



THE REPUBLIC OF UGANDA
MINISTRY OF HEALTH



Uganda Cancer Institute



The 2nd Uganda Conference On Cancer and Palliative Care

Towards Universal Coverage

**Hosted by The Uganda Cancer Institute (UCI) and
The Palliative Care Association of Uganda (PCAU)**

5th - 6th September 2019 At Kampala Serena Hotel

Abstracts





Fred Hutch thanks the **Uganda Cancer Institute** for their ongoing collaboration and dedication as a regional leader in cancer care, training, and research. **We look forward to our continued partnership in innovative, life-saving cancer research.**



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Our Dear Delegates



Dr Henry Ddungu
Conference Chair



Dr Samuel Guma
Co-conference Chair

We warmly welcome you to this 2nd International Uganda Conference on Cancer and Palliative Care in Kampala, Uganda on behalf of the conference organising committees. In particular, we welcome those of you who have travelled from outside Uganda for this important event.

This is an exciting time for all of us working in cancer and palliative care. At this conference, we celebrate the 20 years of the Palliative Care Association of Uganda (PCAU). Over the past 20 years, the work of PCAU has grown, working closely with all of our partners to spread the development of palliative care across the country, working closely with the Ministry of Health. Throughout the past 20 years, the ongoing commitment and support from the Ministry of Health has been critical in the development of services and in Uganda being seen as one of the leaders for palliative care across the region.

Two years ago, we celebrated the Uganda Cancer Institute (UCI) Golden Jubilee and as we came together to celebrate this occasion, it was exciting to hear about the developments in cancer care, the commitment, and the dedication of the teams working at the UCI to ensure that ongoing provision of quality cancer care in Uganda. At this conference, we will reflect on and discuss innovative and evidence-based approaches of working together to reverse the growing burden of cancer and to mitigate its impact on patients and their families, communities, our entire nations and the economy. We will share results from recent research, best practices and lessons from our different institutions and countries with a view to improving cancer and palliative care in our region.

We do hope that this conference helps us to renew our commitment to doing this and enables us to accelerate our actions for achieving a shared vision, mission and objectives. We also hope that the conference will enable you to establish or even strengthen strategic partnerships in cancer and palliative care. Kampala is a beautiful city that was originally built on seven hills but has expanded to cover more than the original seven hills historical cultural sites and excellent weather. We hope you will find an opportunity to explore these.

We are very honoured to be joined by the Right Hon Dr. Ruhakana Rugunda, the Prime Minister of the Republic of Uganda; the Hon. Dr. Aceng Jane Ruth, the Minister of Health of the Republic of Uganda; and the Hon. Dr Diana Atwine, the Permanent Secretary of the Ministry of Health of the Republic of Uganda.

We wish you fruitful deliberations.

Welcome from Dr Jackson Orem, Executive Director, Uganda Cancer Institute



Two years ago, a joint Conference on Cancer and Palliative Care was inaugurated. This was at Speke Resort Munyonyo and was officiated by the Prime Minister of the Republic of Uganda, Rt. Honorable Dr. Ruhakana Rugunda. It opened doors to open discussion of the cancer burden in the country.

This year, the conference brings together health practitioners in a bid to forge ways of reducing the looming global cancer burden in Uganda and East Africa at large. Jointly hosted by Uganda Cancer Institute and Palliative Care Association of Uganda, this conference will see positive outcomes that will influence decision making in the continuum of cancer care. It will offer an expanded scope, enriched experience and unique opportunities to discuss research findings as well as educational sessions on cancer and palliative care.

Statistics indicate that for every 100,000 population, there are 350 incidents of cancer! Yet 80% of the newly diagnosed cancer cases will die in the first year of diagnosis, meaning that only 20% make it after the first year.

The Uganda Cancer Institute has strategies in place to improve survival and also reduce on the number of new cases through creating awareness among others. This conference is also another avenue where important and meaningful discussions are made to avert the cancer burden in the country and also inform other nations of what they should do in their fight against cancer. As we move towards universal coverage, all aspects involved in cancer care should be tackled right from Awareness to palliation. With this, there was no better partner for this conference than you reading this!

I also take this opportunity to thank the Government of Uganda for the continued support to the Uganda Cancer Institute in her efforts to avert the looming cancer burden in the country. Welcome to the 2nd Uganda Conference on Cancer and Palliative Care.

Research is our Resource!

Welcome from Ms. Rose Kiwanuka, Country Director, Palliative Care Association of Uganda



On behalf of the Palliative Care Association of Uganda (PCAU), I would like to welcome you all to the **2nd Uganda Conference on Cancer and Palliative Care**. This is again a joint conference between PCAU and the Uganda Cancer Institute (UCI). The two days conference on Universal Health Coverage (UHC) has a lot to offer. It is going to be exciting days of discussing scientific papers and sharing experiences. The scientific committee organised the programme to cover the continuum of care. It is addressing: prevention, diagnosis, care and treatment, rehabilitation and palliative care. Meaning it is going to be a hectic time.

The Serena Hotel is the right ambiance for learning, I therefore invite you to relax and enjoy the presentations and sharing. The calibre of both plenary and concurrent session speakers presenting at this conference will make it one to remember. All these sessions are meant to give us information that will help to improve our practice in our settings. It is also time for us to take a deep breath and relax from our hectic daily activities. I encourage everybody to attend all the sessions but also to create time for networking and leisure.

At this conference PCAU will celebrate its 20 years of existence. The conference has dedicated the conference dinner to PCAU's 20 years of existence in Uganda hence giving it the theme **20 Years of PCAU dinner**. At this dinner we will eat drink and dance to celebrate the achievements of PCAU, we see that together we are walking towards our vision '**Palliative care for all who need it in Uganda**'. We hope you will all be here.

I hope you will find the conference stimulating and exciting to fuel your passion of caring for those patients who need your care. For the delegates outside of Uganda I encourage you to visit the seven hills of Kampala and other tourist sites in Uganda. I wish you a peaceful stay in Uganda.

Acknowledgements

Sponsors

We are very grateful to all our sponsors for your support towards this conference:

- Fred Hutch
- Centre for Hospice Care (CHC), USA
- AstraZeneca
- Elsméd Health Care Solutions
- Hetero Lab Limited
- Centre for Hospice Care (CHC), USA
- UAP Old Mutual Uganda



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

Conference organising committees

Scientific Committee

- Dr Nixon Niyonzima, Uganda Cancer Institute (Co-Chair)
- Prof. Dr. Julia Downing, Makerere University/ International Children's Palliative Care Network (Co-Chair)
- Lydia Nakawuki, Palliative Care Association of Uganda (Secretary)
- Rose Kiwanuka, Palliative Care Association of Uganda
- Fadhil Geriga, Uganda Cancer Institute
- Dr. Samuel Guma, Kawempe Home Care
- Dr. Dorothy Olet, Hospice Africa Uganda
- Hajjat Mwazi Batuli, Makerere/Mulago Palliative Care Unit
- Dr. Warren Phipps, Uganda Cancer Institute - Fred Hutch
- Isaac Mulyowa, Uganda Cancer Institute
- Sheena Asimwe, Palliative Care Association of Uganda
- Dr. Jacinto Amandua, Palliative Care Association of Uganda
- Dr. Joyce Balagadde, Uganda Cancer Institute
- Joyce Zalwango, Palliative Care Association of Uganda

Publicity Committee

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- Innocent Atuhe, Uganda Cancer Institute (Co-Chair)
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- Zaitun Nalukwago, Palliative Care Association of Uganda
- Christine Namulindwa, Uganda Cancer Institute

- Denis Kawuma, Uganda Cancer Institute
- Joanita Kawalya, Afrigo Band
- Ben Ikara, Uganda Cancer Child Foundation
- Olive Lwanga, New Vision
- Peter Byaruhanga, Volunteer
- Magdalene Kintu, Uganda Cancer Institute - Fred Hutch

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- Ritah Nanyomo, Palliative Care Association of Uganda (Secretary)
- Mark Mwesiga, Palliative Care Association of Uganda
- Innocent Atuhe, Uganda Cancer Institute
- Mrs. Rose Kiwanuka, Palliative Care Association of Uganda
- Ms. Zipporah Kyomuhangi, Palliative Care Association of Uganda

Overall conference steering committee

- Dr. Henry Ddungu, Uganda Cancer Institute (Co-Chair)
- Dr. Samuel Guma, Kawampe Home Care (Co-Chair)
- Mr. Richard Tumwesigye, Uganda Cancer Institute
- Prof. Dr. Julia Downing, Makerere University/ International Children's Palliative Care Network
- Dr. Warren Phipps, Uganda Cancer Institute - Fred Hutch
- Innocent Atuhe, Uganda Cancer Institute
- Mr. Mark Mwesiga, Palliative Care Association of Uganda
- Ms. Zaitun Nalukwago, Palliative Care Association of Uganda (Secretary)
- Dr. Jacinto Amandua, Palliative Care Association of Uganda
- Ms. Tracey Tusaba, Volunteer
- Mr. Ben Ikara, Uganda Child Cancer Foundation
- Ms. Zippora Kyomuhangi, Palliative Care Association of Uganda
- Sheena Asiimwe, Palliative Care Association of Uganda
- Denis Kawuma, Uganda Cancer Institute
- Mrs. Rose Kiwanuka, Palliative Care Association of Uganda
- Ms. Rita Nannyomo, Palliative Care Association of Uganda
- Dr. Jackson Amone, Ministry of Health
- Jacob Ampeirwe, Ministry of Health
- Paul Ebusu, Uganda Cancer Society
- Hajjat Mwazi Batuli, Makerere/Mulago Palliative Care Unit
- Christine Namulindwa, Uganda Cancer Institute
- Lydia Nakawuki, Palliative Care Association of Uganda (Secretary)
- Magdalene Kintu, Uganda Cancer Institute - Fred Hutch
- Isaac Mulwayo, Uganda Cancer Institute
- Sr. Tino Christine, Uganda Cancer Institute
- Dr. Joyce Balagadde Kambugu, Uganda Cancer Institute
- Dr. Jane Nakaweesi, Mildmay Uganda

Select Committee

- Magdalene Kintu (chair) UCI
- Mark Mwesiga PCAU
- Rita Nannyomo PCAU
- Zaitun Nalukwago PCAU
- Richard Tumwesigye UCI
- Innocent Atuhe UCI



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 21 Member Organisations and 1056 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 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 2nd Uganda Conference On Cancer and Palliative Care

DAY 1: THURSDAY 5th SEPTEMBER 2019

7:00 – 8:30am		Registration	
8:30 – 11.00am		Opening Ceremony Conference Chairpersons <i>Dr. Henry Ddungu - Uganda Cancer Institute (UCI)</i> <i>Dr. Samuel Guma - Kawempe Home Care</i>	
	8:30	Welcome Remarks by the Hosting Institutions <i>Ms. Rose Kiwanuka – Country Director Palliative Care Association of Uganda (PCAU)</i> <i>Dr. Jackson Orem – Executive Director Uganda Cancer Institute (UCI)</i>	
	8:40	Entertainment <i>By Uganda Child Cancer Foundation</i>	
	9:00	Global and Regional Status on Access to Cancer and Palliative Care Services <i>Dr. Emmanuel Luyirika - Executive Director African Palliative Care Association (APCA)</i>	
	9:20	Key Note Address: Achieving Universal Coverage to Cancer and Palliative Care Services in Uganda: Key Trends, Gaps, Challenges and Way Forward. <i>Dr. Yonas Tegegn Woldemariam - Country Representative, World Health Organisation (WHO)</i>	
	9.50	Patient's Experience	
	10:10	Remarks from the Permanent Secretary – Ministry of Health <i>Dr. Diana Atwine</i>	
	10:20	Remarks from the Hon Minister of Health of the Republic of Uganda <i>Hon. Dr. Ruth Jane Aceng</i>	
	10:30	Official Opening by the Guest of Honour <i>Rt. Hon. Dr. Ruhakana Rugunda – Prime Minister of the Republic of Uganda</i>	
	10:40	Recognition Awards	
	10:50	Group photo	
11:00 - 11.30am		Tea break	
	11.30	Universal Health Coverage: A Public Health Perspective <i>Prof. Freddie Ssengooba – School of Public Health, Makerere University</i>	
	11:45	Panel Discussion: What are the Critical Resources for Achieving Universal Coverage for Cancer and Palliative Care Services in Uganda? Moderator: <i>Joyce Bagala</i> Dr. Charles Olaro - Director Health Services (Clinical and Community), Ministry of Health Uganda Proscovia Ayebare – Founder/Executive Director, A Pen For Africa – Cancer Survivor Dr. Emmanuel Luyirika – Executive Director, APCA Dr. Jackson Orem – Executive Director, UCI Ms. Rose Kiwanuka – Country Director, PCAU Hon. Rosette K. Mutambi (MP) – Founder, Coalition of Health Promotion and Social Development (HEPS) Uganda Mr. Med S.K Kaggwa – Chairperson Uganda Human Rights Commission	
1.00 – 2.00pm		Lunch Break and Poster Presentations	
2.00 - 3.30pm		Breakaway Session: Capacity Building Chairpersons: <i>Dr. Yvonne Karamagi - Mildmay Uganda</i> <i>Kiboko Petua - Ministry of Health</i> Nile Hall	Breakaway Session: Service Provision/ Paediatrics Chairpersons: <i>Catherine Odeke – Nursing Now</i> <i>Dr. Doreen Agasha Birungi -Hospice Africa Uganda</i> Addis Hall
			Workshop: Human Rights Chairpersons: <i>Mr. Med S.K Kaggwa – Uganda Human Rights Commission</i> <i>Salimah Namusobya – ISER</i> <i>Dr Jackson Amone – Ministry of Health</i> Kyoga Hall
	2:00	Predictors of Kaposi Sarcoma immune reconstitution syndrome among Ugandan patients initiating concurrent antiretroviral therapy and chemotherapy. <i>Innocent Mutyaba – UCI</i>	Strategies used by paediatric oncology nurses to cope with job stress: A case of the Uganda Cancer Institute. <i>Suzan Nabakooza – UCI</i>

2:10	Development, implementation and evaluation of a palliative care education programme for Village Health Teams providing healthcare to South Sudanese Refugees in Adjumani District, Uganda. <i>Vicky Opia – Adjumani Hospital/ Peace Hospice</i>	Psychosocial difficulties experienced by mothers caring for children with cancer: Case series at Mobile Hospice Mbarara. <i>Miriel Kabigarire – Hospice Africa Uganda (HAU)</i>
2:20	Empowering other African countries to initiate and/or integrate African palliative care in their health care system. <i>Dianah Basirika – HAU</i>	Improving Access to Care for Rural Ugandan Paediatric Cancer Patients. <i>Rose Nankinga – UCI</i>
2:30	The East African Centre of Excellence in Cancer Fellowship in Gynaecological Oncology <i>Anthony Okoth Ndira – UCI</i>	Palliative care needs and outcomes of patients with hepatocellular carcinoma in the UCI and Mulago National Referral Hospital. <i>Florence Nalutaya Sserwada – Makerere/ Mulago Palliative Care Unit (MPCU)</i>
2:40	Establishment of the Advanced Diploma in Palliative Care Nursing. <i>Eva Nampiima Kakonge – Mulago School of Nursing and Midwifery</i>	Assessment of the readiness and availability of palliative care services in hospitals in Kampala, Uganda. <i>Eddie Mwebesa – HAU</i>
2:50	Evaluating the impact of the Ugandan Palliative Care Nurse Leadership Programme eighteen months following completion. <i>Julia Downing – Makerere University</i>	Experience of the pain free hospital initiative in a national referral mental hospital in Uganda. <i>Justine Nyegenye – Butabika National Referral Hospital</i>
3:00	Sustained engagement in global oncology nursing. <i>Tino Christine – UCI</i>	Reducing psychosocial issues by involving patients and their families in income generation. <i>Ruth Musimenta – Kawempe Home Care</i>
3:10	The effectiveness of following up palliative care trainees during their clinical placement in Uganda. <i>Dr. Dorothy Adong Olet – HAU</i>	The importance of Paediatric Palliative Care for a child living with a life limiting illness. <i>Maureen Asimwe Buhiire – Kawempe Home Care</i>
3:20	Questions and Answers	Questions and Answers
3.30 - 3.40pm	Break between sessions	

3.40– 4.50pm		Breakaway Session: Health Promotion and Prevention Chairpersons: <i>Dr. Noleb Mugisha – UCI</i> <i>Mike Wargo - Center for Hospice Care</i> Nile Hall	Breakaway Session: Policy and Advocacy Chairpersons: <i>Fatia Kiyange – APCA</i> <i>Immaculate Owomugisha – Uganda Network on Law Ethics and HIV/AIDS</i> Addis Hall
	3.40	Yoga and Mindfulness: A more holistic palliative care approach. <i>Annette Deguch – Centre for Hospice Care</i>	Analysing the legislative and regulatory threats facing improved access to controlled medicines for patients with life limiting illnesses in Uganda. <i>Fred Sebisubi – Ministry of Health</i>
	3.50	Enabling factors for cervical cancer screening uptake in developing countries: An adapted systematic review. <i>Immaculate Mbarusha – UCI</i>	Physical activity events: an avenue for awareness, advocacy and resource mobilisation. <i>Patience Asimwe – Uganda Cancer Society</i>
	4.00	Reaching rural women with cervical cancer screening services. <i>Mutasa Allan – Rays of Hope, Jinja</i>	How are palliative care services financed in Uganda? -Analysis of the implications for sustainability. <i>Jacinto Amandua - PCAU</i>
	4.10	Experiences and supportive care needs of cancer patients in Uganda: Facts behind the figures. <i>Annet Nakaganda – UCI</i>	Fostering a multi-sectoral approach in the fight against cancer in Uganda: the launch of the national cancer symposium. <i>Dennis Olodi – UCI</i>
	4.20	The untapped force of socialising: the case of taws high tea cervical cancer awareness event. <i>Claire Judith Achieng – Thrive a Woman Uganda</i>	Using the national human rights framework to monitor and report on the right to palliative care: Lessons from Uganda. <i>Mark Mwesiga – PCAU</i>
	4.30	Improving access to palliative care services through arts and media engagements. <i>Zaitun Nalukwago - PCAU</i>	Universal Health Coverage in Uganda: Civil Society engagement with Government on resource allocation for cancer and palliative care services. <i>Brian Alex Kiira - ISER</i>
	4.40	Exploring the lived experiences of patients with advanced cancer of the cervix. <i>Germans Natuhwera – Institute of Hospice and Palliative Care in Africa (IHPCA)</i>	The Life:Moving Project: Using film to change perceptions about dying and support end of life care <i>Michele Aaron, University of Warwick</i>
4.50 – 5.15		Tea Break	
6.30		Conference and PCAU @ 20 Dinner <i>Traditional Dress</i>	

DAY 2: FRIDAY 6 th SEPTEMBER 2019			
7.00 – 8.30am		Registration	
8.30 – 10.40am		Plenary Session: Cancer and Palliative Care Services in Uganda: Ensuring Approaches that Leave No One Behind Chairpersons: <i>Dr. Andrew Otero – USAID Defeat TB Project Uganda</i> <i>Dr Fred Sebisubi – Ministry of Health</i>	
	09.00	Creating Appropriate Skills Mix for Cancer and Palliative Care Service Delivery <i>Prof. Francis Omaswa – African Centre for Global Health and Social Transformation (ACHEST)</i>	
	09.20	'Audacity to Love...' <i>Prof. Anne Merriman - HAU</i>	
	09.40	Palliative Care for Oncology Patients and Their Families: Progress, Challenges and Future Plans: <i>Dr. Jackson Orem – UCI</i>	
	10.00	Access to Essential Health Services for Special Populations: A Case Study of the Deaf <i>Ambrose Murangira- Light for the World and Mark Mwesiga - PCAU</i>	
	10.20	Patient Dignity is a Human Right Throughout the Continuum of Care: <i>Dorah Kiconco Musinguzi - Executive Director, Uganda Network on Law, Ethics and HIV/AIDS</i>	
10.40 – 11.00am		Tea Break	
1100 – 12.00		Workshop: Digital Health <i>Paul Mbaka – Ministry of Health</i> <i>Lacey Ahern– Centre for Hospice Care</i> Kyoga Hall	Breakaway Session: Service Provision Chairpersons; <i>Hajat Mwazi Batuli - MPCU</i> <i>Dennis Kidde - Centre for Hospice Care</i> Nile Hall
			Breakaway Session: Paediatrics Chairpersons: <i>Dr. Jane Nakawezi</i> <i>Mildmay Uganda</i> <i>Dr. Joyce Balagadde UCI</i> Victoria Hall
11.00		Factors affecting chemotherapy adherence among breast cancer patients at Uganda cancer institute. <i>Flavia Nalubwama – UCI</i>	Exploring the understanding of illness, death and dying of Ugandan children with life-limiting conditions. <i>Prof. Julia Downing Makerere University/International Children's Palliative Care Network</i>
11.10		Multidrug resistant bacteria- common cause of neutropenic fever among patients with hematologic malignancies in Uganda. <i>Margaret Lubwama – UCI</i>	
11.20		The impact of palliative care in advanced HIV disease. <i>Bertha Kinyatta Amanywa – Kawempe Home Care</i>	Acute Leukaemia, not Burkitt's Lymphoma, is the commonest cancer diagnosed at a south-west Uganda paediatric cancer unit. <i>Barnabas Atwine –UCI</i>
11.30		Volunteer programme essentials. <i>Kristiana Donahue</i> <i>Centre for Hospice Care</i>	
11.40		Attendant and Caregiver Temperature Surveillance (ACTS) for UCI cancer patients. <i>Martha Nantayi – UCI</i>	Presentation and treatment outcomes of children with Burkitt's Lymphoma at Uganda Cancer Institute <i>Geriga Fadhil – UCI</i>
11.50		Questions and Answers	

12.00-1300		Workshop: Sustainable Pain Management in Hospitals in Uganda Chairpersons: <i>Dr. Jackson Amone – Ministry of Health</i> <i>Rinty Kintu – American Cancer Society</i> Kyoga Hall	Breakaway Session: Research and Innovation Chairpersons: <i>Eve Namisango – APCA</i> <i>Dr. Nixon Niyonzima – UCI</i> Nile Hall	Breakaway Session - Paediatrics Cont. Victoria Hall
	12.00		Cross-sectional survey: Serious adverse effects of long-term oral morphine in chronic pain patients in community palliative care. <i>Wilson Acuda – HAU</i>	The lived experience of paediatric oncology nurses caring for terminally ill children: A qualitative study at the Uganda Cancer Institute. <i>Mariam Ndagire – UCI</i>
	12.10		Bringing hope, changing systems, transforming lives; a 10-year review on the impact of integrated palliative care in the academic and national hospital setting in Uganda. <i>Elizabeth Namukwaya - MPCU</i>	
	12.20		<i>Integration approaches of palliative care into primary health care in low -and middle income countries: a systematic review.</i> <i>Dianah Basirika – HAU</i>	Supporting child care givers of HIV/Cancer patients: The experience of PCAU. <i>Lydia Nakawuki –PCAU</i>
	12.30		Breast cancer risk perception and screening behaviours of first degree female relatives to breast cancer patients at Uganda Cancer Institute. <i>Provia Ainembabzi – Makerere University</i>	
	12.40		<i>Utilisation of paediatric radiotherapy services at Uganda Cancer Institute: Baseline results of a quality improvement project.</i> <i>Beatrice Lukundo – UCI</i>	The impact of psychosocial support to vulnerable children and adolescents living with cancer in increasing access to treatment. (New Hope Children’s Hostel, Kawempe Home Care Experience- Uganda. <i>Gereva Niwagaba – Kawempe Home Care</i>
	12.50		<i>Questions and Answers</i>	
1.00 - 2.00pm		Lunch Break and Poster Presentations		
2.00 - 3.30pm		Plenary Session Chairpersons: <i>Dr. Victoria Walusansa: Deputy Executive Director – UCI</i> <i>Fatia Kiyange – Programmes Director - APCA</i> Victoria Hall		

	2.00	Brief remarks from ElsMed Health Care Solutions, UAP and Astrazeneca
	2.15	Palliative Care in Nursing Training Institutions is the Sustainable Approach to Care <i>Dr. Musene Safina - The Commissioner of Business and Technical Education</i>
	2.30	Extending Coverage for Cancer Care in Uganda. <i>Dr. Jackson Orem – UCI</i>
	2.45	Universal Access to Cancer and Palliative Care Services in Uganda: <i>The Journey Continues</i> <i>Rose Kiwanuka - PCAU</i>
	3.00	Can Uganda Find a Great Mix for Cancer, Palliative Care and Universal Health Coverage? <i>Dr. Charles Olaro – Director General Clinical Services – Ministry of Health</i>
	3.15	Conference Awards to Best Oral and Poster Presenters
	3.20	The Second Uganda Conference on Cancer and Palliative Care: The Key Outcomes and Closing Ceremony <i>Prof. Julia Downing</i>
3:30 pm		Conference Closure

Poster Presentations

Abstract ID	Title	Track	Presenting Author
Thursday 5th September 2019			
1	Nurses at Uganda Cancer Institute credentialed for Phase I Clinical Trial implementation	Capacity Building	Jacqueline Asea UCI
2	Diseases and symptom characteristics of inpatient older persons in a Regional Referral Hospital in Uganda.	Health Promotion and Prevention	Taaka Esther Mbale Regional Referral Hospital
3	Assessment of pain on Sicklers with painful crisis in Soroti Regional Referral Hospital children's ward	Paediatrics	Oronon Pius Soroti Regional Referral Hospital
4	Quality of life for paediatric cancer patients at New Hope Children's Hostel, Kawempe Home Care.	Paediatrics	Asiimwe Maureen Buhiire Kawempe Home Care
5	Recognising policy and institutional gaps: Commemoration of 2019 World Cancer Day in Uganda	Policy and Advocacy	Ebusu Paul UCI
6	Uganda National Cancer Control Plan: A step towards Universal Coverage	Policy and Advocacy	Noleb Mugisha UCI
7	A novel green approach towards cervical and prostate cancer treatment: Evidence of selective activity by Silver Nanoparticles from Ethanolic Extracts of Fruits of Annona Muricata	Research and Innovations	Yahaya Gavamukulya Busitema University
8	An assessment of chronic illness and palliative care need in a South Sudanese refugee population within Uganda	Research and Innovations	Natalie Webber MPCU/ PcERC
9	Exploring experiences of family caregivers of adult cancer patients receiving palliative care from Rays of Hope Hospice Jinja.	Research and Innovations	Mbabazi Joanita Rays of Hope Hospice Jinja
10	Exploring palliative care professionals views on illness, death and dying	Research and Innovations	Julia Downing, Makerere University/ PcERC
11	Nurses' perceptions towards reporting chemotherapy administration errors.	Research and Innovations	Hanifah Nabbanja UCI
12	Optimising nutritional status of oncology patients being treated with chemotherapy by obtaining patient weight pre-each cycle and dose verification.	Service Provision	Joseph Semujju UCI

Abstract ID	Title	Track	Presenting Author
Friday 6th September 2019			
13	Palliative care situational analysis in a south Sudanese refugee setting in Adjumani District, Uganda using a Participatory Rapid Systems Appraisal.	Research and Innovations	Peace Bagasha MPCU/PcERC
14	Perception of illness, death and dying by adult patients in Uganda with life-limiting conditions.	Research and Innovations	Julia Downing, Makerere University/ PcERC
15	Prevalence and predictors of cervical cancer in rural Uganda	Research and Innovations	Nita Chai Rays of Hope Hospice Jinja
16	Improving viral suppression among HIV/AIDS children and adolescents through psycho-social support: Continuous quality improvement project	Service Provision	Mufumba Dorcas Kawempe Home Care
17	Patient hostels as service provision for children with cancer: New Children's Hostel, Kawempe Home Care	Service Provision	Clare Namulwa Kawempe Home Care
18	Dissection of the Kaposi Sarcoma tumour microenvironment at the single cell level	Research and Innovations	Waren T Phipps UCI- Fred Hutch
19	Dynamics of the T-Cell Repertoire in HIV+ Adults with Diffuse Large B Cell Lymphoma in Uganda	Research and Innovations	Andrea MH Towleron Fred Hutch Cancer Research Center
20	Cancer early detection services at Uganda Cancer Institute	Service Provision	Edward Takiwereza - UCI
21	Treatment outcomes of HIV patients with Non-Hodgkin's Lymphoma treated with standard dose compared with dose-modified CHOP chemotherapy at Uganda Cancer Institute	Service Provision	Alex Bakenga UCI
22	Could this be a case of Lamivudine Associated Myelodysplasia?	Service Provision	Priscilla Namaganda UCI
23	Factors associated with survival after a diagnosis of AIDS-Related Diffuse Large B-Cell Lymphoma in the ART Era: A prospective study at the Uganda Cancer Institute	Service Provision	Abrahams Omoding UCI
24	Renal dysfunction among patients receiving anti-cancer therapy at Mbarara Regional Referral Hospital Cancer Clinic.	Service Provision	Joanne Kayaga UCI
25	Seeking Cancer Care: Patient's pathways and associated timelines among the commonest cancers at the Uganda Cancer Institute.	Service Provision	Immaculate Mbarusha UCI

Plenary Session One

3C

**Entertainment by 3C -
Children Caring about
Cancer -3C: Little Hands
Beating Cancer**

Children Caring about
Cancer (3C) is a young

people's programme of UCCF, that was conceived in 2010 and later piloted in 2011. The pilot was at St. Mary's College Kisubi (SMACK), Kings College Budo (KCB), Mt. St. Mary's College Namagunga and Gayaza High School (GHS)- All in central Uganda. The mission is to reach everyone who cares about cancer to take action NOW, through the outreaches in schools, sports events, music dance and drama in addition to the annual 3C conferences.

Currently, the programme has reached over 110,000 young people directly and 220,000 guardians indirectly around the country, with presence in Western region (Shema, Bushenyi, Mbarara Districts), Eastern region (Soroti and Serere districts), North Eastern region (Moroto, and Napak districts), Northern region (Lira and Gulu districts), Central region (Wakiso, Entebbe, Kampala, Mukono districts), and West Nile (Arua district). 3C advocates have been able to support patients at the Uganda Cancer Institute with items like; sanitary pads, soap and tissue for the patients admitted at the Hospital and some cancer patient hostels in Kampala and this has always gone a long way to supplementing patients' treatment as they face their road to recovery.

Global and Regional Status on Access to Cancer and Palliative Care Services



*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.

Achieving Universal Coverage to Cancer and Palliative Care Services in Uganda: Key Trends, Gaps, Challenges and Way Forward



*Dr. Yonas Tegegn
Woldemariam
- Country
Representative
World Health
Organisation
(WHO)*

Dr Yonas is an Ethiopian national and holds a Doctorate degree in Medicine. He has over 30 years of experience in general medicine, disaster management, project development, donor relations at different technical and managerial levels.

His international experience includes working with Africa Humanitarian Action (AHA) in Rwanda from 1994-1995, WHO Geneva from 1999-2005, WHO South East Asia Regional office from 2005-2009, WHO India from 2009-2011, as WHO Representative to D.P.R Korea from 2011-2013, and as WHO Representative to Thailand from 2013-2015. Before his reassignment to Uganda, he served as Planning Officer at the WHO Regional Office for South-East Asia, in New Delhi, India from 2016-2018.

The WHO Representative is an accredited representative of the WHO Director-General and the Regional Director and is responsible for negotiations with the host country. The WR also oversees relationships and activities with the government and other partners, provides security for WHO personnel and facilitates functional common services arrangements with other UN agencies.

Universal Health Coverage: A Public Health Perspective



*Prof. Freddie
Ssengooba – School
of Public Health,
College of Health
Sciences Makerere
University*

Dr Freddie Ssengooba is a Professor at the School of Public Health, Makerere University with over 20 years of teaching and research in health policy and systems. He is the Chair of Health Policy Planning and Management (HPPM) department and Director SPEED Project and the Centre for Health Policy and Systems Development (CHPSD) at Makerere University School of Public Health.

Dr Ssengooba trained as a medical doctor and has worked in a clinical setting, as a hospital director and as a District health Officer in Uganda's health system. He has a doctorate covering the intersection of public health policy and institutional economics from the University of London. In the last 17 years, Dr Ssengooba's teaching and research scholarship have focused on health policies, programme design and implementation and health system developments. Dr Ssengooba is well embedded in the national and regional health and development discourses, think-tank taskforces and as advisory boards for health agencies such as the National Planning Authority, WHO-Afro, Wellcome Trust, KEMRI and Health Systems Global. He is well versed in quantitative and qualitative research methods. He has provided technical and consultancy services to WHO, DFID, USAID, World Bank, Ministries of Health, Uganda AIDS Commission and Multi-lateral and Bilateral Agencies and Foundations.

Panel Discussion: What are the Critical Resources for Achieving Universal Coverage for Cancer and Palliative Care Services in Uganda?



*Dr. Charles Olaro
- Director Health
Services (Clinical and
Community) Ministry
of Health Uganda*

Dr Charles is currently the Director Health services - Clinical in the Ministry of Health after serving as a Hospital Director and Senior Consultant surgeon of Fort Portal regional Referral Hospital for 8 years where he joined as a Medical Superintendent in 2008. He served as the Director of Fort Portal Regional Referral Hospital from 2010 – June 2017, having initially served as the Medical Superintendent of the same hospital from August 2008 – October 2010. He has worked as a Senior Consultant Surgeon in the same hospital since July 2009 where he still offers services in that capacity. Prior to this, he served in government as a Medical Superintendent and Consultant Surgeon at Arua RRH from April 2001 – June 2008.

Leading the hospital provided him with the opportunity of being involved in resource mobilisation, planning, budgeting, and managing financial resources, health care logistics and human resources. He also successfully ran private wards in both regional referral hospitals as a source of alternative financing of the health services. This gave him vast experience in mobilisation and management of human, logistical and financial resources. In conclusion He is committed to giving his best to contribute to Universal Health Coverage in Uganda.

Ayebare Proscovia



*Founder/Executive
Director A Pen For
Africa – Cancer
Survivor*

Proscovia is a Lawyer, an International Relations Person and a mother of two. Currently, she is a Senior State Prosecutor with the office of the Director of Public Prosecutions. She possesses vast work experience with the UN Mission Eritrea and Ethiopia (UNMEE) where she served as a Human Rights officer in charge of Press connecting UN Head Quarters and the field office.

She is a Cancer Survivor for 16 years now and Founder and Volunteer Executive Director of A Pen For Africa (APFAF) an organisation to fight Cancer. She serves in other capacities as the Secretary General of the Uganda Association of Prosecutors. She sits in various capacities on boards of Cancer prevention and response organisations including African Cancer Control Alliance, Uganda Cancer Society, Uganda Cancer Fund, and A Pen for Africa (APFAF) among others.

Hon. Rosette K Mutambi (MP)



Founder Coalition of Health Promotion and Social Development (HEPS) Uganda

The Hon. Rosette is a Member of Parliament of Uganda representing the people of Mbarara District, who she has served since May 2016. Prior to that she was the Founder and Executive Director of the Coalition for Health Promotion and Social Development (HEPS) Uganda. HEPS Uganda, founded in 2000 is a health rights organisation that advocates for increased access to affordable essential medicines for the poor and vulnerable in Uganda. She was also the Director of PlanWise Women Uganda from 2007-2010. She obtained her BA Arts (Hons) in Political Science and Public Administration from Makerere University.

Mr. Med S.K. Kaggwa



The overall head of the Uganda Human Rights Commission (UHRC).

He took office as Chairperson of the Commission for the first term in May 2009. Mr. Med Kaggwa has held positions at various regional and international human rights organisations such as the African Commission on Human and Peoples' Rights (ACHPR) and the Organisation of Islamic Cooperation (OIC) on the Independent Permanent Human Rights Commission (IPHRC). He previously served Uganda in various senior capacities which included holding the portfolio for Minister of State in the Office of the President from 1996 to 1998. He had prior to this served as a Delegate to the Constituent Assembly, a body that wrote and promulgated the 1995 Constitution of the Republic of Uganda from 1994 to 1995. Earlier in 1989-1991, he was a Commissioner of the Uganda Constitutional Commission in charge of publicity and Chairperson for Kawempe Division (Kampala District). Mr Med Kaggwa is an accomplished legislator who served as Member of Parliament for Kawempe South in Kampala from 1996 to 2001, and a Member of the East African Legislative Assembly, based in Arusha Tanzania from 2001 to 2006.

He holds a Master of Laws degree from National University of Ireland, a Diploma in Legal Practice from the Law Development Centre, Uganda and a Bachelor of Laws degree from Makerere University, Uganda.

He is a skilled and conscientious legal practitioner with over 30 years in the promotion of constitutionalism, good governance, rule of law and respect for human rights.

Friday 6th September 2019

Plenary Session 2: Cancer and Palliative Care Services in Uganda; Ensuring approaches that leave no one behind

Creating Appropriate Skills Mix for Cancer and Palliative Care Service Delivery:



Prof. Francis Omaswa – African Centre for Global Health and Social Transformation (ACHEST)

Prof. Omaswa is the Executive Director of the African Center for Global Health and Social Transformation (ACHEST) and PI MEPI African Coordinating Center, Chancellor of Busitema University in Uganda, Chair of the African Platform for Human Resources for Health, Chair of Gift of Life Uganda Foundation and Co-chair, Independent Advisory Group to the Regional Director of WHO Africa Region. He was founding Executive Director of the Global Health Workforce Alliance, Director General of Health Services, Ministry of Health in Uganda, founding Director Uganda Heart Institute, founding Chair of the Global Stop TB Partnership Board, Chair of the Portfolio and Procurement Committee of the Global Fund and Chair of Independent Review Committee of the GAVI. He has a keen interest in leadership and governance of health and in access of the poor to health services.

Prof. Omaswa is a graduate of Makerere Medical School, founding President of the College of Surgeons of East Central and Southern Africa, Fellow of Royal Colleges of Surgeons of Edinburgh and Ireland, New York Academy of Medicine, Foreign Associate of the USA National Academy of Medicine. He recently published two books; “African Health Leaders; making change and claiming the future” and “Handbook for Health Ministers”.

Palliative Care is Much More Than Morphine



Prof. Anne Merriman – Founder Hospice Africa Uganda

Prof. Anne is the founder of Hospice Africa with the vision “Palliative care for all in need in Africa”. The palliative care model service for Africa, Hospice Africa Uganda (HAU), commenced in 1993. She brought the magic formula for oral palliative care suitable for taking in the home, for patients in severe pain. This opened the door for holistic care.

From HAU, three further organisations commenced in Uganda, PCAU 1999, APCA 2003 and MPCU 2008. Uganda is recognised as providing some of the best palliative care services in Africa (WHPCA 2014). Today, palliative care, from no services in 1993, has reached 90% of the Districts of Uganda. She is the brain behind the integration of palliative care into the curricula of medical and nursing schools in Uganda with many qualified nurses and doctors graduating with palliative care knowledge and skills. She sees the need to make African palliative care a reality: ie an affordable and culturally appropriate service adapted to every situation where we find our patient and family.

Anne has more than 100 publications including 5 books. 36 years of her professional life have been in Africa. Known as “Mama Africa”, for her work with initiators of palliative care services in other African countries, she has received 3 honorary University doctorates (UK and Ireland) and was nominated in 2014 for the Nobel Peace prize, for her work in bringing peace to the dying in Africa.

Anne has great passion for the suffering patients and their families. Her legacy is to ensure holistic African palliative care reaches all in need, especially those who never see a health worker and are left suffering in their homes. This will only be done through the loving total care, emanating from our palliative care teams, caring for the whole person and family, and not just the disease.

Palliative Care for Oncology Patients and Their Families: Progress, Challenges and Future Plans:



*Dr. Jackson Orem –
Executive Director,
Uganda Cancer
Institute*

Dr. Orem is a graduate of the Makerere University School of Medicine in Uganda. He trained in haematology and oncology at Case Western Reserve University, Cleveland USA. Dr. Orem is the Director of the Uganda Cancer Institute (UCI) and is a Senior Consultant in Oncology. He holds an honorary faculty position at Makerere and is external faculty at the Fred Hutchinson Cancer Research Centre. He is a member of the Non Communicable Disease (NCD) Technical working group of the Ministry of Health and chairs the adverse events and surveillance committee of the HPV vaccine roll out.

Dr. Orem is associate Director of the UCI/Hutchison Cancer Centre Alliance collaboration between the Uganda Cancer Institute and the Fred Hutchison Cancer Research Centre. He is a member of the AIDS Malignancy Consortium (AMC), NCI international BL Clinical Care Committee and is PI for the AIDS Clinical Trial Group (ACTG). His research interests are in infection related cancers - especially viral, and novel treatment of cancer in low resource settings. He was one of the lead investigators in a ground-breaking dose-modified oral chemotherapy trial for AIDS-related non-Hodgkin's lymphoma.

Access to Essential Health Services for Special Populations: A Case Study of the Deaf



*Ambrose Murangira,
Disability Inclusion
Advisor, Light for the
World Netherlands*

Mr. Murangira became Deaf at the age of 10yrs due to mumps. He was frustrated, lost hope and dropped out of school but his mother encouraged him to continue with his education. Studying in mainstream schools both for primary and secondary education and without a sign language interpreter, he managed to complete his Bachelor Degree in Social Work and Social Administration and later Masters in Social Sector Planning and Management both from Makerere University in Uganda. Mr Murangira's BA and MA dissertations were about health – accessing health care by Deaf persons and access to health communication by Deaf persons respectively. In one of his interviews published online, he was quoted asking: *'Now that 75% of health communication is disseminated through radio, how do Deaf persons access such information?'*

Mr. Murangira has dedicated his work to advocating and lobbying for accessible services for marginalized groups with special focus on persons with disabilities. For many years, he has served as CEO and a Member Board of Directors of Disabled People Organizations (DPOs) such as National Union of Disabled Persons of Uganda (NUDIPU); Uganda National Association of the Deaf (UNAD); and National Council for Disability (NCD) – which is a government body responsible for evaluating and monitoring disability inclusion in government and non-government development programs.

Currently Mr Murangira works with Light for the World Netherlands (LftW) – an international organization specialized in

developing tools and training on disability inclusion. At LftW, Ambrose currently, works as Disability Inclusion Advisor and he is assisting over 50 organizations and companies in Uganda (both international and national) in becoming disability inclusive. He is also coordinating Disability inclusion in ICCO in Uganda, Ethiopia, Bangladesh, India, Cambodia and Myanmar among others.

Ambrose has authored a number of papers mainly around disability and development.

Patient Dignity is a Human Right throughout the Continuum of Care:



*Dorah Kiconco
Musinguzi,
Executive
Director, Uganda
Network on Law,
Ethics and HIV/
AIDS*

Mrs. Dorah Kiconco Musinguzi is currently the Executive Director of Uganda Network on Law, Ethics and HIV/AIDS (UGANET). She is A Human Rights Lawyer committed to the pursuit of Social justice for Uganda Communities. She has particular interest in Health rights, HIV/AIDS and Gender justice. She possesses organisational management skills, leadership and governance competences focused at social transformation and is a Member of PCAU.

Plenary Session Three

Palliative Care in Nursing Training Institutions is the Sustainable Approach to Care



*Hajat Dr. Safina
Museene Kisu –
Commissioner
Business technical
and Vocational
Training (BTVET)*

Dr Safina Musene Kisu is a Nurse Educator, started her carrier as a registered nurses

she then become a tutor and later became a Principal heading the following Nursing schools; Mulago, Kibuli and Jinja Schools of Nursing and Midwifery. She is currently the Commissioner Business Technical and Vocational Training (BTVET) under Ministry of Education and Sports. A strong Nurse Advocate and a Fellow of Sub Sahara FAIMER.

Universal Access to Cancer and Palliative Care Services in Uganda: The Journey Continues



*Rose Kiwanuka
- Country Director
- Palliative Care
Association of
Uganda*

Rose Kiwanuka is the Country Director of Palliative Care Association of Uganda (PCAU), a position she has held since 2006. 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, Uganda; a Diploma in Business Administration from London Executive Business College UK; a Diploma in Palliative care with Makerere University through Hospice Africa Uganda; a Clinical Diploma in Palliative care with the Institute of Hospice and Palliative care in Africa and a Diploma in Registered Nursing from St. Francis Nsambya School of Nursing and Midwifery in Kampala, Uganda.

Rose is a strong advocate for palliative care, in 2015 at the UN meeting in Geneva she advocate for the patients right to access pain control medications in the community. Through her role at PCAU,

She has provided leadership for the development of palliative care services in more than 97 districts of Uganda, and the establishment of hospital palliative care teams in 13 Regional Referral Hospitals. She has special interest in education and training, mentorship and support supervision as a way to enhance the integration of palliative care into the health care system in Uganda. She has provided leadership for the development and approval of a National Advanced Diploma Palliative care Nursing curriculum, under implementation by Mulago School of Nursing in Uganda.

Rose is a founding board member of Rays of Hope Hospice Jinja; a Board member of Uganda Heart Institute; a Council member for the Institute of Hospice and Palliative care in Africa; She is a member of International Association of Hospices and Palliative Care (IAHPC) and a Rotarian.

universities in the UK. She is a board member of the Palliative Care Association of Uganda (PCAU) along with the International Association of Hospice and Palliative Care, the Worldwide Hospice and Palliative Care Alliance, and the Palliative Care Research Society. She has been working in palliative care in Uganda since 2001 and goes by the Ugandan name of Nanchya!



The Second Uganda Conference on Cancer and Palliative Care: The Key Outcomes and Closing Ceremony



Prof. Julia Downing, Makerere University and International Children's Palliative Care Network

Prof. Downing is an experienced palliative care nurse, educationalist and researcher. She has been working within palliative care for 29 years, in the UK, Uganda, Africa, Eastern Europe and globally. She is an Honorary Professor at Makerere University and works with the Mulago/ Makerere Palliative Care Team/ Palliative care Education and Research Consortium. She is also the Chief Executive of the International Children's Palliative Care Network and a Visiting Professor at the University of Belgrade, along with several



Uganda Cancer Institute



CONGRATULATIONS PCAU!



Your friends at Center for Hospice Care and Hospice Foundation congratulate you on another successful conference.

Thank you for 10 years of successful partnership through Global Partners in Care!

We are proud to partner with you in achieving your goal of making palliative care available to all those in need in Uganda!



Session 2.00-3.30pm

Breakaway Session – Capacity Building

Predictors of Kaposi Sarcoma immune reconstitution syndrome among Ugandan patients initiating concurrent antiretroviral therapy and chemotherapy.

Innocent Mutyaba^{1,2}, Ponsiano Ocama², Moses Kamya², Jackson Orem^{1,2}, Corey Casper^{3,4,5}, Warren Phipps^{4,5}

¹ Uganda Cancer Institute, Kampala, Uganda; ² Makerere University College of Health Sciences, Kampala, Uganda; ³ Infectious Disease Research Institute, Seattle, United States; ⁴ Fred Hutchinson Cancer Research Center, Seattle, United States; ⁵ University of Washington, Seattle, United States

Background: Treatment of epidemic Kaposi sarcoma (KS) with antiretroviral therapy (ART) can be complicated by an atypical and sometimes severe clinical worsening due to KS immune reconstitution inflammatory syndrome (KS-IRIS). Diagnosis of KS-IRIS is challenging, and optimal management of KS-IRIS remains unknown. We therefore sought to describe the cumulative incidence and predictors of KS-IRIS in KS patients initiating concurrent cancer chemotherapy and ART in Kampala, Uganda.

Methods: We enrolled adult HIV-infected patients with biopsy-proven KS and followed them monthly on initiation of KS treatment. KS-IRIS diagnosis was based on worsening of KS (an increase in number/size of lesions) with a concurrent decrease of HIV VL >1 log within 12 weeks of starting ART. Kaplan-Meier and Cox regression methods were used to determine incidence and predictors of KS-IRIS.

Results: We enrolled 73 participants with median age 31 years (range 18-75); 76% were male and 86% had extensive KS. At baseline, median HIV VL was 5.3 log copies/mL (range 2.35 – 6.67), and CD4 T-cell count was 191 cells/dL (range 3-1437). KS-IRIS cumulative incidence was 46.7% (36%-59%). In univariate analysis, KS-IRIS was associated with abnormal chest x-ray (HR=2.58 [1.04-6.4], p=0.04), and CD4 count <150 cells/mL (HR=2.07 [1.05-4.07], p=0.04); there was a trend towards significance for detection of oral KSHV viremia (HR=2.9 [0.83 -10.15], p=0.09), and platelet count <200 (HR=2.19 [0.94-5.09], p=0.07). In multivariate analysis, KS-IRIS was associated with a platelet count <200 (HR=11.57 [2.39-55.96], p=0.02), abnormal chest x-ray (HR=7.13 [1.66-3.99], p=0.01), and detection of oral KSHV viremia (HR=5.56 [1.17 – 26.23], p=0.03).

Conclusions: KS-IRIS remains common even in the context of concurrent ART and cancer chemotherapy. The risk of KS-IRIS may be higher in patients with pulmonary KS, a lower platelet count, and uncontrolled KSHV replication. These factors warrant further study for their potential as biomarkers of KS-IRIS to facilitate prevention, early diagnosis and appropriate management of KS-IRIS.

Development, implementation and evaluation of a palliative care education programme for Village Health Teams providing healthcare to South Sudanese Refugees in Adjumani District, Uganda.

Vicky Opia¹, Michelle McGannan², Natalie Webber^{2,3}, Fiona Morrison^{2,3}, Peace Bagasha³, Liz Grant⁵, Julia Downing^{3,4,5,6}, Mhoira Leng^{2,3,5}

¹Peace Hospice, Adjumani ²Cairdeas International Palliative Care Trust ³Palliative Care Education and Research Consortium ⁴Makerere University ⁵Global Health Academy University of Edinburgh ⁶International Children's Palliative Care Network

Background: Palliative care (PC) is a national priority in Uganda yet access to services remains limited for those in rural and marginalised communities such as those living in refugee settlements within Adjumani district. Inadequate education and training in PC for Village Health Teams (VHTs) contributes to this inequity and needs to be addressed to achieve Universal Health Coverage (UHC).

Aim: To equip VHTs in Adjumani district with basic PC knowledge to enable the identification of PC patients and facilitate appropriate onward referrals.

Methods: VHTs were invited from all 18 refugee settlements within Adjumani District to participate in a PC training programme. 75 VHTs; 71 % male, 29% female, were divided into three cohorts. Each cohort participated in a three-day training programme facilitated by Peace Hospice, Adjumani and UK mentors from CairdeasIPCT. A proportion of VHTs received bicycles to assist in their new role.

Results: Participants were asked to complete a 5-point Likert pre- and post-course self-confidence assessment for seven key PC domains and an end of course evaluation. Results from the self-confidence assessment showed a significant improvement across all domains in mean pre-course scores (range 1.26-1.8) when compared with mean post-course scores (range 4.34-4.52). Participant feedback demonstrated evidence of learning and attitude change 'I know how to communicate to patients and families', 'I know how to sensitise the community on palliative care'. Six months post-training; 92% of the 60 VHTs questioned had identified and referred patients needing PC to local health services.

Discussion: Engaging VHTs and equipping them with the necessary skills and knowledge to identify and facilitate referral of patients needing PC is important for PC integration. A qualitative study to review their experiences is underway. Engaged VHTs have asked for more recognition, facilitation, mentorship and training. These are crucial steps towards achieving UHC for PC in humanitarian settings.

Empowering other African countries to initiate and/or integrate African palliative care in their health care system.

Basirika Dianah, Prof Anne Merriman, Sylvia Dive, Bernadette Basemera

Hospice Africa Uganda

Background: Palliative Care (PC) is an important aspect in alleviating suffering for all patients with serious or life-threatening illness yet many countries in Africa still lack these Services. International Programmes (IP) carries forward the third objective of Hospice Africa Uganda (HAU) of facilitating the Initiation and expansion of Palliative Care (PC) in Africa through training, clinical mentorship, sensitisation and advocacy while fostering sustainability. The programmes' reference is the HAU model when advocating for culturally appropriate and affordable PC in African countries.

Approach: Short PC courses are held in English and French in Uganda. This includes mobile rounds in patient homes. A few countries organise their own in country PC courses with IP support. Visitors to HAU come for clinical experience, see how liquid morphine

is manufactured using a very simple and affordable formula. Needs assessment is done with IP support, planning and advocacy meetings are arranged and advice offered. Follow up is through emails, phone calls, social media and in-country visits.

Results: Over thirty African countries have initiated PC and thirty-five now declare they have it in their country. A few countries have established National Palliative Care associations to advocate and coordinate PC services in their countries. Some countries have integrated PC in the country mainstream health care in various ways; for example Rwanda has a national Palliative Care Policy. Other countries like Malawi run their own PC courses adapted from the HAU initiators' course. Twenty-two African countries now have affordable oral liquid morphine compared to only 3 in 1993.

Conclusion: African countries that have initiated Palliative Care need to support those still struggling by sharing their experiences. Utilising the available opportunities will facilitate further PC development across the region and enhance its accessibility thereby promoting Universal Health Coverage.

The East African Centre of Excellence in Cancer Fellowship in Gynecological Oncology

Okoth Anthony

Uganda Cancer Institute

Background: The two-year gynaecological oncology fellowship was launched on the 2nd of June 2017 with two fellows. The fellowship was started by the Uganda Cancer Institute, Mulago National Referral Hospital and Makerere School of Health sciences and later joined by the International Gynaecologic Cancer Society (IGCS) Global Curriculum and Mentorship

Programme Goal: To provide the highest level of medical education with a view to producing clinically and academically outstanding gynaecological oncologists. The program provides fellows with the necessary knowledge, skills and experience to independently manage gynaecologic cancer patients with complex treatment requirements and to teach medical students, residents, and allied health care professionals in the clinical or classroom settings.

The program it is hoped shall close the 'care' gap and the 'information' gap that patients at all stages of their cancer experience have about their illness, treatment options, benefits and risks, clinical trials, and how to find emotional, financial and practical support.

The fellows' competence will include medical oncology, radiation oncology, palliative care, colorectal surgery, urogynaecology and pathology.

The Fellows will receive an IGCS Certificate of completion and the fellowship shall be accredited by the East Central and Southern Africa College of Obstetrics and Gynaecology.

Establishment of the Advanced Diploma in Palliative Care Nursing.

Eva Nampiima Kakonge

Mulago School of Nursing and Midwifery

Background Information: Mulago School of Nursing and Midwifery is one of the Public Nursing and Midwifery training school which was founded by the British colonial Government in 1955 to address and promote preventive, rehabilitative as well as curative care. The school was established to meet the needs of Mulago National Referral Hospital. The School has had several milestones from training certificate Nurses/Midwives to Diploma Nurses /Midwives. M.O.H development plan 2015 /16 -2019 /20 projected a need of 700 palliative care practitioners to be trained to handle palliative care services

to patients in moderate and severe pain due to chronic and debilitating illness. Hospice Africa Uganda, the only Institute training palliative care practitioners, graduates less than 15 officers per year. It was estimated by then less than 200 qualified palliative care practitioners were providing care to an estimated 255,000 number of cancer and AIDS patients, let alone other patients with life limiting illness. Due to inadequate number of trained palliative care nurses in the Country (Uganda) , Ministry of Health requested Ministry of Education and Sports in a letter dated 06/04/16 to offer a post basic diploma palliative care course for nurses in their health training Institutions preferably Mulago and Jinja Nursing and Midwifery schools where capacity had been most built among the tutors and the two hospitals in their jurisdiction have been accredited.

Programme mission: The mission of the advanced diploma in palliative care nursing is to develop specialised nurses capable of taking on clinical, educational, managerial, policy and research roles in palliative care.

Programme goals: To produce multi-skilled graduates for Uganda who will develop and manage clinical palliative care services. To increase the number of palliative care practitioners who will prescribe palliative care medications.

Method used: The request was forwarded to the planning and development committee of the school and recommendations were forwarded to full Governing council for approval. The Governing council approved the development of the curriculum and commencement of this noble course. Hospice Africa Uganda offered a working document. Preliminary meetings were held with support from Palliative Care Association Uganda. Technical team was identified to develop the curriculum. The team comprised of PCAU, HAU, MPCU, M.S.N.M and MULAGO Hospital. Developed curriculum was presented to the stake holders and discussions made. Later the drafted curriculum was forwarded to nurses and midwives council and comments made were addressed. Curriculum was further refined by the national curriculum development centre.

Results: Curriculum for ADPCN was approved by the permanent secretary M.O.E& S in November 2018. First enrolment for ADPCN for academic year 2019 was done in January intake with 15 students. Second enrolment for ADPCN will be done in July 2019.

Conclusion: More sensitisation is needed for nurses to embrace the training in ADPCN.

Evaluating the impact of the Ugandan Palliative Care Nurse Leadership programme eighteen months following completion.

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Background: The Uganda Palliative Care (PC) Nurse Leadership programme was delivered from August 2015 to March 2017. By developing PC nurse leaders it was anticipated that it will support the ongoing development and leadership of PC within Uganda. An end-of-project evaluation undertaken in March/April 2017 found that the programme had delivered an *exemplary nurse leadership training*, which can be used as a model for future leadership programmes.

Aim: To gain an understanding of the on-going impact of the Ugandan PC Nurse Leadership Programme.

Methods: Five participants from Kampala took part in the FGD. Interviews were conducted with 11 participants from across Uganda (7 female, 4 male), thus 16/20 (80%)

of those trained were included in the evaluation. Interviews were also conducted with three managers (2 female, 1 male). Interviews and the FGD were conducted in English, 9 interviews were undertaken by phone and 5 face-to-face. Themes were identified and a coding framework developed by the research team. Ethical approval was gained from HAUREC and UNCSST

Results: Five themes were identified: 1) leadership skills and training, how they had been inspired, empowered, promoted and utilised their leadership skills; 2) the extension of PC provision, e.g. developing new services; 3) the challenges experienced with regards to leadership; 4) their feelings and understandings in relation to leadership; 5) mentorship – their ongoing relationship with their mentors as well as providing mentorship to others, and the benefit of mentorship.

Conclusion: The leadership programme has had long lasting impact on the participants. Many have been promoted within their workplace and given more leadership responsibility, and the skills and knowledge acquired has been recognised. Ongoing mentorship and support for the leaders is important in order to support their ongoing growth and development and they should be encouraged to mentor students in future cohorts of the leadership programme.

Sustained Engagement in Global Oncology Nursing

Tino Christine, Arlyce Coumar, Kathleen Shannon Dorcy, Allen Naamala, Nixon Niyonzima, Edith Angella Baitwabusa

Uganda Cancer Institute

Background/Rationale: Predicted incidence of cancer expected to be 22 million by 2032 and the disease burden is disproportionately felt in low- and middle-income countries (58% of new cases and 65% of cancer deaths). The Uganda Cancer Institute (UCI) sees over 4000 new cases each year (2018) and treats 30K-40K outpatients a year. Uganda has a high rate of cancer and UCI is only Cancer Centre in all of Uganda. UCI/Fred Hutch (FHCRC), and the Seattle Cancer Care Alliance (SCCA) have a 14-year collaboration, but with no nursing engagement. SCCA nurse team invited to join in 2016.

Aim: Create a global nursing partnership between institutions to enhance nursing expertise and catalyse mutual efforts to mitigate the increasing burden of cancer in Uganda and the United States.

Methods, Intervention, and Analysis: UCI hosted SCCA nurse team 2/2018, 10/2018, and 1/2019. The initial visit included assessment of perceived needs as well as stakeholder interviews with leaders in HCRI-U and FHCRC to identify areas for capacity building in oncology content. Additionally, surveys were collected with each visit to give insight into job satisfaction, nursing Role Review, career trajectory and educational preparation.

Discussion and Implications: Across the 3 visits 10 Oncology Clinical Content courses were taught over 3-day sessions to 80% UCI nurses. Various platforms were utilised during the year for continued engagement with nurses, including Shared Clinical Case Studies via Live Stream Consultation, online support for quality improvement and research proposals, abstract creation, and clinical problem solving. (i.e. nutrition deficits in oncology care) Another focused program offered at UCI was a two-day Nurse Research Readiness (CITI HSP and GCP training).

The effectiveness of following up palliative care trainees during their clinical placement in Uganda.

Dorothy Adong Olet, Nasur Buyinza, Bernadette Mander, and Harriet Nakiganda
Hospice Africa Uganda

Background: Palliative care (PC) trainees in Uganda have been trained to provide holistic PC country-wide. As part of their training, they are mandated to undertake a clinical placement at one of the partner organisations to enhance their knowledge and skills in PC. Education is one of the requirements to enhance PC provision under Universal Coverage.

Aim: The aim of this project was to establish whether following up PC Trainees during their clinical placement could improve their knowledge and skills and access to PC by patients.

Method: following the theoretical and practical sessions during the face to face, the trainees are mandated by the curriculum to undertake a clinical placement during the recess term where their knowledge and skills gained are translated into practice.

Approach process: Thirteen Bachelor of Science students were followed up by three faculty members at Hospice Africa Uganda, Mulago Palliative Care unit, Kawempe Home Care, Rays of Hope Jinja, Joy hospice Mbale, Adjumani Hospital, Reach out Mbuya, Mobile Hospice Mbarara and Kisoro Hospital. The aim was to explore the scope of palliative care activities, establish existing support and challenges being faced, interview trainees and their administrators on their management of palliative care patients and to identify possible solutions.

Results: During this project, it was noted that trainees had spelt out placement objectives to achieve and the strategies to achieve them. The trainees were also able to analyse which objectives were achieved and which ones weren't achieved and why they weren't achieved. They also acknowledged that follow up enhanced their learning and helped to advocate for PC with in their facilities and districts. System challenges including limited drug supply, poor attitude by some colleagues and inadequate space for patient assessment featured prominent in about 80% of the sites.

Lessons learned: PC trainees on clinical placement are able to translate the knowledge gained in class into skills during their clinical placement. They were eager to transfer the knowledge and skills gained during the PC training to their places of work in order to ensure that holistic PC is availed to their patients. Clinical placement and its follow up are key components to PC training.

Key recommendations: All PC trainees should undertake clinical placements. The PC trainees should be followed up to ensure that they are supervised during the clinical placement and that their clinical placement objectives are being achieved. Documentation is important during the clinical placement. The Local PC association should make sure to support trainees after they graduate.

Strategies used by paediatric oncology nurses to cope with job stress: A case of the Uganda Cancer Institute

Suzan Nabakooza

Uganda Cancer Institute

Background: Nursing staff encounter a high incidence of physical, and psycho-social stressors at work. Paediatric-oncology Nurses are exposed to extremely stress-provoking situations in the complex care of children and their families. The Uganda Cancer Institute (UCI) serves approximately 500 new paediatric cases annually. The paediatric inpatient ward has 12 nurses and 5 nurses in the outpatient. The World Health Organization (WHO) recommends a nurse patient ratio of 1:5 and at UCI the ratio ranges from 1:20. With these ratios the degree of stress is increased for nurses and the quality of care for patients is decreased. It is important to identify how nurses cope with job stress to design strategies to address stressors for UCI paediatric nurses and prevent unfavourable patient care outcomes.

Objective: A pilot study was designed with the specific aim to explore the experiences of paediatric oncology nurses working at the UCI with a goal to formulate a tool, to use in a broader subsequent study aimed at identifying strategies to help nurses decrease job related stress.

Methods: A qualitative study was implemented utilising purposive sampling. The sample population included ten nurses working in the UCI Paediatric department both inpatient ward and OPD. Data collection was conducted through face to face unstructured interviews. Interview data was analysed using a conventional content analysis approach.

Results: Four main themes emerged from the content analysis of the interview transcripts. The strategies used by nurses to cope with job stress were: a. situational control of conditions; b. sharing and seeking help; c. self-controlling; and d. spiritual-coping.

Conclusion: The experiences of the paediatric oncology nurses explored revealed current strategies employed to cope with job stress were inadequate. This information can be foundational for designing strategies that the UCI administration can use to support oncology nurses and increase quality of care delivered.

Psychosocial difficulties experienced by mothers caring for children with cancer: case series at Mobile Hospice Mbarara.

Kabigarire Miriel, Birungi Doreen and Martha Rabwoni

Hospice Africa Uganda

Aim: To share psychosocial difficulties experienced by mothers caring for children with cancer at Mobile Hospice Mbarara.

Methods: Case reviews. Convenience and purposive sampling were employed to select three case scenarios.

Results: There were financial challenges due to transport, accommodation, food, expensive investigations, and chemotherapy. There is lack of support from the spouses, place of work, and isolation by the community (stigma). Broken down families due to prolonged hospital stay, Loss of property (land) leading to homelessness. The rest of

the children feel very isolated and sometimes the mother forgets them completely and concentrates on the sick child alone. The other children even drop out of school. There is a lot of medical bungling by the medical people and not getting enough help.

Conclusion: Findings from these cases indicate that mothers navigate substantial challenges across the continuum of caring for the sick child, given that they are often deserted by their partners following diagnosis of the incurable illness. Palliative care delivered by trained professionals could significantly alleviate suffering mother's experience, support mothers to cope better and improve their quality of life. More research needs to be done to explore in detail the experiences of mothers nursing a child with cancer.

Lesson learnt: Mothers go through a lot of hassle when they have a sick child, they need a lot of support from the medical people to keep the children in hospital to get the treatment and finish. Those who get the support they need the children finish treatment and mothers remain in control of their family.

Improving access to care for rural Ugandan paediatric cancer patients

Kathleen Shannon Dorcy¹, Arlyce Coumar¹, Mulyowa Isaac²

¹Seattle Cancer Care Alliance, ²Uganda Cancer Institute

Background: Uganda Cancer Institute (UCI) serves as the national cancer facility for all of Uganda and neighbouring African nations as well. As a regional cancer centre most UCI patients travel from remote rural areas to seek care. Many are impoverished and speak other languages making comprehensive care and follow up care a significant challenge. Critical to successful outcomes with cancer treatment protocols is the provision of social services in housing, food, transportation, translation and emotional support. These needs are especially urgent in the paediatric population.

Objective: To address access barriers for UCI paediatric patients and families to facilitate successful completion cancer care protocols.

Methods: Hostels have been in existence for some years now but were only officially incorporated into the UCI system in May 2018 and started operating in July 2018. Two such hostels are less than 5km away from UCI. A utilisation overview of these hostel services was completed by UCI paediatric oncology nurses. They analysed hostel referral forms for UCI Paediatric patients who received shelter, food, bedding, first aid, clean water, and transportation.

Results: In this review UCI treated a total of 560 paediatric patients. Of these, 204 were housed at Kawempe Home Care hostel and 142 at Bless the Child Foundation Hostel (n=346, 62% of UCI paediatric patients). It was identified that in addition to expert oncology care, families must have access to basic elements of health such as safety from crime, privacy, and recognition of cultural diversity.

Conclusions: The utilisation of Hostels has greatly reduced the number of patients lost to follow up and improved patient treatment completion. Other challenges do exist for future study, such as provision of palliative care and end of life support to families. Collaboration between UCI and hostels is essential to attaining the best outcomes in cancer care.

Palliative care (pc) needs and outcomes of patients with hepatocellular carcinoma (HCC) in the Uganda Cancer Institute (UCI) and Mulago National Referral Hospital (MNRH)

Florence Nalutaaya¹, Liz Gwyther², Elizabeth Namukwaya^{1,3}, Emmanuel Sseremba⁴, Nixon Niyonzima⁴, Natalie Webber^{1,5}, Mhoira Leng^{1,5}

¹Palliative care Education and Research Consortium ²University of Cape Town ³Mulago National Referral Hospital

⁴Uganda Cancer Institute ⁵Cairdeas International Palliative Care Trust

Background: Hepatocellular carcinoma (HCC) is a leading cause of morbidity and mortality in Uganda. A previous qualitative study showed the multidimensional needs. It was important to ascertain these needs and the patient outcomes.

Aim: To determine the PC needs and outcomes of patients with HCC at UCI and MNRH.

Methods: A longitudinal, quantitative, descriptive study conducted at the UCI and MNRH on patients with a clinical diagnosis of HCC, aged >18, using convenience sampling. A structured questionnaire using validated tools administered by face to face interview at baseline, with telephone follow up at 1, 2 and 3 months. This tool includes socio-demographic and disease information, APCA POS and symptom assessment. Ethics approval granted.

Results: Preliminary baseline results (50 participants) show 74% male with 70% <45yrs. 80% <six months' duration of illness. All stage 3 or 4 disease with 56% ECOG performance status 0 – 2. 35% undergoing chemotherapy. 80% score >3 so moderate to severe pain with only 48% accessing morphine and 30% access to specialist PC. Abdominal fullness reported in 50%. Degree of insight into the illness was 10% 'full', 60% 'some' and 30% 'none'. 68% of patients expected a cure while 30% felt hopeless. 42% reported insufficient spiritual support. Follow up data collection is ongoing and shows high attrition rates (>60% at 1 month) mainly due to high mortality.

Conclusions: The majority of patients are young men presenting with late stage disease. Public education about prevention and early identification of HCC is paramount. There are significant unmet needs including pain which require further strengthening of PC within the medical and oncology services. Heightened existential distress and lack of clear information or goal setting may contribute to unmet spiritual needs. Excellent communication and clear referral pathways are needed to ensure early PC and multidisciplinary support.

Assessment of the readiness and availability of palliative care services in hospitals in Kampala, Uganda.

Eddie Mwebesa, Christine Atuhairwe

Hospice Africa Uganda

Uganda has 350,000 patients with illnesses needing palliative care and 210,000 persons in moderate-severe pain. Palliative care improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It reduces unnecessary hospital admissions and the use of health services.

While Palliative care has been incorporated into the Uganda's Health Sector Strategic and Investment Plans, it has been hampered by minimal resources and huge shortages of health workers. Although Uganda has one of the most rapid growth of palliative care as well as the only country in sub-Saharan Africa graded as having "Stage 4" comprehensive palliative care according to the Global Atlas of Palliative Care severe problems with availability and access to services remains. Despite these accolades, hospital-based palliative care is not universally available throughout the country. In 2014 the Ministry of Health provided only 103 million Uganda shillings for development of Palliative care

in its national budget. This is a small amount to share, and as most hospitals received very little funding for palliative care, it is likely that hospitals used discretionary funds to provide the service.

This cross-sectional study assessed the readiness and availability of palliative care services in hospitals in Kampala, Uganda in 2016.

Results: Only 7 of the 27 hospitals (26%) were offering palliative care, 6 (22%) had a specialised staff offering palliative care and only 5 (19%) had a staff designated to coordinate palliative care services. Overall, the level of readiness to provide palliative care was found to be very low with only 3 of the 27 hospitals (11%) demonstrating readiness as per the set criteria (availability of pain medication in stock, availability of morphine in stock and availability of a healthcare worker to provide palliative care).

Experience of the pain free hospital initiative in a national referral mental hospital in Uganda.

Nyegenye Justine

Butabika National Referral Mental Hospital.

Background: Butabika hospital is the national referral mental hospital in Uganda, and the pain free hospital initiative was unique here because the hospital did not have opioids reason being that the hospital was treating patients addicted to opioids, so there was fear and myths about opioids. The pain free hospital initiative was introduced in Butabika hospital in April 2018 through an orientation of top management and was officiated by the ministry of health in partnership with the palliative care Association of Uganda. Trainings began in June 2018 participants were divided in 7 cohorts, the first training was for clinicians and it was out of station at silver springs hotel and it was for one day, the second training was for senior nurses and ward managers the above two trainings were conducted by the palliative care Association of Uganda. The third and fourth trainings were conducted by Butabika Hospital champion staff team.

Achievements: Great improvement in knowledge, this was seen in the pre-test versus the post-test. By the end of the trainings the myth most health workers had on morphine that it was addictive had been clarified they realised that if morphine was used for the correct purpose then there were very low chances of addiction. Participants also appreciated the USB because it would help them for reference purposes on pain management. Oral morphine and other opioids being availed in Butabika hospital are in final stages.

Challenges: Despite the fact that staff have knowledge on pain management Butabika hospital has only one ladder and so patients with severe pain are not being managed well. During the training most staff did not know how oral morphine looked like.

Way Forward: Need for a trained palliative care team in Butabika Hospital. Avail Morphine in Butabika Hospital, this is in final stages as the double lock cupboard is already in place what remains now is ordering.

Reducing psychosocial issues by involving patients and their families in income generation

Musimenta Ruth

Kawempe Home Care

Introduction: Kawempe Home Care is a Community Based Organisation that provides comprehensive holistic care and support to people living with HIV/AIDS, Tuberculosis, and Cancer in Kawempe Division and Nangabo sub-county. Provision of only medical services does not make sufficient impact on the peoples' health in our poor community whereby some clients cannot afford to meet their basic needs. In July 2008, KHC started

a paper beads project called Beads for Education (BfE) and its success has led to the development of other entrepreneur projects like mushroom growing, piggery, recycled paper bag making and tailoring.

Aim: The aim is to share how economic strengthening of the patients and their families is an important part of comprehensive palliative care in resource limited settings.

Methods: Selection of the beneficiaries is based on being infected or affected by HIV/AIDS and in need of economic support. Community volunteers who monitor the patient's adherence from their homes identify those with psychosocial challenges and are willing to be trained. After training, some are retained at KHC Skills Development and Empowerment department to work.

Results: Since 2008, 425 patients have been trained and empowered in different entrepreneur projects like bead making, mushroom growing, piggery, recycled paper bag making and tailoring. Among the 425 patients, 25 were trained in bead making, 300 were trained in piggery and mushroom farming, 55 were trained in paper bag making and 45 have been trained in tailoring. 95% are able to meet their basic needs and educate their children. This has also contributed to KHC's sustainability.

Conclusion: Economic strengthening improves on patients and their families' economic status, good drug adherence thus contributing towards quality of life.

The importance of Paediatric Palliative Care for a child living with a life-limiting illness.

Maureen Asiimwe Buhiire

Kawempe Home Care

Aim: Paediatric palliative care is a holistic approach aimed at addressing the complex issues related to the care of children and families facing chronic life limiting illnesses. The needs of children are unique and often quite different from those of adults receiving palliative care. Due to the growing epidemic of cancer in Uganda, Kawempe Home Care established the New Hope Children's Hostel in 2016 aiming at increasing access to specialist care for poor and vulnerable children with cancer through provision of paediatric palliative care services.

Methods: In collaboration with the social worker at the ward, children are identified and referred to the New Hope Children Hostel they are assessed using the C-POS and interventions are done according to the identified needs.

Results (Case Study): A 14 years old Joel with albinism developed a pimple on his left cheek that later developed into a very painful wound that caused on and off fevers. So he started seeking treatment from Mbale hospital, where he was later referred to Uganda Cancer Institute for further investigations. At the institute, Joel was diagnosed with an advanced skin cancer and was later referred to the New Hope Children Hostel. At the hostel, Joel was assessed and found with various psycho-social issues that cause more pain beside the disease. Joel had faced rejection at birth by his family, had financial distress, pain of not being able to attend school and suicide tendencies. Continuous counselling sessions were done for Joel and his mother, accommodation, food and transport to hospital was provided and now Joel is able to give a smile, interacts and play.

Conclusion: Paediatric palliative care brings hope, dignity and promotes quality of life. Therefore healthcare professionals, policy makers and all advocates for children can and must do more to integrate palliative care for any child living with a life limiting illness.

Workshop 2.00 – 4.40pm

Human Rights

Med SK Kaggwa¹, Salimah Namusobya²

¹Uganda Human Rights Commission, ²ISER

In 2017, the Uganda Human Rights Commission (UHRC) monitored and reported on the right to palliative care in the Annual Report to the Speaker of Parliament of Uganda. Chapter two of the 20th Annual Report details UHRC's assessment of Palliative Care services, the positive developments, gaps in service provision and makes nine recommendations to government Ministries, Authorities and Departments. The report highlights the achievements made but also points out various gaps in the provision of palliative care services as the lack of a standalone palliative care policy to guide the implementation of palliative care services, the emphasis on institutionalised care as opposed to home care and low funding for services and others.

The UHRC to the Ministry of Health include: expediting the passing of the National Palliative Care Policy, instituting clear monitoring and evaluation strategies for palliative health care services, ensuring that the proposed National Health Insurance Scheme covers palliative care and strengthening national district coordination mechanisms for the provision of palliative care services. Other recommendations touch increasing the budgetary allocations to the Health ministry to cater for palliative care services, implementing the various United Nations (UN) resolutions on provision of palliative care and integrating palliative health care service professionals into the mainstream public service structure.

Workshop will be utilised to engage policy makers on the findings and recommendations made by UHRC with a view of drawing practical steps for the implementation of the recommendations made. The expected outcomes include concrete commitments by the representatives from the relevant government Ministries, Authorities and Departments on implementation of the recommendations.

Session 3.40 – 4.40pm

Breakaway Session – Health Promotion and Prevention

Yoga and mindfulness: A more holistic palliative care approach

Annette Deguch

Center for Hospice Care, Mishawaka, USA.

Introduction: A cancer diagnosis not only impacts physical health, it impacts the person's mind, their spirituality and involves significant loss. Yoga and mindfulness are practices that can be added to palliative care to more holistically and positively impact symptoms of illness.

Discussion: Yoga poses can improve strength, calm emotions, encourage peacefulness and encourage compassion for self and others. Other benefits of yoga will be shared along with how these benefits can impact symptom management. Mindfulness allows patients to be present in the moment, to emotionally feel what they are feeling while providing tools and support to adapt to the new and sometimes challenging reality of life after a cancer diagnosis. These are tools that can also be used for coping with the grief experienced due to the losses that often accompany a cancer diagnosis. The attendees of the presentation will be taught proper deep breathing which can then be taught to patients and their caregivers.

Conclusion: Palliative Care for cancer patients hopes to mitigate symptoms and yoga and mindfulness are tools that can provide a more holistic approach to symptom management. Resources for further study will be provided.

Enabling factors for cervical cancer screening uptake in developing countries. An adapted systematic review

Immaculate Mbarusha

Uganda Cancer Institute

Background: Cancer of the cervix is the second commonest cancer among women worldwide and the leading cause of cancer related deaths in developing countries. Women aged 35-45 years are more vulnerable to cervical cancer infection, the age at which they are most active and productive. Effective screening programmes and follow up have the potential to prevent invasive cervical cancer leading to reduced morbidity and mortality from cervical cancer. Planning and implementing successful screening programs is still a challenge in developing countries despite the great cervical cancer burden and the proven role of screening in the reduction of cancer incidence and prevalence in developed countries.

Methods: Basing on a pre-determined study protocol, articles on uptake of cervical cancer screening published from 2006 to 2017, were searched from Ovid (Medline, Embase, CENTRAL) and CINAHL PLUS. Others were through website search and scanning references of obtained articles. Two independent reviewers selected and assessed the eligibility of relevant articles, extracted and analysed the data. The information was narratively synthesised with limited table and figures.

Results: Ten studies met the inclusion criteria, 2 cluster randomised trials and 8 cross sectional studies. All studies reviewed measured the major outcome plus other related outcomes. Socio economic factors (age, marital status, low educational level, unemployment) were the leading hindrances to screening. Promoting cervical cancer knowledge and screening awareness, improving accessibility, affordability and acceptability of the screening services were the prominent screening facilitators.

Conclusion: In order to reach a large population, cervical cancer awareness campaigns need to target various groups of people; the women, their husbands/partners, community key resource persons and the community at large. A practical means of improving accessibility, affordability and acceptability is integrating cervical cancer screening services in the already existing primary care system. Furthermore, organised instead of opportunistic screening programs are recommended.

Reaching rural women with cervical cancer screening services

Mutaasa Allan

Rays of Hope Hospice Jinja

Background: While cervical cancer in the developed world is a diminishing disease, it counts for 20% of all new cancers in Uganda and 35% of all new female cancers. Around 50% of female cancers at Rays of Hope Hospice Jinja (RHHJ) have cervical cancer, most in advanced stages. Access to screening for cervical cancer is barely available in Busoga Region.

Aim: To identify practical ways to reach the un-reached rural women with cervical cancer screening services. To test a widespread conception of that rural women in Uganda will not come for vaginal exam. Test which mobilisation strategies were useful to bring the women forward.

Method: A three-day camp was planned by RHHJ team, Banda HC staff and community

volunteers with the goal of reaching 300 women. Mobilisation for screening was done by seven community volunteers (6 men and 1 woman). Methods included communication at community gatherings, radio spot adverts, banners, health workers 'information, public address, and community leaders. At the screening, education in cervical and breast cancer was given as group lectures by RHHJ staff as well as what to expect during the screening and if treatment was needed.

Results: 700 women attended, 633 women registered. 11.5% of women of 576 women tested were positive for pre-cancerous or cancerous lesions. Women were happy to wait for service and encouraged friends to join.

Lessons: Women are interested in cervical and breast cancer screening. Community volunteers are effective in implementing mobilisation programs. Gender is not an issue.

Key recommendations: While preparing for universal health care: Regular screening camps with Involvement of community volunteers and health centre staff. Extensive training of rural health centre staff in VIA testing and cryo and thermal therapy Advocacy among political leaders to improve awareness of cervical cancer and screening programmes.

Experiences and supportive care needs of cancer patients in Uganda: Facts behind the figures

Annet Nakaganda¹, Immaculate Mbarusha¹, Kristen Solt², Winfred Nalukenge³ and Jackson Orem¹

¹Uganda Cancer Institute, ²American Cancer Society, ³Medical Research Council

Background: Due to increasing cancer incidence and longer survival, cancer care has evolved from focusing on survival to maintaining and improving quality of life. This makes supportive care a priority for effective/efficient cancer care, however supportive care needs have not been adequately met for cancer patients in Uganda.

Aim: To explore and document patients' experiences of seeking cancer treatment in Uganda to inform the development of navigation programs at Uganda Cancer Institute.

Methods: We conducted a qualitative study over a period of 7 months (September 2017-March 2018). Seventy-three adults (patients and health workers) participated in the study. Purposive/Maximum variation sampling was used to recruit participants from a wide range of experience. Two experienced researchers conducted the in-depth interviews (at UCI and place of work) and Focus Group Discussions. Thematic Analysis was used to analyse the data.

Findings: Themes that emerged include delayed diagnosis due to lack of awareness/knowledge about cancer symptoms; healthcare professionals' low suspicion towards cancer symptoms/signs; inadequate facilities for cancer diagnosis; cancer screening policy implications; and myths about cancer/disease/health. Psychological needs also came out very strongly due emotion distress of knowing the cancer diagnosis, concerns about dying, disclosure issues and stigma/discrimination. Difficulties in getting admitted to the cancer center; retrieving medical records; locating for available services; accessing the senior oncologists caused enormous delays in initiating/receiving cancer treatment. While corruption/bribery; language barriers and problematic/traumatic interactions with medical professionals led to frustrations and emotional distress. Treatment needs included, recurrent drug stock-outs, unaffordable drugs, sourcing for investigations outside the cancer center; poor quality of drugs; medical/drug errors and high cost of radiotherapy treatment.

Conclusion: While cancer diagnosis/treatment services in Uganda are limited, this research suggests that interventions like navigation programs and referral guidelines could address some of the supportive care needs to enhance timely/efficient cancer care that could ultimately improve patient satisfaction and medical outcomes for cancer patients in Uganda.

The untapped force of socializing: the case of TAW's high tea cervical cancer awareness event.

Claire Judith Achieng

Thrive a Woman Uganda (TAW).

Goal: To tap into the social fabric of family and friends as a means to pass cervical cancer message in order to encourage prevention action and seeking of early screening and care services.

Methods: The approach is cognisant of the importance of influential figures in society as chief guests; a strategy intended to ensure that the message is taken more seriously and to help profile the event. It also utilises networking as a means to gain the multiplier effect to attract more individuals to join in the awareness activities organised. All individuals become agents of change, Ambassadors and champions are identified, who are charged with marketing the initiative to ensure recruitment of new members and fundraising. The initiative utilises social media as a core component where continuous cervical cancer awareness takes place.

Results: Over seventy participants attended the high tea event for cervical cancer awareness. The high cervical cancer incidences and prevalence in sub Saharan Africa, East Africa in particular presented shocked and scared the elite participants in attendance. The guest of honour echoed that he was scared to his bones by such revelations. Almost all the guests vowed to encourage other family members to seek for checkups and screening, even themselves to go for screening as soon as possible.

Conclusion: The reality in Uganda today is that there is hardly a person who has not been affected directly or indirectly by cancer – cervical cancer inclusive. It is about time we devise the simplest and new means of contributing to the elimination of cervical cancer amongst ourselves and in the country. Cervical cancer is one of the very preventable diseases once caught early. TAW calls for help for the initiative to foster efforts in raising awareness, support community outreaches and patient support for patients with cervical cancer.

Improving access to palliative care services through arts and media engagements.

Zaitun Nalukwago¹ and Joanita Kawalya²

Palliative Care Association of Uganda¹, Afrigo Band²

Background: The major aim of palliative care is to improve the quality of life of patients and their families through the prevention and relief of suffering. Despite increased access to palliative care in Uganda, there remains an unmet need of lack of access to information regarding the availability and access of the service. This abstract looks at the impact of using prominent people from the arts and media sector and how we can utilise them to make a difference in the livelihood more broadly.

Aim: To raise awareness about availability of pain medicines for patients with life limiting illnesses in Uganda through radio, TV, music and theatre acts.

Methodology: In order to raise awareness on access to the palliative care services, PCAU identified a popular figure from the arts and music industry who embraced the service and is an active ambassador. Developed and agreed on particular messages on pain medications to run on different media houses i.e. radio and television. Selected messages voiced and aired out on the selected local media stations to evidence need.

Results: Four media stations run adverts on the availability and access to oral liquid morphine. In this period, there was an increase in phone calls from the general public on how to access and where to find the services. About more than thirty incoming calls were recorded. Involvement of other arts and major media personalities to advocate for the services. Participation of key media and arts personalities in the different events organised by PCAU. Selected messages in form of entertainment that communicates to the public presented in the different events like the conferences, dinners among others.

Conclusion: It is very important to include key arts and media personalities for advocacy of ongoing issues since they draw attention and awareness creation becomes more meaningful when the face and voice is popular. Therefore, an approach of bringing them on board can improve access to palliative care services to all.

Exploring the lived experiences of patients with advanced cancer of the cervix.

Germans Natuhwera

Institute of Hospice and Palliative Care in Africa

Background: Over 80% of the global burden of CC is concentrated in LIMCs (Mwaka, 2016, Torre et al. 2015), with over 80% of CC diagnosed in advanced stages in Uganda (MOHU, 2010; ICO Information Centre, 2016). However, most of the research (73%) on CC is concentrated in high-income countries while scanty available research on CC in LMICs like Uganda has concentrated on screening, knowledge about the disease, and factors surrounding diagnosis and treatment, with little being known about what it's like for women to live with the advanced disease.

Aims: To explore the lived experiences of women with advanced CC It is thus evident from the available literature that there is significant likelihood that patients are treated based on health worker's assumptions and, or partial view of reality. This study addresses this under-researched area with intent to unearth their experiences. This could inform care planning and improve QOL of patients.

Methods: The study design was qualitative and exploratory using a descriptive approach. Study context was a hospice-; Mobile Hospice Mbarara in South-western Uganda. Study sample was patients with a diagnosis of advanced cervical cancer; stage 2B to 4B, or clinically advanced disease not staged. Convenience, purposive sampling was used. Demographic data were collected prior to conducting audio-taped, semi-structured interviews, translated in local language. Sample size was determined by use of data saturation and 10 women were recruited. Interviews were transcribed verbatim, transcripts read and re-read, and significant statements grouped into emergent, broad themes. Thematic data analysis was used.

Results: 10 participants were interviewed, with the average age of 53.4 and age range 40-71. Six themes emerged from the data-; socio-demographic profiles of the women, road to cancer diagnosis, effects of disease on women's quality of life, experiences with main stream medicine, adapting to having cancer, and needs of the women.

Discussion and conclusion: The study findings show that living with advanced incurable cervical cancer is associated with significant disruptions in all domains of life of the

patient as well as of their family. Good palliative care delivered by qualified professionals can allow these patients to cope and live an optimal quality life towards their end-of-life journey. Poverty and the big knowledge gap about cancer of the cervix among women and health workers are the strongest causes of late advanced diagnoses as evidenced in the findings. More mass sensitisation campaigns and continuous health education among health workers tailored towards increasing cancer awareness is one way to ensure timely referrals and diagnoses, so limiting the profound negative impact of the incurable disease. Future research could focus on psycho-social experiences of children of mothers confronted by advanced cervical cancer, and also quality of life of these women after chemotherapy and radiotherapy.

Breakaway Session – Policy and Advocacy

Analysing the legislative and regulatory threats facing improved access to controlled medicines for patients with life limiting illnesses in Uganda.

Sebisubi Fred, Mwesiga Mark, Donald Zarugaba Tinka, Nanyange Joanne.

Aim of work: The aim of the work was to bring together key stakeholders engaged the supply chain of controlled medicines at a side event during the UCI-PCAU Joint International conference on cancer and palliative care 2017 and form a committee on controlled medicines in Uganda. The committee would analyse the Countries legislation and regulatory frame of controlled medicine and highlight provisions that affect implementation access to medicines, Palliative care, harm reduction strategies and make appropriate recommendations.

Methodology: Key state holders engaged in the importation, manufacture, distribution, prescription and use of controlled medicines were convened at a side event workshop during the UCI-PCAU Joint international Conference in 2017. Stakeholders formed a national committee that was formally appointed into existence by the Ministry of health. The committee analysed legislation and regulation of controlled medicines through review of documents, seeking expert opinions and consultations, benchmarking and holding committee meetings.

Results: A total of 50 participants attended the side event at the UCI-PCAU Joint international Conference on cancer and palliative care. A national committee on access to controlled medicine was established. Committee mobilised and attached funding of up to USD 250,000. Committee engaged various stake holders and rested fears among palliative care providers that the Narcotics and Psychotropic Substances Act 2016 had erased Statutory Instrument allowing specially trained nurses to prescribe certain opioids. Committee submitted detailed report in March 2019 with findings and recommendations to Ministry of Health.

Conclusion/Lessons learned: The UCI-PCAU Joint conference is a great platform for initiating ideas to solve barrier to access to cancer and palliative care services. It is important to establish mechanisms to follow up conference resolutions to address gaps in service delivery.

Universal Health Coverage in Uganda: Civil Society engagement with Government on resource allocation for cancer and palliative care services.

Allana Kembabazi¹, Brian Alex Kiira¹, Mark Mwesiga², Fatia Kiyange³

¹Initiative for Social and Economic Rights (ISER), ²Palliative Care Association of Uganda (PCAU) ³African Palliative Care Association (APCA).

Aim: The Palliative Care Association of Uganda (PCAU) working in partnership with the Initiative for Social and Economic Rights (ISER), sought to build alliances with civil society

organisations working in the area of budget advocacy to include improving resources allocation to palliative care in position papers and asks to government for the financial year 2019-2020.

Method: Civil society budget advocacy organisations were identified and sensitised about Palliative Care and the gap in resources allocation by government. A technical working group on budget analysis was composed to scrutinise ministerial policy statements and the budget framework paper for the financial year 2019-2020. The group was to develop a Statement by Civil Society Organisations in Uganda on Budget Allocation for Palliative Care Services for the Financial Year 2019/2020 and to present it to the Chairperson Committee on Health Committee and to the Deputy Speaker in Parliament.

Results: A total of 16 civil society budget advocacy organisations were sensitised on palliative care issues. A technical working group with representatives from four organisations analysed 3 Ministerial Policy Statement from and the budget framework paper. The civil society statement by organisations in Uganda on budget allocation for palliative care services for the financial year 2019/2020 was developed and submitted the Deputy Speaker of Parliament. Further, PCAU has supported the Ministry of Health to finalise the costing for the National Palliative Care Policy and is engaging with process for the inclusion of palliative care into budget framework process for 2020-2020 as guided by parliament.

Conclusion: Budget advocacy is an elaborate process that requires timeliness of interventions as per the budget cycle. Civil Society organisations require adequate skills in budget analysis to engage properly in budget advocacy. There is low level of appreciation of the palliative care concept among key budget advocacy groups yet there is good will to galvanise working together on the same matter.

Using the national human rights framework to monitor and report on the right to palliative care: Lessons learnt from Uganda

Mark Donald Mwesiga¹, Rose Kiwanuka¹, Priscilla Nyarugoye², Theopista Twembi²

¹ Palliative Care Association of Uganda ² Uganda Human Rights Commission

Aim: The aim of the work was to engage the entire staff structure of the Uganda Human Rights Commission (UHRC) across the country to be able to monitor, document and report on the enjoyment and violations on the Right to Palliative Care in Uganda in the 20th Annual Report of 2018.

Method: The initiative commenced with identifying change agents in the field of the Right to Health to build alliances in engaging the UHRC. Activities on: orientation of change agents on Palliative Care issues, introductory meetings and five day none health professional course on palliative care for all UHRC staff, developed monitoring tools on right to palliative care and to participation in the UHRC consultative process to offer expert opinion during documentation of the UHRC 20th Annual Report.

Results: The 20th Annual Report of UHRC submitted to the Speaker of the Parliament of Uganda in June 2018 contained a chapter on the Right to Palliative Care. It contextualised Palliative Care as a Human Right, covered the Legal Frame work, the situation in Uganda, the assessment of service, highlighted positive developments, identified gaps and made 9 key recommendations. Report was applauded by key policy makers including cabinet Ministers and Members of Parliament for highlighting facts on a salient but less pronounced issue of the right to palliative care.

Conclusion: It is possible to work within the national human rights framework to bring the issue of palliative care to the fore. There is still great need for information dissemination

on palliative care even among key stakeholders like human rights practitioners. Advocacy for Palliative Care is strengthened when key documents like the reports of the National Human Rights Commission mention show facts about the issue. Palliative Care fraternity in Uganda need to utilise the UHRC 20th Annual Report as an advocacy resource to reach all key policy makers and policy makers to influence positive change in the services.

Fostering a multi-sectoral approach in the fight against cancer in Uganda: the launch of the national cancer symposium

Olodi, Asiimwe, and Paul Ebusu

Uganda Cancer Society

Background and Context: The National Cancer Symposium (NCS) is an annual event that was launched on the 28th February 2018 to create an inclusive process where all sectors and stakeholders are engaged in the dialogue and processes leading to effective cancer control in Uganda. This was in line with the 70th World Health Assembly Cancer Resolution.

Aim: To build a systematic and impactful response to cancer epidemic in Uganda through a multi-sectorial approach.

Programme process: A Technical Working Group comprised of representation from Government, WHO, Civil Society, Academia, Professional bodies and International partners, has been constituted to lead the planning, coordination and execution.

Outcome: Increased collaboration and partnerships built among partners as demonstrated in commitment for joint cancer control efforts. A total of over 300 participants attended the event representing different agencies including religious groups, private sector, media, policy makers, government ministries and departments, civil society, development partners, cancer survivors and patients, and the general public. Wider publicity gained as over 3 national level newspapers (New vision, The Observer, and The Monitor publications) running the story. A total of 1,028 people reacted to our posts on Facebook on this day. The Prime Minister made commitment on the procurement of more radiotherapy equipment as the construction of the new bunker progresses. The panel discussion led to the recognition that cancer control requires a multi-sectoral approach if interventions are to become more effective. The Public was called upon to be sensitive to the risk factors including tobacco usage, body activity, proper diet with emphasis on vegetables and fibre, among others.

Conclusion: There is great need for continuous engagement among all stakeholders to influence policy decisions and general intervention in the fight against cancer. We also learned that the media is an important partner for greater visibility to be realised.

How are palliative care services financed in Uganda? Analysis of the implications for sustainability.

Eddie Mwebesa¹, Dr Jacinto Amandua²

¹Hospice Africa Uganda, ²PCAU

Background: Over 250,000 patients in Uganda need Palliative care services, yet many citizens live on less than one US dollar a day and the majority of them are too poor to finance their access to health care. As non-profit charities, Hospices likely rely on sources other than patients to fund their work. Sustainable funding is key for ensuring the quality and coverage of palliative care services.

Methods: This cross-sectional study examined the sources of funding for stand-alone palliative care services in Uganda as well as their services' financial sustainability plans. Researchers conducted a survey of all stand-alone palliative care organisations that had

operated for five or more years, and interviewed key respondents to collect data on the audited financial statements, services provided and sustainability plans.

Results: Nine of the stand-alone palliative care organisations surveyed had operated for five to 25 years. 93% of the funding for palliative care services comes from donations; while 7% is from income generating activities. 94% of the donations are from external sources. The Government of Uganda's major contribution is in the form of medicines, training and payment of taxes. All the organisations had good financial records. Six of the fifteen Hospices/palliative care providers had sustainability plans included in their operational manuals. The older organisations (those that had been operational for more than 10 years) had better resource mobilisation capacity and strategies.

Conclusions: The majority of stand-alone palliative care organisations in Uganda are largely donor funded. They have considerable financial sustainability and fund-raising capacity. Government support is in the form of medicines and training.

Recommendations: The capacity of the stand-alone palliative care services to raise funds should be increased to ensure continuity of services. The Government of Uganda should include palliative care in the national health system and increase funding for these services.

Physical activity events: An avenue for awareness, advocacy and resource mobilisation

Asimwe Patience, Olodi Denis and Ebusu Paul

Uganda Cancer Society

Objective: Physical inactivity is one of the known modifiable risk factors associated with cancer. Results from the Uganda NCD risk factor survey (2014) showed that Ugandans are becoming increasingly physically inactive especially those living in urban areas. Physical inactivity is known to contribute cancer of the Breast, Oesophagus, Endometrium, and the Colon. Uganda Cancer Society (UCS) held a mass dance fitness event dubbed *Sukuma* aimed at promoting improved lifestyles as well as providing an avenue for cancer awareness, advocacy and resource mobilisation.

Methods: UCS partnered with Uganda Cancer Institute, Ministry of Health, Kampala Capital City Council Authority, Uganda Police Force and a professional fitness organisation. The concept was in line with the recently launched National Day of Physical Activity, a national campaign to raise awareness on the growing burden of NCDs in Uganda. The event was to last three hours including a brief talk on the importance of physical activity. Publicity was through social media, peer to peer referral, media press briefing and posters. Resource Mobilisation was through sale of dance-kits and the media present was a platform to promote the Uganda's treatment for all advocacy programme.

Results: The event was attended by over 500 people with high media coverage evidenced in talk shows, interviews and news airing on national TV. Sell of kits amounted to 9.6 million Uganda Shillings alone excluding other forms of support and these funds were dedicated to supporting activities of UCS such as World Cancer Day. Social media prior during and after this event was high with posts having over 1700 reaches minus boosting.

Conclusion: The event was successful given the intended outcomes of cancer awareness; advocacy and resource mobilisation were achieved. Further still, the presence of survivors was a point of inspiration prompting those in attendance to sign up for fitness programs.

The *Life:Moving* Project: Using film to change perceptions about dying and support end of life care

Michele Aaron,
University of Warwick

Centred on a six-month filmmaking project based at John Taylor Hospice in Birmingham, UK, this research project investigated the ethical issues involved in representing end of life experience through the medium of digital film. Through workshops and home visits, participants were given practical and critical training and support to develop and co-create their own films. The six films produced have been shared with end of life communities in the UK and Europe where the insights offered into the experience of dying and end of life care has had a powerful impact upon various audiences, especially within the palliative health community. As well as demonstrating the benefits of such projects for patients and their loved ones and for illuminating the everydayness of dying, *Life:Moving* reveals the value of Arts practice and participatory research for the end of life community.

Film is an extraordinarily powerful, and ever more widespread, medium for communicating universal health challenges. This project aimed to challenge society's misconceptions about terminal illness by providing those experiencing it with the opportunity, skills and platforms to tell their own stories, and by bringing these stories to a wide audience. It prioritised an ethical praxis throughout, to counter the pervasive objectification or disregard of the terminally ill within the public sphere. In these ways, the research sought to better understand the potential of digital film to serve the best interests of the vulnerable lives it so often depicts and then disseminates. It also sought to model best practice for the increasing use of filmmaking for creating compassion and change within universal health and palliative care initiatives.



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Friday 6th September 2019

Session 11.00 - 13.00

Breakaway Session – Paediatrics

Exploring the Understanding of Illness, Death and Dying of Ugandan children with life-limiting conditions.

Downing Julia^{1,2,3}, Kemigisha Ruth⁴, Nakayiwa Ruth⁵, Namyeso Juliet⁶, Ankunda Collins⁶, Lebu Priscilla⁷, Nabirye Liz¹, Ellis Judith⁸, Namukwaya Liz¹, Grant Liz² and Leng Mhoira^{1,2,9}

¹ Makerere and Mulago Palliative Care Unit, Makerere University, Kampala, Uganda. ² Global Health Academy, University of Edinburgh, Edinburgh, UK. ³ International Children's Palliative Care Network, South Africa ⁴ Alive Medical Services, Kampala, Uganda ⁵ Children's AIDS Fund, Kampala, Uganda ⁶ Mildmay Uganda, Kampala, Uganda ⁷ Peace Hospice, Adjumani, Uganda ⁸ THET, UK ⁹ Cairdeas International Palliative Care Trust, UK

Background: Exploring children's understanding of illness, death and dying has been identified as a priority area for CPC research. A deeper understanding of how children develop their ideas; communicate them; and act out their feelings plays impacts on CPC services development thus improving outcomes for children and their families.

Aim: To explore children's understanding of illness, death and dying such that PC services in Uganda reflect this.

Methods: Fifteen interviews were conducted with children aged between 8 and 17 (average 13), 10 girls and 3 boys. Ten interviews were conducted in English (3 Mildmay, 4 HAU, 3 Alive Medical Services), and 5 in Madi (Peace Hospice Adjumani). Each interviewer was fluent in the language and experienced at counselling children. Informed consent and assent were obtained. Interviews were transcribed and translated. Themes identified and a coding framework developed collaboratively by the research team. Ethical approval was gained through HAUREC and the UNCST.

Results: Five main themes were identified: 1) Support and who this was received from; 2) beliefs around death and their faith; 3) Feelings, ranging from fear and anger, to positivity and pride; 4) their lived experience e.g. stigma, abuse, the impact on their self-esteem and also being a refugee; and 5) issues around their illness including awareness/knowledge, adherence, independence and acceptance. All participants, including the young ones, felt able to talk about their illness and its impact on their lives.

Conclusion: Children as young as eight are able to articulate an understanding of their life-limiting condition and its impact on them and their families. CPC provision in Uganda needs to: take into account children's need for support from different groups; provide opportunities for children to explore their feelings, their lived experiences and their beliefs in a safe non-threatening environment; ensure age appropriate communication with children, providing information as required.

Acute Leukaemia, not Burkitt's Lymphoma, is the commonest cancer diagnosed in south west Uganda.

Atwiine, B^{1,2}; Ankunda, S³, Tibenderana, B⁴, Kumbakumba E^{1,2}, Mwanga, J^{1,2}, Weinstein, H^{5,6}.

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²Mbarara Regional Referral Hospital, Department of Paediatrics and Child Health, Mbarara, Uganda ³Mulago Hospital Complex, Department of Paediatrics and Child Health, Kampala, Uganda ⁴Uganda Cancer Institute, Department of Radiation Oncology, Kampala, Uganda ⁵Massachusetts General Hospital, Department of Paediatrics and Child Health, Paediatric Haematology and Oncology, Boston, Massachusetts, USA. ⁶Harvard Medical School, Department of Paediatrics and Child Health, Paediatrics Haematology and Oncology, Boston, Massachusetts, USA.

Background: Burkitt's lymphoma and other solid tumours are reported as the commonest paediatric malignancy in most regions of Africa, different from the Western world, where acute leukaemia predominates.

Aim: To describe the patterns of cancer diagnosis and treatment outcomes of children treated at Mbarara Regional Referral Hospital (MRRH) Cancer Unit, in South West Uganda to show the changing trends of childhood cancer epidemiology.

Methods: In a 3-year retrospective analysis, between January 2016 and December 2018, data regarding age, sex, cancer diagnosis, treatment and outcomes was extracted from medical files of all children <16 years diagnosed with cancer at the Paediatric Cancer Unit of MRRH in South West Uganda. Descriptive statistics and Kaplan-Meier curves were used to describe the diagnostic patterns and treatment outcomes respectively. Approval was offered by the Institutional Review Board (IRB) of Mbarara University of Science and Technology (MUST).

Results: A total of 202 children were diagnosed with cancer over the three years (43, 65 and 94 in 2016, 2017 and 2018 respectively), of whom 107(53%) were male, 95(47%) 1-5 years, 62(30.6%) 5-10 and 45 (22.2%) >10 years. Acute leukaemia was diagnosed in 50(24.7%) children [41 Acute Lymphoblastic Leukaemia and 9 Acute Myeloid leukaemia], 40(19.8%) Wilms tumour, 26(12.8%) rhabdomyosarcoma, 22(10.9%) Hodgkin lymphoma, 15 (7.4%) Burkitt lymphoma and 49(24%) with miscellaneous conditions. Eighty-five (42%) children are alive, 68(33.7) died and 49(24%) abandoned therapy.

Conclusions and recommendations: Acute leukaemia is the commonest cancer diagnosed at our centre, different from what's reported in most African regions. Cancer programs need to make adjustments to actively identify, diagnose and treat children with acute leukaemia.

Presentation and treatment outcomes of children with Burkitt's Lymphoma at Uganda Cancer Institute

Fadhil Geriga¹, Innocent Mutyaba¹, Joyce Kambugu¹, Suzanne McGoldrick^{2, 3}, Corey Casper³, Jackson Orem¹

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Background: Childhood Burkitt lymphoma (BL) is endemic to sub-Saharan Africa, and is the commonest childhood cancer in Uganda.

Objective: To describe the presentation and treatment outcomes of children with BL seen at Uganda cancer institute (UCI).

Methods: We conducted a retrospective chart review for children diagnosed with BL from July 2012-July 2014. Children with suspected BL received histology and staging work-up; confirmed cases also received chemotherapy, and adherence support through phone call reminders and transport refund. We described BL presentation using medians and percentages, and 1-year survival outcomes using Kaplan-Meier methods.

Results: Of the 173 children with suspected BL, 70% (121/173) were confirmed to have BL. BL patients had a media age of 7 years (range: 1-18); 61% were male. Of the 121 confirmed cases, 65% had facial/jaw disease, 14% abdominal disease, and 20% had CNS involvement. Median hemoglobin was 10.4 (3.8 – 18.3) g/dL; 12% (13/110) had ECOG > 2, 21% (22/110) were malnourished, and 54 % (44/82) had elevated LDH. First line chemotherapy –with Cyclophosphamide, Vincristine and Methotrexate (COM)– given every other week was initiated in 79 % (95/121) of BL cases and of these, 69 % (66/95) completed at least 6 cycles, 13 % (13/95) died during treatment and the rest were switched to second line treatment or lost to follow-up. Ninety four percent (62/66) had tumor response assessment: 54 (87 %) had complete response and 8 (13%) had partial response or progressive disease. The 1-year overall survival was 51 % (95% CI: 37%- 64%).

Conclusions: A significant proportion of children with BL present with extensive disease and comorbidities such as anaemia and malnutrition. Many children experience early mortality probably due to extensive disease and treatment related complications. Interventions aimed at promoting early diagnosis and improving supportive care during treatment may improve treatment outcomes.

The lived experience of paediatric oncology nurses caring for terminally ill children: a qualitative study at the Uganda Cancer Institute

Ndagire Mariam, Geriga Fadhil, Nabakooza Susan

Uganda Cancer Institute

Background: Globally, more than 300,000 children are diagnosed with cancer annually. Majority of these children with cancer live in low- and middle-income countries (LMICs), and their chances of survival are often less than 20%. Due to this high acuity of terminally ill paediatric patients, nurses in LMICs are faced with suffering and death daily. The Uganda Cancer Institute (UCI) registers more than 500 new paediatric cases annually. The paediatric department has 14 dedicated paediatric oncology nurses who interact with the intense suffering of children and families and may too personally experience similar feelings.

Objective: Describe the lived experience of UCI paediatric oncology nurses who care for terminally ill children.

Design/Methods: A qualitative pilot study was conducted by in-depth, unstructured individual interviews with open-ended questions to evaluate the lived experiences of five UCI paediatric oncology nurses with at least two years of experience who consented to participate. Interviews were conducted over two months by a single interviewer and one nurse, in English, at UCI. Interviews (60-90 minutes) were tape recorded, transcribed and analysed using content analysis.

Results: The nurses' lived experiences were categorised in four main themes: attachment, repressed feelings, feeling of helplessness, and the need to be supported.

Conclusions: Findings from the pilot study confirmed that nurses who look after children with cancer face traumatic experiences and would benefit from support. For paediatric oncology nurses to continue to deliver the highest quality care to children with cancer and their families, nurses themselves must be afforded options for mutual support, systems to manage loss and organisational staffing provisions for best care practices to be realised.

Supporting child care givers of HIV/Cancer patients: The experience of PCAU.

Lydia Nakawuki, Rose Kiwanuka, Mark Mwesiga, Zaitun Nalukwago
PCAU.

Background: In an effort to provide a future to child care givers of HIV/Cancer patients in Uganda, PCAU in partnership with Center for Hospice Care started up the Road to Hope program in 2012 with an aim of providing school fees and scholastic materials to the beneficiaries. Currently the program has 58 from 15 districts of Uganda. 46 of these children are in primary, 7 in secondary and 4 in vocational institutes. The program has so far graduated off two children who completed their studies.

Method: Children are identified through palliative care practitioners in different health facilities annually, consideration given to the most vulnerable. An assessment of a child's status is completed. Regular follow-up/monitoring is undertaken to ensure sustained wellbeing of the children.

Results: The program is currently supporting 58 children with school fees and psychosocial support. It has seen 3 children graduate through school. Health workers and parents are relieved of stressful concerns about these children. There is a greater engagement between the PC practitioners and the community resulting in increased visibility for PCAU.

Conclusion: Child care givers are a unique group neglected in the wider palliative care response. Palliative care providers should provide specific support to meet their needs in order to complete the cycle of care. They should also be exposed to equal opportunities as other children.

Lessons Learnt:

- It has improved children's quality of life through empowering them to share, speak out and express themselves better.
- Children's self-esteem has improved and their hopes are restored.
- Given equal opportunities, child care givers can become important people in society.

Recommendations: As we invest in Palliative Care for Universal Health Coverage, it is important to support children care givers. They are psychosocially tortured and affected by the loss and or condition of their parents/guardians and siblings

The impact of psychosocial support to vulnerable children and adolescents living with cancer in increasing access to treatment. (New Hope Children's Hostel, Kawempe Home Care Experience- Uganda.)

Gerever Niwagaba, Claire Namulwa, Guma Samuel
Kawempe Home Care

Background: Kawempe Home Care is a not for profit organisation providing holistic care to persons living with HIV/AIDS, TB and Cancer in Kawempe division Kampala City. According to the Uganda Cancer Institute 7,000 children are estimated to develop cancer annually. Children face many psychosocial problems as they seek treatment from the only cancer treatment centers in Uganda; Limited bed capacity, Lack food, transport, treatments fees and accommodation make carers lose hope, go back home and even stop treatment of their children.

Aim: Increase access to specialised cancer treatment and care for 300 vulnerable children adolescents through provision of hostel services in 3 years.

Methodology: KHC established a referral and linkage system with Uganda Cancer institute

Targeting children below 18 years from less able families. Provided free accommodation, nursing care, Psychotherapy, play therapy, legal aid support, meals, patients transport support and social workers closely attended to children with special needs.

Results: Children's quality of life improved due to availability of arrange of quick holistic palliative care services. Free transport increased service demand and timely treatment access for 375 patients in two and half years. Majority of Children felt safe and comfortable at the hostel (patients lodge) rather than at home during the course of treatment

Conclusion: Strong Psychosocial support system using children's hostel model is a catalyst in increasing access to Care and improves survival and treatment outcomes for children and adolescents living with cancers in limited resource settings.

Session 11.00 - 12.00

Workshop

Digital Health

Paul Mbaka¹, Lacey Ahern²

¹Ministry of Health, ²Centre for Hospice Care

Palliative Care Association of Uganda (PCAU) in partnership with Center for Hospice Care/Hospice Foundation (CHC/HF) and the University of Notre Dame started the mHealth surveillance project in May 2015 to mitigate the issues of lack of accurate and updated information on palliative care services in Uganda. This was in a bid to better support and strengthen palliative care services by improving the collection of relevant and accurate data on current states of palliative care services provision. The overall aim of the project is to obtain and avail credible data to aid evidenced decision making and thereby enhancing the availability and use of palliative care services in Uganda. Specific aims of the project are to develop a surveillance system to collect accurate and timely data on palliative care throughout the country, to provide training and capacity building for palliative care providers to collect and use this data, to sustainably scale up the project country-wide and to integrate the system into other credible sources of health data such as the District Health information System (DHIS2).

The project is now collecting data in 20 facilities across Uganda. Key to scalability and sustainability is the collaboration with the Ministry of Health (MOH) and integration of this data collection into MOH digital health infrastructure.

The workshop will be utilised by the key implementing partners to collect feedback from stakeholders as to what indicators for palliative care should be regularly collected. Groundwork has been done with sections of palliative care among project participants. The workshop will be utilised to solicit feedback on these with the aim of creating a concise and useful form to collect data on palliative care for DHIS2. The workshop will also be used to share an overview of the project and seek feedback from participants as to how to achieve the set objectives. Key outcomes of the workshops will therefore include: stake holders being informed about the mHealth surveillance project, draft indicators for inclusion in the DHIS2 and set up committee to accomplish the indicator by end of 2019.

Breakaway Session – Service Provision

Factors affecting chemotherapy adherence among patients with breast cancer at Uganda Cancer Institute

Flavia Nalubwama

Uganda Cancer Institute

Background: Cancer is a public health challenge and Breast cancer is ranked the most common cancer worldwide, increasing from 1.7 million incident cases in 2005 to 2.4 million cases in 2015. Oncology has made notable strides in the development of effective treatment to improve cancer survival, but surprisingly the adherence appears to be almost as significant problem in oncology for these potentially lifesaving medications. This has reduced patients' quality of life, wasted health care resources and directly impaired the ability of health care systems around the world to achieve population health goals.

Aim: The aim of this study was to investigate the factors affecting chemotherapy adherence among breast cancer patients at Uganda Cancer institute.

Methodology: It was a cross section descriptive study design where 70 participants were selected using convenient sampling. A questionnaire was used as a data collection tool and was obtained from the five steps recommended by WHO and (Kripalani, 2009)

Results: The participants were females, 49% were between 30-50 years and 51 years and above were 21%. The results indicated that socio-demographics significantly influenced medication adherence. Factors that pre-determine medication adherence included: financial status (54.3%), doctors and nurses never explain about chemotherapy (57.1%), (71.4%) said they don't take part in decision making about their treatment, long duration of treatment (52.9%), drugs are expensive (65.7%), traveling long distances (77.3%) among others.

Conclusion: The factors affecting medication adherence are very complex and require a lot of attention in order to be adequately addressed. Specific interventions targeting pre-determining factors associated with non-adherence would result in the best use of resources and more efficient interventions. This can potentially help reduce the mortality rate and economic burden to the health sector and the country at large.

Multidrug resistant bacteria- common cause of neutropenic fever among patients with hematologic malignancies in Uganda

Margaret Lubwama¹, Freddie Bwanga¹, David Kateete¹, Jackson Orem², Barbara Nabiryo³, Warren Phipps^{4,5}

¹Makerere University, Kampala Uganda ²Uganda Cancer Institute ³Hutchinson Centre Research Institute Uganda

⁴Fred Hutchinson Cancer Research Center ⁵University of Washington, Seattle, Washington

Background: Bacteremia in hematologic cancer patients with neutropenia is associated with increased morbidity and mortality.

Aims: The aim of this study is to determine the predominant species causing bacteremia and their antimicrobial resistance profiles among hematologic cancer in-patients with febrile neutropenia at the Uganda Cancer Institute (UCI).

Methods: Blood was drawn from participants with a febrile neutropenic episode (fever $\geq 37.5^{\circ}\text{C}$ and neutrophil count ≤ 1000 cells/ μL) and cultured in the BACTEC 9120 blood culture system. Bacteria were identified biochemically. Antimicrobial susceptibility testing was performed with the Kirby-Bauer disc diffusion method.

Results: 276 participants have been enrolled in this study to date. Eighty-seven (32%) had at least one febrile neutropenia episode. Positive blood cultures were obtained from

28 (32%) participants. Of the 41 aerobic bacteria isolated 32 (78%) were Gram-negative, the most common being *Klebsiella pneumoniae* (11; 34%). Seventeen (53%) of the Gram-negative bacteria displayed the extended spectrum beta lactamase phenotype and 5 (16%) were resistant to carbapenems. One of eight *Enterococcus* species was vancomycin resistant.

Conclusion: Multidrug resistant bacteria are the main cause of bacteremia in febrile neutropenic hematologic cancer patients at the UCI. To guide appropriate therapy and address emerging antimicrobial resistance at our institution, enhanced microbial surveillance, infection control and antimicrobial stewardship programs are needed.

The impact of palliative care in advanced HIV disease

Kinyatta Amany Bertha, Namusoke Sharon, Asiimwe Maureen Buhiire, Guma Samuel.
Kawempe Home Care

Aim: Palliative care improves the quality of life a person and also decreases the burden of mortality and morbidity. Palliative care also addresses and integrates the psychosocial and spiritual aspects of a person with Advanced HIV Disease for better treatment outcome through relief from pain and distressing symptoms. According to the WHO, Advanced HIV Disease is defined as CD4 of less than 200 cells/mm³ or a clinical stage 3 or 4 event at presentation for care for adults, adolescents, and children older than 5 years. All children less than 5 years of age are considered having advanced HIV disease.

Methods: Once an AHD patient has been notified, screening for opportunistic infections using the various parameters such as TB-LAM, CrAg and Viral load is done. Timely Anti-retroviral Therapy initiation in conjunction with adherence counseling is done for such clients, which is important in management and retention in care. Opportunistic infections and pain control are managed either at the facility, or through our home-based care approach whereby the fully-equipped team travel to meet unwell clients in their homes, and finally through the community network of care.

Results: In a 12 month cohort of 85 TB/HIV co-infected clients, 19(22%) reported pain related symptoms and after palliative care interventions, 16 (84%) had symptom relief. 27 active clients who were diagnosed with different cancers, 10(37%) had pain, but currently, the 10(100%) clients are pain free and most of our clients have been able to resume pre-disease performance without restriction.

Conclusion: Palliative care in Advanced HIV Disease is an interdisciplinary process intended to relieve suffering and improve quality of life for patients and their families thus to preserve the persons sense of dignity.

Volunteer programme essentials

Kristiana Donahue
Centre for Hospice Care - USA

Introduction: Having multitudes of volunteers knocking down your door seems like an ideal scenario. However, reality shows us that having an effective volunteer program is much more than mere numbers. From the introduction to the eventual volunteer placement, learning how to engage, prepare and retain quality volunteers is the real goal.

Discussion: When meeting with a volunteer for the first time, we can get a sense of the person's compassion and drive. The essentials to an effective volunteer program begin with the introduction. To properly place a volunteer, we first have to identify their goals and desires and if that fits our needs. Having clear job descriptions for different volunteer roles is important to finding the right placements for your volunteers. Preparing volunteers

effectively takes time. Rushing a volunteer into the field without the proper training is bound to result in problems. Volunteers need to know their expectations and their job duties, just like employees. Initial orientation and continued training give volunteers the assurance that their roles are valued and important. Once trained, it is so important to utilise the volunteers immediately and regularly. Underutilisation of volunteers is one of the best ways to lose a volunteer. Make sure to keep them engaged and communicate clearly to make sure that their role is fitting their gifts and talents effectively.

Conclusion: The most effective volunteer programs may not have the biggest number of volunteers, however, a good program will meet the needs. An effective volunteer program includes understanding the drive of the volunteer, preparing them well and utilising them to their capacity. When done well, volunteers are satisfied and patients and families are served.

Attendant and Caregiver Temperature Surveillance (ACTS) for UCI cancer patients

Martha Nantayi, Emmanuel Olupot, Leilia Naluyima

Uganda Cancer Institute

Aim: Uganda Cancer Institute (UCI) sees over 4000 new cancer cases. (2018) Approximately 93 nurses work at UCI. Financial constraints limit staffing so patient to nurse staffing ratios can be high and workloads intense, particularly in sub-Saharan Africa. Vital signs at the time of fever could be done utilising the patient attendants to help in the fever monitoring process. Early detection of fever will allow for concurrent blood draws for cultures to identify organisms.

Methods: At the time of admission, the patient's family attendants on two of the UCI Wards (STC and LTC) would be given education on observing for sepsis, log books, and digital thermometers for the patient to keep throughout their stay at UCI. Attendants will take temperatures every 6 hours. They would be instructed on how to record in the log book. Blood cultures could be obtained at the time of fever and sepsis could be identified faster.

Results: An inter professional committee has been created to manage all the elements of this project. A protocol will be submitted to the UCI IRB and FHCRC IRB for this process of attendant monitoring of fevers in UCI patients. Funding for digital thermometers will be sought to assure each patient attendant access with log books for monitoring. The system for education of the attendants and the patients is coordinated by the nurse led research team and then disseminated to the UCI nursing staff in all units.

Conclusion: The best care of the potentially septic patients could be evaluated in proximity to elevation in temperature. Compilation of the causative organisms in the septic events will be obtained and appropriate anti-microbial therapy can be placed on the hospital formulary for prescribing and immediate treatment.

Session 12.00 – 1.00pm

Workshop

Sustainable Pain Management in Hospitals in Uganda

Jackson Amone¹, Rinty Kintu²

¹Ministry of Health, ²American Cancer Society

Since 1993, Uganda has seen improvement in improving access to pain medicines for palliative care patients by ensuring certain medications on the Essential Medicines lists. Uganda has also developed a model for local production of low-cost oral liquid morphine that has been instrumental in improving access to pain medicine among palliative care patients. There is a Public Private Partnership (PPP) for the importation, manufacture and distribution of morphine in the country. Government funds the manufacture of the medicine at Hospice Africa (HAU) and this is distributed to public health facilities by the National Medical Stores (NMS), and to private facilities by the Joint Medical Stores (JMS). The 2004 task shifting instrument that allowed palliative care trained nurses to prescribe certain analgesics including oral liquid morphine also contributed to availability of morphine is available to now 234 health facilities in the country.

To add to the efforts of improving the quality and access to pain management, the Palliative Care Association of Uganda (PCAU) in partnership with the Ministry of Health have implemented the Pain Free Hospital Initiative (PFHI) in a total of 14 Hospitals in Uganda since 2015. The PFHI is a one-year hospital-wide quality improvement initiative to integrate pain treatment into routine hospital care. The program is designed for hospitals where pain relief is available, but remains under-prescribed.

The overall purpose of this workshop will be to bring together key stakeholders from the Ministry of Health, Public and Private teaching Hospitals, civil society and patient's representatives to discuss experiences, lessons, the scale up and the sustainability of the Initiative in Uganda.

The specific objectives for the workshop will therefore be to bring together identified key stake holders in the implementation of the PFHI, to offer them a platform for sharing success stories from both Uganda and other countries, draw good lessons for replication, scalability and to draw an action plan for the sustainability of the initiative at implementing hospitals. The workshop will also aim to form a Ministry of Health lead PFHI committee for Uganda. Key outcomes of the formation of the Ministry of Health lead PFHI committee and the initiation of the action plan for the scalability and sustainability of the PFHI in Uganda.

Breakaway Session – Research and Innovation

A cross-sectional survey: serious adverse effects of long-term oral morphine in chronic pain patients in community palliative care.

Barbara Duncan¹, Wilson Acuda²

¹King's College London, ²Hospice Africa Uganda

Background: Hospice Africa Uganda patients with chronic non-cancer and/or chronic cancer pain receive long-term oral solution of morphine for pain control. Global evidence exists of Opioid Use Disorder (OUD) in chronic pain patients taking long-term opioids. Morphine-related problems have arisen in chronic pain patients at Hospice Africa Uganda (HAU) in Kampala.

Aim: To identify Kampala HAU patients on long-term morphine and address adverse effects.

Design: A cross-sectional file survey identified patients with chronic pain taking long-term oral morphine. They were offered a biopsychosocial and spiritual assessment with a pain specialist. Assessments were at hospice clinic or patients' homes. If indicated, referral for psychological/psychiatric or social assessment was offered. Pain management options were discussed with patients.

Setting/Participants: HAU provides community palliative care on 3 sites in Uganda and introduced cheap oral morphine solution into Uganda in 1993.

Results: 49, out of 653 patients, were identified as taking long-term morphine for chronic pain. 33 participants had a biopsychosocial and spiritual assessment. 23 participants had chronic non-cancer pain alone. 10 cancer survivors were on long-term morphine for a minimum of 3 years.

One participant was addicted to oral morphine. One participant had probably diverted prescribed morphine. One participant had opioid-induced hyperalgesia.

Conclusion: Further research on harm of long-term opioids prescribed for chronic non-cancer pain in Uganda is indicated. Introduction of opioids into the Global South must overcome opiophobia and educate health care professionals and public on the risks of long-term opioids in those with chronic non-cancer pain.

Bringing hope, changing systems, transforming lives: A 10-year review on the impact of integrated palliative care in the academic and national hospital setting in Uganda.

Leng M^{1,2,3,5}, Grant L², Murray SM², Downing J^{1,4,5}, Turyahikyio J^{1,5}, Bagasha P^{1,5}, Namukwaya L^{1,5}

1Makerere Palliative Care Unit, Department of Medicine Makerere University, Kampala 2University of Edinburgh 3Cairdeas International Palliative Care Trust, UK 4International Children's Palliative Care Network 5Palliative care Education and Research Consortium, Uganda.

Background: Effective government hospital and academic models are crucial for integrated palliative care (PC). The MMPCU model was developed 10 years ago to 1) improve access to quality, evidence-based PC for patients and families, 2) develop a cadre of leaders 3) offer clinical modelling, training and capacity-building and 4) build partnerships.

Aim: To evaluate and assess outputs and outcomes over the past 10 years with particular reference to the research agenda (3 strands: patient, family and caregiver issues, staff, volunteer and health care worker issues and health systems issues) underpinning the strategic plan (2011-2016).

Methods: Data from embedded strategic outputs and outcomes was reviewed in stages. The database of clinical activity, training and capacity building was collated alongside quantitative and qualitative outcome indicators. Research capacity building was subjected to a survey-based impact assessment, and collation of publications, presentations and academic achievements by staff members and key partnerships.

Results: 3,189 patients received documented care from the specialist PC team, and an additional 6,669 identified and received generalist PC by link nurses (731 referred for specialist support). Along with family members more than 16,527 received support. 4,630 individuals were trained including undergraduate (medicine, nursing, pharmacy), postgraduate (Diploma, Degree and 4 Med programmes), and in-service short courses. 1,223 of those trained were in 8 additional countries. Staff gained 5 BSc, 2 Masters, 1 PhD. 192 abstracts at national and international conferences and 53 publications. National and regionally relevant impact assessments include: evaluation of integrated models, nurse

prescribing, outcome of PC interventions, morphine use, experience of patients and staff and service evaluations. Financial sustainability remains a significant challenge though organisational stability is supported by the launch of the PC Education and Research Consortium.

Conclusions: The MMPCU model of specialist PC empower other hospital staff and integrating capacity building underpinned by research is effective. Mentorship and leadership training is essential. High visibility, academic credibility and engagement in the work of the institutions supports ownership. Strong partnerships are crucial and creative.

Integration approaches of palliative care into primary health care in low -and middle income countries: A systematic review

Basirika Dianah

Hospice Africa Uganda

Background: Many patients in Low- and Middle-Income Countries (LMICs) suffer and die in pain without accessing Palliative Care (PC) despite PC being available. Integrating PC into national Primary Health Care (PHC) systems could improve access and minimise unnecessary suffering.

Aim: To search existent literature on the integration of Palliative Care into Primary Health Care in LMICs and to clarify the approaches for that integration.

Methods: A systematic review was undertaken following a protocol. Systematic searches were conducted on PubMed, CINAHL, EMBASE, PsycINFO and MEDLINE OVID using text words and Medical Subject Headings related to Palliative Care integration in LMICs. Additional publications were obtained by searching reference lists from selected manuscripts. Published peer reviewed English journal articles of primary and secondary research were included and data abstraction was guided using the Primary Health Care Performance Initiative (PHCHI) Framework. All grey literature was excluded from the review.

Results: Eleven articles were included in the review with 39 LMICs represented. Many countries were struggling to integrate PC into PHC as the concept was still relatively new in some regions. Approaches of integrating PC into PHC included; lobbying for government support, training and education, availing essential medicines, incorporating PC in existing healthcare services, building partnerships, establishing separate PC infrastructures, task shifting, involving community volunteers in home-based care and empowering them to own the service and undertaking research to guide policy and clinical practice.

Conclusion: The Review highlighted that there several contextual approaches to the integration of PC into PHC and that some countries fare better than others with the integration of PC into PHC, while others are still at the early stages of integration. The integration of Palliative Care into Primary Health Care guided by the PHCPI Framework, if fully adopted, has the ability to address a nation's social determinants of health and to promote universal health coverage.

Breast cancer risk perception and screening behaviours of first degree female relatives to breast cancer patients at Uganda Cancer Institute

Provia Ainembabzi

Makerere University

Introduction: Breast cancer is the second most common cancer among women in Uganda. First degree relatives have a twofold to threefold increase in the risk of breast cancer development. Breast cancer screening is considered one of the effective tools for reducing breast cancer mortality.

Objective: To determine the self-perceived risk of breast cancer and breast cancer screening among first-degree female relatives of breast cancer patients attending Uganda

Cancer Institute

Methodology: We conducted a cross-sectional study using a pre-coded questionnaire among 125 first degree female relatives aged 18 years and above with no known personal history of breast cancer. Data was entered into Epidata version 3.1 and was then exported to STATA version 13 for analysis.

Results: Majority of the participants (57.6%) perceived themselves to have a low risk of developing breast cancer. The most performed breast cancer screening method was Breast Self-Examination (57.6%) followed by Clinical Breast Examination (28%) and the least being an Ultrasound Scan (10.4%). For women aged 40 years and above, (8.3%) had done mammography. Of the participants that performed Breast Self-Examination, 62% last performed it less than a month ago. In addition, most participants started Breast Self- Examination at 35 years (Mean 30.4 ± 10.5) ranging from 13 years to 60 years. There was no significant association between risk perception and breast cancer screening.

Conclusions: Generally, first degree relatives have low breast cancer risk perception and low engagement in breast cancer screening services. There is a need for programs targeting uptake of screening services in this population in order to reduce late-stage presentation with breast cancer.

Utilisation of paediatric radiotherapy services at Uganda Cancer Institute: Baseline results of a quality improvement project

Beatrice Rukundo

Uganda Cancer Institute

Introduction: Radiotherapy is life saving for most childhood solid tumours. Radiotherapy access in Africa, patient preferences, experiences and sociocultural influences can affect adherence to treatment protocols and treatment outcomes. A radiotherapy QI project was initiated and a dedicated clinical follow up team was formed at the Uganda Cancer Institute (UCI) Paediatric Service in March 2018 to improve access to radiotherapy.

Purpose: To report on the baseline assessment of radiotherapy utilisation and patient reported challenges in UCI Paediatric Department following radiotherapy QI project initiation.

Methodology: We conducted a file review of all children who had been recommended for radiotherapy from March 2018 to October 2018. We collected data on patient demographics, cancer diagnosis, and radiotherapy treatment. To assess challenges, we utilised semi-structured clinical interviews either on a one on one or telephone interviews.

Results: A total of 56 patients files were reviewed indicating 31/56 (55.4%) were male with mean age of 64.8 months (5.4years). The commonest radiotherapy referral diagnosis

were Wilms Tumour 27/56 (48.2%), Retinoblastoma 15/56 (26.8%) Rhabdomyosarcoma 13/56 (23.2%) Hodgkin 1(1.8%). A total of 49/56 (87.5%) completed radiotherapy sessions while 7(12.5%) were lost to follow up. From phone call or one on one clinical interview 53/56 (94.6%) were reached of whom 47/53 (88.67%) reported having completed radiotherapy. 3 patients could not be reached. Shared challenges reported by patients who had completed radiotherapy and those lost to follow up were delays or recurrent postponement of radiotherapy 43/53 (81.1%), pre-radiotherapy starving 40/53(75.4%) and sociocultural reasons 5/53 (9.4%). Concurrent traditional medicine and religious reasons were cited.

Conclusions: The baseline results show that while majority patients completed radiotherapy sessions significant challenges were reported. We recommend follow up assessments to quantify impact of radiotherapy access to treatment outcomes which is critical for cure of children with solid cancers in resource limited settings.

Poster Presentations

Thursday 5th September 2019

Nurses at Uganda Cancer Institute credentialed for Phase I Clinical Trial implementation

Kathleen Shannon Dorcy, Tino Christine, Jacqueline Asea, Arlyce Coumar,

Seattle Cancer Care Alliance/Fred Hutchinson Cancer Research Centre, Uganda Cancer Institute, Fred Hutchinson Cancer Research Institute/Uganda Cancer Institute, Seattle Cancer Care Alliance

Background/Rationale: Non-Hodgkin's lymphoma (NHL) is one of the most common cancers in Uganda with a high mortality rate. A Phase I clinical trial was approved by the Institutional Review Boards in USA and Uganda, necessitating mandatory USA Food and Drug Administration (FDA) nurse credentialing for Clinical Trial implementation. Uganda Cancer Institute (UCI), with Hutchinson Centre Research Institute-Uganda (HCRI-U) and Seattle Cancer Care Alliance (SCCA) nurses convened a collaborative team to assess and strategise on how on to achieve mandatory regulatory credentialing for UCI clinical nurses.

Aim: To achieve nurse credentialing at UCI for the administration of the research agent and Phase I clinical trial implementation.

Methods, Intervention, and Analysis: The UCI Clinical Trials Director worked with UCI nursing staff of 93, to identify 13 nurses to complete mandatory credentialing. (The Collaborative Institutional Training Initiative (CITI) Human Subjects Protection, (HSP) and Good Clinical Practices (GCP) training.) Training was conducted at HCRI-U campus with partnership teaching from the UCI Clinical Trials Director, 2 SCCA nurses, UCI and HCRI-U nurses and nurse leaders, physicians, IT, and staff education members. All 13 UCI nurses successfully completed the online CITI modules and attended courses on research implementation, NHL, and sepsis.

Discussion and Implications: The UCI/HCRI-U nursing team is credentialed and knowledgeable about protocol adherence, GCP and HSP. Research protocol implementation requires knowledge of best clinical practices that protect patients and allow for informed decision making. The Phase I Clinical Trial can proceed to accrual with essential nurse capacity established for clinical research implementation. This UCI-HCRI-U nurse clinical accomplishment serves as the foundation for the HCRI-U research endeavours to ultimately lessen the morbidity and mortality of NHL in Uganda.

Diseases and symptom characteristics of inpatient older persons in a Regional Referral Hospital in Uganda.

Esther Taaka

Mbale Regional Referral Hospital

Background: Older persons are faced with many health conditions from the natural aging process as well as increasing incidences of Non-communicable diseases (NCDs) which require palliative care interventions. These conditions are associated with distressing symptoms, which are associated with suffering and negative effects on patients and family wellbeing.

Aim of the work: To provide onsite capacity building for staffs aimed at improving capacity of hospital staff to assess, document, monitor and manage pain.

Methods: Over a period of 9 months (July 2017 to March 2018), clinical hospital staff of Mbale Regional Referral Hospital, longitudinally assessed and scored pain for inpatients on 6 wards. We also collected demographic and clinical data. The patients were also asked reasons for their visit to the hospital.

Results: data collected from the medical ward showed that out of the 267 admitted patients, 35 (13%) were older persons of which 38% suffered from Non Communicable Diseases (NCDs) including diabetes-3%, hypertension-6%, cancers-6%, cardiac conditions 11%, stroke-6%, kidney condition-3% and cerebral conditions-3%. HIV with co infections was 9% and TB /pneumonia at 23%. The remaining had abdominal obstruction, ulcers, and anaemia. For 60% of the patients, the main reason for visiting the hospital was pain followed by difficulty in breathing (17%). Other symptoms for visiting the hospital included; body weakness, high blood pressure and dizziness.

Conclusion: over 70% of older persons admitted to the hospital suffer from NCDs and other conditions that would benefit from palliative care and should be included in palliative care interventions. There is need for more awareness on improving pain and symptom management for older persons.

Assessment of pain on Sicklers with painful crisis in Soroti Regional Referral Hospital children's ward

P Oronon, M Nakuya, F Alaroker

Soroti Regional Referral Hospital

Background: Sickle cell contributes 15% mortality in children under 5 years in sub-Saharan Africa. In Uganda, about 20,000 babies are born annually with sickle cell disease. Data for Soroti district is not available, however in 2018, 7186 children were admitted. More than half of these (55.78%) were sicklers. Of these, 94.26% had painful crisis (Ward records). In February, March, April 1,495 children were admitted. 12.79% (190) were sicklers in painful crisis requiring analgesics. Morphine is a drug of choice, given 4 hourly after assessing and rating pain (titrating morphine dose against the rate of pain). This ensures rational use of morphine, preventing wastage and stock outs. The main objective of the study therefore was to ascertain how often these patients were re-assessed within 24 hours of administration of first morphine dose.

Methods: Retrospective study involving review of paediatric admission record (PAR) books, pain assessment charts for the 190 children admitted in February, March and April 2019 that presented with pain.

Results: 88.36% patients were assessed for pain at admission, 11.58% not assessed. Of those assessed, 55.36% patients were reassessed once, 2.98% reassessed >1, while

41.67% not re assessed.

Conclusion: Despite the interest and efforts to control pain, its assessment and documentation remains low. Patients were barely re-assessed. These data therefore helps look into staffing levels versus work load, need to improve on assessment and documentation thus helping us track morphine consumption.

Recommendations: Include pain assessment charts in the PAR books. Improve on Staffing levels. Encourage the staff to assess for pain before each morphine dose. Continue with refresher trainings.

Appreciation goes to SRRH, MCRI, PCAU, MOH, paediatric ward staff and the patients.

Quality of life for paediatric cancer patients at New Hope Children's Hostel, Kawempe Home Care.

*Asiimwe Buhiire Maureen, Natasha Phionah, Wambalya Timothy, Samuel Guma
Kawempe Home Care*

Aim: The study aimed at determining the effect of the hostel model of palliative care on the quality of life and treatment outcomes of children with cancer who are receiving specialised care.

Methodology: A longitudinal study design using quantitative methods was carried out among 80 respondents (patients and care givers) to enable us to assess the changes in quality of life over a period of 2 months with the Children Palliative Care Outcome Scale monitoring for every after 2 weeks from the time they are enrolled to the time of discharge. At the hostel, accommodation, meals, transport, psychosocial, spiritual, and palliative care support are provided for the children through counseling, nursing care, psycho, music and play therapy.

Results: After period of 2 months monitoring of the children and their care givers depending on the POS questions Pain, Symptoms and Feeling worried from the time of arrival to the time of discharge, there is a significant impact caused by psychosocial interventions thus quality of life.

Conclusion: A hostel is a model of care through which paediatric palliative care can be provided for children with cancer and their families, to provide relief from the symptoms, reduce stress of the illness and bring hope. Care givers described the diagnosis and treatment of a child with cancer as one of the most stressful times in their lives. So with the psychosocial support rendered at the New Hope Hostel, the person sense of dignity is preserved, hence promoting quality of life.

Recognising policy and institutional gaps: Commemoration of 2019 World Cancer Day in Uganda

*Paul Ebusu
Uganda Cancer Society*

Objective: Uganda Cancer Society together with Uganda Cancer Institute partnered with government and other stakeholders to commemorate 2019 World Cancer Day. The global theme for 2019 which is "I AM. I WILL" explores how everyone collectively or as an individual can do their part to reduce the burden of cancer.

Aim: The purpose was to increase advocacy and involve the general public along with government in raising awareness about cancer by recognising its burden, efforts made to control it as well as the gaps that exist in fighting the epidemic.

Method: We built collaborations within our membership and Uganda Cancer Institute fostering joint planning. The planning drew activities including lighting of the monument, screening, and physical activity. The physical activity arose from the Uganda NCD risk factor survey (2014) which showed that Ugandans have high physical inactivity especially among the urban population where 8% of adults were considered physically inactive compared to 3.5% among the rural population.

Results: There was increased collaboration and partnerships built among stakeholders bringing together government, civil society, media, private sector and the general public in planning and commemoration. The physical activity and screening attracted the public to join the ceremony. Media coverage included press conference, media question and answer sessions at the ceremony, and live streaming on television and radio stations. Notably, 5 articles were published in major national newspapers with Facebook page posts generating 4,100 likes, and up to 1,610 people engaged as there were also 333 tweets and retweets on twitter.

Conclusion: The solidarity with which partners worked together both in the preparations and commemoration, including government's commitment to create an enabling policy environment showed that together we can harness greater results in cancer control in Uganda.

Uganda National Cancer Control Plan: A step towards Universal Coverage

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A country's National Cancer Control Plan (NCCP) is a laid-out strategy to reduce the country's cancer incidence, prevalence, morbidity and mortality. It should be based on the country's cancer burden, risk factor burden, resources available and the culture and health-care system of the country. It spells out strategies for all members of the country's population, collaborators and development partners from outside the country to play their roles to contribute towards cancer control. Uganda Cancer Institute has led the efforts of developing a comprehensive national cancer control plan for Uganda since March 2016 and the draft is complete.

To formulate a cancer control plan for Uganda, the Executive Director of Uganda Cancer Institute (UCI), the government agency mandated by law to lead cancer control efforts in Uganda constituted a National Cancer Control (NCC) secretariat of 12 people after wide consultations. The secretariat constituted a multi-sectoral National Steering Committee (NSC) to provide guidance and oversight. A writing group was constituted and organised into smaller writing teams which drafted different sections (pillars) of the plan. The drafting exercise involved extensive review of literature including existing national cancer control plans in over 50 meetings.

The plan envisions "a healthy and productive population". It is organised in eight pillars which lay down strategies addressing the continuum of cancer control from primary prevention to palliative care at all levels of society and health care system for all stakeholders across all sectors including development partners and other external collaborators. UNCCP has a research strategy in every pillar to promote continuous generation of evidence and costed frameworks for implementation, monitoring and evaluation and sources of resources identified to ensure translation into action.

This will be a critical step towards universal coverage for cancer services in Uganda.

A novel green approach towards cervical and prostate cancer treatment: Evidence of selective activity by Silver Nanoparticles from Ethanolic Extracts of Fruits of *Annona Muricata*

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Busitema University, Mbale, Pan African University Institute for Basic Sciences (PAUSTI), Kenya. Kenya Methodist University, Meru Kenya. University of Nairobi, Kenya. Jomo Kenyatta University of Agriculture and Technology, Nairobi, Kenya. Cairo University, Egypt.

Background: Green synthesised nanoparticles have potential applications in nanomedicine including development of better anticancer drugs.

Aims: To synthesise silver nanoparticles (AgNPs) from ethanolic extracts of fruits of *Annona muricata*, characterise the synthesised AgNPs and to explore their anticancer activities.

Methods: AgNPs were synthesised via AgNO₃ solution and characterised using spectroscopy and microscopy techniques. The anticancer activities of the AgNPs and standard anticancer drug 5-Fluorouracil (5FU) were studied on a cervical adenocarcinoma cell line (HeLa), a prostate adenocarcinoma cell line (PC3) and PNT1A normal cells. The resazurin metabolic assay, migration assay and colony formation assays were employed for the study.

Results: The AgNPs had an absorption maximum of 427 nm and were stable under different temperature, pH and storage conditions. FTIR spectroscopy revealed the functional groups responsible for the synthesis and stabilisation of the AgNPs. SEM and XRD analysis revealed the spherical and crystalline nature of the AgNPs with an average size of 60.12 nm. The AgNPs displayed significant antiproliferative effects against HeLa cells with an IC₅₀ of 38.58 µg/ml and PC3 cells with an IC₅₀ of 48.17 µg/ml but selectively spared normal PNT1A cells (selectivity index of 7.8), in comparison with standard drug 5FU, whose selectivity index was 3.56. The migration assay revealed potential inhibition of the metastatic activity of the cells by the AgNPs while the colony formation assay indicated the permanent effect of the AgNPs on the cancer cells yet being reversible on the normal cells in contrast with 5FU.

Conclusion: An efficient, eco-friendly and cheap method for the synthesis of AgNPs using ethanolic extracts of fruits of *Annona muricata* as both reducing and capping agents has been reported. The study further presents evidence that biosynthesised AgNPs can be used in the development of novel and safer anticancer drugs.

An assessment of chronic illness and palliative care need in a South Sudanese refugee population within Uganda

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Background: Palliative care (PC) is an essential component of healthcare provision in humanitarian settings. Uganda hosts the largest refugee population in Africa, with Adjumani District home to 250,000 refugees, mostly South Sudanese, in 18 settlements. Yet little is known about their PC needs.

Aim: To determine chronic illness burden and PC need amongst refugees in Adjumani District.

Methods: 75 Village Health Teams (VHTs), supported by health centres with PC trained Health Care Workers, received a 3-day training in PC. 24 trained VHTs, from 11 refugee settlements, then supported a household survey identifying 331 potential individuals with PC need. After screening, consent was sought from individuals (> 17) or parents (> 8), with assent from children >10 years. Structured interviews were conducted with 110 individuals (96 adults, 14 children) including the APCA-POS (or C-POS), POS-S, ECOG and socio-demographic variables.

Results: 29% of potential participants were not available to survey; many had travelled outside the district. Musculoskeletal conditions (38%) were most prevalent, then organ failure (22%), HIV (19%) and neurological conditions (13%). 89% lived with their condition > 1 year. Significant symptom burden; median number of symptoms 5, 67% reporting pain scores 4-5/5. Only 7% had access to oral morphine and 14% received PC. Median total APCA-POS score was 18 out of 35; reflecting unmet holistic PC needs. Social demographics revealed huge challenges including access to running water, sufficient food and paid employment.

Discussion: There is a significant burden of chronic disease and unmet PC care need amongst refugees in Adjumani district. Chronic pain needs further review as it may be linked to complex trauma. VHTs as community representatives are key in identifying those in need and supporting referrals. Stakeholder engagement and a health systems strengthening approach is needed to ensure the implementation of PC through government led multi-sectoral planning.

Exploring experiences of family caregivers of adult cancer patients receiving palliative care from Rays of Hope Hospice Jinja.

Joanita Mbabazi

Rays of Hope Hospice Jinja

Background: Cancer presents a burden of care which requires support from close relatives of patients from onset of disease. Family caregivers face many experiences, but less effort to study this is put to this field by palliative care providers.

Aim: The aim was to explore the experiences and identify evidence-based support required by family care givers of adult cancer patients receiving palliative care from Rays of Hope Hospice Jinja (RHHJ)

Method: This was a qualitative study where individual interviews were conducted among 15 selected family caregivers who were above 18 years and caring for adult cancer patients for over six months. Data was collected during home visits using a semi-structured interview guide and the process involved audio recording of information following participants' informed consent and permission from the study site.

Results: Interviews were conducted in the local language; recorded information was translated into and transcribed in English and major themes were developed. These included: *Physical exhaustion* from daily duties causing significant impacts on the physical well-being of caregivers. *Emotional distress* - constant fear and worry among caregivers because a cancer diagnosis meant death. *Social relationships and challenges* - helping patients was perceived as an obligation in majority of caregivers though some were stigmatised by their communities. *Prognosis and source of hope* - hope was derived from God, treatment and supporting organisations like RHHJ. *Financial challenges* - cancer presents financial demands which are exacerbated in rural areas. *Forms of support* - Help with pain medicines, counselling, basic needs and financial assistance. Understanding family caregivers' holistic experiences requires spending valuable time with them. **Conclusion:** The experiences mainly present as challenges in the form of

physical exhaustion, emotional distress, change in social relationships, financial difficulties and finding sources of hope. Caregivers of cancer patients require extensive support from palliative care providers due to this huge role.

Exploring palliative care professionals views on illness, death and dying

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Background: Increased knowledge into the understanding of death and dying in Uganda provides an evidence base for the development of palliative care (PC) services. Insight gained from PC professionals will help identify how their understanding of death and dying shapes PC provision.

Aim: To understand the views of Ugandan palliative care professionals with regards to illness, death and dying and how this impacts on the provision of PC.

Methods: Eight interviews were conducted to date with PC professionals from five health facilities – Kabale and Masaka Regional Referral Hospitals, Serere and Nsangi Health Centres and Mildmay Uganda. Interviews were conducted with 5 nurses, 1 midwife, 1 counsellor and 1 clinical officer. Interviews were conducted in English, continued until data saturation was reached and transcribed. Themes identified and a coding framework developed collaboratively by the research team. Ethical approval was gained through HAUREC and UNCST.

Results: Six themes were identified: 1) the impact of their role as PC professionals including physical and emotional; 2) how they see their role, being committed, motivated and caring, putting their patients first; 3) how they cope working in PC; 4) their understanding of illness; 5) beliefs about death and dying and its normality; and 6) beliefs. Communication, how and what they communicate, was an underlying cross-cutting issue, along with how each theme impacts the care given.

Conclusion: Whilst PC professionals understanding of illness, death and dying impacts on the care they give, the provision of PC also impacts on their understanding of illness, death and dying. The emotional/physical impact of providing PC is great but offset by individuals commitment and motivation and underlying belief in the impact that PC has on quality of life. It is important to provide a supportive and safe environment for HPs working in PC where they can express/explore their feelings.

Nurses' perceptions towards reporting chemotherapy administration errors.

Hanifah Nabbanja

Uganda Cancer Institute

Objective: Oncology nurses have a major role which is chemotherapy administration but chemotherapy administration errors may cause severe clinical problems due to high toxicity of chemotherapy therefore this study assessed Nurses' Perceptions towards Reporting Chemotherapy Administration Errors at Uganda Cancer Institute (UCI).

Methodology: This was a descriptive cross-sectional study that used quantitative methods. We purposely selected 56 nurses who directly administered chemotherapy for at least five years. Among them, a random sample of 44 nurses was selected, interviewed and data collected in December 2018. The tool for data collection was a structured questionnaire that consisted of two sections; demographic data of participants and questions about chemotherapy errors with a five-point Likert scale.

Results: A total of 44 questionnaires were returned; most of the participants (68.2%) were females, 54.5% were Diploma holders and 79.5% had administered chemotherapy for a period of 5-10 years. All nurses knew what a chemotherapy administration error meant and 77.3% had ever made at least an error during chemotherapy administration. 79.5% of the nurses agreed that errors affect patients in various ways, and it was important to report them however, 81.8% feared to report these errors because of consequences from reporting them. 79.5% of the participants reported fear as the major barrier towards reporting chemotherapy errors and 86.4% of the participants agreed that UCI had no adverse events report forms to chemotherapy errors, hence hindering reporting.

Conclusion: While UCI nurses reported barriers towards reporting, it was observed that they had good perceptions towards reporting errors despite the various expected consequences towards reporting. This indicates that UCI should establish a patients' safety committee that would set up a standardised approach for reporting chemotherapy administration errors. Risk management strategies should be embraced at UCI as this would prevent occurrence of chemotherapy errors.

Optimising nutritional status of oncology patients being treated with chemotherapy by obtaining patient weight pre-each cycle and dose verification.

Joseph SSemujju, Emmanuel Olupot

Uganda Cancer Institute

Aim: The Uganda Cancer Institute (UCI) sees over 4000 new cases of cancer each year with approximately 30K-40K outpatient visits a year (2018). Nurses are responsible for administering chemotherapy as ordered by the medical provide. Chemotherapy has complications for nutritional status of patients. The ideal standard of care requires patient weight and recalculation of chemotherapy dosage with each new cycle. Current practices do not consistently have this standard of practice incorporated into the care of patients. The weight and height collected upon initial admission to the cancer centre prior to beginning any chemotherapy cycles may be utilised over multiple subsequent cycles of chemotherapy. Complications of chemotherapy are intensified when patients' dosages are not adjusted to the current weight, BSA, and dose calculation prior to each cycle. System improvements are needed to assure the ideal standard of care is observed and quality of life will be preserved for patients.

Methods/Approach Taken: UCI nurses observed this gap in clinical best practices and convened a group of oncology nurses to increase compliance with the ideal standard for BSA and chemotherapy dose calculation. Working together with patients, physicians, pharmacy and nursing, a collaborative shared commitment to assure BSA recalculation with each chemotherapy cycle was recommended. A proposal for creation of a checklist to be instituted was designed.

Results: Nurses are playing a significant role in modifying the checklist with all clinical team members represented. Work is ongoing to facilitate process for modification of the chemotherapy orders based on changes in weight.

Conclusions/Lessons Learned: Thursday Conferences could be a utilised as a forum for ongoing assessment of this project. All care team members must take responsibility for ensuring recent weight is checked and patient is receiving accurate chemotherapy dosing, thereby decreasing chemotherapy complications. One additional barrier to ensuring that weights is ready accessibility to scales.

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Friday 6th September 2019

Palliative care situational analysis in a south Sudanese refugee setting in Adjumani District, Uganda using a Participatory Rapid Systems Appraisal.

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Background: In humanitarian settings palliative care (PC) is rarely prioritised. New WHO & SPHERE guidelines support integration. 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 refugee population in Africa. Adjumani District with 240,000 population hosts 260,000 refugees.

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

Methods: Using Participatory Rapid Systems Appraisal a research team reviewed all documentation and mapped the roles of key stakeholders. Interviews were conducted with 4 groups: leaders in the refugee and host community, Ministry of Health, Peace Hospice and humanitarian stakeholders; those living with chronic disease including mental health issues; PC providers and those who refer or interact with PC, alongside field observations.

Results: From 69 qualitative interviews in 5 refugee communities the 9 themes emerged: PC is missing in almost all communities yet recognised by stakeholders *'It has been a key lacking point'*; challenges exist in coordination, integration, financing and planning.; *'integration is the way forward'*; cultural barriers to care with stigma and effects of trauma including mental health; limited PC education; need and impact of PC from patients and families. PC *'is like losing hope — then hope appears suddenly like the sun'*

Conclusion: Evidence from this analysis as well as outcomes of training packages for health care workers, village health teams and family caregivers as well as a household needs survey have been presented to MOH and humanitarian stakeholders. There is agreement on the gap identified and planning in process to take forward MOH led integration as part of a UHC programme. Refugee communities must have empowerment and ownership to ensure issues of culture and stigma are understood and host communities included to avoid a 2-tier system.

Perception of illness, death and dying by adult patients in Uganda with life-limiting conditions.

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Background: Palliative care (PC) provision needs to address the issues faced by individuals with life-limiting conditions, thus it is important to review their understanding in order to effectively shape and refine PC service provision.

Aim: To understand the views of our adult PC patients with regards to their illness, death and dying in order to ensure that our PC services are 'fit for purpose' and meeting their needs.

Methods: Thirteen interviews were conducted with adults aged between 23 and 85 (average 53), 6 men and 7 women. Three interviews were conducted in Lugisha, 5 in Luganda and 5 in English. 5 patients had cancer, 2 HIV, 4 had other NCDs and 2 did not have a confirmed diagnosis. Interviews were continued until data saturation was reached and were transcribed and translated. Themes identified and a coding framework developed collaboratively by the research team and reviewed by the PI. Ethical approval was gained through HAUREC and the UNCST.

Results: Six main themes were identified: 1) their social support system including family, community, finances and modern/traditional medicine; 2) emotions e.g. fear, grief and worry; 3) the impact of their illness on themselves, their family, the community and the place of care; 4) their understanding of their illness such as diagnosis, prognosis and physical symptoms; 5) beliefs about death and dying; and 6) coping and resilience impacted by past experiences, faith, colleagues, family and community.

Discussion: Adults respond and react differently to life threatening illness, however despite this, there are common themes that need to be addressed when providing PC. Their ability to cope and be resilient depends on a variety of reasons which impact on how they respond in other areas such as their support systems, the impact of their illness and their emotions.

Prevalence and predictors of cervical cancer in rural Uganda

Nita Chai

Rays of Hope Hospice Jinja

Background: In Uganda, cervical cancer accounts for 20% of new cancers and 35% of female cancers – many presenting at advanced stages. Experts believe eradication of cervical cancer depends on strong screening programs. Rays of Hope Hospice Jinja (RHHJ) provides palliative care in rural Uganda and started a screening programme for women with little access to these services.

Aim: We quantified the gynaecological profiles of women in rural Uganda and determined prevalence and predictors of cervical cancer in the area.

Research process: RHHJ, in partnership with the Ministry of Health and other health organisations, hosted a 3-day screen-and-treat camp for cervical and breast cancer. Women were screened using Visual inspection with acetic acid (VIA) or Pap smear. Treatment and biopsy support were free-of-charge. Medical records were retroactively analysed.

Results: Of the 700 women who attended, 576 were screened for cervical cancer.

85.2% were VIA-negative. 9.9% were VIA-positive. 2.4% were suspicious for or had cancer and were sent for biopsy. Fourteen women received Pap smears. Based on the VIA results and gynaecological and histology samples analysed, 11.5% of women screened were positive for pre-cancerous or cancerous cells. Among the risk factors, HIV status was not associated with a VIA-positive result.

Discussion/Conclusion: Some believe rural Ugandan women would not consent to a pelvic exam. We found women were interested and grateful to be screened. The prevalence of VIA-positive results and cervical cancer calls for urgent action, including accessible screening and treatment programs, sensitisation for stakeholders, and continued HPV vaccination efforts. We did not see HPV-HIV/AIDS co-infection but should be noted that most women had been tested more than one year prior to being screened. At this camp, treatment was free-of-cost and all women received treatment. Researchers should investigate whether rural women are willing/able to pay for treatment.

Improving viral suppression among HIV/AIDS children and adolescents through psycho-social support: Continuous quality improvement project

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Kawempe Home Care

Aim: Viral load monitoring is a more effective means of HIV treatment assessment and management compared to CD4 and clinical monitoring yet children and adolescents are at a higher risk of viral non-suppression due to poor adherence caused by psycho-social challenges.

Methods: A single centre quantitative study of children and adolescents (0 – 19) active in care at Kawempe Home Care aimed at improving viral suppression among HIV infected children and adolescents (0-19 years) from 66.7% in December, 2017 to 90% by June, 2019 through a continuous quality improvement project. Viral load data was obtained from medical records on a monthly basis and those were categorised as having viral load count > 1000 copies/mL, are assessed to identify independent factors associated with viral non-suppression through test changes like adherence counselling, education caregiver's and adolescents meetings, clinical intensified home and school visits, peer support meetings and psychotherapy.

Results: During this study children/adolescents revealed challenges with disclosure, pill burden, treatment fatigue, social isolation and lack of resources. However through the tested changes above viral suppression rate raised from 66.7% in December 2017 to 92.7% in May 2019.

Conclusion: Children and adolescents have worse treatment adherence and viral suppression compared to adults due to psychosocial challenges but through the tested changes; routine adherence counselling, continuous caregiver's and adolescent meetings, intensified home and school visits, children are able to suppress.

Patient hostels as service provision for children with cancer: New Children's Hostel, Kawempe Home Care

Claire Namulwa, Maureen Asiimwe Buhiire and Samuel Guma

Kawempe Home Care

Aim: Kawempe Home Care (KHC) is a private not for profit organisation, that started in 2007, aims at improving the quality of life for people living with HIV/AIDS, TB and Cancer through the creation of a sustainable community based model of holistic care that comprises of treatment, prevention and care. In September 2016, KHC opened the New Hope Children's Hostel that provides palliative care services for children with cancer who are receiving treatment at the Uganda Cancer Institute (UCI). The hostel also provides free accommodation, food and daily transport to the UCI.

Method: The package of palliative care includes; monitoring and supporting the children to adhere to pain and symptom controlling medicines prescribed by the paediatric oncologists. Emergency treatment is also given for new symptoms that arise while in the hostel and the child is referred for further management at UCI. The psychosocial issues that the children may have are handled using cognitive behavioural therapy, counselling, play therapy and music therapy. The children's spirituality is achieved through daily prayers. The APCA children's POS is used to measure the quality of life of the children every two weeks.

Results: A quantitative research method was carried out among 30 respondents to enable us to assess the changes in quality of life over at least four times within a period of 2 months. The study found out that there was a significant impact of 30% in psychosocial

interventions thus quality of life has improved.

Conclusion: The New Hope Children's Hostel has helped to improve the quality of life of children with cancer through the provision of holistic care and support. We recommend that all children's hostels provide palliative care services to their guests.

Dissection of the Kaposi Sarcoma tumour microenvironment at the single cell level

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Background and Aims: Kaposi sarcoma (KS) is an AIDS-defining cancer and a cause of enormous cancer morbidity and mortality in sub-Saharan Africa. KS lesions comprise a complex tumor ecosystem with heterogeneous malignant and non-malignant cellular components. Characterising the elements that comprise KS tumors and how these components interact *in vivo* will advance our understanding of KS tumorigenesis.

Methods: We evaluated KS tumor and normal skin samples obtained from HIV-positive and HIV-negative adults with KS enrolled in an ongoing study at the Uganda Cancer Institute – Fred Hutch Cancer Centre in Kampala, Uganda. We have developed and implemented a platform for isolating and interrogating viable single cells from KS biopsies. Cryopreserved single cell suspensions are subsequently analysed on a BD FACS Aria™ II sorter, using a panel of antibodies to identify non-malignant cells such as CD3⁺CD8⁺ T-cells and candidate KS tumor cells carrying the CD34⁺/VEGFR3⁺/LYVE-1⁺ surface phenotype. To date, targeted transcriptional profiling and T-cell receptor-alpha (TRA) / T-cell receptor-beta (TRB) variable region sequencing was performed on single CD8⁺ T-cells from KS tumour biopsies.

Results: Transcriptional profiling of single CD8⁺ T-cells using multiplex RT-PCR with primers for 24 genes relevant to lineage, function, proliferation, or exhaustion, followed by high-throughput sequencing of indexed PCR products, revealed significant heterogeneity in the expression of many genes, but uniformly low expression of several genes associated with proliferation and functional activation, including Ki-67, granzyme B, and TNF-alpha. Sequencing of TRA and TRB CDR3 regions carried in single CD8⁺ T cells from KS biopsies revealed several TRB sequences that our group has tentatively identified as candidate “public” KS-specific TCRs.

Conclusions: Our preliminary data suggest that the transcriptional profile of CD8⁺ cells in KS tumours is consistent with an “exhausted” profile, which may have implications for the use of therapeutic agents for reversing T-cell exhaustion in the treatment of KS.

Dynamics of the T-Cell Repertoire in HIV⁺ Adults with Diffuse Large B Cell Lymphoma in Uganda

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Background/Aims: Survival of HIV⁺ adults in Uganda with diffuse large B cell lymphoma (DLBCL) is poor. We hypothesise that one-year survival after diagnosis of DLBCL in HIV⁺ adults will be associated with superior reconstitution of the T-cell repertoire.

Methods: We performed serial high-throughput DNA sequencing of the T-cell receptor β (TRB) and T-cell receptor α (TRA) loci in peripheral blood T-lymphocytes of HIV⁺ adults

who presented to the Uganda Cancer Institute with confirmed DLBCL. Clinical data and blood samples were prospectively collected from subjects at study entry and after 6 and 12 months of follow-up. *TRB/TRA* sequencing was also performed on blood T-cells of two control populations from the US: (1) 16 HIV-seronegative adults without cancer, and (2) 30 HIV⁺ adults without cancer. The diversity and composition of the T-cell repertoire at 0, 6, and 12 months in the HIV⁺ subjects with DLBCL was inferred from the *TRB/TRA* sequence data, compared with that in the control groups, and analysed for potential associations with clinical outcome.

Results: T-cell repertoires of HIV⁺ adults with DLBCL were significantly less diverse than those of HIV⁺ and HIV-seronegative controls, and often dominated by expanded T-cell clones. “Public” *TRB* and *TRA* sequences associated with prototypic T-cell responses to HIV and herpesviruses such as CMV and EBV were frequently identified in the HIV⁺ DLBCL and HIV⁺ control cohorts, as were semi-invariant *TRA* sequences associated with NK/T-cell responses to mycobacterial lipids. No significant increase in repertoire diversity was observed in the minority of HIV⁺ DLBCL subjects who survived to the 6- or 12-month assessments.

Conclusions: Survival of HIV⁺ adults with DLBCL in Uganda remains poor, despite ART and chemotherapy. T-cell repertoires in these subjects contain expanded populations of T-cells associated with prototypic responses to viral and mycobacterial pathogens, suggesting that concurrent infection contributes to poor clinical outcome.

Cancer early detection services at Uganda Cancer Institute

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Background: World Health Organization (WHO) recommends that every country establishes a comprehensive National Cancer Control Plan (NCCP) with established pathways that facilitate early detection of common cancers in primary care. Although a NCCP is still being developed, UCI provides cancer early detection services through daily CCCP static clinics and community outreaches. As part of a quality improvement cycle, in April and May 2019, we conducted a survey to describe the clients attending the static clinic and the services they receive.

Main question: Who attends and what services are received in the cancer early detection clinic at UCI?

Methodology: This was a cross sectional surveys, 120 clients attending the CCCP cancer early detection static clinic at UCI, Kampala, Uganda were interviewed.

Results: Of all the clients interviewed, women were 72% (ages; 30-64yrs) presenting to be screened for breast and or cervical cancer, 26.5% were men (ages; 30-64yrs) presenting for screening for prostate cancer, 1.5% were both men and women (ages;30-64yrs) presenting to be screened for other conditions, 60% resided in central Uganda, 80% arrived at the clinic by 8.00am, all (100%) registered clients attended group cancer education, 76% required translation to their local language, 89% had all their requested investigations done at UCI, all clients whose investigations were done at UCI received their results and were reviewed by the health care provider in the clinic.

Conclusion: Efforts are needed to correct gender imbalance by attracting more men and to ensure health education is effective by translating information into clients' local languages in UCI's cancer early detection clinic.

Treatment outcomes of HIV patients with Non-Hodgkin's Lymphoma treated with standard dose compared with dose-modified CHOP chemotherapy at Uganda Cancer Institute

Alex Bakenga

Uganda Cancer Institute

Background: Despite the increased access to effective combination ART, there is still significant mortality associated with malignancies in HIV-positive patients. Because majority of patients present late especially with advanced disease, some of whom may not be able to tolerate standard dose chemotherapy, the Uganda Cancer Institute utilises both standard dose and dose-modified CHOP chemotherapy for HIV-related NHL. We evaluated HIV patients with NHL treated with standard dose or dose-modified CHOP with the aim of accessing treatment outcomes.

Methods: A retrospective cohort study was conducted among patients who received chemotherapy at the UCI between January 2004 to December 2014. 410 eligible patients were reviewed and information on demographics, clinical characteristics, chemotherapy regimens, treatment outcomes and vital status at 6-months after completion of chemotherapy

Results: Overall 450 patients were available for screening, 12 did not receive chemotherapy and 37 received other chemotherapy regimens. 410 patients with HIV-related NHL were analysed with 291 receiving standard dose and 119 patients received dose-modified CHOP chemotherapy. 83.2% in the standard dose and 79.8% in the dose-modified group had advanced disease. A complete response was achieved in 67 of the 291 (23%) patients who received 6 standard dose chemotherapy cycles and 32 of the 119 (27%) patients who received 6 cycles dose-modified chemotherapy. The overall mortality was (18/202) 8.9%; 13/143 (9.1%) in the standard dose group and 5/59 (8.5%) in the dose-modified group. On multivariate analysis, female gender (OR 1.71, 95% CI 1.02-2.85, at least 6 cycles of chemotherapy (OR 0.31, 95% CI 0.11-0.87), chemotherapy received on schedule (OR 0.52, 95% CI 0.30-0.90) and disease progression (OR 3.58, 95% CI 1.01-12.63) were significantly associated with mortality.

Conclusions: The complete response rates and mortality were not different; thus, the recommendation is to consider dose-modified therapy because of the fewer associated side effects and lesser chemotherapy associated toxicities. Although, this was not statistically significant.

Could this be a case of Lamivudine Associated Myelodysplasia?

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Introduction: Myelodysplastic syndromes (MDS) are a heterogeneous group of clonal haematologic diseases, characterised by dysplastic haemopoietic and peripheral cytopenia, caused by molecular lesions involving the stem cells. For patients with HIV infection not yet on antiretroviral therapy, dysplastic marrow changes are a frequent finding and often resolve on antiretroviral treatment. There are few reports of MDS in well-controlled HIV infection. Here, we describe a patient presenting with myelodysplastic features in a setting of well-controlled HIV infection.

Case report: A 59-year-old lady presented with a 2-month history of features of anaemia in December 2018. She is HIV positive since 2012 at WHO stage 3. She started antiretroviral therapy –zidovudine/lamivudine/nevirapine (AZT/3TC/NVP) in May 2013. At the time of admission, her ART had been switched to tenofovir/lamivudine/efavirenz (TDF/3TC/EFV) a week before. Her complete blood count (CBC) showed haemoglobin of 2.5g/

dl, MCV 131 fl, with white cell count and platelet counts within normal limits. Liver and renal function tests and lactate dehydrogenase were normal. CD4 count was 260 cells/mm³ and undetectable viral load at <20 copies/ml. She was suspected to AZT-induced anaemia and given blood products. In May 2019 she was readmitted with anaemia (Hb 8.9g/dl) and leucopenia (WBC 2.88 x 10⁹/L) and a platelet count of 176x10⁹/l. Peripheral blood film evaluation showed mild lymphopenia, and mild normocytic normochromic anaemia. Bone marrow studies showed hyperplastic bone marrow with megaloblastic erythroid precursors, dysplastic erythropoiesis and megakaryopoiesis and concluded that this could be megaloblastic anaemia with a need HIV myelopathy is a differential. Serum vitamin B12 levels were 709pg/nl. Cytogenetic analysis not done because of lack of resources. She was then referred to Uganda Cancer Institute for further care as a case of HIV associated myelodysplasia. At UCI, 3TC was suspected to be the cause of the myelodysplasia presenting with peripheral blood cytopenia. She was referred to Infectious Diseases Institute for consideration of changing her ART drugs to a combination without 3TC. At IDI, her ART regimen was switched to TDF/DTG which she is still taking. Current CD4 count is 557 cells/ml, viral load is still undetectable at <20 copies/ml, haemoglobin of 12.9g/dl, WBC 2.7x10⁹/L, platelet count of 227x10⁹/L.

Conclusion: In this case report we demonstrate the role of ART specifically 3TC in the aetiology of MDS in well controlled HIV infection. There have been several reports of well controlled HIV infected persons whose MDS symptoms have resolved after switching from a 3TC based regimen to a none 3TC based regimen, these reports unfortunately have not been published. Well controlled HIV patients with recurrent anaemias should be investigated for possible drug-induced myelodysplasia and consider drug switching.

Factors associated with survival after a diagnosis of AIDS-Related Diffuse Large B-Cell Lymphoma in the ART Era: A prospective study at the Uganda Cancer Institute

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Background: Diffuse large B-cell Lymphoma remains the most common Non-Hodgkin Lymphoma subtype among HIV-seropositive individuals accounting for 40%-50%¹. It is a highly aggressive form of lymphoma with two distinct types namely germinal Centre (GC) and Non-germinal Centre (Non-GC). Survival and factors associated with survival after AIDS Related DLBCL diagnosis are multiple and complex, and not yet well described in resource limited settings. Our understanding of the factors associated with survival will guide a risk-stratified adapted therapeutic approaches in this patient population. We hypothesise that tumour related factors, immunological factors, Virological factors and treatment factors are associated with survival after diagnosis of DLBCL among HIV⁺ subjects and these we seek to determine.

Methods: We prospectively enrolled consenting subjects referred to the Uganda Cancer Institute with confirmed DLBCL diagnosis using IHC. We collected clinical data and blood samples for CD4⁺ / CD8⁺ T-cells, LDH, CBC, HIV Viral Load, EBV viral Load, EBER and serum PBMC for sequencing. Staging work-up with imaging ultra-sound, chest x-rays, bone-marrow biopsy and aspiration, lumbar puncture for CSF findings were collected. Up on completion of staging work-up, subjects were offered chemotherapy at the discretion of the attending oncologist and were followed-up for vital status at 6, 12, and 24 months.

Results: In total, 55 of the 120 subjects screened were eligible for study enrolment. Of

those, 60% were female with median age of 41 (22-68) years. Median duration on ART was 4 (1-19) years, 68% had Ann Arbor stage III/IV DLBCL with 56% with intermediate-High IPI-score. 78% were ECOG 0-2. Median CD4+ was 243 (6-2090), with HIV viral load median of 51 (0-4,387,274). 61% received CHOP-21 chemotherapy, 51% received 4-6 cycles of chemotherapy. Of these subjects, 17% registered Complete Response while 25% had progressive disease, 3% stable disease and 11% partial response. The 1-year overall survival was 25% with over 50% (27/49) mortality within the first 6 months of study enrolment. Age, LDH level, IPI-Score, ECOG, HIV viral load, haemoglobin level, Ann Arbor stage and CD4+ level had a trend to association with survival at both univariate and multivariate regression; but without statistical significance.

Conclusions: Survival of AIDS related DLBCL is still inadequately low in low and middle income country settings at 25%, with over 50% mortality within the first 6 months of diagnosis. Complete Response (CR) to chemotherapy is at 17% and Non-CR at 39%. Factors associated with survival after diagnosis of AIDS related DLBCL had a trend to association but without statistical significance because the study was not powered given its small sample size. Accruals and analysis on PMBC sequencing, sub-typing of DLBCL, EBER testing is on-going.

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Renal dysfunction among patients receiving anti-cancer therapy at Mbarara Regional Referral Hospital Cancer Clinic.

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Background: Renal dysfunction in the cancer patient is associated mortality moreover its aetiology is multifactorial. The main to determine the proportion of cancer patients who develop dysfunction after receiving antineoplastic chemotherapy and determine some of the factors associated with this outcome.

Methods: A mixed methods study was carried out at MRRH in February 2017. We included all patients who had received chemotherapy between January 2013 and April 2017 with creatinine measures at baseline and at 12 weeks from treatment included socio-demographic, medical and drug history, along examination and serum creatinine measurement. Data analysis STATA 13.0.

Results: A total of 150 eligible patients were studied. Females the participants. The mean age was 46.6(+/- 17.63). In our patients had significant renal dysfunction at 12 weeks from receiving more than 3 cycles of antineoplastic chemotherapy the development of renal dysfunction Ad. OR 3.01, (95%CI normal body mass index was protective against renal dysfunction

0.03, 0.72) *p-value*=0.02.

Conclusion: The burden of renal dysfunction in cancer patients' antineoplastic chemotherapy is high and this risk increases 3 cycles of chemotherapy. We recommend measurement each cycle of chemotherapy.

Seeking cancer care: Patient's pathways and associated timelines among the commonest cancers at the Uganda Cancer Institute.

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Background: Whereas early detection and treatment of cancer yields good prognosis,

a delay in provision of these services increases the proportion of advanced disease in cancer patients with an impact on outcomes and quality of life.

Purpose: To study the patient pathway to obtaining cancer care at the Uganda Cancer Institute (UCI) and the associated timelines so as to determine points of delay in accessing diagnosis and treatment.

Methods: We conducted a retrospective chart review of adult patients admitted to UCI in 2017 with any of the 4 cancer diagnoses of interest - prostate, cervix, breast and oesophagus. Four key points in care were considered; First symptom, referral to UCI enrolment into UCI and initiation of treatment. Data was abstracted in relation to the patients' path to care. Time between the key points was calculated basing on the dates recorded in the files.

Results: We enrolled 1017 participants with these cancers; 42% cervix, 26% breast, 17% oesophagus and 13% prostate. Seventy three percent were females, 36.6% were aged between 40 -54 years and 59.3% presented with advanced cancer (stage III or IV). On average, after seeing a symptom it takes a patient one year to get referred to UCI; patients with cancer of oesophagus are referred earlier (6months), those with prostate cancer take up to 2 years. When referred patients take 4 weeks to come to UCI. At UCI files are opened on the same day and patients clerked within a week. Patients are reviewed by an oncologist within 3 to 4 weeks. Treatment is received within 2 weeks (Chemotherapy) to 11weeks (radiotherapy).

Conclusion: There is a significant delay before patients are referred to UCI. Both common people and health care providers in primary health units need education about early signs and symptoms of cancer. Timelines at UCI need to be streamlined to avoid secondary delays.



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