



SOCIOECONOMIC BURDEN OF A DIAGNOSIS OF CERVICAL CANCER AMONG WOMEN IN RURAL UGANDA: A PHENOMENOLOGICAL STUDY

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INTRODUCTION

Cervical cancer (CC) remains a major global health problem.

The greatest burden of CC is seen in low- and poor-resourced regions, e.g. in sub-Saharan Africa where over 85% cases and 88% deaths due to CC occur

OBJECTIVE

To diagnose the socioeconomic burden and impact of CC in rural women in a low-resourced country, Uganda.

METHODS

Design and setting: A multi-site descriptive qualitative inquiry, conducted at three hospice settings: Mobile Hospice Mbarara in south-western, Little Hospice Hoima in Western, and Hospice Africa Uganda Kampala in central Uganda.

Sampling: A purposive sample of women with a histological diagnosis of CC.

Data collection: open-ended, audio-recorded interviews. Interviews were transcribed verbatim in English.

Analysis: Braun and Clarke's (2019) framework of thematic analysis was used.

Ethics: Approved by Hospice Africa Uganda Research Ethics Committee, HAUREC 055/18.

RESULTS

Three major themes emerged: (1) Impact of CC on women's relationships, (2) disrupted and impaired Activities of Daily Living (ADLs), and (3) Economic disruptions.

THEME 1: IMPACT ON RELATIONSHIPS

a. Social and psychological stigma and distress

"I was fat but now see (she points to her emaciated body) ... but clothes hide a lot... It [cancer] reduced me (She cries). It has done me so bad. At times, it makes you fail to eat, lose appetite for food, then also pain on urination! Some of my relatives, when they knew it is cancer, they feared and thought it spreads to others. They ran away from me.... It is bad! Ok, it is unbearable! My children know I have cancer. They know it kills. They hear it from other people that cancer doesn't cure and kills" (**Cacx 4A, 40 years**)

"...even smelling for myself, padding yourself all the time from year to year. I now even feel I'm tired of myself for real, and no longer want to mix with the public. It's like I smell for them. I am tired of myself for real, because I have been sick for long and its worse. I have no one to help me" (**Cacx 2B, 50 years**)

b. Disrupted patriarchal gender roles

"The marital relationship with my husband was greatly affected. For the man, he thinks you don't want to sleep with him and you just create reasons to dodge him. When I became sick my husband deserted me and married another woman. You see, I look after myself and my four children" (**Cacx 3A, 46 years**)

THEME 2: DISRUPTED AND IMPAIRED ACTIVITIES OF DAILY LIVING (ADLs)

"...I am just trying hard despite lack of energy. I force myself to have a garden, so that I have like; millet and I drink porridge, it is self-sacrifice" (**2B+HIV, 69 years**)

I'm at home alone. I used to plan for myself, like baking bread, hawking second-hand clothes But now, I'm too weak! I can't even lift a jerry can. But the problem is that I'm unable to boil water for drinking...

(**Advanced Cacx + HIV, 41 years**)

THEME 3: IMPACT OF CC ON WOMEN'S ECONOMICS

a. High out-of-pocket expenditures on treatment

"The facility we went to first, to process biopsy, they needed shs.170, 000 which I did not have. We went to another lab where they asked for shs. 90,000, I didn't have it either, and they wanted cash. The 'boda boda' man then took me to the third place where they charged me shs.70, 000"

(**Cacx 3A, 41 years, Widow**)

b. Corruption/bribery in health system

"When I reached Mulago, I found the machine (radiotherapy) was for money. You pay 1million, 2million... depending on the health worker who has seen you. I looked for the money (1.8million) and I paid, and the doctor started putting me in the machine). The money is too much. Remember I told you previously; I'm the mother and the husband. In fact, the top up (Shs 450,000) I paid for radiotherapy I borrowed it"

(**Advanced Cancer+HIV, single mother**)

c. Impact on family's financial standing

My children (four) were at the university but now they are seated home. I have real suffering. All the money got finished on the pain and the disease. I need my children to study. At least if I can get well-wishers to support my children to continue with education (**41 years, widow**)

CONCLUSIONS AND RECOMMENDATIONS

CC impairs socioeconomic domain of a woman and her family. It worsens poverty and disrupts relationships. Decentralizing cancer care services to regional centres, increased funding, including medicines, curbing corruption in the public healthcare system, intensifying awareness about CC, further training and strengthening human resource, integrating Palliative care into all levels of the health system, further research to examine long-term impact of CC on women's and families' economics are key.

ACKNOWLEDGEMENTS: Consultant Peter Ellis (my primary mentor) and Prof Wilson Acuda for their unwavering support