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Evaluating the Effect of a Video Education Curriculum for First Time Breast Cancer Patients: a Prospective RCT Feasibility Study

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Abstract

Newly diagnosed breast cancer patients seek information through a variety of sources. In this small pilot study, we evaluated the feasibility of providing personalizable breast cancer video education prior to the first oncology consultation and compared outcomes to patients receiving standard of care educational materials. Personalized videos included detailed information on a patient's specific grade, stage, and tumor subtype (e.g., grade 2, stage 3, triple negative breast cancer) in addition to general videos that defined the terms of grade, stage, and cancer subtype. Newly diagnosed breast cancer patients who were scheduled for an initial oncology appointment at two sites were enrolled in this prospective, randomized control trial. Twenty-eight patients were assigned to receive either video education (experimental group) with the possibility of personalization or a video explaining how to view cancer education materials at the cancer center website (control group). Sixteen oncologists at the two centers also participated in evaluating patient outcomes. Pre- and post-education surveys queried patient-perceived understanding of breast cancer and treatment, perceived ability for decision-making, confidence in providers, and anxiety and depression symptoms. We observed that patients given video education had greater improvements in some of these areas, with the biggest improvement seen in patients who received a personalized video on their specific tumor subtype (based on tumor receptor status). Overall, however, there were no statistically significant differences between the study groups. We conclude that providing personalized video education during the time prior to first oncologic consultation is feasible and may provide benefit for patients, especially for explaining complex components of a diagnosis, such as a cancer subtype. Further research is needed to determine how to optimally provide education tailored to a given patient and tumor type, and how to leverage patients' electronic devices as an education delivery vehicle.

Keywords Breast cancer · Breast cancer education · Video education · Cancer education

Introduction

A breast cancer diagnosis is a life-changing moment for any patient and can be overwhelming for a multitude of reasons. Patients may experience difficulty in understanding and navigating the ample and sometimes inaccurate and conflicting information regarding breast cancer available through various mediums. It is also not uncommon to experience significant

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resultant psychological distress [1]. A 2011 meta-analysis including 10,071 patients at varying stages of disease in oncological and hematological settings, found the prevalence of mood disorders, including anxiety and depression, to be as high as 38.2% [2].

After learning of their diagnosis, but prior to the first appointment with a breast cancer specialist, patients frequently seek information on breast cancer from a variety of sources. During this time, personalized guidance that effectively introduces patients to the complexities of a breast cancer diagnosis and the available treatment options is not readily available. This time period is further complicated when patients do not know their specific diagnosis (e.g., unknown receptor status) and thus may be more likely to consume information that does not apply to them. Tertiary cancer centers offer written and online educational materials to patients prior to the first appointment; however, the content of these resources is often limited, non-personalized, and can be overwhelming and difficult to understand, particularly for those with language barriers and low literacy rates. Per the National Center for Education Statistics, 30 million Americans have below basic literacy skills, meaning that they can only complete the most simple and concrete literary tasks [3]. One study that examined 10 different cancer brochures found that the mean reading level needed for comprehension was grade 12 [4], a reading level that exceeds the education level attained by many Americans. There is clearly a need for improving the approach to providing information to newly diagnosed breast cancer patients using other forms of media such as video, especially during the interval between diagnosis and the first encounter with a medical provider.

The possible benefits of improved cancer education provided through web-based and video formats are several-fold, as previously demonstrated. One study of 109 newly diagnosed breast, colon, and lung cancer patients who were receiving chemotherapy found that patients who received a computer-based intervention that included education about disease and treatment had significantly less depression and anxiety than control patients [5]. Another study of adult cancer patients in a radiation oncology clinic who were given an educational video about radiation therapy found that an overwhelming majority stated the video helped them feel prepared, and 66% said they felt "not scared" after watching it. Importantly, 38% of participants shared that they would have liked to see a video specifically about their type of cancer [6]. Thomas et al. demonstrated that in a group of 220 newly diagnosed breast cancer patients undergoing chemotherapy or radiation, patients who received an educational video about treatment had significantly lower scores of anxiety and depression than patients who did not receive such a video [7].

In addition to decreasing fear and emotional distress, educational videos have also been associated with improved patient knowledge about cancer treatment. Matsuyama et al. showed that patient knowledge about radiation therapy increased after viewing an educational video before the initial oncology consultation [8]. Another study found that in prostate cancer patients preparing for their first radiation treatment, patients who received a preparatory video instead of a pamphlet tended to feel more prepared, though the results of this small study did not meet statistical significance [9].

Although many studies have used educational videos with cancer patients [5–14], much of the research has been conducted in educating patients on specific aspects of cancer care such as chemotherapy or radiation. What is less clear is to what degree video education that overviews key breast cancer topics that influence decision-making around treatment recommendations, such as tumor stage, grade, and receptor status, would be beneficial for newly diagnosed patients before the initial consultation. There is also limited data on how to leverage personal laptops, tablets, and smartphones to deliver this education. Personalized video education tailored to patient and tumor specifics has not been studied, although prior studies have suggested that there is a desire for such videos [6]. We conducted a feasibility study to evaluate the effect of electronically delivered personalizable video education compared to standard of care educational materials when given prior to the first oncology consultation, in the newly diagnosed breast cancer patient population.

Materials and Methods

Study Design

This was a two-center, prospective, randomized control feasibility study comparing personalizable video education (experimental group) vs. standard of care educational materials (control group) that was conducted over a 16-week period from November 2016 to May 2017. Newly diagnosed stage I–III breast cancer patients scheduled to be seen at the Seattle Cancer Care Alliance (SCCA) or University of Texas (UT) Health Sciences Center at San Antonio, as well as the breast cancer physicians with whom they had a scheduled appointment, were invited to participate.

Patients who consented to the study were assigned using simple randomization to receive either video education (experimental group) with the possibility of personalization if requisite health information was available or a video explaining how to view cancer education materials at the cancer center website (control group). Patients in both arms were asked to complete surveys at baseline, after reviewing the educational material but before their appointment (post-education), and post-appointment. Physicians were asked to complete a baseline survey, and then a survey after each appointment with a given patient in the study. Physicians were blinded to the patient's assigned intervention arm but could

be unblinded if patients disclosed this information during their appointment.

The study was comprised of three phases: (1) video education development, (2) subject recruitment, and (3) surveys and data collection.

Video Education Development

The study team created the video educational curriculum presented to patients in the experimental group. The content of the videos included information available on both cancer centers' websites. The videos went through multiple iterations and were reviewed and approved for quality and accuracy by a group of breast oncologists, many of whom had appointments with patients in the study. The curriculum was divided into three sections, each comprised of 2–4 min videos: (1) understand your disease, (2) meet your team, and (3) your treatment basics. Videos in "understand your disease" discussed the basics of breast cancer biology including defining tumor subtype (based on estrogen receptor (ER), progesterone receptor (PR), and human epidermal growth factor receptor 2 (HER-2) status), stage, and grade with videos using text, pictures, and motion graphics accompanied by an audio voiceover. All patients in the experimental arm received these videos. Personalized video content for specific tumor grade, stage, and subtype was also created and was assigned to patients by study staff if this information was available through biopsy and imaging results prior to the appointment. Patients receiving these specialized videos were considered the "personalized" group within the experimental arm. The "meet your team" section included videos of a patient's assigned team of medical, surgical, and radiation oncology physicians and breast cancer nurse navigator, each individually introducing themselves, as well as a video introducing the cancer center and a video of what patients should expect at their first appointment. Lastly, the "your treatment basics" section featured videos of oncologists explaining some of the main breast cancer treatment options available from the fields of surgical (mastectomy versus lumpectomy, axillary lymph node dissection versus sentinel lymph node biopsy), medical (endocrine therapy, chemotherapy, and HER-2 targeted therapy), and radiation oncology.

Subject Recruitment

Patient Enrollment Newly diagnosed stage I–III breast cancer patients were recruited to participate by study staff over the phone or in person using a standardized script after they scheduled their first appointment or at the time of disclosure of their biopsy results. A patient's eligibility status was assessed by accessing their electronic medical record. Patients who were non-English speaking, who had known decisional impairment, prior diagnosis of breast cancer, and/or were under 18 years of age were considered ineligible.

Eligible and interested patients were given access to a website where they could set up a personal health information (PHI) de-identified profile and join the study. They were asked to view an informational video outlining the objectives of the study as well as its associated risks and benefits. A transcript of the video was also available. After viewing the video, patients could choose to join the study online. If a patient agreed to participate, they were then assigned via simple randomization to receive a short video describing how to access standard cancer center website-based educational materials (control) or a personalizable video educational curriculum (experimental).

Physician Enrollment Medical, surgical, and radiation oncology physicians specializing in breast cancer at the two centers were also invited to participate in the study. In total, 25 physicians were eligible to participate. Their study enrollment and profile creation process was identical to that of patients. Physicians were not assigned to view patient educational videos. Nurses were not recruited in order to control for the degree of medical training.

All Participants Those who joined the study online were also required to read a study information sheet and sign an informed consent document stating that their data was intended to be used for publication. Subjects were not compensated for their participation. The study was approved by the Fred Hutchinson Cancer Research Center Institutional Review Board (IRB) and UT-Health Sciences Center IRB.

Surveys and Data Collection

All patient participants were asked to take Likert scale surveys at three different times: baseline, post-education/pre-appointment, and post-appointment. These surveys collected demographic information and assessed patient perceived understanding of breast cancer and its treatment, perceived decision-making ability, confidence in their providers, and anxiety and depression symptoms (see supplementary materials). Demographics questions were adapted from the CAHPS Visit Survey 2.0. Anxiety and depression symptoms were assessed using the GAD-2 and PHQ-2 using a 4-point Likert scale (0 = not at all, 3 = nearly every day). All other outcomes were measured on a 5-point Likert scale (0 = not at all, 4 = very much) using questions developed specifically for this study by the study team, which have not been validated. The experimental group completed the post-education survey after watching the videos, and the control group was given access to the post-education survey 2 days before their appointment, with the assumption that they had viewed standard of care materials by then. Our team could track what percentage of assigned videos patients in the experiment group

viewed. Completing survey questions was not required for access to educational materials or videos for either study group.

Physician participants were asked to take surveys at two different time points: at baseline and after each appointment with a given patient in the study (see supplementary materials). The baseline survey collected demographic information, and the post-appointment survey asked physicians to evaluate their patient's understanding of breast cancer, decision-making, and their visible anxiety and depression symptoms during the appointment. All outcomes were measured on a 5-point Likert scale (0 = not at all, 4 = very much), including anxiety and depression symptoms which were measured using adapted PHQ-2 and GAD-2 instruments.

Statistics

Descriptive statistics of patients in both groups were tabulated using frequencies and percentages for categorical variables and means and ranges for continuous variables. Two-sample *t* tests were used to compare the mean change in survey outcomes between the experimental and control groups. The one-way ANOVA was used to compare the mean change in scores across the control group, the experimental group with video personalization, and the experimental group without video personalization on the outcomes of grade and subtype understanding. Linear regression models were used to test if the relationship between the treatment group and survey outcomes were affected by age, education, or treatment site.

Results

During the 16-week study period, 65 patients were eligible and offered enrollment between the two centers. Of those 65, 32 (49.2%) patients participated in the study. Fourteen were randomized to the control group and 18 to the experimental group. Twenty-eight participants (control = 10; experimental = 18) completed the baseline survey, 19 at the SCCA (control = 7; experimental = 12), and 9 from UTHS (control = 3; experimental = 6). Twenty-five patients (control = 8; experimental = 17) completed the post-education survey, and 15 (control = 4; experimental = 11) completed the post-appointment survey. Experimental group participants watched an average of 88.9% of their assigned videos, with 13 of the 18 participants watching > 95% of their total assigned video duration. Most patients were Caucasian (89%), greater than 54 years old (61%), and had at least a 4-year college education (68%). There were no significant differences between the control and experimental groups with respect to race, age, income, or education. Twenty-five breast cancer oncology physicians were offered enrollment, and 16 (9 medical, 4 surgical, and 3 radiation oncologists) signed consent for study participation.

After receiving education, the experimental group showed a greater numerical mean improvement in scores for perceived understanding of breast cancer and its treatment, perceived ability for decision-making, and confidence in their providers compared to the control group (see Table 1). These differences, however, did not reach statistical significance. There was a minimal observable difference in scores of anxiety and depression symptoms between the two groups. When examining the effect of personalized videos (see Table 2), patients in the experimental group who received a personalized video about their breast cancer subtype ($n = 11$) trended towards having a greater improvement in their understanding of breast cancer subtypes compared to both the experimental group participants without personalization ($n = 4$) and the control group ($n = 10$), though this difference was not statistically significant ($p = 0.07$).

Physicians evaluated 24 of the participants (control = 8; experimental = 16) on their understanding of breast cancer and its treatment, decision-making, and anxiety and depression symptoms. No trends or significant differences were found between the mean scores in the two groups given by the physicians.

There were three statistically significant interactions observed. First, those participants in the intervention group with at least a 4-year college degree exhibited a significantly greater improvement in their perceived treatment decision-making ability from pre-education to post-education when compared to participants in the intervention group with less education ($p = 0.04$). Second, age interacted with intervention group when patients were grouped as greater than or less than 54 years old: participants in the intervention group who were < 54 years old experienced a greater reduction in anxiety after video education than patients in the intervention group who were > 54 years old ($p = 0.001$). Lastly, patients in the intervention group with at least a 4-year college education exhibited a greater improvement in perceived confidence in their providers as compared to patients in the intervention group with less education ($p = 0.01$).

We did not examine patient responses from the post appointment survey given that nearly half of our study sample ($n = 13$) was lost to follow up at that time point.

Discussion

A new breast cancer diagnosis can be overwhelming due to the associated psychological distress and the challenge of obtaining accurate and tailored information regarding prognosis and treatment options. The interval from initial diagnosis, where one awaits additional pathology and imaging results, to first oncological consultation is a particularly stressful period for many patients and can last up to several weeks. How to most effectively provide education to patients during this time

Table 1 Mean change in outcome scores (5-point Likert scale) from Baseline to Post-Education in experimental vs control groups

Outcome Measures	All Patients		Control		Experiment		P-Value
	N	Mean Change	N	Mean Change	N	Mean Change	
Breast Cancer Basics	25	1.0	8	0.8	17	1.1	0.66
Grade	23	1.5	8	0.4	15	0.5	0.51
Subtype	25	1.6	8	1.1	17	1.9	0.19
Breast Cancer Treatment	24	0.5	8	0.2	16	0.6	0.29
Anxiety	24	0.0	8	0.0	16	0.0	0.80
Depression	25	0.2	8	0.1	17	0.2	0.69
Decision Making	24	0.2	8	-0.3	16	0.4	0.16
Provider Confidence	23	0.4	8	1.3	15	1.7	0.73

period has not been fully studied. The purpose of this pilot was to test the feasibility of creating and providing personalizable video education electronically to newly diagnosed breast cancer patients awaiting their first consultation, and to compare those provided with such video education to a control group who only accessed standard of care educational materials. Outcomes studied included perceived patient understanding of breast cancer and its treatment, perceived ability for decision-making, patient confidence in providers, and anxiety and depression symptoms.

The greatest improvement in outcomes after receiving an education was observed in favor of experimental group patients who received personalized video education on their tumor subtype (based on ER, PR, and HER-2 status). These patients exhibited a mean improvement of 2.4 points on a 5-point Likert scale in their perceived understanding of breast cancer tumor subtypes after receiving a video on their specific breast cancer subtype compared to experimental group participants who did not receive such a video (1.0-point mean improvement) and the control group (1.1-point mean improvement). Though this difference was not statistically significant, the observation that the experimental group improved the most on a specific outcome such as subtypes rather than general concepts is consistent with past research. Matsuyama et al. [8] showed that patients given video education improved their understanding of radiation therapy and work conducted by Dawdy et al. [9] suggested that video education helped new patients feel better prepared for radiation therapy specifically as well. There was a trend towards improved perceived decision-making ability and confidence in providers in the experimental group, although this did not reach statistical significance. There was no trend observed between groups on anxiety and depression outcomes. Interestingly, physicians did not tend to rate experimental group participants as superior on any measured outcomes. One possible explanation is that it may have not been clear to physicians whether they were evaluating patients at the beginning of the appointment or at its end. If they perceived the latter, then they may have felt that after their conversation with their patient, the patient's resultant knowledge level was high regardless of pre-appointment level. There may have been a detectable difference if physicians were explicitly instructed to evaluate patients at the beginning of the appointment. In addition, we did not specifically track which physicians saw which patients, so given our small numbers, it is possible that a given physician only assessed patients in the control group, which would introduce bias into the results. Finally, physicians were not given the patient survey until a day after the appointment, and it is plausible that by that time they had limited recollection of the visit.

In this study, we also explored how to integrate multimedia education into clinical care. The approach we took was having staff send anonymized but personalized invitation links over email so that patients could view video education on their own devices ahead of appointments. We additionally

Table 2 Mean change in understanding of grade and subtype scores (5-point Likert scale) from Baseline to Post-Education in experimental group with personalized videos vs experimental group without personalized videos vs control group

Outcome Measures	All Patients		Control		Experimental – No Personalization		Experimental – Personalization		PValue
	N	Mean Change	N	Mean Change	N	Mean Change	N	Mean Change	
Grade	23	1.5	8	1.3	7	1.1	8	1.9	0.57
Subtype	25	1.6	8	1.1	4	1.0	10	2.4	0.07

allowed the option of having staff present video education on tablets for patients to view while in the clinic. Anecdotally, we did hear that some patients were not tech savvy enough to access the videos at home. Given that many cancer patients are of older age and may be less comfortable with technology, we hypothesize that giving patients the option to view multimedia materials in the clinic in addition to home viewing would improve accessibility.

This study had several limitations and confounding factors. With our small sample size of 28 patients, we were both limited in our power to test for statistically significant differences between the experimental and control group and were at risk for sampling error. Additionally, our simple randomization protocol and attrition in the control group resulted in the study groups being unequally balanced, with 10 and 18 participants in the control and intervention group, respectively, which further limited our study's power to detect statistically significant difference. Though no statistically significant results were found, we heard anecdotally from several patients that they appreciated the video education and found it helpful. Several physicians also told us that they could readily discern which patients had watched the videos as they could discuss cancer topics much more readily and at a higher level. Our study sample was also not representative of the general population. Our participants were mostly white (89%) and more educated than the general US population (68% in a study with at least 4-year degree vs 33.4% in general population) [14]. Our highly educated sample, which was equally represented in both the control and experimental group, may have had less to gain from video education than perhaps a less educated, less literate group of patients. This could have confounded the benefit of video education. Our data however suggested that treatment group effect varied by level of education for some outcomes. More educated patients (at least 4-year college education) who were given video education were more likely to gain higher confidence in their providers and be more confident in making decisions after watching the videos than less educated patients who were also given video education. The reason for this is unclear. Our measurement of patient understanding of breast cancer and its treatment was also evaluated subjectively, not objectively. Our subjective measurements may not have accurately captured what patients learned with video education as we only assessed their perceived knowledge level. However, at this early stage of diagnosis, this difference may not have significance for patients as what may be most important for their wellness is that they believe they are understanding concepts better. These measures also have not been previously validated and were developed by the study team. Lastly, providing control group participants with a video explaining how to access and view cancer center website information may have served as an intervention by increasing engagement with standard of care educational materials online. This could have potentially confounded the benefit of video education compared to control.

In summary, even though none of our results reached statistical significance, our findings suggest that there may be a benefit to providing newly diagnosed breast cancer patients with video education prior to their first oncological consultation. Video education may be especially helpful for educating patients about particularly complicated concepts, such as breast cancer subtypes. This study also demonstrates that providing video education electronically to patients before the initial in-person consultation is feasible. We were able to send patients email links to an online hub of videos without technical difficulty.

Conclusion

Newly diagnosed breast cancer patients frequently seek easily accessible, concise, and relevant information about their disease. The time interval between breast cancer diagnosis and first oncologic consultation is particularly stressful, and this is when patients may feel the most lost and benefit from personalized education from their cancer center. During this time, video education endorsed by reputable cancer centers may be useful for providing trustworthy information and for explaining complex components of a diagnosis, such as a cancer subtype, which can then be reviewed face-to-face at the first visit. Given patients' varying levels of education, learning styles, and comfort level with technology, patients should be given the option to view education through multiple mediums including videos, pamphlets, and web-based materials both at the clinic and at home.

Future research on this topic should aim to recruit a larger, more demographically diverse study sample, which would allow for improved detection of statistical significance. One could also investigate the benefit of providing personalized educational videos at different time points, such as after the first or second appointment, when there is likely more diagnostic information available. Videos at this time could also help solidify important concepts discussed between patient and physician. More generally, further work should be done to determine how to best leverage a patient's own electronic device to be a powerful multi-media delivery vehicle in the healthcare setting. Lastly, it should be considered that patient understanding of new concepts be evaluated with objective measures rather than subjective report.

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Compliance with Ethical Standards

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

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