Communication with Breast Cancer Survivors

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Abstract:

Breast cancer survivors must manage chronic side effects of original treatment. To manage these symptoms, communication must include both biomedical and contextual lifestyle factors. Sixty breast cancer survivors and 6 providers were recruited to test a conceptual model developed from uncertainty in illness theory and the dimensions of a patient-centered relationship. Visits were audio-taped, then coded using the Measure of Patient-Centered Communication (Brown, Stewart, & Ryan, 2001). Consultations were found to be 52% patient-centered. Chi-square Automatic Interaction Detection (CHAID) analysis showed that survivor self-reported fatigue level and conversation about symptoms were associated with survivor uncertainty, mood state, and survivor perception of patient-centered communication. Survivors may want to discuss persistent symptom concerns with providers, due to concerns about recurrence, and discuss lifestyle contextual concerns with others.

Article:

INTRODUCTION

A steady increase in breast cancer survivorship has resulted in more women managing the long-term side effects of breast cancer treatment that impact daily life. Currently 98% of White and 90% of African American women diagnosed with localized breast cancer are expected to survive 5 years or longer (American Cancer Society, 2003). Yet survivor concerns about symptoms, such as chronic fatigue, experienced as a result of original treatment, persist (Clayton, Mishel, & Belyea, 2006; Gil et al., 2006).

Management of these chronic symptoms requires a patient-centered style of communication that addresses symptoms and illness factors, as well as individualized contextual lifestyle factors, and further, encourages survivor involvement in goal setting and planning to achieve an optimum quality of life (Degner, Kristjanson, et al., 1997; Degner, Sloan, & Venkatesh, 1997; Inui, 1998). Thus, the major aim of this cross-sectional study was to investigate how a patient-centered style of communication (the degree to which providers respond to patient comments and concerns) is associated with survivor uncertainty, survivor mood state, and survivor perception of patient-centered communication for breast cancer survivors experiencing varying fatigue levels.

BACKGROUND AND SIGNIFICANCE

Frustration with the communication process has been consistently reported by both providers and patients (Hack, Degner, Parker, & The SCRN Communication Team, 2005; Levinson, Stiles,

Inui, & Engle, 1993; Nisselle, 2000; Schwenk, Marquez, Lefever, & Cohen, 1989). Less than optimal communication can result in women having trouble managing and/or understanding the meaning of their symptoms, creating uncertainty about recurrence and mood state up to 2 or more years after original diagnosis and treatment (Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000; Gray et al., 1998; Krupat et al., 1999; Mast, 1998; McKinley, 2000). Further, although nurse practitioners and physician assistants often interact with breast cancer survivors during follow-up consultations, there is very little literature exploring survivor-provider communication processes specific to nonphysician providers (Earnshaw & Stephenson, 1997; Extermann et al., 2004; Romero, 1999; Spigelman, 1997).

Communication has been described as one of the most important variables in the patient-provider relationship. Communication has been associated with the patient's perception of the quality of care, including provider interpersonal and technical competence, as well as predicting patient satisfaction with the patient-provider relationship (Inui, 1998). Yet, when specifically asked about the communication process, a substantial number of breast cancer patients report communication difficulties with their providers well into survivorship (Bloom, Stewart, Chang, & Banks, 2004; Hack et al., 2005; Lerman et al., 1993). Breast cancer survivors report that providers do not understand their concerns or, worse yet, ignore their complaints. Moreover they report that providers make assumptions about symptom management issues and goals, and do not seek their input (Crooks, 2001; Loescher, Clark, Atwood, Leigh, & Lamb, 1990; Savage & Armstrong, 1990; Wilmoth, 2001). Indeed, baseline data from the HINTS¹ database show that on average, only 55% of patients report that their providers consistently listen carefully, provide understandable explanations, and demonstrate respect for their opinions (U.S. Office of Disease Prevention and Health Promotion, 2003).

Communication problems can contribute to outcomes such as increased uncertainty (Krupat et al., 1999). Uncertainty, in turn, affects both negative mood state and depression in breast cancer survivors (Mast, 1998; Polinsky, 1994). Women who cannot manage or understand the meaning of their symptoms report uncertainty about recurrence and mood state up to 2 or more years after original diagnosis and treatment (Bleiker et al., 2000; Clayton et al., 2006; Porter et al., 2006). In particular, women who are older, less educated, and who have other illnesses may be unclear about whether the cause of their physical symptoms is the aging process, another illness, or a recurrence of breast cancer (Clayton, et al., 2006; Crooks, 2001; Mast, 1998).

Due to persistent patient complaints of patient-provider communication difficulties, and the assumption that responsibility for effective communication rests with the provider, interventions were developed to enhance the communication skills of providers (Cowan & Laidlaw, 1993; Doak, Doak, Friedell, & Meade, 1998; Faulkner, Argent, & Jones, 2001). However, this assumption is being challenged, suggesting that responsibility for communication lies with both the provider and the patient. Providers have reported an inability to obtain necessary information from survivors to help them effectively manage their chronic symptoms (Levinson et al., 1993; Nisselle 2000; Schwenk et al., 1989). Supporting this provider complaint, many breast cancer survivors report enduring long-term symptoms that they have never discussed with their providers (Crooks, 2001). In addition, some women do not want to participate in treatment decision making, even when encouraged to do so by providers (Degner, Kristjanson, et al., 1997;

Degner, Sloan, et al., 1997; Gil et al., 2006). Moreover, not all survivors are willing to disclose their goals, values, and lifestyles to providers (Brown et al., 2002; Clayton et al., 2006).

Fatigue is an ideal symptom around which to study patient-centered communication. Fatigue is known to be a prevalent side effect of breast cancer treatment, especially for those who received chemotherapy, persisting well into survivorship (Gil et al., 2004; Jacobsen & Stein, 1999; Mast, 1998). Further, there is much survivor as well as medical uncertainty about the cause, and most effective treatment, of fatigue due to the complexity of causal factors (Bower et al., 2000; Mast, 1998; Okuyama et al., 2000; Yellen, Cella, Webster, Blendowski, & Kaplan, 1997).

Medical uncertainty about the most efficacious treatment for symptoms, in addition to vague and subjective patient descriptions of symptoms, also contributes to less than optimal communication (Schwenk et al., 1989). Providers have difficulty identifying the source of fatigue due to the subjective and context-laden nature of fatigue, which incorporates physical, psychological, behavioral, and cognitive components (D'Antonio, Zimmerman, Cella, & Long, 1996; Okuyama et al., 2000; Yellen, et al., 1997). Moreover many providers are unwilling to disclose their uncertainty to patients, fearing a loss of credibility or the creation of a perception of incompetence (Beresford, 1991; Henry, 2006). Thus, based on both patient and provider communication concerns it is important to investigate the communication process to assist women to achieve optimal communication with providers.

This study of survivor-provider communication is guided by uncertainty in illness theory (Mishel, 1988), and informed by the theoretical dimensions of a patient-centered relationship (Mead & Bower, 2000). Uncertainty in illness theory predicts that uncertainty occurs when women are unable to predict the course of their illness or attribute meaning to their symptoms (Mishel, 1988). Effective survivor-provider communication has been shown to improve understanding of symptoms, thereby reducing uncertainty, improving mood state and adaptation to survivorship (Mast, 1998).

Patient-centered communication has evolved from a loosely defined provider attempt to elicit the patient's viewpoint and participation in decision making to an explicit clinical method of communication that elicits survivor values, needs, and goals, as well as demonstrating mutual relationship and partnering skills (Mead & Bower, 2000; Roter, 2000; Stein, Jacobsen, Blanchard, & Thors, 2004). Mead and Bower proposed a framework for assessing patient-centered communication based on a metasynthesis of existing research suggesting five dimensions of patient-centered communication: a biopsychosocial approach (indicating a provider willingness to address the physical components of a disease as well as ideas and concerns about signs and symptoms), an acknowledgement of the patient as a person (addressing contextual factors), an ability to mutually share power and responsibility, the development of a therapeutic alliance, and an acknowledgement of the provider as a person (addressing medical uncertainty).

A conceptual model (Figure 1) was developed to guide the investigation of three survivor-focused outcomes (uncertainty, mood state, and survivor perception of patient-centered communication). The sample size (N = 60) and design (a limited number of providers) precludes a full test of the model using path analysis. Thus our focus was on predictors of the three

outcomes, including a more specific analysis of the relationship between fatigue and patient-centered survivor-provider communication. The purpose of this study was to investigate how fatigue and communication are related to survivor uncertainty and mood state, and survivor perception of patient-centered communication for women with varying fatigue levels. This primary aim was followed by a finer grained analysis of the relationship between survivor fatigue and specific patient-centered aspects of communication. An investigation of the moderating effects of medical uncertainty was added to the model to more fully capture the dimensions of patient-centered communication (Brown, Stewart, & Ryan, 2001).

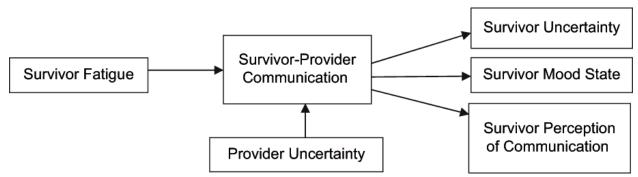


FIGURE 1. Model of survivor-provider communication, uncertainty, mood state, and survivor perception of communication, about chronic fatigue.

METHODS

Sample and Setting

This study was conducted in a large, ethnically diverse oncology practice serving patients with a wide range of socioeconomic status. Providers saw patients on a first-available basis, thus effectively randomizing the provider seen by a woman. Sixty recurrence-free breast cancer survivors 2 or more years posttreatment were recruited (White = 43; African American = 16; Asian = 1). Survivor sample size required to detect an R^2 of .20 (effect size) in a multiple-regression model with six predictors was calculated using a significance level of α = .05 to achieve 80% power (Borenstein, Rothstein, & Cohen, 2001). Effect size was based on previous research showing that communication explained 22% of the variance in thoughts of recurrence, and uncertainty explained 16% of the variance in mood state (Clayton et al., 2006; Gil et al., 2006). Two-year survival was selected so that the acute side effects of original treatment would have abated, allowing the emergence of chronic symptoms (Jacobsen & Stein, 1999). Women of all ages and ethnicities were recruited. No restriction was placed on participant age because contextual factors such as employment and child rearing may affect survivor fatigue. Six providers (3 oncologists, 2 physician assistants, and 1 nurse practitioner) were recruited. Four providers were women; five were White. Four providers had practiced less than 5 years.

Procedures

This research was approved by the Institutional Review Board and the participating oncology practice. Providers and patients gave written consent for participation. To avoid sensitizing women and providers to the target symptom of fatigue, the study was presented as addressing potential long-term side effects of treatment, including fatigue. Women were prescreened for fatigue level (in addition to collection of demographic information and verification of inclusion criteria) 1 week prior to the scheduled office visit, additionally reducing sensitization to the

target symptom of fatigue. Cognitive competence was also assessed during previsit screening using the Mini-Mental Status Exam Short Form (score > 14; Folstein, Folstein, & McHugh, 1975).

On the day of their appointment women were met in the office. Written consent was obtained for audio-taping and administration of postvisit self-report measures. Each audio-tape represents a single, routinely scheduled, follow-up encounter between a breast cancer survivor and her provider. Survivor outcome measures were completed at the immediate conclusion of the visit to facilitate the assessment of uncertainty, perception of mood state, and perception of communication within the immediate visit context.

Measures

Substantive study variables evaluated included fatigue, survivor uncertainty, mood state, survivor-provider communication, survivor perception of communication, and provider uncertainty. Fatigue was assessed during prescreening using the Multidimensional Fatigue Symptom Inventory-Short Form (MFSI-SF), a 30-item self-report scale evaluating the somatic, cognitive, affective, and behavioral symptoms of fatigue (Stein et al., 2004; Stein, Martin, Hann, & Jacobsen, 1998). Items were rated on a 5-point scale ranging from 0 (*Not at all*) to 4 = (*Extremely*) indicating how true each statement was for the respondent during the last week. The total fatigue score was obtained by summing the scores, then subtracting the "vigor" subscale score, creating a response range from -24 to 96. Higher scores indicate more fatigue (Table 1). The MFSI-SF discriminates across women undergoing treatment, posttreatment, and without breast cancer (Dittner, Wessely, & Brown, 2004; Stein et al., 2004; Stein et al., 1998). Concurrent validity has been demonstrated by correlations with the Profile of Mood States fatigue subscale and the SF-36 vitality subscale (Stein et al., 1998).

TABLE 1. Reliability, Range, Mean, and Standard Deviation of Instruments

Measure	Reliability	Range	M	SD
MFSI-SF	0.95 (Cronbach's a)	-18 to 80	17.63	22.68
Survivor Uncertainty	0.87 (Cronbach's a)	34-69	53.28	12.73
POMS-SF	0.97 (Cronbach's a)	0-84	19.82	21.50
PPCS	0.82 (Cronbach's a)	1-3	1.60	0.50
Physician Uncertainty	0.90 (Cronbach's a)	34-69	47.50	14.03
MPCC (total) $N=55$.7798 (Interrater reliability)	26-87	51.96	16.29
MPCC (Dimension 1)				
Exploring illness and disease		5-72	30.54	15.80
MPCC (Dimension 2)				
Exploring the whole person		0-100	47.70	38.58
MPCC (Dimension 3)				
Finding common ground		25-100	77.5	17.16

Note. Totals may not add up to 100% due to rounding. POMS-SF = Profile of Mood States—Short Form; MPCC = Measure of Patient-Centered Communication.

Survivor uncertainty was measured postvisit using the Uncertainty in Illness Scale—Survivor Version (Mishel, 1997). This 22-item self-report scale assesses the uncertainty associated with breast cancer survivorship using a 5-item response format ranging from *strongly agree* to *strongly disagree*. Scores are summed, with a total ranging from 0 to 110. Higher scores reflect greater levels of uncertainty (Table 1). Statements were adapted by Mishel from the original adult version of the scale to reflect concerns experienced by survivors, as opposed to those experiencing acute illness events (Gil et al., 2006). Items include: "I have been told different things about what my treatment side-effects mean," and, "I don't know if my cancer will ever come back." Support for construct validity is demonstrated by consistent positive associations with measures of mood state, fears of recurrence, and symptom bother (Clayton et al., 2006; Hilton, 1994; Porter et al., 2006).

Mood state was measured postvisit using the Profile of Mood States—Short Form (POMS-SF; Curran, Andrykowski, & Studts, 1995). The POMS-SF is a 37-item adjective rating scale measuring six affective mood states: tension-anxiety, depression-rejection, anger-hostility, vigoractivity, fatigue-inertia, and confusion-bewilderment. Responses range from 0 (not at all) to 4 (extremely). The vigor subscale was reverse-scored before items were summed, and added to the total. Total scores ranged from 0 to 148. Scores can be interpreted as ranging from a low score indicative of comparative well-being, to a higher score indicative of comparative distress (Table 1). Validity of the POMS-SF in breast cancer survivors up to 3 years posttreatment is demonstrated by a consistent inverse relationship with the Cancer Rehabilitation Evaluation System (Coscarelli & Heinrich, 1988) and by strong associations with uncertainty and survivor thoughts of recurrence (Gil et al., 2006). Convergent validity of the POMS-SF is supported by positive correlations with both uncertainty and troublesome thoughts of recurrence (Clayton et al., 2006; Porter et al., 2006). Further evidence of the POMS-SF's ability to discriminate among cancer patients is supported by correlations with the Center for Epidemiologic Studies Depression Scale (CES-D), the Self-Rated Karnofsky, and the Medical Outcomes Study Short Form (MOS SF-20) (Baker, Denniston, Zabora, Polland, & Dudley, 2002).

Survivor-provider communication was audio-taped, transcribed, then coded using the Measure of Patient-Centered Communication (MPCC; Brown et al., 2001). This coding scheme captures three of the dimensions of patient-centered communication proposed by Mead and Bower (2000), addressing (a) exploration of illness and symptoms, including medical information and provider attempts to understand the survivor's illness experience; (b) exploration of the whole person, or understanding the survivor within the context of family, work, and culture; and (c) mutual definition of the problem by establishing goals of treatment and identifying the roles of survivor and provider. Patient-centered scores are computed for each dimension by evaluating initial and subsequent discussion of patient concerns, validation of patient concerns, and/or dismissal of patient-initiated topics, then averaging awarded points by a maximum possible score for each dimension. A total score is then computed for the entire patient-provider discussion by averaging the three dimension scores (Table 1). Total scores can range from 0 (not at all patientcentered) to 100 (very patient-centered). Support for validity of the MPCC is shown by association with survivor outcomes of recovery, emotional health, treatment adherence, and survivor satisfaction with providers (Stewart, 1995; Stewart et al., 1999). Once established, interrater reliability was maintained by having both coders code every 10th transcript (Table 1).

Survivor perception of communication was measured postvisit using the 14-item Perception of Patient-Centeredness Scale (Stewart et al., 2000). This self-report scale addresses the same dimensions as the MPCC but from the survivor's point of view. Items indicate whether patients perceive their concerns to have been addressed, were able to adopt chosen participation level, asked questions, whether the purpose of the visit was understood by providers, and a final item about how much they perceive the provider to care about them as a person. Responses can range from *completely* (or *very much*) to *not at all* (1-4), with lower scores indicating a higher perception of patient-centeredness. A total score is computed. Validity is supported by an association with improved emotional health up to 2 months postvisit, as well as improved symptom resolution (Stewart et al., 2000).

Provider uncertainty, another dimension of patient-centered communication (Mead & Bower, 2000), was measured using the Physician Reaction to Uncertainty Scale, a 21-item self-report scale measuring provider anxiety due to uncertainty, concern about bad outcomes, and reluctance to disclose medical uncertainty (lack of knowledge, inconclusive testing, uncertain prognoses) to patients (Gerrity, White, DeVellis, & Dittus, 1995). Higher scores indicate greater medical uncertainty by a provider (Table 1). Provider uncertainty was measured once, just after obtaining provider consent for participation.

RESULTS

Sample Characteristics

There was very little missing data in this analysis because subject data booklets were checked for completeness prior to the subject leaving the medical office. Initially, results were analyzed descriptively (Table 2). African American women comprised 27% of this sample, representative of the population of African American women in North Carolina, with the remainder self-identifying themselves as White, plus one Asian woman. Slightly over half of this sample had a high school education or less. The vast majority of women had surgical treatment, usually combined with chemotherapy, radiation, or both (Table 2). Of the 96 women identified as eligible by the office research nurse, 28 were unable to be contacted by phone. Of the remaining 68 names given to the research team, 60 agreed to participate. Seven women refused due to the time commitment of staying in the office for 20 min postvisit; one woman was ineligible. Five visits were not audio-recorded. Four of these were due to technical reasons; one woman agreed to complete self-report measures but declined to have her visit recorded.

TABLE 2. Breast Cancer Survivors: Sample Characteristics

	Minimum	Maximum	\mathbf{M}	SD
Age	31	87	61.67	11.30
Education (years)	7	19	13.35	2.44
		n	%	
Treatment				
Chemotherapy		1	1.7	
Surgery		6	10.0	
Surgery and chemotherapy		19	31.7	
Surgery and radiation		10	16.7	

TABLE 2. Breast Cancer Survivors: Sample Characteristics

	Minimum	Maximum	M	SD
Surgery, chemotherapy, and radiation		24	40.0	
Marital status				
Married		37	62.7	
Separated or divorced		10	17.0	
Widowed		11	18.6	
Employment status				
Retired		32	54.2	
Unemployed		12	20.4	
Employed full or part time		15	25.4	
Income (per month)				
Less than \$1,000		9	15.8	
\$1,001-\$4,000		35	61.4	

Note.N = 60. Totals may not equal 100% due to rounding or participant nonresponse.

Communication Coding

Total and subscale MPCC scores for consultations are shown in Table 1. Analyses were conducted using total patient-centered scores, as well as by the illness, contextual, and planning dimensions. Total patient-centered scores ranged from 26 to 87, (M = 52), with higher scores indicating more patient-centered communication. The dimension of exploring illness and symptoms had the lowest mean amount of patient-centered communication, with contextual and planning dimensions, respectively higher (Table 1).

Statistical Analyses

SPSS was used for data entry, data validation, scale computations, descriptive statistics, and reliability analyses. Initially a correlation matrix was constructed (Table 3) to investigate relationships between variables. As theoretically expected, survivor self-reported fatigue levels were highly and positively correlated with self-reported mood state and uncertainty levels. Unexpectedly there was no correlation between the objective measure of patient-centeredness (verbal coding using the MPCC), and the companion subjective measure evaluating a survivor's perception of the degree of patient-centeredness. Examining age as a covariate, a moderate positive correlation was found between age and the overall amount of patient-centered communication. However, an inverse relationship was observed between age and dimension 2 of the MPCC, exploring the whole person. Further, visits with providers reporting more medical uncertainty were correlated with a survivor perception of more patient-centered communication.

TABLE 3. Correlation Matrix of Variables and Outcomes

Survivo Fatigue		MP CC Tot al	ss MP	ole Per son MP	mon Grou nd	e Menti	od Sta	or Uncert	Perceptio n of Communi cation	A ge	Educa tion	e in Prac	
	Survi vor fatigu e	00	17	.10	09	11	.80 * <u>*</u>	.60 <u>**</u>	.23	- .0 4	04	04	.20
MPCC Total			.43 <u>*</u> *	.87 <u>*</u> *	.32 <u>*</u>	.06	.08	.02	.04	.2 9 <u>*</u>	.26	01	.00
MPCC 1				.09	.02	.13	.05	05	.25	- .0 8	.16	.23	41 <u>**</u>
MPCC 2					04	03	.20	.03	.03	- .3 2 <u>*</u>	.19	11	.05
MPCC 3						.16	- .24	.04	19	.0 2	.12	.02	.29 <u>*</u>
Was fatigue mentione d							.01	.05	03	- .0 1	.05	16	14
Mood state								.58 <u>**</u>	.18	- .2 8	.06	02	.08
Survivor uncertain ty									.07	.2	09	04	08
Perceptio n of communi cation										.1 6	05	.03	31 <u>*</u>
Age											24	.04	24
Educatio n												.15	.15
Time in practice													.16

Note. N = 60. MPCC = Measure of patient-centered communication.*p < .05. **p < .01. The exploratory variable provider uncertainty, reflecting a provider's anxiety and concerns about sharing medical uncertainty with patients, was modestly and inversely correlated with communication variables. Visits with providers who reported more medical uncertainty were correlated with less exploration of the disease and illness (dimension one of the MPCC) yet higher levels of finding common ground, the mutual planning and goal setting dimension of the MPCC (dimension 3). Further, visits with providers reporting more medical uncertainty were correlated with a survivor perception of less patient-centered communication.

Because the research questions dealt with variables with both continuous and categorical levels of measurement, and because we anticipated that we might encounter nonlinear relationships, we employed an exploratory analysis technique known as chi-square automatic interaction detection (CHAID). CHAID has been shown to be useful in the explication of complex relationships (Dudley, Dilorio, & Soet, 2000). CHAID works somewhat like multiple-regression with stepwise entry in that one provides a dependent variable and a set of potential predictors. All potential predictor variables are evaluated, and the sample is partitioned into mutually exclusive groups based on a targeted outcome variable. CHAID analysis techniques have been used in health-related research to identify problems contributing to asthma mortality, barriers to receiving HIV care, and whether subgroups of older women match the national mammography screening average (Barton, McKenzie, Walters, & Abramson, 2005; Huba et al., 2001; Larson et al., 2001; Rakowski & Clark, 1998).

A unique feature of CHAID is that the output is represented as a decision tree, with each branch representing a homogeneous, mutually exclusive, sample grouping based on the best predictor variable. In effect, the analysis segments the sample with regard to the predictors. As in stepwise regression analysis, the analysis identifies the most powerful predictor (smallest *p* value) and then continues in a stepwise fashion until all significant predictor variables have been identified. For example, if gender were the most significant predictor of the target variable "cooking" then two subgroups (male and female) would be identified. For females perhaps the best predictor of cooking is creativity, whereas for males the best predictor of cooking is hunger, and so on until all predictor variables for identified subgroups have been identified. In each reiteration the entire sample is evaluated for the significance of the predictor variable. As stated earlier, CHAID accepts all levels of variables. When the target variable is continuous, an *F* test is calculated; when categorical variables are identified, the chi-square test is used. Analysis was allowed to proceed without forced entry of any variable.

Overall, the proposed relationships shown in the conceptual model were supported, demonstrating associations between antecedent and outcome variables (Figure 1). Fatigue level was the best predictor of uncertainty, supporting the theoretical link between symptoms and uncertainty (Mishel, 1988). Fatigue was conceptualized as a continuum from less to more self-reported fatigue. Most women reported lower levels of fatigue, with half of women reporting fatigue levels between -18 and 11 (Table 1; Figure 2). Based on previous research, the low incidence of extreme fatigue was expected (Clayton et al., 2006). However, fatigue is known to be extremely bothersome for some women, and indeed 20 % of women in this study reported fatigue levels between 41 and 80.

Frequency

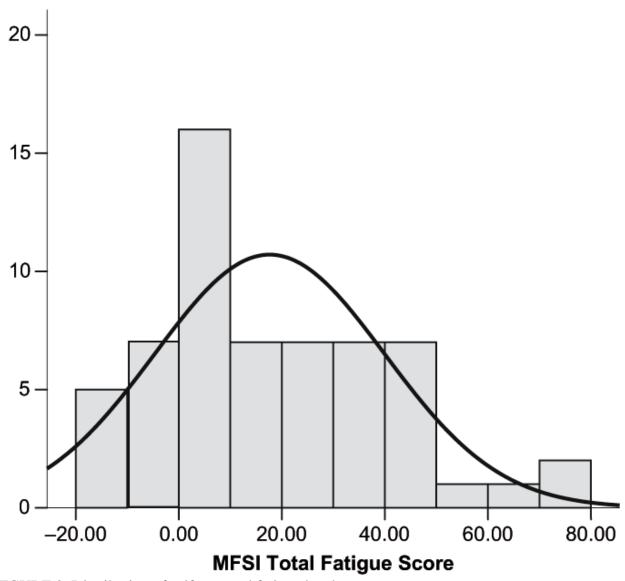


FIGURE 2. Distribution of self-reported fatigue levels.

Because CHAID is used as an exploratory analysis technique, where little is known about the relationships between variables being studied, continuous variables such as fatigue level are partitioned in such as way as to maximize differences between groups with respect to the outcome. Thus, as can be seen in Figure 3, CHAID partitioned the levels of fatigue (MFSI) into three mutually exclusive groups (<4.00, Node 1; 4.00-22.00, Node 2; >22.0, Node 3). Partitioning of fatigue is different in subsequent figures with different outcome variables. Returning to Figure 3, we can see that this is a linear relationship, such that lower fatigue levels are associated with lower uncertainty (M for uncertainty in Node 1 = 44.00) with increases in uncertainty seen as fatigue level increases (Node 2 M = 50.71; Node 3 M = 61.74).

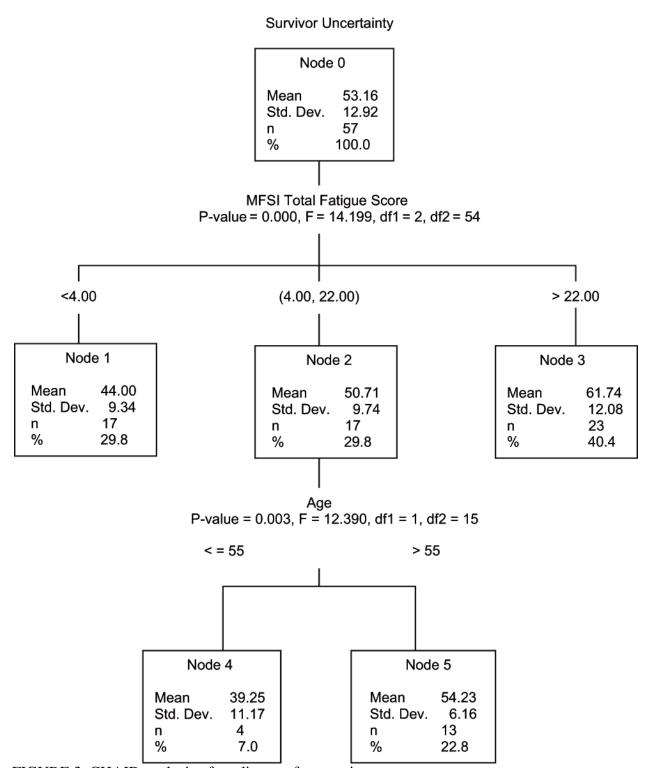
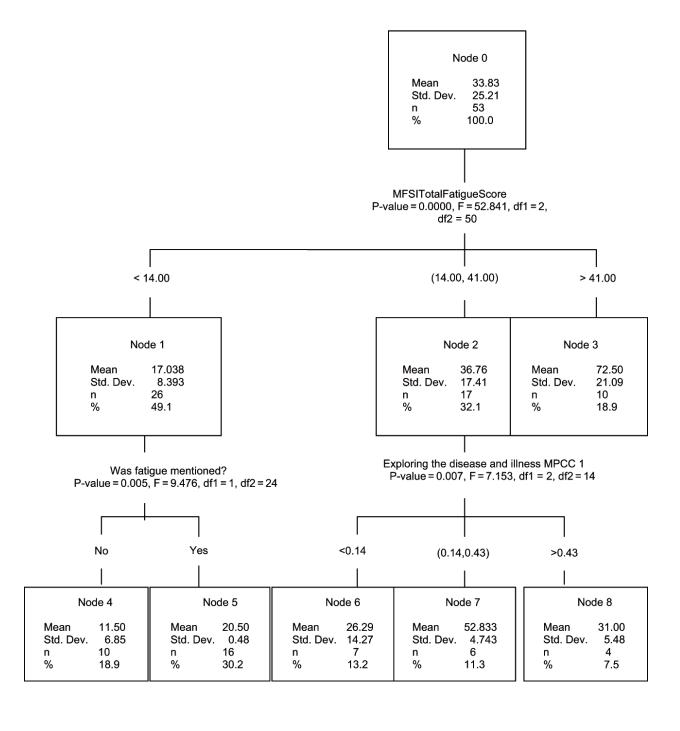


FIGURE 3. CHAID analysis of predictors of uncertainty.

Given that the analyses are provided in this tree format, it may be useful to reexamine the nature of the output. Because the outcome (uncertainty) is continuous, CHAID reverts to an analysis of variance (ANOVA) model. The predictors (MFSI) are grouped so as to maximize the *F* test

statistic while maintaining the ordinal nature of the predictor. Also note that within each node one can locate the mean and standard deviation for the outcome as well as the subsample size and percentage of the sample. This is analogous to a table of means that one would see in a one-way ANOVA result. It is important to keep in mind that the mean reported in each node is the mean of the outcome variable.

A similar pattern is seen in the relationship between fatigue (MFSI) and mood state (POMS total) in Figure 4. Mood state was conceptualized as a continuum from better to worse. Again we see that CHAID has partitioned levels of fatigue into three levels, similar but not identical to the partitioning in Figure 3, and that fatigue (MFSI) is positively related to mood state (POMS). However, in this analysis we can also see that communication variables were also predictive of survivor mood state at various levels of fatigue. Thus, among women who are generally less fatigued (reported fatigue levels below 14; Figure 4, Node 1), women who mentioned their fatigue to providers reported a worse mood state than women who did not mention fatigue (POMS of 20.5 vs. 11.5, respectively). In addition, we can see that for those women with moderate levels of fatigue (reported fatigue levels 14-41; Figure 4, Node 2), whose consultations had a lower (<.14) or higher (>.43) amount of exploration of the disease and illness, there were differences in reported mood state (26.29 and 31.00, respectively). Women who had more exploration of their symptoms reported a worse mood state. However, note that in Figure 4, Node 7, women whose consultations were scored between these extremes in exploration of the disease and illness (symptoms) reported the worst mood state (POMS = 52.83). Thus, this aspect of the communication was predictive of mood state, but was predictive in a nonlinear fashion. It is important to note that this nonlinear relationship between exploration of symptoms and mood state would not have obtained significance in traditional linear regression.





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Abstract

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associated with survivor uncertainty, survivor mood state, and survivor perception of patient-centered communication for breast cancer survivors experiencing varying fatigue levels.

BACKGROUND AND SIGNIFICANCE

Frustration with the communication process has been consistently reported by both providers and patients (Hack, Degner, Parker, & The SCRN Communication Team, 2005; Levinson, Stiles, Inui, & Engle, 1993; Nisselle, 2000; Schwenk, Marquez, Lefever, & Cohen, 1989). Less than optimal communication can result in women having trouble managing and/or understanding the meaning of their symptoms, creating uncertainty about recurrence and mood state up to 2 or more years after original diagnosis and treatment (Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000; Gray et al., 1998; Krupat et al., 1999; Mast, 1998; McKinley, 2000). Further, although nurse practitioners and physician assistants often interact with breast cancer survivors during follow-up consultations, there is very little literature exploring survivor-provider communication processes specific to nonphysician providers (Earnshaw & Stephenson, 1997; Extermann et al., 2004; Romero, 1999; Spigelman, 1997).

Communication has been described as one of the most important variables in the patient-provider relationship. Communication has been associated with the patient's perception of the quality of care, including provider interpersonal and technical competence, as well as predicting patient satisfaction with the patient-provider relationship (Inui, 1998). Yet, when specifically asked about the communication process, a substantial number of breast cancer patients report communication difficulties with their providers well into survivorship (Bloom, Stewart, Chang, & Banks, 2004; Hack et al., 2005; Lerman et al., 1993). Breast cancer survivors report that providers do not understand their concerns or, worse yet, ignore their complaints. Moreover they report that providers make assumptions about symptom management issues and goals, and do not seek their input (Crooks, 2001; Loescher, Clark, Atwood, Leigh, & Lamb, 1990; Savage & Armstrong, 1990; Wilmoth, 2001). Indeed, baseline data from the HINTS¹ database show that on average, only 55% of patients report that their providers consistently listen carefully, provide understandable explanations, and demonstrate respect for their opinions (U.S. Office of Disease Prevention and Health Promotion, 2003).

Communication problems can contribute to outcomes such as increased uncertainty (Krupat et al., 1999). Uncertainty, in turn, affects both negative mood state and depression in breast cancer survivors (Mast, 1998; Polinsky, 1994). Women who cannot manage or understand the meaning of their symptoms report uncertainty about recurrence and mood state up to 2 or more years after original diagnosis and treatment (Bleiker et al., 2000; Clayton et al., 2006; Porter et al., 2006). In particular, women who are older, less educated, and who have other illnesses may be unclear about whether the cause of their physical symptoms is the aging process, another illness, or a recurrence of breast cancer (Clayton, et al., 2006; Crooks, 2001; Mast, 1998).

Due to persistent patient complaints of patient-provider communication difficulties, and the assumption that responsibility for effective communication rests with the provider, interventions were developed to enhance the communication skills of providers (Cowan & Laidlaw, 1993; Doak, Doak, Friedell, & Meade, 1998; Faulkner, Argent, & Jones, 2001). However, this assumption is being challenged, suggesting that responsibility for communication lies with both the provider and the patient. Providers have reported an inability to obtain necessary information from survivors to help them effectively manage their chronic symptoms (Levinson et al., 1993; Nisselle 2000; Schwenk et al., 1989). Supporting this provider complaint, many breast cancer survivors report enduring long-term symptoms that they have never discussed with their

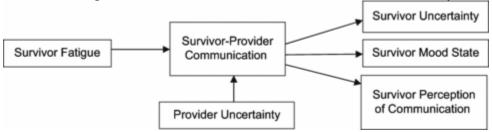
providers (Crooks, 2001). In addition, some women do not want to participate in treatment decision making, even when encouraged to do so by providers (Degner, Kristjanson, et al., 1997; Degner, Sloan, et al., 1997; Gil et al., 2006). Moreover, not all survivors are willing to disclose their goals, values, and lifestyles to providers (Brown et al., 2002; Clayton et al., 2006). Fatigue is an ideal symptom around which to study patient-centered communication. Fatigue is known to be a prevalent side effect of breast cancer treatment, especially for those who received chemotherapy, persisting well into survivorship (Gil et al., 2004; Jacobsen & Stein, 1999; Mast, 1998). Further, there is much survivor as well as medical uncertainty about the cause, and most effective treatment, of fatigue due to the complexity of causal factors (Bower et al., 2000; Mast, 1998; Okuyama et al., 2000; Yellen, Cella, Webster, Blendowski, & Kaplan, 1997). Medical uncertainty about the most efficacious treatment for symptoms, in addition to vague and subjective patient descriptions of symptoms, also contributes to less than optimal communication (Schwenk et al., 1989). Providers have difficulty identifying the source of fatigue due to the subjective and context-laden nature of fatigue, which incorporates physical, psychological, behavioral, and cognitive components (D'Antonio, Zimmerman, Cella, & Long, 1996; Okuyama et al., 2000; Yellen, et al., 1997). Moreover many providers are unwilling to disclose their uncertainty to patients, fearing a loss of credibility or the creation of a perception of incompetence (Beresford, 1991; Henry, 2006). Thus, based on both patient and provider communication concerns it is important to investigate the communication process to assist women to achieve optimal communication with providers.

This study of survivor-provider communication is guided by uncertainty in illness theory (Mishel, 1988), and informed by the theoretical dimensions of a patient-centered relationship (Mead & Bower, 2000). Uncertainty in illness theory predicts that uncertainty occurs when women are unable to predict the course of their illness or attribute meaning to their symptoms (Mishel, 1988). Effective survivor-provider communication has been shown to improve understanding of symptoms, thereby reducing uncertainty, improving mood state and adaptation to survivorship (Mast, 1998).

Patient-centered communication has evolved from a loosely defined provider attempt to elicit the patient's viewpoint and participation in decision making to an explicit clinical method of communication that elicits survivor values, needs, and goals, as well as demonstrating mutual relationship and partnering skills (Mead & Bower, 2000; Roter, 2000; Stein, Jacobsen, Blanchard, & Thors, 2004). Mead and Bower proposed a framework for assessing patient-centered communication based on a metasynthesis of existing research suggesting five dimensions of patient-centered communication: a biopsychosocial approach (indicating a provider willingness to address the physical components of a disease as well as ideas and concerns about signs and symptoms), an acknowledgement of the patient as a person (addressing contextual factors), an ability to mutually share power and responsibility, the development of a therapeutic alliance, and an acknowledgement of the provider as a person (addressing medical uncertainty).

A conceptual model (Figure 1) was developed to guide the investigation of three survivor-focused outcomes (uncertainty, mood state, and survivor perception of patient-centered communication). The sample size (N = 60) and design (a limited number of providers) precludes a full test of the model using path analysis. Thus our focus was on predictors of the three outcomes, including a more specific analysis of the relationship between fatigue and patient-centered survivor-provider communication. The purpose of this study was to investigate how fatigue and communication are related to survivor uncertainty and mood state, and survivor

perception of patient-centered communication for women with varying fatigue levels. This primary aim was followed by a finer grained analysis of the relationship between survivor fatigue and specific patient-centered aspects of communication. An investigation of the moderating effects of medical uncertainty was added to the model to more fully capture the dimensions of patient-centered communication (Brown, Stewart, & Ryan, 2001).



[Enlarge Image]

FIGURE 1. Model of survivor-provider communication, uncertainty, mood state, and survivor perception of communication, about chronic fatigue.

METHODS

Sample and Setting

This study was conducted in a large, ethnically diverse oncology practice serving patients with a wide range of socioeconomic status. Providers saw patients on a first-available basis, thus effectively randomizing the provider seen by a woman. Sixty recurrence-free breast cancer survivors 2 or more years posttreatment were recruited (White = 43; African American = 16; Asian = 1). Survivor sample size required to detect an R^2 of .20 (effect size) in a multiple-regression model with six predictors was calculated using a significance level of α = .05 to achieve 80% power (Borenstein, Rothstein, & Cohen, 2001). Effect size was based on previous research showing that communication explained 22% of the variance in thoughts of recurrence, and uncertainty explained 16% of the variance in mood state (Clayton et al., 2006; Gil et al., 2006). Two-year survival was selected so that the acute side effects of original treatment would have abated, allowing the emergence of chronic symptoms (Jacobsen & Stein, 1999). Women of all ages and ethnicities were recruited. No restriction was placed on participant age because contextual factors such as employment and child rearing may affect survivor fatigue. Six providers (3 oncologists, 2 physician assistants, and 1 nurse practitioner) were recruited. Four providers were women; five were White. Four providers had practiced less than 5 years.

Procedures

This research was approved by the Institutional Review Board and the participating oncology practice. Providers and patients gave written consent for participation. To avoid sensitizing women and providers to the target symptom of fatigue, the study was presented as addressing potential long-term side effects of treatment, including fatigue. Women were prescreened for fatigue level (in addition to collection of demographic information and verification of inclusion criteria) 1 week prior to the scheduled office visit, additionally reducing sensitization to the target symptom of fatigue. Cognitive competence was also assessed during previsit screening using the Mini-Mental Status Exam Short Form (score > 14; Folstein, Folstein, & McHugh, 1975).

On the day of their appointment women were met in the office. Written consent was obtained for audio-taping and administration of postvisit self-report measures. Each audio-tape represents a single, routinely scheduled, follow-up encounter between a breast cancer survivor and her provider. Survivor outcome measures were completed at the immediate conclusion of the visit to facilitate the assessment of uncertainty, perception of mood state, and perception of communication within the immediate visit context.

Measures

Substantive study variables evaluated included fatigue, survivor uncertainty, mood state, survivor-provider communication, survivor perception of communication, and provider uncertainty. Fatigue was assessed during prescreening using the Multidimensional Fatigue Symptom Inventory-Short Form (MFSI-SF), a 30-item self-report scale evaluating the somatic, cognitive, affective, and behavioral symptoms of fatigue (Stein et al., 2004; Stein, Martin, Hann, & Jacobsen, 1998). Items were rated on a 5-point scale ranging from 0 (*Not at all*) to 4 = (*Extremely*) indicating how true each statement was for the respondent during the last week. The total fatigue score was obtained by summing the scores, then subtracting the "vigor" subscale score, creating a response range from -24 to 96. Higher scores indicate more fatigue (Table 1). The MFSI-SF discriminates across women undergoing treatment, posttreatment, and without breast cancer (Dittner, Wessely, & Brown, 2004; Stein et al., 2004; Stein et al., 1998). Concurrent validity has been demonstrated by correlations with the Profile of Mood States fatigue subscale and the SF-36 vitality subscale (Stein et al., 1998).

TABLE 1. Reliability, Range, Mean, and Standard Deviation of Instruments

Measure	Reliability	Range	\mathbf{M}	SD							
<i>Note</i> . Totals may not add up to 100% due to rounding. POMS-SF = Profile of Mood States—Short Form; MPCC = Measure of Patient-Centered Communication.											
MFSI-SF	0.95 (Cronbach's a)	-18 to 80	17.63	22.68							
Survivor Uncertainty	0.87 (Cronbach's a)	34-69	53.28	12.73							
POMS-SF	0.97 (Cronbach's a)	0-84	19.82	21.50							
PPCS	0.82 (Cronbach's a)	1-3	1.60	0.50							
Physician Uncertainty	0.90 (Cronbach's a)	34-69	47.50	14.03							
MPCC (total) N=55	.7798 (Interrater reliability)	26-87	51.96	16.29							
MPCC (Dimension 1)											
Exploring illness and disease		5-72	30.54	15.80							
MPCC (Dimension 2)											
Exploring the whole person		0-100	47.70	38.58							
MPCC (Dimension 3)											
Finding common ground		25-100	77.5	17.16							

Survivor uncertainty was measured postvisit using the Uncertainty in Illness Scale—Survivor Version (Mishel, 1997). This 22-item self-report scale assesses the uncertainty associated with breast cancer survivorship using a 5-item response format ranging from *strongly agree* to *strongly disagree*. Scores are summed, with a total ranging from 0 to 110. Higher scores reflect greater levels of uncertainty (Table 1). Statements were adapted by Mishel from the original adult version of the scale to reflect concerns experienced by survivors, as opposed to those

experiencing acute illness events (<u>Gil et al., 2006</u>). Items include: "I have been told different things about what my treatment side-effects mean," and, "I don't know if my cancer will ever come back." Support for construct validity is demonstrated by consistent positive associations with measures of mood state, fears of recurrence, and symptom bother (<u>Clayton et al., 2006</u>; <u>Hilton, 1994</u>; <u>Porter et al., 2006</u>).

Mood state was measured postvisit using the Profile of Mood States—Short Form (POMS-SF; Curran, Andrykowski, & Studts, 1995). The POMS-SF is a 37-item adjective rating scale measuring six affective mood states: tension-anxiety, depression-rejection, anger-hostility, vigoractivity, fatigue-inertia, and confusion-bewilderment. Responses range from 0 (not at all) to 4 (extremely). The vigor subscale was reverse-scored before items were summed, and added to the total. Total scores ranged from 0 to 148. Scores can be interpreted as ranging from a low score indicative of comparative well-being, to a higher score indicative of comparative distress (Table 1). Validity of the POMS-SF in breast cancer survivors up to 3 years posttreatment is demonstrated by a consistent inverse relationship with the Cancer Rehabilitation Evaluation System (Coscarelli & Heinrich, 1988) and by strong associations with uncertainty and survivor thoughts of recurrence (Gil et al., 2006). Convergent validity of the POMS-SF is supported by positive correlations with both uncertainty and troublesome thoughts of recurrence (Clayton et al., 2006; Porter et al., 2006). Further evidence of the POMS-SF's ability to discriminate among cancer patients is supported by correlations with the Center for Epidemiologic Studies Depression Scale (CES-D), the Self-Rated Karnofsky, and the Medical Outcomes Study Short Form (MOS SF-20) (Baker, Denniston, Zabora, Polland, & Dudley, 2002). Survivor-provider communication was audio-taped, transcribed, then coded using the Measure of Patient-Centered Communication (MPCC; Brown et al., 2001). This coding scheme captures three of the dimensions of patient-centered communication proposed by Mead and Bower (2000), addressing (a) exploration of illness and symptoms, including medical information and provider attempts to understand the survivor's illness experience; (b) exploration of the whole person, or understanding the survivor within the context of family, work, and culture; and (c) mutual definition of the problem by establishing goals of treatment and identifying the roles of survivor and provider. Patient-centered scores are computed for each dimension by evaluating initial and subsequent discussion of patient concerns, validation of patient concerns, and/or dismissal of patient-initiated topics, then averaging awarded points by a maximum possible score for each dimension. A total score is then computed for the entire patient-provider discussion by averaging the three dimension scores (Table 1). Total scores can range from 0 (not at all patientcentered) to 100 (very patient-centered). Support for validity of the MPCC is shown by association with survivor outcomes of recovery, emotional health, treatment adherence, and survivor satisfaction with providers (Stewart, 1995; Stewart et al., 1999). Once established, interrater reliability was maintained by having both coders code every 10th transcript (Table 1). Survivor perception of communication was measured postvisit using the 14-item Perception of Patient-Centeredness Scale (Stewart et al., 2000). This self-report scale addresses the same dimensions as the MPCC but from the survivor's point of view. Items indicate whether patients perceive their concerns to have been addressed, were able to adopt chosen participation level, asked questions, whether the purpose of the visit was understood by providers, and a final item about how much they perceive the provider to care about them as a person. Responses can range from completely (or very much) to not at all (1-4), with lower scores indicating a higher perception of patient-centeredness. A total score is computed. Validity is supported by an

association with improved emotional health up to 2 months postvisit, as well as improved symptom resolution (Stewart et al., 2000).

Provider uncertainty, another dimension of patient-centered communication (Mead & Bower, 2000), was measured using the Physician Reaction to Uncertainty Scale, a 21-item self-report scale measuring provider anxiety due to uncertainty, concern about bad outcomes, and reluctance to disclose medical uncertainty (lack of knowledge, inconclusive testing, uncertain prognoses) to patients (Gerrity, White, DeVellis, & Dittus, 1995). Higher scores indicate greater medical uncertainty by a provider (Table 1). Provider uncertainty was measured once, just after obtaining provider consent for participation.

RESULTS

Sample Characteristics

There was very little missing data in this analysis because subject data booklets were checked for completeness prior to the subject leaving the medical office. Initially, results were analyzed descriptively (Table 2). African American women comprised 27% of this sample, representative of the population of African American women in North Carolina, with the remainder self-identifying themselves as White, plus one Asian woman. Slightly over half of this sample had a high school education or less. The vast majority of women had surgical treatment, usually combined with chemotherapy, radiation, or both (Table 2). Of the 96 women identified as eligible by the office research nurse, 28 were unable to be contacted by phone. Of the remaining 68 names given to the research team, 60 agreed to participate. Seven women refused due to the time commitment of staying in the office for 20 min postvisit; one woman was ineligible. Five visits were not audio-recorded. Four of these were due to technical reasons; one woman agreed to complete self-report measures but declined to have her visit recorded.

TABLE 2. Breast Cancer Survivors: Sample Characteristics

	Minimum	Maximum	\mathbf{M}	SD
Note.N = 60. Totals may not equal 100% du	ie to rounding	g or participan	t nonre	sponse.
Age	31	87	61.67	11.30
Education (years)	7	19	13.35	2.44
		n	%	
Treatment				
Chemotherapy		1	1.7	
Surgery		6	10.0	
Surgery and chemotherapy		19	31.7	
Surgery and radiation		10	16.7	
Surgery, chemotherapy, and radiation		24	40.0	
Marital status				
Married		37	62.7	
Separated or divorced		10	17.0	
Widowed		11	18.6	
Employment status				

TABLE 2. Breast Cancer Survivors: Sample Characteristics

	Minimum	Maximum	M	SD
Retired		32	54.2	
Unemployed		12	20.4	
Employed full or part time		15	25.4	
Income (per month)				
Less than \$1,000		9	15.8	
\$1,001-\$4,000		35	61.4	

Communication Coding

Total and subscale MPCC scores for consultations are shown in <u>Table 1</u>. Analyses were conducted using total patient-centered scores, as well as by the illness, contextual, and planning dimensions. Total patient-centered scores ranged from 26 to 87, (M = 52), with higher scores indicating more patient-centered communication. The dimension of exploring illness and symptoms had the lowest mean amount of patient-centered communication, with contextual and planning dimensions, respectively higher (<u>Table 1</u>).

Statistical Analyses

SPSS was used for data entry, data validation, scale computations, descriptive statistics, and reliability analyses. Initially a correlation matrix was constructed (<u>Table 3</u>) to investigate relationships between variables. As theoretically expected, survivor self-reported fatigue levels were highly and positively correlated with self-reported mood state and uncertainty levels. Unexpectedly there was no correlation between the objective measure of patient-centeredness (verbal coding using the MPCC), and the companion subjective measure evaluating a survivor's perception of the degree of patient-centeredness. Examining age as a covariate, a moderate positive correlation was found between age and the overall amount of patient-centered communication. However, an inverse relationship was observed between age and dimension 2 of the MPCC, exploring the whole person. Further, visits with providers reporting more medical uncertainty were correlated with a survivor perception of more patient-centered communication.

TABLE 3. Correlation Matrix of Variables and Outcomes

		Dise	Wh	Com								
Survi N	ЛР	ase	Ole Don	mon	Fatigu	Mo	Surviv	Perceptio n of Communi cation			Tim	Medica
vor (CC	mile	con	Grou	e	od	or	n of	A	Educa	e in	1
Fatig T	ot	MP	MP	nd	Menti	Sta	Uncert	Communi	ge	tion	Prac	Uncert
ue a	l	CC	CC	MPC	oned	te	ainty	cation			tice	ainty
		1	2	C 3								

Note. N = 60. MPCC = Measure of patient-centered communication.

*
$$p < .05.$$
 ** $p < .01.$ Survi vor fatigu -.00 -.17 .10 -.09 -.11 $\frac{.80}{*}$.60** .23 .0 -.04 -.04 .20

TABLE 3. Correlation Matrix of Variables and Outcomes

	Survi vor Fatig ue	\mathbf{CC}	WIP	ole Per son	Grou nd	e Menti	od Sta	or Uncert	Perceptio n of Communi cation	A	Educa tion	e in Prac	
MPCC Total			.43 <u>*</u> <u>*</u>	.87 <u>*</u> <u>*</u>	.32 <u>*</u>	.06	.08	.02	.04	.2 9 <u>*</u>	.26	01	.00
MPCC 1				.09	.02	.13	.05	05	.25	.0 8	.16	.23	41 <u>**</u>
MPCC 2					04	03	.20	.03	.03	- .3 2 <u>*</u>	.19	11	.05
MPCC 3						.16	- .24	.04	19		.12	.02	.29 <u>*</u>
Was fatigue mentione d							.01	.05	03	- .0 1	.05	16	14
Mood state								.58 <u>**</u>	.18	- .2 8	.06	02	.08
Survivor uncertain ty Perceptio									.07	.2	09	04	08
n of communication										.1 6	05	.03	31 <u>*</u>
Age											24	.04	24
Educatio n												.15	.15
Time in practice													.16

The exploratory variable provider uncertainty, reflecting a provider's anxiety and concerns about sharing medical uncertainty with patients, was modestly and inversely correlated with communication variables. Visits with providers who reported more medical uncertainty were correlated with less exploration of the disease and illness (dimension one of the MPCC) yet higher levels of finding common ground, the mutual planning and goal setting dimension of the MPCC (dimension 3). Further, visits with providers reporting more medical uncertainty were correlated with a survivor perception of less patient-centered communication.

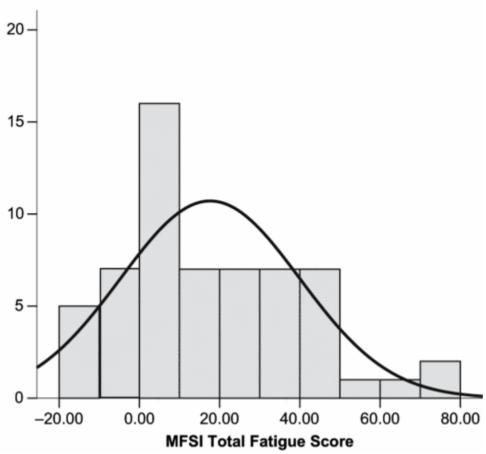
Because the research questions dealt with variables with both continuous and categorical levels of measurement, and because we anticipated that we might encounter nonlinear relationships, we employed an exploratory analysis technique known as chi-square automatic interaction detection (CHAID). CHAID has been shown to be useful in the explication of complex relationships (Dudley, Dilorio, & Soet, 2000). CHAID works somewhat like multiple-regression with stepwise entry in that one provides a dependent variable and a set of potential predictors. All potential predictor variables are evaluated, and the sample is partitioned into mutually exclusive groups based on a targeted outcome variable. CHAID analysis techniques have been used in health-related research to identify problems contributing to asthma mortality, barriers to receiving HIV care, and whether subgroups of older women match the national mammography screening average (Barton, McKenzie, Walters, & Abramson, 2005; Huba et al., 2001; Larson et al., 2001; Rakowski & Clark, 1998).

A unique feature of CHAID is that the output is represented as a decision tree, with each branch representing a homogeneous, mutually exclusive, sample grouping based on the best predictor variable. In effect, the analysis segments the sample with regard to the predictors. As in stepwise regression analysis, the analysis identifies the most powerful predictor (smallest *p* value) and then continues in a stepwise fashion until all significant predictor variables have been identified. For example, if gender were the most significant predictor of the target variable "cooking" then two subgroups (male and female) would be identified. For females perhaps the best predictor of cooking is creativity, whereas for males the best predictor of cooking is hunger, and so on until all predictor variables for identified subgroups have been identified. In each reiteration the entire sample is evaluated for the significance of the predictor variable. As stated earlier, CHAID accepts all levels of variables. When the target variable is continuous, an *F* test is calculated; when categorical variables are identified, the chi-square test is used. Analysis was allowed to proceed without forced entry of any variable.

Overall, the proposed relationships shown in the conceptual model were supported, demonstrating associations between antecedent and outcome variables (Figure 1). Fatigue level was the best predictor of uncertainty, supporting the theoretical link between symptoms and uncertainty (Mishel, 1988). Fatigue was conceptualized as a continuum from less to more self-reported fatigue. Most women reported lower levels of fatigue, with half of women reporting fatigue levels between -18 and 11 (Table 1; Figure 2). Based on previous research, the low incidence of extreme fatigue was expected (Clayton et al., 2006). However, fatigue is known to be extremely bothersome for some women, and indeed 20 % of women in this study reported

fatigue levels between 41 and 80.



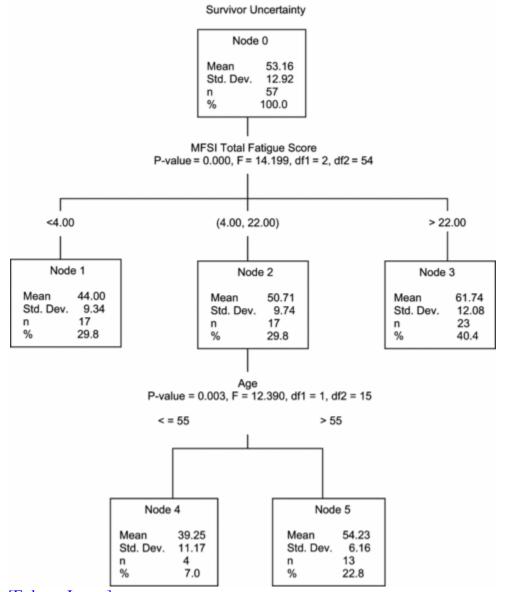


[Enlarge Image]

FIGURE 2. Distribution of self-reported fatigue levels.

Because CHAID is used as an exploratory analysis technique, where little is known about the relationships between variables being studied, continuous variables such as fatigue level are partitioned in such as way as to maximize differences between groups with respect to the outcome. Thus, as can be seen in Figure 3, CHAID partitioned the levels of fatigue (MFSI) into three mutually exclusive groups (<4.00, Node 1; 4.00-22.00, Node 2; >22.0, Node 3). Partitioning of fatigue is different in subsequent figures with different outcome variables. Returning to Figure 3, we can see that this is a linear relationship, such that lower fatigue levels are associated with lower uncertainty (*M* for uncertainty in Node 1 = 44.00) with increases in

uncertainty seen as fatigue level increases (Node 2 M = 50.71; Node 3 M = 61.74).



[Enlarge Image]

FIGURE 3. CHAID analysis of predictors of uncertainty.

Given that the analyses are provided in this tree format, it may be useful to reexamine the nature of the output. Because the outcome (uncertainty) is continuous, CHAID reverts to an analysis of variance (ANOVA) model. The predictors (MFSI) are grouped so as to maximize the *F* test statistic while maintaining the ordinal nature of the predictor. Also note that within each node one can locate the mean and standard deviation for the outcome as well as the subsample size and percentage of the sample. This is analogous to a table of means that one would see in a one-way ANOVA result. It is important to keep in mind that the mean reported in each node is the mean of the outcome variable.

A similar pattern is seen in the relationship between fatigue (MFSI) and mood state (POMS total) in <u>Figure 4</u>. Mood state was conceptualized as a continuum from better to worse. Again we see that CHAID has partitioned levels of fatigue into three levels, similar but not identical to the partitioning in <u>Figure 3</u>, and that fatigue (MFSI) is positively related to mood state (POMS).

However, in this analysis we can also see that communication variables were also predictive of survivor mood state at various levels of fatigue. Thus, among women who are generally less fatigued (reported fatigue levels below 14; Figure 4, Node 1), women who mentioned their fatigue to providers reported a worse mood state than women who did not mention fatigue (POMS of 20.5 vs. 11.5, respectively). In adsdition, we can see that for those women with moderate levels of fatigue (reported fatigue levels 14-41; Figure 4, Node 2), whose consultations had a lower (<.14) or higher (>.43) amount of exploration of the disease and illness, there were differences in reported mood state (26.29 and 31.00, respectively). Women who had more exploration of their symptoms reported a worse mood state. However, note that in Figure 4, Node 7, women whose consultations were scored between these extremes in exploration of the disease and illness (symptoms) reported the worst mood state (POMS = 52.83). Thus, this aspect of the communication was predictive of mood state, but was predictive in a nonlinear fashion. It is important to note that this nonlinear relationship between exploration of symptoms and mood state would not have obtained significance in traditional linear regression.

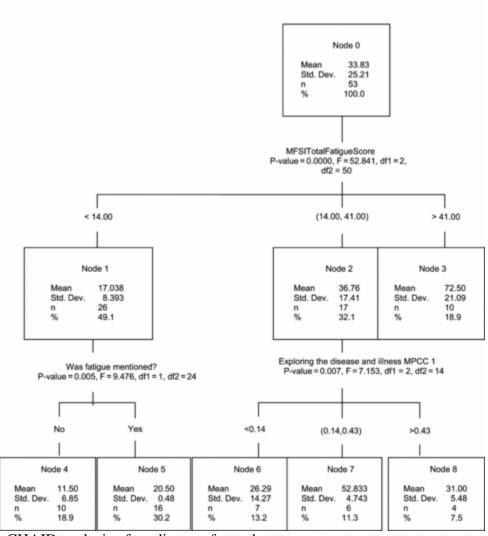
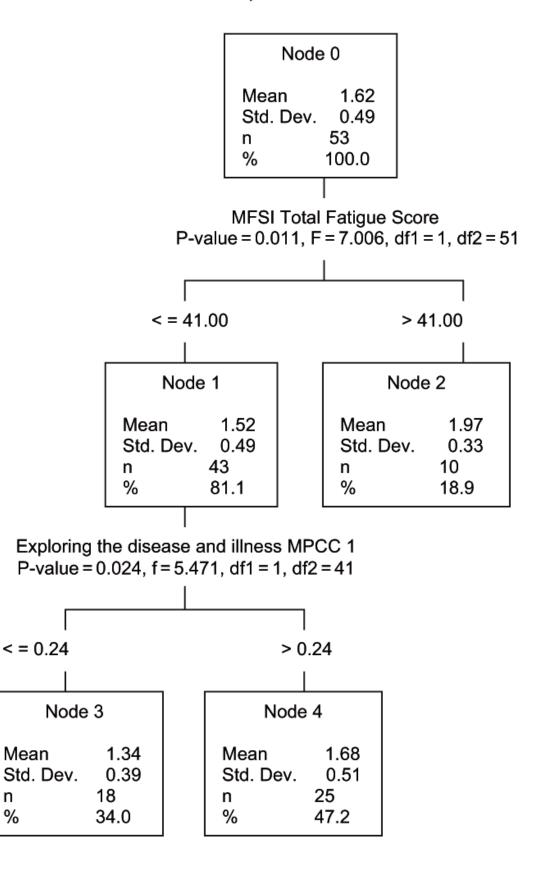


FIGURE 4. CHAID analysis of predictors of mood state.

Survivor self-reported fatigue level was the best predictor of survivor uncertainty (Figure 3). Reported fatigue level was also the best predictor of survivor mood state and survivor perception of patient-centered communication, as seen in the CHAID output trees (Figure 4, Nodes 1-3; Figure 5, Nodes 1-2.). Among those who reported less fatigue with respect to the outcome variable survivor perception of patient-centered communication, there was a direct relationship between the amount of exploration of symptoms and a woman's perception of the amount of patient-centered communication (Figure 5, Nodes 3-4). More exploration of illness (>0.24) predicted a higher patient perception of the amount of patient-centeredness for women with less reported fatigue (<41.0). For women reporting moderately low levels of fatigue (4-22), there was also a direct relationship between a woman's age and her level of uncertainty, with women over age 55 reporting more uncertainty than women age 55 or younger (Figure 3, Nodes 4-5).

Survivor Perception of Patient-Centeredness



n

%

FIGURE 5. CHAID analysis of predictors of survivor perception of patient-centered communication.

Content analysis of visits showed that only 58% of women mentioned fatigue to their providers, yet there was no difference in fatigue levels between those who did and did not mention fatigue (t=1.06; df=53; p=0.29). To further explore the relationship between fatigue levels and mentioning fatigue to providers, we conducted additional analyses but found no increased likelihood for those women with the highest levels of fatigue to mention fatigue during consultations (cutoff was MFSI score = 50, based on the distribution shown in Figure 2; 6.7% of the sample; $\chi^2 = .119, df = 1, p = .73$). However, there were relationships between fatigue level and other quality of life outcome variables. For example, women with more self-reported fatigue (MFSI = 40 chosen due to the CHAID partitioning of levels of fatigue) reported more uncertainty $(t = 3.75, df = 57, p \le .01)$, comparatively poorer mood states $(t = 8.08, df = 55, p \le .01)$, and a lower patient perception of patient-centered communication $(t = 2.97, df = 57, p \le .01)$.

Additional content analysis of open-ended questions administered prior to the visit revealed that 78% of visits were considered by women to be routine follow-up visits and that 63% of women had a very specific plan for these visits, such as asking specific questions, discussing specific symptoms or concerns, and/or requesting additional medications. Thirteen percent had no plan for their visit, and the remainder had a general plan such as to "get my regular blood work and make sure I'm OK."

There was no correlation between the objective measure of patient-centered communication and the subjective measure of a survivor's perception of communication (Table 3). Most women considered their concerns to be "completely" or "mostly" addressed (M = 1.6, Table 1). Item analysis showed that the single item "cares about you as a person" was rated as "very much" (the most patient-centered choice) by 89% of the women, possibly indicating a ceiling satisfaction effect. Other items were not as favorably answered, with the most variation involving items addressing a survivor perception that goals and managability of treatment options had been addressed and that participation role preferences had been discussed. These items all had item means between 2 (mostly) and 3 (a little).

Because there has been so little literature addressing nonphysician communication with cancer survivors, we conducted an exploratory nested analysis to evaluate provider characteristics and specialty relationships with communication and outcome variables. Participants were nested within provider specialty (nurse practitioner, physician assistant, and oncologist), thus evaluating survivor outcomes based on type of provider seen as opposed to communication analyses between one woman and one provider. Nurse practitioner and physician assistant specialties were collapsed into one specialty, nonphysician providers, resulting in a distribution of three nonphysicians (seeing 60% of women) and three physicians (seeing 40% of women).

Nonphysician providers (physician assistants and nurse practitioners) had patient-centered communication scores on average 8 points higher than physician providers in this nested analysis, suggesting the need for further research with greater numbers of providers to more fully understand this preliminary exploratory finding (t = 1.85; df = 49; p = .07). Other analyses were

conducted looking at survivor outcomes by provider gender and ethnicity, but no significant results were found.

DISCUSSION

A major strength of this study is the use of a verbal coding system that facilitates a blend of qualitative inspection of content, as well as quantitative exploration of associations between variables. The use of CHAID as an analysis method helps to identify concerns that are specific to different groups of survivors. This approach may help to target interventions to specific groups of survivors in an effort to assist women to achieve and maintain a high quality of life during breast cancer survivorship.

Symptoms

Contrary to expectations that contextual communication would predict better patient outcomes, findings showed that discussion about symptoms was most influential in predicting survivor mood state and survivor perception of communication, despite reflecting the least patient-centered dimension of the MPCC. Perhaps women assign more importance to patient-provider communication about the medical aspects of symptoms, rather than issues of symptom management within the context of work or home environments. These results suggest that it is most important to breast cancer survivors for providers to listen to their thoughts and ideas about experienced symptoms, captured in dimension 1 of the MPCC.

Both the literature and anecdotal comments made by women in this study suggest that a motivator for focusing on symptoms, rather than on contextual concerns, may be fear of recurrence. Concerns about recurrence are known to be prevalent in breast cancer survivors and can be triggered by events such as an office visit, or by the uncertainty and unpredictability of long-term side effects of treatment, such as fatigue (Gil et al., 2004; Johnson-Vickberg, 2001; McKinley, 2000). Content analysis of audio-tapes suggests that questions about the possibility of recurrence were frequent, although sometimes phrased obliquely such as "my tiredness doesn't mean anything, right?"

Uncertainty in illness theory suggests that symptoms have a positive relationship with uncertainty, which in turn affects adaptation to illness (Mishel, 1988). Part of adaptation to chronic illness (a way of interpreting the constant need for management of persistent symptoms during survivorship), is how one manages thoughts about cancer recurrence. Women may be motivated to discuss their concerns about persistent symptoms with providers as a way of seeking reassurance about the possibility of recurrence, thereby reducing their uncertainty about the future and breast cancer recurrence. However, sometimes the reduction of uncertainty is not an immediate goal of a cancer survivor. Rather, in any given time, preserving hope by avoiding discussions of symptoms and subsequent possible recurrence may reflect a more positive adaptation to illness (Brashers et al., 2000). Uncertainty management theory suggests that information may be sought or avoided as a way of managing chronic uncertainty (Brashers et al., 2000). This type of management strategy has been observed in chronic illnesses such as HIV (Brashers et al., 2000), and may help to explain why some women chose not to mention fatigue symptoms to providers.

Discussing Fatigue

In this study, only slightly more than half of the women mentioned fatigue to their providers during audio-taped visits, despite the fact that there was no difference in self-reported fatigue levels between those who did, and those who did not mention fatigue to providers. These findings support previous research showing that the majority of cancer patients do not mention fatigue to providers (Passik et al., 2002). Further, there was no difference in the likelihood of mentioning fatigue to providers even among the small subset of women with the highest fatigue levels. Perhaps, in addition to information avoidance as an uncertainty management strategy, another explanation for why fatigue was or was not mentioned to providers may be that the perceived impact of fatigue (as opposed to the amount of fatigue) on daily life is higher for some women than others. The perceived impact of fatigue was not measured in this study. However, distress about fatigue level, regardless of actual fatigue level experienced, could cause fatigue to be in the forefront of a woman's mind during her office visit, and might be a motivating factor to discuss this symptom with providers. The idea that the prevalence of symptoms may not necessarily be related to the bother attributed to symptoms for breast cancer survivors has been reported previously in the literature (Brown et al., 2002; Clayton et al., 2006).

Another possibility for why women chose not to discuss concerns may be a more passive participation preference (Degner, Kristjanson, et al., 1997; Degner, Sloan, et al., 1997). Brown and colleagues (2002) emphasize the need for provider understanding of, and adaptation to, patient preferences for information and participation as a way of enhancing the relationship between a breast cancer patient and her oncologist. Preferences for information and participation in subsequent visits may differ if women want to acquire specific information about a symptom or management topic as a way of reducing uncertainty (Brashers et al., 2000). In fact, research suggests the importance of the match between patient and provider in terms of active or passive participation preferences to enhance patient satisfaction (Krupat, Fancey, & Cleary, 2000; Krupat, Rosenkranz, et al., 2000).

More simply, not mentioning fatigue may be related to a survivor perception that all useful provider-offered information had been previously obtained. Perhaps contextual symptom management concerns, as opposed to illness-focused concerns, may be communicated to persons other than providers, especially for women who have not experienced a recurrence of their breast cancer. Previous research has shown that providers may not be considered the best source of management information (such as how to manage fatigue in the workplace) by cancer survivors (Hesse, 2003). When cancer patients are asked where would they go for cancer information 50% report they would ask their providers, followed by 24% who report they would use the Internet. However, when asked where did they go, only 11% of cancer patients consulted providers; instead 49% reported consulting the Internet, family, and friends (Hesse, 2003). Other research has found that 47% of cancer patients report that the provider's failure to offer them interventions for fatigue was a primary reason for not mentioning fatigue to providers (Passik et al., 2002). One final possibility for not mentioning fatigue is that women are afraid of being perceived as critical or ungrateful. Passik and colleagues (2002) found that 28% of cancer patients did not mention fatigue to providers due to a desire to not criticize their providers. Similarly, Johnson and colleagues (1996) found that although 76% of women with newly diagnosed breast cancer (M age = 54.6) had specific fears about their diagnosis, only half revealed these fears to their providers. Gratefulness for a successful outcome may help explain why some women, even with very high levels of fatigue, did not mention fatigue to providers. Regardless, the fact that only

slightly more than half of women in this study discussed their fatigue with providers supports previous research showing that many breast cancer survivors don't discuss their concerns with providers and suggests avenues for further research (Brown et al., 2002; Crooks, 2001).

Theory

The association between symptoms, uncertainty, mood state, and adaptation to illness has been a consistent finding (Clayton et al., 2006; Gil et al., 2006; Gil et al., 2004; Mishel et al., 2005). The many relationships between self-reported fatigue level and other survivor outcomes throughout these analyses reemphasize this strong theoretical link. Women with comparatively higher fatigue levels had more uncertainty and worse mood states, suggesting once again that symptoms do impact quality of life, regardless of whether symptoms are discussed with providers.

The patient-provider relationship has also consistently been shown as important to breast cancer survivors (Ganz et al., 1996; Wilson, Andersen, & Meischke, 2000). In uncertainty in illness theory, the provider is represented as a structure provider, offering resources that aid the patient in understanding and interpreting symptoms (implying a focus on illness-related concerns), thereby theoretically reducing uncertainty (Mishel, 1988). When the patient has trust and confidence in the health care provider's ability to manage an illness, uncertainty is reduced for patients with acute and chronic illnesses (Santacroce, 2000).

Education is another theoretical structure provider that helps patients to interpret the meaning of their symptoms. Although the role of the provider is consistently clear, supporting the link between the patient-provider relationship and uncertainty, the role of education is less clear. In this study there was no relationship between uncertainty and a woman's amount of education. This is similar to other research finding no association between educational attainment and uncertainty (Galloway & Graydon, 1996; Mishel, 1984; Wong & Bramwell, 1992).

Age

Given that the mean age of women in this study was over 61 years, an interesting finding is the positive correlation of age with overall patient-centered communication, yet an inverse correlation of age with the specific dimension of contextual communication. As age increased, the amount of contextual patient-centered communication decreased. Previous research has shown that older patients desire as much information about a variety of concerns as younger patients (Turk-Charles, Meyerowitz, & Gatz, 1997). Yet research among patients with mixed cancer diagnoses has shown that there is a general decrease in information seeking from medical establishments as age increases (Turk-Charles et al., 1997). Older adults have been shown to seek more information from nonmedical sources when their desire for information was high (Turk-Charles et al., 1997). This study suggests that providers may be consulted primarily for concerns about symptom diagnosis and treatment, but not for contextual management concerns, especially for older women.

Moderate fatigue may be difficult to interpret for women, contributing to uncertainty, especially for women older than 55 years (Figure 3). This finding provides insight for future research into the best way for clinicians to address women with moderate fatigue based on age. Women less than 55 years with moderate fatigue reported less uncertainty about their fatigue level than those of all ages with the lowest fatigue scores (Figure 3, Nodes 1, 4). Perhaps these women are

beginning to develop a cognitive schema of normal aging, where a few symptoms, such as fatigue, are expected and thus pose no cause for alarm. Conversely, older women with moderate fatigue may be more uncertain about the meaning of their fatigue because their ideas about what constitutes normal aging have been previously formed. When their fatigue level did not conform to their expectations, older women with moderate fatigue experienced uncertainty about the meaning of this symptom.

Provider Type

Although no results were found when nesting women within type of provider to assess the association between provider characteristics and outcome variables, it is reemphasized that power for these analyses was low. These analyses were conducted from a purely exploratory point of view to suggest avenues for further study about how provider characteristics are related to patient outcomes. This is important because patient reports of communication difficulties with providers remain commonplace.

Research has shown that patients who report receiving more support from their providers view their providers as more important information sources (compared to family and print materials), emphasizing the need for research on what constitutes, and how to maintain, an effective patient-provider relationship (Aaronson, Mural, & Pfoutz, 1988). In addition, more patient-centered visits have been shown to enhance patient satisfaction, implying that sensitivity by providers to the patient's current concerns and type of information management style is important in reducing or managing uncertainty and to the quality of the patient-provider relationship (Krupat, Fancey, et al., 2000). In this study, increased fatigue was associated with a lower survivor perception of patient-centered communication.

As expected, there was an inverse correlation between medical uncertainty as reported by providers and the degree of exploration of symptoms; as medical uncertainty increased, the amount of patient-centered conversation about symptoms decreased in this exploratory analysis. Yet as medical uncertainty increased, the survivor perception of patient-centeredness improved, possibly reflecting increased provider attention to patient-offered information as a way of provider information acquisition to manage medical uncertainty. Investigating the role of medical uncertainty on interactions with other types of cancer survivors would provide more knowledge about variables associated with survivor-provider interaction.

Verbal Coding

We were surprised that there was no correlation between our objective measure of patient-centeredness (verbal coding using the MPCC) and a survivor's perception of the amount of patient-centeredness. Patient-centered scores showed that most survivors thought their visits were highly patient-centered with no participant feeling that concerns had been completely unaddressed (Table 1). This lack of an association between objective and subjective measures suggests either a ceiling satisfaction effect from the patient's viewpoint, or that we have failed to identify variables associated with what survivors define as patient-centeredness. Although the objective measure suggests survivor needs are not being met, in that their concerns are not being addressed almost half the time, survivors were mostly happy with consultations. It should be noted that the patient perception of patient-centered communication was obtained postvisit in the medical office. In an effort to reduce ceiling effects, the investigator reminded each participant

that she was not associated with the practice in any way and that providers would not see their responses.

Verbal comments made to the investigator by women during postvisit data collection generally reflected a huge sense of relief that "my test results showed I'm OK." This relief at not having any indications of breast cancer recurrence may have predisposed women to favorably rate their interaction with providers. It should also be noted that nonverbal communication was not measured in this study. The majority of participants were observed hugging their providers at the conclusion of the consultation, perhaps reflecting a sense of connection and caring that was absent from the audio-taped verbal exchange during office visits. These observations suggest both the need for nonverbal measures of communication, and the emphasis women place on reassurance about recurrence, possibly explaining the lack of correlation between the objective and subjective measures of patient-centeredness.

CONCLUSION

This research adds to a growing knowledge of breast cancer survivorship, reinforcing that women experience chronic long-term side effects of original treatment, such as fatigue, yet still experience difficulty managing these symptoms. Communication results show that irrespective of fatigue level and actual amount of patient-centered communication, conversation about symptoms was most influential in predicting survivor mood state and survivor perception of patient-centered communication. Perhaps women want to discuss their symptoms with providers based on a need for reassurance about breast cancer recurrence, while discussing more contextual (lifestyle) symptom management issues with others. When women experience uncertainty due to chronic symptoms, their desire for information may fluctuate as a way of managing this uncertainty and maintaining hope. Further, despite much literature on the importance of soliciting and addressing patient input during consultations, this study found that routine follow-up breast cancer survivor consultations were only 52% patient-centered, suggesting that providers do not consistently attend to issues and concerns raised by survivors. This finding has the potential to impact the patient-provider relationship as well as survivor adaptation to illness.

Limitations

Limitations of this study consisted of technology concerns that caused portions of the interviews to be unintelligible or unrecorded. Conversation may have been affected by the presence of audio-taping equipment; however, research has shown that this is forgotten shortly after the start of sessions (Ickes, 1994). Further, despite the delay between recruitment and audio-taping the office visit, women may have been sensitized to fatigue, influencing their communication about this symptom. A limitation of the perception of patient-centered conversation includes the fact that women may have been unwilling to criticize their providers when filling out the patient perception of patient-centeredness instrument. Nonverbal communication was not measured but may have enhanced subject's perceptions of the amount of patient-centeredness of their consultations. It is also difficult to unravel the associations between fatigue and mood state, thus our high correlation between these measures could be anticipated. Finally, power to assess provider influences on the communication process is very low and based on information from only six providers, thus the rationale for treating this analysis as exploratory, merely suggesting directions for future research.

With regard to the limitation of statistical analysis using CHAID, we have employed CHAID because it tends to uncover relationships that may not appear in more traditional analyses. In the spirit of exploration we have removed the Bonferonni correction option. CHAID is exploratory in nature and the identified relationships should be taken as preliminary until further testing either confirms or refutes these findings.

Despite these limitations, this study continues to unravel the complexity of factors associated with adaptation to survivorship. As the impact of specific variables becomes associated with specific subgroups of survivors, interventions can be developed to maximize adjustment to survivorship, ultimately improving quality of life for breast cancer survivors.

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Notes

¹1 HINTS: The Health Information National Trends Survey, conducted by the National Cancer Institute. Nationally representative of the public's need, access, and use of cancer information, as well as health communication practices and trends.