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## Information needs, access and coping strategies for cervical cancer clients at Mulago Uganda Cancer Institute.

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**Background and Purpose:** The advent of effective infection control and treatment measures has shifted the burden of disease from mainly infectious causes to chronic, non-communicable diseases. Diseases like diabetes and cancer are on the rise globally, mostly in low income world due to low levels of awareness among other factors. In recent past, information and communications technology are increasingly being considered important in helping people more aware of cancer. This study identified information needs priorities about cervical cancer (CaCx) and coping information access strategies for CaCx clients and the general public and develop an interactive information portal to help increase disease awareness.

**Methods:** Focus groups, key informant and in-depth interviews were audio-recorded, transcribed and analyzed using Atlas.ti to generate information themes.

**Results:** Cancer clients demonstrated need for extensive information concerning cancer, treatment, and prognosis. Causes and risk factors for CaCx, and where to access CaCx services were the most important information themes to the general public. Study revealed that at the gynae-clinic, information is being shared by word of mouth and this does not facilitate adequate information sharing.

**Conclusion:** These findings can be used by Oncology professionals to better address the information needs of CaCx clients and those of the general public in an effort to fill knowledge gaps in the fight against CaCx. Information needs vary between CaCx clients and those of the general public yet between CaCx clients and health professionals, they were comparable.

**Keywords:** Cervical cancer, information access, information needs, cancer awareness

### 1 Introduction

The advent of effective infection control and treatment measures has shifted the burden of disease from infectious causes to chronic; non-communicable diseases (NCDs) [1]. Diseases such as cardiovascular and cancer are on the rise globally with a rapidly growing crisis in low-income and middle-income countries (LMICs) [2][3]. In 2015 for example, cancer was responsible for 8.8 million deaths globally and approximately 70% of these deaths occurred in LMICs [4]. With lung, female breast, stomach and colorectal cancers combined with liver and cervical cancer (CaCx) explaining over half the incidence burden (54%) in LMICs [1][5].

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For CaCx, the pattern is striking since around 85% of women diagnosed and 87% of those who die from the disease live in LMICs [1]. The rise can be attributed to limited access to effective screening services hence late disease identification [4][6] or due to low levels of awareness [7][8] among other factors.

In Africa, CaCx is high in the sub-Saharan region with Uganda being ranked 10th on the continent with 44.4/100,000 women; Age-standardized incidence rate of CaCx cases [9]. Among the contributing factors for the high incidence of the disease in the country include; lack of screening tests and vaccines to prevent HPV [6][10], limited access to cervical screening programs [10] as well as lack of information [7] among others.

Until the 1980s, information about disease, treatment, and prognosis was assumed to increase patient emotional distress, physical complaints, and treatment refusal. Yet, these assumptions were not supported by evidence [11].

Literature on information-sharing in cancer clients revealed that clients indeed have unmet information needs especially those with advanced disease [12]. This study therefore investigated the information needs priorities about CaCx and coping information access strategies for CaCx clients and the general public.

## 2 Material and methods

The study was conducted at Uganda Cancer Institute (UCI) gynae-clinic and participants were women with CaCx (CaCx clients), women without CaCx (general public) and healthcare professionals in active care for CaCx (gynae oncologists, nurses, & clinical officers). All participants were first informed of the study and those willing to take part, were recruited between April and May, 2018.

For eligibility, participants had to be adults of above 18 years, able to speak the local language (Luganda) or English or both, confirmed evidence of CaCx or CaCx negative. Clients who were attending the clinic for the first time, and unaware of their diagnoses were excluded.

While recruiting CaCx clients, a list was generated and participants randomly selected. For healthcare professionals and women without CaCx, convenient sampling and simple random sampling were used.

Interviews were audio recorded and hand-written notes were done throughout the interview session. Data collection took place between 2nd week - 4th week of May 2018.

Focus Group Discussions (FGDs) comprised of participants with and without CaCx to explore what kind of information participants needed to know, how and when to access it. Key informant interviews (KIIs) comprised of nurses (n=2) clinical officers (n=2) and gynae-oncologists (n=2). The investigator explored what information health providers share with CaCx clients, and the general public. In-depth individual interviews (IDIs) comprised of women without CaCx (n=4) focusing on what kind of information they would prefer to know about CaCx, and how to access it. Interviews were transcribed then verbatim transcriptions were generated. Analysis of data was done using Atlas.ti version7 taking an exploratory approach (inductive content analysis) [13], and findings presented as themes.

Research and Ethics Committees of Makerere University, and Uganda Cancer Institute (UCI-REC) approved this study, and participants consented to take part. Each participant consented before taking part in the study.

## 3 Results

In total, two FGDs of 7-10 participants respectively were conducted. In addition, six KIIs (2 gynae-oncologists, 2 clinical officers and 2 nurses), and four IDIs with women without CaCx were conducted. Information needs of CaCx clients from both FGDs were generally comparable. All participants considered providing health information an important aspect of CaCx care not only to CaCx clients but also to their families and to care givers. It was evident that clients desire more extensive information concerning the disease, treatment, and prognosis and this needed to be prioritized.

However, the study also recognizes that clients vary in how much information they want and that this may change during their CaCx journey. Important information themes that emerged are highlighted in ***bold italics*** backed up by respective quotes in italics from interviews.

### 3.1 Information needs for CaCx clients.

#### ***CaCx Symptoms***

CaCx clients expressed a strong need for information especially on the early symptoms of the disease. They noted that if such information was known to them and to the general public, there is/was a high likelihood for them to seek medical attention when the disease has not reached advanced stages. From an FGD conducted in English;

*Information to do with warning signs and symptoms; if health professionals had told us about them, it could have been helpful. We wish health providers sensitize us about CaCx because some of us and many people in villages don't know what the cervix is and we are always in dark [English FGD].*

#### ***Screening***

Participants needed to be armed with screening information in regard to where to find this service, how it is done and who to seek for it and when. By availing this information, will do away with fear associated with screening service and reduce knowledge gap hence increase its uptake. Also, it will help in early diagnosis; a point when medical intervention can still make a long-term difference.

*Also, women are worried of CaCx screening process because they are scared of exposing themselves during the screening exercise. Therefore, screening process needs to be elaborated to women and again women be sensitized about it in order to help in early diagnosis. Some of our diagnoses were confirmed when we had started experiencing vaginal bleeding, others during screening experienced strange signs of CaCx disease while others had dizziness [Luganda FGD-after translation to English].*

#### ***Dos and Don'ts***

Participants expressed great worry of not knowing what to avoid and what they should capitalize on in order to improve their health. Information concerning health-lifestyle which contributes to improved health was among what needed to be shared to CaCx clients as supported hereunder.

*Now that we have the disease, we need to know what we should do and what we should avoid (Dos and Don'ts). This will make us further improve on our life without not necessarily visiting health care givers frequently [English FGD].*

#### ***Treatment Side Effects***

CaCx clients want to know information concerning the side effects of the different kinds of treatment lines they receive along their care journey. They noted that along treatment, both short and long-term side effects occur; something they need to be cognizant of since some effects turn out to lead to a deteriorating health.

### 3.2 Information needs for women without CaCx (from in-depth interviews)

#### ***CaCx and its Causes***

Many people seem not aware of this silent killer as it emerged that basic information relating to CaCx such as what it is, where it affects, who is at risk and the risk factors among others were not obviously known to them and needed to be shared to the public.

### 3.3 Information shared by health professionals (from key informant interviews)

From the perspective of health professionals, information being shared to people differs by their status as presented in table 3.1 below.

Information theme	Justification
To newly diagnosed with CaCx	
Informed about CaCx staging, in line with the treatment and side effects	There are many approaches. i.e one of surgery, chemo. All these have different side effects.
CaCx clients who have been on treatment for fairly a long time (Expert clients)	
Possible long-term side effects	These vary along treatment journey; some manifest early while others late.
The relevance of regular screening and symptoms of cancer	To identify the disease while still at young stage for treatment to have positive impact.
CaCx Survivors	
The relevance of Screening	There is a likelihood of having another cancer once you had one before.
To those simply worried of CaCx	
They are informed of what CaCx is, its causes, how it can be prevented, detected and later treated	A lot of information is shared to these people because they happen to have time to listen.
To the rest of the people out there	
It is general information like that shared to those worried of CaCx.	

**Table 1.** information being shared by healthcare professionals

### 3.4 Coping information access strategies

It evidently came out that health professionals share a broad range of information to kinds of people. The commonest mode of information sharing is by the word of mouth (face-face) and this does not facilitate adequate information sharing since the clinic is high volume with small numbers of care providers, also affected by language barrier.

*It is a one-on-one talk. We don't have any other way yet we need programs of how we can talk to clients even when they are not here in a language they better understand. We need to use all available resources if we are to win; you can't keep it one channel [KI-2].*

*This information is not anywhere instead it's in our heads; what I learnt is what I give out. We do one-on-one talk or group talks especially for those who have come for screening [KI-4].*

With this kind of information sharing, many participants believed they don't get adequate information as quoted below.

*No, we don't access the right information we need; some medics are hesitant to tell us this information. The way we receive information from healthcare givers is not all good, its poor and we can give it only 5% score [English FGD].*

*Not really, most things are simply hinted on; for example, in Nankabirwa ward, there comes a health professional who briefly gives educative talks to people every Monday but always the information is not adequate [Luganda FGD].*

## 4 Discussion

The study attempts to address CaCx awareness gaps by exploring the information needs of both the CaCx clients and those of the general public.

Participants reported that information on symptoms of CaCx needed to be shared as a way of increasing disease awareness because this could help people presenting themselves for care when the disease has not progressed to advanced stages.

This is consistent with [10] who stated that; lack of awareness of risk factors and symptoms for cancer may lead to late diagnosis and poor prognosis.

The need for information on CaCx symptoms can also be linked to the fact that most clients especially the expert ones are more worried of recurrence of the disease. Similarly, [14] found that 90% of cancer clients had a high degree of information needs regarding the prognosis of the disease, including issues related to the probability of recurrence and metastasis.

Prioritizing of screening information was based on the fact that its increased uptake will contribute to reduction in morbidity and mortality caused by the disease yet lack of knowledge about CaCx screening is among the most significant barrier to screening among women. Besides CaCx is treatable once detected early, and the need to know where to access screening service and what really happens in the process of screening, contributes to increased awareness of the disease hence increased uptake. Failure for women to be aware of where to access CaCx screening will deny them the likelihood of detecting the disease at early stages once they have it. Similar to this is [15] who stated that women who do not have access to CaCx screenings (i.e., routine Pap tests) have a significantly higher risk of developing CaCx. Making screening information available will further help address misconceptions about screening. This is comparable with findings by [6] where women who had not screened reported lack of awareness on CaCx as a barrier to screening.

The great desire to know the several causes and risk factors for CaCx can be attributed to the fact that most of these causes are avoidable and that the disease is treatable once detected early. It may seem obvious but knowledge about causes of CaCx and associated risk factors is limited among people. This is supported by for example, the Union for International Cancer Control (UICC) reported that more than a quarter of Africans surveyed believed that cancer had no cure once diagnosed and only 36% referred to cancer as an important health issue. In the same way, early healthcare-seeking is possible if women become aware of the CaCx risk factors and are able to avoid them. This is comparable with [10] that; early healthcare-seeking may be promoted if women become more aware about CaCx risk factors. Most often cancer is fatal due to the late stage of clinical presentation, something in turn a consequence of inadequate information and awareness [16].

Cancer interventions have got both long- and short-term side effects. It is important for clients to know what they are likely to experience after being initiated on cancer treatment. Some treatments have got very traumatizing side effects just like the disease itself which may deter some clients not to continue with the treatment. To many victims of these treatment side effects, have come to believe that they might be suffering from other strange illnesses which are unknown to them yet this is not the case.

Sharing such information is linked to help in adherence and also to elimination of fears in clients as well as dealing away with the negative attitude clients may have towards treatment. Similarly, Lila, et al, revealed that; newly diagnosed clients in the treatment phase needed information on stages of the disease, treatment plans, and treatment-related side effects; yet, clients who completed treatment still expressed a need for information on side effects, rehabilitation, and self-care [17].

Use of Information Communications Technology (ICTs) has the potential to enable provision of information especially in control and prevention for cancers to a wide population as well as increasing disease awareness. However, majority study participants indicated that they would require face-to-face communication for counseling and rehabilitation support which will most likely create more bonding between clients and care giver and bring about adherence.

This study had methodological limitations that should be addressed; focus groups were only for CaCx clients sampled though with varying socio-demographic and clinical variables.

## 5 Conclusion

Information needs slightly differed between CaCx clients and those of the general public yet between CaCx clients and healthcare professionals, they were comparable. Majority CaCx clients prefer to receive extensive information at their first diagnosis. Information about treatment, procedures as well as side effects, and prognosis are of particular relevance. Findings demonstrated that information seeking continues from diagnosis to follow-up. Therefore, healthcare providers listening to the clients might be more effective way to prevent and fight CaCx. It is also imperative to make use of the increasing adoption of ICTs to develop a centralized information portal on CaCx where all awareness information can easily be accessed by whoever might need it. Then efforts be made by referring and encouraging clients to use this portal as an effective way to further increase CaCx awareness.

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**Conflict of Interest:** the authors declare that they have no competing interests.

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