy Lichtenthal

Founding Director of the Centre for the Advancement of Bereavement Care, Sylvester Comprehensive Cancer Centre at the University of Miami

Dr. Eve Namisango

Programmes and Research Manager, African Palliative Care Association

Ms. Ratidzo Khuoge

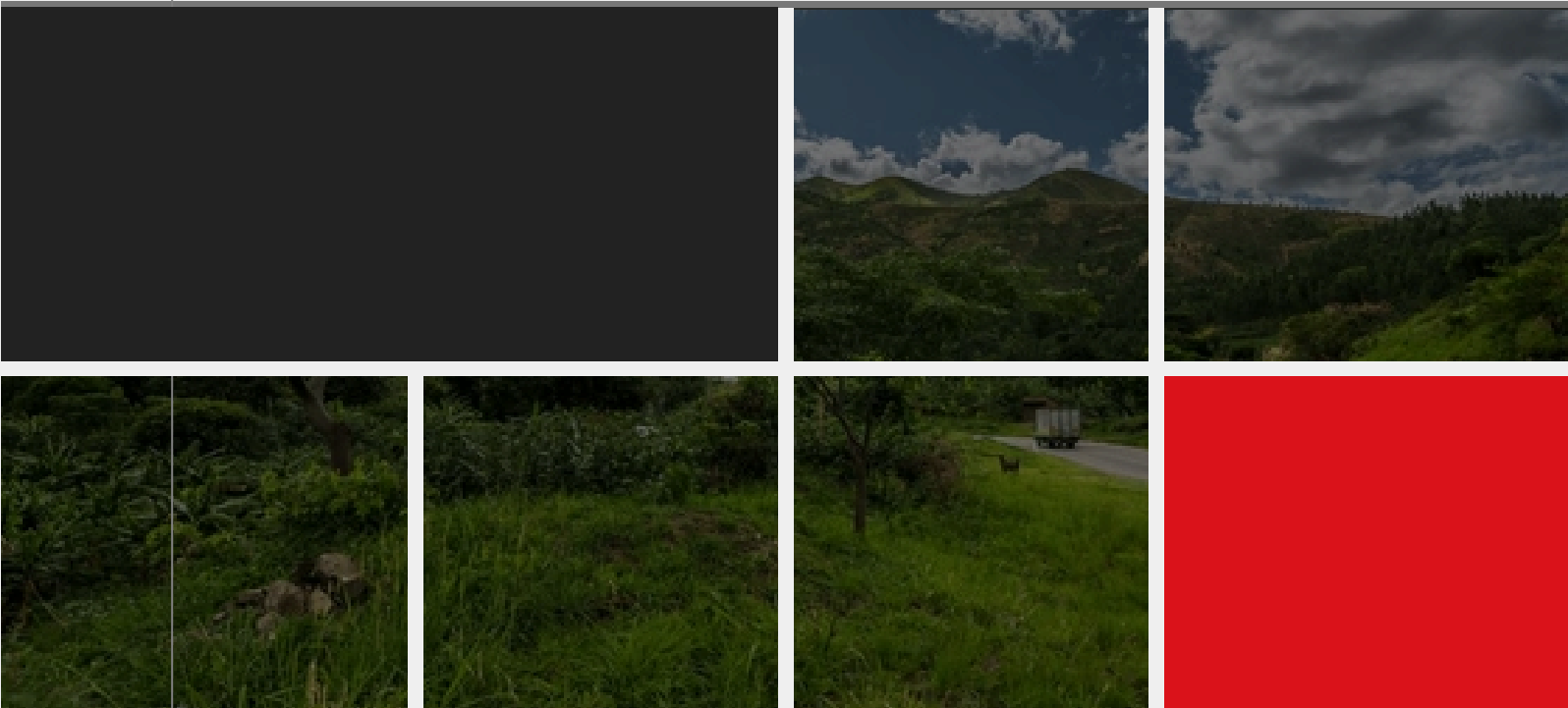
Clinical Social Work Practitioner, Island Hospice and Health Care Zimbabwe

Mr. Saif Mohammed

Academic Consultant, Institute of Palliative Medicine, WHO CC

Dr. Kennedy Nkhoma (Moderator)

Research Fellow in Global Health, King's College London, Cicely Saunders Institute





Symposium Summary

Grief and Bereavement Care in Africa

Grief and bereavement are universal experiences, but formal support systems for those with complicated or prolonged grief reactions remain limited or inaccessible in many African contexts. In the absence of such care, individuals in such states may be required to navigate loss in isolation, compounding emotional distress and complicating the grieving process. This session addressed the urgent need for grief and bereavement support that is both culturally attuned and community driven. By highlighting scalable, context-specific models of care, the session advanced the symposium's broader goal of integrating psychosocial support within palliative care frameworks to improve quality of life for patients, families, and caregivers across the lifespan.

Community-Based Grief and Bereavement Support in Rural Uganda

Dr. Iddi Matovu and Dr. David Muwonge presented a community co-designed approach to increasing awareness about grief and bereavement in rural communities. This model emphasized the importance of local involvement in identifying grief care needs and delivering culturally appropriate support. Given that many individuals in rural communities experience prolonged emotional distress due to a lack of adequate grief support, their approach integrated grief services within palliative care settings to provide holistic, community-centred care.

Dr. Wendy Lichtenthal and Dr. Eve Namisango introduced the development of an evidence-informed bereavement care protocol to guide community-based grief support in rural settings. Their approach aimed to create a standardized yet adaptable framework to support grieving individuals more effectively. A central component of this work was the use of the Bereavement Risk Inventory and Screening Questionnaire (BRISQ), a tool designed to identify individuals at higher risk of experiencing complicated grief. By embedding tools like BRISQ within local care models, the protocol supports the delivery of tailored interventions. Collaboration between healthcare teams and trained community grief counsellors was emphasized as key to ensuring comprehensive, culturally sensitive bereavement care.



Grief and Bereavement Support at Island Hospice, Zimbabwe

Dr. Ratidzo Khuoge shared the Island Hospice, Zimbabwe grief and bereavement model, which integrates grief care with palliative care services. The model uses the nine-cell tool to identify various responses to grief and support the development of appropriate care strategies. Island Hospice's community-based programs, such as the training of grief counsellors, aim to address the emotional needs of bereaved individuals across different cultural contexts. This model has shown effectiveness in reducing grief distress and fostering resilience, particularly in vulnerable populations such as children and survivors of disasters.

Bereavement Companionship Programme in Kerala, India

Mr. Saif Sabel introduced the Bereavement Companionship Programme, an initiative developed by the Institute of Palliative Medicine in Kerala, India. Unlike traditional grief counselling, this initiative focuses on training community members to offer compassionate companionship to grieving individuals. Their goal is to ensure that at least one person in every grieving family or community is equipped with the skills to provide informed emotional support. By emphasizing active listening, emotional validation, and the identification of high-risk grief, this model aims to empower communities to offer sustained support to individuals coping with loss.

Key Takeaways: Grief and Bereavement Care in Africa

A central takeaway was that grief support must be accessible, culturally sensitive, and community driven. Through the presentations, it became clear that empowering local communities with the knowledge and skills to provide grief support can be highly effective. Moreover, the development of evidence-informed protocols, such as the BRISK tool, and the training of community grief counsellors are essential steps toward improving grief outcomes. These models, tailored to specific cultural and socio-economic contexts, provide a sustainable approach to supporting those who have lost loved ones and improve mental health outcomes in grieving individuals.

Symposium Summary

End-of-Life and Advanced Care Planning

Featured Speakers

Dr. Layne Heller

Co-founder of Casa Ahavá, NGO Voices of the World Mozambique

Dr. Eve Namisango

Programmes and Research Manager, African Palliative Care Association

Dr. Craig Sinclair

Senior Research Fellow, University of New South Wales - School of Psychology

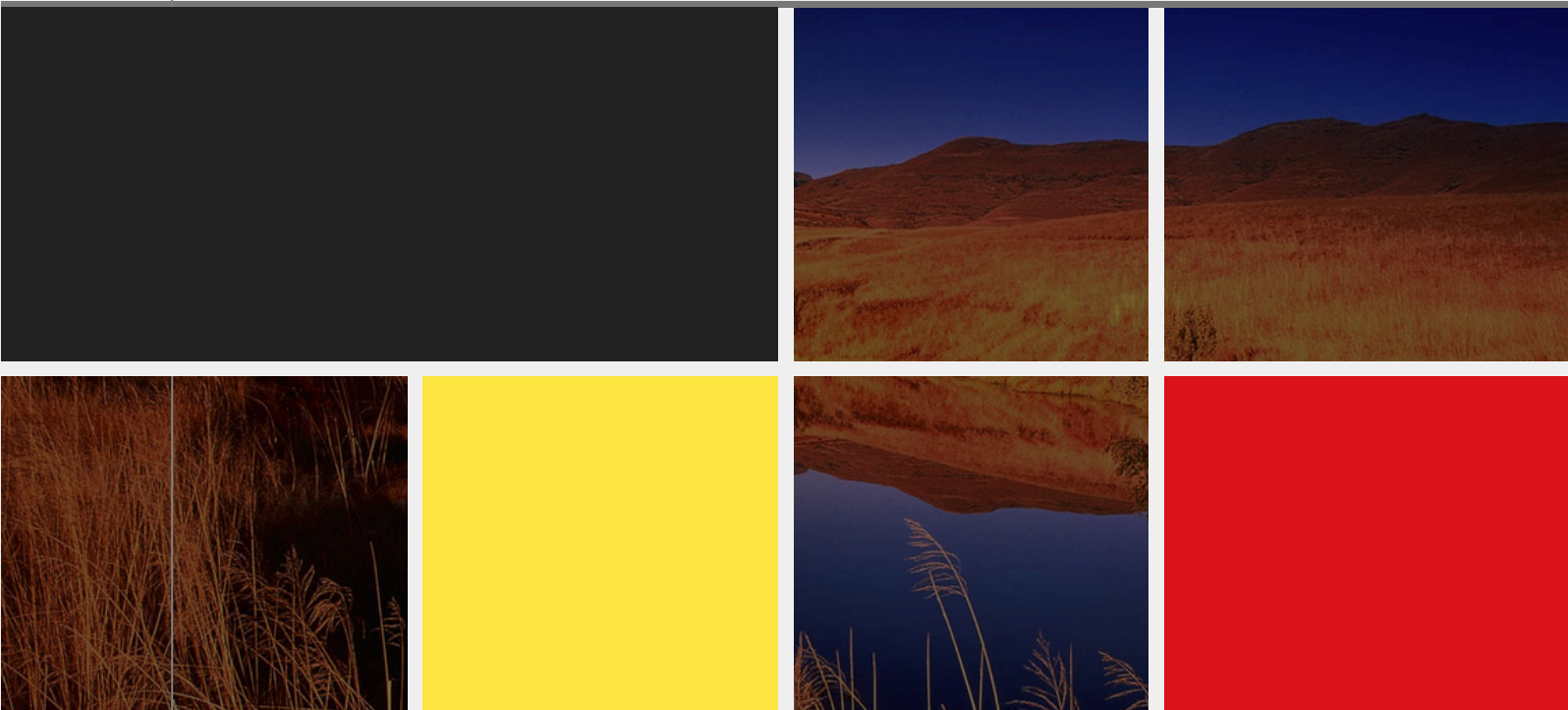
Dr. Allan Sentongo


Assistant Medical Director, St. Francis Naggalama Hospital

Dr. Breffni Hannon (Moderator)

Clinician Investigator, Princess Margaret Cancer Centre

Rose Family Chair in Palliative Medicine and Supportive Care, University of Toronto





Symposium Summary

End-of-Life and Advanced Care Planning

Across diverse cultural and healthcare settings, end-of-life and advanced care planning remain critical yet under-addressed components of quality care. In many African contexts, structural barriers, limited resources, and sociocultural taboos surrounding death and dying inhibit meaningful dialogue and planning. This session examined the obligation to promote person-centred, values-driven approaches that honour patient autonomy and cultural context. In doing so, it advanced the symposium's commitment to equitable, dignified, and compassionate care for individuals facing serious illness at the end of life.

Exploring End-of-Life Care Preferences in Mozambique

Dr. Layne Heller presented an overview of end-of-life care in Mozambique, emphasizing the disconnect between national palliative care policies and the realities of implementation on the ground. While the country has developed frameworks—including policies, training manuals, and curricula—palliative care remains largely absent from routine healthcare delivery. Dr. Heller noted that there is only one dedicated palliative care unit in the country, serving a narrow patient population and leaving significant gaps in access and support. Her presentation drew attention to the burdensome journey of many patients, particularly those with advanced cancer, who must navigate long waits and multiple transportation hurdles. Through a cross-sectional survey, she explored patient preferences surrounding treatment decisions, place of death, and the use of traditional medicine. Her findings revealed the importance of culturally rooted approaches that honour communal care structures and spiritual beliefs. Dr. Heller called for the development of African models of palliative care that are both responsive to patient values and integrated meaningfully into the health system.



Enhanced Advanced Care Planning and Life Review, Longitudinal Intervention

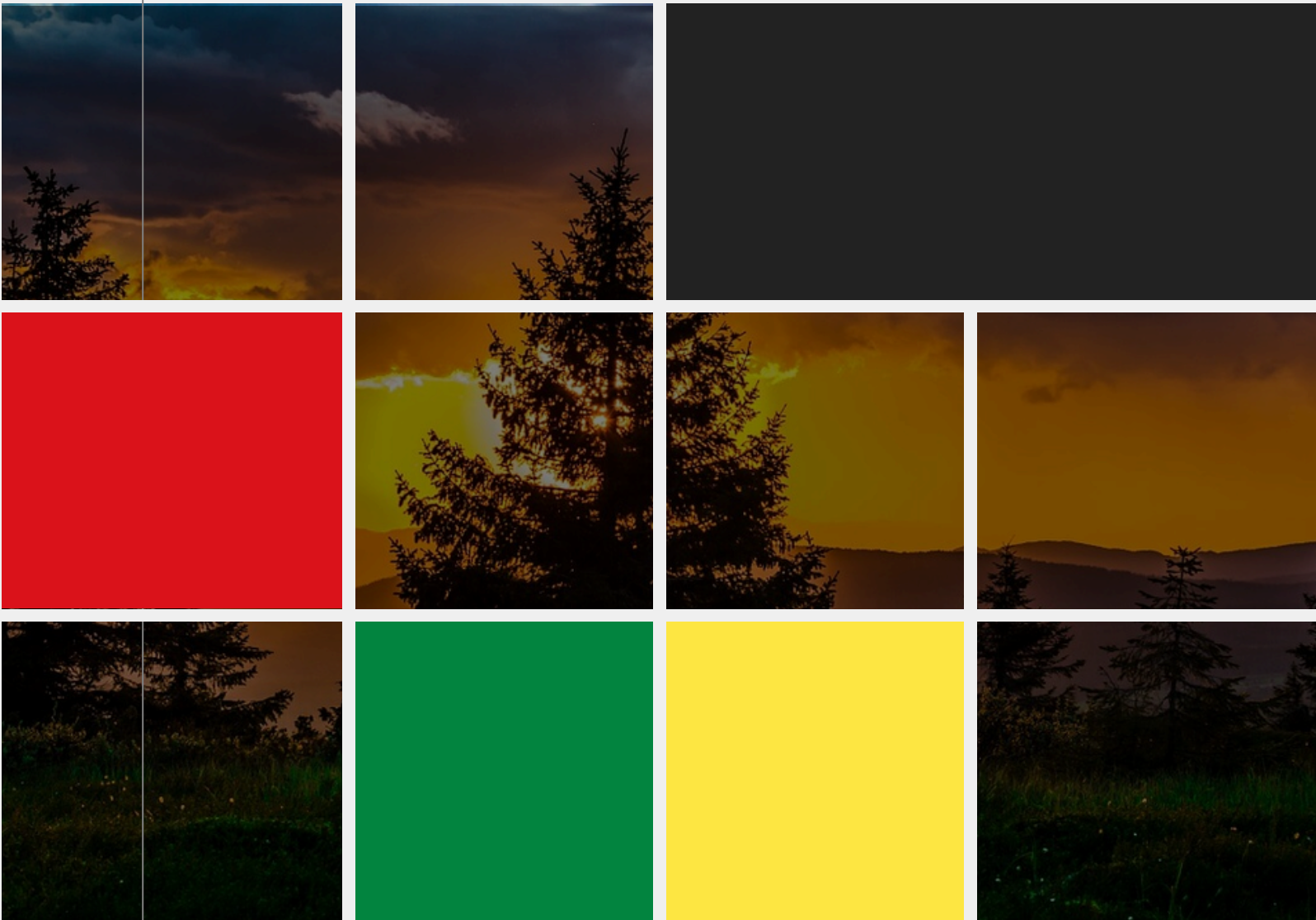
Dr. Craig Sinclair, from the University of New South Wales, presented on the Enhanced Advance Care Planning and Life Review Longitudinal Intervention (EARLI) Project. This initiative aims to strengthen the quality and timing of advance care planning by integrating life story work into early conversations about future care. Rather than focusing solely on anticipatory medical decisions, the EARLI Project centres on eliciting patients' values, goals, and preferences to inform care that reflects what matters most to them. Designed for individuals on a frailty or cognitive decline trajectory, the intervention includes a series of structured sessions that support reflection on personal history and identity, leading to more meaningful and timely advance care planning. By fostering earlier engagement and involving families and healthcare providers, the project seeks to improve documentation, reduce decisional conflict, and enhance emotional well-being for both patients and caregivers.

Key Takeaways: End-of-Life and Advanced Care Planning

This session highlighted the crucial role of advanced care planning in improving end-of-life care. Dr. Heller's presentation on Mozambique underscored the need for culturally sensitive models that prioritize patient preferences, while Dr. Sinclair's work in Australia emphasized the importance of earlier engagement in advanced care planning, using life story work as a key tool to help patients articulate their values and make informed decisions about their future care. Both speakers shared a commitment to improving patient autonomy and ensuring that care aligns with individuals' values, goals, and cultural contexts. These insights provide valuable lessons for enhancing palliative care practices across the globe.

Emerging Themes

The GIPPEC Africa Symposium on Psychosocial, Palliative, and End-of-Life Care illuminated several emerging themes critical to enhancing care for patients with advanced diseases, particularly within the African context. These themes centred on cultural relevance in care models, integration of psychosocial support, the role of community and family, and the development of tools for improved end-of-life care experiences. The presentations collectively pointed to a pressing need for tailored, context-specific interventions in palliative care, as well as the importance of addressing both the physical and psychosocial aspects of terminal illness.





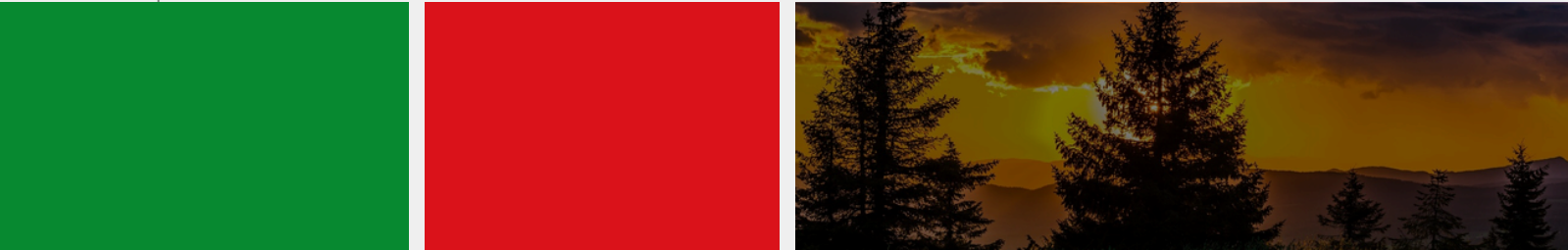
Emerging Themes

Cultural Relevance in Palliative Care Models

One of the most prominent themes that emerged throughout the symposium was the need for culturally relevant palliative care models. Dr. Layne Heller's work in Mozambique, along with discussions in the QODD-RGV session, highlighted the significance of understanding and adapting interventions to local cultural practices and beliefs. In Mozambique, for instance, traditional medicines and spiritual beliefs play a crucial role in the patient experience of illness and death. The integration of CALM, a psychotherapeutic intervention that addresses existential and relational distress in cancer patients, was recognized as particularly valuable in contexts where mental health and cancer care resources are limited. However, the adaptation of such models requires a deep understanding of local cultural frameworks, which can significantly influence care delivery. Similarly, the adaptation of the QODD-RGV tool for use in African settings involved culturally sensitive modifications, ensuring that the tool reflects local beliefs about death and dying. These insights emphasize the importance of developing palliative care solutions that are not only clinically effective but also resonate with the cultural values of the patients they serve.

Psychosocial Support and Mental Health in Palliative Care

Another recurring theme was the integration of psychosocial support in palliative care. Several presentations underscored that palliative care must go beyond physical symptom management to address the emotional, psychological, and existential needs of patients and their families. Dr. Rodin's presentation on CALM demonstrated the potential role of supportive-expressive therapy in helping patients navigate their distress and find meaning in their experiences. The CALM framework provides a structured approach to address the emotional and relational aspects of living with advanced cancer, thereby enhancing patients' quality of life. This was echoed in Dr. Craig Sinclair's presentation on advanced care planning



in Australia, where Life Story Work (LSW) is used as a tool to engage patients in discussions about their values and preferences (Kaiser & Eley, 2016, p. 16). These interventions emphasize the importance of providing patients with the space to reflect on their life story and prepare for the future in a way that respects their individual needs and desires.

Family and Community Involvement in End-of-Life Care

The involvement of family and community in end-of-life care emerged as a key theme across the symposium. Dr. Namisango's insights into the African perspective on death emphasized that a "good death" is deeply rooted in the presence and support of loved ones, as well as the emotional and spiritual support they can provide. This communal approach contrasts with more individualistic models of care seen in the West. The importance of family caregivers was also discussed in the QODD-RGV session, in which the tool's development considered the critical role of caregivers in the dying process. Family members not only serve as emotional supporters but also as key decision-makers who often face the dual burden of caregiving and managing their own grief. Supporting caregivers through training, emotional support, and involvement in care planning is crucial to improving the end-of-life experience for both patients and families.

Need for Early and Proactive Advanced Care Planning

Another theme that emerged throughout the symposium was the need for early and proactive advanced care planning. Dr. Craig Sinclair highlighted the importance of engaging patients in advanced care planning discussions before they are faced with a crisis, such as hospital admission or the decline associated with chronic conditions like frailty. Early planning, he argued, provides patients with the opportunity to reflect on their goals, values, and preferences in a more familiar and less stressful environment. This is consistent with the findings from the CALM framework, which emphasizes the importance of addressing existential concerns at the "tipping point" in a patient's journey, when they perceive their time may be limited. By broaching advanced care planning early, healthcare providers can ensure that decisions made later reflect the patient's preferences and that the burden of decision-making is shared with family members.



Global Collaboration and Knowledge Exchange

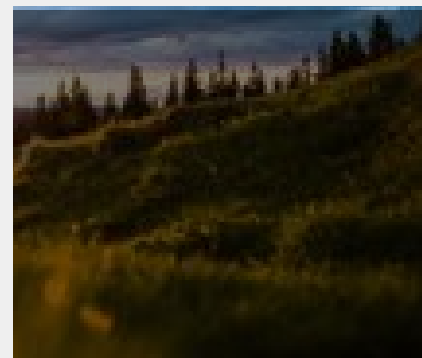
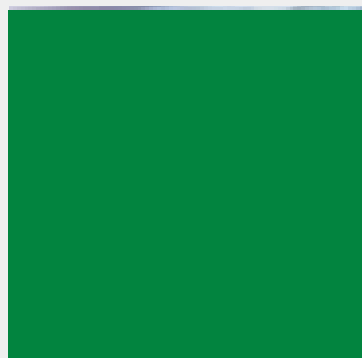
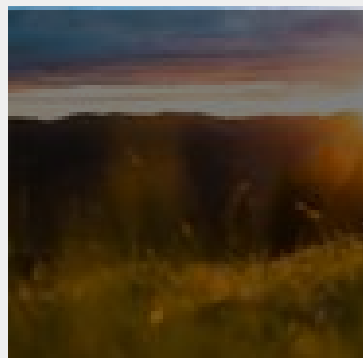
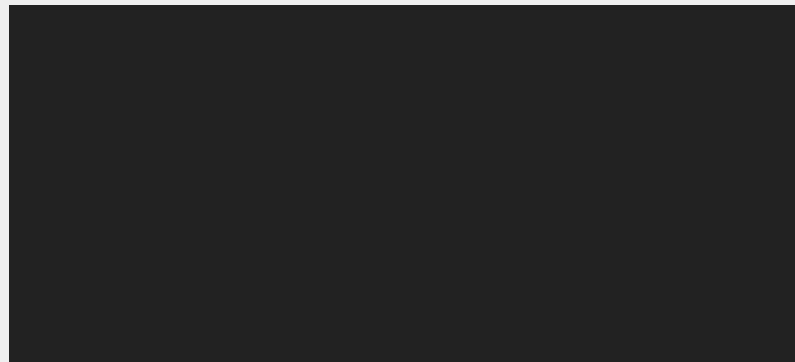
The final theme that emerged was the importance of global collaboration and knowledge exchange in improving palliative care. The discussions highlighted that the challenges in providing palliative and end-of-life care are global, but that solutions must be locally adapted. The symposium provided a platform for international collaboration, with speakers from different regions sharing their experiences and approaches to palliative care. This cross-cultural exchange is vital for advancing the field, as it allows practitioners and researchers to learn from each other's successes and challenges. Moreover, the research shared during the symposium, such as the ongoing validation of the QODD-RGV tool in North America and Malawi, emphasizes the need for collaborative efforts in developing and refining palliative care tools that can be used globally.

Conclusion

Overall, the GIPPEC Africa Symposium highlighted the need for culturally relevant, supportive, and community-oriented palliative care approaches. The integration of psychosocial support, family involvement, early advance care planning, and culturally modified tools, such as CALM and the QODD-RGV, are crucial for improving the quality of care for patients facing advanced diseases. It was highlighted throughout the symposium, that palliative care should not only address physical symptoms but also encompass the emotional, spiritual, and social dimensions of the patient's journey. This holistic approach promises to enhance the quality of life and dying for patients, their families, and communities, fostering a more compassionate and culturally attuned model of care globally.

Research Directions and Key Priorities

The GIPPEC Africa Symposium served as a critical forum for identifying research priorities and actionable strategies in the domains of psychosocial, palliative, and end-of-life care across African contexts. Drawing from post-symposium surveys and expert discussions, a number of recurring themes emerged that reflect both the urgency and complexity of improving care for individuals with advanced illness. These themes underscore the importance of culturally grounded, community-informed, and systems-based research that attends to the realities of care delivery in low-resource settings. From the pivotal role of family and community supports to the integration of traditional medicine and the advancement of contextually relevant assessment tools, each identified priority area highlights the multifaceted nature of palliative care needs. The ensuing sections synthesize these focal areas, offering a roadmap for future inquiry and collaboration that centers on dignity, equity, and cultural sensitivity in care.





Research Prospects and Recommendations

Community and Family Support in Palliative Care

A recurrent theme from the post-symposium survey responses was the importance of community and family support structures in the delivery of palliative care. Respondents highlighted that strengthening these support systems is essential to improving the quality of life for patients and their families. As noted by one survey respondent, "Community and family support in palliative care should be a priority." Research should focus on the development and implementation of community-led models of care, particularly in rural and underserved populations, where access to formal healthcare is often limited. Furthermore, the integration of family caregivers into the care process is critical for ensuring holistic, patient-centred palliative care. Investigating the effectiveness of culturally grounded grief interventions for rural communities is particularly important for addressing the unique needs of these populations.

Cultural and Spiritual Dimensions of Palliative Care

Cultural beliefs, spirituality, and religious practices play a significant role in shaping patients' perceptions of death, dying, and care decisions, especially in African settings. The data shows that spirituality and religious beliefs in end-of-life care decisions were considered a priority for future research. As one participant emphasized, research should focus on "understanding traditional and cultural ways of grief," which will be crucial for adapting palliative care models to local contexts. Palliative care interventions must be sensitive to these cultural dimensions to improve patient satisfaction and enhance care experiences. Moreover, the integration of alternative and traditional medicine approaches in symptom relief for palliative care patients remains a critical area for exploration. Research should examine how traditional healing practices can complement formal palliative care, especially in areas with limited access to pharmaceuticals.



Culturally Relevant Assessment and Outcome Measures


The survey results highlight the need for validating and implementing culturally relevant assessment and outcome measures. The development of tools, such as the Quality of Dying and Death - Revised Global Version (QODD-RGV) is a step in the right direction, but further research is needed to validate these tools across diverse cultural settings. Respondents noted the a need to create outcome measures that resonate with the experience of local populations experiences, ensuring that these tools are both effective and widely applicable. This research could help improve the global standardization of palliative care quality metrics while also making them more culturally appropriate and sensitive.

Health System Gaps and Access to Care

Health system gaps and access to care, especially in LRSs, were flagged as key issues by many survey participants. There is a clear need for research to identify and address the systemic barriers preventing equitable access to palliative care. Survey responses emphasized the importance of policy advocacy and health system integration to ensure sustainable and equitable access to care. This includes not only improving infrastructure but also addressing economic and financial barriers to accessing palliative and end-of-life care. Further research should investigate how health policies can be restructured to incorporate palliative care services as an essential component of healthcare, with a particular focus on L-MICs.

Digital Health Tools and Technological Innovations

The potential for digital health tools and technology to enhance patient support and care delivery was another area highlighted in the survey. Innovations, such as AI-driven mental health support systems, virtual reality for pain management, and telemedicine for remote consultations are emerging as promising solutions in palliative care. As noted by survey respondents, such tools could help overcome challenges posed by geographic barriers and limited access to specialized care. Future research should focus on developing and testing digital tools that are



adaptable to local conditions and can improve both patient care and healthcare provider support. These technologies could also help track patients' conditions, offering real-time insights and support to caregivers.

Training and Capacity-Building for Healthcare Professionals


The importance of training and capacity-building for healthcare professionals and caregivers in palliative and psychosocial care cannot be overstated. Respondents pointed out that there is a critical need to build local expertise in providing palliative care, which includes both formal training programs for healthcare workers and educational initiatives targeting community caregivers. Additionally, enhancing the knowledge and skills of healthcare professionals regarding culturally sensitive approaches to palliative care will help foster more effective communication and improve patient outcomes. This also ties into the broader need for policy advocacy to incorporate palliative care education into medical curricula across various countries.

Economic Impact of Caregiving and Policy Interventions

Several respondents underscored the economic impact of caregiving as a significant challenge in palliative care. There is an urgent need for research into the economic costs associated with caregiving, both in terms of financial burdens on families and the wider societal costs. This research could inform policy interventions to improve affordability and access to palliative care services, ensuring that caregivers are not left to bear the financial and emotional weight of care alone. Research into economic and financial barriers to accessing palliative care will also be essential for shaping future funding strategies.

Conclusions

The post-symposium survey and short-answer responses highlight several important directions for future research in psychosocial, palliative, and end-of-life care. Key priorities include addressing health system gaps, integrating cultural and spiritual perspectives into care, and



improving community support structures. Digital health tools and technological innovations present exciting opportunities for expanding care access, particularly in LRSs. Furthermore, there is a pressing need to develop culturally relevant assessment tools, build healthcare professional capacity, and assess the economic implications of caregiving.

To advance the field, future research must embrace an interdisciplinary approach, involving healthcare professionals, caregivers, policymakers, and communities in a collaborative effort to improve palliative care outcomes. A focus on innovations—particularly those that are contextually relevant—will be crucial for addressing the unique challenges faced by patients and their families, particularly in LRSs.

These research directions are not only vital for improving palliative care in Africa but also have global implications for enhancing the dignity, quality of life, and compassionate care of individuals facing serious illness and end-of-life.







Conclusion


The Africa Symposium on Psychosocial, Palliative, and End-of-Life Care provided an enriching and impactful platform for sharing insights, experiences, and strategies aimed at improving palliative care across the continent. The symposium facilitated critical discussions around the integration of psychosocial and palliative care in Africa, offering a space for local and international professionals to collaborate on the challenges and opportunities in the field. Presentations on various models, including CALM therapy, the Quality of Dying and Death (QODD-RGV) tool, the Symptom Tool Kit and advance care planning, illuminated the complex issues surrounding end-of-life care, particularly in low resource settings. The event successfully highlighted the need for culturally adapted care models and emphasized the importance of integrating psychological, relational, and existential support for patients and their families.

The symposium received overwhelmingly positive feedback, with participants expressing their appreciation for the quality and depth of the discussions. The virtual platform was particularly praised for its accessibility and ease of use, enhancing engagement and participation. According to the post-symposium survey, attendees were particularly interested in continuing to expand the reach of CALM therapy globally, with a focus on adapting and applying the model in diverse African contexts. A significant portion of responses emphasized the importance of community and family support in palliative care, highlighting the need for research into culturally grounded interventions for grief and bereavement, particularly in rural and underserved areas.



Further research was widely recommended in areas, such as the validation and implementation of culturally relevant assessment and outcome measures, the integration of alternative and traditional medicine approaches in symptom relief, and the exploration of digital health tools to enhance patient support and care delivery. Many



respondents also noted the importance of addressing the economic and financial barriers to accessing palliative care, advocating for policy changes that improve the affordability and sustainability of services. Other key themes included the importance of training healthcare professionals and caregivers in psychosocial and palliative care and integrating spiritual and religious considerations into end-of-life care decisions.



In conclusion, the symposium underscored the critical role of research in shaping the future of palliative care in Africa, particularly in terms of adapting interventions to local cultural and socioeconomic contexts. There was consensus about the need for continued collaboration, innovation, and the development of comprehensive, community-based care models that prioritize the needs of patients, families, and caregivers. The success of the symposium and the valuable feedback provided by participants will serve as a foundation for future endeavours aimed at improving the quality of life for individuals facing advanced illness in Africa.



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ACP-i 2025, September 24-26



ACP-i 2025

INTERNATIONAL CONFERENCE AUSTRALIA

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Appendix A.1

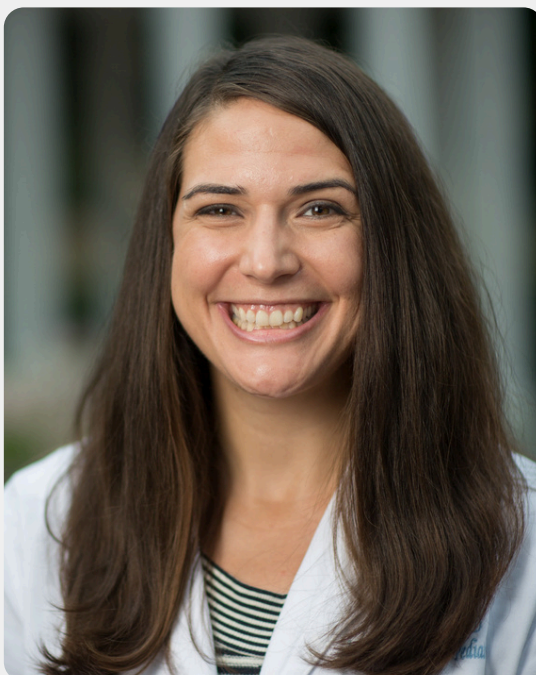
Planning Committee



Dr. Gary Rodin
MD



Director of the Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC) and Professor of Psychiatry at the University of Toronto. He is a clinician-investigator with expertise in the psychiatric and psychosocial aspects of cancer and other medical illnesses. Dr. Rodin leads research on the psychological impact of advanced and terminal disease in affected patients and their families.



Dr. Alyssa Tilly
MD



Assistant Professor in the Departments of Medicine and Pediatrics at the University of North Carolina (UNC) School of Medicine. Dr. Tilly is board certified in Hospice and Palliative Medicine, Internal Medicine, and Pediatrics. She is part of the Inpatient Adult Palliative Care and Children's Supportive Care Teams and leads the Hospice and Palliative Medicine Fellowship. Her research focuses on global oncology palliative care for patients of all ages.

Appendix A.2

Planning Committee



Dr. Eve Namisango
PhD



Programmes and Research Manager at the African Palliative Care Association and honorary senior health scientist at the College of Health Sciences, Makerere University. Dr. Namisango holds a master's and PhD in palliative care and rehabilitation from the Cicely Saunders Institute, King's College London. Her research interests include end-of-life care, quality of death and dying, social justice, health systems strengthening, and the use of technology in palliative care.



Lesley Chalklin
MSc.



Program Manager for GIPPEC. Lesley completed her Masters in Health Administration and holds a Project Management certification. In addition to her role with GIPPEC, she has worked as Project Manager with the Global Cancer Program, the Department of Supportive Care, and the Adolescent and Young Adult Program at the Princess Margaret.

Appendix B.1.

Speaker Biographies



African Palliative Care Association

Relieving Pain & Suffering

Dr. Emmanuel Luyirika

MFM, MPA, BPA, MB, CHB

Dr. Emmanuel Luyirika is Executive Director of the African Palliative Care Association a pan-African palliative care organization with programmes in several African countries. He is a board member of the Worldwide Hospice Palliative Care Alliance. He has been President of the Board of CoRSU Hospital for the last 8 years. Previously, he was clinical and country director of Mildmay International in Uganda from 2002 to 2011.

He also worked for the Department of Health in South Africa and lectured in Family Medicine at the Medical University of Southern Africa. He has served on several technical committees at Ministry of Health Uganda, Uganda AIDS Commission, WHO, UNICEF and UNAIDS and as Vice Chairperson of the Council of the Institute of Hospice and Palliative Care in Africa.

He has also been part of International Atomic Energy Agency/WHO ImPACT missions in Africa. He studied medicine at Makerere University in Uganda, Medical University of Southern Africa, and the University of Stellenbosch in South Africa. He is a co-investigator on ongoing studies in palliative care and has been an investigator and published on several HIV, cancer and palliative care research projects and served on Data Safety Monitoring Boards and technical steering committees of research studies in Africa. He has been a co-author of several chapters in cancer and palliative care books.

Appendix B.2

Speaker Biographies



Mr. John Lule

Dip.ClinMedPH

I hold a diploma in Clinical Medicine and Public Health with 2 years of experience in the medical field as a Medical Clinical Officer and 17 months of working as a CALM Therapist at Kitovu Mobile Hospice.

I am a graduate of Aspire Leaders Program and alumni as well. I have undergone a short course training in Palliative Psychiatry organized by African Palliative Care Association (APCA) and taking on a short course in Managing Sickle Cell Disease prepared by Enrich. I am currently undergoing biweekly CALM Therapy supervision sessions with Dr. Gary Rodin (GIPPEC) that check and improve the quality of therapy provided to patients living with advanced diseases.

With that skill set, I am capable of handling palliative care patients at all levels especially those living with advanced diseases and I am a potential team leader.

Appendix B.3

Speaker Biographies



Mr. John Bosco Kafuuma

RN

Kafuuma Johnbosco is a professional councillor, registered nurse with a credential in Palliative care psychiatry from APCA dedicated with over 5 years of clinical practice currently serving as a medical ward manager at St. Francis Naggalama hospital overseeing a team of nurses and actively implementing initiatives to enhance patient care quality.

Kafuuma Johnbosco is a CALM Therapist working in hand with the palliative care team of St. Francis Hospital Naggalama, with its exceptional patient care with composure and proficiency, the team offers end of life care at secondary/intermediary level to clients with life limiting illness within central and parts of the eastern Uganda.

Appendix B.4

Speaker Biographies



Dr. Jared Lowe
MD, HMDC



Dr. Jared Lowe is an Assistant Professor in Medicine. He is board certified in Internal Medicine and is board certified in Hospice and Palliative Medicine. Dr. Lowe is an attending physician in the UNC adult palliative care program and is a team physician with UNC Hospice.

Dr. Lowe completed medical school at the University of North Carolina. He received his residency training in internal medicine at Duke University and served as chief resident, as well as completed his fellowship in Hospice and Palliative Medicine at Duke University. His clinical interests are in improving the delivery of hospice and palliative care in the community.



Ms. Mary Goombs
MSc.



Mary Goombs is a Clinical Research Analyst within the Department of Supportive Care at the Princess Margaret Cancer Centre. She recently completed her MSc at the Institute of Medical Science at the University of Toronto under the supervision of Dr. Gary Rodin. Her current ongoing work involves the validation of the Quality of Dying and Death – Revised Global Version (QODD-RGV) questionnaire, a novel questionnaire aimed at measuring the quality of dying and death using proxy ratings provided by bereaved caregivers. In the past her work has involved analysing and comparing data collected in Uganda and Kenya using the Quality of Dying and Death (QODD) questionnaire, the predecessor of the QODD-RGV questionnaire.

Appendix B.5

Speaker Biographies



UNC Project
Malawi

UNC | INSTITUTE FOR GLOBAL HEALTH
AND INFECTIOUS DISEASES

Ms. Maria Chikasema

BSc.

Ms. Maria Chikasema is a senior research nurse, oncology team leader, and palliative care specialist with 29 years of clinical experience. She holds a BSc in Palliative Care from Makerere University and leads efforts to integrate palliative care at Malawi's National Cancer Centre while training multidisciplinary teams. She currently works with the University of North Carolina Project-Malawi Cancer Program and is pursuing a Master's in Palliative Care. She has served 22 years as a Research Nurse, contributing to pivotal studies such as HPTN 024, BAN, and ACTG 5263 and has been a Certified oncology nurse for 11 years leading multiple trials on cancers prevalent in Malawi, including lymphoma, breast, and oesophageal cancers. Her professional training includes programs with Canada's Cross Cancer Institute and De Souza Institute. She is dedicated to advancing oncology and palliative care through innovative research, improving patient outcomes, and presenting findings at international platforms such as AORTIC.

Appendix B.6

Speaker Biographies



Dr. Kennedy Nkhoma

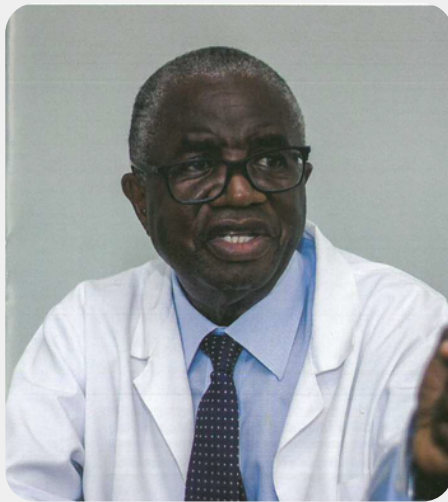
RN, MSc, BA, FHEA.

Dr. Nkhoma has a background in nursing education, practice and health services research. He joined King's College London, Cicely Saunders Institute in 2016 as a Research Fellow (Florence Nightingale training fellowship). His fellowship focused on self-management interventions for people living with HIV/AIDS. He is currently the Scientific lead for an NIHR funded project on Global Health Palliative Care (GHAP) across three countries in Africa (Uganda, South Africa and Zimbabwe). He is a co-applicant in the ExtraCECI project.

Dr. Nkhoma has worked on a number of global health research projects to develop his expertise in both quantitative and qualitative research methods as applied to palliative care: such as 1) ASSET: heAlth Systems StrEngThening in sub-Saharan Africa, 2) Digi-Pall: Digital technology in palliative care, 3) PRISM: Pain Relief Interventions using Self-Management, 4) MAPS: Modelling an appropriate pain self-management intervention for adolescents with HIV/AIDS in Malawi, 5) REaCH: Remote consulting in primary care, 6) person centred care for patients with serious illness, and 7) MAP-care: MAP-care: Multimorbid Ageing Primary Palliative Care.

Appendix B.7

Speaker Biographies



Prof. Seggane Musisi

MD, FRCP(C)

Prof. Seggane Musisi is the former Head of Psychiatry at Makerere University College of Health Sciences where he obtained his medical degree and then went for specialist Psychiatry training at the University of Toronto, Canada. With research interest in Psychosomatics, Liaison and Intensive Care Psychiatry, he published on Eating disorders, Depression, Sleep disorders, Tourette's syndrome and Intensive Care Psychiatry. Upon return to Uganda, he founded the African Pyscare Research Organization (APRO), to research, teach and consult on mental health problems in Africa focusing on emerging new mental health challenges. He has researched and published widely on brain degenerations in Africa, HIV mental health problems, war-related psychological trauma, severe mental illness and old age psychiatry as well as traditional healing practices connecting traditional and contemporary approaches to mental wellness, cognizant of cultural influences on African psychiatric symptom presentation and health seeking. He has written papers, books, book-chapters, editorials and has convened conferences. He sits on various boards, has been Editor-In-Chief of two scientific journals and has won grants and awards, including the Fulbright New Century Scholars award. He is a Fellow of the Uganda National Academy of Sciences (UNAS) and is the founder and CEO of Entebbe Lakeside Hospital in Entebbe, Uganda. Prof. Seggane Musisi has been the architect of general hospital psychiatry in Uganda thus championing the integration of psychiatry in general hospital medical practice in this country, thus bringing mental health care to the common person at their nearest health facility or Health Centre. He is an internationally celebrated and industrious psychiatrist, teacher, researcher, clinician and medical innovator.

Appendix B.8

Speaker Biographies



Dr. Racheal Alinaitwe

MBChB. MMED (Psych)

Dr. Racheal Alinaitwe is a young psychiatrist and researcher with a special interest in old-age mental health. She has worked as a program manager for several research projects in the Department of Psychiatry, at Makerere University for the past 5 years since the completion of her master's degree training. She is also a practicing psychiatrist and the head of the mental health department at Jinja Regional Referral Hospital, Uganda. She recently completed a D43 research fellowship with Washington University in St. Louis and Makerere University. She has conducted research on the feasibility of community health workers in identifying and referring older persons with cognitive impairment in the community.

Her PhD work is on unmet needs of caregivers of older persons with dementia within the Ugandan rural community. In this work, Dr. Alinaitwe continues to identify the need for early access to care for people with dementia and their caregivers.

Appendix B.9

Speaker Biographies



Dr. Paul Kiwanuka-Mukiibi

MD

Dr. Paul Kiwanuka-Mukiibi is the Executive Director and founder Board member of the Uganda Alzheimer Association. Before his current role, he was the Managing Director/Founder of PS Consulting a health development and management consulting firm.

He has over two decades of experience as a research, policy, and development specialist working with the public, private-not-for-profit and private sectors in Uganda, Kenya, Lesotho, Malawi, Mozambique, South Sudan, South Africa, Tanzania, Zambia and Zimbabwe.

He has provided technical assistance to the Uganda Ministry of Health and other line-ministries, and ministries of health in the region, as well as to national health programmes funded by Development Partners including the WHO, World Bank, USAID, UKAID/DfID, AusAID, KfW and Irish Aid, amongst others. He has served as a Senior Policy and Strategy Adviser seconded to ministries of health within the region, and as a member of numerous national policy-formulation and implementation bodies and technical working groups.

Appendix B.10

Speaker Biographies



Dr. F. Akosua Agyemang

PhD

Dr. F. Akosua Agyemang is a Senior Lecturer at the University of Ghana, Legon, specializing in social gerontology, ageing, and social support systems. She holds a PhD in Social Work from the University of Ghana and has over 37 years of experience in social work, community development, and elderly care.

Dr. Agyemang has lectured at multiple institutions, including the Family Health Department at the University of Ghana Medical School, the College of Physicians and Surgeons, and international universities such as Jönköping and Södertörn Universities in Sweden. She has conducted extensive research on ageing, long-term care, and social well-being, publishing widely on these topics. She actively mentors students and supervises theses at the master's and PhD levels.

Dr. Agyemang has also worked internationally, including at Ruth Sheets Elderly Day Care Centre (USA), and affiliated with professional associations such as the National Alliance for Caregiving. She plays a key role at the Centre for Ageing Studies, advocating for elderly welfare and stakeholder engagement.

Appendix B.11

Speaker Biographies



Dr. Jane Frank Nalubega

PhD

Jane Frank Nalubega (PhD), a seasoned Senior Lecturer, Executive Manager, and Consultant with two decades of experience in mental health, I bring a wealth of expertise to address vulnerable populations and foster positive change. My background includes extensive work in clinical psychology, management, and leadership, complemented by a PhD. Since 2009, I've been actively involved in higher education, developing curricula and mentoring students. I am a passionate advocate for elderly mental health and quality of life, and I've developed innovative programs and models to improve their well-being. My research, spanning ethnographic fieldwork and the development of community-based interventions, focuses on assessing quality of life and empowering community resources. My commitment is to utilize my skills to enhance the mental, physical, and social functioning of high-risk groups and the general population, especially in times of crisis.

Appendix B.12

Speaker Biographies

**Mr. Michael Jjemba***B.Sc.*

A professional Nutritionist having over 6 years of Experience working in Nutrition implementation and programming with a Degree in Human Nutrition from Makerere University. Has worked with hospitals such as Mukono church of Uganda hospital and Hoima regional referral hospital, NGOs like FHI360 and BFSUMA Pharmaceuticals. Michael has featured in several TV and radio talk shows about Good Nutrition in children, Pregnant women and other adult special groups. Michael is the President of the Allied Nutritionists Association of Uganda which brings together all Nutritionists in Uganda and oversees their professional practice with regulation from the Allied Health Professionals Council.

**Dr. Wendy Lichtenthal***PhD, FT, FAPOS*

Wendy Lichtenthal, PhD, FT, FAPOS is Founding Director of the Center for the Advancement of Bereavement Care at the Sylvester Comprehensive Cancer Center and Professor, Pending Rank, in the Department of Public Health Sciences at the University of Miami Miller School of Medicine. She is a licensed clinical psychologist and federally funded researcher specializing in grief and bereavement whose work has been recognized through awards from the American Psychosocial Oncology Society, International Psycho-Oncology Society, and Association for Death Education and Counseling.

Appendix B.13

Speaker Biographies



Dr. Iddi Matovu

MPH, PhD

My background is in clinical medicine and public health, with expertise in palliative care and programs management. I have extensive experience in health research, programme design and management, spanning over 20 years managing and leading high-performance program teams in palliative care, preventive healthcare, health promotion, clinical practice, and health systems evaluation and strengthening mainly in the areas of palliative care service development, cancer, HIV/AIDS and TB prevention, care and treatment, mental health, and general healthcare for vulnerable populations in Uganda.

I have served in various leadership positions, gaining valuable experience in health research and service development, monitoring and evaluation, advocacy and policy development. I currently lead a project aimed at improving end of life care experiences for people with advanced disease in a palliative care setting. The project is implemented in partnership with the African Palliative Care Association and the Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC)

Appendix B.14

Speaker Biographies



Ms. Ratidzo Khuoge

MSc., BSW

Ratidzo Khuoge is a Clinical Social Work practitioner for Island Hospice and Health Care Zimbabwe. Mentors and supervises social workers and students. A career spanning over 35 years in development, health and child welfare. Has conducted numerous PSS sessions for palliative/end of life patients and families, grief and bereavement sessions, training and capacitating communities. Ratidzo has worked in the NGO, Private and Government sectors.

She has represented Zimbabwe in different fora including multi-cultural continental task team, where she visited different countries of Africa and developed a policy document 'Sustainability Guidance for OVCs programs in Africa and Middle East'.

Ratidzo holds a MSc Dev studies Degree, BSW University of Zimbabwe. Dip Training Witwatersrand, Potchefstroom and Maccauvlei SA and numerous other in-house courses. Ms Khuoge is Founder of Krayons Junior school, director Children's Ministries and enjoys swimming, flower gardening, reading business & leisure magazines.

Appendix B.15

Speaker Biographies



**INSTITUTE OF
PALLIATIVE MEDICINE**



WHO Collaborating Centre for
Community Participation in
Palliative Care and Long Term Care

Mr. Saif Mohammed

Mr Saif was the first State Project Manager for Palliative Care in Kerala under the National Health Mission, leading efforts for initiating primary palliative care programs, empowering Local Self-Governments and facilitating specialized palliative care programs in secondary and tertiary hospitals. He has also supported the works in formulating the palliative care policy for the Government of Kerala and has served as the State Coordinator of the palliative care program under the Additional Skill Acquisition program of the Government of Kerala.

He is now serving as the consultant and faculty member of the World Health Organization Collaborating Centre, Institute of Palliative Medicine, the service provision and training arm of Pain and Palliative Care Society. In this capacity, he facilitates capacity development workshops for governments and organizations in L-MICs. As a faculty member of the global fellowship program organized by IPM WHOCC and St.

Christopher's Hospice London, he imparts his expertise to participants from around the globe. He is also actively involved in implementing the International Program for developing Bereavement Companions in collaboration with the support of the Death Literacy Institute, Australia, and the Institute of Palliative Medicine

Appendix B.16

Speaker Biographies

**Dr. Breffni Hannon**

MBBChBAO, MMedSci



Dr. Breffni Hannon leads the palliative care program at the Princess Margaret Cancer Centre, Toronto, and holds the Rose Family Chair in Palliative Medicine and Supportive Care at the University of Toronto. Her research interests include early integrated palliative care for patients with advance cancer as well as interventions targeting family caregivers.

**Dr. Craig Sinclair**

PhD

**UNSW**
SYDNEY

Dr. Craig Sinclair is a Senior Research Fellow in the School of Psychology at the University of New South Wales. His key research interests include advance care planning and support decision-making. He is currently leading an NHMRC funded clinical trial of reminiscence-based life story work and advance care planning, among older and culturally diverse adults receiving home care services in Australia.

Appendix B.17

Speaker Biographies



UNIVERSITY of MARYLAND
BALTIMORE

Dr. Layne Heller

MSc., PhD (c)

oLayne Heller is a palliative care specialist, having earned her Master's degree in palliative care in 2020 and is currently in her final year of dissertation work towards her doctorate in palliative care through the University of Maryland Baltimore. She and her husband moved from the United States to Maputo, Mozambique 15 years ago and successfully founded the first convalescent and hospice home for cancer patients in the country. It is named Casa Ahavá, meaning "House of Love". Casa Ahavá has been operating for nearly 13 years and has grown to a 17-bed capacity. This home is joined to her family home, giving her unique insights into the lives of cancer patients. Her years of work have fuelled her passion towards developing palliative care which meets the unique needs of the Mozambican population.

Appendix C.1 - CALM Case #1

Mr. John Lule's Case





Case Overview

The patient, a 44-year-old male, was diagnosed with advanced colon cancer and had undergone multiple rounds of chemotherapy. Initially, he was overwhelmed with fear, anxiety, and distress about his diagnosis and treatment, leading to thoughts of giving up on the treatment regimen. His family members were also struggling to support him emotionally due to their lack of understanding about his condition. The patient's concerns were centered around his worsening symptoms, the uncertainty of his prognosis, and the social stigma surrounding cancer.

Intervention

CALM therapy was introduced to the patient in February 2024. Over the course of six (6) sessions, the therapist and patient engaged in a supportive-expressive therapeutic relationship that allowed the patient to explore his emotional and existential concerns. The therapist used open-ended questions to create a reflective space for the patient to process his fears about his illness and the impact on his family.



Key areas addressed during the sessions included:

1) Disease Management and Relationship with Healthcare Providers

The therapist helped the patient navigate his treatment plan and communicate better with his healthcare providers, ensuring he understood the goals of his treatment.

2) Changes in Self and Relationships with Close Others

The patient discussed the emotional impact of his illness on his family and the changes in his sense of self and his relationships. This was an area where CALM helped the patient renegotiate his relationships with family members, especially his spouse.

3) Sense of Meaning and Purpose

The patient was encouraged to explore his spiritual beliefs and find new meaning in life despite his diagnosis. The therapist worked with him on making peace with his mortality and preparing for the possibility of death, while still finding hope in his daily life.

4) Mortality and Future-Oriented Concerns

The patient expressed significant death anxiety and concerns about the future. CALM helped him reframe his fears and discuss his wishes for the future, enabling him to prepare for the end of life in a way that aligned with his personal values.

Outcomes

By the end of the intervention, the patient reported a marked reduction in anxiety and distress. He became more open about his fears and wishes, which allowed for better communication with both his healthcare providers and his family. The patient's quality of life improved as he felt more empowered to make decisions about his treatment and future. His family also expressed relief at having a clearer understanding of his emotional and psychological state, which helped them better support him during his illness.

Key Insights from the Case

- CALM's ability to reduce death anxiety and depressive symptoms in patients with advanced cancer.
- The importance of incorporating spiritual and existential discussions into cancer care.
- CALM's flexibility in addressing both practical and emotional aspects of cancer treatment, providing a holistic approach to care.

Appendix C.2- CALM Case #2

Mr. John Bosco Kafuuma's Case





Case Overview

The patient, a 50-year-old male, was a former trader who had developed an advanced, ulcerating tumor in his left arm. The tumor had caused significant pain, swelling, and discomfort, severely limiting his ability to care for himself and perform basic daily tasks. He was also emotionally distressed, experiencing feelings of isolation due to his physical appearance and the social stigma associated with his illness. Additionally, his family had been unable to provide the support he needed due to financial difficulties and emotional strain, leading to family separation during his illness.

His primary concerns included the spreading of his cancer to other parts of his body, the worsening of his symptoms, and the fear of dying without reconciling with his family, particularly his estranged children.

Intervention

CALM therapy was introduced to the patient in March 2024. Over five (5) sessions, the therapist worked with the patient to address his emotional and existential struggles. The patient was initially in denial about his illness and the prognosis, and he struggled with feelings of hopelessness. However, through CALM, the patient was encouraged to openly discuss his fears, relationships, and hopes for the future.



Key areas addressed during the sessions included:

1) Disease Management and Relationship with Healthcare Providers

The therapist helped the patient understand his treatment options, including pain management strategies, and how to better communicate with healthcare providers.

2) Changes in Self and Relationships with Close Others

The patient was guided through the process of renegotiating relationships with his family, particularly his children who had been separated from him due to the illness. This session was critical in helping the patient come to terms with his relationships and the changes in his sense of self.

3) Sense of Meaning and Purpose

The therapist encouraged the patient to find new meaning and purpose in life, even in the face of terminal illness. The patient was able to rediscover sources of joy, including spending time with his family and pursuing spiritual activities.

4) Mortality and Future-Oriented Concerns

The patient expressed significant distress related to his prognosis and death. CALM allowed the patient to discuss his fears of dying alone and unprepared. He was encouraged to create a sense of closure with his loved ones and to come to terms with his mortality.

Outcomes

The patient showed significant improvement in his emotional well-being. By the end of the intervention, he reported feeling more at peace with his condition and his relationships. His anxiety about death and dying decreased, and he expressed greater hope for the future, despite his terminal diagnosis. He was able to re-establish communication with his children, which brought him considerable emotional relief. His caregiver, his sister, also reported a decrease in the burden of caregiving, as the patient had become more open and less distressed.

Key Insights from the Case

- The therapeutic value of renegotiating family relationships and addressing social isolation in palliative care.
- The importance of integrating physical, emotional, and spiritual care in the treatment of advanced cancer.
- The role of CALM in reducing distress and improving quality of life by providing a reflective space for patients to address existential concerns

Appendix D

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