



# Information Needs Amongst Women with Cancer of the Cervix in National Cancer Centre Mulago

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## Background

A diagnosis of cancer has a devastating effect on the physical, psychosocial and emotional well being of patients, while its treatment and outcome may invoke uncertainty, fear and loss. This can in part be alleviated by adequate and accessible information appropriate to their needs. The African Palliative care Outcome Scale (POS), a validated tool, was used when reviewing the case notes from 165 patients known to Makerere Palliative Care Unit in 2012. 75% of patients expressed they had insufficient information about their illness to help them plan for the future.

This study aimed to explore the cancer patients' perspective of information needs and sources to enhance the quality of their lives.

## Methods

A qualitative exploratory study with purposive sampling of 15 patients all of whom had a diagnosis of cervical cancer was conducted using semi structured interviews. All patients were being treated in Mulago National Referral Hospital and admitted in a hostel which accommodates patients undergoing radiotherapy.

## Discussions

Cancer diagnosis is a life changing experience; patients leave consultations unsure about their prognosis, confused about the meaning of and need for further diagnostic tests, unclear about the management plan and the true therapeutic intent of treatment. The study reveals that understanding of the illness; treatment options, outcomes and consequences on relationships were reported as the major information needs.

This need is also deep rooted in beliefs about cancer which can lead to mistaken understanding and beliefs about the disease and reliance on inaccurate information sources.

Inadequate information causes much distress for patients and their families, who often want considerably more information than is usually provided. Providing information to cancer patients and their families in a form they can understand can have significant benefits. The preference for verbal communication emphasises the need for effective communication though it is of note that written material has a place even with low levels of literacy as a means for shared communication on sensitive issues such as sexuality.

## RESULTS



Findings revealed that the majority of respondents knew they had cancer but they lacked full insight into their disease and the consequences associated with cancer treatment. Many access information from informal sources and do not rely on written material.

... "For us who are undergoing radiotherapy treatment, they don't tell us much. They just come and ask you "did you go for treatment?" and you say "yes". (Patient 3)

"..What I know is not enough, I would like to know all about cancer and how it is treated and prevented for the sake of my family." (Patient 9)

Inadequate information raises a lot of questions

"When I get radiotherapy treatment, do I get completely cured after treatment or the cancer comes back after sometime". (Patient 5)

"When you finish the radiotherapy treatment, do your sexual feelings return, because others say that after radiotherapy you don't have sexual feelings, so for me who is married, won't that destroy my marriage?" (Patient 8)

There was deep rooted beliefs about the nature, cause and outcomes of cancer which reflected myths and poor information sources.

"I hear from my fellow patients who have been here. They tell you things which are scary. Like when I just came, I was told that when you go for radiotherapy treatment you get wounds, feel dizziness and vomit but now with the 2 weeks I have been here, its not the same like what I was told. I have not yet got wounds. (Patient 2)

Yes most of the information is from the patients and they scare you a lot and you feel discouraged (Patient 4)

Preferred sources to address the information needs

Patients preferred to obtain information verbally from attending doctors:

"I would want a medical person like you to explain to me" (Patient 11)

While others demonstrated a preference for written sources of information:

"Written material would be very good. It can be used later as a reference when I am talking to my relatives, for them to understand my condition" (Patient 8)

"Yes if I get written material I can read later,... I can even take it to my husband as evidence to show him what ..... some of us have husbands who can be violent. He may what evidence do you have from the medical team that you should not have sex with me?" (Patient 10)

Paucity of information in general and in particular about sexual relations also stood out as a great concern.

"..... I want to know, after I have been discharged from radiotherapy, I am supposed to come back after 2 month, so in that instance I am a married woman, so what do I do with regard to sexual relations with my husband?" (Patient 6)

"They don't tell you everything ....like side effects. Maybe they fear you will get frightened." (Patient 7)

## CONCLUSION and RECOMMENDATIONS

This research demonstrated that patients need as much information as possible regarding their condition and this should be accessible, appropriate and accurate. Effective and skilled communication about their condition is key to optimal health outcomes. Inadequate information causes much distress for patients and their families, who often want considerably more information than is usually provided.

Palliative care support should integrate awareness, training and patient feedback to improve this area for their patients and within the health systems.

