



3/16/2021

COMMEMORATION OF INTERNATIONAL WOMEN'S DAY 2021:

**COMMUNITY DIALOGUE ON
CANCER AND COVID 19
PREVENTION AND MANAGEMENT
AT CHAIN OFFICES IN KIWENDA**



COMMUNITY HEALTH AND INFORMATION NETWORK (CHAIN)

Contents

INTRODUCTION	2
REMARKS	2
ABOUT CHAIN	3
CANCER AWARENESS, PREVENTION AND TREATMENT	3
Ms. NAKIGUDDE’S STORY- DIAGNOSED WITH BREAST CANCER	4
CANCER AND ITS CAUSES	5
SIGNS OF CANCER	6
Cervical cancer :.....	6
Breast Cancer :.....	7
TREATMENT AND PREVENTION OF CANCER	7
SHARING OF STORIES	8
CANCER AND STIGMA	10
RECOMMENDATIONS FOR CANCER	11
COVID 19 PREVENTION AND MANGEMENT	11
CHALLENGES FACED BY VHTS DURING COVID 19 PANDEMIC	13
EFFECTS OF COVID 19 ON COMMUNITY ENGAGMENTS AND WORK CONTINUITY	14
Virtual meetings	14
Social media meetings	14
Telephone calls/meetings	14
OPPORTUNITIES - COVID 19	14
CONCLUSION	15
PICTORIAL	15

INTRODUCTION

In commemoration of the international women's day 2021 whose theme was *Women in leadership: Achieving an equal future in a COVID-19 world*. Community Health And Information Network (CHAIN) in partnership with Uganda Women's Cancer Support Organization (UWOCASO) and World Patient Alliance (WPA) organized a community dialogue on cancer and COVID 19 prevention and management. The dialogue was attended by carefully and purposively selected participants who included representatives of Village Health Teams (VHTs), teachers from primary schools within Busukuma sub county and Orphans and vulnerable children guardians. The community dialogue was organized in accordance with the Ministry of Health COVID 19 guidelines with 21 participants (18 women and 3 men) and emphasis on social distancing, hand washing, sanitization and wearing of masks.

REMARKS



The Executive director of CHAIN Ms. Mariam Regina Namata Kamoga welcomed the participants and noted that the international women's day is a global day to celebrate the social, economic, cultural and political achievements of women. It is a day to celebrate all women and girls across the globe with their incredible roles, it is therefore important to ensure that they are offered opportunities, a conducive environment, effective policies, tools and skills to empower them to stand up to the challenges they face and make informed decisions.

The appointment of the new Director General, Dr. Ngozi Okonjo- Iweala of World Trade Organization, the first woman and the first African woman to lead the organization, is a testimony that women continue to rise in top leadership positions and gives hope to others that they too can get there.

Ms. Kamoga acknowledged the difficult times women have gone through as a result of COVID 19 including loss of jobs, domestic violence among others. She urged participants to continue advocating for women's rights. She called on relevant key stakeholders to offer women the necessary support including; building their capacity in human rights, access to justice, education, social protection and inclusiveness. "The women need to have a voice and be heard", she said.

The need for health literacy among women is also critical mainly because they are the care takers of the sick and the responsibility of caregiving falls heavily on them. Thus the focus on cancer and covid-19 prevention and management.

ABOUT CHAIN

The program manager of CHAIN Ms. Gladys Nalukenge introduced CHAIN and its program which include empowering communities affected by both communicable and non-communicable diseases through information sharing to promote prevention and treatment of disease; Promotion of health literacy and patient safety where families, patients and communities, are educated on their rights and responsibilities as health system users, they are also urged to seek early diagnosis and treatment; Support for Orphans and vulnerable children through provision of educational and health care support; Access to safe water through the promotion of the Solvatten technology (a solar water purifier) to get rid of water borne diseases and to conserve the environment; promotion of permaculture using organic seeds, pesticides and fertilizers to promote household organic vegetable growing and boost nutrition, health and household incomes for the community.

CANCER AWARENESS, PREVENTION AND TREATMENT

The session was facilitated by Ms. Gertrude Nakigudde the Chief Executive Officer of UWOCASO and a board Member of Uganda Cancer Institute(UCI). She introduced UWOCASO as an organization that started 15 years ago by 5 women survivors of breast and cervical cancers. UWOCASO focuses on educating and creating awareness on cancer with emphasis on breast and cervical cancers; offering counseling to cancer patients and survivors; empowering cancer survivors

with skills in income generation and positive living; working with government to ensure availability and access to cancer treatment. UWOCASO is a membership organization with current membership of 200 cancer survivors with two branches in Kampala, and Gulu with future plans of establishing regional offices in Mbale and Mbarara. This is intended to ease access to services for cancer patients and survivors across the country.

Ms. NAKIGUDDE'S STORY- DIAGNOSED WITH BREAST CANCER



Ms. Nakigudde was diagnosed with breast cancer in 2002 as a young woman fresh from the University and had just started working.

“I had a painless lump in my breast for some time, one day I disclosed to my employer who told me to immediately go for checkup. I didn’t share this with any of my family members so when I went for checkup, I wasn’t given any counseling. Even when the results came out and they were positive the health worker blatantly broke the news to me and told me they were going to cut off my breast. I was devastated! I feared to tell my family because I knew they would object since I was not married and didn’t have any children. However, I made up my mind and saved the funds that were needed for the operation. On the day of the surgery everyone was scaring me including the health workers. I remember the gentleman who wheeled me to the theater asked me, “Are you the one going for surgery?” when I

responded yes, he asked me if I would return alive from the theatre. By the time I reached the theater I was wailing...”

Ms. Nakigudde ‘s experience brings to light many issues pointing to lack of patient centered care .The need to counsel patients and give them adequate information about their condition to cope and make informed decisions is critical. She informed participants that she is happy that the Uganda Cancer Institute has opened up a desk for patient navigation to help first time patients, answer their questions and support them through the process of receiving care. She noted that this is among the achievements of their advocacy.

CANCER AND ITS CAUSES



Through a participatory approach Ms. Nakigudde asked participants what they knew about cancer, this elicited several responses with most of the respondents relating it to a wound that doesn’t cure and a dangerous disease.



One participant, a VHT from Busukuma sub county said that, *“I have always known cancer to be a dangerous disease that doesn’t cure but now that I have seen you a survivor, I have learnt that cancer can be cured”*.

Ms. Nakigudde explained to the participants that cancer doesn’t start as a wound but only progresses if not diagnosed early and treated. The most common cancers in Uganda are breast, cervical and prostate cancers with 6000 new cases of cervical cancer reported in 2018 and half of these dying due to the same. Participants were asked if any of them had been screened for cancer of the cervix and none of them had.

Some of the causes of cancer listed were; obesity, personal and family history, some drugs that are used to treat different diseases; environmental pollution such as industrial fumes, cars etc; sexual intercourse with multiple partners and starting sex at an early age, poor life styles such as eating processed foods, drinking of alcohol and use of tobacco and other drugs, and not doing regular exercises. People with compromised immunity for example people living with HIV are at a higher risk.

SIGNS OF CANCER

The signs of cervical and breast cancer were highlighted and include;

Cervical cancer:

Pain during sexual intercourse, unusual(smelly) discharge and vaginal bleeding during sex, abdominal pains and having repetitive menstrual periods. The need for early screening before signs was emphasized. Cervical cancer can easily be treated if diagnosed early. Government of Uganda has adopted vaccination for young girls with the HPV vaccine to protect them from getting cancer of the cervix and the service is free of charge at government health facilities.

Breast Cancer:

The signs of breast cancer mentioned were having painless lumps in the breast, secretion of blood, water or milk from the breast when the woman is not pregnant or breastfeeding, having perforated skin patches on the areas near the breasts. Breast cancer affects both women and men hence it is important to get familiar with one's body, always ensure Breast-Self-Examinations (BSE) are done regularly.

TREATMENT AND PREVENTION OF CANCER

Participants were asked to share on how cancer was treated within their communities. They agreed that since people do not have adequate information about cancer most people use herbal medicines from traditional practitioners, vendors and herbalists while others resort to prayers. Ms. Nakigudde cautioned participants against opting for herbal medicines that have not been validated by the authorities.

She outlined the different types of treatment for cancer which included; Surgery, Chemotherapy, radiotherapy and hormonotherapy. Most treatments take 6 weeks depending on the stage the patient is. However, most treatments have side effects such as extreme fatigue, change in the physical outlook such as loss of hair, weight and color. It is also important that the treatment is completed and the patient needs to follow the instructions of the health workers. Support from care takers and family members is also key.

There are many misconceptions about cancer in the community so participants were urged to acquire and share information with their communities. She emphasized a change in lifestyles to prevent cancer.

SHARING OF STORIES



Participants were thankful that they were selected to take part in this dialogue. Many of them indicated that they had questions and misconceptions about cancer and have mishandled cancer cases in their families and community.

I am so grateful for this session and I thank CHAIN for organizing such an engagement and educating us about cancer. To be honest this teaching was meant for me, my own sister was diagnosed with cancer recently after she had suffered from and been treated for COVID 19. It has been a very trying moment because they required her to do several tests and we were wondering why they were doing all these tests. I started to complain because we don't have any history of cancer in our family

so I didn't believe that cancer diagnosis. **(Female Head teacher Busso muslim primary school, Busukuma sub county)**

"I am happy that the person teaching us has gone through this and many of us have never had an opportunity to see a cancer survivor. We have cases of cancer in our communities but people don't have this information we are getting here today, so they don't know how to help. Recently we lost a community member to cancer" **(Female VHT Busukuma)**



Another participant shared a story about his sister who declined to go the health facility and opted for traditional practitioners.

His sister who already had HIV was diagnosed with cancer of the breast. She did not believe the diagnosis and said it was witchcraft. She stopped going for treatment and destroyed all her medical documents. Family members took her to a traditional practitioner who cut her and put medicine in her armpit where the lump was, she became worse with water oozing out from the nipple and the wound. The arm is swollen and she is in terrible pain but she still declines to go to a health facility. After acquiring knowledge on cancer the participant realized how he urgently needed to intervene and save his sister.

QUESTION AND ANSWER SESSION



Some of the questions raised include;

- Understanding the relationship between HIV and cancer
- Why there is a lot of stigma related to cancer yet it's not a communicable disease,
- How do you deal with effects of cancer treatments like chemotherapy?

- How long did it take you for your hair to come back after chemotherapy because I now see you have a lot of hair?
- Can cancer be transmitted through contact for example if I touch the clothes of a patient which are soiled, can i get cancer?

CANCER AND STIGMA

Stigma and particularly self-stigma is very common among people with cancer mainly because of the perceptions of the community. Most cancer patients and survivors don't want people to know that they have suffered from cancer for fear of losing jobs, failure to get married or their children being rejected for marriage. Other people know cancer as a wound that doesn't cure so they imagine that people with cancer keep touching an open wound. Ms. Nakigudde recalled where a man in a community she had gone to create awareness about cancer asked her if she is not cold as a woman because of having one breast. She noted that up to 50% of the husbands to their members had abandoned their wives after their breast was cut off. She called for research into cancer and stigma.

Participants shared stories and experiences of cancer related stigma that they have witnessed.



“I have an elder sister and the two of us have been very close since childhood. When I learnt that she has cancer I started avoiding to share a bed, bathroom and toilet with her. I have been fearing that she will infect me with cancer...” (Female participant, Busukuma sub county)

We were fundraising for our organization and one of the survivors who is highly placed refused to contribute to our cause because she doesn't want to be associated with us (Ms. Nakigudde)

Most people look at cancer as a death sentence to the extent that most parents even stop educating their children when they are diagnosed with cancer. Loss of self

esteem is also very common among breast cancer survivors and increases self stigma, coming to terms with living with one breast is not easy and not being sure of what to use (for lack of artificial breasts), Some women use cotton wool or socks to replace the lost breast which affects their self-esteem. Ms. Nakigudde informed participants that there are artificial breasts that women can buy and use though they are not easily accessible in Uganda and are very expensive .One artificial breast goes for about \$200. UWOCASO has received support from a well wisher Ms Edith Cooper from Brisbane, Australia who donates artificial breasts and special bras to the organization. The need though is still high as they receive about 1,000 requests of artificial breasts a year. She urged participants to connect people to their organization and others doing similar work for support and counseling to be able cope with and after cancer.

In her concluding remarks, she called upon participants and partners to create awareness and support cancer patients in their communities because COVID-19 pandemic increased their psycho-social needs yet there are not many organizations to reach all of the patients across the country.

RECOMMENDATIONS

Recommendations were made to improve the management of cancer;

- There is need to create awareness and demystify the misinformation about cancer and also address the issue of stigma
- Need for regular community engagement cancer activities.
- There is need for the government of Uganda to have a cancer control plan
- There is need for health workers to be skilled to be able to offer adequate support to cancer patients.

COVID 19 PREVENTION AND MANGEMENT

A session on COVID 19 prevention and management was conducted. Participants were taken through facts about COVID 19 including the common symptoms, risk factors, prevention and treatment. The risk factors discussed include; being older than 60 years, being overweight, unfit and having multiple health conditions such as hypertension, diabetes, chronic kidney, heart and lung disease, cancer, HIV and TB.

The symptoms of COVID 19 include; Fever, new continuous cough, shortness of breath, tiredness, loss of taste/smell, muscle aches, congestion or runny nose, headaches, sore throat, Nausea or vomiting and diarrhea.

Participants were advised that if anyone is diagnosed with COVID; they shouldn't go to work or out of home for 14 days, shouldn't use or go to public places, avoid visits and gatherings, should stay calm and keep in touch with loved ones through phone calls.



Hand hygiene was emphasized and participants took turns to demonstrate proper hand washing. It was however noted that the community still needs to be sensitized on hand washing because people have relaxed on the Ministry of Health guidelines

with only a few still wearing masks and washing hands. They were guided on where to refer patients if suspected to have covid 19.

They noted that the proper steps for hand washing are not followed by the community because it's considered a waste of time and many people still don't believe that COVID is real

Participants were asked to share what they have learnt with members of the community and continue to observe the Stand Operating Procedures for Covid 19 as they are the community role models.

Participants share on how they have reached out to community members as highlighted below;

- Before COVID 19, CHAIN had done massive community sensitization on handwashing and supported households and schools to construct tippy taps

as hand washing facilities and these were the ones families and schools are using for hand washing.

- Partnering with the local authorities in their communities has helped them to reach out to the members of the community.
- Home visits; in some communities' families would gather on Sunday to pray so VHTs would do the home visits to talk about COVID prevention to people who had come for prayers.
- Using megaphones distributed by government to sensitize people in trading centers on wearing masks and washing hands and social distancing.
- Schools head teachers are leading the enforcement of SOPs as it was a requirement for opening of schools. They have put covid 19 signs on the school compound and ensure that children are not allowed in school without a mask as well as teachers and support staff.

CHALLENGES FACED BY VHTS DURING COVID 19 PANDEMIC

The VHTs pointed out the challenges they have faced in doing their work during the pandemic;

Some people in the communities still don't believe that COVID exists, they have become reluctant and no longer observe the Ministry of health guidelines, even in the hospitals the SOPs are no longer being followed as they were before. They noted that many people in their communities think that COVID was just a political move to silence the opponents of the government and now that the election is over, COVID has ended.

“People only realize that COVID is there when they lose someone in the family. My family only accepted the existence of COVID when we lost 4 family members in one month” (A female teacher, Nabitalo primary school Busukuma sub county)

“I stay near a market and I put a hand washing facility but it's not used. They do not also wear masks; they laugh and mock you if you put it on. There is need for continuous awareness on COVID” (Female VHT, Busukuma)

“During the lockdown we distributed maize flour and beans on behalf of government which was not enough to reach everyone ,so people accused us of refusing to give them food yet we now give them masks so they refuse to wear them and they tell us that they don't eat masks” (Male VHT, Buskuma sub county)

Because of the fear of COVID 19, VHTS said they had been chased away by some households when they went to sensitize them about it.

EFFECTS OF COVID 19 ON COMMUNITY ENGAGEMENTS AND WORK CONTINUITY

COVID 19 affected work in different ways, however to ensure continuity, there had to be a shift from the normal way of working. The different means of work included;

Virtual meetings

Several people had to adopt virtual meetings as the new way of working. This however was affected by unstable internet connections, high cost of internet, differences in time zones especially for international meetings and unstable power supply.

Social media meetings

Engagements that involved many people organizations and groups used social media platforms like face book and WhatsApp chats. These too were affected by unstable internet and affordability.

Telephone calls/meetings

Conference calls were organized where several people were connected at the same time and be able to make their contribution. These didn't require internet connection however, there were challenges with network for participants in areas with poor network coverage, no electricity to charge phones and balancing between family responsibilities and taking part in the telephone interviews.

“One time we had to conduct interviews with mothers in the community and health workers on the effects of COVID 19 on child health, we couldn't move to the communities so we conducted the in-depth interviews and focus group discussions on phone.” (Research assistant Uganda)

OPPORTUNITIES BROUGHT ABOUT BY MY COVID 19

The virtual meetings and workshops widened the scope for networking to some people.

“Through these virtual meetings, I have been able to meet different people across the world that I would probably would never have met” (Ms. Gertrude Nakigudde, CEO UWOCASO)

People have adapted to the new way of doing things which has proved effective. Before COVID 19 working from home was not common as today. It has turned out to be effective and efficient.

CONCLUSION

The community dialogue revealed the need for more regular sensitization on cancer and covid 19 and particularly the focus on community owned resources such as the VHTs, local leaders, teachers, and traditional, religious leaders as they are the first point of contact for communities.

Strengthening community systems cannot be over emphasized. All key stakeholders are needed to support in their different ways and level.

PICTORIAL





