

Implementation and Evaluation of Educational Videos to Improve Cancer Knowledge and Patient Empowerment

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PURPOSE Low health literacy is a leading cause of treatment abandonment among patients receiving cancer care at Kamuzu Central Hospital (KCH) in Malawi.

METHODS We developed cancer educational videos featuring Malawian providers and played them in the KCH oncology clinic. The videos addressed cancer-related topics, including disease biology, common myths, diagnostic procedures, treatment, side effects, and survivorship. After 6 months of implementation, we compared results from 50 pre- and postintervention surveys to assess change in cancer knowledge and care experience.

RESULTS Both pre- and postintervention cancer knowledge were good: a median of nine questions were answered correctly of 11 in both assessments. Despite the intervention, most continued to incorrectly identify cancer as an infection (pre: n = 26, 52%; post: n = 25, 50%; $P = 1.0$), although improvements were observed in patients' knowledge of correct actions for fever at home (pre: n = 38, 76%; post: n = 43, 86%; $P = .31$). Care experiences were overall good. Postintervention results indicate that more patients felt always listened to by their providers (pre: n = 18, 36%; post: n = 29, 58%; $P < .01$). However, we also noted a higher rate of patient dissatisfaction of care as more patients felt that they could not understand chemotherapy counseling (pre: n = 11, 22%; post: n = 22, 44%; $P < .01$). Assessments of video satisfaction indicate that patients found the videos very helpful in terms of understanding their disease (n = 47, 96%) and side effects (n = 48, 98%) and felt empowered to speak up with their providers (n = 46, 96%).

CONCLUSION Standardized education materials for patients that can be feasibly implemented throughout sub-Saharan Africa are urgently needed. Cancer educational videos are a low-cost way to educate and empower patients with cancer in resource-constrained settings although in-person discussions remain a crucial part of care.

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INTRODUCTION

Low health literacy and misinformation about cancer are highly prevalent throughout sub-Saharan Africa (SSA) and remain recurring challenges for cancer care across the region.¹ Patients and their guardians report receiving misleading information in their communities, which influences decisions to seek care and receive treatment.^{1,2} Furthermore, patients report poor understanding of their disease, even after pathologic diagnosis and counseling in dedicated oncology units.²⁻⁴ Poor cancer knowledge affects clinical teams' efforts to treat and/or palliate a patient's disease. In Malawi, we have shown that low cancer health literacy is a leading cause of treatment abandonment among children and adolescents, and this has also been observed elsewhere in adults and children in SSA.^{1,2,5-7}

In high-income settings, standardized patient cancer education is often facilitated through a comprehensive

educational session by a nurse educator at the time of diagnosis. Educational videos and other technology-based educational interventions for cancer-specific patient education have been successful in these settings.⁸⁻¹³ Technology-based educational interventions such as educational videos can ensure that patients access standardized cancer information, tailor-made to their health literacy. In SSA, a few studies have successfully incorporated cancer-specific patient educational videos and tablets to improve cancer knowledge, with published data on cervical cancer and Kaposi sarcoma.¹⁴⁻¹⁸

In a resource-constrained setting, such as Malawi, providers are often overworked and clinics are understaffed, so providing comprehensive cancer patient education is not feasible. Health care delivery has historically been driven by providers, and shared decision making is limited. In addition, cancer clinics in many low- and middle-income settings are often

ASSOCIATED CONTENT

Data Supplement

Author affiliations and support information (if applicable) appear at the end of this article.

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CONTEXT

Key Objective

Can passive viewing of cancer education videos improve cancer knowledge and empower patients in resource-constrained settings?

Knowledge Generated

Surveys performed after playing educational cancer videos in Kamuzu Central Hospital's Cancer clinic showed that baseline cancer knowledge and care experiences were overall good, without a significant change after the video intervention. Cancer educational videos did, however, serve to empower patients to engage with their providers about their care, important in resource-constrained settings, where patients are not often involved in shared decision making regarding their care.

Relevance

Educational cancer videos could be developed as a means to provide standardized cancer education and empower patients in other resource-constrained settings.

characterized by long patient wait times. Therefore, incorporating standardized patient education videos can increase the efficiency of oncology service delivery. In an effort to improve cancer knowledge among patients receiving care in the Kamuzu Central Hospital (KCH) oncology clinic and to offset the educational responsibilities of the oncology clinical team, we developed comprehensive and culturally appropriate cancer education videos for patients and families to watch while waiting in the clinic. We report our experience in incorporating standardized educational videos into a public cancer clinic in Malawi and evaluate their impact on patients' cancer knowledge and care experiences.

METHODS

Setting

Malawi is a landlocked country in southeastern Africa with a population of approximately 19 million. It is a low-income country with an annual gross domestic product per capita of \$411 US dollars and a United Nations Development Programme Human Development Index rank of 174 of 189 countries.^{19,20} KCH is a national public teaching hospital in Lilongwe, the capital, and is one of two hospitals in the country that provide cancer treatment. KCH receives cancer referrals from the northern and central regions, serving an estimated nine million people.

The KCH oncology clinic has approximately 720 new cancer diagnoses per year and sees 45 patients per week in clinic (30 receiving chemotherapy). It is staffed by government-employed and University of North Carolina (UNC) Project-Malawi providers. There are numerous ongoing prospective clinical research studies for patients, led by the UNC Project Malawi research team.²¹⁻²⁹ Patients enrolled in these studies are followed by UNC Project-Malawi providers and undergo a comprehensive informed consent before enrollment, which includes additional cancer education. Before implementing patient educational videos in clinic, patients received cancer education from their individual providers per local standards of care.

Creation of Patient Education Video Intervention

In 2018, we developed culturally appropriate, standardized educational videos focused on cancer care for patients and their families. These educational videos feature Malawian clinicians and nurses who work at the KCH oncology clinic, both government and UNC Project-Malawi employees, and address a range of cancer-related topics including basic cancer biology and review of the common cancers in Malawi, explanation of diagnostic tests that patients may encounter (blood draw, lumbar puncture, bone marrow aspirate, and biopsy), what to expect during treatment and types of cancer treatment (chemotherapy, surgery, and radiation), common symptoms that patients encounter, side effects of treatment, review of warning signs and instructions on when to seek care, general health and wellness, and common myths and misconceptions related to cancer. The total educational content runs 85 minutes. All cancer-related educational information is provided in Chichewa, the local language in Malawi.

We feature testimonials from eight cancer survivors who received care at the KCH clinic (run time: 22 minutes). Interspersed between cancer educational segments, we incorporated four music videos created with local Malawian artists who composed cancer-related songs for this project (total run time: 14 minutes, 2.5-4.5 minutes each). Music videos were also played on the radio and television to improve cancer education and awareness in the community. The videos we created are currently available on YouTube in Chichewa with English subtitles (*Cancer Education for Malawi*).³⁰

Study Design and Population

To assess the feasibility, acceptability, and impact of the educational videos, we administered surveys to a total of 100 patients with cancer receiving care at the KCH oncology clinic, 50 participants before the educational videos were implemented, and 50 at least 6 months after. Both the pre- and postintervention cohorts were separate convenience samples.

Study Procedures

To obtain baseline preintervention data, we administered a cancer knowledge assessment and care experience questionnaire before we began playing the educational videos in clinic. The questionnaire consisted of 11 questions on basic cancer knowledge and 13 questions about the patients' care experience (Data Supplement). Questions were multiple choice with three answer choices, except for one question that rated the overall cancer care experience on a 0-10 scale. The cancer knowledge questions were created by the research team using basic knowledge that they would expect patients with cancer to know, and all topics are covered in the educational videos. The care experience questions were created by the research team after reviewing existing care experience surveys used in high-income settings, making a set of questions applicable for our setting.³¹ Surveys were conducted at various times throughout the treatment course through convenience sampling, but always after participants received the standard patient education at their initial visit. Surveys were conducted in Chichewa, the national language of Malawi. All questionnaires were completed with help from a Malawian research assistant trained in survey methodology, who read question items to participants, because of low literacy in our patient population. This is a practice commonly used in research projects with this patient population.³²

We began playing the educational videos on a loop in the clinic waiting area and chemotherapy infusion room in March 2019. Patients spend most of the day in these areas, awaiting appointments or receiving infusions. After 6 months of playing educational videos (postintervention), we administered the

same cancer knowledge assessment and care experience multiple-choice questionnaire (11 cancer knowledge and 13 care experience; Data Supplement) as preintervention. In addition, the postintervention cohort answered an education video satisfaction questionnaire (nine questions [seven multiple-choice and two open-ended questions]; Data Supplement). Surveys were conducted at various times throughout the treatment course because of convenience sampling, but always after receiving the standard-of-care education and viewing the videos at least once.

Analysis

Pre- and postintervention survey data were summarized using simple descriptive statistics. Fisher's exact test and exact Mantel-Haenszel chi-square tests were used to compare answers to specific questions pre- and postintervention, and the Mann Whitney U Test was used to compare overall summed scores (1 point for every correct answer) pre- and postintervention ($\alpha = .05$). Participants with missing survey answers were excluded from overall score calculation but were included in the question-specific pre-/postcomparison if there was an item-level response. To address any bias introduced by the presence of UNC clinical trial participants in the pre- and postintervention sample, we conducted a sensitivity analysis stratifying the overall scores by patient type. All analyses were conducted using R 4.0.2 (Vienna, Austria) or SAS v9.4 (Cary, NC).

Ethical Review

This quality improvement project received Institutional Review Board exemption from the University of North Carolina-Chapel Hill and the Malawi National Health and Sciences Research Committee.

TABLE 1. Cancer Knowledge Among Patients Receiving Care in the Kamuzu Central Hospital Oncology Clinic Pre- and Posteducational Video Intervention
No. (%) selected correct answer

Question	Preintervention (n = 50)	Postintervention (n = 50)	P
What is cancer?	21 (42)	21 (42)	1.00
Which statement is true about cancer transmission?	41 (84)	45 (90)	.39
How often will you need to come to the hospital for cancer treatment?	28 (62)	38 (76)	.18
If you have a lot of pain from your cancer, what can you do?	50 (100)	48 (96)	.49
After starting chemotherapy treatments, you start to feel better and can no longer feel your tumor at all! You should...	46 (92)	47 (94)	1.00
What may happen if you are late for your treatment?	50 (100)	49 (98)	1.00
Which test helps the doctors know if there is cancer in your brain?	14 (30)	14 (28)	1.00
A few weeks after starting chemotherapy, your hair started to fall out. What should you do?	50 (100)	49 (98)	1.00
After receiving your chemotherapy treatment, you had a lot of vomiting in the hospital and for a few days at home. It was so bad you had trouble eating and drinking. You should...	47 (94)	47 (94)	1.00
You have cancer and are currently getting chemotherapy treatments. At home in-between treatments, you develop fever, chills, and do not feel well. You should...	38 (76)	43 (86)	.31
If you have both cancer and HIV, you should...	50 (100)	50 (100)	NA

NOTE. During the interview, some questions were voluntarily skipped by the participants, and missing values are excluded.
Abbreviation: NA, not available.

RESULTS

Fifty pre- and postintervention participants completed surveys in the KCH adult oncology clinic. Most participants answered the majority of questions correctly. The median score for participants before the intervention was 9 (interquartile range [IQR]: 8-9, $n = 43$) correct answers of 11 total questions. After the intervention, the median score remained at 9 (IQR: 8-10; $n = 50$; $P = .20$).

Cancer Knowledge

Four of the 11 questions were almost always answered correctly (> 95% of participants chose the correct answer)

both pre- and postintervention: what to do about pain (pre: $n = 50$, 100%; post: $n = 48$, 96%; $P = .49$), what to do about hair falling out and understanding that it is a temporary side effect of chemotherapy (pre: $n = 50$, 100%; post: $n = 49$, 98%; $P = 1.0$), the importance of coming to chemotherapy appointments on time (pre: $n = 50$, 100%; post: $n = 49$, 98%; $P = 1.0$), and what to do if the patient has both cancer and HIV (pre: $n = 50$, 100%; post: $n = 50$, 100%; [Table 1](#)). Other two of the questions that were usually answered correctly (90%-95% of participants answered correctly) in both pre- and postintervention assessments are as follows: importance of completing all chemotherapy cycles even if

TABLE 2. Cancer Care Experiences Among Patients Receiving Care in the KCH Oncology Clinic Pre- and Posteducational Video Intervention

During Your Cancer Treatment at KCH...	Preintervention $n = 50$ (%)			Postintervention $n = 50$ (%)			<i>P</i>
	Yes	Somewhat	No	Yes	Somewhat	No	
Did you feel comfortable to ask your medical team questions about your care?	29 (62)	4 (9)	14 (30)	22 (44)	16 (32)	12 (24)	.55
Did your medical team explain what your chemotherapy medication was for in a way that was easy to understand?	37 (74)	2 (4)	11 (22)	18 (36)	10 (20)	22 (44)	< .01
Did your medical team clearly explain how your cancer and chemotherapy could affect your normal daily activities?	32 (64)	1 (2)	17 (34)	24 (48)	6 (12)	20 (40)	.29
Did your medical team explain your diagnostic procedures to you before you had to do them (eg: tumor biopsy, bone marrow biopsy, and lumbar puncture) in a way that was easy to understand?	44 (88)	1 (2)	5 (10)	32 (64)	3 (6)	15 (30)	< .01
How well did your medical team explain your radiographic tests (eg: x-ray, Ultrasound, CT scan, and MRI scan) in a way that was easy to understand?	35 (70)	2 (4)	13 (26)	29 (59)	6 (12)	14 (29)	.50
Did your medical team tell you to call them immediately if you have certain symptoms or side effects?	43 (88)	0 (0)	6 (12)	35 (73)	3 (6)	10 (21)	.14
Did you and your medical team talk about symptoms and side effects that you could experience related to your cancer or chemotherapy medication (eg: pain, vomiting, constipation, and fatigue)?	43 (88)	0 (0)	6 (12)	38 (76)	3 (6)	9 (18)	.27
Did your medical team advise you about or help you deal with these symptoms or side effects that you may have been experiencing (eg: pain, vomiting, constipation, and fatigue)?	38 (78)	0 (0)	11 (22)	32 (65)	3 (6)	14 (29)	.36
Did your medical team clearly explain ways for you to stay healthy and strong while undergoing cancer treatment?	36 (73)	0 (0)	13 (27)	37 (76)	2 (4)	10 (20)	.72
	Always	Sometimes	Never	Always	Sometimes	Never	
Did your medical team listen carefully to you?	18 (36)	6 (12)	26 (52)	29 (58)	20 (40)	1 (2)	< .01
How often did your medical team explain things in a way that was easy to understand?	24 (48)	14 (28)	12 (24)	19 (38)	15 (30)	16 (32)	.34
	Median (IQR)			Median (IQR)			
Considering all your cancer care at Kamuzu Central Hospital, using any number from 0 (worst) to 10 (best), what number would you use to rate your overall cancer care experience?	91 (75-99)			84 (71-95)			.15

NOTE. During the interview, some questions were voluntarily skipped by the participants, and missing values are excluded.

Abbreviations: CT, computed tomography; IQR, interquartile range; KCH, Kamuzu Central Hospital; MRI, magnetic resonance imaging.

TABLE 3. Postintervention Survey of Educational Video Satisfaction Among Patients Receiving Care in the Kamuzu Central Hospital Oncology Clinic

Question <i>Did you find the educational videos helpful to better understand...</i>	Very Helpful, No. (%)	Somewhat Helpful, No. (%)	Not Helpful, No. (%)
What is cancer?	47 (96)	2 (4)	0 (0)
Your cancer treatment?	46 (96)	2 (4)	0 (0)
Your symptoms and side effects that you could experience when receiving treatment for your cancer?	48 (98)	1 (2)	0 (0)
Dangerous symptoms and knowing when to call your doctor or knowing when to go to the hospital for an evaluation?	48 (98)	0 (0)	1 (2)
How to take care of yourself while undergoing cancer treatment?	48 (98)	1 (2)	0 (0)
How to empower yourself to ask your doctor questions and speak up when you are experiencing symptoms?	46 (96)	2 (4)	0 (0)
Did you find the educational videos entertaining to watch while you were in clinic?	47 (98)	1 (2)	0 (0)

NOTE. During the interview, some questions were voluntarily skipped by the participants, and missing values are excluded.

feeling better and the tumor disappeared (pre: $n = 46$, 92%; post: $n = 47$, 94%; $P = 1.0$) and what to do if they have vomiting at home that prevents the patient from eating or drinking (pre: $n = 47$, 94%; post: $n = 47$, 94%; $P = 1.0$). Two other questions were usually answered wrong ($< 50\%$ of participants chose the correct answer) both pre- and postintervention: what cancer is (pre: $n = 21$, 42%; post: $n = 21$, 42%; $P = 1.0$) and the correct diagnostic test for cancer in the brain (pre: $n = 14$, 30%; post: $n = 14$, 28%; $P = 1.0$). For these responses, most participants answered that cancer is an infection (pre: $n = 26$, 52%; post: $n = 25$, 50%; $P = 1.0$) and that the test for brain cancer is a tumor biopsy (pre: $n = 29$, 62%; post: $n = 34$, 68%; $P = .53$). The remaining three questions showed an improvement post-intervention of $> 5\%$ in the percent of patients who answered the questions correctly although none was statistically significant: cancer transmission (pre: $n = 41$, 84%; post: $n = 45$, 90%; $P = .39$), frequency of cancer treatment (pre: $n = 28$, 62%; post: $n = 38$, 76%; $P = .18$), and what to do if unwell and having fever at home in between chemotherapy treatments (pre: $n = 38$, 76%; post: $n = 43$, 86%; $P = .31$).

Patient Experience

Overall, cancer care experiences were positively rated, but patient dissatisfaction with care was higher in the post-intervention group (Table 2). More patients felt that they could not understand chemotherapy counseling (pre: $n = 11$, 22%; post: $n = 22$, 44%; $P < .01$), and more patients felt that their providers did not explain the diagnostic procedures in an easily comprehensible way after the intervention (pre: $n = 5$, 10%; post: $n = 15$, 30%; $P < .01$). Despite this, more patients felt always listened to by their providers (pre: $n = 18$, 36%; post: $n = 29$, 58%; $P < .01$).

Video Satisfaction

Postintervention assessments of video satisfaction indicate that patients found the videos very helpful across all queried domains, with $> 95\%$ of patients reporting that

the videos were very helpful and only one participant reporting that the videos were not helpful in one domain (Table 3). Patients felt that the videos were very helpful in terms of understanding their disease ($n = 47$, 96%), their treatment ($n = 46$, 96%), how to take care of themselves during treatment ($n = 48$, 98%), expected side effects of treatment ($n = 48$, 98%), and when to contact providers with dangerous symptoms ($n = 48$, 98%). Patients felt empowered to speak up to their providers ($n = 46$, 96%) and found the videos entertaining ($n = 47$, 98%). Favorite parts of the videos included learning about different types of cancers and the associated symptoms and side effects. Patients also enjoyed the educational aspects that were entertaining and recommended having additional motivational songs, comedies, and dramas, as these forms of education are more engaging and entertaining. Others recommended including more survivors in the videos to provide hope, including more information on appropriate foods to eat, and bringing cancer education to rural areas for awareness.

Participation in Research

When we compared the inclusion of UNC research participants in the study sample pre- and postintervention, a higher percentage of participants were UNC research participants before the intervention as compared with after (pre: $n = 22$, 44%; post: $n = 13$, 26%; $P = .09$). As participants enrolled in clinical trials through UNC Project-Malawi, we hypothesized that the difference in score pre- and postintervention may differ by participation in a clinical research study as they receive additional education through the informed consent process. When we considered only KCH patients without UNC research experience, the median score preintervention was 8 (IQR: 8-9) and the median score postintervention was 9 (IQR: 8-10; $P = .24$; Fig 1). Among participants who had already participated in research activities with UNC, the median score preintervention was 9 (IQR: 8-9) and the median score postintervention was 10 (IQR: 9-10, $P = .07$).

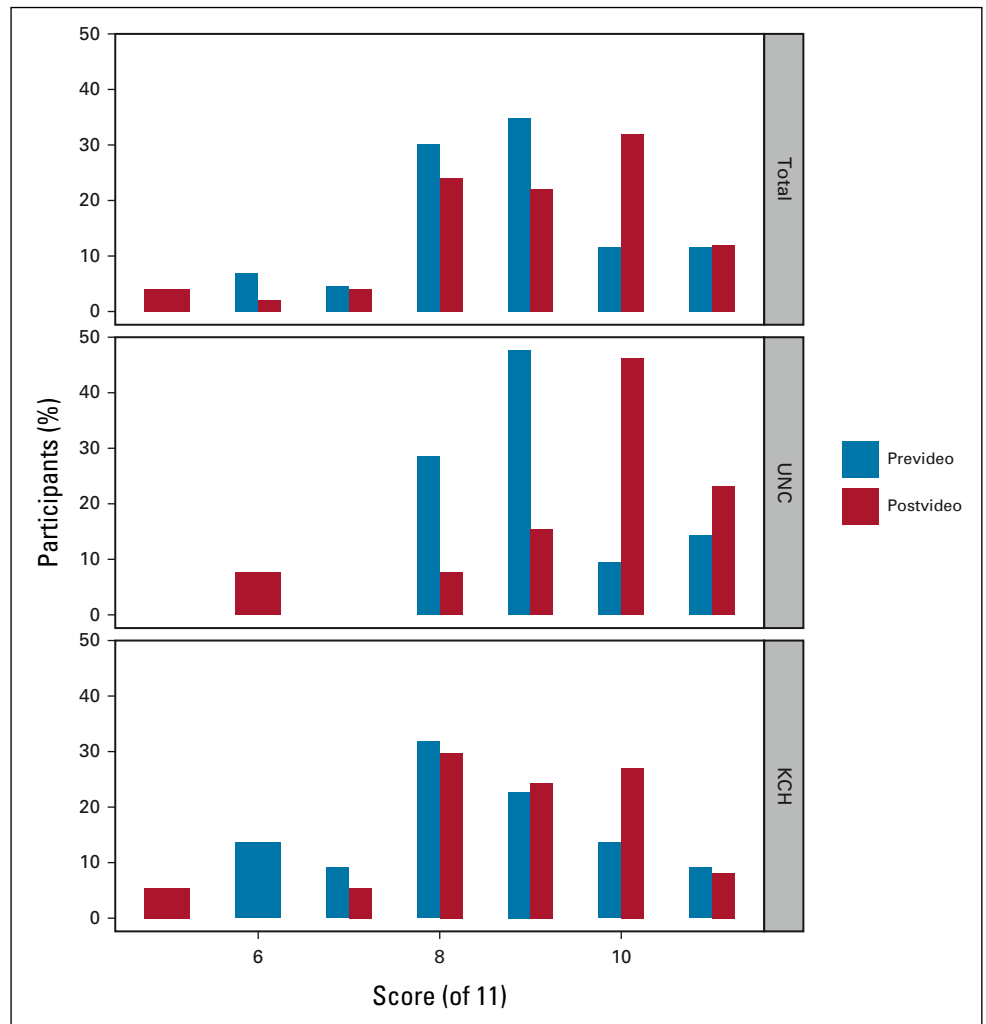


FIG 1. Scores stratified by patient type. Scores were only calculated for participants who provided answers to all 11 questions (pre: n = 43; post: n = 50). KCH, Kamuzu Central Hospital; UNC, University of North Carolina.

DISCUSSION

Cancer educational videos and educational tablets are a low-cost and entertaining way to educate and empower patients with cancer in resource-constrained settings, but published literature from SSA is scarce and limited to cervical cancer and Kaposi sarcoma.¹⁴⁻¹⁸ The videos developed for this patient education intervention provided comprehensive standardized cancer-specific, site-specific patient education and reduced the education responsibilities of clinicians and nurses. However, our experience highlights major misconceptions about cancer even in the context of the educational videos and standard counseling. Despite these misconceptions, patients reported improved patient empowerment after watching the videos. This is important in our setting, where patients are often not involved in shared decision making with their providers regarding their health care.

Overall, a majority of patients correctly answered questions related to cancer knowledge in the preintervention surveys. We compared pre- and postintervention surveys to identify

areas of improvement in patient disease knowledge and instructional gaps. Postintervention assessments showed improvements in areas where preintervention knowledge was poor, such as frequency of treatment and how to respond to a fever at home. Notable gaps in patient preintervention knowledge were incorrectly believing that cancer is an infection and not knowing the correct test to detect if cancer is in the brain. These knowledge gaps remained in postintervention assessments, despite being discussed in the educational videos. This finding may in part be because many cancers in Malawi are associated with infections, and the question might have been confusing to the participants. Patients might also benefit from a more active participation in education, through focused viewing of the videos, perhaps in smaller groups with a nurse educator present to answer questions and facilitate conversation. Coupling comprehensive video-based patient education with a small group led by a nurse educator may be feasible and more effective, which we plan to test in future studies.

Other technology-based educational interventions in SSA have assessed the impact of educational videos immediately

postintervention in individual patients. The act of completing the preintervention survey may prime individuals to be more aware of the information imparted by the videos, which would have led to an overestimation of the videos' impact. We designed our study intentionally to assess the impact of passive viewing of the educational videos over time, sampling different pre- and postintervention groups via convenience sampling to minimize bias. Our data instead evaluate knowledge retention beyond the immediate postintervention period, which other studies have not assessed.¹⁴⁻¹⁸ Overall, patients' knowledge of basic cancer topics is good although this suggests that our survey could be improved by adding questions on specific topics covered in detail in the videos to further assess if the videos improved knowledge.

However, the use of the convenience sample limits direct comparability between the cohorts as they might have differed with respect to age, sex, cancer diagnosis, and education status. The study is also limited by the inability to control for time in treatment and level of exposure to the videos. Participants' knowledge possibly increases over time through more medical interactions and repeated exposures to the educational videos, which could lead to an overestimation of the effect of the educational intervention. We did stratify our analyses by UNC research participant status to minimize potential bias from other study procedures and saw improved knowledge, although not statistically significant. For future interventions, we plan to conduct focus group discussions with patients and trial active viewing of the educational videos in small group settings with facilitation by a nurse educator.

Postintervention assessments of care experience suggest increased dissatisfaction among patients with their care

and with providers' explanations of their disease and treatment. This could be because the assessment asked specifically about the medical team explaining various things, and in the postintervention cohort, the patient education could have been perceived as occurring less by the medical team as it has been shifted to the educational videos. Furthermore, patients felt less listened to and included in decisions regarding their care. This could possibly be explained by factors related to the progression of cancer treatment, with patients later in their treatment course experiencing more tasks related to the execution of therapy and having less time for education. Paradoxically, patients reported feeling empowered by the information they learned in the videos, perhaps a result of patients becoming more informed about what questions to ask and knowledge to seek, as these videos encourage patients to become more informed. Taken together, our results highlight the importance of shared decision making and the need to further encourage this to be standard of care for patients and their oncology providers.

In conclusion, standardized educational materials for patients and families that can be reproduced, translated, and feasibly implemented throughout SSA are urgently needed. Cancer educational videos are a low-cost and entertaining way to educate and empower patients with cancer in resource-constrained settings. Findings suggest that in-person discussions between patients and providers remain a crucial part of cancer care, as a more active approach to patient education may be necessary in low health literacy settings. The videos we created are currently available on YouTube (*Cancer Education for Malawi*)³⁰ and are freely available for translation and adaptation by other groups.

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DISCLAIMER

The funding agencies had no role in study design, data collection, data analysis, data interpretation, writing of the report, or the decision to submit it for publication. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

EQUAL CONTRIBUTION

A.E.T. and G.K.E. contributed equally to this work.

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