REPORT ON THE COMMEMORATION OF WORLD CANCER DAY

4TH FEB, 2016

THEME: WE CAN. I CAN

COMMEMORATED AT UGANDA CANCER INSTITUTE

Report by:

Uganda Cancer Society
1. ACKNOWLEDGEMENTS

Uganda Cancer Society (UCS) thanks government of Uganda through Ministry of Health (MoH) and Uganda Cancer Institute (UCI) for the partnership extended to stakeholders including Civil Society and the media during the commemoration of World Cancer Day (WCD) 2016. We would like to particularly thank UCI for hosting the commemoration of WCD 2016 at the institute's premises.

In a special way, UCS would like to thank the panelists (Ass. Commissioner Clinical Services MoH, Dr. Jackson Amone; the Managing Director UCI, Dr. Jackson Orem; the Head, Community Cancer Program UCI, Dr. Noleb Mugisha; and the CEO Uganda Non-Communicable Diseases Alliance (UNCDA), Ms. Grace Amongi) who made submissions and provided clarifications during the breakfast dialogue meeting on WCD 2016. Appreciation is also extended to the Program Director UCS, Mr. Paul Ebusu for moderating the said breakfast dialogue meeting on WCD 2016. It’s in the same way that UCS thanks each and every one who participated and made a contribution during this informative breakfast dialogue meeting.

We thank and appreciate all organizations who took an active part in the preparation and commemoration of WCD 2016 including; Uganda Cancer Institute (UCI), Uganda Child Cancer Foundation (UCCF), Uganda Women’s Cancer Support Organization (UWOCASO), Patient Relief Mission (PRM), Cancer Aid Organization (CAO), Uganda Non-Communicable Disease Alliance (UNCDA), Palliative Care Association of Uganda (PCAU), Kawempe Home Care (KHC), African Palliative Care Association (APCA), Bless a Child Foundation (BCF), Centre for Health and Information Network (CHAIN), Health Aid Uganda (HAU), Save A woman Initiative (SAWI), Cancer Charity Foundation (CCF), East African NCD Alliance (EANCDA), Uganda Cancer Fund (UCF), NACAS, and American Cancer Society (ACS). Indeed the turn up was remarkable which is both humbling and encouraging.

Similarly, gratitude goes out to the different media organizations for their active involvement and participation in covering the commemoration of WCD 2016 including; UBC TV and radio, Bukedde fm, BBS TV, NTV, Power fm, Star fm, Gulu fm, CBS fm, Urban TV, Channel 44 TV, Monitor publications, and New vision Uganda, among others. Your cooperation and active involvement to cover the commemoration of WCD 2016 amidst heavy political climate characterized by national election campaigns (which usually are the attraction of most of your viewers and listeners), goes to only show your deep commitment to the cancer fight which we sincerely recognize and appreciate.

We also thank members who spared their time and went to the cancer wards to share fruits with the patients. Great gratitude goes to Patient Relief Mission and African Palliative Care Association for sponsoring the fruits that were distributed to the patients. Your reach and care for patients makes a true difference in the fight against cancer.

Last but not least, appreciation goes to the UCS secretariat and UCI for actively mobilizing and coordinating the preparations and commemoration of WCD - 4th Feb, 2016.
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3. INTRODUCTION

Globally, World Cancer Day (WCD) is commemorated on 04th February of each year. This year, the global WCD theme is: “WE CAN. I CAN”. In marking WCD, the world unites to recognize the burden of cancer and appreciate efforts made and challenges faced in the fight against the epidemic through awareness raising.[1,2]

In recognizing and highlighting the burden of cancer, Uganda just like many countries is indeed affected. Cancer accounts for 5% (17,600) of the country’s total deaths (353,000) annually.[3] Based on the Kampala Cancer Registry (KCR), Uganda has one of the highest cervical cancer incidence rates in the world with an age standardize rate of 47.5 per 100,000 which is three times higher than the global average estimate of 15.8 per 100,000.[4] Prostate cancer which remains the most common among men with an annual incidence rate of 20.2% (2288 cases) with a mortality rate of 20.5% (2275 deaths) has a low survival rate among patients in Uganda.[5] On another note, there is a growing number of childhood cancer cases being received at the Uganda Cancer Institute (UCI) each year with about 700 (40%) of 1700 new cancer patients annually being children. [6]

However, some achievements on the fight against cancer in Uganda can be recounted. The launch and implementation of the national HPV vaccination program for adolescent girls aged 10-13 is key in reducing the high incidence and mortality from cervical cancer among women in Uganda. It also goes a long way in achieving World Cancer Declaration (WCD) target 4. The passing of WHO Framework Convention on Tobacco Control (FCTC) compliant Tobacco Control law 2015 was a major government commitment towards curbing down tobacco use as a major cancer risk factor and in the attainment of WCD target 3 in the country. Also the fact that Uganda Cancer Institute (UCI), which is the only national cancer referral unit, gained an autonomous status and became a centre for excellence in the East African region is a big milestone for cancer control in Uganda. The establishment of the Fred-Hutch Cancer Research Centre (FHCRC) facility at UCI will go a long way in improving cancer treatment and management in Uganda through research. The steady growth of a civil society movement for patient support, awareness raising and policy advocacy for a supportive legal environment for cancer prevention and control cannot go without mention.

Nonetheless, there still remains room for improvement. To start with, Uganda needs to pass a national cancer control law that will provide a supportive environment for prevention and control of cancer in the country. Similarly, national indicators for NCD’s and a national program for cancer control need to be adopted to guide national cancer programming. There is also a need to intensify both policy research and policy advocacy to get government to pass the much needed national cancer control law, establish a national program and indicators to measure both the burden and progress of cancer plans implemented. Also there is need to aggressively create capacity for healthcare workers in management of cancer as well as decentralization of services including screening. Awareness raising too needs to be intensified with nationwide coverage to
help dispel myths around cancer and provide lifesaving information on screening and early detection.

As such, in recognizing the above stated burden caused by cancer and in appreciating efforts made and challenges faced in the fight against cancer in Uganda through awareness raising, the Uganda cancer control community jointly led by UCI and Uganda Cancer Society (UCS) joined the rest of the world in commemorating WCD 2016. The Uganda cancer control community and other stakeholders converged at UCI to commemorate WCD on 4th Feb, 2016 under the stated global theme: “WE CAN. I CAN.”

This year’s theme - “We can. I can.” (which runs until 2018), explores how everyone as a collective or an individual can do their part to reduce the global burden of cancer. Just as cancer affects everyone in different ways, all people have the power to take action and make a difference to reduce the burden of cancer on individuals, families and the community. Thus, WCD is an opportunity for everyone to reflect on what they can do to pledge and take action against cancer.

Therefore, this report comes to highlight the events and activities of the Uganda cancer control community in commemoration of WCD- 4th February, 2016.

4. OBJECTIVE OF COMMEMORATING WCD

The objective of commemorating WCD – 4th February, 2016 was to bring Uganda’s stakeholders together in raising awareness about cancer by recognizing the burden of the disease, efforts made to control it as well as the challenges faced in the fight. This was intended to remind government, individuals and the community across the country to take more action against cancer and save thousands of preventable deaths each year.

5. ACTIVITIES FOR THE COMMEMORATION OF WCD

Agenda for WCD 2016

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Person in charge</th>
</tr>
</thead>
<tbody>
<tr>
<td>07:00 – 09:00am</td>
<td>Breakfast meeting</td>
<td>UCI &amp; UCS</td>
</tr>
<tr>
<td>09:30 – 11:00am</td>
<td>Banner signing / T-Shirt branding</td>
<td>UCCF / all</td>
</tr>
<tr>
<td>11:30 – 01:00pm</td>
<td>Visiting patients</td>
<td>ALL ORGANISATIONS</td>
</tr>
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5.1. Breakfast Dialogue

The intent of the breakfast dialogue meeting was to provide a platform for exchange of ideas and sharing of information among stakeholders across the board. Among others the government through MoH and UCI was represented, civil society under UCS umbrella, the media, as well as
patients and survivors etc were present. The breakfast dialogue meeting ran from 9:30am to about 11:30-12 o’clock. The agenda for the breakfast meeting program was laid out as follows;

**Agenda for WCD Breakfast meeting dialogue**

<table>
<thead>
<tr>
<th>Item</th>
<th>Responsible person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prayer</td>
<td>Moderator, PD UCS, Mr. Paul Ebusu / All</td>
</tr>
<tr>
<td>Introductions / welcome remarks</td>
<td>CEO UNCDA, Ms. Grace Amongi</td>
</tr>
<tr>
<td>Submission from civil society</td>
<td>CEO UNCDA, Ms. Grace Amongi</td>
</tr>
<tr>
<td>Submission from UCI</td>
<td>MD UCI, Dr. Jackson Orem / Head, Community Cancer Program UCI, Dr. NelobMugisha</td>
</tr>
<tr>
<td>Submission from MoH</td>
<td>Ass. Commissioner Clinical Services, Dr. Jackson Amone</td>
</tr>
<tr>
<td>Open discussion</td>
<td>Moderator / All participants</td>
</tr>
<tr>
<td>Close of dialogue</td>
<td>Moderator</td>
</tr>
</tbody>
</table>

5.1.1 Welcome Remarks

The breakfast dialogue meeting marked the beginning of the events in commemoration of the WCD 2016. Paul Ebusu, the Program Director, UCS opened the meeting with welcoming remarks at 8:00am.

The dialogue moderator Paul Ebusu thanked all members present for their participation in the commemoration of WCD 2016. He highlighted the day’s program and activities and welcoming everyone to take part during the dialogue so as to enhance information exchange and knowledge sharing and acquisition. He noted the importance of commemorating WCD while reechoing the day’s theme – We Can. I Can. He then invited the first panel speaker to submit on behalf of civil society, the CEO UNCDA, Grace Amongi.
Grace Amongi acknowledged that the theme: We Can. I Can is well fitting and befits the concerted efforts that civil society and other partners have put in place to address the cancer burden. She said that civil society in Uganda is concerned about the growing cancer scourge in the country noting that Low and Middle Income Countries (LMIC) have a bigger cancer burden for which Uganda is among.

Grace appreciated the efforts of government especially the MoH and UCI towards fighting cancer. She further recognized and applauded the support from the World Health Organization (WHO), United States Agency for International Development (USAID), Fred-Hutchington, World Diabetes Association, CISU Denmark and the department of Non-Communicable Diseases (NCD) at MoH among others.

Amongi further noted government’s efforts in reducing the cancer burden through the ongoing formulation of policies and guidelines, training and capacity building and the proposal to open cancer control regional referral centers in Mbarara, Gulu and Mbale.

But she noted that there is still a huge task ahead especially for LMICs given the fact that the WHO statistics in 2005 indicated that 58 million deaths due to NCDs occur in LMICs of which cancer accounts for 35 million deaths. This places an enormous burden on the health systems of developing countries like Uganda. She added that CSOs who are working around cancer control in Uganda still face challenges including limited resources for advocacy and awareness creation, poor coordination and NCDs are still not integrated into the Health Information Management Systems (HIMS). This means that there is no definite statistics/evidence to use for advocacy.

She therefore called upon international bodies, and government to increase cancer control budgets so as to support programs. Ms. Amongi suggested the establishment of a basket fund where CSOs can compete and get awarded funds to facilitate their cancer control efforts. Last
but not least, she noted the need to expedite the process of instituting policies, strategies and guidelines to streamline interventions directed towards cancer control.

5.1.3 Submission from MD UCI, Dr. Jackson Orem

Dr. Jacckson Orem began by recognizing the contribution of the media in cancer awareness.

“The media involvement started in 2005 and sparked a movement which led to the creation of CSOs. This has gained an unstoppable momentum”, said Dr. Orem. Dr. Orem also informed participants about UCI’s mandate including providing care to cancer patients, ensuring the care is in line with the needs, training and capacity building of the workforce, coordinating all efforts to have effective cancer control and aid MoH in policy formulation.

“The good news is that, government will soon form a basis upon which UCI operates-the UCI bill 2015”, said Dr. Orem. He revealed that the bill is now at committee stage and is optimistic that once Parliament resumes, this bill will go to the floor of Parliament for its second reading.

He added that the National Cancer policy is in the offing and once it is out, no one will operate outside its legal framework.Dr. Orem then added saying that UCI has started a comprehensive community cancer program with four objectives including awareness creation, screening, early detection and access to health services. At that point, he concluded by inviting the Head, Community Cancer Program UCI, Dr. Noleb Mugisha to elaborate more on the activities of the community cancer program and what they are doing currently.

5.1.4 Submission from Dr. Noleb Mugisha, Head, Community Cancer Program UCI

Dr. Noleb Mugisha said that in 2009, UCI started to create an avenue to increase cancer awareness in communities and carrying out screening clinics. He however said that emphasis will be put on cervical cancer which is the most common cancer among women, noting that in 2012, about 10,392 women died of cervical cancer. He said emphasis will also be directed towards prostate cancer because it is the most common among the men.
Dr. Mugisha urged CSOs to increase awareness and encourage children between the ages of 9-13 years to get the Human Papillomavirus (HPV) vaccine against cervical cancer. He added that those who missed out on vaccination should do regular screening for early detection and treatment. Dr. Mugisha further encouraged women to regularly do self-examination of their breasts as a way of early detection and treatment of breast cancer. He noted that the biggest challenge in cancer control is late detection. He therefore called for collective participation in awareness creation saying that statistics on cancer patients should be reversed by the next WCD.

"With effect from 4th February 2016, UCI will carry out daily screening of all types of cancer and there will be no fee charged" - Dr. Mugisha.

5.1.5 Submission from Dr. Jackson Amone, Assistant Commissioner Clinical Services MoH
Dr. Jackson Amone conveyed apologies from Dr. Jacinto Amandua, the Commissioner Clinical services at MoH who was the expected representative from MoH for not making it to the meeting – Dr. Jacinto was away on leave. He then went ahead to applaud UCI for all the good work they have done and specially recognized Dr. Jackson Orem’s efforts in cancer control. Dr. Amone further appreciated donors for committing their resources into establishing UCI and their various efforts in cancer control.

He also recognized the efforts of CSOs saying that they are always highlighting the cancer agenda and reminding government of its role. He noted that cancer survivors are living examples of the continued efforts in cancer control. Dr. Amone said that unlike many years ago where the environment was not conducive for cancer control, things are now different and progressing because government is committed to reducing the cancer burden.

Dr. Amone enumerated some of the interventions that government has instituted to reduce the cancer burden including introduction of the HPV vaccine which is available in all hospitals and health centre 4s. The government has further developed policies to control NCDs and mobilized resources. In regard to future plans, in a bid to reach the bigger population, Dr. Amone reiterated that cancer centres will be opened in Gulu, Mbale, and Mbarara.

“It is also planned that there will be an improvement in the provision of mobile cancer services through UCI while increasing funding with the main objective of making the institute a reference point for the whole of East Africa.” - Dr. Jackson Amone

Government further plans to improve on palliative care services and reduce on the suffering that cancer patients go through. This will be done through training and recruitment of more staff specialized in palliative care.

Dr. Amone however said that despite all the efforts, government faces numerous challenges including limited resources which he blamed on the country’s poor economy and this leads to referral of patients outside Uganda. The other challenge is low awareness levels amongst the rural population and yet the cancer burden is increasing among the rural communities.

Dr. Jackson Amone concluded his submission informing the audience that cancer can be prevented and is curable. He therefore appealed to the population to embrace routine screening to avoid cases of late detection. He also urged people to live healthy by avoiding harmful practices like smoking, excessive drinking of alcohol and most importantly, eat healthy.

5.1.6 Open Discussion with Q&A

During the open discussion session which was moderated by UCS PD Mr. Paul Ebusu, participants directed their questions to the panelists while others made comments and or submissions. The following questions and concerns were raised during the first round;

- Role of government in regulating traditional herbalists
- Government’s plan to open training centers for cancer care
- Does government have a plan to scale up screening of the cancer of the esophagus
- Concern over health workers taking advantage of the ignorance of the patients

**Responses from the panelists to round one of the questions**

**Dr. Noleb Mugisha**

He clarified that any part of the body is prone to becoming cancerous; emphasis should however be put on routine screening. But he said that there is need to put better strategies for dealing with the cancer of the esophagus. He noted the need to form networks for various types of cancers so as to maximize the available interventions. He informed the meeting that UCI has improved on the mobile screening van adding that there is now a monthly clinic in Arua and Mayuge while Mbarara Referral hospital holds regular cancer clinics. On the issue of health workers taking advantage of patients, he blamed this on the rising number of quack doctors who do not know and disregard ethics of the medical profession but are only out to make profits. He called upon CSOs to increase awareness on cancer and inform the public about where the services can be accessed. Dr. Mugisha asked the CSOs to work with UCS to produce materials and strategies to scale up their awareness campaigns.

**Dr. Jackson Orem**

In regard to training centers, Dr. Orem revealed that East African Countries are working together with the African Development Bank to put up the East African Oncology centre of excellence and tertiary education. Kenya is expected to have an institution specializing in Kidney medicine, Tanzania will have one in heart medicine, Rwanda will specialize in Biomedical engineering, Burundi specializes in nutrition while Uganda will train experts in the region in all aspects of cancer medicine.
Dr. Orem added that the ADB has already set aside USD 45M for physical infrastructure, equipment and training for everyone involved in cancer control. The first phase of this project will be done for five years and the continuity of the project is dependent on the progress of the first phase.

Dr. Orem further told the meeting that UCI is working in partnership with the International Atomic Energy Agency to use Information Communication Technology (ICT) training for lower level health care workers in cancer control. He said that in Uganda, the facility is available and UCI is working with Makerere University and the University’s department of ICT is housing a platform for training the course online.

Dr. Jackson Amone, Commissioner Clinical Services - MoH

He said that until recently, medical personnel were reluctant to get specialized training in cancer related courses. Dr. Amone said that now the MoH intends to work with universities and find ready placements for those who specialize in palliative care and also encourage nurses to receive specialized training in palliative care.

In regard to regulation of traditional herbalists, he said the MoH has engaged the medical council to regulate such operations. He said the other challenge is attitude which the communities have towards herbalists saying people believe in tradition. Dr. Amone urged CSOs to scale up attitude change towards traditional herbalists.

The following were asked during the second round of the Q&A session
• What cancer treatment is free?
• How is palliative care being integrated into government interventions?
• How can risk communication be mitigated?
• How to deal with cases where one is misled that some cancers cannot be screened?
• What is the plan to increase resources/funds for CSOs?
• Why are CSOs not included in national programs?
• At what level can CSOs engage government in policy formulation and implementation?
• What is the time frame for establishment of regional cancer centers?

Responses

Dr. NolebMugisha-UCI

He allayed fears that there are some cancers that cannot be screened and detected. He said that screening does not give conclusive results but if the need arises, a person is referred to a diagnostic centre for further investigations after screening.

Grace Amongi-UNCDA

She urged CSOs to know their schedules to avoid duplication and maximize the impact of cancer control. Grace also strongly urged CSOs to take advantage of the Parliamentary Forum on NCDs whenever they are fronting their policy and legislative agendas.
Dr. Jackson Orem- MD UCI

He clarified that UCI offers free treatment and medication to all cancer patients. Dr. Orem said that some patients prefer private services and those are available. But he stressed that the treatment is the same. “Cancer treatment is common protocol, treatment in Uganda is the same as that received from outside Uganda”, said Dr. Orem. He however said that the problem is that not all personnel are the same with some soliciting for money. He said that this is caused by the very lengthy procurement process and difficulties in accessing treatment. UCI however reprimands personnel found soliciting money although the patients are normally fearful to report such cases.

In a bid to improve and integrate palliative care in cancer control, UCI plans to introduce a fellowship program, according to Dr. Orem. He said that this will be done in partnership with HOSPICE, African Palliative Care Association among others.

Dr. Orem informed members that establishment of new cancer centers depends on the availability of funds. But government has already identified funds for Gulu and Mbarara centers and these are expected to be operational within the next two years because this is within the current five year strategic plan of MoH.

He said that CSOs involvement in policy formulation is at the level of coordination of services. He assured the meeting that implementation of the Cancer Bill will not be a problem because the implementation body-UCI is already in place.

Closing remarks

The moderator Mr. Paul Ebusu closed the meeting at 11:00am. He expressed appreciation to all the participants for their active participation and invited them to participate in the signing of WCD banners, T-shirt painting dubbed “Moment of Madness and Fun” and thereafter, patient visit to deliver fruits to patients in their wards.

5.2 Signing of Banners

Following on the breakfast dialogue was signing of the WCD banners. This concept involved writing of personal motivational and awareness messages on cancer. This was done outside UCI-Fred Hutch where the breakfast meeting place from.

*From left to right; Rebecca Kiziri Mayeng, Chairperson UWOCASO and Ben Ikara the Transitional Director UCS / Tam Leader UCCF signing on the banner with the messages about cancer*
5.3 T-shirt Branding / painting dubbed - “Moment of Madness and Fun”

This was a fun moment in which participants explored the beauty of seeing their white t-shirts filled with different colors and words of their choice. All the words were on cancer awareness in line with the theme: “We Can. I Can”. Participants moved around the UCI campus and wards sharing fruits with the patients and sending out a loud message on the solidarity against cancer. This act creating too much attention and appreciation for the work being done on cancer control in the country.

5.4 Patient Visit and Fruit Distribution

The concept of patient visit and fruit sharing with patients had two significant component; the first was the expression of solidarity through care and support for those battling with cancer –
the patients, and the second was an illustration of healthy eating through the fruits. This was the most sensitive yet very important part of the day. Members were brought face to face with the reality of cancer through the patients but this also provided them with an avenue to show love and care to the patients. Members were sub divided into groups so as to cover all the wards. Many types of fruits were given to the patients including, mangoes, bananas, pineapples, avocado, watermelon, pawpaw among others.

6. CONCLUSION

By and large, given the short time in preparation, the objective of activities commemorating WCD 2016 was achieved with activities being considered largely successful. Members finished the day feeling re-energized in cancer control with knowledge and the attitude that they can contribute to reduction of the cancer burden in Uganda with that “We Can. I Can” spirit. The breakfast dialogue left participants with very rich information in cancer control. Participants not only had fun in painting/spoiling t-shirts, signing of the banners and photo moments, but they also identified with this noble cause and reinforced their commitment in cancer control. By visiting the cancer patients and giving them fruits, the participants reminded the patients that they were not alone reinforcing their hope and courage to carry on with the fight for survival.

Important to note is the solidarity with which partner organisations worked together both in the preparations and commemoration of WCD 2016. The sense of working together truly showed that together we can harness greater results in cancer control in Uganda. It demonstrated that civil society organisations are useful partners in the fight against cancer and have a great role to play. It also specifically demonstrated how central the role of UCS is in coordinating civil society efforts for systematic engagements. It goes without much emphasis that this day was a success.
References


