

# The Effect of Narrative Information in a Publicly Available Patient Decision Aid for Early-Stage Breast Cancer

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This study was designed to (1) evaluate the effect of narratives used in a popular, publicly available patient decision aid for early-stage breast cancer on hypothetical treatment decisions and attitudes toward the decision aid and (2) explore the moderating effects of participant numeracy, electronic health literacy and decision-making style. Two hundred women were asked to imagine that they had been diagnosed with early-stage breast cancer and viewed one of two versions of a video decision aid for early-stage breast cancer. The narrative version of the aid included stories from breast cancer survivors; the control version had no patient stories. After viewing the video decision aid, participants made a hypothetical treatment choice between lumpectomy with radiation and mastectomy, answered several questions about their decision, and evaluated the quality of the decision aid. Participants received \$100 for completing the study. The two conditions differed in their motivations for the treatment decision and perceptions of the aid's trustworthiness and emotionality but showed no differences in preferences for surgical treatments or evaluations of the decision aid's quality. However, the impact of patient narratives was moderated by numeracy and electronic health literacy. Higher levels of numeracy were associated with decreased decisional confidence and lower ratings of trustworthiness for the decision aid in the narrative video condition but not in the control video condition. In contrast, higher levels of electronic health literacy were associated with increased decisional confidence and greater perceptions of trustworthiness and credibility of the decision aid in the narrative video condition but not the control video condition.

Patient narratives, or stories, are illustrative examples of other patients' experiences with a disease or disorder (Bekker et al., 2012). They have been used in health care

materials to (a) provide information about a multitude of health care issues (Jibaja-Weiss et al., 2006; Volandes et al., 2007), (b) make health care materials more engaging (Green, 2006; Kreuter et al., 2007; Volk et al., 2008), (c) model targeted behaviors (Volk et al., 2008), (d) persuade a target population to engage in health behaviors or to cease unhealthy behaviors (Hinyard & Kreuter, 2007; Volk et al., 2008), and (e) provide comfort to patients and families (Hinyard & Kreuter, 2007; Kreuter et al., 2007).

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Narratives are also a popular component of patient decision aids, interventions designed to assist people in making a choice between two or more medical treatments when the decision is *preference-sensitive*, or no single “best” therapeutic course of action exists. However, researchers consider this practice to be highly controversial for two reasons (Butow, Fowler, & Ziebland, 2005; Holmes-Rovner et al., 2007). First, there are compelling theoretical arguments from cognitive and social psychology that suggest narratives are more powerful than other message formats because narrative messages have the ability to “transport” the reader or viewer into the story (Green, 2006; Green & Brock, 2000); narrative messages are likely to cause greater elaboration (Petty & Cacioppo, 1986); and people tend to underutilize statistical information relative to case studies (Taylor & Thompson, 1982). Furthermore, dual-process models and the affect heuristic suggest that narratives influence health care decisions by facilitating different modes of information processing than other message formats (Finucane, Alhakami, Slovic, & Johnson, 2000; Peters, Lipkus, & Diefenbach, 2006; Slovic & Peters, 2006; Slovic, Peters, Finucane, & MacGregor, 2005). According to dual process models of cognition, narrative information is likely to be processed using our more immediate, affective system (System 1), while statistical data are likely processed using our more deliberative, cognitive system (System 2) (Epstein, 1991; Evans, 2003; Kahneman, 2003; Peters & Slovic, 2000; Sloman, 1996; Slovic & Peters, 2006; Smith & DeCoster, 2000; Stanovich, 1999). Because of this, patient stories may enjoy a processing advantage, which could result in greater weight given to narrative information during decision making. Although this may be a beneficial characteristic of narratives when their goal is to persuade people to use sunscreen, it is of great concern when narratives are used to support preference-sensitive decisions.

Second, narratives remain controversial among researchers because studies about their impact on health care decisions have yielded conflicting results (Winterbottom, Bekker, Conner, & Mooney, 2008). Although there is a rich, and largely consistent, literature on the effect of narrative messages in other areas of social science such as marketing and consumer behavior (Adaval & Wyer, 1998; Escalas, 2004, 2007; Hong & Park, 2012; Polvorat, Alden, & Kim, 2007; Wentzel, Tomczak, & Herrmann, 2010), there is less evidence about how narratives impact decisions about our health. Furthermore, the existing evidence is mixed with regard to (a) whether narratives have any effect on health care decisions and (b) whether their impact is positive or negative. A review by Winterbottom and colleagues (2008) identified 17 studies that examined the effect of narratives on decision making in medically relevant contexts; none of these studies looked at the impact of narratives within a patient decision aid. Although the majority of these studies demonstrated that patient narratives have very little influence on decision making when compared with no

additional information and/or statistical information (Cody & Lee, 1990; Cox & Cox, 2001; Greene & Brinn, 2003; Kopfman, Smith, Ah Yun, & Hodges, 1988; Morman, 2000; Rook, 1986; Sherer & Rogers, 1984; Slater & Rouner, 1996; Wilson, Mills, Norman, & Tomlinson, 2005), five studies reported that providing narratives altered health-related decisions (Fagerlin, Wang, & Ubel, 2005; Rook, 1987; Ubel, Jepson, & Baron, 2001). Additionally, recent work has demonstrated that narratives impact preferences for end-of-life care (Kerstholt, van der Zwaard, Bart, & Cremers, 2009; Volandes et al., 2009), have a greater effect on hypothetical choices for dialysis treatment than advice from a physician (Winterbottom, Bekker, Conner, & Mooney, 2012), and increase risk perception for colorectal cancer and interest in screening (Dillard, Fagerlin, Dal Cin, Zikmund-Fisher, & Ubel, 2010).

Despite these concerns, the vast majority of decision aids (84%) available to patients include some type of personal narrative (Khangura, Bennett, Stacey, & O'Connor, 2008). Moreover, no empirical research has examined the effect of narratives used in these publicly available patient decision aids. To address this gap in the literature, this study was designed to examine the impact of narratives in a popular publicly available patient decision aid for early-stage breast cancer on hypothetical treatment decisions and attitudes toward the decision aid. In addition, because a growing body of literature has demonstrated that individual differences are an important predictor of decision making, risk perception, and health outcomes (e.g., Appelt, Milch, Handgraaf, & Weber, 2011; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Peters, Vastfjall, Slovic, & Dieckmann, 2006), we also examined interactions between narrative use and numeracy, decision-making style, and electronic health literacy because we hypothesized that these three measures will be predictive of the impact of patient narratives.

Numeracy can influence how information is understood and processed (Lipkus & Peters, 2009). Individuals with low levels of numeracy have difficulty comprehending health statistics and are less likely to recall risk information, understand survival curves, and complete time trade-off measures (Lipkus & Peters, 2009; Schwartz, Woloshin, Black, & Welch, 1997; Woloshin, Schwartz, Moncur, Gabriel, & Tosteson, 2001; Zikmund-Fisher, Smith, Ubel, & Fagerlin, 2007). Numeracy is also related to information seeking, depth of processing, and the acceptance of numerical data (Lipkus & Peters, 2009). However, there are no data about how numeracy affects the impact of patient stories. Because patient decision aids often include a combination of statistical information and patient testimonials, research is needed to understand how patient numeracy interacts with the type of information presented in a decision aid.

Although decision-making style has received little attention in the medical literature, various measures of decision-making style have been shown to predict a wide variety of non-health-related behaviors, including delay discounting

judgment, performance on a gambling task, performance on simulated business tasks, subjective decision complexity, information search, risk for traffic accidents, and negative life events indicative of poor decision making (Bruine de Bruin, Parker, & Fischhoff, 2007; Davis, Grove, & Knowles, 1990; Ferrari & Dovidio, 2000; Franken & Muris, 2005; French, West, Elander, & Wilding, 1993; Hinson, Jameson, & Whitney, 2003; Shiloh, Koren, & Zakay, 2001). Although decision-making style is a more recent construct, analogous concepts, such as need for cognition and rational versus experiential processing, have been shown to impact information acquisition, information processing, and decision making in general (e.g., Bakker, 1999; Graham, 2007; Kuvaas & Kaufmann, 2004; Levin, Huneke, & Jasper, 2000; Smith & Levin, 1996). Because decision-making style will likely have a broad impact on information processing, we chose to explore whether decision styles impact the weight given to patient narratives when choosing a preferred medical treatment.

We also chose to measure electronic health literacy, which describes how well individuals use technology to find and evaluate health information (Norman & Skinner, 2007). We focused on this construct because the Internet provides increasingly more opportunities to find health information and patient stories. A recent national survey reported that 42% of adults use social media to find information about the health experiences of their friends and family, and 32% of adults use social media to find information about other patients' experiences with a disease (Health Research Institute, 2012). People with higher electronic health literacy might be more likely to access patient stories, given their availability on the Internet and social media sites. Therefore, differences in electronic health literacy could help to predict the effect of patient narratives.

## METHOD

### Participants

Two hundred females were recruited from a Midwestern state through an advertisement in a local newspaper, a posting on the Internet, and flyers in public places. Participants were required to be 18 years or older, native English speakers, not currently pregnant, and have no previous history of breast cancer diagnosis. The age and pregnancy requirements were chosen to avoid recruiting a vulnerable population, as defined by the institutional review board (IRB). We recruited native English speakers because we wanted to ensure adequate comprehension of all aspects of the stimulus materials. We also restricted the sample to women without prior history of breast cancer because we wanted treatment choices to reflect novel thought processes rather than reports of a previous decision. Screening for these conditions was conducted via an online survey. Invitations to participate in

the study were extended to a portion of those who completed the survey and met eligibility requirements, typically within a week of completing the online screening form. However, preference was given to older adults to increase the mean age of our sample in order to more accurately reflect the distribution of age among new breast cancer patients. Participants were predominately Caucasian (77.5%) and ranged in age from 21 to 78 years, with a mean age of 48.11 years. This sample was highly educated; 56% of the sample had a bachelor's degree and an additional 22% of the women had a master's degree or another advanced degree (e.g., MD, JD, PhD, etc.). Additionally, 44% of the sample reported having at least one family member who had been diagnosed with cancer, and 63% of the sample had at least one friend who had been diagnosed with breast cancer.

### Materials

To assess the impact of patient narratives used in current practice, we chose a video decision aid produced by Health Dialog that covers surgical options for early-stage breast cancer, BCS001 v03. A short section of information from a second Health Dialog video on breast reconstruction, BCR001 v01, was also included to ensure adequate coverage on this topic for those who would factor it into their treatment decision. The resulting video, which is referred to here as the *narrative* video, was approximately 1 hour long and included stories from 12 breast cancer survivors: nine women were Caucasian and three were African-American; all women were approximately middle-aged.

The narratives covered three general topics: patients' emotional reaction to the diagnosis, strategies for making the treatment decision, and discussions about the aspects of the surgeries that were most and least important to them (e.g., reducing local recurrence risk, maintaining their natural breast shape, etc.). All topics discussed in the narratives were also presented in other sections of the video decision aid. The narratives were simply used to provide illustrative examples of the concepts covered by the video's narrator. Thus, there was no additional knowledge gained by viewing the narratives.

Although the narratives addressed the challenges associated with diagnosis and treatment of early-stage breast cancer, the vast majority of the comments were positive. None of the patients expressed any regret about their decision-making process or the decisions themselves. Only one woman provided commentary that could be in any way characterized as negative. Specifically, she described the discomfort she experienced during radiation treatment and indicated that her breasts appeared uneven after two surgeries. Although the narratives used in this study are unique to this decision aid and are breast cancer specific, they are fairly typical of those used in other publicly available patient decision aids. Khangura and colleagues (2008) reported that 70% of the decision aids surveyed included only positive narratives,

while 30% included some combination of positive and negative narratives.

The *control* video was created by removing the patient stories included in the narrative video; the rest of the content was unchanged. The resulting video decision aid was 45 minutes in length.

To measure individual differences in electronic health literacy, numeracy, and decision styles, we used the e-Health Literacy Scale (eHEALS; Norman & Skinner, 2007), Subjective Numeracy Scale (SNS; Fagerlin et al., 2007; Zikmund-Fisher et al., 2007), and the Decision Making Styles Inventory (DMI; Nygren, 2000; Nygren & White, 2002). We chose to use the eHEALS because it is the only validated measure of electronic health literacy.

In contrast, there are several measures of numeracy; we chose to use the SNS because it is strongly correlated with objective measures of numeracy but is superior on a number of dimensions (Fagerlin et al., 2007). Specifically, objective measures of numeracy take longer to complete and result in larger proportions of missing data than the SNS. Participants also report being more annoyed, stressed, and frustrated with the objective measures. The SNS has a four-item cognitive subscale that measures beliefs about mathematical ability and a four-item preference subscale that measures preferences for numerical presentation (i.e., verbal descriptions vs. numbers).

Decision-making style is a more recently explored and more loosely defined construct than numeracy. It has been operationalized in a number of ways using a variety of scales, which are often discipline specific. Therefore, we chose to use the DMI, which was developed by Nygren and White to capture global differences in decision-making style across a number of decision environments (Nygren, 2000; Nygren & White, 2002). The DMI describes individuals on three noncompensatory subscales: rational, intuitive, and regret-based. Rational decision makers describe themselves as making careful, reasoned, and informed choices, while intuitive decision makers report making quick, gut-based responses. In contrast, regret-based decision makers describe their process as being filled with worry about future decisions and often view past decisions with remorse.

## Procedure

After the online screening, the remaining portion of the study was completed in person at the Decision Making Research Lab at Wichita State University. Participants were asked to imagine they had been diagnosed with early-stage breast cancer following the detection of a lump during a breast self-exam. A one-page description of the diagnostic process was provided to aid participants in this task; see Appendix. Participants were randomly assigned to view one of the two video decision aids, the control video decision aid ( $n = 100$ ) or the narrative video decision aid ( $n = 100$ ). After watching the video, participants reported their preference for

lumpectomy with radiation or mastectomy; participants preferring mastectomy were also asked to indicate whether they would consider breast reconstruction. All women then identified the primary reason for their surgical choice: possibility of cancer returning in the breast or breast area, appearance following treatment, side effects of radiation, amount of time devoted to treatment or recovery, or other. Women evaluated their decision using four Likert-scale items: confidence, decisional difficulty, likelihood of changing their mind, and feeling overwhelmed. Perceptions of the decision aid were evaluated using seven Likert-scale measures: overall quality, perceived helpfulness, satisfaction, likelihood of recommending the video, emotionality, trustworthiness, and credibility. We constructed these Likert-scale items because there are no short validated measures designed to assess confidence and decisional difficulty or provide evaluations of the utility of the decision aid. Although the task was hypothetical, we believed that the task could evoke emotional responses in our participants because of the prevalence of breast cancer among participants' friends and family and the heightened awareness about the disease from prominent media campaigns. All Likert-scale questions utilized 5- or 6-point response scales. See Table 2 for all question wording. Participants also completed the SNS, DMI, and eHEALS. After finishing the study, all women were paid \$100 for their participation.

Prior to data collection, the study was reviewed and approved by the institutional review board at Wichita State University. Data were collected using MediaLab software (v2006.2.40). Statistical Analyses were conducted using SAS 9.1.3 (SAS Institute, Inc., Cary, NC) and SPSS 16.0.1 (SPSS, Inc., Chicago, IL).

## RESULTS

We compared the characteristics of the participants in the two randomized conditions using a series of chi-squared tests, adjusting alpha levels for multiple comparisons; see Table 1. There were no significant differences between the participants in the two conditions.

We compared the surgical preferences of women who viewed the control video with those who watched the narrative video and found no significant differences between the two groups,  $\chi^2(1) = 0$ ,  $p = 1.00$ . Fifty-two percent of women in both groups indicated they preferred mastectomy to lumpectomy with radiation. Moreover, the two conditions did not differ in their preference for breast reconstruction, with 67% of women in the control condition and 65% of women in the narrative condition indicating they would be likely to choose reconstruction,  $\chi^2(1) = 0.04$ ,  $p = .84$ . Treatment preference was also unrelated to whether the participant had a friend with breast cancer,  $\chi^2(1) = 0.02$ ,  $p = .88$ , or a family member with breast cancer,  $\chi^2(1) = 0.01$ ,  $p = .95$ .



TABLE 1  
Characteristics of Sample by Condition (n)

	Control Video (n = 100)	Narrative Video (n = 100)
Age (years)		
Less than 40	25	25
40–49	30	28
50–59	28	30
Above 60	17	17
Race		
White	76	79
Black or African American	13	17
Other	11	4
Education		
Some or high school graduate	12	6
Some college	33	37
College graduate	29	23
Some graduate school	6	10
Master's or advanced degree	20	24
Income		
Less than \$30,000	23	22
\$30,001 to \$50,000	25	32
\$50,001 to \$75,000	19	20
\$75,001 to \$100,000	22	12
Above \$100,000	11	14
Previously detected lump in breast	30	26
Family history of breast cancer	46	42
Friends with breast cancer	60	66

However, the two groups differed in the primary reason for their surgical choice,  $\chi^2(4) = 10.33$ ,  $p = .04$ ; see Figure 1. Although local recurrence and appearance were the top two reasons for both groups, women who viewed the control video were more likely to cite local recurrence as their primary reason than women who watched the narrative video. In contrast, women viewing the narrative video were more likely to cite appearance as their primary reason than women viewing the control video. Additionally, women who viewed the narrative video were more likely to cite side effects of radiation as the primary motivator for their choice, while women who viewed the control video were more likely to cite time and energy of the treatment. Primary reason for the surgical choice was unrelated to whether the participant

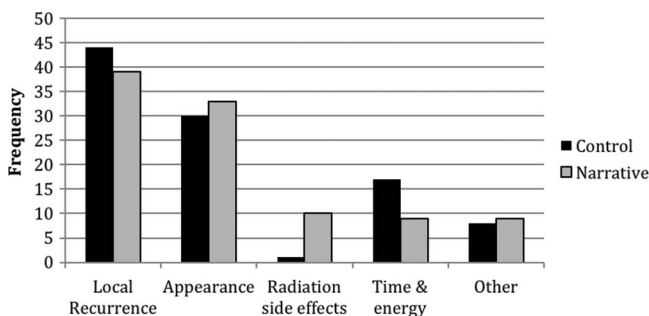


FIGURE 1 Primary reason for treatment decision by condition.

had a friend with breast cancer,  $\chi^2(4) = 5.32$ ,  $p = .26$ , or a family member with breast cancer,  $\chi^2(4) = 0.68$ ,  $p = .95$ .

We compared the two groups on the four Likert-scale items designed to evaluate their treatment decision using a multivariate analysis of variance (MANOVA) and found no significant differences in confidence, decisional difficulty, likelihood of changing their mind, and feeling overwhelmed, Wilks lambda = 0.99,  $F(4, 195) = 0.38$ ,  $p = .82$ ; see Table 2. Using two additional MANOVAs, we found there were no main effects of having a friend with breast cancer, Wilks lambda = 0.96,  $F(4, 189) = 1.90$ ,  $p = .11$ , or a family member with breast cancer, Wilks lambda = 0.96,  $F(4,$

TABLE 2  
Mean Ratings (SD) for Dependent Measures

Dependent Variable	Control Video	Narrative Video
How <b>confident</b> are you in your choice? 1 = extremely unconfident 6 = extremely confident	4.97 (0.94)	4.95 (0.95)
How <b>likely</b> are you <b>to change</b> your mind? 1 = extremely unlikely 6 = extremely likely	2.50 (0.95)	2.59 (1.14)
How <b>overwhelmed</b> did you feel about this choice? 1 = not overwhelmed at all 5 = extremely overwhelmed	2.42 (1.18)	2.34 (1.08)
Describe the level of <b>difficulty</b> associated with making your choice. 1 = not difficult 5 = extremely difficult	2.37 (1.18)	2.40 (1.11)
Overall, how would you rate the <b>quality</b> of the program? 1 = poor 5 = excellent	4.48 (0.69)	4.34 (0.66)
How <b>likely</b> are you <b>to recommend</b> this program? 1 = extremely unlikely 6 = extremely likely	5.41 (0.68)	5.42 (0.67)
How <b>satisfied</b> were you with the information in the program? 1 = extremely dissatisfied 6 = extremely satisfied	5.34 (0.67)	5.33 (0.65)
How <b>helpful</b> did you find the program? 1 = not helpful 5 = extremely helpful	4.30 (0.70)	4.29 (0.67)
How <b>credible</b> was the information in the program? 1 = not credible 5 = extremely credible	4.10 (0.80)	4.20 (0.59)
How <b>trustworthy</b> was the program? 1 = not trustworthy 5 = extremely trustworthy	4.01 (0.77)*	4.21 (0.57)*
How <b>emotional</b> was the program? 1 = not emotional 5 = extremely emotional	2.24 (1.05)*	2.55 (0.96)*

\*Indicates significant differences between the groups,  $p < .05$ .

189) = 1.75,  $p = .14$ , on the four decision evaluation items. We then used a series of univariate linear regressions to test for main effects and interactions of numeracy, electronic health literacy, and decision-making style with the four decision evaluation measures. There were no main effects of numeracy or electronic health literacy on the four measures, but there was a significant main effect of the DMI regret subscale on decisional difficulty ( $F(7, 192) = 2.18, p = .04, \beta = 0.25, t(192) = -2.44, p = .02$ ) and feeling overwhelmed ( $F(7, 192) = 2.78, p = .01, \beta = 0.32, t(192) = 3.09, p = .002$ ). Participants whose decision processes are characterized by worry reported greater decisional difficulty and were more likely to feel overwhelmed during the decision process. These results are qualified by a significant numeracy by condition interaction ( $F(5, 194) = 2.01, p = .07; \beta = -0.73, t(194) = -2.20, p = .03$ ) and a significant electronic health literacy by condition interaction ( $F(5, 194) = 2.01, p = .07; \beta = 0.81, t(194) = 2.08, p = .04$ ) on confidence ratings. Using additional univariate regression analyses, we determined that the numeracy results were driven by the ability subscale ( $F(5, 194) = 1.95, p = .09; \beta = -0.53, t(194) = -2.05, p = .04$ ), not the preference subscale ( $F(5, 194) = 1.51, p = .19, \beta = -0.27, t(194) = -0.74, p = .46$ ). Higher levels of perceived mathematical ability were associated with decreased decisional confidence in the narrative video condition but not the control video condition. In contrast, higher levels of electronic health literacy were associated with *increased* decisional confidence in the narrative video condition but not the control video condition. There were no significant interactions with having a friend or family member diagnosed with breast cancer or the three DMI subscales.

We used a MANOVA to compare the control and narrative video conditions on the seven Likert-scale items used to evaluate the decision aid and found that the two groups differed significantly, Wilks lambda = 0.92,  $F(7, 192) = 2.44, p = .02$ . Post hoc univariate analyses of variance (ANOVAs) revealed no significant differences in ratings of video quality, helpfulness, credibility, satisfaction, and likelihood of recommending the video,  $F_s(1, 198) < 1.10, p_s > .05$ ; see Table 2. However, the narrative video was perceived to be more emotional ( $F(1, 198) = 4.78, p = .03$ ) and trustworthy ( $F(1, 198) = 4.32, p = .04$ ) than the control video. Using two additional MANOVAs, we found there were no main effects of having a friend with breast cancer, Wilks lambda = 0.95,  $F(7, 186) = 1.46, p = .18$ , or a family member with breast cancer, Wilks lambda = 0.96,  $F(7, 186) = 0.67, p = .69$ , on the seven items evaluating the decision aid. We then used a series of univariate linear regressions to test for main effects and interactions of numeracy, electronic health literacy, and decision-making style with the same seven measures. We found no main effects of numeracy, electronic health literacy, or decision style. However, these results are qualified by a significant numeracy by condition interaction ( $F(5, 194) = 3.69, p = .003, \beta = -0.85, t(194)$

$= -2.60, p = .01$ ) and a significant electronic health literacy by condition interaction ( $F(5, 194) = 3.69, p = .003, \beta = 1.18, t(194) = 3.08, p = .002$ ) on the perceived trustworthiness of the aid. Using additional univariate regression analyses, we determined that the numeracy results are driven by the ability subscale ( $F(5, 194) = 3.40, p = .01, \beta = -0.60, t(194) = -2.33, p = .02$ ), not the preference subscale ( $F(5, 194) = 3.41, p = .001, \beta = -0.54, t(194) = -1.50, p = .14$ ). Higher levels of perceived mathematical ability were associated with lower levels of perceived trustworthiness in the narrative video condition but not in the control video condition. In contrast, greater levels of electronic health literacy were associated with higher levels of perceived trustworthiness of the aid in the narrative video condition but not in the control video condition. Additionally, there was a significant condition by electronic health literacy interaction on the perceived credibility of the decision aid ( $F(3, 196) = 3.72, p = .01, \beta = 0.98, t(196) = 2.62, p = .01$ ). Greater electronic health literacy was associated with higher perceived credibility in the narrative video condition but not in the control video condition. There were no significant interactions with having a friend or family member diagnosed with breast cancer or the three DMI subscales.

## DISCUSSION

Although the vast majority of publicly available decision aids include patient stories (Khangura et al., 2008), no empirical research has examined the effect of narratives used in these aids. To address this gap in the literature, this study was designed to evaluate the effect of patient stories used in a popular video decision aid for early-stage breast cancer on hypothetical treatment decisions and evaluations of the decision aid. We found that narratives affected motivations for treatment decisions and perceptions of the aid's trustworthiness and emotionality but had no effect on preferences for surgical treatments or evaluations of the decision aid's quality.

These findings are in contrast with some previous research, which suggests that narratives impact preferences for health care (e.g., Kerstholt et al., 2009; Ubel et al., 2001). The discrepancy between the results of this study and the previous research may be due to variability in the evaluative valence of the narratives. By evaluative valence, we mean a patient's general expression of their satisfaction with the process of making a health care decision, the outcome of a health care decision, or any experiences associated with the health care decision. In both studies (Kerstholt et al., 2009; Ubel et al., 2001), the narratives discussed "negative" aspects of the available options. For example, in the narratives used by Ubel and colleagues (2001), some patients reported that the treatment was not effective and described negative symptoms of the condition. The narratives used by Kerstholt and colleagues (2009) discussed how the choice

to die at home, rather than in a nursing home or hospital, placed a larger burden on family members. In contrast, the narratives used in this study were largely “positive” in nature. Though the women acknowledged the challenges associated with the both treatments, the messages mostly revolved around overcoming the obstacles associated with having breast cancer and feeling positively about their treatment decision. Although the narratives used in this study differ from those used in previous research, they are fairly typical of those used in other publicly available patient decision aids. Khangura and colleagues (2008) reported that 70% of the decision aids surveyed included only positive narratives, while 30% included some combination of positive and negative narratives.

However, one woman did provide commentary that could be characterized as negative. Specifically, she described the discomfort she experienced during radiation treatment and indicated that her breasts appeared uneven after two surgeries. Although these comments represented a very small portion of total narrative content, they appeared to be very powerful. The two conditions differed in the primary reason for their surgical choice, and participants in the narrative group were more likely to cite the side effects of radiation as their primary reason for choosing mastectomy than the control group. Therefore, the impact of patient narratives may be at least partially dependent upon the evaluative valence of the stories. Narratives that describe negative components of a treatment, particularly outcomes, may have very different effects on decision making than narratives that are largely positive. More research is needed to determine the specific effect of narrative valence.

We also assessed the impact of narratives on evaluations of the decision aid. Including narratives did not impact ratings of the decision aid’s quality or credibility. However, the decision aid with narratives was perceived to be more trustworthy and more emotional than the aid without narratives. It is fairly unsurprising that a decision aid with narratives is perceived to be more emotional, given that narratives provide a more vivid element of the emotional component of breast cancer decisions. On the other hand, the fact that narratives increase the perceived trustworthiness of the decision aid is potentially very important. Greater trust in a decision aid could result in greater use of the aid during the decision-making process.

However, the specific impact of narratives appears to be related to patient numeracy and electronic health literacy. In this study, narratives were less beneficial to women with greater perceived mathematical ability; in the narrative video condition, these women reported lower decisional confidence and perceived the aid to be less trustworthy than women with lower perceived mathematical abilities. It is possible that in addition to having better comprehension of risk information, women with greater perceived mathematical ability may believe that the narrative information is biased. Therefore, when provided with both types

of information in a decision aid, narratives may actually decrease the objectivity of the information for these women and make them more skeptical of the decision aid.

In contrast, narratives appeared to be *more* beneficial for women with higher levels of electronic health literacy, a measure that assesses comfort and skill with using electronic health information (Norman & Skinner, 2007). In the narrative condition, greater electronic health literacy was associated with increased decisional confidence and greater perceptions of trustworthiness and credibility of the decision aid. Given that people with greater electronic health literacy may have more exposure to narratives on the Internet and social media sites, it is possible that these findings are driven by increased exposure to and familiarity with narrative information.

There are limitations to this study. First, our sample was highly educated and had very little racial or ethnic diversity. It is unclear whether these findings would apply to women from other racial or ethnic backgrounds or women with less education. Second, the treatment decisions made in this study were hypothetical and may not generalize to “real” treatment decisions. However, more than 80% of our sample had a friend and/or family member who had been diagnosed with breast cancer. With this personal history, it is likely that our participants have already spent a significant amount of time thinking about how they would handle their own diagnosis.

Although this study indicated that including narratives in a patient decision aid does not necessarily “bias” health care decisions, substantial work still needs to be done to identify characteristics of narratives or patients that may moderate their impact. For example, different types of patient stories (e.g., stories about a treatment experience vs. stories about a treatment outcome) may have different effects on the decision making process. Thus, future research should focus on identifying and testing distinct narrative types, a process that may help to explain the discrepant findings in the literature.

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## APPENDIX

### FOR THE PURPOSES OF THIS EXPERIMENT, PLEASE IMAGINE YOURSELF IN THE FOLLOWING SCENARIO:

You have recently discovered a lump in your breast during a routine breast self-exam. Following this discovery, you made an appointment with your primary care physician to have the lump examined. After examining the lump, your physician arranged for you to have a mammogram, which is an x-ray of your breast. The radiologist reading the mammogram characterized the lump as suspicious and recommended a biopsy of the lump. Your physician then referred you to the local Breast Center, a facility specializing in the diagnosis and treatment of breast cancer, to have the lump biopsied. A breast biopsy involves removing a small section of breast tissue for examination. After the biopsy, the tissue sample was sent to a pathologist, a person who diagnoses disease by examining organs, tissues, bodily fluids, etc. The pathologist's job is to determine whether the cells were malignant (i.e. cancerous) or benign (i.e. not cancerous).

You returned to the Breast Center to discuss the results of the biopsy. You were informed that the lump was malignant, and you were referred to an oncologist at the Breast Center

for treatment. An oncologist is a physician who organizes the care of cancer patients. After reviewing the reports from the biopsy and mammogram, your oncologist informed you that you have early stage breast cancer. Typically, early stage breast cancer is treated through local therapy—one of two types of breast surgery. Local therapy is often followed by systemic therapy, such as chemotherapy, which is a course of treatment that travels through the blood stream, affecting cells all over the body.

There may be several treatment decisions to make; however, the oncologist explained that the first decision you must make is what type of surgery to have. The other decisions will be made after viewing the pathology report from your surgery. Based on estimates of the tumor size from the biopsy and mammogram, the oncologist informed you that

you have two surgical options: lumpectomy with radiation or mastectomy (with or without breast reconstruction).

Your task is to imagine that you have been diagnosed with early stage breast cancer. In this experiment, you will be asked to do the following things:

1. Watch a 45-minute (60-minute) video that describes your two treatment options: lumpectomy with radiation and mastectomy.
2. Decide whether you would choose to have a lumpectomy with radiation or a mastectomy.
3. Answer several questions about your decision making process.
4. Provide your opinion about the video that you watched.

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