

Planning the Feasibility of Esophageal Cancer Early Detection through Prompt Symptom Recognition, Care seeking and health system navigation Model in Uganda (ESOCAN-EDM)

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Executive summary

Objectives

This study aimed to explore the current esophageal cancer (EC) detection and management-related context and plan an appropriate study protocol to test the feasibility of an EC early detection through prompt symptom recognition and care seeking, health system navigation for quick confirmatory diagnosis, and appropriate treatment in Uganda.

Activities

Conducted 10 participatory monthly planning meetings at the Uganda Cancer Institute (UCI) with the selected EC patients and the patients' advocate organizations, the Uganda Women Cancer Support Organisation (UWOCASO) and Uganda Cancer Society (UCS). We also interviewed seven cancer experts and 14 EC patients; conducted two stakeholders' engagement meetings, each with 25 participants (UCS, UWOCASO, UCI, District PHC workers, EC patient caretakers, academia-Makerere University School of Public health; and reviewed literature on the available evidence and gaps locally and elsewhere in the world regarding EC early detection efforts.

Outcomes

Several barriers to EC early detection were identified; barriers to access to information, linkage to care, early identification, treatment services, and difficulty to navigate the health system right from the community level. These are detailed in a manuscript titled "Early Detection and Management of Esophageal Cancer in Uganda: Patients and Healthcare Professionals' Perspectives". As a result, a community trial was recommended and the protocol was developed, titled "Esophageal Cancer Early Detection through Prompt Symptom Recognition, Care-seeking and health-system-navigation Model in Uganda (ESOCAN-EDM): A Community Cluster Randomized Controlled Trial"

Challenge

- ❑ Limited access to EC detection tests especially Endoscopy was observed. In addition, the patients and stakeholders observed that the costs of esophageal cancer diagnostic tests especially, endoscopy for diagnosis and CT scan for staging are unaffordable to some patients.
- ❑ The qualitative study indicated significant barriers to access to information, linkage to care, delay to early identification of the EC, and access to treatment services right from the community level.



Esophageal Cancer Early Detection through Prompt Symptom Recognition, Care-seeking and health-system-navigation Model in Uganda (ESOCAN-EDM): A Community Cluster Randomized Controlled Trial

Direct involvement of patient experts

During the study planning, the UCS and UWOCASO) participated in the preliminary planning of this protocol. These formative consultations helped the researchers to refine the study protocol. The UWOCASO and the UCS have further pledged readiness to engage in the second phase of the study activities as indicated in their attached letters of support. During the grant implementation, the EC cancer patients will be engaged through interviews while the cancer patients' advocates will further be consulted and engaged throughout the project implementation cycle. In a qualitative needs assessment, 14 EC patients and 7 Healthcare professionals were interviewed to determine the EC symptoms and period lived with the symptoms before accessing care and describing the factors influencing early detection of EC from the provider and clients' perspective.



Incorporating feedback

Feedback from the monthly meetings, stakeholders' engagement meetings, and a qualitative study were used to propose a suitable study design and refine the overall study protocol. A community trial with two primary outcomes and three secondary outcomes was recommended. The primary end-points were; to compare stage of EC at diagnosis among of EC patients in the intervention arm and the control arm, and to compare the quality- of life scores among EC patients in the intervention arm and the control arm. Secondary end-points were to compare time to diagnosis among EC patients in the intervention arm and the control arm; to compare time to treatment initiation among EC patients in the intervention arm and the control arm, and to compare survival of EC patients in the intervention arm and the control arm.



Impact on study design

The primary and secondary research questions were guided by a preliminary qualitative study titled "Early Detection and Management of Esophageal Cancer in Uganda: Patients and the Healthcare Providers Perspectives". The findings of the preliminary study highlighted the gaps in early detection and management Esophageal cancer in Uganda. Addressing barriers to access to information, linkage to care, early identification, treatment services, and helping the patients to navigate the healthcare system are crucial for improving early detection and access to care. Training healthcare providers on the common symptoms of Esophageal Cancer that the patient could present with and educating the communities on the EC symptoms to facilitate timely referral and diagnosis at all levels of health facilities are recommended. Therefore, this study is guided by the findings from the patients' perspective, triangulated with the healthcare professionals' perspectives. A Community Cluster Randomized Controlled Trial was proposed as a suitable higher-level evidence design to test the effect of Esophageal Cancer Early Detection through Prompt Symptom Recognition, Care-seeking, and health-system-navigation Model in Uganda (ESOCAN-EDM). In this study, in addition to the secondary outcomes, two primary outcomes will be evaluated; to compare stage of EC at diagnosis and quality of life scores among of EC patients in the intervention arm and the control arms.

conclusions

The pre-application grant planning phase and the quality study findings engaged the EC patients and cancer patients' advocates and highlighted the critical gaps in early detection and management Esophageal cancer in Uganda. Research that seek to explore and address barriers to access to information, linkage to care, early identification, treatment services, and helping patients to navigate the healthcare system using a higher-level-evidence study design such as a randomized control trial is crucial for improving early detection and access to care. In addition, capacity-building interventions such as training healthcare providers on the detection of common symptoms of Esophageal Cancer that the patient could present with and educating the communities on the EC symptoms to facilitate timely referral and diagnosis at all levels of health facilities are recommended.

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Applying for the pre-application grant

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Activities proposed

- ❑ The stakeholders and the patients advocates noted the need for including a budget to cover the critical cost of esophageal cancer diagnosis, for example, the cost of endoscopy and CT scan for patients that may not afford the test fees..
- ❑ A Community Cluster Randomized Controlled Trial was proposed to test the effect of Esophageal Cancer Early Detection through Prompt Symptom Recognition, Care-seeking and health-system-navigation Model in Uganda (ESOCAN-EDM).

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Outcomes & incorporating them back into endpoint and trial design

Providing pre-application funding for patient involvement

A new grant mechanism called "pre-application grants" has been launched. These small grants are to close the funding gap for patient experts to provide input to the development of a grant application/protocol.

We are aiming at supporting patient organizations during this early phase with a budget. The budget should be planned to cover travel costs to preparatory meetings and the work time invested by staff or patient experts. This work should be carried out as a preparation step prior to the submission of a clinical research grant application to RTFCCR

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Conclusion