



CaLioS | Improving Cancer Literacy Using Online Stories in Sub-Saharan Africa, Illustrated by the Example of Kenya

1. Project data

Project type

interdisciplinary pilot project cross-sector project global health postdoc fellowship

Research areas involved (check all that apply)

Biomedical sciences Public health
 Social sciences and humanities Engineering and other sciences

Project duration

June 2023 – May 2025

Project team

Name	Organization	Discipline(s)
Dr. Stefanie Harsch	Universität Freiburg	Public Health
Prof. Dr. Dinah Kassaman	Aga Khan University, Nairobi Kenya	Nursing
Dr. Victor Oria	Integrated Cancer Research Foundation (ICRF), Kenya	Biochemistry
Dr. Ruth Mbugua	Mama Ngina University College, Kenya	Nursing
Mary Nafula	Warriors of Hope Foundation	Cancer expert
David Ouna	ICRF, Kenya	Data engineer

Further partners collaborated with the postdoctoral researcher during different parts of the project: Dr Kristine Sorensen (Public Health, Health Literacy Expert), Dr James Kiilu (Medicine), Joel Mlala (Media expert), Dr Felix Anemba Ollinga (Pharmacy), Dr Laura Awuor (Medicine), Vanneziah Kiptalam (Pharmacy), Christine Kili (Radiology), Mary Mwangi (Accountance), Millicent Kagonga (cancer expert), Lea Weber (Research assistant Public Health), Helena Ketterern (Public Health), Dr Sarah Bett (Nursing), Dr Nilufar Jivray (Nursing), Joy T. Anyira (Nursing)



Case study

The prevalence of cancer is rising globally, including in sub-Saharan Africa, and this places many challenges on healthcare systems and individual patients. In order to cope with these challenges and engage with treatment more effectively, cancer patients and their family members need to develop cancer health literacy. Cancer health literacy is the ability to find, understand, appraise and apply information related to cancer in order to improve treatment and quality of life. Cancer health literacy is poor in African countries such as Kenya, where there are few educational resources available. Sharing the experiences of other cancer patients through testimonials and narratives can be a useful way to improve cancer health literacy. Technological improvements could help to reach out to many newly diagnosed cancer patients. In Kenya, almost everyone has access to the internet. However, the potential of digitalisation and narratives has not yet been fully exploited to improve cancer health literacy in Kenya.

The Calios research project aimed to investigate whether online narratives shared by cancer patients in sub-Saharan Africa could be used to improve cancer health literacy and develop an educational website, as well as evaluating this educational offering. In addition to preparations such as obtaining ethics approvals and research licences and training research assistants, the following research activities were carried out. The key findings from the eight sub-questions are presented below.

First, a scoping review was conducted to assess the state of the art regarding cancer-related health literacy evidence in Kenya. This revealed that, while numerous studies document a lack of knowledge, few interventions have been evaluated, and most interventions focus on increasing knowledge rather than improving CHL. Services for cancer patients are particularly scarce.

Secondly, the potential and limitations of using online shared disease experience reports were assessed based on twenty expert interviews.

Thirdly, an in-depth understanding of the experiences of cancer patients in Kenya was gained through 40 narrative interviews with breast and prostate cancer survivors. These interviews revealed the subjective and diverse nature of cancer experiences in Kenya, ranging from proactive preliminary examinations to waiting until the last minute, doctors who explained things very well to those who reacted insensitively, support from family and friends to partners secretly disappearing, major financial burdens, doubts about faith, and regaining strength through faith and social support. Despite these experiences being subjective, certain commonalities emerged, such as difficulty accessing the healthcare system, a high financial burden, the need for social support, and an optimistic outlook on the disease.

Fourthly, the Maisha Na Cancer website and YouTube videos, an online intervention, were codesigned with cancer patients, video experts, etc. (see <https://maishanacancer.co.ke>).



Figure 1: Example stories from the maishanacancer.co.ke website.

Fifthly, a scale for CHL was developed based on narrative interviews and a Delphi survey of cancer patient experts. This scale contains 26 questions across four domains: functional CHL; interactive, family-related CHL; interactive, healthcare-related CHL; and critical CHL.

Sixthly, the validity and reliability of the self-developed questionnaire, as well as the level of cancer-related health literacy, were assessed in a cross-sectional study. The scale's internal consistency is high (all domains have a Cronbach's alpha value ranging from .849 to .876). Based on a sample of 836 cancer patients from across Kenya, it was shown that CHL is generally rather low.

Seventh, an online single-group, pre-post intervention study tested the acceptance and effectiveness of using online videos to improve CHL among cancer patients. Findings based on 293 cancer patients showed that watching the videos can increase CHL statistically significantly. Also the patients liked the videos and website, and would highly recommend them to others.

Eighthly, the acceptance and effectiveness of using online videos with nursing and medical students, and the potential for integrating narrative into university studies, were tested using an explanatory sequential mixed-method design. The study of 491 nursing students and 87 medical students revealed that their CHL increased. Furthermore, the students provided numerous suggestions for integrating narratives into their academic education.

The findings were finally used to develop teaching concepts for students, design information material for patients, revise the website and submit three research proposals (two smaller ones and one more extensive one). They were also used to carry out preliminary work for a follow-up project.

Resources

Further information, a list of publications and updates about the research project can be found on <https://maishanacancer.co.ke/about-the-initiative/findings/>

Contact

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2. Contact

German Alliance for Global Health Research (GLOHRA)

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