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EFFECTS OF USING ONLINE NARRATIVE AND DIDACTIC INFORMATION ON HEALTHCARE PARTICIPATION FOR BREAST CANCER PATIENTS

Meg Wise, PhD^{1,*}, Jeong Yeob Han, M.A.¹, Bret Shaw, PhD², Fiona McTavish, M.A.¹, and David H. Gustafson, PhD¹

¹Center for Health Enhancement Systems Studies, University of Wisconsin - Madison

²Department of Life Sciences Communication, University of Wisconsin - Madison

Abstract

Objectives—To determine the effects of online narrative and didactic information on breast cancer patients' healthcare participation and the interaction effects of race.

Methods—Sample: 353 breast cancer patients (111 African Americans) using an eHealth program with narratives (audiovisual and text) and didactic information (text only). Measures: healthcare participation scale (0, 4 months), online information use. Analyses: hierarchical regression.

Results—Narrative ($\beta = .123, p < .01$) and didactic ($\beta = .104, p < .05$) information use had independent and positive effects on healthcare participation. Effects of both were significantly greater for African Americans.

Conclusions—Findings are consistent with and advance prior research on online learning processes and outcomes for breast cancer patients: (1) Benefits accrue with using a variety of online learning tools; and (2) African Americans use and benefit more from online narrative and didactic information than do Caucasians.

Practice implications—eHealth programs should provide both didactic and narrative information—especially for African Americans and might consider making greater use of interactive and audiovisual formats. As patients increasingly use of the web for cancer information, clinicians should provide lists of web high quality resources that provide both narrative and didactic information.

Keywords

breast cancer; online patient education; narrative information; didactic information; healthcare participation; African Americans

1. Introduction

A breast cancer diagnosis can turn one's life upside down and demands a steep learning curve to decide upon and manage treatments. Active participation in treatment decision-making and adherence, follow-up screening, and effective self-care improves coping and quality of life

* Corresponding author: Meg Wise, PhD, Assistant Scientist, Center for Health Enhancement Systems Studies, University of Wisconsin, 610 Walnut Street, Room 1132, Madison, WI 53726, phone: (608) 263-1736, FAX (608) 263-4523, mewise@wisc.edu.

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[1,2,3,4,5]. Healthcare participation requires considerable health literacy, which entails understanding the diagnosis and treatment, as well as communication and decision-making skills [6,7,8,9]. According to social learning theory, information is critically important for such participation and is an effective strategy for coping with a serious illness [10,11,12]. But seeking, comprehending and applying relevant information in a compressed timeframe can be overwhelming. Fortunately, many providers and websites provide patients with timely and accurate information [4,13,14]. Patient information is most commonly provided in didactic formats (e.g., fact sheets, brochures, questions and answers, charts, articles). Recently, patient educators have suggested that salient patient narratives in print or video presentations may be more effective [15], because they are more engaging and show how real people integrate technical knowledge into their healthcare within a specific cultural context—thus providing social role models [10,11].

The Internet is an important source of breast cancer information and can help patients ask their doctors better questions [16,17,18,19,20]. Despite generally lower access to the Internet, [21] African Americans use and benefit from online breast cancer information as least as much as Caucasians when provided computers and home Internet access [22,23,24,25]. However, no studies have parsed out the effects on healthcare participation of using online narrative and didactic information—neither for Caucasian nor for African American breast cancer patients. Such research could help website developers allocate their resources more effectively and better tailor programs to assess and meet individual learners' needs.

1.1. Didactic and Narrative Formats in Breast Cancer Information

Didactic information is most commonly provided to breast cancer patients [26,27]. Considered the foundation for technical knowledge [11], it distills facts about the medical, psychosocial and practical aspects of breast cancer into forms such as pamphlets, articles, short answers to frequently asked questions (FAQs), and fact sheets. Effective didactic information is clear, acknowledges controversies and the limits of knowledge, and allows readers to efficiently pull out and consider relevant facts. But if used exclusively, it may limit full healthcare participation. Some critics claim objective presentation about emotional issues privileges expert knowledge over the lived experience and may unwittingly embed dominant cultural subtexts (e.g., presumption of desired autonomy) [28]. Others suggest “knowing that” (the domain of didactic information) is not enough to “understand and know how” to manage a crisis [29]. For instance, knowing that or how radiation will disrupt daily life does not help patients to imagine how they can survive (or even find benefit in) the experience.

Personal narratives have garnered considerable interest among cancer educators, program designers, and researchers [15]. Several psychological and learning theories suggest how patient narratives can encourage healthcare participation. According to Polkinghorne [30], we lead “storied lives” and thus construct ourselves and experiences in a series of ongoing narratives. Cognitive learning theories suggest that people process, store and retrieve complex and interrelated data better in narrative formats than in lists of discrete facts [31,32]. Illness narratives can impose a sense of order over chaos and allow for reflection, appraisal and problem-solving [33,34,35]. Stories of joy and suffering can appeal to aesthetic sensibilities [36] and can transport people into others' experience [37] and thus build identity with, affection for, and a desire to emulate their attitudes or behaviors [38,39]. Narratives may also be more salient for people with low-literacy, or from African American or other minority cultures that maintain a strong oral storytelling tradition [40,41,42,43].

Narratives privilege practical experience and can model how to apply technical knowledge to one's real life situation [10,11]. For instance, a story about resolving challenges of deciding upon and getting through lumpectomy and radiation may help a newly diagnosed woman use her technical knowledge to talk more effectively with her oncologist, and to cope with side

effects in the face of emotional concerns. Stories can also inspire, build hope and competence, and model positive disease self-management behaviors—especially for people from non-dominant cultures [41,42,43]. Given the number of cancer narratives in the popular media and the recent scholarly attention to illness narrative, it is not surprising that some theorists suggest that narratives may be a promising alternative to the more traditional didactic approaches for cancer patient education [15,27].

However, such “Either/or” debates may be limiting. Certainly, social learning theory accommodates both types of information with didactic forms for presenting facts and alternatives and narratives of similar others for social role modeling [10, 44]. The adult education literature suggests that some people learn better with narrative, some with didactic, and some by using both formats [45]. Learning style assessments use continuous scales in cognitive/affective, technical/experiential, concrete/abstract, and relational/autonomous domains [45,46,47,48]. Cognitive, abstract, technical, and/or autonomous learners may prefer didactic information; affective, experiential, concrete and/or relational learners may prefer narratives; and those in the middle of these scales may prefer both. However, preferences may change in the face of new challenges, when old strategies no longer work [29,49]. If this is so, cognitive, autonomous, or technical learners may seek out stories to understand how others weathered emotional challenges; affective, experiential, relational learners may seek didactic information to master facts before talking to the physician.

Thus, one could argue that both narrative and didactic information could improve healthcare participation. In fact, Slater and colleagues [27] found dietary narratives were more believable than didactic messages but no different regarding clarity, usefulness, or self-efficacy. Thus, the more salient question may be about the independent rather than the comparative effects of narrative and didactic information.

1.2. CHESS: Integrated Web-based Breast Cancer Information

The Comprehensive Health Enhancement Support System (CHESS) is developed by an interdisciplinary team of, healthcare clinicians and system engineers, health educators and communication specialists, computer programmer and. It provides didactic and narrative information about medical, practical and psychosocial issues. Information content is driven by a comprehensive needs-assessment process, [50] written at an easy-reading level and reviewed and reviewed annually by experts and patients [4,13,14,22]. Several studies have found that CHESS improves quality of life, perceived social support, information competence and healthcare participation [4,13,14,22,24]. Information use was found to have independent and positive effects on information competence and doctor-patient communication [51,52]— the effects were even greater when information was used with CHESS’s communication and interactive learning tools. However, these analyses combined didactic and narrative information and did not test their independent and interactive effects.

CHESS studies have also shown that African American women’s lower baseline levels of quality of life rose to or exceeded those of their Caucasian counterparts at post-test [4,23,24, 25]. Despite their lower prior computer experience, African Americans used CHESS as much, but differently, than Caucasians. They used the discussion group less for sharing stories [22], but the information and analysis services more (4, 23, 24, 25). However, the effects of using different information formats on healthcare participation have not been studied—neither for Caucasian nor for African American breast cancer patients.

1.3. Aims and Hypotheses

The above discussion suggests that active healthcare participation requires technical knowledge (typically the domain of didactic information) and practical knowledge (typically

the domain of narrative information). While overall use of CHES information has improved healthcare participation [4], no studies have parsed out the effects of narrative and didactic information on that improvement. We hypothesize that both narrative and didactic information use will have independent and positive effects on healthcare participation. Furthermore, African Americans benefit more from their overall use of information in CHES than do Caucasians, and, like other minority groups, they have maintained a strong oral storytelling tradition [40,43]. Therefore, we also hypothesize that African American women's use of both didactic and narrative information will have greater effects on their healthcare participation.

2. Methods

2.1. Sample and Data

Data from 353 women (32% African American) for this study were originally collected from three studies where recently diagnosed women evaluated *CHES: Living with Breast Cancer*. The first two studies were multi-site randomized trials, funded by the Department of Defense (DOD) and the National Library of Medicine (NLM). The present study includes 122 NLM and DOD participants who were randomized to CHES and completed the pre-test and the 4-month post-test (99% of pretest respondents). The third study, the Digital Divide Pilot Project (DDPP), was funded by the National Cancer Institute and the John and Mary Markle Foundation. This population-based study recruited 286 underserved women from rural Wisconsin and Detroit, Michigan; all were given access to CHES for 4 months. The present study of 353 women includes the 231 women who completed the pretest and post-test (81% return rate) for the DDPP study and the 122 women from the DOD and NLM studies.

All three studies provided computers and Internet access as needed, collected the same data, and delivered the same CHES intervention with hands-on training on how to use CHES content and tools and telephone support. There were no directives for how much or little to use CHES or what features to use. We merged and matched pretest and four-month post-test survey data and four months of CHES use data from all three samples to increase statistical power and demographic diversity (DOD and NLM: 23.7% African American and 46.9% with at least a bachelor's degree; DDPP: 35.9% African American and 15.6% with at least bachelor's degree).

2.2. Intervention

CHES, as described above, provided information, communication and interactive learning services. This study investigated use of the narrative and didactic information, which was written or selected by experts for accuracy, cultural competence and readability and annually reviewed by experts and patients. Both didactic and narrative information addressed medical, psychosocial, and practical issues.

Didactic information was provided via: (1) Questions & Answers, as shown in Figure 1, address specific questions (e.g., radiation side effects, chemotherapy, stress, hair loss); and (2) Instant Library provides links to patient education articles, pamphlets and statistics that were hosted on the National Cancer Institute and other quality websites. Didactic information was accessed through hierarchical topic menus or by keyword search. The bulk of didactic information addressed medical and treatment topics.

CHES narrative services provide real-life accounts of the cancer experience developed through patient interviews by trained journalists. Transcripts were honed into a basic story with links to detailed vignettes on specific themes (e.g., diagnosis, treatment, decision-making, side effects, relationships, work, personal growth, spirituality). There were two narrative services: (1) Personal Stories were text-based. Race was identified in fewer than half of the stories (most

of those who were identified were Caucasian) and (2) Video Gallery provided videotaped personal stories accompanied by text, as shown in Figure 2. About half of the videos were of African American women, both services were accessible by keyword search and by alphabetical menus of pseudonyms with a descriptive tagline.

2.3. Measures

2.3.1 Dependent Variable: Healthcare Participation—Healthcare participation, the dependent variable, was measured with a 7-item, 5-point response scale (0 = *never* to 4 = *always*) developed by CHEAD to assess participation preferences, confidence, and communication with the doctor. It has been used in a number of studies with high reliability [4,20,23,24,25]. Respondents were asked how often they (1) prefer to have all the details (including possible risks) regarding their breast cancer and treatment options, (2) feel comfortable in asking the physicians or nurse questions, (3) feel confident in making decisions about their breast cancer, (4) know what questions to ask their doctors, (5) are able to be assertive with their doctors, (6) have confidence in their doctors, and if (7) having information about their breast cancer, treatment, and outlook gives them a sense of control. Healthcare participation was operationalized as an additive index of the seven items (pretest reliability $\alpha = .76$; posttest reliability $\alpha = .80$). One study combining DOD and NLM data showed that CHEAD has a positive effect on healthcare participation [4] but this is the first study to combine these three study samples and to investigate what how narrative and didactic information use contributes to these effects.

2.3.2. Independent Variables: Didactic and Narrative Information Use—CHEAD didactic information and narrative information use were the independent variables. CHEAD use was measured by a browser that automatically collected use data on all page selections and data inputs made by participants. This capability enabled us to track each patient's code name, date and time, and URL of every Web page requested. For this study, the CHEAD use variables included two measures of CHEAD Information service use: didactic information services and narrative information services. These measures were operationalized as total minutes spent in each type of service during the four-month study.

Because of the positively skewed distribution of the variables, we took the logarithms (after adding 1 minute to all scores to eliminate non-loggable zeros) and used them in the subsequent analyses. The measure of time spent in a narrative or didactic information service is based on the assumption that greater time exposure is associated with greater opportunity to learn. Time exposure to cancer information has been found to predict higher levels of cancer-related knowledge [51,53].

2.3.3. Control variables—To reduce error in the dependent variable, we statistically controlled for age, educational level, and ethnicity (a dummy variable with Caucasian coded 0 and African American coded 1). We also controlled for stage of cancer, because it has been shown to affect psychological adjustment and distress [54,55]. Early stage (0, 1, 2) was coded as 0; late stage (3, 4, or inflammatory) was coded as 1. Finally, we controlled for the pre-test level of the dependent variable, health care participation.

2.4. Analytic framework

The aims of this study were to test whether use of both narrative and didactic information would improve healthcare participation (H1) and whether African Americans would benefit more from using both types of information (H2).

Hierarchical regression analyses were performed to test the relationship between CHEAD didactic and narrative service use and healthcare participation. To examine the main effect of

didactic and narrative information service use (H1), the control variables and the pretest score of the dependent variable (i.e., healthcare participation) were entered as an initial set in the regression analysis. In the next blocks, use of didactic and narrative information services were entered separately, because of multicollinearity caused by use of both narrative and didactic information services ($r = .58$) [56].

To test interactive effects between narrative and didactic information use and race (H2), the same procedures were repeated by first controlling for demographics and pretest healthcare participation, then by the main effects of both narrative and didactic information use, and finally by the two interaction terms (African American = 1; Caucasian = 0). Consistent with recommendations for testing interaction terms, all main effect variables were standardized [57].

3. Results

3.1. Sample Characteristics

As shown in Table 1, the mean sample age was 51 years; 67.8% of women were Caucasian and 32.2% African American. About two-thirds of the sample had at least some college education; approximately three-quarters had early stage cancer (Stage I or II).

3.2. Descriptive Statistics

Mean values of healthcare participation were 14.80 ($SD=3.15$) for the pretest and 15.97 ($SD=3.03$) for the four-month post-test. The change in healthcare participation from the pre- to post-test was statistically significant ($t=7.39$, $p < .001$): effect size calculated via Cohen's $d = .38$. Comparing CHESS use by ethnicity, average time spent in the didactic and narrative service were both greater for African American women (Didactic: $M = 19.70$, $SD = 31.10$, Narrative: $M = 17.16$, $SD = 38.19$) than for Caucasian women (Didactic: $M = 18.30$, $SD = 28.62$, Narrative: $M = 15.78$, $SD = 36.60$).

3.3. Main Effects

Table 2 summarizes the results of the two hierarchical regression analyses to test the effects of didactic and narrative information use on healthcare participation (H1). As expected, pre-test levels of the dependent variable had a strong, significant relationship with the dependent variable ($\beta = .543$, $p < .001$). Furthermore, women with early stage cancer had greater healthcare participation than those with late stage ($\beta = -.109$, $p < .05$). Finally, both narrative ($\beta = .123$, $p < .01$) and didactic ($\beta = .104$, $p < .05$) information use were found to have significant, independent and positive effects on healthcare participation with an R^2 change of 1.6% ($p < .05$), thus confirming our first hypothesis.

3.4. Interaction Effects of Race

Table 3 shows the results of the hierarchical regression model to test the interaction effects of narrative and didactic information use and race (0 = Caucasian, 1 = African American) on healthcare participation (H2). After controlling for demographics, pre-test healthcare participation and use of CHESS on narrative and didactic services (main effects), interactions were significant between race and both didactic information ($\beta = .131$, $p < .05$) and narrative information ($\beta = .112$, $p < .05$).

Figures 3 and 4 plot the interaction effects of race on these findings. As shown in Figure 3, healthcare participation increased with greater use of didactic information for both African American and Caucasian women. However, the African American women's healthcare participation improved more with didactic information use than did Caucasian women's. Similarly, Figure 4 suggests that there was a moderate positive effect of narrative service use

among Caucasian women but a stronger positive relationship between narrative service use and healthcare participation among African American women. In sum, as we hypothesized, African Americans benefited more than Caucasians from using both kinds of information.

4. Discussion and Conclusion

4.1 Discussion

This study explored the effects of online narrative and didactic information use on health care participation among Caucasian and African American breast cancer patients. Both of our hypotheses were confirmed: narrative and didactic information use had positive and independent effects on healthcare participation, and these effects were greater for African Americans than for Caucasians.

4.2 Conclusion

Although case-based learning, using rich narrative and experiential material, has been integrated into traditional didactic medical education [58,59,60], this is the first study we are aware of to evaluate the independent effects of using case-based, or narrative learning, and didactic information on healthcare participation for breast cancer patients. These findings advance prior CHES research which has found that benefits accrue by using a variety of online information, social support and interactive problem-solving tools [51,61], and that African Americans use and may benefit more from such use than Caucasians [22,23,24,25]. This study suggests that using a variety of information formats can also improve patient healthcare participation and confirms that eHealth programs should continue to provide both didactic and narrative information—especially for African Americans.

These findings also suggest that further research is needed to explain these effects.

4.2.1. Effects for each type of service—Patient participation requires a high degree of health literacy, which is defined as a complex set of technical and instrumental knowledge and skills [1,2,3,8,9]. Information builds knowledge and knowledge builds skills [10,11]. Didactic information is broadly associated with technical knowledge and narrative with understanding and practical knowledge [11,15,27]. This study found that both information formats had positive and independent effects on healthcare participation—but did not confirm the type of knowledge gained by each format. We suspect that narratives may reinforce and help people store and retrieve technical knowledge initially gained from didactic information—and a bulleted list in a didactic FAQ may summarize practical information embedded in a narrative. But further research is needed to tease out what factors contributed to African Americans' greater benefit, such as less access to other educational or Internet resources (and thus more hunger for information), as well as the significant cultural and breast cancer factors, beyond cancer stage, that affect them [62].

4.2.2. Greater Effects for African American Patients—A particularly interesting finding was that African Americans benefited more from narrative information than did Caucasian women. Social learning theory and health communication theories suggest that homophily, or learning from similar others, is an important attribute for narrative learning [10,11]. Thus, we might hypothesize that African Americans selected and benefited more from the stories of African American patients versus those of Caucasian patients [44]. However, most text-only stories have not identified race and African Americans accounted for only half of the video stories. Given the complexities of individual lives and cancer, other similarities such as the age, spirituality, marital status or cancer-related issues might also contribute to a narrative's effectiveness. Clearly, further research is needed to determine what factors are important for matching storytellers and learners.

4.2.3. Benefit of Received Narrative versus actively—Narrative Creation Further research is also needed to determine the benefits of receiving expert-derived narrative information versus actively telling one's story or reading others' in online support groups. Our research has found consistently that despite their strong cultural oral storytelling tradition [40], compared to Caucasian women African Americans do not often share their stories in the online discussion group [22,23,24,25]. Research on barriers to posting stories in the discussion group (e.g., reading/writing/keyboard skills, time constraints, anonymous self-disclosure) and whether narrative information provides a social connection may shed further light on African American women's low discussion group use, but high use of and benefit from expert-derived narratives of other women.

4.3. Practice Implications

The video gallery, which was the only audiovisual format within CHES, may have accounted for the greater use and benefit of narratives among African Americans. Therefore, web-based interactive multimedia programs (IMM) and education entertainment [41,64] may hold great promise for providing information to people with lower educational and health literacy levels and for reducing health disparities [63]. IMM, used in case-based medical education [58,59, 60], can integrate narratives, simulate didactic information summaries of key information from narratives, and use interactive questions and answers to deepen the learning experience. Because IMMs use multiple and sensorily vivid learning pathways [64], they have several advantages over print to engage the learner, convey basic information, and guide people through higher-order learning processes that enhance their ability to apply information toward active healthcare participation [64,65].

Educational television and radio dramas have effectively promoted healthy behaviors in the developing world [66,67,68,69,70,71,72,73,74] and recently have been integrated, with promising results, into interactive breast cancer decision guides for low-income women in the United States [75]. Thus, new technologies that combine phone, Internet and video culturally competent entertainment education may be another avenue to engage low literacy populations. But more research is needed to determine whether fictionalized accounts—no matter how entertaining and moving—are as effective as real-life accounts. Finally, as patients increasingly use the web for cancer information, clinicians and healthcare organizations should recommend websites that provide accurate didactic information and effective cancer narratives.

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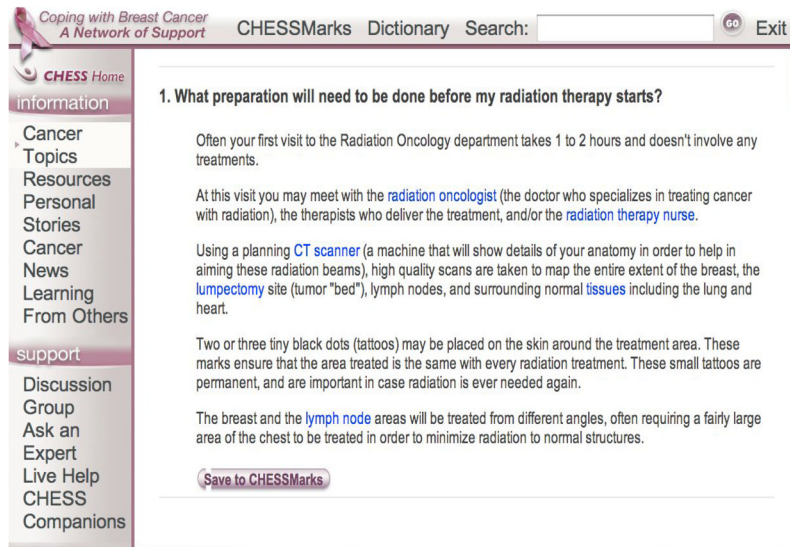


Figure 1.
CHES Didactic Information: Question and Answer about Radiation

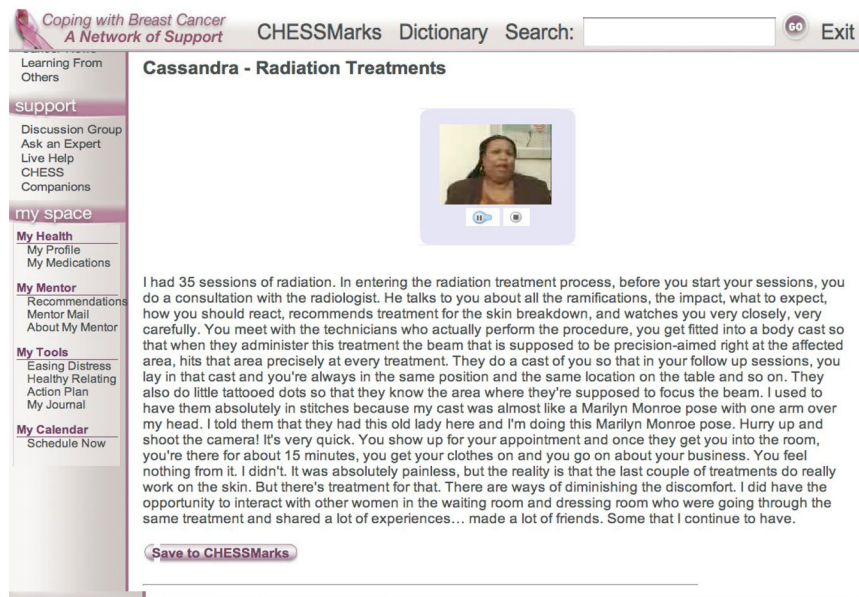


Figure 2.
CHESS Video Gallery Personal Story about Radiation (Narrative Information)

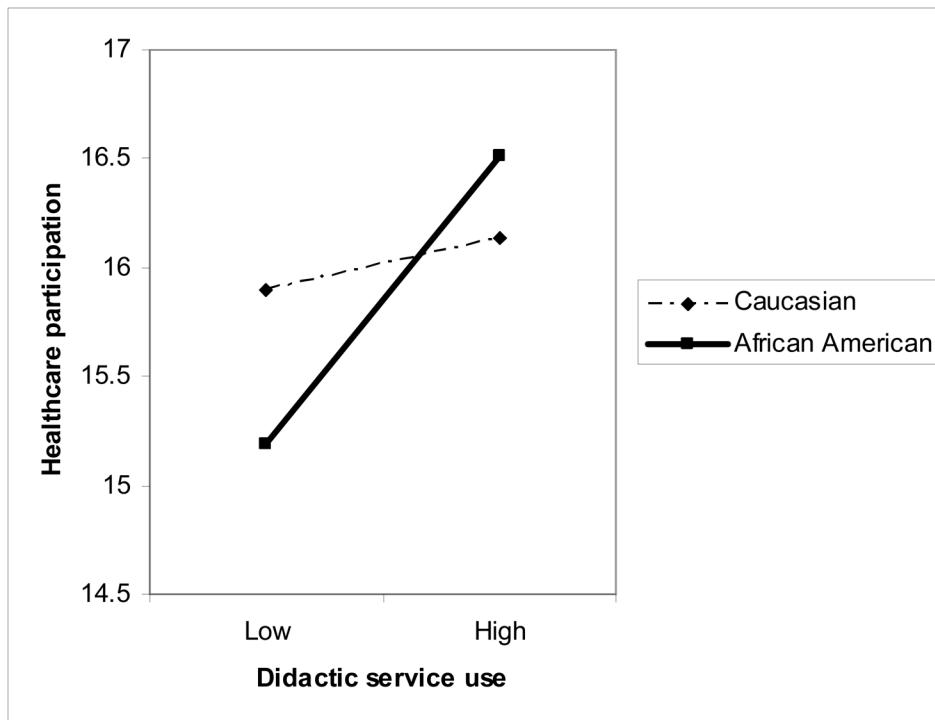


Figure 3. Interaction effect between didactic information service use and race in predicting four-month healthcare participation
 Note: - Pretest score of healthcare participation was controlled.

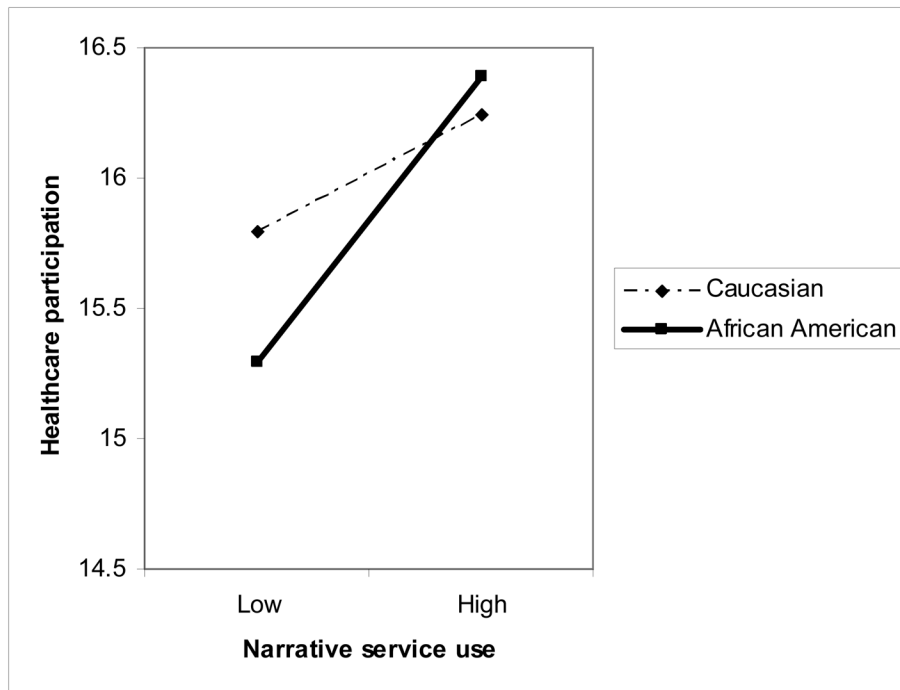


Figure 4. Interaction effect between narrative information service use and race in predicting four-month healthcare participation.
 Note: - Pretest score of healthcare participation was controlled.

Table 1

Demographic characteristics (N = 353)

Age	
Mean (SD)	51.15 (11.34)
Ethnicity	
Caucasian	234 (67.8%)
African American	111 (32.2%)
Education	
Some junior high	2 (0.6%)
Some high school	32 (9.3%)
High school degree	83 (24.1%)
Some college	93 (27.0%)
Associate or technical degree	45 (13.1%)
Bachelor's degree	56 (16.3%)
Graduate degree	33 (9.6%)
Stage of cancer	
Early stage (stage 0,1,2)	260 (74.9%)

Table 2
Regression analyses predicting healthcare participation (posttest): Main effect

	Beta (standardized)
<i>Control variables (5)</i>	
Age	-.020
Race (1=African American; 0=Caucasian)	-.023
Education	-.011
Early or late stage (1=late stage)	-.109*
Healthcare Participation (pretest)	.543***
<i>R² Change (%)</i>	30.6***
<i>Main effect: CHES\$ use^a(2)</i>	
Didactic service ^l	.104*
Narrative service ^l	.123**
<i>R² Change (%)</i>	1.6*

Note:

^aMain effects of CHES\$ use were entered separately to the regression model in order to avoid multi-collinearity problems.

^lLog transformed due to the positive skewness of the distribution.

*
 $p < .05$,

**
 $p < .01$,

 $p < .001$.

Table 3
 Regression analyses predicting healthcare participation (posttest): Interaction effect

	Beta (standardized)
<i>Control variables (5)</i>	
<i>R² Change (%)</i>	30.6 ^{***}
<i>Main effect: CHES use (2)</i>	
Didactic service ¹	.104 [*]
Narrative service ¹	.123 ^{**}
<i>R² Change (%)</i>	1.6 [*]
Interaction effect^a	
Didactic service ¹ × Race (1=African American)	.131 [*]
Narrative service ¹ × Race	.112 [*]
<i>R² Change (%)</i>	1.2 [#]

Note:

^aTwo interaction terms were entered in the final block of the hierarchical regression model following control variables and two types of CHES service use variables.

¹Log transformed due to the positive skewness of the distribution.

[#]*p* < .10,

^{*}*p* < .05,

^{***}*p* < .001.