THE REPUBLIC OF UGANDA
MINISTRY OF HEALTH

Uganda Cancer Institute

PALLIATIVE CARE ASSOCIATION OF UGANDA (PCAU)

The 3rd Uganda Conference On Cancer and Palliative Care

Cancer and Palliative Care in Covid-19 and Other Challenging Situations

Abstracts and Conference Programme Book

Business Unusual

Hosted by

The Uganda Cancer Institute (UCI)

and

The Palliative Care Association of Uganda (PCAU)

September 23rd- 24th 2021

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Message from the Conference Co-Chairs

On behalf of the Organising Committees, we warmly welcome you to this 3rd Joint Uganda Conference on Cancer and Palliative Care which is organised by the Uganda Cancer Institute (UCI) and the Palliative Care Association of Uganda (PCAU).

This year's conference occurs during an unusual season when the entire globe's *modus operandum* has drastically changed due to the COVID19 pandemic. It is therefore business unusual and the conference title: "Cancer and Palliative care in Covid-19 and other challenging situations" befits the current atypical nature of our work.

It has been a difficult period for all of us working in cancer and palliative care during COVID19, and the provision of palliative care puts health professionals at risk at a time when oncology and palliative care services are already financially constrained. COVID19-related lockdowns aiming to control infection spread have made patients access to health harder. Despite these challenges, resilience and innovation are winning the race- and at this conference we shall be celebrating these attributes. Delegates will share about their adaptability and the use of technology to ensure continuity of care in the pandemic, how the most vulnerable have been reached with messages of healing and hope, and how resilient caregivers, despite their marked exhaustion, have sustained cancer and palliative services.

We are very honoured to be joined by the Right Hon Robinah Nabbanja, the Prime Minister of the Republic of Uganda, the Hon. Dr. Jane Ruth Aceng, the Minister of Health of the Republic of Uganda, many eminent academicians and clinicians, and all of you delegates who have spared your time to join this conference.

Unlike previous conferences, this one will be virtual. While we shall miss the closeness of the interpersonal relations and warmth of social events, we are confident that the conference will offer a rewarding experience for the delegates. Through its online nature we aim go far beyond the confines of the podium so we reach the population with messages of how oncology and palliative care are being integrated and becoming more universally accessible and available.

We wish you fruitful deliberations and a time of great impact!

Dr. Innocent Mutyaba
Conference Co-Chair

Dr. Eddie Mwebesa
Conference Co-Chair

Welcome Remarks from Uganda Cancer Institute Executive Director

Dr Jackson Orem
Executive Director, Uganda Cancer Institute

Ladies and gentlemen, I warmly welcome you to the 3rd Uganda Conference on Cancer and Palliative Care. Whereas the COVID-19 pandemic has prevented us from meeting together in person, we are excited about the opportunity of holding an innovative virtual conference. This is the first time this conference has been organized virtually by the Uganda Cancer Institute in conjunction with the Palliative Care Association of Uganda and Ministry of Health. Holding this conference this way is a great opportunity for us to explore how Cancer and Palliative Care can be managed during the COVID-19 pandemic as well as other challenging situations.

The conference will stimulate scientists, clinicians, oncologists, people with lived experience in cancer and palliative care as well as family members from around the world to present innovative and culturally significant research and clinical innovations in cancer care and early interventions.
The burden of cancer is not just for specialists but for everyone in the community including family members, and policy makers. Reaching new frontiers in cancer and palliative care requires fresh vision and novel strategies which we hope to gain from this conference. Producing the conference online fits perfectly with these aims as it has allowed us to reach out to a wider audience than a traditional conference can possibly include.

This 3rd Uganda conference on cancer and palliative care presents an opportunity for Uganda to inspire Africa and the World at large with a perspective of hope in cancer prevention, research, treatment and palliative care. We are hopeful that you all find this conference rewarding, stimulating, and meaningful for the betterment of us all.

Once again, I wish to welcome you all and wishing you fruitful deliberations.
Research is Our Resource!

Welcome Remarks from the Palliative Care Association of Uganda Country Director

Mark Donald Mwesiga
Country Director
Palliative Care Association of Uganda (PCAU).

Our Chief Guest, other guests, speakers, presenters, and conference delegates.
Welcome to the 3rd Uganda Conference on Cancer and Palliative Care. Thank you the conference co-chairs and members of the organizing committees for working through the Covid-19 Pandemic uncertainties to deliver this virtual conference. It is the 3rd time that the PCAU is holding a joint conference with the UCI. We held one in 2017 and another in 2019. I would like to thank UCI leadership for maintaining this partnership.

Palliative Care is key to achieving Universal Health Coverage which is target 3.8 of the UN SDGs. The WHO estimates that each year, 40 million people require palliative care globally; 78% of these live in low- and middle-income countries like ours. Only 11% of those in need access the service in Uganda. PCAU records show that there are at least 226 health facilities in 107 out of 146 districts that offer palliative care in the country.

The government has created a Division of Palliative Care at the Ministry of Health and continues to cover the costs of palliative care medicines as listed in the Essential Medicines and Medical Supplies list. In March 2021, the Director-General tasked all hospitals to establish palliative care units. PCAU commends these efforts. But there is more to be done. We appeal for a National Palliative Care Policy, for increased investment, for recognition of palliative care specialists in civil service structures, for more training and research.

The Covid-19 Pandemic and restrictions imposed to mitigate the spread of the disease affected access to palliative care services. Hospices and Palliative Care organizations had to scale down. I would like to thank all health workers who have been at the front line. PCAU applauds H.E the President of Uganda who directed that District Health Officers (DHOs) should ensure access to palliative services by patients and families during the lockdown last year. I extend my sympathies to all families that lost loved ones to the Covid-19 disease.

During this conference, members of the public will participate by following all the plenary sessions on UBC TV as well as on social media platforms. I encourage the public to utilize the opportunity and to interact with the specialists and the policymakers who lined up as per the program.
Lastly, I would like to appeal to all of you attending this conference to support the work of PCAU. You can subscribe and become a member. We have provided details on how to support our work in the information packs provided.

I thank you all and wish you good experiences at this year's conference.

Acknowledgements

We are grateful to all our sponsors and partners

- Ministry of Health
- Center for Hospice Care (CHC)
- Fred Hutch
- American Cancer Society (ACS)
- Open Society Foundations (OSF)
- Open Society Initiative for Eastern Africa (OSIEA)
- Fairway Hotel & Spa, Kampala
- Uganda Broadcasting Cooperation Television (UBC TV)

Sponsors

Conference attendance at Satellite Facilities

We would like to thank the following hospitals which offered teleconference facilities and accepted to host delegates from the respective regions to attend the conference in their premises.

1. St. Francis Hospital Nsambya
2. Mengo Hospital
3. Bombo Military Hospital
4. China-Uganda Friendship Hospital Naguru (CUFH-N)
5. Soroti Regional Referral Hospital
6. Lira Regional Referral Hospital
7. Jinja Regional Referral Hospital
8. Mbale Regional Referral Hospital
9. Msaka Regional Referral Hospital
10. Fort Portal Regional Referral Hospital
11. Kabale Regional Referral Hospital
12. Mbarara Regional Referral Hospital
13. Mubende Regional Referral Hospital
14. Hoima Regional Referral Hospital

We would like to thank everyone who has been involved in the organising of this conference including the following:

OVERALL CONFERENCE ORGANISING COMMITTEE

Name	Organization
Conference Co-Chairs	
1. Dr. Innocent Mutyaba	Uganda Cancer Institute
2. Dr. Eddie Mwebesa	Hospice Africa Uganda
Secretaries to the Committee	
1. Zaitun Nalukwago	Palliative Care Association of Uganda
2. Zipporah Kyomuhangi	Palliative Care Association of Uganda
Committee Members	
3. Dr. Jackson Orem	Uganda Cancer Institute
4. Mark Donald Mwesiga	Palliative Care Association of Uganda
5. Irumba Lisa Christine	Palliative Care Association of Uganda
6. Ritah Nannyomo	Palliative Care Association of Uganda
7. Joyce Zalwango	Palliative Care Association of Uganda
8. Cynthia Kabagambe	Palliative Care Association of Uganda
9. Dr. Amandua Jacinto	Palliative Care Association of Uganda
10. Dr. Nixon Niyonzima	Uganda Cancer Institute
11. Dr. Henry Ddungu	Uganda Cancer Institute
12. Ms. Rose Kiwanuka	Lweza Community Health Program
13. Dr. Miriam Ajambo	Ministry of Health
14. Dr. Jackson Amone	Ministry of Health
15. Collins Gyezaho	Uganda Cancer Institute
16. Bugeiga Douglas	Fredhutch Uganda Cancer Institute
17. Dr. Noleb Mugisha	Uganda Cancer Institute
18. Collins Mpamani	Uganda Cancer Institute
19. Cynthia Kabagambe	Palliative Care Association of Uganda
20. Denis Kawuma	Uganda Cancer Institute
21. Dr. Noleb Mugisha	Uganda Cancer Institute
22. Christine Namulindwa	Uganda Cancer Institute
23. Prof Julia Downing	International Children's Palliative Care Network/ Palliative care Education and Research Consortium

SCIENTIFIC COMMITTEE

Name	Organization
Co-Chairpersons	
1. Prof Julia Downing	International Children Palliative Care Network/ Palliative care Education and Research Consortium
2. Dr. Nixon Niyonzima	Uganda Cancer Institute
Committee Secretary	
3. Lisa Christine Irumba	Palliative Care Association of Uganda
4. Diana Basirika	Hospice Africa Uganda
Committee Members	
5. Mark Donald Mwesiga	Palliative Care Association of Uganda
6. Dr. Eddie Mwebesa	Hospice Africa Uganda
7. Rinty Kintu	American Cancer Society
8. Dr. Henry Ddungu	Uganda Cancer Institute
9. Antonia Kamate	Mobile Hospice Mbarara / Hospice Africa Uganda
10. Irene Nakabugo Katumba	Reach One Touch One Ministries
11. Ms. Rose Kiwanuka	Lweza Community Health Program
12. Dr. Doreen Agasha	Hospice Africa Uganda
13. Prof Wilson Acuda	Hospice Africa Uganda
14. Dr. Liz Namukwaya	Palliative Care Education Research Consortium.
15. Dr. Eve Namisango	African Palliative Care Association
16. Hajjati Mwazi Butali	Islamic University in Uganda
17. Dr. Ludoviko Zirimenya	Uganda Virus Research Institute
18. Dr. Amandua Jacinto	Palliative Care Consultant
19. Dr. Miriam Ajambo	Ministry of Health
20. Dr. Jackson Amone	Ministry of Health
21. Dr. Noleb Mugisha	Uganda Cancer Institute
22. Dr. Joyce Kambugu	Uganda Cancer Institute
23. Dr. Nakawesi Jane	Mildmay Uganda

ICT COMMITTEE

Name	Organization
Committee Co-Chairs	
1. Denis Kavuma	Uganda Cancer Institute
2. Cynthia Kabagambe	Palliative Care Association of Uganda
Committee Secretary	
3. Cynthia Kabagambe	Palliative Care Association of Uganda
Committee Members	
6. Collins Gyezaho	Uganda Cancer Institute
7. Bugeiga Douglas	Fredhutch Uganda Cancer Institute

FINANCE COMMITTEE

Name	Organization
Committee Co-Chairs	
1. Gerever Niwagaba	Kawempe Home care
2. Richard Tumwesigye	Uganda Cancer Institute
Committee Secretaries	
3. Rita Nanyomo	Palliative Care Association of Uganda
4. Ezra Anecho	Uganda Cancer Institute
Committee Members	
5. Doreen Nalwadda	Palliative Care Association of Uganda
6. Dorish Asibazuyo	Global Health Uganda
7. Carol Violet Alony	Hospice Africa Uganda
8. Paulina Mukago	Uganda Cancer Institute
9. Mark Donald Mwesiga	Palliative Care Association of Uganda
10. Martin Mpabura	Uganda Cancer Institute
11. Irumba Lisa Christine	Palliative Care Association of Uganda

PUBLICITY COMMITTEE

Name	Organization
Committee Co-Chairs	
1. Zalwango Joyce	Palliative Care Association Of Uganda
2. Christine Namulindwa	Uganda Cancer Institute
Committee Secretary	
3. Zaitun Nalukwago	Palliative Care Association Of Uganda
4. Zipporah Kyomuhangi	Palliative Care Association Of Uganda
Committee Members	
5. Mark Donad Mwesiga	Palliative Care Association of Uganda
6. Irumba Lisa Christine	Palliative Care Association of Uganda
7. Kintu Magdalene	Uganda Cancer Institute
8. Ayesiga Patience	
9. Emmanuel Lutamaguzi	Hepatitis Aid Organization
10. Joanita Kawalya	Musician and Palliative Care Association of Uganda
11. Zipporah Kyomuhangi	Palliative Care Association of Uganda
12. Richard Okwii	Ministry of Health
13. Jacob Ampeire	Ministry of Health
14. Tadeo Atuhura	Mildmay Uganda
15. Moses Muwulya	Kitovu Mobile
16. Kavuma David	Mildmay Uganda
17. Patricia Batanda	African Palliative Care Association
18. Carol Natukunda	African Centre for Global Health and Social Transformation

Uganda Cancer Institute

About Uganda Cancer Institute (UCI)

The Uganda Cancer Institute was founded in 1967 through a joint venture with the American National Cancer Institute, the Makerere Department of Surgery, and the British Empire Cancer Campaign. The two original wards of the Institute, the Lymphoma Treatment Centre (LTC) and Solid Tumour Centre (STC), were designed to provide space for clinical trials of chemotherapy on cancers that were highly common in East Africa, such as Burkitt's lymphoma and Kaposi's sarcoma.
The LTC was dedicated to Denis Burkitt, the first surgeon who described the unusual children tumour that targets the jaw and the abdomen in 1950s. Burkitt described that this particular cancer could be cured with chemotherapy other than surgery.

During the political turmoil of the 1970's, the American staff left, but put a Ugandan oncologist, Professor Charles Olweny to be in charge of the facility. Ugandans continued to carry out serious cancer research during a decade of profound economic instability and mercurial violence. Throughout the 1980s, 1990s, and 2000s, Dr. Edward Katongole-Mbidde worked as the Institute's Director and for a long time the sole oncologist in the country, providing oncology services in a severely underfunded context, and continuing with the Institute's research mission largely by focusing on HIV and cancer. Since the late 2000s, Dr. Jackson Orem assumed leadership of the Uganda Cancer Institute, and today the UCI is in the middle of a profound infrastructural and institutional transformation.

Uganda Cancer Institute is currently a body corporate established by an Act of Parliament, the Uganda Cancer Institute Act 2016, and whose functions include but not limited to: (a) developing policy on the prevention, diagnosis and treatment for cancers and on the care for patients with cancer and cancer related diseases; (b) undertaking and coordinating the prevention and treatment of cancers in Uganda; (c) providing comprehensive medical care services to patients affected with cancer and cancer related diseases; (d) providing palliative care and rehabilitation services to patients with cancer; (e) overseeing the management of cancer and cancer related services in public and private health centres; and (f) conducting or coordinating cancer related research activities in Uganda and outside Uganda.

UCI maintains an in-patient's facility and attends to an average of about 200 patients daily. We are focusing on research, training, cancer prevention and cancer treatment in areas of Paediatrics, Oncology, Gynaecology, and Radiotherapy, surgery, pharmacy and recently venturing into bone marrow transplants. Our patients also receive palliative care and rehabilitation services.

In the past ten years, the UCI has shifted from a place where you were "sent to die" to a centre of excellence in research and clinical care. It is no wonder that the Uganda Cancer Institute's slogan is "Research is Our Resource."

About the Palliative Care Association of Uganda (PCAU)

The Palliative Care Association of Uganda (PCAU) is the National Association for Palliative Care providers in Uganda. PCAU was established in 1999 and registered as a Non-Governmental Organisation (NGO) in 2003 to support and promote the development of palliative care in Uganda. This year, PCAU is commemorating 20 years of coordinating and advocating for palliative care in Uganda. Currently, PCAU is composed of 24 Member Organisations and over 1200 individual Members. PCAU works in partnership with the Ministry of Health, other line government ministries, agencies, departments, civil society and individuals to accelerate the integration of palliative care into the health care system in Uganda.

Vision
Palliative Care for all in need in Uganda.

Mission
To accelerate the integration of Palliative Care in the Uganda health care system through Capacity Building, Advocacy, Research and Resources Mobilisation.

Goal
To increase access to culturally appropriate palliative care through strengthening health care systems in Uganda in collaboration with partners

The Core Focus Areas of PCAU are:

Capacity Building:

Integrating palliative care services in every district of Uganda by 2021 through a system of focused training, mentorship and support supervision.

Advocacy and Awareness Creation:

Increasing the awareness and understanding of palliative care issues among stakeholders and thus leading to a supportive environment for the providers and the services.

Palliative Care Research and Information:

PCAU to become a hub of palliative care research and information, by undertaking palliative care research and hosting relevant research and leading the collection, storing, analysis of data and by regularly disseminating information to improve palliative care services**.**

Governance and Financial Resource Mobilisation for Palliative Care:

Strong Governance and resource mobilisation for the sustainability of Palliative Care Services in Uganda.

The 3rd Uganda Conference On Cancer and Palliative Care

Day 1: 23rd September 2021	
CONFERENCE OPENING 11:00 am – 1:00 pm	
11:00 am	**Conference Opening Ceremony -** On Zoom & Live Session on Uganda Broadcasting Corporation TV **Session Chairs** *Dr. Innocent Mutyaaba – Physician, Uganda Cancer Institute (UCI)* *Dr. Eddie Mwebesa -- Clinical and International Programs Director, Hospice Africa Uganda (HAU)*
11:05am	**Welcome Remarks by the Heads of Hosting Institutions** *Dr. Jackson Orem – Executive Director, Uganda Cancer Institute (UCI)* *Mr. Mark Donald Mwesiga – Country Director, Palliative Care Association of Uganda (PCAU)*
11:30 am	**Key Note Address:** Inclusivity of cancer and palliative care services during emergencies (Lessons learnt and way forward) *Dr. Tedros Adhanom - Director General, World Health Organization (WHO)*
11:50 am	**Remarks from the Hon. Minister of Health** *Hon. Dr. Jane Ruth Aceng*
12:20pm	**Recognition Awards** *Institutions and individuals that have excelled & been exemplary especially during the COVID-19 pandemic*
12:30pm	**Official Opening by the Guest of Honor** *Rt. Hon. Robinah Nabbanja – Prime Minister of the Republic of Uganda*
1:00 – 2:00pm	**LUNCH BREAK**
	PRESENTATION OF ABSTRACTS – on Zoom

2:00 – 3:30pm	**Track 1:** Innovation and creativity during the response to COVID-19 and other challenging situations **Chairs**: • ***Dr. Noleb Mugisha*** *– Chair Comprehensive Cancer Programs, Uganda Cancer Institute (UCI)* • ***Hajjati Mwazi Batuli*** *– Health Tutor, Islamic University in Uganda and Board Member, Palliative Care Association of Uganda (PCAU)*	**Track 2**: Providing care to the vulnerable populations during the response to COVID-19 and other challenging situations **Chairs:** • ***Dr. Ekiria Kikule*** *– Principal, Institute of Hospice and Palliative Care in Africa (IHPCA)* • ***Dr. Geriga Fadhil*** *– Deputy Head Paediatric Heamato – Oncology, Uganda Cancer Institute (UCI)*
2:00-2:05pm	**Introduction**	**Introduction**
2:05-2:12pm	The journey walked: Palliative care and COVID-19 *Nazziwa Octivia Evelyn – Hospice Africa Uganda (HAU)*	Palliative Care for vulnerable populations: Needs and challenges *Professor Wilson Acuda – Hospice Africa Uganda (HAU)*
2:12-2:19pm	Effects of COVID-19 on paediatric oncology *Rose Nankinga – Uganda Cancer Institute (UCI)*	Cultural and religious beliefs and traditions affecting attending the clinic for cancer and palliative care in Uganda: Findings from a cross-sectional survey in Uganda *Germans Natuhwera – Hospice Africa Uganda (HAU)*
2:19-2:26pm	Our success story with COVID–19 *Taaka Esther – Mbale Regional Referral Hospital*	Cancer patients' perceptions of their interactions with palliative care services in Uganda, Zimbabwe and Nigeria: A qualitative study *Dr. Elizabeth Namukwaya – Makerere Mulago Palliative Care Unit (MPCU)*
2:26-2:33pm	Psychosocial support for front line palliative care providers in Uganda through online engagements *Joyce Zalwango – Palliative Care Association of Uganda (PCAU)*	"Money was the problem": Caregivers' self-reported reasons for abandoning their children's cancer treatment in Southwest Uganda *Dr. Barnabas Atwiine – Mbarara University of Science and Technology (MUST)*

2:33-2:40pm	Health professionals' perceptions of use of digital technology in palliative cancer care: A multi-centre study in Uganda, Zimbabwe and Nigeria *Liz Nabirye – Makerere Mulago Palliative Care Unit (MPCU)*	Clinical outcomes of conventional (CFRT) versus hypo-fractionated (HFRT) pelvic radiotherapy for locally advanced cervical cancer *Dr. Awusi Kavuma – Uganda Cancer Institute (UCI)*
2:40-2:47pm	The development and evaluation of a mobile phone-based intervention to facilitate continuity of care, symptom monitoring and self-management in patients with advanced cancer in a refugee settlement in northwestern Uganda *Dr. Eve Namisango – African Palliative Care Association (APCA)*	Retention in care: Psychosocial support for vulnerable children with cancer during COVID-19 lockdown *Claire Namulwa – Kawempe Home Care (KHC)*
2:47-2:54pm	"Scattered": The lived experiences of patients with end stage kidney disease in Uganda *Dr. Peace Bagasha – Makerere Mulago Palliative Care Unit (MPCU)*	Increasing access for cervical cancer screening services to the Namayingo community: An experience of Rays of Hope Hospice Jinja, Uganda *Kebirungi Harriet – Rays of Hope Hospice Jinja (RHHJ)*
2:54-3:01pm	Leveraging the use of a mobile phone and 'boda bodas' in the continuity of palliative care provision during COVID-19 lockdowns: An innovative experience at Mobile Hospice Mbarara (MHM) *Martha Rabwoni – Hospice Africa Uganda (HAU)*	Gastrointestinal Carcinogenicity of Artificially-sweetened and Sugar-sweetened Soft Drinks: A Meta-analysis *Dr. Alfred Jatho – Uganda Cancer Institute (UCI)*
3:01-3:25	*Panel Discussion with Speakers*	*Panel Discussion with Speakers*
3:25-3.30pm	**BREAK TO CHANGE ROOMS**	

3:30 – 5:00pm	**PANEL DISCUSSION - On Zoom & Live Session on Uganda Broadcasting Corporation TV**
	Cancer and palliative care in COVID-19 and other challenging situations in Uganda: Experiences, observations, lessons and recommendations for future emergencies **Moderator**: Ms. Josephine Karungi **Panelists** **1.** *Lt. Col. Dr. Kyobe Bbosa – National COVID-19 Incident Commander* **2.** *Dr. Agasha Doreen Birungi – Chief Executive Director, Hospice Africa Uganda (HAU)* **3.** *Dr. Abrahams Omoding – Oncologist, Uganda Cancer Institute (UCI)* **4.** *Ms. Rose Kiwanuka – Palliative Care Nurse Specialist* **5.** *Dr. Victoria Walusansa – Deputy Executive Director, Uganda Cancer Institute (UCI)*

Day 2: 24th September 2021	
11:00 am – 1:00pm	**Plenary Session** - On Zoom & Live Session on Uganda Broadcasting Corporation TV **Chairs:** 1. *Dr. Jackson Amone – Commissioner Clinical Services, Ministry of Health (MoH)* 2. *Dr. Ocero Andrew – Deputy Chief of Party, Health Systems Strengthening and Policy Advisor, University Research Company* **Speakers:** **1. Health systems strengthening and financing for cancer and palliative care: What next? What needs to happen?** *Dr. Ayume Charles – Member of Parliament for Koboko and Chair, Committee of Health, Parliament of Uganda* **2. Implications of COVID-19 pandemic on universal access to palliative care services: Africa region perspective** *Dr. Emmanuel Luyirika – Executive Director, African Palliative Care Association (APCA)* **3. Implications of COVID-19 pandemic on childhood cancers and palliative care in Uganda (diagnosis and treatment)** *Dr. Joyce Balagadde – Head of Pediatric Oncology, Uganda Cancer Institute (UCI)* **4. Strengthening access to pain relief medicines in Africa: What more should stake holders do?** *Ms. Rinty Kintu - National Coordinator, American Cancer Society (ACS)* **5. Available education opportunities for cancer and palliative care services** *Dr. Nixon Niyonziima – Head of Laboratory Research and Training, Uganda Cancer Institute (UCI)* **6. Strengthening access to cancer and palliative care through international collaborations** *Cyndy Searfoss – Director of Partnerships, Global Partners in Care* **7. Compassionate care during life-threatening epidemics in Africa** *Prof. Dr. Anne Merriman – Founder, Hospice Africa and Hospice Africa Uganda (HAU)* **8. Health care equity and access for marginalized populations: What are the lessons paused by the COVID-19 pandemic?** *Aggrey David Kibenge – Permanent Secretary, Ministry of Gender, Labour and Social Development* **9. *Nursing Now* in cancer and palliative care during the COVID-19 pandemic** *Sr. Amuge Beatrice – Commissioner in Charge of Nursing, Ministry of Health*

1:00 -2:00pm	**LUNCH BREAK**	
	PRESENTATION OF ABSTRACTS & WORKSHOPS – On Zoom	
2:00 -3:30pm	**Track 3:** Sustainability of cancer and palliative care services in Uganda during the response to COVID-19 and other challenging situations **Chairs;** 1. ***Dr. Samuel Guma*** – *Executive Director, Kawempe Home Care (KHC)* 2. ***Mackuline Atieno*** – *Executive Director, Kenya Hospices and Palliative Care Association (KEHPCA)*	**Workshop 1:** Integrating pain management into routine service care delivery at hospitals in Uganda **Chair;** 1. ***Dr. Neville Oteba*** – *Commissioner Department of Pharmaceuticals and Natural Medicines (Ministry of Health)* 2. ***Mrs. Rinty Kintu*** – *National Coordinator, American Cancer Society (ACS)*
2:00-2:05pm	Introduction	
2:05-2:12pm	Transition towards three-dimensional conformal radiotherapy in Uganda: Our progress, challenges and lessons learnt *Dr. Solomon Kibudde – Uganda Cancer Institute (UCI)*	
2:12-2:19pm	Establishment of an incident learning and reporting system as a tool for quality management of radiotherapy services in Uganda *Dr. Ignatius Komakech – Uganda Cancer Institute (UCI)*	
2:19-2:26pm	Incidence, predictors, and biomarkers of Kaposi Sarcoma Immune Reconstitution Syndrome: Kaposi Sarcoma patients initiating antiretroviral therapy and chemotherapy in Uganda *Dr. Innocent Mutyaba - Uganda Cancer Institute (UCI)*	
2:26-2:33pm	Empowering health professionals through education and mentorship to improve children's palliative care provision in Uganda *Florence Nalutaaya – Makerere Mulago Palliative Care Unit (MPCU)*	
2:33-2:40pm	Integrating health promotion in palliative care: A Case of Lweza Community Health Programme *Rose Kiwanuka – Lweza Community Health Programme (LCHP)*	
2:40-2:47pm	Improving palliative care data collection at Fort Portal Regional Referral Hospital *Ian Batanda – Fort Portal Regional Referral Hospital (FRRH)*	
2:47-2:54pm	Palliative care in Uganda: Quantitative descriptive study of key palliative care indicators 2018-2020 *Ainur Kagarmanova – University of Notre Dame and University of Chicago*	

2:54-3:01	Psychometric properties of the EORTC QLQ-C30 in Uganda *Dr. Allen Naamala – Uganda Cancer Institute (UCI)*	
3:01-3:25pm	*Panel Discussion with Speakers*	
3:25-3.30pm	**BREAK TO CHANGE ROOMS**	
PRESENTATION OF ABSTRACTS & WORKSHOP – On Zoom		
3:30 -5:00 pm	**Workshop 2:** Improving national data on palliative care services in Uganda **Chair:** 1. ***Lacey Ahern**, MPH – Faculty Member University of Notre Dame Eck Institute of Global Health* 2. ***Dr. Miriam Ajambo** – Senior Medical Officer and Palliative Care Focal Person, Ministry of Health (MoH)*	**Track 4:** Resilience, caring for care givers and sustainability of services **Chairs:** 1. ***Antonia Kamate** – Site Programs Manager, Mobile Hospice Mbarara (MHM)* 2. ***Warren T. Phipps** – Medical Director, UCI-Fred Hutch Collaboration and Associate Professor, Fred Hutch Vaccine and Infectious Disease Division*
3:30 -3:37pm	Establishing SOPs for continuity of palliative care services amidst COVID-19 pandemic *Irumba Lisa Christine – Palliative Care Association of Uganda (PCAU)*	
3:37 -3:44pm	Supporting frontline health workers during COVID-19 and beyond *Naida Agnes – Rays of Hope Hospice Jinja (RHHJ)*	
3:44 -3:51pm	Integration of palliative care into healthcare provision for South Sudanese refugees and host communities in Adjumani and Obongi districts, Uganda; A rapid systems appraisal evaluation *Liz Nabirye – Makerere Mulago Palliative Care Unit (MPCU)*	
3:51-3:58pm	Factors associated with survival of cancer patients receiving palliative care: A case study of HAU *Mumbere Ronald – The Judiciary of Uganda*	
3:58-4:05pm	Palliative care in the forefront towards universal health coverage *Nakami Sylvia – Rays of Hope Hospice Jinja (RHHJ)*	
4:05-4:12pm	The mortality of medical doctors and dental surgeons in Uganda since January 2017 *Dr. Amandua Jacinto – Retired Commissioner Clinical Services Ministry of Health*	

4:12-4:19pm	Empowering child caregivers to be resilient during the COVID-19 Pandemic: A case of the Road to Hope Program *Steven Kasula – Palliative Care Association of Uganda (PCAU)*
4:19-4:26pm	Yoga and mindfulness: Caring for the caregiver *Annette Deguch – Center for Hospice Care (CHC)*
4:26-4:33pm	"…I got to understand what it means to have a cancer diagnosis, what it means to be a patient in our healthcare system, because I went through that myself. I now understand what pain means, what it means to go through chemo." Phenomenological evidence from healthcare professional cancer survivors in Uganda *Germans Natuhwera – Hospice Africa Uganda (HAU)*
4:33-4:55pm	*Panel Discussion with Speakers*
4:55-5:00pm	**BREAK TO CHANGE ROOMS**
Change to Main Conference Plenary Platform and Live on Zoom and on Uganda Broadcasting Cooperation TV	
5:00 -5:45pm	**Conference Closing Ceremony – Reflections on Universal Access to Cancer and Palliative Care Services in Uganda** **Session Chair** *Ms. Fatia Kiyange* – Deputy Executive Director at Center for Health, Human Rights and Development (CEHURD) *Board Member, Uganda Cancer Institute (UCI)* **Panelists** 1. **Prof. Charles Olweny** – Board of Governors Chair, Uganda Cancer Institute (UCI) 2. **Dr. Henry Ddungu** – Board Chair, Palliative Care Association of Uganda (PCAU) 3. **Dr. Jackson Orem** – Executive Director, Uganda Cancer Institute (UCI) 4. **Mark Donald Mwesiga** – Country Director, Palliative Care Association of Uganda (PCAU)
5:45 -6:00pm	**Awards: Best Oral Presenters & Brief on the Highlights of the 3rd Uganda Conference on Cancer and Palliative Care** *Prof. Julia Downing – Palliative care Education and Research Consortium (PcERC), International Children's Palliative Care Network (ICPCN)*

Poster Presentations			
1.	Analysis of the NIH-HEALS tool to assess psychosocial and spiritual healing from trauma: Cognitive interviewing	Dr. Eve Namisango – African Palliative Care Association (APCA)	*Innovation and creativity*
2.	COVID–19 restrictions: Facing the risks of the girl child	Mukiibi Henry Kikonyogo – Rays of Hope Hospice Jinja (RHHJ)	*Innovation and creativity*
3.	Developing best practices for patient and public involvement and engagement in palliative care research in resource limited settings	Dr. Eve Namisango – African Palliative Care Association (APCA)	*Innovation and creativity*
4.	Improving palliative care accessibility through training health workers in rural areas: A case for Rays of Hope Hospice Jinja	Mbabazi Joanita - Rays of Hope Hospice Jinja (RHHJ)	*Innovation and creativity*
5.	Delivering palliative care education at The Institute of Hospice and Palliative Care in Africa – Hospice Africa Uganda amidst the COVID-19 pandemic: Opportunities and challenges	Dr. Dorothy Adong Olet – Hospice Africa Uganda (HAU)	*Innovation and creativity*
6.	Palliative care during the COVID-19 pandemic and total lockdown in the Busoga Region, 31 March –26 May 2020: Interventions carried out by Rays of Hope Hospice Jinja, evaluation of impact with lessons learned and issues to be addressed.	Mutaasa Allan - Rays of Hope Hospice Jinja (RHHJ)	*Innovation and creativity*

7. Responding to cancer prevention and early detection needs amidst-and-post COVID-19 pandemic	Dr. Alfred Jatho - Uganda Cancer Institute (UCI)	*Innovation and creativity*
8. Innovations in palliative care in Uganda during the pandemic	Ronald Kawuki – Pain Support Organisation (PSO)	*Innovation and creativity*
9. Socioeconomic burden of a diagnosis of cervical cancer in women in rural Uganda: Findings from a phenomenological study	Germans Natuhwera - Hospice Africa Uganda (HAU)	*Providing care to vulnerable populations*
10. Defaulting and factors affecting time to recovery among children with severe acute malnutrition receiving outpatient therapeutic care in Nakivale refugee settlement.	Gordon Kibirige – Clinical Epidemiology Unit, Makerere University	*Providing care to vulnerable populations*
11. Patient case study	Dr. David Kansheba – Tanzania	*Providing care to vulnerable populations*
12. Risk of child undernutrition in households with life-limiting disease in Busoga Region and Buikwe District, Uganda	Josephine Namugambe – Rays of Hope Hospice Jinja (RHHJ)	*Providing care to vulnerable populations*
13. Influence of Dietary Zinc Intake, socio-economic status, H. pylori infection, and lifestyle on Gastric Cancer Risk: A Case-Control Study	Dr. Alfred Jatho - Uganda Cancer Institute (UCI)	*Providing care to vulnerable populations*
14. Resilience and caring for caregivers	Turyamureba Martin – Lira Regional Referral Hospital	*Resilience and caring for caregivers*

15. Psychosocial and emotional morbidities after a diagnosis of cancer: Qualitative evidence from lived experiences of healthcare professionals' cancer patients and survivors in Uganda	Germans Natuhwera - Hospice Africa Uganda (HAU)	*Sustainability of cancer and palliative care services*
16. The Public Health Codes for Cancer Prevention: 14 Ways to Reduce Your Cancer Risk	Dr. Alfred Jatho Uganda Cancer Institute (UCI)	*Sustainability of cancer and palliative care services*
17. Breast radiotherapy management after COVID-19 diagnosis during treatment: A case report.	Dr. Solomon Kibudde – Uganda Cancer Institute (UCI)	*Sustainability of cancer and palliative care services*
18. Data base is an essential part of palliative care	John Mwayi – Rays of Hope Hospice Jinja (RHHJ)	*Sustainability of cancer and palliative care services*
19. Experience of providing palliative care in a rural district in Uganda	Davis Muwanguzi – Butemba Health Centre	*Sustainability of cancer and palliative care services*
20. Dietary management for gynecological cancer patients in an evidence-based approach: A Systematic Review	Dr. Alfred Jatho - Uganda Cancer Institute (UCI)	*Sustainability of cancer and palliative care services*
21. Cancer risk and burden and universal health coverage 'effective coverage index' in Uganda relative to the regional & global outlook: Data visualization	Dr. Alfred Jatho Uganda Cancer Institute (UCI)	*Sustainability of cancer and palliative care services*

Plenary Presentations

Thursday 5th September 2019

Plenary Session One

Dr Tedros Adhanom Ghabreyesus,
Director General, World Health Organization

Dr Tedros was appointed as the Director-General of the World Health Organisation in 2017. He is an Ethiopian and is the first African in this role, endorsed by the African Union. He served as the Minister of Health in Ethiopia from 2005-2012 and the Minister of Foreign Affairs from 2012-2016, and was recognised in Time magazine as one of the 100 Most Influential People of 2020.

Hon Dr Jane Ruth Aceng,
Minister of Health, Uganda

Dr Aceng is the Minister of Health for Uganda and holds a Masters in Public Health alongside her medical degree. She has vast experience as a manager and clinical doctor, including as a Senior Consultant Paediatrician, Hospital Director and prior to her appointment as the Minister for Health she was the Director General Health Services,

Rt. Hon. Robinah Nabbanja,
Prime Minister of the Republic of Uganda

Rt. Hon Robinah Nabbanja has been the Prime Minister of Uganda since 2021 and is the first female to hold this position. Prior to this she was the State Minister of Health for General Duties in the Ugandan cabinet, serving from 2019 until 2021. She is the elected Member of Parliament for Kakumiro District Women Constituency, a role that she has served in since 2016.

Plenary Session 2

Panel Discussion: Cancer and Palliative Care in COVID-19 and other challenging situations in Uganda: Experiences, observations, lessons and recommendations for future emergencies

Lt. Col. Dr Kyobe Bbosa
National COVID-19 Incident Commander

Lt Col Dr Kyobe Henry Bbosa is the Incident Commander for COVID-19 in the Ministry of Health. Prior to this role, he was a senior public health specialist with the Outbreak and Epidemics pilot programme at African Risk Capacity, a specialized agency of African Union. He been an applied epidemiology research fellow with Uganda MOH/CDC/ Makerere University School of Public Health Fellowship Program based at the Department of Arbovirology, Emerging and Re-emerging Infectious Diseases of Uganda Virus Research Institute, Entebbe.

He is a Medical doctor, a graduate of Makerere University, Kampala; holder of Master of Science, Public Health (Epidemiology and Disease Control) from the Institute of Tropical Medicine, Antwerp Belgium. He has a Post Graduate Diploma in Control of Infectious Diseases from University of Ancona, Italy. He is currently a PhD student at Wits School of Health Sciences, and a scholar at the University of Oxford focusing on systematic reviews and meta-analysis. His PhD work focuses on vaccine immunology.

Dr Agasha Doreen Birungi,
Chief Executive Director, Hospice Africa Uganda (HAU)

Dr. Agasha Doreen Birungi is the Chief Executive Director at Hospice Africa Uganda (HAU). She is a medical doctor with a Master's degree in Public Health and a Post Graduate Diploma in Monitoring and Evaluation. She has worked with different organizations over the last 15 years gaining extensive knowledge and experience in leadership and management. Dr. Agasha has led and continues to lead HAU and its teams through the COVID-19 pandemic with its related challenges. Despite the pandemic, HAU continued to deliver palliative care services at all the three sites in Kampala, Mobile Hospice Mbarara and Little Hospice Hoima.

HAU's Institute of Hospice and Palliative Care in Africa continued to support Diploma, Degree and Masters Students from within and abroad in Africa through their education and research using already established online platforms. HAU launched its first online health professionals course for palliative care initiators attracting participants from all over sub-Saharan Africa.

Dr Agasha is a wife and mother and aspires to see equity in access to healthcare for all Ugandans.

Dr Abrahams Omoding –
Oncology, Uganda Cancer Institute (UCI)

Having trained as a doctor at Makerere University, Dr Omoding undertook his MMed at Mbarara University of Science and Technology and a Fellowship programme at the University of Washington/ Fred Hutchinson Cancer Research Centre. He is an oncologist working at the UCI.

Ms Rose Kiwanuka,
Palliative Care Nurse Specialist

Rose Kiwanuka was the Country Director of the Palliative Care Association of Uganda (1999-2019). She was the first Ugandan palliative care nurse and worked in senior clinical and education roles at Hospice Africa Uganda for 15 years before moving to PCAU. She was the first head of the education department at Hospice Africa Uganda, which has evolved into the Institute of Hospice and Palliative care in Africa (IHPCA). Rose holds a Bachelor's Degree in Nursing from Aga Khan University, Kampala, and is a strong advocate for palliative care, providing leadership for the development of palliative care services across Uganda.

Dr Victoria Walusansa-Abaliwano,
Deputy Executive Director, Uganda
Cancer Institute

Dr Walusansa is an oncologist and Deputy Executive Director if UCI. She graduated from Makerere University and completed her MMed in 2004. She trained as an Oncology Fellow at the Fred Hutchinson Cancer Research Centre in Seattle, Washington and was the first Ugandan doctor to undergo this training. She is a hands-on, patient-centered and outcome-drive doctor with over 12 years of experience in Medical Oncology. She is passionate *to making a positive difference in the lives of cancer patients*, especially women and keeping the hope of a cure for cancer alive. She leads the Breast cancer services at UCI.

Plenary Session Three

Health systems strengthening and financing for cancer and palliative care: What next? What needs to happen?

Dr. Ayume Charles
Committee on Health, Parliament of Uganda.

Dr Ayume is the Chair of the Committee on Health in the Parliament of Uganda. Medical Doctor and Politician. He the serving Member of Parliament representing Koboko Municipality. He qualified as a doctor in 2004 and became a Member of Parliament in May 2021.

Implications of COVID-19 pandemic on universal access to palliative care services: Africa region perspective.

Dr. Emmanuel Luyirika
Executive Director,
African Palliative Care

Association (APCA)Dr. Luyirika has been the Executive Director of the African Palliative Care Association (APCA) since August 2012. He is also a board member of the Worldwide Hospice and Palliative Care Alliance, was a commissioner on the Lancet Commission on Global Access to Palliative Care and Pain medicines, President of the board of CoRSU Hospital - a charitable rehabilitation and plastic surgery service for children and adults with disability due to orthopedic, plastic, malignancy and other acquired or congenital disability. Before APCA, he was the Country Director of Mildmay International in Uganda, previously working for the Ministry of Health in Limpopo Province in South Africa where he also lectured in Family Medicine at the Medical University of Southern Africa. He has also served on several technical committees at WHO and UNAIDS. He studied medicine at Makerere University in Uganda, Family Medicine at MEDUNSA and Public Policy and Management at the University of Stellenbosch both in South Africa. He has also published on HIV and palliative care and has served on several research DSMBs and steering Committees on HIV and palliative care in Africa.

Implications of COVID-19 pandemic on childhood cancers and palliative care in Uganda (diagnosis and treatment)

Dr. Joyce Balagadde
Head of Pediatric Oncology, Uganda Cancer Institute (UCI)

Dr.Balagadde is a Consultant Paediatric Oncology and heads the children's department at UCI. She is the incoming Continental President of the International Society of Paediatric Oncologist (SIOP Africa). She has more than 10 yeasr experience in the field and is a passionate advocate for childhood cancer in developing countries, believing every child with cancer deserves the best treatment possible within the confines of available resources. She holds a Master's degree in Paediatrics and Child Health from Makerere University and a Certificate of Medical Oncology from the University of Cape Town.

Strengthening access to pain relief medicines in Africa: What more should stake holders do?

Mrs. Rinty Kintu
National Coordinator Uganda, Treat the Pain/ Global Cancer Treatment American Cancer Society (ACS)

Rinty is a registered nurse with a bachelor's degree, specialized in oncology, infectious diseases and in access to health care. She has been working for the last 15 years on access to pain relief, palliative care and cancer treatment both in Europe as well as in Sub-Saharan Africa.
Rinty has a vast experience in improving access to health care, both in rural communities as well as major urban hospitals within Uganda. With both her experience in clinical service as well as policy development she is able to be the bridge the gap between patients, health workers and government institutions.
Rinty is the director of KIWI Development Consultancy and has been working over the last 5years as a consultant for the American Cancer Society's Treat the Pain program and Global Cancer Treatment program. In this capacity she supports governments and cancer treatment centers of 12 countries in Sub-Saharan Africa to improve access to pain relief and access to cancer treatment.

Available education opportunities for cancer and palliative care services

Dr. Nixon Niyonzima
Head of Laboratory Research and Training, Uganda Cancer Institute (UCI)

Dr Niyonzima is a cancer researcher at UCI working on the molecular characterisation of cancers in sub-Saharan Africa and the development of affordable low-cost diagnosis for cancers in resource-limited settings. He completed his Doctoral Studies at the Unievrsity of Washington. He is an investigator on several studies seeking to elucidate the molecular profile of breast cancer in SSA. He is also involved in building capacity for cancer laboratory diagnostics in Uganda.

Strengthening access to cancer and palliative care through international collaborations

Cyndy Searfoss –
Director of Partnerships, Global Partners in Care

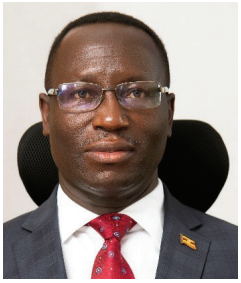
Cyndy is the Director of Education and Collaborative Partnerships Hospice Foundation. In addition to overseeing Global Partners in Care's partnerships, Cyndy is also a fund raiser and writer with extensive experience in raising friends and funds. She integrates traditional and emerging media to tell stories in a unique, engaging way. Cyndy received her BA from Indiana University and MA from the University of Notre Dame. She has worked as a newspaper reporter, managing partner of an advertising agency, director of creative services, director of alumni affairs at Indiana University South Bend, director of advancement an independent school and as an adjunct instructor at Purdue University and Saint Mary-of-the-Woods College.

Compassionate care during life-threatening epidemics in Africa

Prof. Dr. Anne Merriman
Founder, Hospice Africa and Hospice Africa Uganda (HAU)

Professor Dr Merriman, MBE, introduced palliative care to Uganda in 1993 when she commenced Hospice Africa Uganda the model for Hospice Africa, with the vision of "Palliative care for all in need in Africa".
She was key in the foundation of the Palliative Care Association of Uganda, African Palliative Care Association and Makerere Mulago Palliative Care Unit. She had a huge impact on the introduction and development of palliative care in Singapore, founded Home care, later to become the Hospice Care Association in Singapore which is one of the best services in the world. Anne has spent over 40 years working in Africa including 10 years where she served as a missionary doctor in Nigeria. Anne Merriman is a Nobel Peace Prize nominee but has won several other awards and notable is the Presidential Distinguished Service Award for the Irish Abroad.

Health care equity and access for marginalized populations: What are the lessons paused by the COVID-19 pandemic?



Aggrey David Kibenge
Permanent Secretary, Ministry of Gender, Labour and Social Development

Aggrey David Kibenge is an education, public policy, administration and management graduate (with a Bachelor's degree in Education and Masters degree in Public Administration and Management). He has over 25 years of experience in administration, having crossed from teaching into the administrative cadre, with the greater part of this at the Ministry of Education (1993-2012) and (2016-2019). He had a brief stint, as Under Secretary, at the Ministry of Tourism, Wildlife and Antiquities (February-November 2012) and thereafter, the Office of the Prime Minister (November 2012 – November 2016) before returning to the Ministry of Education and Sports where he served up to 28th August 2019 when he was appointed Permanent Secretary and eventually deployed to the Ministry of Gender, Labour and Social Development in September 2020.

Nursing Now in cancer and palliative care during the COVID-19 pandemic

Sr. Amuge Beatrice
Commissioner in Charge of Nursing, Ministry of Health

Sr. Amune is Commissioner Health Services – Nursing and Midwifery at the Ministry of Health. She is a Public Health Specialist, a researcher and a member of the Institutional Review Committee for MUK-College of Health Sciences and Mulago National Referral Hospital.

Plenary Session Four

Reflections on Universal Access to Cancer and Palliative Care Services in Uganda.

Dr. Jackson Orem
Executive Director, Uganda Cancer Institute (UCI)

Dr. Orem is a medical oncologist and Executive Director of the Uganda Cancer Institute (UCI). UCI is a teaching and research institute of the Government of Uganda under the Ministry of Health affiliated with Makerere University and is spearheading all aspect of cancer research and training in oncology in Uganda. UCI is designated as the oncology centre of excellence for East Africa which comprises six countries (Rwanda, Burundi, Kenya Tanzania, South Sudan and Uganda).

Dr. Orem is leading the operationalization of the East Africa Centre of Excellence in Oncology (EACOE) at the Uganda Cancer Institute. The mandate of this is to provide specialized cancer care research and training for the entire East Africa region under the East African Community (EAC) network of Centers of Excellence (CoEs).

He is also leading the development of several international collaborations with renowned international cancer centres and institutions for infrastructure, human resource capacity development. Such institutions include Fred Hutchinson Cancer Research Center, University of Washington, Case Western Reserve University, National Cancer Center of Korea (NCC) and lately University of Cambridge.

He is an honorary lecturer at Makerere University College of Health Sciences, School of Medicine and an Associate Clinical Professor (Adjunct), McMaster University, Faculty of Health Sciences Department He is principal investigator in several NIH supported research projects through NIAID, AMC, ACTG and is recipient of a number of industry supported grants such as GSK funded Open Lab, MERCK, ROCHE. Jackson has strong international collaboration with civil society organizations such as American Cancer Society (ACS), and is the alternate chair for African Cancer Coalition an initiative with ACS and NCCN to harmonize cancer treatment guidelines for Sub-Saharan Africa.

He has strong working relationships with IAEA through their support to development of radiotherapy services for which he is the national lead (counterpart). Jackson is a member of the ASCO International affairs committee representing Africa, an active member of American Society of Hematology (ASH) and Society for Immunotherapy of Cancer (SITC).

Dr. Orem is a graduate of Makerere University Kampala, Case Western Reserve University Cleveland Ohio and Karolinska Institutet, Stockholm.

Mr. Mark Donald Mwesiga
Country Director, Palliative Care Association of Uganda (PCAU)

Mark Donald Mwesiga is the Country Director at The Palliative Care Association of Uganda (PCAU). Before being appoint appointed CEO at PCAU, he was Head of Programs at the same organization for five years. Mwesiga holds a Master of Management (MMS) from Uganda Management Institute (UMI), a Post Graduate Diploma and a Degree in Social Sciences from Makerere University. He is finalizing a Masters of Public Health (MPH) at Uganda Martyrs University. He is recent fellow at the Centre for Compassionate Leadership USA. He has attained various short course qualifications in Project Planning and Management, Drug Policy, Diplomacy and Public Health from The Graduate Institute in Geneva – Switzerland.

Professor Charles Mark Lwanga Olweny,
physician, oncologist, academic and medical researcher

Professor Charles Mark Lwanga Olweny, is a Ugandan physician, oncologist, academic and medical researcher. The Professor has written over 20 books and over 120 professional articles. He is currently the Chairman Board of Directors at Uganda Cancer Institute and also Board chair Nsambya Hospital. Professor Olweny attended St. Peter's College Tororo, for his O-Level education (S1-S4). He attended St. Mary's College Kisubi for his A-Level classes (S5-S6). In 1961, Olweny joined Makerere University School of Medicine, graduating with the degree of Bachelor of Medicine and Bachelor of Surgery (MBChB), in 1966. Later, he obtained the degree of Master of Medicine in Internal Medicine (MMed). He followed that with the degree of Doctor of Medicine (MD), all from Makerere University. Olweny's chosen speciality is medical oncology.

Charles Olweny served as the first Ugandan Director of the Uganda Cancer Institute, from 1972 until 1982. Under his stewardship, the team of Ugandan medical researchers were the first group to demonstrate that liver cancer could be successfully treated with chemotherapy using the drug doxorubicin, which is still the mainstay of treatment for liver cancer today. They were also able to confirm that Burkitt lymphoma could be cured with a high dose of chemotherapy and showed that the same was true for childhood Hodgkin disease. They documented the incidence of endemic Kaposi's sarcoma in children and conducted clinical trials on how to treat it.

During the same timeframe, Olweny served – first as a lecturer, then senior lecturer and later as professor of Medicine – in the Faculty of Internal Medicine, at Makerere University School of Medicine, serving as head of department, from 1979 until when he left the country for Australia due to political insurgencies in 1982.

While in Australia, he served as clinical professor at the Department of Medicine & Surgery, University of Adelaide, Adelaide, South Australia. He also served as Senior Director for Medical Oncology, Cancer Control Programme, and Royal Adelaide Hospital.

Dr. Henry Ddungu, MD Consultant
(Hematology-Oncology) Uganda Cancer Institute

Dr. Ddungu graduated from Makerere University in 1998 and later did his Master of Medicine (Internal Medicine) from the same University in 2003.

Dr. Ddungu has been working on his PhD that is focused on strategies for the optimal use of blood and platelet transfusion supportive for patients with hematological malignancies in sub-Saharan Africa. He is a Consultant Physician at the Uganda Cancer Institute, where he holds a number of clinical and administrative responsibilities.

Dr. Ddungu is the President and Chair of the Association of Physicians of Uganda. He is also the President and Chair of the Board, Palliative Care Association of Uganda (PCAU) Dr. Ddungu has a Fellowship in International Pain Policy obtained at the Pain and Policy Studies Group, University of Wisconsin, Madison and was a member of an International Expert Collaboration (IEC) for advancing opioid availability globally.

For a long time, Henry worked with Palliative Care organizations in Uganda and Africa, initially as a clinician providing palliative care services to terminally ill cancer and AIDS patients and later as an Advocacy Manager for the African Palliative Care Association. He has extensive experience in palliative care in Africa where he has been involved in the care of patients as well as advocating for improved access to palliative care services. Dr. Ddungu is active in research in hematology and palliative care and has published several papers in international journals and written chapters in 5 books. He has also supervised more than 10 Master of Medicine dissertations.

Oral Presentations: Track 1

Thursday 23rd September 2021, 2:00PM – 3:30PM

Innovation and creativity during the response to COVID-19 and other challenging situations

Our COVID -19 Success Story at Mbale Regional Referral Hospital

Taaka Esther
Mbale Regional Referral Hospital

Background: Mbale Hospital palliative care unit serves both in-patient and outpatient clients. It's one of the government hospitals in the country where palliative care home visits are carried out amidst limited resources. Our small team comprises of 5 Village Health Teams, 2 Social workers and 1 palliative care nurse. Below is the number of Covid registered cases: Admissions 541, discharges 470, Referrals 18, cumulative Home-based isolation 1336 (attached to health workers and VHTs) and 41 deaths to date inclusive of palliative care patients.

Aim: The aim of the work of the palliative care unit was to ensure the continuity of palliative care amidst the COVID-19 Pandemic.

Methods: We used volunteers including village health teams/ social workers for easy accessibility to palliative care patients since they stay in the same locality. Phone calls were made weekly to check on patient's wellbeing and how best to access medications in case of stock out, current complaint and the kind of help needed. Palliative care activities were integrated into hospital programs for example by escorting of COVID-19 patients to their homes after discharge. Video conferencing via Skype or Zoom were utilized. We liaised with other partners that were carrying out home to home deliveries of medicines. Use of Boda-Bodas to pick client's medicines using their prescription Networking and referral of patients to palliative care providers within their reach.

Lessons: We need to embrace the technology of Telemedicine. Networking is key in patient's care. Palliative care activities need to be allocated a budget by government for their smooth running.

Conclusion: Village health teams and social workers play a greater role in management of palliative care patients in communities and therefore should be equipped with necessary palliative care knowledge and skills.

Psychosocial support for front line palliative care providers during COVID 19 in Uganda through online engagement

Joyce Zalwango, Mark Mwesiga, Lisa Irumba,
Palliative Care Association of Uganda (PCAU)

Background: The Palliative Care Association of Uganda (PCAU) is the national association for palliative care providers in Uganda established in 1999. It is composed of 24 organizations members and over 1,200 individuals. The association coordinates civil society efforts and works closely with the Ministry of Health (MoH) to accelerate the integration of Palliative care services in Uganda's health care system. Psychosocial support addresses a person's emotional, social, mental and spiritual needs which are essential elements of positive human development. COVID-19 produced a lot of uncertainty and persistent worries on safety and continuity of palliative care service delivery.

Aim: To enhance the resilience of frontline palliative care providers to maintain the momentum of care for all patients in need of palliative care amidst the pandemic.

Methods: PCAU conducted a survey among frontline palliative care providers that established the need for psychosocial support. Findings indicated that there was increased workload, fatigue and burnout, risk of infection and fear of infecting family members as well as patients, reduced patient contact due to transport restrictions and lack of enough personal protective equipment.

Results: PCAU established a teleconference facility to support online engagements with frontline palliative care providers. A total of 6 bi- weekly webinars were held with an average attendance of 50 participants to discuss selected topics facilitated by experts in regards to psychosocial support. A toll free line was established to respond to psychosocial issues of front line palliative care providers in the different regions of the country. Developed a module shared with the ministry of health on continuity of palliative care as an essential service amidst the lockdown. Supported 10 hospices and palliative care organizations with COVID 19 screening logistics.

Conclusion: Psychosocial support helps build resilience during global pandemics which cause a lot panic and slowdown of activities. Improved access to quality preventive, curative and rehabilitative information during this emergency to support frontline palliative care providers to continue patient care was very vital. Given the findings, PCAU commissioned an ongoing study on mental health and psychosocial challenges among palliative care providers.

Health Professionals' Perceptions of Use of Digital Technology in Palliative Cancer Care: A Multi- Centre Study in Uganda, Zimbabwe and Nigeria

Elizabeth Nabirye[1], Yu Fu[2], Elizabeth Namukwaya[1], Eve Namisango[3], Matthew Allsop[4]

[1]Department of Medicine, Makerere University, [2]Leeds Institute of Health Sciences, University of Leeds, [3]African Palliative care Association, [4]Academic Unit of Palliative Care, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

Background: WHO recommends use of digital technology to help in increasing access to health care services and with increasing access to internet and mobile phone use, there has been a surge in medical applications that are targeting healthcare professionals who are key stakeholders in implementation of use of digital technology. For this technology to be implemented successfully health professionals perceptions on acceptability, usefulness, challenges and benefits are important for planning and implementation of digital technology. However, little is known about health professionals' perceptions of digital technology in the provision of palliative cancer care in the sub Saharan Africa.

Aims: This study aimed to establish the health professionals' perceptions of the use of digital Technology in palliative cancer care and to identify implications for managers and developers about healthcare givers perceptions of use of digital technology.

Methods: This was a qualitative secondary analysis of data collected for a larger study from three African countries (Uganda, Zimbabwe, Nigeria). Participants were purposively sampled and recruited from hospital and home based PC teams. Inductive and deductive thematic analysis was conducted. Ethical approval for the primary study was obtained from the national research and ethics bodies.

Results: A total of 59 health professionals' transcript were analysed. We identified the following themes; Source of current data available to inform patient management , Existing gaps in data and information to inform palliative cancer care, Perceived potential benefits of applying digital technology, Factors influencing the quality of digital technology in cancer care provision and Perceived challenges and concerns of the use of digital technology.

Conclusion: Health professionals supported the use of digital technology in palliative cancer care and described its potential benefits. They described systems needed for technology implementation in cancer care and the likely challenges of use of digital technology.

The development and evaluation of a mobile phone-based intervention to facilitate continuity of care, symptom monitoring and self-management in patients with advanced cancer in a refugee settlement in north western Uganda

Eve Namisango[1], Emmanuel BK Luyirika[1], Elizabeth Namukwaya[2], Shaunna Burke[3], Matthew J Allsop[3]

[1]African Palliative Care Association, Uganda, [2]MakerereUniversity, Uganda, [3]University of Leeds, UK

Background: There is an urgent need for feasible approaches supporting continuity of care for palliative care patients during the COVID-19 pandemic. Recommendations by leading global palliative care consortia suggest continuity of care whilst delivering services at a distance should explore telemedicine approaches.

Aim: To co-design and pilot test a mobile phone application and clinician dashboard to support continuity of care for patients with advanced cancer in a refugee population during the COVID-19 pandemic.

Methods: A mixed-methods study design was used. Research phases included: i) co-design workshops gathering requirements for the digital health intervention (DHI) with patients with advanced cancer and their caregivers; ii) DHI design and refinement of prototypes led by patient and staff feedback at Bidi Bidi Refugee Settlement; iii) pilot study at Bidi Bidi Refugee Settlement including qualitative interviews with patients with advanced cancer (n=30) routinely reporting outcomes data (APCA I-POS) alongside COVID-19, tuberculosis and hepatitis B symptoms via the mobile phone application shared to a palliative care team staff online dashboard. Data analysis included descriptive analysis of sample characteristics, tabulated APCA data, summaries of intervention uptake and usage, and framework analysis to explore patient and staff experiences in intervention usage and factors influencing engagement. Hospice Africa Uganda Research and Ethics Committee and Uganda National Council for Science and Technology provided ethical approval.

Results: The pilot study is underway and will be completed in August 2021. We will present an overview of the DHI development process, digital health intervention content (including real-time, tailored self-management guidance in response to symptom reports), and preliminary findings from the pilot study.

Discussion: Digital technology approaches are an acceptable approach to augmenting palliative care provision in Uganda. Our research provides novel data to inform optimal DHI content and implementation to support the provision of palliative cancer care for a refugee population.

"Scattered", the lived experiences of patients with end stage kidney disease in Uganda

Peace Bagasha[1], Mhoira Leng[1], Elizabeth Namukwaya[1], Elly Katabira[2]
[1]Palliative care Education and Research Consortium, [2]Makerere University

Background: End Stage Renal Disease (ESRD), the final stage in the progression of Chronic Kidney Disease, necessitates the use of renal replacement therapy in the form of, peritoneal dialysis, hemodialysis or kidney transplant to sustain life. In sub-Saharan Africa, 85% of individuals for whom hemodialysis is initiated will discontinue it leading to premature death. There is a dearth of information on the lived experiences of patients with ESRD in subSaharan Africa.

Aims: To explore the multidimensional lived experiences of patients with ESRD receiving care in Mulago National referral hospital.

Methods: Using a phenomenological approach, we purposively recruited a maximum variation sample of patients meeting the inclusion criteria; 18 years and above with documented evidence of ESRD (defined as an estimated glomerular filtration rate of 15mls/min/1.73m2 and below). We then carried out semi structured interviews and analysed transcripts using Thematic Analysis. Ethics approval was obtained from all relevant bodies.

Results: Thirty-five patients were recruited; median age 40years(19-71years); 54% male, 82% unemployed, 69% lacking spousal support and 51% on non-HD management modality. Five major themes were identified namely; Spiritual health, Physical health, Social Health, Psychological health and Daily life. In Social health; Families faced separation to access treatment "I will get satisfied when I am better when I have collected my family together but as of now am still scattered." Psychological Health; healthcare was costly and with widespread effects "...I've sold everything, yet this dialysis is still going on…what I will do for my other children." and there was gross deficiency of information: "actually I was ignorant…..I felt it was like any other disease and it would heal".

Conclusion: A multi-dimensional holistic approach, as is used in palliative care, including financial, cognitive, behavior and educational interventions needs to be incorporated into healthcare systems if outcomes of patients with ESRD in Uganda are to be improved.

Leveraging the use of a mobile phone and 'Boda Bodas' in the continuity of Palliative care provision during COVID-19 lockdowns. An innovative experience at Mobile Hospice Mbarara (MHM)

Martha Rabwoni
Hospice Africa Uganda

Introduction: Unprecedented situations can introduce devastating disruptions to healthcare access and provision. Covid-19, and its associated lockdowns and travel restrictions made transport difficult, and heightened vulnerabilities among palliative care (PC) patients. At MHM, the mobile phone and 'boda bodas' became the ultimate bridge for the clinical team to reach, and provide PC to patients.

Aim: To highlight the role of a mobile phone and 'boda bodas' in the continuity of PC provision to patients/families during COVID-19 lockdowns.

Methods: At MHM, bi-directional communication between the clinical team and patients/families was maintained via the hospice clinical phone. The patient would give their hospice card to the 'Boda Boda' man. On arrival at MHM, the clinician/nurse would call back the patient/home caregiver to get details of the main complaints. The clinical staff would then pack medicines and send to the patient through the rider. Another phone call would later be made to the patient/home caregiver to confirm the medicines were delivered.

Results: Using mobile phone and 'boda boda', MHM was able to provide PC to patients amidst Covid-19 lockdowns and travel restrictions. The mobile phone and 'boda boda' innovation was also used in coordinating referrals and enrolling new patients. MHM also facilitated some very poor patients with transport through the hospice patient comfort fund.

Challenges: During lockdown, MHM's daily clinic attendance dropped from 15-25 to 10-15 patients. Some, especially the very distant and very poor patients could not afford 'boda boda' charges. Poor network connectivity (communication barrier), difficulty conducting holistic assessment of the patient, heightened psychological suffering among patients/families were the other challenges faced.

Lessons learnt and conclusions: PC provision can prove more difficult in unprecedented circumstances like in the Covid-19 lockdowns. But, in PC, 'there's always something that can be done', as evidenced in the use of mobile phone and 'boda boda'.

Clinical outcomes of conventional (CFRT) versus hypofractionated (HFRT) pelvic radiotherapy for locally advanced cervical cancer.

Awusi Kavuma
Radiotherapy Department, Uganda Cancer Institute

Background and Purpose: Cervical cancer incidence in Uganda is 40.1/100000. We annually treat over 800 new cervical cancer patients (40% of our workload) which is challenging to optimally treat large numbers in limited resources settings. Locally advanced cervical cancers account for nearly 85% of all cancer patients. Between 2011-2013, the department elated to use 45 Gy/15# as an alternative to 50 Gy/25#, for treatment of locally advanced cervical cancers. The main purpose of this study is to compare the 5-year followup outcomes.

Material and Methods: A total of 414 were retrospectively reviewed according to demographic/clinical data, radiotherapy fractionations and outcomes. Inclusion criteria were FIGO stages IIB–IIIB cervical cancer cases and had completed EBRT and ICT. The study evaluated the survival probability patterns for patients treated with CFRT vs HFRT, known HIV serology, stage IIB, IIIA, IIIB and patients < 50 years vs ≥ 50 years of age. Results: Squamous cell carcinomas were 93.6%, adenocarcinomas 3.0% and others. The Median age was 49.5 (range of 24–80) years. Stages IIB/IIIA/IIIB were 36.2%/8.2%/55.6% respectively. HIV serology was positive, negative and unknown in 70(16.9%), 116(28.0%) and 228(55.1%). Chemotherapy was administered in 40.8% and only 51.2% completed. CFRT and HFRT were 221 (53.4%) and 193 (46.6%). At 3 months, the overall response rate was 67.4% for CFRT compared to 65.6% for HFRT (p-value 0.158). Re-treatments for CFRT/HFRT were 10.4%/7.8% (p-value = 0.354). At the end of treatment, the grades 0-1 and 2–4 toxicities were 76.1% and 23.9% for CFRT, while 78.2% and 21.8% for HFRT (pvalue=0.355). At 60 months, the survival probabilities were 44.9% for CFRT and 46.6% for HFRT (p-value=0.293).

Conclusions: HFRT for locally advanced cervical cancer provides similar outcomes. In high volume cervical cancer patients' and low resource settings, HFRT should be considered Abstract ID: 29 for UCI-PCAU Conference (Auto-Generated August 11, 2021 1:25 pm) Copyright 2021 UCI-PCAU Conference powered by WPAbstracts Pro because of its resource friendliness and convenience to the patients.

Distributive Ethics and COVID-19: The Impact of Accessibility and Potential Implications for Hospice and Palliative Care

Matthew Misner,
The National Catholic Bioethics Center (NCBC), Pediatric Hospice Physician, Center for Hospice Care, Mishawaka, USA

Aims: The COVID-19 pandemic brings to light the impact that social dynamics of health have on people living in low-resource settings. The lack of accessibility to treatment and medical care is an important social dynamic that merits attention when considering the potential long-term effects of this disease.

Discussion: The US sociologist *W.E.B. Du Bois* observed at the turn of the twentieth century, while studying the plight of those living in urban Philadelphia at that time, that living conditions and unbalanced distribution of wealth are important considerations when determining overall health. Among individuals living in many non-Westernized countries, such as Peru and Uganda, disparity exists

between their access to a COVID-19 vaccine and those of other nations. Disparity of unconditional access to services even exists among certain populations living in more westernized countries such as the United States. Current medical data suggests that American Latinos, African-Americans, and Native Americans who live in certain regions in the US, such as the Central Valley of California, are more likely to be hospitalized or die from COVID-19 complications.
By evaluating any available resources related to the pandemic situations in United States, Peru, and Uganda, as well as personally visiting Peru in August, I hope to share any information received in order to shed more light regarding this important subject. Attention will not only be given to the current situation, but possible long-term effects that may require palliative care or hospice intervention in the future.
Conclusion: A pandemic, such as COVID-19, lends an opportunity to consider the social dynamics that may lead to the survival or the demise of someone suffering with this virus. One might assume that having unequal access to resources such as vaccines might impose an increased burden on health outcomes. An increase in the need for palliative care and hospice services could potentially present itself.

The Journey Walked; Palliative Care and COVID -19

Octivia Naziwa
Hospice Africa Uganda

Background: On 22 March, the first case of COVID-19 in Uganda was confirmed. The effects of the lockdown on the health care system were tremendous. Access to Palliative Care and service delivery were hampered. The immediate impact of the shutdown was on the survival of the country's hardest-hit citizens whose livelihoods depended on what the president put on their tables as well as health support. In the case of a rural setting, specifically Hoima District, palliative care patients, care takers and specialist had to squeeze continuity of service within the presidential directives and also keep with the Ministry of Health guidelines; a trail of challenges were met.
Aim: to share my experience and ways devised for care to continue amidst Lockdowns at Little Hospice Hoima.

Challenges: At the first declaration of lock down, I anticipated that it would be a short while, however the lock down kept on being extended by extra weeks and this made life very difficult for patients to access care continually. Lock down of public transport crippled movement of palliative care patients and families' access to treatment. Those from far places, found it nearly impossible to access continual treatment to the nearest health centers. Permission to seek movement from the Resident District Commissioner (RDC) was unbearable and the patients who would manage to get to the RDC always found a long queue which meant they had to wait for hours.

Conclusion: In amidst of all challenges encountered during Covid- 19, other modes of care were devised to make sure that palliative care services reach everyone in need. Minimal home visits to the very sick ones were done following the MoH standard operating procedures, OPD clinics were daily open and routine Telephone calls made to ensure no one was left in agony.

Oral Presentations: Track 2

Thursday 23rd September 2021, 2:00pm – 3:30pm

Providing care to the vulnerable populations during the response to COVID-19 and other challenging situations

Palliative care for vulnerable populations- needs and challenges

Professor Wilson Acuda
Institute of Hospice and Palliative Care in Africa, Hospice Africa Uganda, Kampala, Uganda

Introduction: Vulnerability is defined as the diminished capacity to anticipate, cope with, resist and recover from the impact of natural or man-made hazards. It is a universal condition but is experienced differently depending on one's susceptibility, resilience and capacity. All persons are vulnerable in certain situations, at various times and circumstances. In health care, vulnerable people are a separate group of people with unique or special palliative care needs. They include Children, older adults, people with severe and persistent mental illnesses and drug dependence, sex workers, refugees, people with physical and sensory disabilities, pregnant women, prisoners, and members of the armed forces, the homeless, and the very poor. Providing palliative care to vulnerable populations can be challenging more so within the context of Covid-19 pandemic.

Objectives: To outline the additional challenges faced by vulnerable individuals with life threatening illnesses in accessing palliative care. To highlight the impact of Covid-19 on vulnerable populations To suggest methods of delivering appropriate palliative care for vulnerable populations

Methods: A review of existing literature on vulnerable people and end of life care

Results: There is a dearth of published evidence base for palliative care for vulnerable people in Uganda and Africa. Much of the available literature are from high income countries The available publications indicate that vulnerable people with life threatening illnesses face numerous challenges/barriers in accessing palliative care. Palliative care patients are vulnerable by virtue of their illness e.g. cancer, but other conditions or factors increase their vulnerability and present unique and complex palliative care needs and challenges to the palliative care providers. Vulnerable people are at an increased risk of Covid-19. This presentation will outline the special challenges vulnerable individuals with life threatening illnesses face and suggest interventions to meet their specific palliative care needs.

Conclusions and recommendations: There is urgent need for research which can inform the development of appropriate palliative care policies and interventions for vulnerable populations.

Cultural and Religious Beliefs and Traditions Affecting Attending the Clinic for Cancer and Palliative Care in Uganda. Findings from a Cross-sectional Survey in Uganda

Anne Merriman[1], Germans Natuhwera[2], Eve Namisango[3],
[1]Hospice Africa Kampala Uganda, [2]Little Hospice Hoima, Hospice Africa Kampala Uganda, [3]African Palliative Care Association, Kampala Uganda

Aim: To examine cultural beliefs and traditions affecting access for cancer care and palliative care in Uganda.

Methods: This was a cross-sectional mixed-methods pilot survey (n=30) conducted between September and November 2020 in three regions i.e. central, western, and southwestern Uganda. Purposive sampling was used. 10 participants comprised of five cancer patients and five key informants (KIs) i.e. spiritual and traditional leaders were recruited from each region. Structured face-to-face interviews were used.

Results: Quantitative findings found participants attributed the cause of cancer to; infection and catching from others (66.7%), witchcraft (46.7%), Heredity/genetics (30.0%), and offending/punishment from God (23.3%). Commonly used forms of medical advice and treatment for cancer were; spiritual (80%), traditional herbal (76.7%), modern (76.7%), and traditional (23.3%). Barriers to cancer care access were; cost and advice from others (family, friends, health workers etc.) each at 93.3% and distant healthcare services (53.3%). Findings from qualitative interviews yielded two broad themes; (1) socioeconomic constraints and (2) cultural barriers

Discussion: Beliefs and traditions as a subset of culture are very varied and complex in nature. They vary from person, place and time. They directly impact and people's values, norms, cultural practices, religiosity and spirituality. Hence, they greatly influence their healthcare seeking behaviors and choices for cancer and palliative care. Poor knowledge about cancer, poverty, accessibility challenges and strong cultural beliefs are commonest barriers to cancer care

Conclusions: Findings underline the significant existing knowledge gap about cancer and its treatment. There is need for; (1) Multi-stakeholder approaches to address this gap i.e. reduce barriers to care access, (2) Education to demystify myths and false beliefs, (3) Adoption of culturally appropriate and affordable care.

Cancer Patients' perceptions of their interactions with palliative care services in Uganda, Zimbabwe and Nigeria; a qualitative study

Elizabeth Namukwaya[1], Elizabeth Nabirye[1], Eve Namisango[2], Bassey Ebenso[3], Matthew Allsop[3]

[1]Department of Medicine, Makerere University, [2]African Palliative care Association, [3]Academic Unit of Palliative Care, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

Background: The increasing burden of cancer, late patient presentation to health services and high mortality associated with cancer in Sub-Saharan Africa (SSA) highlight the great need for palliative care (PC) in this region. There is a growing number of palliative care services in SSA in response to this need and it is important to ensure that high-quality and patient-centred care is provided. Patients' perceptions of their interactions with PC services are vital in planning for patient-centred care that is responsive to their needs. However, there is paucity of empirical research on this subject. AIM: To explore cancer patients' perceptions of their interactions with PC services in Uganda, Zimbabwe and Nigeria

Methods: A secondary data analysis was conducted using transcripts from an existing dataset of a larger study—a multi-country cross-sectional qualitative study that was conducted in three countries in SSA (Nigeria, Uganda and Zimbabwe) by the authors. Patients in the larger study were purposively sampled and recruited from hospital and community PC settings. The framework approach to thematic analysis of data was adopted. Ethical approval for the primary study was obtained from the national research and ethics bodies in each of the three countries. FINDINGS: Patient transcripts (n=62) were analysed, 56% of participants were female, mean age 51.6 years. The findings revealed the following themes: i) multidimensional impact of cancer on the patients; ii) forms of patient interaction with PC services; iii) patients' needs and expectations when they sought PC; iv) patients' experiences of PC, and; v) when and how patients felt PC matters to them.

Conclusion: Patients' perceptions of their interactions with PC services revealed positive experiences in relating with health professionals, improvement in well-being and receiving holistic care. Patients felt PC was valuable throughout their disease trajectory but recommended that the intensity of PC interventions be matched to their needs.

"Money was the Problem": Caregivers' Self-Reported Reasons for Abandoning their Children's Cancer Treatment in South West Uganda

Barnabas Atwiine[1], Imelda Busingye[2], Rose Kyarisiima[2], Siyadora Ankunda[2], Gertrude Kiwanuka[1]

[1]Mbarara University of Science and Technology [2]Mbarara Regional Referral Hospital

Introduction: Treatment abandonment contributes significantly to poor survival of children with cancer in low-and-middle-income countries (LMIC).

Aim: In order to inform an approach to this problem, we investigated why caregivers withdraw their children from treatment.

Methods: In a qualitative study, carried out in October and November 2020, in-depth interviews were conducted with caregivers of children who had abandoned their cancer treatment at the Pediatric Cancer Unit of Mbarara Regional Referral Hospital in Southwestern Uganda. Recorded in-depth interviews were transcribed and analyzed to identify themes of caregivers' self-reported reasons for treatment abandonment. The study obtained ethical approval from the Review and Ethics Committee of Mbarara University of Science and Technology.

Results: Seventy-seven out of 343 (22.4%) children diagnosed with cancer at the PCU of MRRH abandoned treatment during the study period; 20 contactable and consenting caregivers participated in the study. The median age of the caregivers was 37 years and most (65%) were mothers. At the time of this study, eight (40%) children were alive and 5 (62.5%) were males; with a median age of 6.5 years. Financial difficulty, other obligations, the child falsely appearing cured, preference for alternative treatments, belief that cancer was incurable, fear that the child's death was imminent and chemotherapy side-effects were the caregivers' reasons for treatment abandonment.

Conclusions and Recommendation: Seeking cancer treatment for children in Uganda is an expensive venture and treatment abandonment is mainly caused by difficult experiences of caregivers. This problem needs to be approached with empathy and support other than blame.

Retention in Care: Psychosocial Support for Vulnerable Children with Cancer during COVID19 Lockdown.

Claire Namulwa, Samuel Guma
Kawempe Home Care, Kampala, Uganda

Background: In Uganda, it is estimated that 3,000 children are affected with cancer annually. Only 750 are registered for treatment at Uganda cancer institute (UCI).Due to close clinic appointments most of the children from up country brave harsh conditions and camp on the verandahs at UCI as they await their next appointment. Some families abandon treatment and return home resulting in many unnecessary deaths. Kawempe Home Care (KHC), a nongovernment organization in Kampala, opened New Hope Children's Hostel (NHCH) in September 2016 to support vulnerable children with cancer and their families to increase access to specialized oncology and palliative care services.

Aim: To retain children in cancer care through provision of psychosocial support during the COVID-19 lockdown and ensure that they complete treatment.
Method: Poor and vulnerable children with cancer and their families identified and referred to NHCH by UCI social workers for psychosocial support. NHCH provides, medicine and all basic needs. Those with appointments were transported to UCI daily. Follow up telephone calls were made to remind patients at home of their next visit, collaborated with health centers, District Health Officers, LC5 Chairpersons and nearby Hospices to support transportation of the children for treatment. Civil society actors led by the Uganda Cancer Society in partnership with UCI organized transport for patients who had completed treatment to travel back to their homes.

Results: During the 3 most difficult months (March - June 2020) NHCH cared for 95 patients each with a care taker, of these 55 were followed up, 37 returned for their appointments, 30 were in the hostel, 10 were admitted at UCI and sadly 14 died.

Conclusion: Despite the tough times covid19 has caused, NHCH managed to offer psychosocial and palliative care services to the children suffering from cancer. Childhood cancer care requires a holistic approach to address the psychosocial needs of the children.

Increasing access for cervical cancer screening services to the Namayingo community - An experience of Rays of Hope Hospice Jinja, Uganda.

Kebirungi Harriet
Rays of Hope Hospice Jinja, Uganda

Background: In Uganda, cervical cancer is the number one cause of cancer-related deaths in women, accounting for 20% of all new cancers and 35% of all female cancers – 80% presenting with advanced disease. At Rays of Hope Hospice Jinja, cervical cancer is the most common cause of cancer and death.

Aims: To provide access to early diagnosis and treatment for cervical cancer for the mothers living in Namayingo. To develop a model for accessible screening to be used at other rural health centers.

Methods: Presently access to free cervical cancer screening in Busoga Region is only available at Jinja and Masaf hospitals - beyond reach for most rural women. In November 2020, RHHJ in partnership with Makerere University School of Public Health wzcarried out a cervical cancer screening training for health care workers in Namayingo district. Equipment for screen and treat was provided to the health centers and the centers were followed by supportive supervision to ensure quality of services.

Results: Screen and treat services were launched in January 2021 and are now successfully established in Banda HC III and Buyinja HC IV. Screenings are regular and women with positive VIA are treated on-site with thermo-coagulation. If more advanced disease or other gynecological problems are diagnosed the women are referred for further management and supported financially if needed. The experiences earned in this process are providing the basis for a model to further disseminate cervical cancer screening in Busoga Region and beyond.

Conclusion: In collaboration with local partners RHHJ has facilitated the integration of screening services into the existing district health program. Following the Covid-19 especially in hard-to-reach areas, RHHJ plans to further its reach of screen and treat to the entire district and region through advocacy programmes that are currently being undertaken.

Oral Presentations: Track 3

Friday 24th September 2021, 2:00pm – 2:30pm

Sustainability of Cancer and Palliative Care Services in Uganda during the response to Covid-19 and other challenging situations

Transition towards three-dimensional conformal radiotherapy in Uganda; our progress, challenges and lessons learnt.

Solomon Kibudde, A. Kavuma, I. Luutu, CN. Bangidde, I. Komaketch, M. Seguya, M. Alinda, C. Nakato, D. Kanyike, J. Orem.
Uganda Cancer Institute

Background and purpose: Three-dimensional conformal radiotherapy (3-D CRT) refers to the design and delivery of radiotherapy with aid of 3-D image data, enabling treatment fields individually shaped to treat only the target tissue. This reduces dose to surrounding critical structures, allows dose escalation to the tumour area and results in high tumour local control and survival benefit over 2-D radiotherapy techniques. Following the procurement and installation of the first linear accelerator at UCI, we report the current progress, challenges and lessons learnt since inception of 3-D CRT in January 2021.

Methods: A systematic review of resources was conducted using a self-assessment tool developed by International Atomic Energy Agency for evaluation of transition from 2-D to 3D CRT. The tool assesses staffing, equipment, commissioning procedures, and 3-D CRT planning and treatment process.
Results: There are at least three radiation oncologists (ROs), three radiation therapy technicians (RTTs), and three medical physicists (MPs) with competence in conventional radiotherapy, cross-sectional and radiological anatomy, target volumes and critical structure delineation, immobilization, and CT simulation protocols. The team has knowledge on radiotherapy planning using the Varian Eclipse Treatment planning system (TPS), quality control measures including treatment verification with daily portal image review, and action levels for different errors. Notably, staff need to expand knowledge on immobilization for CRT, contouring of target volumes and critical structures, and radiotherapy plan evaluation.

Equipment: The available equipment includes a linear accelerator (LINAC) with multi-leaf collimators (MLCs), a CT scanner (shared with radiology) with a flat top couch and alignment lasers, immobilization devices, image-based TPS, a record and verification (R & V) system, and QC equipment for dosimetry measurements. There is urgent need for a dedicated CT-scanner, additional immobilization equipment, and expanding stations for graphic planning.

Commissioning: 3D-CRT has been commissioned with nearly 20 patients actively on treatment. There is need to ensure an independent second dose calculation by the MPs, and daily offline verification.

Establishment of an Incident learning and reporting systems tool for Quality management of radiotherapy services in Uganda

Ignatius Komakech[1], Awusi Kavuma[1], Solomon Kibudde[1], Denis Okello[2], Annette Wygoda[3]
[1]Uganda Cancer Institute , [2]Makerere University, [3]Ministry of Health, Israel

Background: The quality and safety of radiotherapy services in Sub-Saharan Africa has been a subject of major concern as highlighted in several reports. As for Uganda, it has been practicing 2D Radiotherapy since 1995. In 2019, another cobalt-60 and a linac were acquired. The introduction of the linac induced a move to more advanced techniques. In order to make the transition safer, it was agreed to evaluate errors and develop a reporting and learning system; the first step of a broader Quality Management system.

Methods: We reviewed records of 1164 radiotherapy-treated patients from 2018 - 2020 and extracted data on prescribed total/daily doses, treatment fractions, prescription depths, treatment times/doses, setup instructions, etc. Treatment times/doses were re-calculated and compared with the values in the treatment chart/record and verification system. Quantitative analysis of the collected data was performed using Excel software.

Results and Discussion: Errors found ranged from under-dosing (causing recurrences) to overdosing (toxicities) of patients and were in dosimetry and procedures. Dosimetry: Dose errors were mainly due to omission of the block tray factor in the treatment time calculation (15.9%), field size alteration (6.6%), incorrect prescription depths (5.6%), omission of bolus effect (4.7%), incorrect beam weighting (3.0%), failed second calculation checks (2.3%). A total of 1538 treatment sites were re-calculated and 88% produced doses difference within ±5%. Dose calculation accuracy increased over the years from 82.8%, 86.1%, and 93.2% in 2018, 2019, and 2020 respectively. This is attributed to the introduction of a compulsory second calculation check in January 2020.

Procedures: Identified issues of great concern were incomplete setup instructions (57%) and missing patient data in R&V (60.1%).

Conclusions: This result shows evidence of gaps in the delivery of quality radiotherapy services in Uganda. In the event that these issues are addressed, the quality and safety of the treatments will greatly improve.

Incidence, Predictors, and Biomarkers of Kaposi Sarcoma Immune Reconstitution Syndrome Kaposi Sarcoma Patients Initiating Antiretroviral Therapy and Chemotherapy in Uganda.

Innocent Mutyaba
Uganda Cancer Institute

Background: Kaposi sarcoma immune reconstitution inflammatory syndrome (KS-IRIS) is challenging to diagnose and manage. We sought to describe the cumulative incidence and predictors of KS-IRIS in KS patients initiating concurrent cancer chemotherapy and ART in Kampala, Uganda.
Methods: HIV-infected patients with biopsy-proven KS were followed monthly on initiation of KS treatment. Suspected KS-IRIS diagnosis was based on worsening of KS and decrease of HIV VL >1 log within 12 weeks of starting ART. Competing risks survival regression methods determined the incidence and predictors of KS-IRIS.

Results: Among the 84 participants studied, median age was 31.5 years (18-75); 76.2% were male. ACTG staging was T1 for 84.5%, I1 for 54.8%, and S1 for 71.4% of participants. HHV-8 viremia was detected in over 95% and oral shedding in 61.9% of the participants at baseline. Median plasma concentration was 7.2(5.5 – 8.3) for C-reactive protein (CRP) and 1.2(0.3 – 1.5) for IFN-γ. At 90 days from ART initiation, 30 patients developed KS-IRIS, 2 patents died, and 52 were censored. The medium time to KSIRIS was 48 days (13 - 87). KS-IRIS cumulative incidence was 35.7% (25.7%-45.9%). In the multivariate model, KS-IRIS was significantly associated with baseline abnormal chest X-ray findings (HR=3.04 [1.04 -8.90], p=0.04), WBC (HR=0.75[0.57 – 0.99] per 1000 cells/dl increase, p=0.05), CD4 count (HR=0.86(0.76 – 0.99) per 50 cells/dl increase, p=0.03) , CRP (HR=15.68(1.04 – 236.67) per log increase , p=0.05), and IFN-γ (HR=0.15 [0.04 -0.50] per log increase, p=0.002) but not with platelet count (p=0.54).

Conclusions: KS-IRIS remains common even in the context of concurrent ART and cancer chemotherapy. The risk of KS-IRIS increased with pulmonary KS and high CRP, and decreased with increasing WBC, CD4 count, and IFN-γ . These factors warrant further study for their potential as biomarkers of KS-IRIS development to facilitate prevention, early diagnosis and appropriate management of KS-IRIS.

Empowering Health professionals through education and mentorship to improve children's palliative care provision in Uganda.

Florence Nalutaaya[1], Elizabeth Nabirye[1], Elizabeth Namukwaya[1], Mhoira Leng[1], Grace Kivumbi[1], Julia Downing[1,2]

Palliative care Education and Research Consortium, [2]International Children's Palliative Care Network

Background: Globally more than 5.3 million children experience serious health-related suffering, with 2.5 million dying who need access to pain relief and palliative care (PC). More than 98% of these are from low- and middle-income countries. An estimated global need for PC in children is >21 million, with as many as 120 per 100,000 children needing PC in countries in sub-Saharan Africa. Services do not meet this need and so children are suffering needlessly.

Aim: We aimed to empower health professionals through education and mentorship to improve access to and provision of children's PC in Uganda.

Methodology: Initial children's PC training was conducted at Mulago National Referral Hospital for doctors, nurses and pharmacists. A review of registers from the paediatric wards in Mulago hospital and the Uganda Cancer Institute revealed eight districts showing frequent referrals: Jinja, Mbale, Arua, Adjumani, Kabale, Kabarole, Hoima and Bundibugyo. In conjunction with the clinical leads for the hospitals and hospices, health professionals were identified from these districts and trained in a five-day workshop involving lectures, problem-based learning, case-based discussions, pre and post-test evaluations, clinical visits and ongoing clinical mentorship

Results: 16 registered nurses, 10 enrolled nurses / midwives, 3 doctors, 5 pharmacists/dispensers, 6 clinical officers, and 2 counsellors were trained and 26/42 participants were females (26/42). Pre and post assessments showed a median score increment of 30%. Competency improved with the majority scoring 1- 3 pre course and 3-4 post course.

Conclusion: Participants were empowered with skills and knowledge in children's PC and provided with ongoing mentorship and placements at palliative care units or hospices. It is anticipated that there will be increased access to Peadiatric PC in these districts through early identification and management of children with PC needs.

COVID – 19 Restrictions: Facing the Risks of the Girl Child

Mukiibi Henry Kikonyogo
Rays of Hope Hospice Jinja Abstract

Background: In March 2020, the Government of Uganda announced the first phase of COVID-19 lock down and schools were closed for an indefinite time period. This affected the rural palliative care families in particular – leaving vulnerable households in a bad state. With the children at home for several weeks, there was an increased stress on the food security in the households. The girls who would leave their homes in search for food were at a very high risk of rape, early pregnancies and so would result in early marriages and giving up on education. AIMS. To improve livelihoods of school going girls supported by Rays of Hope Hospice Jinja through provision of welfare items like food.

Strategy Used: By March 2020, 126 children were being supported with school fees. With the lockdown instituted, a plan was drawn to support the children with food packs, clothing, monthly counselling sessions, self-study materials, books and assignments in their homes. Parents were guided in how to keep the children occupied in the homes. KEY RESULTS. The routine monitoring and counselling sessions at home enabled the girl child is kept safe and settled with their families. All the children are continuing with their education, only 1 became pregnant. Reading books and other school materials kept the children active, revising and ready to return to school.
Conclusion: The COVID-19 pandemic and the strict lock-down measures created increased food insecurity for already poor families. The girl child was at high risk for early pregnancies and marriage. The comprehensive, holistic RHHJ support programme designed for the 126 children during the COVID-19 school closure proved very successful.

Database is an Essential Part of Palliative Care

John Mwayi
Rays of Hope Hospice Jinja

Background: Rays of Hope Hospice Jinja provides care to patients with chronic diseases over a very wide region, this requires a good data system in place. However, since its start in 2005 there had been serious challenges with records system.This created a great need to improve in the records management of the organization.

Aims: Improve on the patients' follow up system, improve on records keeping, improve on filling system, create central data monitoring and management system

Methodology: It was both retrospective and prospective study where the following measures were put in place; studied the filling system. This was done through checking box files to identify redundant charts and lost for follow up. Purchased two file stores: These were plastic containers that were used to handle the box file from and to the field. Employment of the data officer, creation of the excel sheet for capturing the records, introduction of double checking system of the box files, introduction of the driver's guide and acquiring of new office with inbuilt filing cabinets

Results: Twenty four active routes were formed and each route was given to a clinician to take responsibility. Active patients on each route were identified and their numbers were maintained by tracking the route performances. Improvement on lost for follow up. Improvement of the missed patients from 21% to below 6.6% in 202. Early submission of reports.

Conclusion: In order to have up to dated palliative care patients' records, there is need to have a clear records management system in place for the organizations
Recommendations: Every palliative care organization should have a data base in place for easy monitoring of the progress of patients and records management.

Defaulting and Factors affecting time to recovery among children with severe acute malnutrition receiving outpatient therapeutic care Nakivale refugee settlement.

Gordon Kibirige, Dr. Ezekiel Mupere, Joan N.Kalyango
Clinical Epidemiology Unit, School of Medicine, College of Health Sciences, Makerere University, Kampala

Background: Outpatient therapeutic care (OTC) is critical in the management of children with uncomplicated severe acute malnutrition. Despite the occurrence of a varied duration of stay on the program and defaulting in the refugee settlement, treatment outcome and factors for time to recovery remains unclear.

Aim: To determine the treatment outcomes of outpatient therapeutic care, factors affecting time to recovery, and to explore factors influencing defaulting of children 6-59month with uncomplicated SAM in Nakivale refugee settlement. Southern western Uganda.

Methods: A mixed-methods sequential explanatory of 386 records collected using a pretested structured questionnaire. In-depth interviews from 10 mothers using a semi structured interview guide. Data was entered into EPI-data version 4.4.2.1and exported to Stata for analysis. Descriptive analysis was conducted using; mean, median, frequency, Kaplan Meir, and Cox proportional-hazard regression were used. All statistical tests in this study were declared significant at p.value 0.05. The interviews were translated, transcribed, and exported to open code software for analysis.

Results: The overall recovery rate was 64.2% (95% CI: 59.2% - 68.9%), 29.1%, (95% CI:
24.7% - 33.9%) defaulted, and 0.8%, (95% CI: 0.3%-2.5%) died. The median recovery time was 61 days (IQR= 39, 89), mean rate of weight gain 3.5g/kg/day and the factors associated with time to recovery were: type of the facility (aHR=0.47, 95% CI: 0.33-0.6, p<0.001), baseline Mid-upper circumference (MUAC) (aHR=1.26, 95%CI 1.1-1.5, p.value 0.003) and clients follow-up (aHR 2.79, 95% 1.14-6.83, p=0.025). Defaulting was influenced by irregular stock out , sharing of therapeutic food, long distances.
Conclusion: Outpatient therapeutic care performs below expectation. Type of facility, follow-up affected the time to recovery. Irregular availability and access to therapeutic foods promote defaulting. Further studies need to show the effect of maternal education, household income in the refugee settlement to time to recovery.

Delivering palliative care education at The Institute of Hospice and Palliative Care in Africa-Hospice Africa Uganda amidst the Covid-19 pandemic: Opportunities and challenges

Olet Adong Dorothy, Nakiganda Muganga Harriet, Dipio Racheal, Prof Wilson Acuda, Luyombya Emmanuel, Buyinza Nasur, Mandera Bernadette, Nyakake Janepher
Hospice Africa Uganda

Aim: To conduct an effective professional Palliative Care (PC) training amidst COVID-19 Pandemic

Approach taken: Opening the institute to students was guided by the need to relieve pain and distresses experienced by all those in need in Africa through training PC specialists to offer the much needed holistic pain management to the patients disadvantaged because of effects of lock down and those that were subjected to psychosocial distress and isolation due COVID-19 diagnosis. Four face to face teaching segments were conducted starting 25th January till 1st April 2021 each lasting one month for years: three, two and one of the bachelor's program and year one of master's program with some overlapping. As a preventive measure, a temperature monitoring gun and hand washing at IHPCA entrance was instituted. Every office and lecture room had sanitizer at the entrance. Social distancing was emphasized. Students were required to wear their masks appropriately. On reporting, students were sensitized and reminded about the COVID-19 dangers.

Challenges: Preparing to teach during a pandemic is financially draining and time consuming as the investment needed to put SOPs in place is big. The faculty need to be trained and psychologically prepared to handle a mixture of local and international students some of whom had much worse COVID-19 outbreaks in their countries of origin. Some of the students didn't report for classes due to COVID-19 diagnosis.

Results: The face to face teaching was successfully conducted without any infection of COVID-19 being recorded. In the period, the Master of Science program in PC was successfully launched.

Lessons learned: With proper planning, preparations and strict observation of SOPs, face to face teaching can be successfully conducted without spreading COVID-19. Discharged COVID-19 patients need more PC interventions than had been previously thought.

Establishing Sops for Continuity of Palliative Care Services amidst Covid-19 Pandemic

Irumba Lisa Christine[1], Mark Mwesiga[1], Joyce Zalwango[1], Miriam Ajambo[1], Lacey Ahern[2]

[1]Palliative Care Association of Uganda, [2]University of Notre Dame

Goal: At the onset on the Covid-19 Pandemic in Uganda, the Palliative Care Association of Uganda (PCAU) in collaboration with the Ministry of Health developed, disseminated, and supported the implementation of Standard Operation Procedures with a goal of reducing chances of exposure to the SARS-CoV-2 among palliative care health workers, patients, caregivers, and the community. 9 SOPs were developed for implementation.

Approach: Development - Wide consultative meetings including participation by representatives from Ministry of Health, palliative care specialists, hospices and palliative care organizations. Composition of an expert team for drafting the SOPs led by PCAU and MoH. Presentation - The Draft SOPs were then presented to the National Covid-19 Pillar Committee on Case Management and later to the National Covid-19 Sub Pillar Committee on Infection Prevention and Control (IPC) for Review. Approval was by the Ministry of Health. Printing and dissemination of the SOPs was done. Training of Trainers on SOPs for selected leaders in Hospices & PC teams across the country as leaders were availed training material. Supporting implementation of SOPs, Monitoring and Evaluation of the SOPs.

Results: 200 Copies of SOPS printed and disseminated to Hospices and Palliative Care Teams across the County. 30 participants from 12 health facilities were trained who then trained all their teams at their facilities. 10 hospices and palliative care teams reached with training Acknowledgment of SOPs by facilities as valuable Continuity of care through different models of care delivery e.g. at facilities, Home Care, and outreach.

Lessons learned: The SOPs built confidence among the teams and ensured safety for the teams, patients and the caregivers while continuing to offer the essential service.

Experience of Providing Palliative Care in A Rural District in Uganda

Davis Muwanguzi
Butemba Health Center

Background: Palliative care (PC) development has made significant progress in many parts of Uganda especially in health facilities however in many rural areas it is difficult to have continuity of care after discharge, especially when people spend most of their time in the community and often prefer to die there yet there are few home based care options. Butemba Health Center is 160 kilometers from Kampala the capital city started to meet this need to ensure continuum of care and quality of life.
Aim: To develop a PC service based at a rural health Centre to include home based care.

Method: Starting in the HIV clinic the lead clinician followed up patients (PTS) to their homes.2. Following PC specialist/ leadership training the PC services were fully integrated into the HIV clinic to respond to an increasing number of PC referrals from the community. 3. Negotiation with the District Supervisor led to a sustainable plan. Home visits were supported with a motorbike and follow up by phone. 4. 12 health workers were trained in basic PC services.

Results: Has reduced overcrowding on the ward and unwanted emergencies at outpatient department from an average of 1040 in 2017 to 156 PTS in 2020. This coordinated model of home care has ensured that bedbound PTS receive PC. The number of home visits increased from 52 in 2017 to 208 in 2020 Has provided a good referral system between the facility and the community. The staffs and the family members have a better understanding of PC.

Conclusion: Model of care which combines facility based PC services with home based care services ensures continuity of care. Effective use of available resources is important in a resource limited settings like Uganda. Home based care has ensured the equality of care for both mobile and bedbound PTS.

Experience of Providing Palliative Care in a Rural District in Uganda

Davis Muwanguzi
Butema Health Centre

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Conclusion: Model of care which combines facility based PC services with home based care services ensures continuity of care. Effective use of available resources is important in a resource limited settings like Uganda. Home based care has ensured the equality of care for both mobile and bedbound PTS.

Improving Palliative Care Data Collection at Fort Portal Regional Referral Hospital

Ian Batanda[1], Jenifer Mbambu[1], Cynthia Kabagambe[2], Lacey Ahern[3]
[1]Fort Portal Regional Referral Hospital, [2]Palliative Care Association of Uganda, [3]University of Notre Dame and Center for Hospice/Hospice Foundation, USA

Background: Before 2019, there was no MOH data on palliative care from Fort Portal Hospital. The HMIS at the time had just one indicator – 'pain requiring palliative care, which is the only indicator still present in the HMIS 108. This was inadequate to inform the improvement of palliative care services at the Hospital. In April 2019, the PCAU's M-Health surveillance program was introduced and has been beneficial in identifying and informing key areas of improvement for palliative care at the hospital.

Aim: The aim of the surveillance is to mitigate the problem of lack of accurate and updated information on palliative care services at the hospital and across Uganda.

Methodology: Data is aggregated from patient files and registers and entered in the ODK collect app on an Android device provided by PCAU. The aggregated data is sent to PCAU monthly. In return, PCAU generates a detailed report of the data submitted. This is provided back to the hospital management and palliative care team to aid in decision-making for palliative care services at the hospital.
Results: M-Health made compiling and submitting reports easier. The data helped identify the number of patients needing morphine, lobby, and plan for morphine supply. Also identified were areas requiring re-enforcement such as knowledge gaps among health workers and the involvement of hospital administrators in the improvement of palliative care services. These can be target groups for CME's. The surveillance highlights the growing number of patients in need of palliative care. This evidence is necessary to lobby for additional resources such as expanding the palliative care team and availing space for palliative care. This however is still a work in progress.
Conclusion: With the development of HMIS tools in addition to the surveillance, the palliative care teams hope this will support evidence-based decision making and lobbying for improvement of palliative care in the hospital.

Improving Palliative Care Accessibility through Training Health Workers in Rural Areas-A Case for Rays of Hope Hospice Jinja

Mbabazi Joanita
Rays of Hope Hospice Jinja

Background: The increasing numbers of patients with advanced disease registered for palliative care on the Rays of Hope Hospice Jinja (RHHJ) program coupled with minimal referrals from health facilities in the region over time indicated a training need in early diagnosis of cancer and appropriate referral for treatment and palliative care for health workers within Busoga region.
Aims: Bridge the knowledge gap about cancer and palliative care among the health workers. Strengthen referral system for palliative care patients. Strengthen networking and collaboration with health care facilities within the region. Design methods and approach taken It was both a retrospective and prospective quantitative study where records of sources of patient referrals for palliative care to RHHJ between July 2020 and April 2021 were studied. A three days' introductory course to palliative care for frontline health workers was developed by the Rays of Hope Hospice Jinja clinical team. Meetings were organized for health administrators from 4 hospitals and 2 health centre IVs from distant districts to improve collaboration. Health workers' trainings were conducted between September 2020 and April 2021 in five districts.
Annual target tool put in place to track referrals from trained health workers between July 2020 and April 2021.

Results: Eighty-four health administrators from 4 regional hospitals and 2 health centre IVs were trained. One hundred sixty-two health workers from 81 health facilities were trained in a 3-days course. A notable increase in the referral of patients following the training. Increased collaboration with health facilities through fixed clinic days set up at the 4 hospitals and 2 health centres.

Conclusion: Training health workers in palliative care and cancer is important for earlier referrals for patients in need of care.

Main Lessons learnt: There is still a huge knowledge gap among health workers concerning palliative care and cancer. There is a need to continue sensitization for health workers in palliative care and cancer.

Integrating Health Promotion in Palliative Care: A case of Lweza Community Health Programme

Rose Kiwanuk, Basirika Diana
Lweza Community Health Program (LCHP)

Background: Lweza cell B community faces a number of health-related issues which encourage ill health yet access to health care services remains a challenge especially to the vulnerable. This has made Palliative care more essential than ever.
Aim: To relieve the unnecessary suffering associated with serious illnesses by enabling the community of Lweza cell B to take charge of their own health through behavioral change.

Methods: A community initiative was founded. The local council I committee was fronted to attract community support. Stakeholders including community volunteers and Health care workers within the community were identified and invited for meetings and sensitization to get their buy in and support for the initiative.
A community Needs assessment was undertaken and the major pressing health-related issues were identified. Programmes geared at promoting good health habits focusing on the identified priority issues were initiated including; sensitization and training, outreach clinics, home based health care services besides Palliative care. Other services offered include; blood donation, medical camps; rehabilitation, skilling, legal health care services, community policing and bi-weekly cleaning of the village.

Results: The community embraced the initiative and it reawakened the spirit of humanity. A number of community members including the vulnerable were supported to get early diagnosis, enrol and access affordable health care services in specialized health care institutions through contact persons. Collaboration and networks were established. Relationship between local leaders and the community was strengthened.

Lesson learnt: Access to the right information promotes healthy living. Accessible and an affordable services encourage good health seeking behaviours and minimise the occurrence of serious illnesses in the community which impact on patients' quality of life.
Conclusion: Health promotion drives are essential in strengthening Palliative care in the community.

Palliative Care in Uganda: Quantitative Descriptive Study of Key Palliative Care Indicators 2018-2020

Ainur Kagarmanova[1] Sheba Nyakaisiki[3] Mark Donald Mwesiga[2] Matthew L. Sisk[1] Cynthia Kabagambe[2] Tom Marentette[1] Lacey N. Ahern[1, 4]

[1]University of Notre Dame, Indiana, United States [2]Palliative Care Association of Uganda, Kampala, Uganda [3] Uganda Martyrs University, Kampala, Uganda [4]Center for Hospice Care/Hospice Foundation, Indiana, United States

Background/Aim: The first audit of palliative care services in Uganda was conducted in 2009. Since then, Uganda has made great strides in palliative care development, including policy, education, and services implementation. This study provides an overview of the current availability of palliative care services and morphine use across the country and the challenges that still exist.

Methods: We conducted a descriptive quantitative study of secondary data on nationwide morphine distribution, collated a list of accredited facilities, and analyzed key palliative care indicators from the mhealth Surveillance Project present at a subset of accredited facilities. Analysis involved non-parametric tests using SPSS, mapping geographical distribution of available palliative care services using Geographic Information System, and identification of challenges from the subset of accredited facilities.

Results: There were 226 accredited palliative care facilities across Uganda's 135 districts in 2020. Thirty districts lacked an accredited palliative care facility. The population coverage was 88.5%. The majority (68.1%) of accredited facilities were public, and private facilities received slightly more pain-relieving morphine. There was an alternating trend in volumes of morphine delivered to public and private facilities. More than a third of palliative care patients were diagnosed with non-communicable diseases, highlighting their significance alongside cancer and HIV/AIDS as conditions requiring palliative care. Palliative care accredited facilities offered six types of services: outreach, home visits, psychosocial, legal, bereavement, and spiritual support, but only for an average of seven months a year due to lack of facilitation and transportation.

Conclusion: Palliative care in Uganda developed in quality, volume, and geographic coverage since 2009. The shift in palliative care patients' primary diagnosis from HIV/AIDS to non-communicable diseases marks an important epidemiologic transition. The availability of oral morphine still faces challenges in Uganda. More research is needed to address this as well as the geographical accessibility of palliative care services.

This project has not been presented at any other national/international meeting. It is an analysis of existing data and was exempted from ethics review. Co-author LNA's employer, Center for Hospice Care/Hospice Foundation, has partially funded the mHealth surveillance project which supplied some of the data for this analysis.

Psychometric Properties of the EORTC QLQ-C30 in Uganda

Allen Naamala[1,2] , Lars E. Eriksson[3,4,5], Jackson Orem[2], Gorrette K. Nalwadda[1], Zarina Nahar Kabir[6] and Lena Wettergren[7,8]

Objective: Generic instruments used to assess self-reported HRQoL need validation. Such instruments adapted for use among Ugandans with cancer is lacking; Study aimed at evaluating the psychometric properties of EORTC QLQ-C30 in adults with cancer in Uganda.

Method: Cross sectional study conducted on adult patients with various types of cancer, cared for at the Uganda Cancer Institute. 385 patients answered the EORTC QLQ-C30 in Luganda or English language, the two most spoken languages in the country. The two language versions were evaluated with regard to data quality (floor and ceiling effects and missing responses), reliability (internal consistency) and validity (construct, known-group and criterion). Construct validity was examined through CFA. Mean scores were compared between groups differing in disease stage to assess known-group validity. Criterion validity was examined according to associations between two QLQ-C30 subscales (Global QoL and Physical function) and the Karnofsky Performance Scale (KPS).

Results: Floor and ceiling effects were observed for several scales in the Luganda and English versions. All EORTC scales with the exception of Cognitive function (Luganda $\alpha = 0.66$, English $\alpha = 0.50$) had acceptable Cronbach's alpha values (0.79–0.96). The CFA yielded good fit indices for both versions (RMSEA = 0.08, SRMR = 0.05 and CFI = 0.93). Known-group validity was demonstrated with statistically significant better HRQoL reported by stages I–II compared to stages III–IV patients. Criterion validity was supported by positive correlations between KPS and the subscales Physical function (Luganda $r = 0.75$, English $r = 0.76$) and Global QoL (Luganda $r = 0.59$, English $r = 0.72$).

Conclusion: The Luganda and English versions of the EORTC QLQ-C30 appear to be valid and reliable measures and can be recommended for use in clinical research to assess HRQoL in adult Ugandans with cancer. However, the cognitive scale did not reach acceptable internal consistency and needs further evaluation.

Oral Presentations: Track 4

Friday 24th September 2021

Resilience, caring for care givers and sustainability of services

Establishing SOPS for Continuity of Palliative Care Services amidst Covid-19 Pandemic

Lisa C Irumba[1], Mark Mwesiga[1], Joyce Zalwango[1], Miriam Ajambo[2], Lacey Ahern[3]
[1]Palliative Care Association of Uganda
[2]Ministry of Health Uganda
[3]University of Notre Dame

Background: At the onset on the Covid-19 Pandemic in Uganda, the Palliative Care Association of Uganda (PCAU) in collaboration with the Ministry of Health developed, disseminated, and supported the implementation of Standard Operation Procedures (SOPs) for palliative Care teams in the Country.

Goal: The goal was to reduce chances of exposure to the SARS-CoV-2 among palliative care health workers, patients, caregivers, and the community. 9 SOPs were developed for implementation.

Approach: Development - Wide consultative meetings including participation by representatives from Ministry of Health, palliative care specialists, hospices and palliative care organizations. Composition of an expert team for drafting the SOPs led by PCAU and MoH. Presentation - The Draft SOPs were then presented to the National Covid-19 Pillar Committee on Case Management and later to the National Covid-19 Sub Pillar Committee on Infection Prevention and Control (IPC) for Review. Approval was by the Ministry of Health. Printing and dissemination of the SOPs was done. Training of Trainers on SOPs for selected leaders in Hospices & PC teams across the country as leaders were availed training material. Supporting implementation of SOPs**,** Monitoring and Evaluation of the SOPs.

Results: 200 Copies of SOPS printed and disseminated to Hospices and Palliative Care Teams across the County. 30 participants from 12 health facilities were trained who then trained all their teams at their facilities. 10 hospices and palliative care teams reached with training Acknowledgment of SOPs by facilities as valuable Continuity of care through different models of care delivery e.g. at facilities, Home Care, and outreach.

Lessons learned: The SOPs built confidence among the teams and ensured safety for the teams, patients and the caregivers while continuing to offer the essential service.

Supporting Frontline Health Workers during COVID-19 And Beyond

Naida Agnes
Rays of Hope Hospice Jinja

Background: The most important asset of Rays of Hope Hospice Jinja is our staff of 28 people, including 5 volunteers. During the COVID-19 lockdown and following restrictions high quality patient care was needed more than ever; yet it as crucial to ensure the mental and physical health and safety of the front-line health workers and other staff throughout the organization.

Aims: To maintain physical and mental health of frontline workers To support health workers and their families during the pandemic period with its increase in the cost of living

Approach taken: During the lock-down period alternative schedules were put in place to avoid crowding at the work place. Twice per week phone conferences involving all staff kept all up to date on patients' care issues. PPE were provided to all staff and volunteers. Extra food support was given to the families of staff in order to cope with increased prices. Staff members were free to excuse themselves from field work (but none did). When lock-down was lifted meetings on self-care and social events (with SOP) were conducted. Training was also given for all staff in financial literacy and entrepreneurship.

Results: The patients' care programme continued and no staff contracted the virus. The service to the patients was maintained at the high quality needed and wanted. No staff member withdrew from their duties and nobody resigned. The successful management of the pandemic challenges left a highly motivated team ready to continue giving their best services. This has confirmed the need to continue giving priority to caring for the caregivers making them fit to face the many challenges which will continue beyond the pandemic.

Integration of palliative care into healthcare provision for South Sudanese refugees and host communities in Adjumani and Obongi districts, Uganda; a Rapid Systems Appraisal evaluation

Mhoira E Leng[1,2], Liz Nabirye[1], Vicky Opia[3], Elizabeth Namukwaya[1], Julia Downing[1,2], Liz Grant[2]

[1]Makerere University Palliative Care Unit, [2]University of Edinburgh, [3]Peace Hospice Adjumani

Background: In humanitarian settings palliative care (PC) is rarely prioritised or integrated despite WHO & SPHERE guidelines. Evidence is needed from field settings to inform service development and enable integration as part of a health system strengthening approach. Uganda hosts one of the largest global refugee populations and previous work has sought to integrate PC in Adjumani (210,000refugees) district and is now being extended to the new Obongi district (120,000).

Aim: To evaluate the setting and systems affecting chronic disease and health related suffering for refugee and host populations in Adjumani and Obongi districts.

Methods: Using Rapid Systems Appraisal all documentation was reviewed, stakeholders mapped and filed observations completed. Interviews conducted with 4 groups: leaders in refugee and host communities, MOH, Peace Hospice and humanitarian stakeholders; those living with chronic disease; PC providers & those who refer or interact with PC.

Results: From 34 qualitative interviews the following themes emerged: PC is largely missing but welcomed by stakeholders 'PC is like manna from heaven' 'I pledge to include in district planning'; challenges in planning, pathways of care and integrating resources 'so many people in the community with chronic illness but by the time we discover them, it is too late so we need to create awareness'; cultural and information barriers to care; impact of complex trauma, limited PC education, need to extend 'VHTs are a very big resource therefore their training is key.'; impact of PC is effective 'PC touches us all'

Conclusion: PC service integration is needed and previous interventions effective but we need to extend into planning. Refugee and host communities must have ownership to address issues of culture and stigma. Further evidence on the PC need will be collected, alongside a comprehensive education package for HCW, VHTs and family caregivers and community mentors.

Factors Associated with Survival of Cancer Patients Receiving Palliative Care a Case Study Hospice Africa Uganda

Ronald Mumbere
Makerere University

Background: The Uganda Ministry of Health with the Palliative Association of Uganda has made efforts towards the delivery of palliative care services. Interventions of the Ministry of health and PCAU are aimed at improving access to palliative care in Uganda. However, less has been done; to highlight the risk factors that impact the survival time of the patients; to explore and characterize survival time data of cancer patients.

Aim: To determine the risk factors associated with the survival of cancer patients receiving palliative care and to compare the effects of covariates on the survival time distribution using the Cox proportional hazards model and the censored quantile regression.

Method: A retrospective cohort study design was conducted for patients on palliative care treatment. Secondary data from Hospice Africa Uganda was used to estimate the effect of cancer risk factors on the survival distributions of patients on palliative care. it was further used to determine the method that provides a better characterisation of the covariate effect across the survival time distribution between censored quantile regression and Cox's proportional hazards models.

Results: The risk of death was 12 percent lower for the cancer patients on palliative care who were HIV positive as compared to the HIV negative patients on palliative care. The risk of death of smokers is 1.34 times more as compared to non-smokers. Further, the risk of death was 39 percent more for the heavy consumers of alcohol and 65 percent lower for the moderate consumption of alcohol, all compared to patients who do not use alcohol. In addition, the risk of death of a patient increased as the patient gets older.

Conclusion: The study concludes that using both model frameworks to ascertain the dynamic effects of different prognostic risk factors for the survival of cancer patients receiving palliative care would give the researchers more insights.

Palliative Care in the Forefront towards Universal Health Coverage

Nakami Sylvia
Rays of Hope Hospice Jinja

Background: The UN STG calls for universal health coverage for all by 2030. Presently, the rural Ugandan population have little or no access to adequate quality health care. This inequity was further highlighted during the COVID-19 lock-down. Palliative care programmes working in the poor rural communities have an important role in leading the way towards reaching universal health coverage for all.

Aim: To identify access barriers faced by cancer and palliative care patients; to implement interventions to overcome and improve the individual patient's treatment outcome. Identify ways to improve access in the future.

Methods: Records of new clients enrolled in 2019 were reviewed and reasons for delayed treatment or care were analyzed. Six main access barriers were identified and strategies and operational plans were developed to overcome them.

Results: Rays of Hope Hospice Jinja (RHHJ) developed and implemented practical and affordable intervention(s) for each barrier for the individual patient and at community level. With this approach the treatment outcome for the patient was much improved, and at community level understanding of the importance of early diagnosis and treatment has increased . The district health authorities have increased their support for improved care for patients with cancer and for palliative care.

Conclusion: The road to Universal Health Coverage in Uganda is very rough and long. As palliative care professionals working at the grassroots level, we must identify, address and share the results of present access barriers and improvements when these are lifted or flattened. Palliative care professionals are on the front-line where the battle often is life and death. This position gives us a huge responsibility of having the courage to address and share the inequities leading to the extreme suffering all too often seen in the rural areas of Uganda.

The Mortality Medical Doctors and Dental Surgeons in Uganda since January 2017

Jacinto Amandua[1], Eddie Mwebesa[2]

[1]Retired Commissioner MOH-Clinical Services, [2]Hospice

Aim: To study the profile, causes, and patterns of mortality among medical doctors and dental surgeons in Uganda.

Methods: A retrospective study exploring the cause of death among medical doctors and dental surgeons in Uganda. All deaths registered with the Uganda Medical and Dental Practitioners Council were analyzed using a standard questionnaire. Particulars of the medical doctors and dentists were obtained from the workstations of the deceased staff.

Results: 99 deaths of medical doctors and dentists were registered since 1st January 2017.

Of these 86 (87%) were males. The mean age at death was 61 years (range 24 to 103 years). The major causes of death were cancer (26%), COVID-19 (22%), alcohol-related deaths (7%), diabetes (6%), road traffic accidents (5%), hypertension (4%), CKD (3%), HIV/AIDS (3%), homicide (2%), suicide (2%), PD (2%) and pneumonia (2%). Other causes included gunshot wounds, diverticulitis, fracture/ malaria, stroke, and an undetermined cause. In 8% of the cases, the causes of death were not stated. The majority of the doctors were medical officers (26%), followed by public health specialists (12%), physicians (10%), and surgeons (8%). The most affected ranks were senior consultants (28%), medical officers (23%) and principal medical officers (10%), consultants

(7%), medical officers special grade (6%), and professors (5%). The main ethnic groups affected were Baganda (37%), Lango (7%), Bakiga (7%), Lugbara (6%), Basoga (6%), Banyankole (6%), Acholi (4%),

Banyoro (4%), Alur (3%), Batoro (2%) and Japadhola (2%). Others (1% each) were Bwamba, Dutch, Irish, Italian, Iteso, Kumam, Munyole, Samia, and Tanzanian.

Conclusion: Non-communicable diseases and COVID-19 are the main causes of death of doctors and dental surgeons in Uganda since January 2017. However, alcohol-related deaths, trauma, violence and suicide are becoming issues of concern for doctors' mortality.

Supporting children who are heading families with adults or children receiving palliative care to be resilient during the Covid-19 Pandemic: A case of the Road to Hope Program.

Steven Kasula, Joyce Zalwango, Mark Mwesiga, Anita Balikobaku
Palliative Care Association of Uganda

Introduction: The effects of Covid-19 and the restrictions imposed to mitigate spread of the disease have been expansive more so on the indigent. Families with patients with life limiting/chronic illness have faced effects of the pandemic. Lockdown and travel restrictions impacted access to medicines, other medical supplies, access to information, and appointments for hospitals/hospice visits and medical professional support for patients at home. Families also faced real livelihood challenges including lack of basic home items and food due to restrictions on movements and casual labor. PCAU in partnership with Center for Hospice Care (CHC) run a program to support children heading families with persons living with palliative care needs.

Aim: To support 54 children heading families to thrive the effects of the Covid-19 Pandemic.
Method: PCAU conducted a telephone survey to establish of families headed by children and with family members enrolled on palliative care. PCAU strengthened social support systems for families and advocated for waiver of transport for the sick during lockdown, facilitated palliative care providers to visit families, supported continued learning for children at home, ensured access to relevant information and established a surveillance system to enable support Covid-19 testing and treatment for children and family members.

Results Established top needs for families that included: Food, shelter and other basic needs support, access to medical care, homeschooling, social skills and entrepreneurship. A total of 54 children and 34 families reached and supported: 27 male, 27 female, with median age of 14 years. Children and families tested positive of Covid-19 supported to self-isolate and obtain treatment.

Conclusion Strong social support systems are important to support for the resilience of the vulnerable populations during emergencies. PCAU appeals for stronger advocacy and consideration for the vulnerable as response to Covid-19 progresses in developing world.

Yoga and Mindfulness: Caring for the Caregiver

Annette Deguch
Center for Hospice Care, Mishawaka, IN, USA.

Introduction: Caring for others can lead to exhaustion, compassion fatigue and impact health care worker physical and mental health. Yoga and mindfulness are practices that can be a part of self-care which can mitigate the impact.

Approach: Yoga poses can improve strength, calm emotions, encourage peacefulness and encourage compassion for self. Mindfulness allows caregivers to be present in the moment, to emotionally feel what they are feeling while providing tools and support to cope with the sometimes challenging reality of caregiving. The presenter will share benefits of yoga along with how these benefits can positively impact the health of the caregiver. The attendees of the presentation will be taught proper deep breathing and yoga poses that can improve caregiver health and support their continued work.

Discussion/Conclusion: Being a health care provider has an impact on our health and yoga and mindfulness are tools that can improve our coping with stressful and challenging situations. The COVID-19 pandemic has introduced additional stress and challenges for health care workers. This is an approach for self-care that is virtually no cost and in the control of the health care worker. Resources for further study will be provided.

"…I Got To Understand What It Means To Have A Cancer Diagnosis, What It Means To Be A Patient In Our Healthcare System, Because I Went Through That Myself. I Now Understand What Pain Means, What It Means To Go Through Chemo". Phenomenological Evidence from Healthcare Professional Cancer Survivors in Uganda.

Germans Natuhwera[1], Peter Ellis[2], Stanley Wilson Acuda[3], Elizabeth Namukwaya[4]

[1]Hospice Africa Kampala Uganda, [2]Canterbury Christ Church University, United Kingdom, [3]Institute of Hospice and Palliative Care in Africa, Hospice Africa Uganda, [4]Makerere Mulago Palliative Care Unit

Objectives: The study sought to; (1) examine healthcare professionals' (HCPs) lived experiences of cancer and (2) generate evidence to inform policy and clinical practice for cancer care

Methods: This was a qualitative phenomenological study conducted on HCPs who are ill with, and or survived cancer in Uganda. The study was approved by Hospice Africa Uganda Research Ethical Committee (HAUREC) protocol number HAUREC-079-20. Purposive sampling was used to recruit eligible participants. A demographic form and an open-ended topic guide were used to collect. Face-to-face and telephone interviews were conducted in English, audio-recorded and data saturation was reached. Colaizzi's framework of thematic analysis was used.

Findings: Eight HCPs cancer patients from medical, allied health, and nursing backgrounds participated in the study. Their mean age was 56 years with age range of 29-85 years. Five were female and three were male. Four broad themes emerged from the interviews; (1) prediagnosis and receiving bad news experience, (2) impact of cancer on the HCPs, (3) healthcare system and treatment experiences, and (4) the gaps and what needs to be done.

Conclusions: Many HCPs are increasing receiving a diagnosis of cancer. Becoming ill with cancer is a challenging experience for the professional. It is associated with remarkable disruptions and suffering in nearly all domains of their quality of life i.e. their professional identity and work, social, emotional, physical and economic. Like lay cancer patients, HCPs cancer patients as well experience practical challenges in accessing cancer care. The study showed that health workers are not well prepared to handle their colleagues (HCPs) who become cancer patients. Policy makers and other stakeholders need to work towards improving cancer care services for both the HCPs who are patients of cancer, and also the general cancer patients.

Abstracts for Poster Presentations

31 March –26 May, 2020

Palliative Care during the Covid-19 Pandemic and Total Lock–Down in the Busoga Region

Mutaasa Allan
Rays of Hope Hospice Jinja

Background: As the strict lock-down in Uganda started 31st March, 2020 with prohibition of public and private transport Rays of Hope Hospice Jinja (RHHJ) faced serious challenges for our home-based care programme. In expectation of COVID-19 spreading to Uganda RHHJ purchased in mid-March a 3-month stock of medicines and personal protective equipment for staff and volunteers. All activities involving crowds were cancelled.

Aims: The overall aim in preparation, plans and interventions were to protect the staff and to ensure sufficient medicines, uninterrupted cancer treatment services, basic food supply for the most poor and continuing contact with patients and families.

Methods: Following the initial pre-lock down preparations a comprehensive plan was made to ensure continuity of services. Pain medication and other essential medicines were stocked for 2 months with the patients, a transport programme to and from UCI put in place, increased food supply provided, and hotline and other phone contacts to patients established along with continuing home visits with priority to the very sick.
At the end of the lock-down a survey including 60 patients was carried out to evaluate the outcome of the interventions.

Results: Only 41 of the 146 worries listed at the beginning of the lock-down came through. In spite of possible isolation of the patients, 62% of all clients were physically the same or even stronger as compared with before the lock-down. However, 61% of all patients had less buying power than before.

Conclusion: The new measures to operate during the pandemic were imperative and successful in maintaining continuity of care for the less-privileged patients in the Busoga Region. Valuable lessons were learnt, but the deep poverty continues to be an enormous challenge in the fight for improved palliative care in the rural areas.

Gynecologist, Oncologist And Palliative Care Advisor At Amsterdam Medical Center

Guus Fons, Marieke Kansheba Tacken, Merchardes Bugimbi,
Rubya Hospital

Background: World Health Organization declared the coronavirus disease 2019 (COVID-19) outbreak to be pandemic on March, 12, 2020. Maisha Mema is a dispensary located in Muleba district, a rural and hard-to-reach district covering an area of approximately 2500 square kilometers, with a total population of 600,000 inhabitants (2012 Census).Tanzanian Government announced 3 months

of serious movement restrictions, schools, church and pubs got closed, people scared to attend hospitals. In this period of time we observed few number of patients attending at Hospital due to fear of CORONA VIRUS transmission.

Aim: To provide the most affordable pain and symptom management to cancer and other patients with curable and life-threatening illnesses during COVID 19 pandemic.

Approach taken: This was evidenced when Maisha Mema received a patient DER aged 85 with an extensive fungating penile wound. Patient has been sick 9months before COVID PANDEMIC. He had an offensive wound discharge with thick pus in severe pain. Pain was managed well by dicloper and metronidazole powder for the foul smell. He never married and lost his family during kagera war, used to stay with community friends, due to Covid 19 restrictions and poverty he was abandoned.

Results: Penile amputation was done due to Giant Condylomata. The patient did not have a place to stay we managed to put up a small shelter in the compound since he was homeless. He is a born again and Trust in God Patient received pain assessment and management that greatly improved his life. However after treatment he is scared to go back to his society of fearing segregation, and getting Covid 19, he requested to stay.

Lessons learned: Community need to have knowledge about COVID -19 Pandemic Effects**.** In the era of COVID-19, patients must continue receiving the much needed holistic care following SOPs put in place.

Psychosocial and Emotional Morbidities after a Diagnosis of Cancer: Qualitative Evidence from Lived Experiences of Healthcare Professionals' Cancer Patients and Survivors in Uganda

Germans Natuhwera[1], Peter Ellis[2], Wilson Stanley Acuda[3], Elizabeth Namukwaya[4], Eddie Mwebesa[1]

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Introduction: Globally, cancer is a major, and growing public Health problem. Inevitably, many healthcare professionals (HCPs) are diagnosed with cancer. However, there is very little evidence about their lived experience of this.

Aims: This inquiry aimed to; (1) examine the psychosocial and emotional sequelae associated with cancer patient-hood experience in healthcare professionals (HCPs) in Uganda, (2) generate evidence to inform policy and clinical practice about the needs of HCPs patients with cancer.

Methods: This phenomenological study was conducted in purposely recruited HCPs in Uganda. Data was collected via semi-structured interviews either face-to-face or over the phone. Interviews were audio-recorded and transcribed verbatim. Thematic analysis was guided by Colaizzi's seven step framework.

Results: Eight HCPs cancer patients from medical, allied health, and nursing backgrounds participated in the study. Their mean age was 56 years, range 29-85 years. Thematic analysis yielded three major themes: (1) From a healthcare provider to a patient, (2) Socioeconomic challenges, and (3) Coping and support strategies.

Conclusions: Becoming ill with cancer is a challenging experience for nearly all HCPs participants in this study. It is associated with remarkable disruptions and suffering in nearly all domains of their quality of life i.e. their professional identity and work, social, emotional, physical and economic. Policy makers and stakeholders need to work towards eliminating disparities and barriers to cancer care access for the HCPs

Resilience and Caring for Caregivers

Turyamureba Martin
Lira Regional Referral Hospital.

Goal of the study: To understand the challenges encountered by caregivers and counteracting measures employed by them.

Introduction: When a chronic disease enters a family it affects every member, Caregivers play an important role in ensuring that patients receive care and support throughout the course of illness. This comes with demands from all dimensions of life to meet this sacrifice of life and often times caregivers aspect is less focused on which is equally demanding too.

Method: A qualitative design using interviews for data collection among men and women caring both children and adults with chronic illnesses including cancers, HIV/AIDS in lira district during the month of May 2021. A total of twenty caregivers with different chronic diagnoses were targeted however, only ten were interviewed. Content analysis was employed to identify themes of data .Caregivers were staying with patients and willing to participate were interviewed and informed consent procedures were observed and ethical protocols.

Results: Some of the challenges faced by caregivers in the process of offering care were clustered into financial burden that is cost of treatment, transport to health facilities for services. psychosocial impact that includes fear, hopelessness ,sadness and depression, disruption of family life and physical effects sleeplessness, and fatigue. Participants identified some coping strategies that have helped them to keep moving which were spiritual support, counselling from health carer workers and through sharing experiences with other people of relative problems that give them comfort.

Conclusion: Given the magnitude of challenges caregivers go through in the continuum of care for patients, they greatly need a lot of psychosocial support in all dimensions of spiritual, physical social-economic, mental and emotional to address their distressing features as they are faced with the task of caring progressing diseases and their wellbeing is pivotal in providing holistic continuous care.

Risk of child undernutrition in households with life-limiting disease in Busoga region and Buikwe district, Uganda

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Background: Rays of Hope Hospice Jinja (RHHJ) is an NGO providing homebased palliative care for patients with severe life-limiting diseases in Busoga Region). For the very poor, disease has disastrous economic consequences, leaving the family with few resources. Dedicated health workers in RHHJ have for long observed that food in households receiving palliative care is scarce, and suspect that the children are suffering from undernutrition, but data on this specific high-risk population is lacking. The research project is a close collaboration between Center for Global Health at Aarhus University and Rays of Hope Hospice Jinja.

Aims: To investigate the relation between nutritional status of children under five in households receiving palliative care in the Busoga region. In addition, to investigate the relation between child nutrition in households receiving palliative care in the Busoga region and household food diversity, household food security and health care barriers.

Methods: A comparative study with comparison of households receiving care from RHHJ and neighbours of these households. Two validated questionnaires are used for the data collection: Household Dietary Diversity Score (HDDS) and Household Food Insecurity Access Scale (HFIAS). Further, questions concerning food intake format and health care barriers are developed by the research group. A sample size of 152 pairs of households is calculated. The data is collected between April 2021 and July 2021 followed by statistical analysis calculating odds ratio.

Results: The results are still pending. Perspective: A scientific publication of the study is expected. If significant undernutrition of the risk population of children is shown, the next step is to identify relevant nutritional intervention for the children. The NGO will assure that the research actively is used as a tool for national and international political advocacy to support a nutritional intervention, which can ensure a sustainable intervention.

Socioeconomic Burden of a Diagnosis of Cervical Cancer in Women in Rural Uganda: Findings from a Phenomenological Study

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Objective: The aim of the study was to examine the socio-economic burden and impact of a diagnosis of Cervical Cancer (CC) in rural women in the context of low-resourced country Uganda, using a phenomenological enquiry.

Methods: This was a multi-site phenomenological inquiry, conducted at three hospice settings; Mobile Hospice Mbarara in southwestern, Little Hospice Hoima in Western, and Hospice Africa Uganda Kampala in central Uganda. A purposive sample of women with a histologically confirmed diagnosis of CC was recruited. Data was collected using open-ended audiorecorded interviews conducted in native languages of participants. Interviews were transcribed verbatim in English, and Braun and Clarke's (2019) framework of thematic analysis was used.

Results: 13 women with mean age 49.2 and age range 29-71 years participated in the study. All participants were of low socio-economic status. Majority (84.6%) had advanced disease at diagnosis. A fuller reading of transcripts produced three major theme clusters (1) Impact of CC on women's relationships, (2) disrupted and impaired Activities of Daily Living (ADLs), and (3) Economic disruptions.

Conclusions: A diagnosis of CC introduces significant socio-economic disruptions in a woman's and her family's life. CC causes disability, impairs women's and her family's productivity hence exacerbating levels of poverty in the home. High and expensive out-of-pocket expenditure on treatment, investigations, and transport costs further compound the socio-economic burden. Decentralizing cancer care services to regional centers, scaling up screening services, subsidizing costs of cancer care services, or making cervical cancer care treatment free of charge, strengthening monitoring mechanisms

in public facilities to curb the vice of healthcare workers soliciting bribes from patients, increased mass awareness campaigns about cancer, training more healthcare professionals in cancer management, and palliative care, and introducing an introductory course on gynecologic cancers into all health training institutions are recommended.

Gastrointestinal Carcinogenicity of Artificially-sweetened and Sugar-sweetened Soft Drinks: A Meta-analysis

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Background: There remain inconclusive findings from previous observational epidemiological studies on whether consumption of artificially-sweetened soft drinks (ASSDs) or sugar-sweetened soft drinks (ASSDs) increases the risk of gastrointestinal (GI) cancer. This study aimed to investigate the associations between the consumption of ASSDs and SSSDs and the risk of GI cancers using a meta-analysis.

Methods: This study employed a systematic review and meta-analysis design. Core databases were searched using keywords until May 2020 to identify observational epidemiological studies on the association between the consumption of ASSDs and the risk of GI cancer. The same core databases were searched until August 2020 using keywords to identify studies on consumption of SSSDs and the risk of GI cancer. The data were analyzed using the DerSimonian and Laird method of random-effects model.

Results: In the random-effects meta-analysis on ASSDs, consumption of ASSDs was not significantly associated with the risk of overall GI cancer (odds ratio (OR)/relative risk (RR), 1.02; 95% CI, 0.92-1.14). In the subgroup meta-analysis by type of cancer, consumption of ASSDs was significantly associated with the increased risk of liver cancer (OR/RR, 1.28; 95% CI,1.03-1.58). Pertaining to SSSDs, consumption of SSSDs was modestly associated with an increased risk of GI cancer (OR/RR, 1.08; 95% CI, 1.01-1.16). Also, in the subgroup meta-analysis by study design, there was a significant association between the consumption of SSSDs and GI cancer in cohort studies (RR, 1.11; 95% CI, 1.03-1.20). In the subgroup meta-analysis by type of cancer, consumption of SSSDs was significantly associated with the increased risk of colorectal cancer (OR/RR, 1.13; 95% CI, 1.07-1.19) and a borderline increased risk of pancreatic cancer (OR/RR, 1.12; 95% CI, 0.99 -1.27). In addition, a significant positive dose-response relationship was observed between SSSDs and overall risk of GI cancers.

Conclusions: These findings suggest that overall, there is no significant association between the consumption of ASSDs and the risk of GI cancer, however, there was a pointer to hepato-carcinogenic role. Nonetheless, consumption of SSSDs significantly increased the overall risk of GI cancers, most important, colorectal and pancreatic cancers, suggesting gastrointestinal carcinogenic potential of SSSDs. These findings are envisaged to support evidence-based public health policy, practice and decision-making in cancer prevention, in particular, framing of public health promotion messages

regarding artificially or sugar sweetened soft drinks and GI cancer risk.

Keywords: *Artificially-sweetened soft drinks, sugar-sweetened soft drinks gastrointestinal cancers, artificial-sweeteners, sugar-sweeteners, observational studies, meta-analysis.*

Dietary management for gynaecological cancer patients in an evidence-based approach: A Systematic Review

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Background: Gynaecological cancers are characterized by specific energy metabolism alterations, cancer-related and treatment related complications and symptoms such as anorexia which result in a cachexia syndrome and reduced patient quality of life (QoL) and survivorship. This systematic review aimed at providing an evidence-based approach in dietary management for gynecological cancer patients.

Methods: A Systematic Review design was employed. PubMed, EMBASE, the Cochrane Library, Scopus, CINAHL, and ClinicalTrials.gov were searched in April 2021 to identify suitable studies on dietary management for gynaecological cancer patients.

Results: Out of 1843 articles retrieved from databases and relevant bibliographies, a total of 38 studies met the final criteria for reviewed, fifteen of which were randomized control trials (RTCs), four were systematic review and meta-analysis of RTCs, and the rest were observational epidemiological studies and experiments. Five thematic areas of evidence emerged; dietary management of gynaecological cancer patients during pre- and post-operative (surgical) intervention, during chemo-and-radiotherapy, improving quality of life and survival time through dietary management of gynaecological cancers, the therapeutic (anti-cancer) effect of diet and or nutrition on gynaecological cancers.

Conclusion: This study identified critical dietary interventions that can be implemented before, during and after the conventional cancer treatment modalities and as combination regimen to improve patient QoL and survival times. Appropriate dietary therapeutic protocols with effective psychological and social support are crucial for enhanced dietary management benefit.

Key words: *Dietary management; Gynaecological cancer; Evidence-based approach; Systematic Review*

Cancer Risk and Burden and Universal Health Coverage 'Effective Coverage Index' in Uganda Relative to the Regional and Global Outlook: Data Visualisation

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Background: Monitoring the patterns of the leading causes of cancer burden and their underlying risk

factors and health system related attributes such as financing is imperative for resource mobilization and identifying interventions to reduce future burden. This analysis aimed to provide a visual easy to understand information on the top ten causes of cancer morbidity and mortality, and their background risk factors exposure prevalence in Uganda, relative to the regional and global burden.

Methods: Existing cancer risk and burden related data, selected health coverage indicators and financing were explored and reviewed using data obtained from the Global Cancer Observatory 2020, the "Institute for Health Metrics and Evaluation (IHME)", the Global Health Expenditure Database". Bar chats and conditional Colour-rated tables were used for data visualization.

Results. In 2020, the top 10 causes of cancer morbidity and death in Uganda were cervix, Kaposi sarcoma, breast, prostate, non-Hodgkin lymphoma, esophagus, liver, leukemia, ovary, and colon. Of these top 10 cancers, Uganda experienced a relatively higher cancer incidence and mortality compared to the aggregated incidence and mortality rates observed in Eastern Africa, Africa and the world, except for breast cancer. In Uganda, the most prevalent cancer related risk factors exposures were household indoor air pollution from solid fuels, diet low in at least five servings of fruits per day, metabolic risk from high blood pressure, lead, occupational particulate matter and fumes which were, overall, close to the exposures observed in Africa, but different from the global exposure prevalence. Moreover, cancer related service indicators coverage in the universal health coverage index remains low compared to other health sector indicators at all levels.

Conclusion: Enhancing the overall health sector funding, with national cancer control program sub-component among the top priorities and targeting the most common cancer types and their leading risk factors as priorities could be an effective and efficient use of health-sector resources. This is anticipated to maximize the cancer related universal health coverage effective index with favourable technical, productive, and allocative efficiency.

Keywords: *Cancer risk factors, Risk exposures, Cancer burden, universal health coverage index*

Responding to cancer prevention and early detection needs amidst-and-post COVID-19 pandemic

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Background: The global and national preventive measures deployed against COVID-19 pandemic led to the health services adjustments. This might have compromised other diseases management, including cancer control. For example, studies estimated that up to 67% of expected cervical cancer screenings were missed in 2020 in the US due to COVID-19. Also, in many countries, HPV vaccination is provided in schools, which had their activities interrupted during this pandemic. Moreover, social restrictions could have also impacted negatively on lifestyle / behavioral related cancer risk factors such as physical inactivity, diet, stress, and smoking. Despite implementation of many safety precautions, delivering cancer prevention and early detections services may vary by country, and facility type during COVID-19 pandemic, therefore, this article explored how to respond to cancer prevention and early detection needs amidst-and-post COVID-19 pandemic.

Methods: Emerging studies on cancer control during the COVID-19 pandemic and the recommended safety measures for healthcare facilities to operate effectively during COVID 19 pandemic were reviewed.

Results. Feasible recommendations for healthcare facilities to operate effectively during COVID 19 pandemic exists. These recommendations address: Worker Safety and Support; Patient Service Delivery; Data Streams for Situational Awareness, Facility Practices; and Communications. Recommended services adjustment for health facilities and health workers with strict adherence to infection control may facilitate the new normal of cancer prevention and early detection services. The suggested examples of key messages to the public & clients on cancer prevention and early detection services and access included in this article may provide reassurance and support resumption of cancer prevention and early detection services amidst and post COVID-19 pandemic.

Conclusion: COVID-19 pandemic should be viewed as one of the diseases / health events that the health system deals with without compromising the other diseases prevention and control efforts. Therefore, with adherence to the health facility infection prevention and control measures, healthcare facilities and community health outreaches may operate effectively during COVID 19 pandemic and other similar future infectious disease outbreak.

Keywords: *COVID-19, Pandemic, cancer prevention, cancer early detection, cancer control*

Influence of Dietary Zinc Intake, socio-economic status, H. pylori infection, and lifestyle on Gastric Cancer Risk: A Case-Control Study

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Background: Preclinical and epidemiological studies have indicated that diet, in addition to lifestyle factors play a vital role in the aetiology of gastric cancer. In particular, Zinc has been suggested to reduce the development cancer. Therefore, this study investigated the association between dietary Zinc intake, socio-economic status, H. pylori infection, and lifestyle factors versus gastric cancer risk.

Methods: This study applied a case-control study design in Korean population using a validated semi-quantitative food frequency questionnaire (SQFFQ) based on a 24-hours recall. The dietary Zinc intake values were was computed using a computer-based nutritional software analysis program knowns as Can-Pro 4.0, developed by Korea Nutrition Society). Logistic regression modelling was used to assess the association between dietary Zinc intake, socio-economic status, H. pylori infection, and lifestyle factors.

Results. Higher education level (OR: 0.131(0.022 – 0.790)) and income level (OR: 0.528 (0.343-0.814)) respectively, and being physically active regularly (OR: 0.540(0.401 – 0.725)) exhibited inverse associations with gastric cancer risk. Conversely, H. pylori infection (OR: 7.065 (4.551 – 10.966)), and current smoking (OR:1.625(1.110 – 2.379)) were significantly associated with increased risk of GC. Overall, despite a modest decrease in risk, dietary intake of Zinc was not significantly associated with gastric cancer risk by median (OR: 0.942 (0.703 – 1.263), tertile (OR: 0.906 (0.633 – 1.298)) and quartile (OR: 0.967 (0.636– 1.472)) intake values. Also, the sensitivity analysis for the association of dietary Zinc intake and gastric cancer in a complete-case analysis stratified by sex and age group, there was no significant association between dietary Zinc intake and GC risk in both the sex stratum ((males: OR: 1.219 (0.702 – 2.116); females: OR: 0.729 (0.364 – 1.461)) and the age group stratum, age group below (OR: 1.642 (0.751 – 3.589) and above 50 years (OR: 0.808 (0.480 – 1.359).

Conclusion: In this case-control study, overall, despite a modest decrease in risk, dietary intake of Zinc was not significantly associated with gastric cancer risk in the Korean population, but being physically active regularly may be protective against GC. H. pylori infection remains a significant risk factor for GC. Pertaining the role of Zinc, large-scale prospective studies and a meta-analysis are needed to provide more insights on the effect of dietary Zinc intake on gastric cancer risk.

The Public Health Codes for Cancer Prevention

14 Ways to Reduce Your Cancer Risk

Keywords: *Dietary Zinc, socio-economic status, H. pylori infection, Gastric Cancer, Case-Control Study*

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Background: A wealth of evidence on potential cancer risk factors with modifiable options exists. Therefore, encouraging the public to avoid or reduce the extent of exposure to these risk factors especially those with significantly higher population attributable fractions, may reduce on the risk of developing certain types of cancer with well elucidated etiologies. This article aimed to provide to the general public "The Public Health Codes for Cancer Prevention: Ways to Reduce Your Cancer Risk."

Methods: Existing evidence on the known and putative cancer risk factors were reviewed and summarized into key easy to understand public health messages for cancer prevention.

Results. The key public health messages for cancer prevention dubbed "The Public Health Codes for Cancer Prevention: Ways to Reduce Your Cancer Risk" are:

1. Do not smoke.
2. Make your home smoke free and avoid smoke-filled environment.
3. Not drinking alcohol is better for cancer prevention. If you drink alcohol of any type, limit your intake.
4. Be physically active in everyday life. Limit the time you spend sitting and engage in at least 30 minutes of regularly physical activity per day or on most days of the week.
5. Maintain your body weight within a healthy range. Your health worker can help you know if your weight and body fatness is in a healthy range.
6. Eat healthy food:
   Eat plenty of healthy food such as whole grains, pulses, fruits, and vegetables,
   Balance your diet with various types of healthy foods,
   Limit food high in sugar or fat and avoid sugary drinks,
   Limit the amount of your salt intake,
   Limit red meat and avoid processed meat,
   Do not eat burnt or charred food.
7. Engage in safe sexual behaviour to avoid sexually transmitted diseases that can cause or increase the risk of certain types of cancer such as cervical, Kaposi sarcoma, lymphoma, and liver cancer
8. Ensure your children are vaccinated against Hepatitis B Virus (for newborns) and Human papillomavirus (for girls) following the vaccination schedule for the appropriate age group. If you are at risk of getting infected with Hepatitis B virus or live in a community / region most at risk of Hepatitis B virus infection, get vaccinated against Hepatitis B Virus.
9. In the workplace, including agricultural work, protect yourself against cancer-causing substances by following the health and safety instructions.
10. For women, breastfeeding reduces risk of certain types of cancer such as breast cancer. If you can, breastfeed your baby.
11. Hormone replacement therapy (HRT) increases the risk of certain types of cancer. If you can, avoid or limit use of HRT.

12. For children and persons with albino, avoid too much sun. Use sun protection.
13. Ensure routine health check-ups especially for the most common types of cancer amenable by screening (cervical, breast, colorectal or prostate cancer).
14. Seek more information on cancer prevention and report any cancer suspicious symptoms or signs to your nearby hospital / health centre

Conclusion: Wide dissemination of these key public health messages for cancer prevention at all levels of health services delivery including community level and through various mass media and social interaction opportunities could increase access to cancer preventive messages. This might further stimulate seeking more cancer information, prevention services and adoption of healthy behaviour.

Keywords: *Cancer prevention, Public Health, Key Public health Messages*

Developing best practices for patient and public involvement and engagement in palliative care research in resource limited settings

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Background: Patient and public involvement and engagement (PPIE) are pivotal to maximise the impact of research on clinical care. Despite this need, there a lack of evidence on best practices for making this realistic in Africa.

Aim: To establish best practice for engaging patients and their families in the PPIE initiative.

Methods: We, conducted two focus group discussions stratified by gender (male and female). We identified adult cancer patients through the Uganda Cancer Institute, purposively selecting those that had lived with cancer for at least three months. We recruited adult cancer patients who were actively receiving care and willing to participate in a focus group discussion (FGD). The focus group topic guide included: 1) added value of PPIE in research, 2) how patients wish to engage in supporting research, 3) roles in the research process, 4) options for structuring PPIE sessions 5) capacity building needs. The FGDs were audio recorded, transcribed verbatim and analysed thematically

Results: 20 adult cancer patients participated in focus groups (10 male and 10 female). Our findings indicated that PPIE was as a platform to empower patients to engage in the research. Themes on how patients wished to be involved included: identify priority areas for research priorities, participating in ethical reviews, recruitment of patients and data collection, and engagement in the dissemination and prioritization of recommendations for patient care in healthcare and policy. Preferences for structure were workshops and panel discussions, with a quarterly schedule. Training needed to focus on areas such as capacity building and empowerment for the role.

Conclusion: We provide evidence on best practices to engage patients meaningfully in research on palliative care in Uganda. Our work has formed two PPIE groups, whose capacity should now be built to contribute towards meaningful patient involvement in research and evaluation on impact on research to drive improvement.

Analysis of the NIH-HEALS tool to assess Psychosocial and Spiritual Healing from trauma: Cognitive Interviewing.

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Evidence demonstrates that there are seriously ill or terminal patients who progress beyond the experiences of psychological trauma, coping, and acceptance. We aimed to examine item performance of the NIH HEALS Assessment (healing experience during all life stressors) tool in Uganda.

Methods: Cross-sectional qualitative study design using the cognitive interview approach alongside standard piloting, using the think aloud technique and concurrent probing. The study was conducted at Hospice Africa Uganda, a tertiary palliative care centre. We consecutively recruited adults with advanced care from outpatients and community settings. All interviews were audio recorded, transcribed verbatim and subsequently imported into Nvivo 12 for content and thematic analysis. The results were indexed using the following Tourangeau's model of the response process (comprehension of questions, retrieval from memory, decision process, and response process).

Results: We recruited 30 patients, 51% of these were male. Thirty percent (30%) reported multi-morbidities, such as HIV and hypertension. The mean age was 52 years, minimum 26 years and maximum 86 years. We found issues with comprehension for five (14%) of the thirty-five items and patients noted that the items were relevant but suggested the use of examples to improve the comprehensiveness. The Likert response scale of 1-5 was appropriate and the 30-day recall period for retrieval of information from the memory was also rated as appropriate. The themes emerging from patients' definition of psychosocial/spiritual healing mapped on to the know factors of the NIH-HEALS of 1) connection, 2) reflection and inspection, 3) trust and acceptance, but we noted that the connection was more with the supernatural being than social networks.

Conclusion: The NIH-HEALS has sufficient face and content validity properties for use in palliative care patients in Uganda. The development of a user's manual is recommended detailing the meaning intent for each item, with examples to aide comprehension for users.

Breast radiotherapy management after COVID diagnosis during treatment; a case report.

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Uganda Cancer Institute (UCI)

Background and purpose: The Corona virus diseases- 2019 (COVID-19) diagnosis in a cancer patient represents a growing therapeutic dilemma for clinical oncologists particularly in the setting of ongoing treatment with radiotherapy. We present a case of symptomatic COVID-19 in a young female receiving conventional regimen of adjuvant radiotherapy for breast cancer and explore therapeutic options of handling radiotherapy interruptions related to COVID infection.

Case report: We report a 36 years old female, premenopausal, with right breast, invasive ductal carcinoma pT3N0M0 stage IIB, hormone receptor (ER/PR) positive and Her2neu positive disease, managed with a right breast, modified radical mastectomy, adjuvant chemotherapy with cyclophosphamide, Adriamycin and 5-fluorouracil, and scheduled for adjuvant radiotherapy to the right chest wall, axilla and supraclavicular field with 50 Gy in 25 fractions at 2 Gy per fraction. During routine treatment check at 26 Gy, she reported loss of smell for 5 days, high grade intermittent fevers, dry cough and shortness of breath for same duration. She reported no headache or diarrhoea, or sore throat or change in mental status. Clinically, her vital signs were; axilla temperature of 39°C, heart rate of 120 beats per minute and respiratory rate of 28 breaths per minute. Further respiratory-, and other system examination was unremarkable. A COVID PCR test was POSITIVE, she was hospitalized due to dyspnoea and radiotherapy treatment interrupted until two weeks after recovery.

Discussion: Adjuvant postoperative radiotherapy to this patient is categorized as a high priority intervention necessary to optimize locoregional control. The adverse risk factors are young age at diagnosis (<40 years), and symptomatic COVID-19 during radiation therapy. Favourable clinicopathological features include luminal-A molecular portrait, absence of Her2neu expression, and tumour resection with clear margins. Hypofractionation is a preferred approach to reduce the frequency of hospital visits thus minimizing the risk of infection exposure to patients and staff. However, for high-risk patients, conventional fractionation is still commonly prescribed, with boost irradiation. Due to potentially high risk of adverse outcomes from symptomatic COVID-19, adjuvant radiotherapy was interrupted immediately after presentation and confirmation of SARS-Co-V2 PCR results. The patient was offered endocrine therapy with tamoxifen, and supportive treatment. The appropriate interval from recovery from COVID-19 to resumption of radiotherapy is unknown but several investigators suggest 10-14 days. Adjuvant breast radiotherapy is a category 2 indication, and hence interruptions in radiotherapy leading to an extension of overall treatment time of more than five days are detrimental to both local control and survival. Radiotherapy management options upon recovery from COVID-19 will include hypofractionation so as to keep within acceptable timeframe. Several trials report no difference in survival and locoregional control between hypofractionation and conventional fractionation. In addition to hypofractionation, the traditional method for management of unscheduled treatment interruptions has been adjusting Time/Dose/fractionation using radiobiology BED, and EQD2. The two options will be weighed depending on the time when patient recovers from COVID-19.

Conclusion: The risk and benefit of adjuvant breast radiotherapy should be discussed in setting of multidisciplinary team and elaborated to patient. These decisions should be supported with adequate clinic-pathological data to categorise patient's risk. Hypofractionation reduces treatment duration, without compromising outcomes for patients with breast cancer, and should be prioritized in the COVID era.

Notes

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