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Bethany Karnes April 6, 2022

Needs for and Barriers to Patient Education: Can a Website Help Bridge the Gap?

by

Bethany Karnes

Dr. Gregg Orloff
Advisor

Biology

Dr. Gregg Orloff

Advisor

Dr. Rebecca D. Pentz

Committee Member

Dr. Arri Eisen

Committee Member

2022

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Bethany Karnes

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Abstract

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Oncology patient education is a sensitive and complex field, especially with the rise of internet use for health information. This study aims to understand how oncology physicians educate patients, the barriers physicians experience throughout this process, and what educational formats are preferred by physicians and patients. From December 2021 through March 2022, physicians, patients, and caregivers at Winship Cancer Institute participated in interviews regarding their experiences with oncology patient education. A review of CancerQuest.org was also conducted during these interviews, as the information obtained from this study is intended to improve this website as an educational resource. Respondents reported a variety of methods used by physicians to educate patients, and patients expressed a preference for resources to refer to outside of appointments. Barriers to education identified by physicians included health literacy, misinformation, lack of time, and emotional barriers. 79% of patients and caregivers used the internet to educate themselves about cancer, but feedback from physicians indicates that the resources that patients access are rarely reliable or helpful to the educational process. Although none of the patients or caregivers had seen the CancerQuest webpage before, 79% felt that it would have been helpful and 85% of physicians said that they would refer patients to this resource. This data indicates the potential benefits of increased use of this website as an educational tool.

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BACKGROUND

Introduction

Patient education is a critical component of the treatment experience, specifically for oncology patients. The heightened mental and emotional turmoil associated with a cancer diagnosis amplifies the need for patients and family members to be maximally informed about diagnosis, prognosis, and treatment. Patient education occurs through a variety of forums, including physicians during clinic appointments and patient-initiated internet searches. It is crucial that patients have access to accurate patient education, both through patient-physician relationships and through outside resources. Gaps remain in our understanding of barriers to patient education.

One outside educational tool available to patients is the CancerQuest website (www.cancerquest.org). CancerQuest is part of a non-profit organization at Emory University with the purpose of educating patients, family members, and other interested individuals about the biology and treatment of cancer. It is designed, using text, graphics, and animations, to be used by individuals of all educational backgrounds and understanding levels. It is available in English, Spanish, and Mandarin Chinese, and is visited by an average of 9,000 people daily worldwide. Although CancerQuest has been established as a strong educational resource, unpublished data show that it is not utilized as frequently as expected (Pentz et al., 2022).

This study was designed to investigate clinician and patient preferences for avenues and formats of patient education. We also studied how healthcare professionals approach educating their patients and the barriers facing these efforts. The insight gained from this study will be used to improve the access to and efficacy of CancerQuest. We hypothesized that health professionals primarily utilize verbal communication to educate their patients about cancer diagnoses, and that their primary burden to education is inadequate time. We also hypothesized that educational videos/animations are the preferred educational format for patients and physicians.

The primary aim of this study was to interview physicians about the methods they use to educate their patients, the barriers to education that they experience, and their preferred presentation format. The CancerQuest website was reviewed for the particular disease site of their specialty and suggestions for improvement recorded. We also interviewed patients about their experience with cancer education, what resources they were given, what resources they utilized, and their preferences for educational resource formats. The CancerQuest website information about their disease was reviewed and suggestions for improvement recorded.

Literature Review

History of Patient Education

Patient education as we know it today was not always the standard in healthcare. Until the 1960s, the medico-centric model prevailed, in which the physician possessed sole jurisdiction over medical information. Patients were not considered active participants in treatment plans and were often not even provided with educational information (Hoving et al., 2010). Beginning in the 1970s, the rise in consumerism and prioritization of consumer health information initiated an increase in patient education. With the *Patient's Bill of Rights* in 1972, the American Hospital Association established the patient's right to know. Outside sources, such as news media and television, also became sources of consumer health information. This, combined with structural changes that decreased time physicians spent with patients, increased consumers' desire to seek out their own health information (La Rocco 1994). In the 1980s, patient education grew due to the rise of patient advocacy organizations, new legislation, and the development of technology such as slide presentations and videos. In the 1990s, patients began to be held responsible for their choices regarding their health and dialogues between patients and physicians as equals began to become the norm. The physician-patient dynamic was also affected by the increased access to electronic sources of health information, allowing patients to acquire information on their own that they brought into conversations with healthcare professionals (Hoving et al., 2010). Today, patient education is a primary component of the patient-clinician relationship. It is particularly the case in oncology. This is reflected in the training received by physicians and other medical professionals. The first steps towards prioritization of this training were initiated in 1996 at the International Conference on Teaching in Medicine in Oxford, followed by several similar conferences that resulted in the establishment of patient education organizations. That taught patients how to self-regulate and communicate with their providers. The standard practice in the 21st century has evolved to reflect not only an equal relationship between patient and clinician, but a consideration of social factors when making treatment decisions (Kluetz, et al., 2018, Hoving et al., 2010). Because of the autonomy acquired by patients in the early 2000's, studies that investigated the sources used by breast cancer patients showed that, now more than ever, patients have a desire to acquire current and accurate information to be maximally informed about their conditions (Satturlund et al., 2003). The relationship between patients and clinicians is more balanced than ever before, emphasizing the importance of both clinician-provided and patient-identified sources of health information. A study of 283 breast and lung cancer patients from two cancer centers found that cancer patients who report achieving their desired involvement in the decision-making process are less likely to report below average health-related quality of life than those who do not (Samuel et al., 2019).

Strategies of Patient Education

There are several avenues available for clinicians to educate patients, including time spent during clinic appointments and referral to external resources, such as pamphlets and websites. The American Society of Clinical Oncology Consensus Guideline provides guidance to healthcare physicians on how to improve physician-patient relationships and provide a platform for the patient to better understand their diagnosis. This resource emphasizes the use of clear communication and the importance of addressing topics such as goals of treatment, treatment selection, and end-of-life care (Gilligan et al., 2017).

In addition to direct caregiver-patient conversations, several other teaching strategies have also been employed to provide a more holistic educational experience for patients. Gockley et al. showed that tablet-based education during clinical appointments improved patient knowledge of HPV-related cancers by testing patient knowledge before and after they accessed the resources (Gockley et al., 2019). App-based videos provided in clinic waiting rooms also received positive feedback from participating patients. In a study of 152 patients, 62% of patients were interested in receiving further tablet-based education and 73% found the education to be moderately or very helpful (Highland et al., 2021). The addition of animations in chemotherapy education has also been proven to increase understanding and reduce anxiety. Kumar et al. demonstrated that 24.3% more patients who viewed videos were at least somewhat confident in their knowledge and 46.8% reported reduced anxiety after viewing the videos (Kumar et al., 2021, Pentz, et al. 2019). Although videos have been proven to be an effective teaching tool, studies have shown that they can be less effective if they are created for commercial intent (Kumar et al. 2021, Bae and Baxter, 2017). The use of audiovisual formats has been associated with higher patient satisfaction rates than traditional strategies, such as the distribution of written materials (Saeed, 2018). Additionally, the use of multimedia or a combination of teaching strategies has proven successful in educating patients, and is associated with increased knowledge, decreased anxiety, and increased satisfaction (Friedman et al., 2011, Loiselle et al., 2010). A study of patients and caregivers revealed that there are still unmet informational needs among cancer patients (Truccolo et al., 2018).

Barriers to Patient Education

Several barriers to patient education have been documented by healthcare professionals. For example, clinicians are experiencing a dramatic decrease in the amount of time that they have available to meet with each patient, resulting in less time for education (Tai-Seale et al., 2017). There is an abundance of misinformation available to patients on the internet and an inability of users to be able to decipher this misinformation. This further emphasizes the need for physicians to spend adequate time providing accurate information to their patients (Iammarino et al., 2018). Because of the nature of their disease, oncology patients in particular experience a variety of emotions, including fear, anxiety, and worry. These emotions have been demonstrated to impact cancer-related decision-making, again highlighting the need for quality patient education (Mazzocco et al., 2019). Through a study of providers' barriers to educating patients, Freda demonstrated the need for relevant and understandable educational materials available to providers to refer patients to, as well as a lack of provider training in patient education in general (Freda, 2004).

Although some barriers to patient education by clinicians have been documented, significant gaps remain in our understanding of this critical issue. Understanding the barriers is crucial to the creation and delivery of quality education that can overcome these obstacles.

The Effects of COVID-19 on Oncology Patient Education

The COVID-19 pandemic has affected the oncology education process in a variety of ways. Since the beginning of the pandemic, 44% of individuals involved in cancer education reported a change in their daily patient education routines and 63% reported a change in their ability to develop patient education materials. This change represented either a decrease in development of cancer education materials or a shift towards the creation of COVID-19 specific resources (Lawrie et al., 2022). A study of 169 cancer patients reported decreased emotional functioning and increased feelings of isolation due to the pandemic (Bartels et al., 2021). A study of cancer-care physicians demonstrated that 62% of respondents had feelings of COVID-related anxiety, specifically worries regarding their ability to provide treatment to their patients and concern that their patients will not receive an adequate level of care (Thomaier et al., 2020). Many cancer patients also have experienced decreased social support, which is typically viewed as an integral to helping patients endure cancer diagnoses and treatment (Gallagher et al., 2021). These added obstacles further complicate the educational process for oncology patients and physicians.

The Internet as a Source of Health Information

The internet has become an increasingly popular source of health information for both patients and clinicians. In the United States, 80% of adults who use the internet have reported searching the web for online health information (Fox, 2020). Health-related internet use varies drastically among various demographics. Lower levels of education are associated with lower likelihood of searching for healthcare physicians online, using the internet to communicate with physicians, using the internet to monitor personal health information, and using mobile devices to download health information (Kontos et al., 2014). Demographic groups that are more likely to use the internet for health-related purposes include younger generations (younger than 35 years), females, non-Hispanic Caucasians, and those with higher socioeconomic status (Naz Din et al., 2019). Although older individuals (65 years and older) are less likely to use the internet for cancer-related information, studies have shown that they are more likely to be satisfied with perceived emotional support from educational websites than younger individuals. Higher satisfaction with perceived emotional support was also associated with greater recall of information (Bol et al., 2013). Bass et al. also demonstrated that patients use the internet as a tool to both acquire health information and gain confidence to make important health decisions. Studies have shown that increased internet use among cancer patients is associated with stronger patient-physician relationships, including factors such as patient question asking and compliance with treatment. There is also a relationship between internet use and patient self-efficacy, as defined by confidence in contributing to treatment decisions, sharing concerns with physicians, and asking them questions (Bass et al., 2007). Internet usage has also been correlated with improved patient-physician communication, but this effect depends on the quality of the information accessed and whether this information is discussed with physicians (Langford et al., 2020). A study of 460 dermatology patients showed that 81.4% of respondents perceived internet searches for health-related information to have a neutral effect on the patient-physician relationship (Gantenbein et al., 2020). However, research is still needed to determine physicians' perspectives on how, and to what degree, online research affects the patient-physician relationship and patient education process.

MATERIALS AND METHODS

We investigated oncology patient educational experiences using virtual interviews of both physicians and patients. This study is considered oncology clinical research and underwent a multistep review process to gain approval. The protocol first required approval from the Winship Cancer Institute Protocol Review and Monitoring Committee (PRMC). Once PRMC approval had been acquired, the protocol was reviewed and approved by the Emory University Institutional Review Board (IRB).

The structured interviews were developed in consultation with the PIs and based on a literature review of the history, strategies, and barriers to patient education, as well as COVID-19 implications and health-related internet usage. This physician interview was cognitively tested with five research ethics colleagues and the patient interview with three patients to determine that the questions were clear and are interpreted in the manner which we intended.

Cognitive tests included reviewing each prospective question with the interviewees, asking them to provide their interpretation of what the question is asking, and recording any feedback regarding how the question could be clearer. This feedback was compiled to create the final list of questions. Standard demographic questions were also included in the questionnaire.

Phase one of this project involved interviews of physicians at Winship Cancer Institute. Any physician practicing at Winship Cancer Institute was eligible to participate. Clinicians received a mass email with a link to a Google form that allowed them to submit their contact information and preferred method of communication. They were then contacted to schedule a virtual interview of approximately 15-30 minutes. When the interview was confirmed, they were sent links to both the Homepage (https://www.cancerquest.org/) and Cancer by Type (https://www.cancerquest.org/patients/cancer-type) pages of the CancerQuest website and asked to briefly review beforehand. Consent to record the interview was obtained at the beginning of the meeting. Interview questions (shown in Table 1 below) were shown on the screen during the meeting, and probes were added verbally if necessary (shown in parentheses). During the CancerQuest-specific questions (questions 7-9), participants were given the option to view the website on the screen to refresh their memory. Participants were also asked demographic questions (shown in Table 2 below) in order to better understand the study population. Recordings were stored securely in a password-protected server and only the research team had access to video recordings. All data acquired during interviews were qualitative.

Table 1. Physician Interview Questions

Questions asked to physicians during interviews are shown. Questions were displayed on the screen. Probes shown in parentheses were added verbally when necessary. During questions 7-9, physicians were given the option to view either the questions or the website on the screen.

1. What methods do you utilize to educate patients? (ex. Drawing on a whiteboard, providing a pamphlet, showing a video, etc.)
2. What format do you think is best for providing information to patients? (ex. Text, animation, etc.)
3. What barriers do you encounter when educating patients? (ex. Not enough time, access to resources, patient understanding level, patient emotions, etc.)
4. Could an educational website, such as CancerQuest, alleviate any of these barriers?
5. What types of medical information do you want patients to have at the beginning of their diagnosis?
6. How is the educational process affected by patients accessing outside resources? (ex. Googling their disease before their appointment)
7. Ideally, who would refer patients to this website? (ex. Physician, PA, front desk, nurse)
8. What recommendations do you have for improving the CancerQuest website?
9. Would you refer patients to this website? Why or why not? When in their diagnosis would you want them to access it?

Table 2. Physician Demographic Questions

Demographic questions shown below were asked at the end of interviews. Respondents were informed that they had the right to decline to answer any questions.

10. How old are you?
11. Are you…… Male Female
12. What is your oncological specialty? Gastrointestinal Genitourinary Dermatology Breast Aerodigestive Tract Hematology Head and Neck Pediatrics Orthopedics Other, specify ___________________________________
13. How many years have you been practicing medicine? 0-5

5-10 10-15 15-20 20-25 25-30 30-35 35-40 40+
14. Are you involved in conducting phase I clinical trials? Yes No
15. If yes, for how many years have you been involved? 0-5 5-10 10-15 15-20 20-25 25-30 30-35 35-40 40+

Phase two of this project involved interviews with patients and caregivers at Winship Cancer Institute. A flyer was posted in patient areas. The flyer contained a QR code directing patients to a Google Form to submit their contact information. Like clinician interviews, participants were contacted via their preferred method of communication and asked to participate in virtual interviews of approximately 15-30 minutes. When the interview was confirmed, they were sent links to both the Homepage (https://www.cancerquest.org/) and Cancer by Type (https://www.cancerquest.org/patients/cancer-type) pages of the CancerQuest website and asked to briefly review beforehand. Consent to record the interview was obtained at the beginning of the meeting. Interview questions were shown on the screen during the meeting (shown in Table 3 below), and probes were added verbally if necessary (shown in parentheses). During the CancerQuest-specific questions (questions 9-12), participants were given the option to view the website on the screen to refresh their memory. Interviewees were asked to rank the website in four different categories that were proven effective in a previous study regarding educational website evaluation, including appearance, content, functionality, and usability (Ryan et al., 2015). Participants were also asked to provide demographic information (shown in Table 4 below) in order to gain an understanding of the interview sample. Recordings were stored securely in a password-protected server and only the research team had access to video recordings. All data acquired during interviews were qualitative. As an incentive, patient and caregiver participants were provided with their choice of a $20 Visa gift card (sent via mail) or $20 Amazon eGift Card (sent via email) upon completion of the interview.

Table 3. Patient and Caregiver Interview Questions
Questions asked to patients and caregivers during interviews are shown. Questions were displayed on the screen. Probes shown in parentheses were added verbally when necessary. During questions 9-12, respondents were given the option to view either the questions or the website on the screen.

1. How much time did your providers spend educating you on your disease in your initial appointment? In a typical (subsequent) appointment?
2. Is the time spent adequate to answer your questions?
3. What methods did/do they utilize to educate you? (ex. Talking to you, drawing on a whiteboard, providing a pamphlet, showing a video, etc.)
4. What educational format stuck with you?
5. What barriers did you have to understand what they explained to you? (ex. Not enough time, too emotional, words were too advanced and technical, etc.)
6. How have you used the internet to educate yourself about your disease?
7. When using the internet for health education, how do you determine what information is reliable?
8. Are there other ways you would like to learn about your disease that aren’t available to you?
9. Before we sent this to you, had you seen this webpage?
   If so, how did you find it? Was it helpful for you?

If not, would this webpage and CancerQuest in general have been helpful to you?
10. For each of the following categories, rank the CancerQuest website on a scale from 1-10: Appearance (design, color, font-size, pictures, etc.) Content (relevance, difficult to engage with, clarity, etc.) Functionality (ability to download pictures, send articles, print pages, etc.) Usability (easy to navigate, hard to navigate)
11. What was your favorite part about the website?
12. What would make you want to use the website more?

Table 4. Patient and Caregiver Demographic Questions

Demographic questions shown below were asked at the end of interviews. Respondents were informed that they had the right to decline to answer any questions.

13. How old are you?
14. Are you…… Male Female
15. Which of the following best describes you? Are you ... Asian or Pacific Islander Black or African American Latino, Hispanic or of Spanish origin or descent Native American/Aboriginal White Some other race, specify:______________________________
16. What is the last grade or year that you completed in school? Less than high school Some high school High school graduate or GED Some college College graduate Some post-graduate Post-graduate or Professional degree Other, specify ____________________________________
17. Which of the following best describes your employment or student status? Employed Full-Time Employed Part-Time Retired Not Employed Disabled Student

18. Which category best describes your combined family income in the last year (before taxes)?
    < $5,000
    $5,000 - $19,999
    $20,000 - $39,999
    $40,000 - $59,999
    $60,000 - $79,999
    > $80,000
    Don't know
    Refused

All interviews were recorded, and the interviewer took notes on the questionnaire throughout the interview. The recording was transcribed and coded, with all identifiers removed. Two independent investigators developed a codebook to code open ended questions after the first 6 interviews based on the interview guide or deductive codes set by the research team. Coding involved first transcribing interviews and recording answers to each question. Each answer given was assigned to a number indicating a code, so that each number represented an answer provided by at least one respondent. These codes could then be used to identify trends and determine if saturation of themes had been reached. Code books were compared, discrepancies were resolved, and a final code book was created to be used in coding all interviews. There were three questions after the meeting with the second coder for the physician codebook that needed to be resolved by the PI. All interviews were then coded with the themes entered in a Microsoft Excel spreadsheet. 10% of the interviews were double-coded, which is the standard percentage used in data saturation, and discrepancies resolved by consensus (Guest et al., 2006). A third independent coder resolved any remaining disagreements. After codebooks had been finalized, the frequencies of each response were added up to identify common themes. Interviews were conducted until saturation of themes was met, which is defined as the point when there is enough information to replicate the study and when further coding was no longer feasible (Fusch and Ness, 2015). This was determined in consultation with the PIs when the answers provided to interview questions, particularly those that elicited strong themes, were repeated by a large enough percentage of the sample. Due to the broad spectrum of the specificity of questions, these percentages ranged from 46-54% of physician responses and 43-93% of patient and caregiver responses.

Participants were not exposed to any stress beyond that ordinarily incurred in research interviews. Subjects were informed beforehand that they may decline to answer any questions that may make them uncomfortable. All answers remained confidential.

RESULTS

Fifteen physicians submitted the Google Form to sign up for an interview, 13 of which responded to follow-up emails to schedule a meeting. The demographics of physician respondents are shown in Table 5 below.

Table 5. Physician Demographics
Demographics reported by physicians are shown, as well as the number and percentage of individuals in each category. All respondents (n=13) provided answers to every question.

Variable (n=13)	Number	Percentage of Total
Age		
19-39	4	31
40-59	8	62
60-79	1	8
Sex		
Male	5	38
Female	8	62
Oncological Specialty		
Gastrointestinal	1	8
Genitourinary	1	8

Breast	4	31
Hematology	2	15
Head and Neck	1	8
Other	4	31
Years Practicing Medicine		
0-5	3	23
5-10	4	31
10-15	2	15
15-20	3	23
40+	1	8
Involved in Conducting Phase I Clinical Trials		
Yes	8	62
No	5	38

Google Forms were also completed by 40 patients, 14 of whom responded to schedule an interview. The demographics of patient and caregiver respondents are shown in Table 6 below.

Table 6. Patient/ Caregiver Demographics
Demographics reported by physicians are shown, as well as the number and percentage of individuals in each category. One respondent declined to answer the income question.

Variable (n=14)	**Number**	**Percentage of Total**
Patient/ Caregiver Status		
Patient	10	71
Caregiver	4	29
Age		
19-39	2	14
40-59	8	57
60-79	4	29
Sex		
Male	1	7
Female	13	93
Race		
Asian or Pacific Islander	1	7
Black or African American	3	21
Latino, Hispanic, or of Spanish origin or descent	1	7
White	9	64

Last Grade or Year Completed in School		
Some College	2	14
College Graduate	5	36
Some Post-Graduate	1	7
Post-Graduate or Professional Degree	6	43
Employment or Student Status		
Employed Full-Time	9	64
Not Employed	2	14
Retired	3	21
Combined Family Income Before Taxes		
$40,000-$59,999	4	29
$60,000-$79,999	1	7
> $80,000	8	57
Refused	1	7

Methods of Education

Both verbal education and written handouts were utilized by 69% of physicians. The third most common method mentioned by physicians was referral to outside resources, such as websites, which was reported by 62% of physicians. When asked which format is best for providing information to patients, both graphics and handouts were favored by 46% of physicians. 38% of physicians thought that verbal communication is the ideal format. Physicians noted cancer basics, such as staging (54%), treatment plans and schedules (54%), and treatment goals, expectations, and prognosis (38%) as the most important types of information they want their patients to know at the beginning of their diagnosis.

The majority of patients (93%) reported that their physicians educated them verbally. 43% received printed resources from physicians and 36% were shown images or scans. When asked which methods stuck with them, 57% of patients highlighted verbal education. Note-taking, printed resources, and videos were each mentioned by 14% of patients.

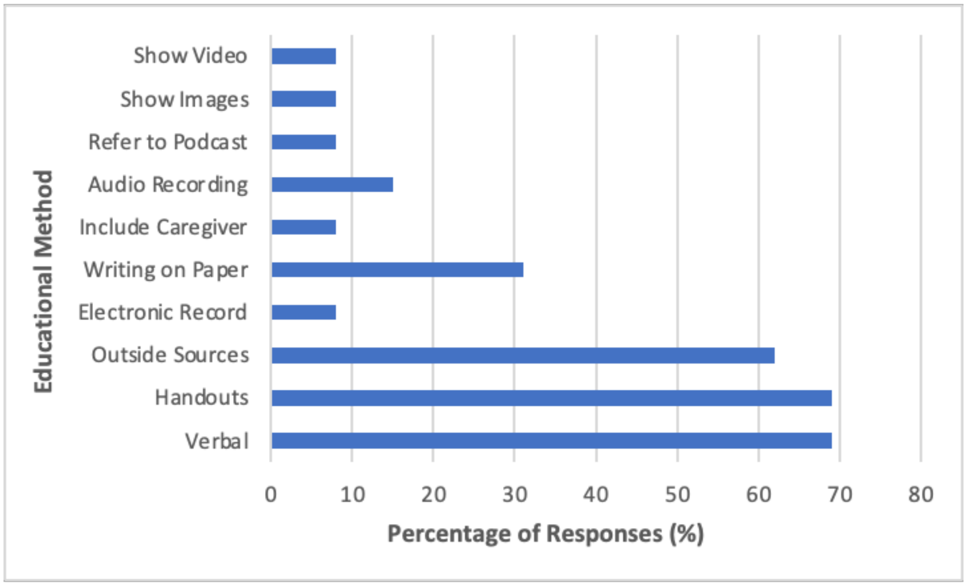

Figure 1. Educational Methods Reported by Physicians
Physicians (n=13) were asked what methods they utilize to educate patients. Responses are shown as the percent of physicians that provided each answer.

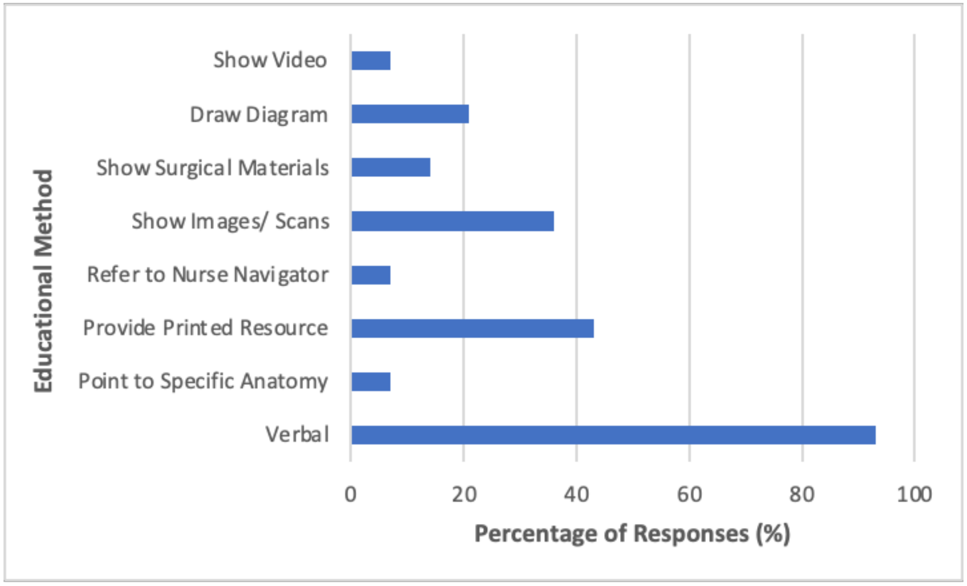

Figure 2. Educational Methods Reported by Patients/ Caregivers
Patients and caregivers (n=14) were asked what methods their providers utilized to educate them about cancer. Responses are shown as the percent of respondents that provided each answer.

The most common time range reported by patients that their physicians spent educating them during their first appointment was 15-29 minutes (43%). In subsequent appointments, 29 % of patients reported physicians spending 0-14 minutes and 36% reported physicians spending 15-29 minutes. The distribution of education time reported by patients is seen in Figures 3 and 4 below. 86% of patients reported that the time their physicians spent educating them was adequate to answer their questions.

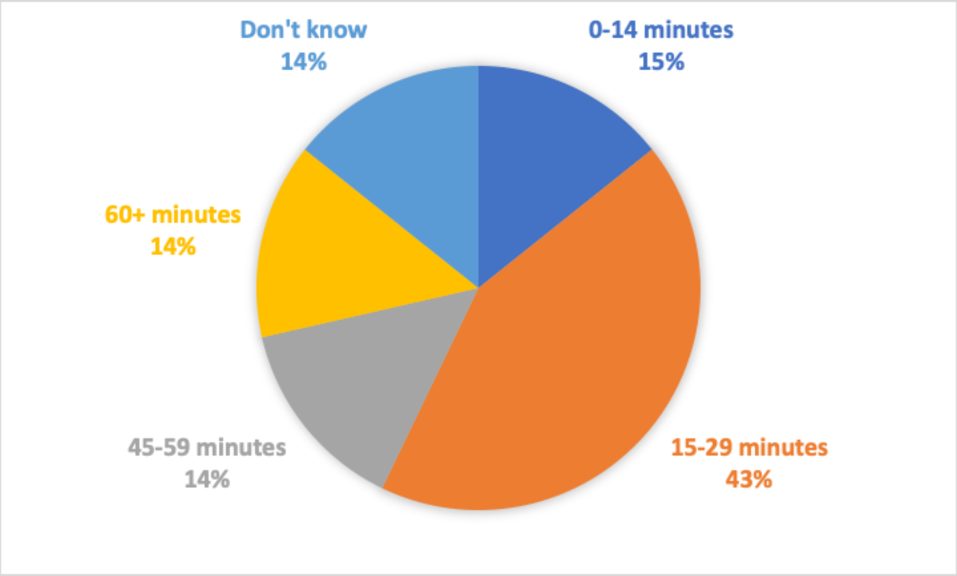

Figure 3. Time Spent on Education During Initial Appointment
Patients and caregivers (n=14) were asked how much time providers spent on education during their initial appointment. Answers were grouped into the time categories shown.

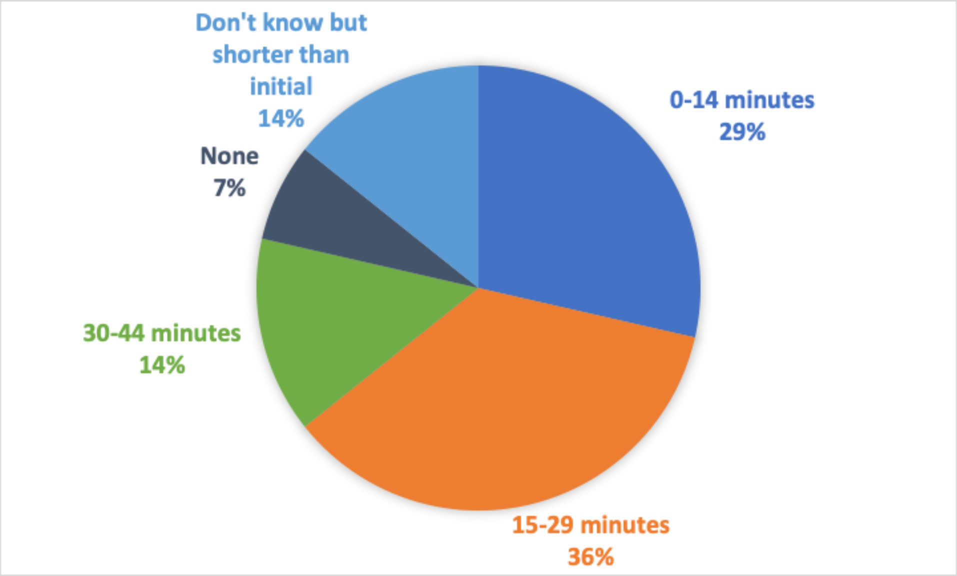

Figure 4. Amount of Time Spent Educating in Subsequent Appointments
Patients and caregivers (n=14) were asked how much time providers spent on education during their second and subsequent appointments. Answers were grouped into time categories as depicted.

Barriers to Education

Over half of physicians (54%) mentioned health literacy as a barrier to educating their patients. Other common barriers reported by physicians included misinformation, lack of time, and emotional barriers, all of which were answered by 38% of interviewees. When asked if an educational website could alleviate these barriers, 100% answered yes (with one physician answering both yes and no). 41% said that the reason these resources could help is because they allow patients to access high quality, reliable information. 43% answered yes but mentioned that there are barriers to accessing these sources, such as lack of internet access.

Almost half of patients (43%) mentioned emotions, such as fear and shock, as barriers to understanding what their physicians were explaining to them. 21% reported advanced terminology as a burden and 36% reported no burdens to understanding.

Patients were also asked if there were any resources that they would have liked to utilize but did not have access to. 21% expressed a desire for more Emory-specific educational resources. Practical information, such as clear discharge instructions, and animations were both mentioned by 14% of individuals. 29% of interviewees felt that they had access to all the resources they needed.

Patient/ Caregiver Internet Use

Patients and caregivers were also asked how they have used the internet to educate themselves about cancer. Overall, 79% of respondents reported using the internet to educate themselves about cancer. Over half (57%) reported accessing credible websites to search for information. 29% used the internet to join support groups. Reading about personal experiences and conducting broad Google searches were each mentioned by 21% of respondents. A similar fraction reported trying to avoid the internet altogether (21%). When asked how they determine which online resources are reliable, 86% of interviewees mentioned accessing resources created by reputable organizations, such as Mayo Clinic, and 29% mentioned asking their physician about the information they find.

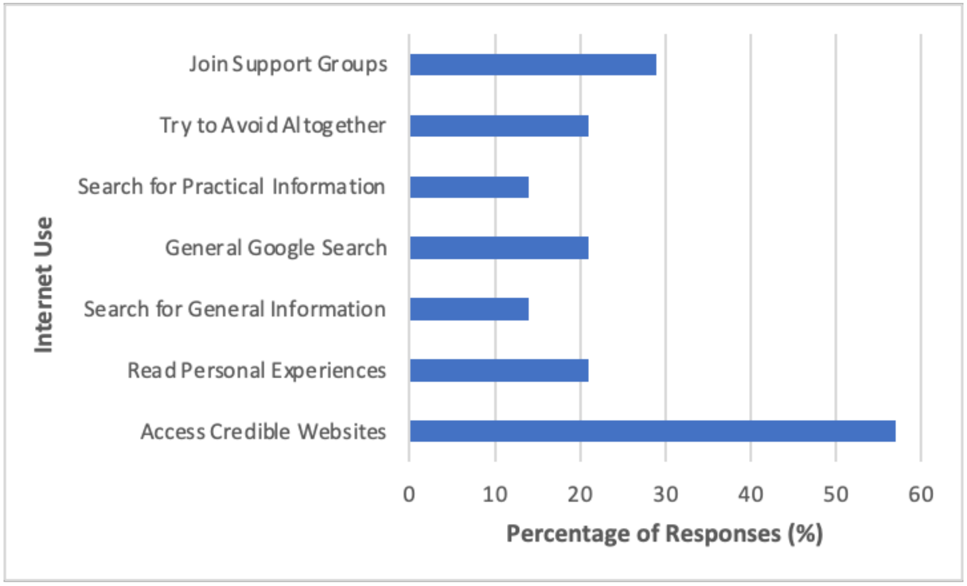

Figure 5. Reported Patient/ Caregiver Cancer-Related Internet Use
Patients and caregivers (n=14) were asked how they have used the internet to educate themselves about cancer. Responses are shown as the percent of respondents providing each answer.

When asked how patient access of outside resources affects the educational process, 92% of physicians cited negative effects due to irrelevant or unreliable information and 46% mentioned outside resources instilling biases and mistrust. On the other hand, 38% of physicians reported positive effects, as the internet allowed patients to be better informed about their disease.

CancerQuest Review

In the review of the CancerQuest website, physicians were asked who would ideally refer patients to the website within the educational process. 54% said that the physicians themselves would refer patients, while 38% said in-hospital ads, 31% said nurses, and 31% said nurse navigators. Physicians were also asked for recommendations for improving the CancerQuest website. Although answers varied dramatically between individuals, 38% recommended simplifying and condensing the information and 23% recommended updating animations and graphics. The addition of symptom management information, the inability to find certain pages, and addition of links to clinical trials were each mentioned by multiple physicians (15%). When asked if they would refer patients to CancerQuest, 85% answered yes overall. The most common reason to possibly not refer patients is that the website is missing information on certain types of cancer (mentioned by 23%). 31% of physicians would want patients to access it before their first appointment and 46% would want them to access it directly after their first appointment.

Before we sent the CancerQuest link to patients and caregivers, 0% of them had accessed the website before. 79% felt that it would have been helpful if they had accessed it earlier. Respondents were asked to rank the website on the categories provided by the website ranking scale. Average rankings on a scale of 1-10 were calculated for the categories of appearance, content, functionality, and usability. Average scores for each category are as follows: 8.68 for appearance, 9.00 for content, 9.08 for functionality, and 9.14 for usability. Two participants declined to provide a functionality ranking because they did not attempt the functions included in this category. Patients and caregivers were also asked what their favorite part of the website was, as well as what would make them want to use it more. Both questions elicited various responses; however, some answers were provided by multiple respondents. The “Cancer by Type” page was the favorite part of 36% of respondents. 21% of people reported that their favorite part was the abundance and detail of the content. Multiple respondents (21%) said that they would want to use the website more if it was linked to their patient portal. 21% also answered that they would not change anything.

DISCUSSION

This study demonstrates that physicians employ multiple methods to employ their patients, both during clinical appointments and through external resources patients can access later. Although there exists an abundance of literature on the efficacy of specific educational methods in both post-diagnosis education and cancer prevention awareness, a gap exists in studying the combination of methods employed by physicians, as well as physician and patient preferences for these methods. A future direction of study could involve presenting patients with information through different combinations of formats and measuring how much information patients accurately retain.

This study aimed to investigate which methods are currently employed by physicians. Both physicians and patients reported verbal education as the most common method utilized, and over half of patients cited verbal communication as the method that was most effective for them. This is consistent with previous findings that oncology physicians rely primarily on verbal education (Epstein and Street et al., 2007). However, more recent studies indicate that verbal communication is interpreted in a wide variety of ways by patients, therefore creating gaps between what the physician intended to communicate and what the patient understood (Kunneman et al., 2020). For this reason, physicians are advised to not rely solely on verbal expressions for communicating with patients. This is reflected in the fact that 92% of physicians in this study reported utilizing multiple educational methods.

Another trend in the data is the preference of patients and caregivers for resources that can be accessed after appointments. 28% of respondents reported either note-taking or printed resources as the most impactful form of education, many of which citing that it is helpful to not have to rely on their memory to absorb everything that is covered in the clinic. Printed cancer education materials have become widely utilized, and efforts have primarily been focused on the creation of tailored materials to target audiences and the assessment of the readability and efficacy of these materials (Kreuter et al. 2003, Parker et al., 2021). The preference of patients to have access to resources outside of their clinical appointments implies that online resources can be beneficial to the educational process.

Perhaps some of the reasons that patients prefer other resources in addition to verbal communication are the barriers to understanding what physicians tell them in the clinic. One of the primary educational barriers mentioned by physicians is patient health literacy levels. A study of 1060 newly diagnosed breast cancer patients suggests that there is still a need for cancer education resources to meet the needs of patients of all health literacy levels, and that cancer patients with lower health literacy have less of their informational needs met (Halbach et al., 2016). In our study, 86% of physicians who cited health literacy as a barrier to education thought that online resources, such as CancerQuest, could help alleviate this barrier. In addition to this feedback from physicians, 21% of patients and caregivers also reported a lack of understanding of terminology as a barrier to full understanding. This information, along with the consensus among physicians that health literacy is a barrier to education, highlights the need for resources to fill these gaps and provide adequate education to all patients.

Misinformation was a barrier mentioned by 38% of physicians. With the recent rise of health-related internet use, the prevalence of online misinformation and the inability of internet users to decipher the accuracy of information has presented a major challenge to the healthcare field (Iammarino et al., 2018). Specifically, a review of cancer-related information on social media found that 30% of posts contained some form of misinformation (Chen et al., 2018). Studies also show that, although internet users are confident in their ability to determine what information is reliable, less than half of them reported checking the quality of sources based on standards of the electronic Health Literacy Scale (Seçkin et al., 2016). Most respondents in our study (79%) reported using the internet for cancer-related information, and they determined which information was reliable primarily by only accessing “reputable” resources (86%) and using their physicians to confirm information (29%). These data could reflect the trend demonstrated by Seçkin et al. that most internet users are confident in their ability to find reliable information. It could also be that the sample used in this study represents a demographic of people with a greater ability to decipher reliable information, whether this be due to high technological literacy, education levels, or health literacy. A possible future area of study is to investigate how effective patient/caregiver strategies are in identifying sources of accurate information, as physicians still noted a prevalence of misinformation among their patients. Among physicians who reported misinformation as an educational barrier, 100% believed that an online educational resource could help mitigate this problem. These data indicate a need and desire for more accurate online cancer information resources.

In general, responses from physicians regarding the effects of patients accessing outside resources were various. The effects were primarily negative, as many cited the prevalence of irrelevant or unreliable information (92%) and the breeding of biases and mistrust (46%). These data reiterate the trend that misinformation is widespread and harmful, and that there is a need for quality resources for patients to access in order to avoid this. On the other hand, physicians also noted that accessing outside resources allows patients to be better informed (38%). This highlights that the quality of the resource in question is crucial and that these tools can be beneficial to the educational process.

Lack of time was also a barrier reported by 38% of physician respondents. These numbers are very similar to a recent survey of 973 physicians in which 38-45% of respondents noted lack of time as a barrier to patient education regarding colorectal cancer (Zhu et al., 2022). In this study, 58% of patients and caregivers reported that physicians spent 30 minutes or less on education in their initial appointment, which is typically when the most amount of information is provided. In follow-up appointments, the percentage of respondents whose physicians spent 30 minutes or less on education rose to 65%. This is in agreement with previous research of 55 video-recorded oncology patient visits in which the average time that patients spent with physicians during an appointment was 29 minutes (Hamel et al., 2014). The lack of time available for physicians to educate in the clinic only exacerbates the need for quality resources that patients can access outside of their appointments. This is reiterated by the fact that 100% of physicians in this study that cited time as a barrier answered that an educational website, such as CancerQuest, could help alleviate it.

The final primary barrier mentioned by physicians was emotional barriers (mentioned by 38% of respondents). Additionally, 43% of patients and caregivers reported that emotions prevented them from understanding everything that their physicians were telling them. Strong emotions related to cancer diagnoses have been documented throughout the literature. These emotions have been cited to affect the patient-physician relationship and cancer-related decision making. Both intensity and cognitive appraisal of these emotions impacted patient decision-making (Mazzocco et al, 2019). Although this barrier will likely never be completely eliminated, it is important that both healthcare physicians and creators of educational resources consider this aspect of the educational process.

The final category of questions was regarding the CancerQuest website. A variety of methods were recommended by physicians to refer patients to this website, including referral by the physician themselves (54%), in-hospital ads (38%), nurses (31%), and nurse navigators (31%). This implies that there are barriers preventing healthcare teams from distributing this website, especially considering that 85% of physicians answered that they would refer patients to this resource, but none of the interviewed patients had been referred before. The process for referring patients and caregivers to CancerQuest should be made easier for physicians. This includes efforts to increase awareness of the website among both patients and providers. Although CancerQuest flyers already exist, it is recommended that they be updated and redistributed so that all Emory physicians are aware of them and have access to them. Additionally, collaborating with nurse navigators to provide patients and caregivers with either a flyer or a direct link to the webpage in the early stages of their diagnosis could increase the utilization of this resource. 21% of respondents also reported that they would use the website more if it was linked to their patient portal, so this could be another method of distributing this resource. 31% of physicians indicated a preference for their patients to access the website before their first appointment and 46% preferred that patients access it right after. Early exposure seems to be the preferred time interval of physicians. Little research exists on the ideal timeframe for patients to access outside resources. Future work could investigate how the timing of patient education affects the educational process by presenting patients with resources at various timepoints throughout their treatment and measuring the efficacy of these resources in the retention of information.

Because 79% of patients and caregivers believe that CancerQuest would have been helpful if they had known about it earlier in their treatment, increasing awareness of this resource would lead to more well-informed patients and caregivers. When patients and caregivers were asked to score the website in four different categories, all provided rankings were high. The lowest average score was for appearance (8.68 out of 10). When asked to provide recommendations, one patient suggested that the website be made more visually appealing, while zero physicians referenced appearance in their recommendations. These data indicate that the CancerQuest's visual appeal is generally positive, although slight improvements can be made.

Content was provided an average score of 9.00, which was the second lowest. Patient recommendations in this area included adding more information about specific treatments (7%), cancer types (7%), and practical information (7%). One patient also suggested that the information be updated based on the dates of references provided. Physicians also provided various recommendations to improve content, each of which was specific to their unique specialty. 38% of physicians recommended that the content be simplified or condensed. On the other hand, 21% of patients noted that their favorite part of the website was the abundance of content present. This conflicting information suggests that there may be a contrast between the amount of information that patients want to have available to them and the amount recommended by physicians. This is also consistent with previous research that found conflicting feedback regarding the amount of information provided by cancer education websites. Kobes et al. found that, in a review of 100 websites relating to prostate cancer, 90% discussed detection, workup and treatment, whereas only 14% discussed prognosis (Kobes et al., 2018). This goes to show that a variety of resources are necessary to provide an education tailored to patients' needs and preferences (Friedman et al., 2011).

Functionality and usability rankings were both high (9.08 and 9.14, respectively), and none of the recommendations by patients and caregivers referenced either of these categories. One physician commented on functionality regarding a nonfunctional link, and two physicians did not find certain pages, indicating that the menu was not as useful as it could be. In general, the feedback on functionality and usability was positive and there is little need for improvement in these categories. A possible future area of study could involve a more in-depth analysis of CancerQuest using more specific website-review methodology, as well as baseline knowledge tests of patients.

This study encompassed several aspects of oncology patient education, and it has several limitations. First, the sample size is relatively small, and physician demographics were slightly skewed. The average age of physicians interviewed was 44.5 years and 62% of respondents were female. This age value is relatively consistent with data from 2016 citing the average age of oncologists as 52, but this study found that only 30% of oncologists were female. However, they noted that 48% of oncology fellows are women, indicating an increase in women entering the field that could have impacted the values in this study (Towle, 2016).

Patient and caregiver respondents were 93% female, 64% white, and the lowest level of education was completion of some college. 86% of respondents possessed a college degree or higher and 69% of those who reported combined family income made at least $60,000 annually. Based on census data from the years 2016-2020, the Atlanta population was made up of 51.3% female, 40.4% of residents were white, 53.4% of the population possessed a bachelor’s degree or higher, and the median household income was $64,179 (U.S. Census Bureau, 2020). Our sample had a higher percentage of females, white individuals, and college degree recipients than the general population. Income levels were relatively consistent with the population as a whole.

Another limitation of this study was in the recruitment of participants. The original mass email was sent to all Winship Cancer Institute Physicians, but the follow-up email was only sent to a small number of them. This could have skewed the data by only acquiring information from a specific subset of the larger population. Additionally, patients and caregivers were required to possess a certain level of technological literacy in order to enroll in the study. They had to be able to scan a QR code, operate email or text, and attend a Zoom meeting.

A final limitation of this study involved the amount of time that respondents spent on the CancerQuest website before the interview. Physicians, as well as patients and caregivers, were sent the links beforehand and asked to take a few minutes to review the website and make notes of suggestions for improvement. The amount of time that participants spent on the site varied, and some of them forgot to review it at all. If this was the case, time was taken out of the interview for them to review it on the spot. This variation could have impacted how participants answered because the more familiar they were with the website, the more informed they were to provide feedback.

Although the sample size was small, we believe that it was adequate because saturation of themes was reached with both groups. Additionally, the study is limited by a lack of demographic variety. However, the sample is generally representative of the population that CancerQuest was primarily created for, which was Winship patients and caregivers. Similarly, the level of technological literacy required by patients and caregivers to enroll in the study is similar to the level required to access the CancerQuest website through their own research.

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PRINCIPAL INVESTIGATOR:

Rebecca D. Pentz, PhD
Department of Hematology and Medical Oncology
(404) 778-5694
rpentz@emory.edu

Gregg Orloff, PhD
Department of Biology
404-727-0308
gregg.orloff@emory.edu

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Table of Contents

1. Study Summary

Study Title	Strategies and Barriers to Oncology Patient Education
Study Design	Interview
Primary Objective	The objective of this study is to assess how health professionals educate cancer patients about their disease, as well as investigate provider and patient preferences for educational format.
Secondary Objective(s)	Use the above findings to maximize the efficacy and accessibility of CancerQuest as a tool for patient education.
Research Intervention(s)/Interactions	Interviews
Study Population	Healthcare providers and patients at Winship Cancer Institute
Sample Size	30-40
Study Duration for Individual Participants	15-30 minute interviews
Study Specific Abbreviations/ Definitions	APP: Advanced Practice Providers NP: Nurse Practitioner PA: Physician Assistant
Funding Source (if any)	N/A

2. Objectives

The proposed study would investigate clinician and patient preferences for avenues of patient education. We will also study how healthcare professionals go about educating their patients and the barriers facing these practices. We hope to use this information to inform better educational resources.

We hypothesize that health professionals primarily utilize verbal communication to educate their patients about cancer diagnoses, and that their primary burden to education is inadequate time. We also hypothesize that educational videos are the preferred educational format for patients and providers.

Specific Aim 1: To interview physicians and advances practice providers about the methods they use to educate their patients, the barriers to education that they experience, and their preferred presentation format. The CancerQuest website will be reviewed for the particular disease site of their specialty and suggestions for improvement recorded.

Specific Aim 2: To interview patients about their experience with cancer education, what resources they were given, what resources they utilized, and their preferences for educational resource format. The CancerQuest website about their disease will be reviewed and suggestions for improvement recorded.

Specific Aim 3: To use the information gathered to maximize the ability of CancerQuest to educate patients.

3. Background

Patient education is a primary component of the patient-clinician relationship, specifically in an oncology setting. There is evidence suggesting multiple benefits of patient education, including improved knowledge and decision-making (Langford et al., 2021). Additionally, patients in our society have a desire to acquire current and accurate information to be maximally informed about their disease (Satturlund et al., 2003).

There are several avenues available for clinicians to educate patients, including time spent during clinic appointments and references to external resources, such as pamphlets and websites. The American Society of Clinical Oncology Consensus Guideline provides guidance to healthcare providers on how to improve physician-patient relationships and provide a platform for better patient understanding and comfort. This resource emphasizes the use of clear communication and the specific addressment of topics such as goals of prognosis, treatment selection, and end-of-life care (Gilligan et al., 2017). Several other teaching strategies have also been employed to provide a more holistic educational experience for patients. The internet has become an increasingly popular source of health information for both patients and clinicians. In the United States, 80% of adults who use the internet have reported searching the web for online health information (Fox, 2020). Several educational resources are available through the internet and have been utilized for patient education. For example, the addition of videos in chemotherapy education has been proven to increase understanding (Sibhold et al., 2021, Pentz, et al. 2019). The use of multimedia or a combination of teaching strategies has been proven successful in educating patients (Friedman et al., 2011, Loiselle et al., 2010). Additionally, culturally appropriate and patient-specific education has been proven more effective than generalized teaching (Friedman et al., 2011). Studies suggest that further research is necessary to optimize cancer education programs for patients (Preminger et al., 2011).

There are several barriers facing healthcare professionals when it comes to educating patients. For example, clinicians are experiencing a dramatic decrease in the amount of time that they have available to meet with patients, which results in less time for education (Tai-Seale et al., 2017). Additionally, there is an abundance of misinformation available to patients on the internet (Wald et al., 2007). Although some of the barriers to patient education by clinicians are known, there are still informational gaps in this area.

4. Study Endpoints

The primary endpoints of this study are the qualitative findings of how oncology clinicians educate their patients, the barriers facing this practice, and preferences of providers and patients regarding format of patient education. The secondary endpoint will be suggested modifications to CancerQuest.

5. Study Intervention/Design

The design of this project will be centered around virtual interviews with both clinicians and patients. In clinician interviews, questions will ask about strategies used to educate oncology patients, barriers preventing optimal education, resources used to educate patients, and preferences for educational resource format. Similarly, patients will be asked about their experiences with education, what resources they were given to aid in education, what resources they utilized, and their preferences for educational research format. Patients will not be asked any potentially triggering questions, including any information about medical history. These interviews will be quantitatively analyzed using standard semantic methodology as described below (Krippendorf, 2004).

6. Procedures Involved

Aims 1 and 2 will be evaluated using a structured qualitative interview (draft attached in Appendix A below). The structured interviews were developed based on a literature review and in consultation with the PIs. This provider interview will be cognitively tested with research ethics colleagues and the patient interview with 5-8 patients to determine that the questions are clear and are interpreted in the manner which we intended. Standard demographic questions will also be included.

Phase one of this project involves interviews of physicians, NP's, and PA's at Winship Cancer Institute. Clinicians will receive a mass email with a link to a Google form that will allow them to submit their contact information. They will then be contacted to schedule a virtual or in person interview of approximately 15-30 minutes. If not enough participants are acquired through this process, we will attend working groups to recruit participants. Any provider practicing at Winship Cancer Institute will be eligible. Consent to record the interview will be obtained at the beginning of the meeting. Recordings will be stored securely in a password-protected server. Only the research team will have access to video recordings. Recordings will be used to review for qualitative double coding and then deleted. All data acquired during interviews will be qualitative.

Phase two of this project involves interviews of patients at Winship Cancer Institute. Pending approval to be present in patients' spaces, we will contact patients in the Infusion Center to inquire about their interest in the project. If they wish to participate, they will provide their contact information to schedule an interview, or they will be interviewed in the infusion center. If we do not receive approval to enter patient-designated areas, we will provide a flyer with a QR code that will direct patients to a google form to submit their contact information. Similar to clinician interviews, participants will be contacted via email and asked to participate in virtual interviews of approximately 15-30 minutes. Consent to record the interview will be obtained at the beginning of the meeting. Recordings will be stored securely in a password-protected server. Only the research team will have access to video recordings. Recordings will be used to review for qualitative double coding and then deleted. All data acquired during interviews will be qualitative.

All interviews will be recorded, and the interviewer will take notes on the questionnaire throughout the interview. The recording will be transcribed and coded, with all identifiers removed. Two independent investigators will develop a codebook to code open ended questions after the first 6-10 interviews based on the interview guide or deductive codes set by the research team. We will compare code books, resolve discrepancies, and create a final code book to be used in coding all interviews. All interviews will then be coded with the themes entered on an excel sheet. 10% of the interviews will be double coded and discrepancies resolved by consensus. A third independent coder will resolve any continued disagreements.

Participants will not be exposed to any stress beyond that ordinarily incurred in research interviews. Subjects will be informed beforehand that they may decline to answer any questions that may make them uncomfortable. Although no personal information will be asked, all answers will remain confidential.

After the study is complete, providers will be debriefed on the findings of the study at a faculty meeting.

7. Data Specimen Banking

N/A

8. Sharing of Results with Participants

Individual responses will not be shared; however, general trends will be shared with providers at a faculty meeting. Results will not be shared with patients.

9. Study Timelines

Participants will only be asked to complete a 15-30 minute interview. The entire study should last from approximately October, when interviews begin, through April, when the project will be complete.

10. Inclusion and Exclusion Criteria

Participants will include 15-20 clinicians who conduct clinical oncology appointments and 15-20 adult patients who have received clinical oncology treatment at Winship Cancer Institute. Patients may be at any stage in their cancer treatment. As we do not have access to a translator, only English-speaking participants are eligible.

11. Population

The population of this study is healthcare providers and adult patients at Winship Cancer Institute.

12. Vulnerable Populations

Individuals receiving cancer treatment could be considered vulnerable because of the mental, emotional, and physical burdens inflicted on them by their disease and treatment. We will assure that patients understand that participation in interviews is completely optional and that they may decline to answer questions or withdraw from the process at any time. We will ensure that participation in the study is a safe, positive, and affirming experience.

13. Local Number of Participants

This study will enroll 15-20 clinicians and 15-20 patients.

14. Recruitment Methods

Participating clinicians will be contacted via email from the Winship Cancer Institute faculty list. There will be a link to provide their name, email address, and convenient times to contact them in order to set up meetings. Participating patients will be either approached in the Infusion Center or contacted via email if they provide their contact information after viewing the flyer. Once contacted, they will be able to choose a convenient time to be interviewed.

15. Withdrawal of Participants

Participants will be able to withdraw from the study at any point. If they decide to withdraw, any answers that they have given up to that point will be destroyed. There are no circumstances under which participants would be withdrawn without their consent.

16. Risk to Participants

Potential adverse effects resulting from participation in study assessments are no different from those associated with all qualitative research. Since no personal experience will be queried in the interview, the major risk is loss of confidentiality.

Assurance of protection of confidentiality is a clinical responsibility and duty of the staff of the Winship Cancer Institute and will be emphasized and monitored regularly by the PI and research team. Each interview will be identified by a study code rather than a name. The code link to identifiers will be stored separately in Emory’s password and firewall protected system and will be destroyed at the completion of data collection.

17. Potential Benefits to Participants

Participants will be aware from the outset that they are participating in a study that was designed to investigate patient education in oncology in order to improve educational strategies and resources. Although there is no direct benefit to individuals, they may appreciate knowing that their participation in the study will benefit patients in the future. The study may improve CancerQuest, which is a valuable resource for patients worldwide.

18. Compensation to Participants

Participating clinicians will not receive compensation for the study. Participating patients will receive a $20 Visa gift card for completing an interview.

19. Data Analysis, Management and Confidentiality

We expect to interview a total of 15-20 providers and 15-20 patients. Saturation of themes is usually reached with this number of participants (Guest et al., 2006). A semantic content analysis method will be used to systematically extract meaning from the transcribed interviews as described above (Krippendorf, 2004). We will read transcripts and run reports of codes. Descriptive statistics will be used. Salient themes across interviews will be drawn and representative quotes that are de identified will be shared.

20. Provisions to Monitor the Data to Ensure the Safety of Participants

N/A

21. Provisions to Protect the Privacy Interest of Participants

All research activities will be conducted in a private, password-protected video conference. Recordings will be destroyed upon completion of analysis. Informed consent will be documented by completion of the interview. We will not access any previously existing records.

22. Economic Burden to Participants

N/A

23. Informed Consent

Consent will be obtained verbally before participation begins and documented by completion of an interview. An information sheet explaining the study will be provided to each participant and will be explained before the interview begins. We will be requesting a waiver of documentation of consent given the minimal risk nature of this study. Since no PHI is retained, no HIPAA information is needed.

24. HIPAA

N/A

25. Setting

The site for this project is Emory's Winship Cancer Institute. All interviews will be completed virtually, and the only physical facility that will be utilized is the Infusion Center.

26. Resources Available

This project will be completed from approximately August 2021 through April 2022 as an honors thesis in the Emory University Biology Department. We will have sufficient access to clinicians and patients through Winship Cancer Institute, as well as access to the Infusion Center facility and a virtual interview platform.

27. Multi-Site Research When Emory is the Lead Site

N/A

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Appendix B. Provider Recruitment Email

Dear Providers,

My name is Bethany Karnes and I am an undergraduate student at Emory College of Arts and Sciences. You may remember me from the faculty meeting earlier this fall. I am currently working on my honors thesis with Dr. Rebecca Pentz and Dr. Gregg Orloff, in which we are investigating oncology patient education in order to improve efficacy and accessibility of resources, such as CancerQuest. We are requesting participation of Winship clinicians in a virtual interview of approximately 15-30 minutes, in which we will discuss your strategies for educating patients, the barriers you have to doing so, and your preferences for educational resource format. If you are willing to participate in this study, please click here to provide your information to be contacted for an interview.

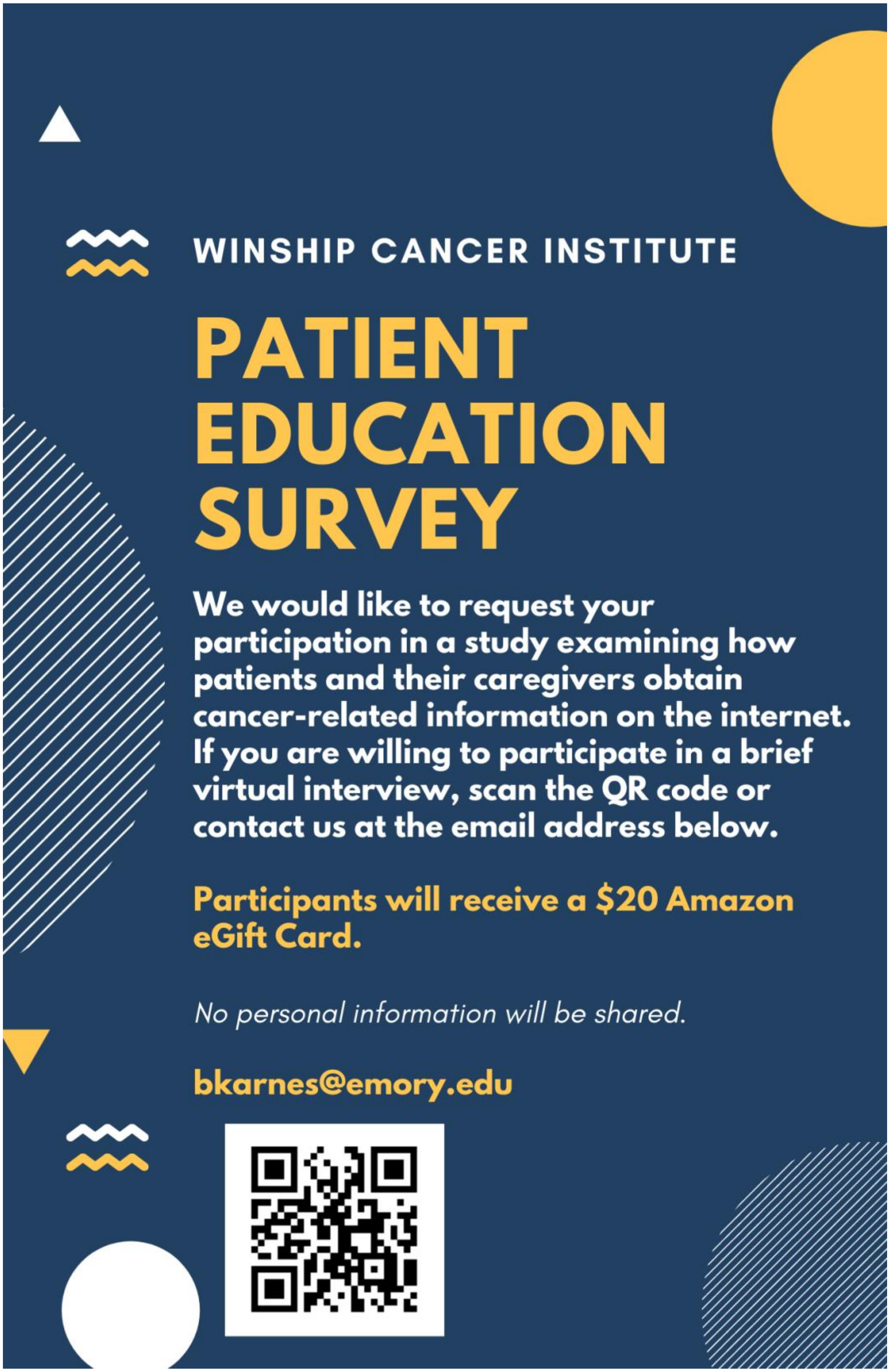
Thank you in advance for your participation!

Best,

Bethany Karnes

bkarnes@emory.edu

Appendix C. Patient/Caregiver Recruitment Flyer



WINSHIP CANCER INSTITUTE

PATIENT EDUCATION SURVEY

We would like to request your participation in a study examining how patients and their caregivers obtain cancer-related information on the internet. If you are willing to participate in a brief virtual interview, scan the QR code or contact us at the email address below.

Participants will receive a $20 Amazon eGift Card.

No personal information will be shared.

bkarnes@emory.edu