

A novel intervention using interactive technology and personal narratives to reduce cancer disparities: African American breast cancer survivor stories

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Abstract

Purpose There has been a paucity of interventions developed for African American women to address persistent health disparities between African American and Caucasian breast cancer patients. We developed and piloted a technologically innovative, culturally targeted, cancer-communication intervention for African American breast cancer patients using African American breast cancer survivor stories.

Methods We rated 917 clips from a video library of survivors' stories for likability, clarity and length, and emotional impact (scaled responses) and categorized each clip by theme (Coping, Support and Relationships, Healthcare Experiences, Follow-up Care, Quality of Life, and Treatment Side Effects). We selected 207 clips told by 35 survivors (32–68 years old; 4–30 years after diagnosis), fitting one of 12 story topics, for

inclusion in the interactive video program loaded onto a touch-screen computer. Videos can be searched by storyteller or story topics; stories with the strongest emotional impact were displayed first in the video program.

Results We pilot tested the video program with ten African American breast cancer survivors (mean age, 54; range 39–68 years), who, after training, watched videos and then evaluated the stories and video-program usability. Survivor stories were found to be “interesting and informative,” and usability was rated highly. Participants identified with storytellers (e.g., they “think a lot like me,” “have values like mine”) and agreed that the stories convinced them to receive recommended surveillance mammograms.

Conclusions This novel, cancer-communication technology using survivor stories was very favorably evaluated by breast cancer survivors and is now being tested in a randomized controlled clinical trial.

Implications for Cancer Survivors Breast cancer survivors can draw support and information from a variety of sources, including from other breast cancer survivors. We developed the survivor stories video program specifically for African American survivors to help improve their quality of life and adherence to follow-up care. Breast cancer survivors' experiences with treatment and living with cancer make them especially credible messengers of cancer information. Our novel, interactive technology is being tested in a randomized controlled trial and will be more broadly disseminated to reach a wider audience.

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Introduction

African American women with breast cancer are at greater risk of being diagnosed at more advanced stages of disease and of dying from breast cancer compared with Caucasian women with breast cancer [1–4]; these differences in mortality between African American and Caucasian women are observed even among patients who were diagnosed at the same stage [5]. Explanations for these persistent disparities have been attributed to patients (e.g., relating to disparities in adherence to recommended treatment and follow-up care [6–8]) and to healthcare providers (e.g., relating to disparities in provision of first-line treatment meeting National Comprehensive Cancer Network standards) [9–12]. Some studies report associations between aspects of quality of life (QOL), such as depressed mood, and acceptance of adjuvant chemotherapy [13], self-reported barriers to cancer care [14], and lower compliance with adjuvant medical treatment [15]. Patient/provider communication patterns also may be associated with breast cancer survival [16, 17]. Thus, strategies to improve QOL among African American patients and to enhance adherence to follow-up care [18] may help reduce disparities in breast cancer outcomes between African American and Caucasian women.

Use of narratives is emerging as an effective health-communication strategy to educate, engage, persuade, or activate the public to engage in health-promoting behaviors [19]. Implementing a narrative approach through storytelling provides a natural and comfortable way of giving and receiving information and allows for the familiarity of human interaction, in contrast to non-narrative, expository, or didactic styles of communication that present reasons and arguments in favor of a particular course of action [20]. Narratives can help make complicated health messages easier to understand, especially for audiences with low literacy and/or numeracy [21].

In an earlier study, Kreuter and colleagues interviewed 36 African American breast cancer survivors and developed a library of professional-quality digital videos of personal narratives for the *Living Proof* Study [22]. In audience testing of the videos, the best predictor of a woman having positive thoughts about the survivor stories was whether she liked and viewed the survivor as similar to herself [22]. Based on these findings, selected narratives were developed into a DVD for a longitudinal study, in which African American women age 40 years and older were randomly assigned to watch either the 20-min *Living Proof* DVD comprised of stories about screening mammography or a content-equivalent, didactic informational DVD delivered by an African American healthcare professional. At a 6-month follow-up, the *Living Proof* DVD was better liked, enhanced recall, reduced counter-arguing, increased breast cancer discussions with family members, and was perceived as more novel than the didactic DVD; in a subgroup analysis of women with less than

a high school education, the *Living Proof* DVD also led to higher screening mammography rates [23]. Thus, the use of narratives in delivering important cancer-prevention information was especially effective for women with fewer years of formal schooling.

To expand upon these previous findings, we set out to understand the psychosocial and behavioral impact of breast cancer survivor stories on newly diagnosed African American breast cancer patients as part of a randomized controlled trial (RCT). Research on the effectiveness of breast cancer survivors' stories on newly diagnosed cancer patients' QOL or adherence to breast cancer follow-up care after definitive surgical treatment is lacking. It is unknown if breast cancer survivors' stories about coping with challenges associated with a cancer diagnosis, treatment, and post-treatment follow-up care will promote newly diagnosed patients' identification with the survivors in the videos and improve patients' QOL and adherence to follow-up care. The purpose of this paper was to describe the selection process of survivor stories from the *Living Proof* library for development of a new health-communication intervention, a technologically novel, interactive video program of breast cancer survivors' stories. We also describe results of a pilot study, which was conducted to refine the video program and interview measures for an RCT that will test the efficacy of the video program to improve survivors' QOL and adherence to recommended follow-up care compared with standard of care.

Methods

The survivor-stories video program was developed in three stages: selecting survivor stories to include, developing the video program (the intervention), and implementing the pilot study with survivors. Results of the pilot study were used to refine the video program and newly developed interview questions for use in the RCT.

Selection of survivor stories

Between November 2008 and February 2009, three study-team members (M.P., J.S., D.K.) at the Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine in St. Louis, Missouri, watched and coded 917 video clips from 36 local African American breast cancer survivors in the *Living Proof* video library [22]. For inclusion in the video program, survivor stories and the storytellers were evaluated for likability (yes/no) and reasons why the video was or was not considered likeable; clarity and length (five-point scale from 1=short, clear and to the point to 5=long and digresses from the point); and emotional impact (five-point scale from 1=not much emotion to 5=strong emotion). Additionally, each storyteller appearing in a story clip was coded

for likability and trustworthiness (yes/no). Elements of our coding criteria (e.g., likability, emotional content) were previously reported to have had favorable effects on the viewer (i.e., storytellers were found to be likable and stories with strong emotional content elicited more positive reactions) [24, 25].

Survivor stories also were coded as fitting one of six themes, determined *a priori* based on the outcomes of interest to the trial and to newly diagnosed breast cancer patients, including coping with breast cancer, support and relationships, health care experiences, follow-up care, QOL/living with breast cancer, and treatment side effects. After viewing and coding all 917 survivor stories, 207 video clips told by 35 different storytellers were selected for inclusion in the survivor-stories video program based on their ratings (for likability, clarity and length, and emotional impact) and by a consensus of the three study-team members who rated all stories. In addition to fitting one of the six themes of interest, each of the 207 survivor stories selected for inclusion in the video program was further categorized using analytic induction [26] and an iterative process of analysis [27] into one of 12 story topics, which emerged from the stories' messages [27, 28]. Topics included My Faith and Spirituality (13 clips), Coping with My Breast Cancer Diagnosis (18 clips), Telling Others I Have Breast Cancer and Their Reaction (17 clips), Receiving Support from Others (19 clips), Support Groups (16 clips), Healthcare Experiences (22 clips), Having Reconstruction or a Prosthesis (12 clips), Dealing with Hair Loss (11 clips), Dealing with Radiation and Chemotherapy Side Effects (20 clips), Follow-up Care and Thoughts about Recurrence (20 clips), Breast Cancer Advocacy (21 clips), and Quality Of Life (18 clips). Each story topic met criteria for one of the six themes of interest, and some themes could be characterized by several topics.

Lastly, we ranked the 207 survivor stories within each topic and within each storyteller for emotional impact, so that stories having the strongest emotional impact were ranked highest, and higher-ranked stories appeared first in the program. Storytellers ranged in age at diagnosis between 32 and 68 years and had been survivors for four to 30 years at the time their stories were recorded for the *Living Proof* study [22]. Each selected survivor story was tagged with a quote summarizing the story's message, and individual stories were edited to exclude extraneous information and shorten the length of the clip.

Development of the survivor-stories video program

Between February and May 2009, survivor stories selected for the video program were developed into an interactive multimedia system by study-team members at the Health Communications Research Laboratory (HCRL) at Washington University George Warren Brown School of Social Work (B.G., C.C., M.K.). The HCRL created a modern, professional, and easy-to-use graphical interface for a FileMaker Pro database

containing the archive of selected survivor stories, which were loaded onto an Axiotron Modbook (an Apple® MacBook® tablet computer developed by Axiotron, Inc.) allowing for use of the computer's touch screen so that keyboard skills were not needed to view stories. Using this interactive video program, survivor stories can be searched either by a storyteller's age group at the time of her breast cancer diagnosis (<40, 40–49, 50–59, or >60 years of age) or by one of the 12 aforementioned story topics. Thus, each survivor story is linked to an individual storyteller in a certain age group and to a distinct story topic in the program. A dictionary of terms relating to breast cancer diagnosis, treatment, and recovery/side effects also was developed. The HCRL tested the survivor-stories program for sound quality, usability, navigation problems (e.g., if an incorrect video played when selected by a particular storyteller or story topic), and to ensure stories were displayed in the appropriate order as dictated by their emotional impact ranking (i.e., stories ranked highest for emotional impact appeared first on the list of available stories either by storyteller or topic).

Implementation of the pilot study

In May 2009, the Institutional Review Board at Washington University School of Medicine approved the pilot study testing the usability of the video program prior to its use in the RCT. In July and August 2009, we identified a convenience sample of African American breast cancer survivors age 30 years or older who had received surgical treatment for first primary ductal carcinoma in situ or stages I–III invasive breast cancer at the Siteman Cancer Center, a National Cancer Institute (NCI)-designated comprehensive cancer center. Following consent, a specially trained study-team member trained each participant how to navigate the video program, search for and play stories, and access the dictionary. After training, participants were asked to spend time using the video player (i.e., the Modbook) to watch survivor stories of their choice; the study-team member was available to answer any questions that arose or address problems that occurred while the participant used the video player. After selecting and watching videos, participants completed a brief, in-person, computer-assisted interview. The interview included questions about demographic characteristics (age, education and employment status, annual household income from all sources), usability of the video program, and other measures being piloted for use in the RCT. Study-team members planned to spend no more than 90 min with each participant, and participants received a \$15.00 gift card as a token of appreciation for their participation.

Usability Using a five-point scale (1=strongly disagree to 5=strongly agree), participants rated 19 items in four categories: (1) Navigation (ease in selecting videos to watch, ability to hear and see videos, ease of use of the graphical interface, and

the functionality of the video player); (2) Content (length of videos was appropriate, and the number of stories and topics included was adequate); (3) Persuasiveness (the survivor stories convinced them to receive follow-up mammograms and, for patients receiving endocrine therapy, convinced them to take hormone therapy as prescribed); and (4) Value (time and effort spent watching videos was worthwhile, participants would recommend the program to other women and would have liked more time to look at the survivor stories and to take the video player home to watch the survivor stories at their leisure). Participants also were asked how much time they would have likely spent watching survivor stories (a few hours, several hours in one day, several hours over a period of days, several hours over a period of 1 week, several hours over a period of two or more weeks) and how long (less than 1 day, 1–3 days, 4–7 days, 2 weeks, more than 2 weeks) they would have liked to keep the video player should they have had the opportunity to take it home with them.

Participants also responded to open-ended questions regarding usability, including the most-liked feature of the survivor-stories video program, what made the video program most difficult to use, and a list of people with whom participants would like to watch the survivor stories.

Identification with survivors Eleven items adapted from the literature [29–31] evaluated participants' level of identification with storytellers in the survivor stories. Items were scored on a five-point scale (1=strongly agree to 5=strongly disagree) and were reverse coded so that higher scores indicate a greater perceived identification with each survivor.

Emotional reactions We piloted 13 items from the Positive and Negative Affect Schedule [32] to measure participants' positive and negative emotional reactions to the survivor stories. Items were scored on a five-point scale (1=extremely to 5=not at all) and comprised two separate scales: a four-item "Positive Affect" scale and nine-item "Negative Affect" scale. Items were reverse coded so that higher scores indicate more positive and more negative emotional reactions in response to watching the survivor stories.

Use of support and cancer-information resources Participants were asked to indicate "which of these resources you have used since you were diagnosed" using a checklist of 15 different cancer survivor resources (e.g., friends, support groups, web sites, 1-800-4CANCER, survivor stories), many of which are included on the Health Information National Trends Survey for cancer communication [33]. Participants were asked to check all that apply.

Utility for newly diagnosed patients Since QOL is the primary RCT outcome of interest, participants were asked to use a five-

point scale (1=strongly disagree to 5=strongly agree) to determine if, at the time of diagnosis, the survivor-stories video program would have: been useful, helped them understand their illness, helped them come to terms with cancer faster, made it easier to cope with their illness, helped with their relationships, and helped to improve their QOL.

We report descriptive statistics for participant responses to the pilot study interview questions that utilized scaled responses. We also report select narrative responses that were offered spontaneously or in response to open-ended questions, which required only brief answers.

Results

Of 21 breast cancer survivors identified for the pilot study, seven refused to participate and four were unable to be contacted. The remaining ten women who agreed to participate in the pilot study (Table 1) were, on average, 54.3 years of age (SD=8.6; range 39–68 years). Most participants had at least a high school education, were unable to work/unemployed, and had an annual household income of less than \$25,000. Only three participants were married.

One participant was unable to use the video program as intended due to technical issues within the FileMaker Pro Database on the Modbook (navigation screens were not working properly, resulting in the inability to access survivor stories within the video program). To make use of her time, we randomly selected nine survivor stories from the Modbook's hard drive for the participant to watch using Apple's QuickTime to play the videos. As a result, this participant could not respond to questions about the ease of use and functionality of the video program, but she could respond to items about the storytellers and their stories. The amount of time the remaining participants spent using the video player ranged between 23 and 42 min, which we obtained from the usage data stored in the Modbook.

Overall reactions to the video program were positive. Responses to open-ended questions indicated the most-liked feature of the video program was the survivor stories themselves. Participants specifically mentioned that the stories were "interesting and informative" and provided "...good information, wide variety of topics." Some participants spontaneously mentioned their identification with individual storytellers and the trustworthiness of their messages, saying they mostly liked "the way that they told their stories" and "the sincere nature of the storytellers." They also reported that "the women were down to earth" and "[I] was able to see women like me." Two participants mentioned that they liked the clips about hair loss and chemotherapy/radiation treatments the most. When asked what made the video program most difficult to use, seven women reported no difficulties at all. Of the few criticisms, one

Table 1 Participant characteristics

	N=10
Marital status	
Married	3
Widowed	1
Divorced/separated	3
Never been married	3
Employment status	
Working at least part time	2
Retired	1
Homemaker	1
Unable to work/unemployed	6
Annual income	
< \$25,000	7
\$25,000–\$75,000	2
> \$75,000	1
Education	
<High school graduate	1
At least high school graduate	6
>High school graduate	3
Resources used since diagnosis	
Doctor at Siteman (phone/E-mail/visit)	9
Nurse (phone/E-mail/visit)	9
Family member	8
Friend	8
Local support group	5
Online support group	0
Psycho-oncology Services at Siteman Cancer Center	3
Cancer Information Center at Siteman Cancer Center	5
Church	6
Video stories of cancer survivors	3
Newspaper or magazine stories about cancer survivors	6
Television news story about cancer	10
Radio news story about cancer	0
A website with cancer information (National Cancer Institute, American Cancer Society, Siteman Cancer Center, other)	5
Telephone hotline (1-800-4-Cancer, 1-800-ACS-2345)	0

participant felt the button to play survivor stories was too small, and another felt there were too many stories to choose from.

Although half of the participants reported that the survivor stories made them feel “concerned,” most reported positive emotional reactions to the stories (Positive Affect scale, $M=4.13$ [$SD=0.76$], range 2.25–5.00), including feeling at least moderately “proud,” “inspired,” “happy,” and “hopeful”. Participants reported few negative reactions to the survivor stories (Negative Affect scale, $M=1.30$ [$SD=0.26$], range 1.00–1.78) and none of the participants reported feeling “frustrated,” “angry,” “suspicious,” or “bored.” Most also reported high levels of

identification with storytellers (Identification score, $M=4.28$ [$SD=0.47$], range 3.55–5.00), with all participants agreeing at least somewhat that the storytellers “think a lot like me,” “have values like mine,” and “are a lot like me.” All participants agreed at least somewhat that they could “identify with the women” and “trust the women” in these survivor stories. Nine participants agreed that they would want to talk to the women in these videos if she had a “question about breast cancer treatment.”

Regarding support and cancer-information resources used by participants (Table 1), nine women reported using a doctor or a nurse (either by phone, E-mail, or during an in-person visit), and eight reported using a family member or friend as resources to obtain cancer information. Although five participants used a local support group, none of the participants used an online support group. Six participants received cancer information from church or a newspaper or magazine story, and five used a website. All participants reported watching a television story about cancer, but none of them used the radio or a telephone hotline for cancer information.

Favorable usability scores regarding the program’s navigation, content, persuasiveness, and value are reported (Table 2). Survivor stories were reported to be worth the “time” and “effort” spent watching them, and participants found the “touch screen” and “survivor-stories program” easy to use and “presented in a way that was easy to understand.” They did not report difficulty reading the words on the screen, and only one participant reported difficulty hearing the storytellers. Some women “wanted to hear survivor stories on other topics that were not included in this program,” but only one woman wished that “the survivor-story program would have included more videos to watch,” and no one felt that the clips were too long. Interestingly, only one participant used the dictionary feature and found it “very user friendly.” Seven participants said they would have spent “several hours” watching survivor stories at their home over a period of “at least several days” if they had been allowed to take the video player home for viewing at their leisure. Only one woman said she would have watched survivor stories for “two weeks or more,” and another said she would have watched survivor stories at home for “only a few hours.” Nine women reported they would like to watch the survivor stories with other family members, and all ten said they would share the survivor stories with friends.

Regarding the two items relevant to adherence, all participants agreed that watching the stories convinced them to receive follow-up mammograms as recommended by their doctor, but responses from the two women who received adjuvant hormone therapy were diametrically opposed; one strongly agreed and the other strongly disagreed that the survivor stories convinced them to take hormone therapy as prescribed.

The video program was rated quite favorably with regard to its potential use for newly diagnosed breast cancer patients

Table 2 Usability items for the survivor-stories video program

Item	Total respondents ^a , <i>N</i>	Strongly disagree, <i>n</i>	Somewhat disagree, <i>n</i>	Neither agree nor disagree, <i>n</i>	Somewhat agree, <i>n</i>	Strongly agree, <i>n</i>
Navigation						
1. The survivor-stories program was presented in a way that was easy for me to understand.	9	0	0	0	2	7
2. The survivor-stories program was easy to use.	9	0	0	0	1	8
3. It was easy to search for survivor stories either by a particular storyteller or by topic.	9	0	0	1	1	7
4. It was easy to use the computer's touch screen.	9	0	0	0	0	9
5. The one-on-one instruction session where I learned how to use the computer was helpful.	9	0	0	0	0	9
6. I had difficulty closing the survivor stories program before turning off the computer.	9	5	1	0	2	1
7. It was difficult for me to read the words on the screen.	9	9	0	0	0	0
8. It was difficult for me to hear the storytellers talk.	9	7	1	0	1	0
Content						
9. I wanted to hear survivor stories on other topics that were not included in this program.	9	3	2	0	3	1
10. The survivor-story clips, on average, were too short.	10	5	3	0	1	1
11. The survivor-story clips, on average, were too long.	10	7	3	0	0	0
12. I wish the survivor-story program would have included more videos to watch on these topics.	9	3	3	2	0	1
Persuasiveness						
13. The survivor-stories program convinced me to receive follow-up mammograms as recommended by my doctor.	10	0	0	0	0	10
14. The survivor-stories program convinced me to take hormone therapy as prescribed.	2 ^b	1	0	0	0	1
Value						
15. The survivor stories were worth the effort I spent watching them.	10	0	0	0	1	9
16. The survivor stories were worth the time I spent watching them.	10	0	0	0	1	9
17. I would recommend this survivor-stories program to other breast cancer survivors.	10	0	0	0	1	9
18. Would you have liked to have had more time to look at the survivor stories using the video player?	9	1	0	0	2	6
19. Is the video player with the survivor stories something that you would like to take home with you to watch at your leisure?	10	1	0	0	1	8

^a One participant was unable to use the video program due to technical difficulties; thus, she provided responses only to items specifically related to the survivor stories themselves

^b Only two participants self-reported receiving hormone therapy and responded to this item

(Table 3). Eight women agreed that the survivor stories “would have been useful to them” and “would have helped them understand their illness.” Six agreed that the stories “would have helped them cope with their illness,” and five agreed the stories “would have improved their quality of life.” All participants agreed that they would recommend this video program to a family member or friend with newly diagnosed cancer and to other breast cancer survivors. Only four women agreed that the video program would have helped them “with their relationships” or “come to terms with their cancer faster.”

Discussion

In this paper, we describe the development of a novel, interactive survivor-stories video program. Most of the breast cancer survivors who participated in the pilot study identified with storytellers, reported positive emotional reactions to survivor stories, rated the usability of the video program favorably, and would recommend the video program to newly diagnosed patients with breast cancer. We corrected the video program's malfunction which rendered one participant unable

Table 3 Participants' perceived utility of the survivor-stories video program for newly diagnosed patients

Item	No. of participants choosing each response					
	<i>N</i> respondents ^a	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
1. When first diagnosed with breast cancer, using this program would have been useful to me.	9	0	1	0	1	7
2. When first diagnosed with breast cancer, using this program would have helped me understand my illness.	9	0	1	0	2	6
3. When first diagnosed with breast cancer, using this program would have helped me come to terms with my cancer faster.	9	1	1	3	1	3
4. When first diagnosed with breast cancer, using this program would have made it easier to cope with my illness.	9	0	3	0	3	3
5. When first diagnosed with breast cancer, using this program would have helped with my relationships.	9	0	2	3	3	1
6. When first diagnosed with breast cancer, using this program would have improved my quality of life.	9	1	1	2	4	1
7. For a family member or a friend who was newly diagnosed with cancer, I would recommend this program.	9	0	0	0	1	8

^a One participant was unable to use the video program due to technical difficulties; thus she provided responses only to items specifically related to the survivor stories themselves

to view stories on the Modbook but determined that we could not enlarge the play button as one participant suggested. Based upon the promising results of the pilot study, we felt the survivor-stories video program was ready to be implemented in the clinical trial with newly diagnosed African American breast cancer patients.

The strengths of the survivor-stories video program are the personal narratives of African American breast cancer survivors, which pilot participants reported as the most-liked feature of the video program. Survivor stories were carefully selected following consensus among study-team members using a rigorous coding process, selecting storytellers who would be viewed as credible messengers of cancer information by newly diagnosed African American breast cancer patients. Qualitative data analysis techniques [26–28] were used to categorize survivor stories into one of 12 story topics that emerged from the stories' messages. The intervention was developed so that newly diagnosed African American breast cancer patients might find the survivor-stories video program relevant to their experience, helping them to become engaged with the survivor stories, potentially enhancing QOL outcomes and adherence to follow-up care in this group of patients. Using a touch-screen computer, this intervention also does not require computer skills or use of a keyboard.

To the best of our knowledge, no other studies have used survivor-story videos specifically to help improve QOL or promote adherence to surveillance mammography and endocrine therapy (if indicated) in breast cancer survivors. A recent study [34] found that either culturally tailored or generic (non-culturally tailored) videos increased the intentions of Chinese American women to obtain a screening mammogram, as compared with printed fact sheets. Another study found that

a tailored, interactive computer program was more effective than either print or video-targeted messages in increasing adherence to mammography screening in low-income African American women [35]. These studies, however, did not examine the effects of their interventions on surveillance mammography outcomes. Another four-arm trial of two counseling interventions for newly diagnosed breast cancer patients (psychoeducational videos or telephone counseling, alone or in combination compared with standard of care) found that psychological well-being increased from time of diagnosis to the completion of adjuvant therapy/6 months post-surgery regardless of study arm, but patients receiving standard of care reported more distress from side effects than women who received psychoeducational videos, telephone counseling, or both interventions [36]. While this psychoeducational-video counseling intervention benefited patients in terms of side effect distress, which is itself likely associated with some aspects of QOL, this study did not find a differential impact on patients' psychological well-being by study arm [36]. Other studies have reported a significant association between breast cancer patients' self-reported surgical-side-effects severity and aspects of QOL, including body image [37], sexual problems [38], and concern about recurrence [39]. It is important to test whether survivor-stories interventions will be associated with greater improvement in QOL compared with standard of care alone.

One home-based, easy-to-use eHealth application tested in breast cancer patients is the Comprehensive Health Enhancement Support System (CHESS), which contains (among other features) an instant library of articles on breast cancer topics, short answers to frequently asked breast cancer questions, decision-making aids, and real-life text and video accounts

of how other women have coped with breast cancer [40]. Results from studies using CHES in both early and late-stage newly diagnosed breast cancer patients have demonstrated that patients with CHES access report better social support [41] and QOL [42, 43] than patients who did not have CHES access. Low-income African American women logged on and spent more time using CHES than more affluent women [40] and uninsured women younger than 60 years of age who used CHES reported fewer breast cancer concerns 2 months following diagnosis than women who received a book about breast cancer [41]. Whereas both CHES and our survivor-stories video program are interactive, easy-to-use, and designed with cancer patients in mind, our program was designed specifically for African American women and relies heavily on delivery of information through the use of narratives, with a small dictionary feature, whereas CHES has a narrative component but does not primarily use narratives to deliver cancer information.

Another study testing the effect of narrative versus didactic information delivery in recently diagnosed breast cancer patients found that African American women benefited more from narrative information than Caucasian women did [44]. It is important to test whether the standard of care can compare with an interactive, survivor-stories video program. Will the program produce more favorable results in terms of African American breast cancer patients' QOL and adherence to surveillance mammography and endocrine therapy? This is an important question to explore. Furthermore, it is important to collect contextual data important for interpreting such an intervention's results, such as the total number of survivor stories watched and the length of time participants used the video player in order to determine whether, and if so the extent to which, participants' levels of engagement with survivor stories, identification with storytellers, and use of the video program are associated with QOL and follow-up care.

Currently, there are few resources designed specifically for African American breast cancer patients to hear stories from survivors with whom they identify and find credible. A study of eHealth resources determined that African Americans accounted for just 5.8 % of online survivor stories even though African Americans account for 8.6 % of prevalent cancer cases [45]. Use of our survivor-stories video program as a cancer-communication tool to improve clinical outcomes in African American breast cancer patients is promising, but promoting use of the Internet alone as the mode of delivery may be ill-advised for this particular group of patients who may not regularly use the Internet. According to a recent report collected as part of the Pew Internet and American Life Project, adults who are older than 65 years of age, have less than a high school education, and live in households earning less than \$30,000 per year are least likely to have high-speed broadband Internet access at home [46]. In addition, although African Americans are more likely than Caucasians to own

any sort of mobile phone [46], smartphones having Internet capability to deliver eHealth resources are less likely to be owned by adults >65 years of age or who have not completed high school [47].

As with all research, this pilot study has several limitations. First, the sample included ten African American breast cancer survivors recruited from one NCI-designated comprehensive cancer center, potentially limiting the generalizability of our findings to women treated in community or rural hospitals. However, generalizing our findings was not the intent of this pilot study, and small samples are commonly used for feasibility and user-testing studies to refine interventions and interview/questionnaire items based on feedback from participants. Second, although the video program saves usage data on the Modbook, for this pilot user/usability study, we report only limited objective usage data from the Modbook (i.e., the number of minutes of use) as we wanted primarily to know from the participants' perspectives whether they experienced problems using the Modbook and the kinds of problems they experienced. A study-team member was available to answer questions and address problems that arose while a participant used the video player, but we relied on participant self-reported data to identify user/usability problems. Third, the survivor-stories video program was designed as an intervention to be used with newly diagnosed breast cancer patients after a new cancer consultation with a breast surgeon to discuss treatment options (including, for example, type of surgery and, for some women, the possible need for neoadjuvant chemotherapy prior to surgery). Therefore, we did not specifically select survivor stories that focused on the treatment decision-making process, although we included several video clips that addressed a patient's decision to undergo breast reconstruction.

Delivery of information through use of narratives has been associated with increased healthcare participation among African American breast cancer patients [44] as well as engagement, ease in understanding, and identification, all of which are theorized pathways of how communication interventions may affect behavior [25]. Breast cancer patients can draw support from different sources, including other women who have survived breast cancer. Whether breast cancer patients view these survivor stories as being supportive is an empirical question that needs to be addressed with further research. The survivor-stories video program uses videotaped narratives of breast cancer survivors to provide clinically relevant information for recently diagnosed breast cancer patients, potentially helping them to cope with their treatment and recovery process. Cancer survivors' experiences with treatment and living with cancer makes them especially credible as messengers of cancer information. It's important for health communication interventions to foster positive attitudes, increase knowledge about and encourage participation in cancer screening/surveillance, while keeping in mind the diversity, cultural

norms, and education levels of the target population [48]. We developed the survivor-stories video program specifically for African American breast cancer patients, hypothesizing that this novel cancer-communication intervention will have a positive impact on newly diagnosed patients' QOL and adherence to follow-up care. The positive results of this study suggest that future interventions that use this technique should be rigorously tested with a view toward understanding the specific mechanisms that will impact its efficacy and will influence its uptake and dissemination among African American breast cancer survivors.

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