Understanding breast-cancer patients' perceptions: Health information-seeking behaviour and passive information receipt

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ABSTRACT

It is critical to understand patients' information use from the patient perspective, especially when patients are from different cultures and levels of health literacy. A cross-sectional survey supplemented with interviews of breast cancer survivors including both Latina and non-Latina women was undertaken. Subjects were classified as active information seekers, passive information receivers, and/or users of information. Subjects were further classified by stage of information use, progressing from unawareness or awareness of available information to use or non-use of information to make health decisions. Information sources used and use patterns were examined. Most were active information seekers; many were also passive receivers. Healthcare providers remain the primary information source. Interpersonal communication was far more often cited than either the internet or traditional print and broadcast media. Important cross-cultural differences were found. This study provides insight into how patients use actively sought and passively received information. Despite dramatic growth of the internet and other new media, healthcare providers currently remain keys to health information. Findings may help develop

more successful communication strategies when viewed in light of the National Cancer Institute's 'Making Health Communication Programs Work' and the four stages it proposes. It is hoped that future work will focus on evidence-based methods to improve health communication, especially for vulnerable populations. A major lesson learned is the importance of understanding where patients decided to seek information outside the traditional provider-oriented approach taken in many health education programmes.

Keywords: health communication, breast cancer, patient preferences, health information

INTRODUCTION

Breast cancer is the most frequent cancer in women worldwide, with the highest incidence rates in North America.[1] Breast cancer is the most frequently diagnosed non–skin cancer and is second only to lung cancer as the leading cause of cancer deaths in women in the USA, with 200,000 women developing breast cancer each year.[2–4] In the USA, the incidence of breast cancer, but also the five–year survival rate, is lower for Latina and African–American women than for Caucasian women.[5–8] Latina ethnicity is associated with decreased survival time[9] and Latina women are more likely than Caucasian women to be diagnosed with advanced–stage disease.[10,11]

Breast cancer is one of the most common health topics on the internet;[12] however, to date there are relatively few evaluations of the quality, accuracy, or utilisation of internet information on breast cancer.[13–18] Currently, most internet information is written at a university reading level.[19] Information may also be inconsistent across websites, and patients may have to visit several sites before finding answers to their questions.[20]

Latinas face additional barriers to access and use of internet-based information. While one cannot assume that all Latinas living in English-speaking countries are primarily Spanish-speaking, examining internet-based health information that is available in Spanish helps to gain a clearer picture of what types of information may be accessed by Latinas generally. Berland and colleagues found that using simple search terms for information on Spanish websites is inefficient, and that coverage of information on Spanish sites is often poor.[21] Like English sites, Spanish sites also require an advanced reading level,[22] which may limit the use of these sites by Latinas with limited formal education. Latinas are also disproportionately affected by the 'digital divide', a lack of internet access for people with lower incomes. For example, in the USA, roughly 5 per cent of Latino/as who make US$15,000 or less annually use the internet.[23]

Health literacy and cross-cultural communication

To compound the complexity of these issues are those of health literacy and cross-cultural communication that have been recognised as vital variables in the ability of a patient to understand and use health information. For example, the Institute of Medicine has recognised in its work the major concern posed by these issues.[24] This is supported by studies that show that 16–38 per cent of adults are illiterate or have low literacy skills and, therefore, have difficulties in accessing and using health information.[25] Despite the widespread use of the internet, adults with low literacy may encounter problems due to health literacy when searching the internet for health information, in part because most health websites require at least a high-school reading proficiency for optimal access.[26] Nonetheless, there is the hope that 'healthcare providers can en-hance the effectiveness and efficiency of the care they provide by recognizing their patient's health literacy'[27] as well as the many issues that could be resolved if differences in cross-cultural communication are addressed.[28,29]

Most current literature on cancer information-gathering behaviour focuses on 'active information seeking' from sources such as the internet or healthcare organisations (eg American Cancer Society). While there is some understanding about the degree to which healthcare decisions are influenced by active or intentional information-seeking, there is a paucity of studies that explicitly examine 'passive receipt' of information — also referred to as 'scanning' and 'incidental' or 'mere' exposure to information — in the course of daily activities such as watching television or reading popular magazines.[30–32] There is presently little evidence on the combined influence of actively sought and passively received cancer information on patients' healthcare decisions.[33] Most literature on passive cancer information receipt focuses on 'typical' passive sources such as television, radio, or newspapers; however, Shim and colleagues postulate that both active and passive receipt of information can occur from all information sources, with information 'scanning' especially common with respect to mammography.[34] Little is known about what type of information most empowers behavioural change,[35] how patients use the many sources and types of information they encounter in information seeking and use, and in what ways patients are influenced by readily accessible information on the internet that was previously available only from healthcare providers.

The Longo model

The trend toward healthcare consumerism, coupled with the information explosion and an emphasis on patient

centredness,[36] means patients take a greater role in learning about their disease and making decisions about treatment and management.[37-39] This concept of patient centredness is foundational to the 'Expanded Conceptual Model of Health Information Seeking Behaviours and the Use of Information for Healthcare Decisions' (Figure 1) proposed by Longo.[40] The approach adapts medical care to current social norms and communication patterns, and has been linked to improved patient satisfaction and lowered symptom burden.[41-43] From this perspective, assessing and meeting patients' health information needs is not only a critical component of a treatment and management plan,[44,45] but also a major factor enabling patients to become informed healthcare decision-makers and effective partners in their care.[46]

The Longo model, initially proposed in *Health Expectations* and further revised in the present paper to take into account more explicitly health literacy and cross-cultural communication concerns, further fills gaps in the current literature by postulating that consumers are not just active 'information seekers' as most of the health communication literature suggests, but that there is a major and vital complementary channel of passive health information receipt. In addition to actively seeking health information, individuals passively receive such information in a variety of venues. The combination of active and passive information receipt, along with individual patient characteristics, influences information use and represents a far more comprehensive and accurate model of consumer health information seeking behaviours, as well as a model to examine how consumers use information to make healthcare decisions. This model is one of two models identified by the National Cancer Institute (NCI)[47] that explain this

phenomenon, and the expanded Longo model is the only model that explicitly classifies patients as active seekers and/or passive receivers of information, taking into account various stages of information access, use and decision-making.

Following the Longo model in the present study, whatever a patient referred to as 'information' was identified as such, as input from prior in-depth interviews and focus groups made clear that exchanges such as informal discussions with friends, relatives and neighbours are considered 'health information' as much as medical provider and media information sources.

This study's communication objectives are to: (1) identify the most frequent information sources used by breast-cancer patients; (2) understand what proportion of patients actively seek and/or passively receive information from these sources; (3) understand the extent to which the revised Longo conceptual model helps explain the interplay of active and passive information receipt and the influence of contextual and personal variables on outcomes; (4) determine what proportion of patients indicate they are able to use available health information; (5) determine what proportion report using this information in making healthcare decisions, and (6) understand differences between Latinas and non-Latinas relative to the above objectives. It is expected that the answers to these objectives will provide the basis for more effective communication programmes for women with breast cancer following the National Cancer Institute's 'Making Health Communication Programs Work' and the four stages it proposes.

METHODS

A total of 158 breast-cancer survivors were surveyed using pre-tested questions
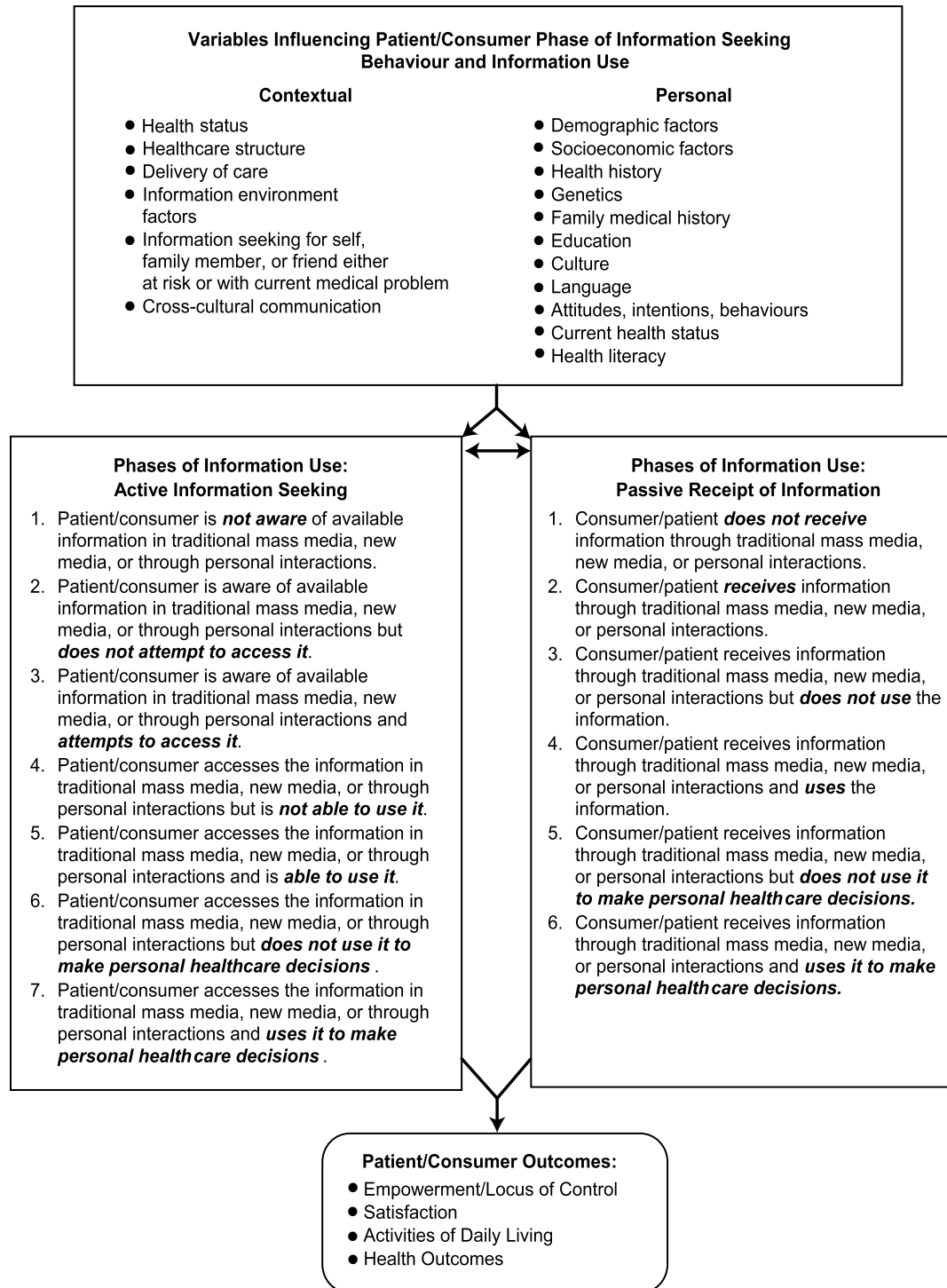
Variables Influencing Patient/Consumer Phase of Information Seeking Behaviour and Information Use

Contextual

- Health status
- Healthcare structure
- Delivery of care
- Information environment factors
- Information seeking for self, family member, or friend either at risk or with current medical problem
- Cross-cultural communication

Personal

- Demographic factors
- Socioeconomic factors
- Health history
- Genetics
- Family medical history
- Education
- Culture
- Language
- Attitudes, intentions, behaviours
- Current health status
- Health literacy

Phases of Information Use: Active Information Seeking

1. Patient/consumer is **not aware** of available information in traditional mass media, new media, or through personal interactions.
2. Patient/consumer is aware of available information in traditional mass media, new media, or through personal interactions but **does not attempt to access it**.
3. Patient/consumer is aware of available information in traditional mass media, new media, or through personal interactions and **attempts to access it**.
4. Patient/consumer accesses the information in traditional mass media, new media, or through personal interactions but is **not able to use it**.
5. Patient/consumer accesses the information in traditional mass media, new media, or through personal interactions and is **able to use it**.
6. Patient/consumer accesses the information in traditional mass media, new media, or through personal interactions but **does not use it to make personal healthcare decisions**.
7. Patient/consumer accesses the information in traditional mass media, new media, or through personal interactions and **uses it to make personal healthcare decisions**.

Phases of Information Use: Passive Receipt of Information

1. Consumer/patient **does not receive** information through traditional mass media, new media, or personal interactions.
2. Consumer/patient **receives** information through traditional mass media, new media, or personal interactions.
3. Consumer/patient receives information through traditional mass media, new media, or personal interactions but **does not use** the information.
4. Consumer/patient receives information through traditional mass media, new media, or personal interactions and **uses** the information.
5. Consumer/patient receives information through traditional mass media, new media, or personal interactions but **does not use it to make personal healthcare decisions.**
6. Consumer/patient receives information through traditional mass media, new media, or personal interactions and **uses it to make personal healthcare decisions.**

Patient/Consumer Outcomes:

- Empowerment/Locus of Control
- Satisfaction
- Activities of Daily Living
- Health Outcomes

Figure 1   Expanded conceptual model of health information seeking behaviours and the use of information for healthcare decisions

Table 1: Demographic characteristics of study subjects*

	Latina (n = 40)		Non-Latina (n = 118)		
	n	(%)	n	(%)	p-value†
Stage of cancer at diagnosis:					0.0277
Stage 0	4	10.0	12	10.3	
Stage 1	11	27.5	48	41.0	
Stage 2	10	25.0	37	31.6	
Stage 3	9	22.5	11	9.4	
Stage 4	5	12.5	4	3.4	
Don't know	1	2.5	5	4.3	
Phase of treatment at time of survey completion:					<0.0001
Phase 2 (evaluation)	1	2.6	0	0.0	
Phase 3 (undergoing treatment)	18	47.4	12	10.9	
Phase 4 (remission or reoccurrence)	19	50.0	95	86.4	
Phase 5 (long term)	0	0.0	3	2.7	
Ethnic/racial background:					<0.0001
African–American/Black	0	0.0	9	7.6	
Asian/Pacific Islander	0	0.0	1	0.8	
Caucasian/White	0	0.0	106	89.8	
Latina	38	95.0	0	0.0	
Multi-ethnic	2	5.0	2	1.7	
Language:					<0.0001
Spanish only	23	57.5	0	0.0	
English or bilingual	17	42.5	118	100.0	
Marital status:					0.0479
Married/living as married	28	70.0	86	72.9	
Divorced	3	7.5	15	12.7	
Separated	4	10.0	1	0.8	
Widowed	2	5.0	10	8.5	
Single, never married	3	7.5	6	5.1	
Education:					0.0005
8th grade or less	5	12.8	3	2.5	
Some high school	8	20.5	5	4.2	
High school diploma or GED	7	17.9	23	19.5	
Vocational school or some college	12	30.8	34	28.8	
College degree	1	2.6	26	22.0	
Professional/graduate school experience	6	15.4	27	22.9	
Age (mean, SD)	53.3	11.6	57.6	10.0	0.0247

*Percentages are calculated from total responses. If totals do not equal 158, this reflects missing values.
†Wilcoxon rank sum test for stage at diagnosis and education (ordinal variables); Chi-square test for categorical variables; two-sample t-test for age (numerical variable, normally distributed).

addressing information–seeking and information use, as well as demographic and quality-of-life questions adapted from validated instruments.[48–56] Subjects were from the Midwest (n = 118) and Northeast (n = 40) regions of the USA. The sample included both Latina (n = 40) and non-Latina (n = 118) women.

Recruitment

Participants were recruited through clinics, breast-cancer support groups,

flyers, and newsletter announcements. The survey was administered to eligible women (age 18 or older, diagnosed with breast cancer) after obtaining informed consent. The research was approved by the University of Missouri-Columbia and University of Medicine and Dentistry of New Jersey Institutional Review Boards (see Appendix for Patient Health Communication and Information Survey questionnaire).

Data analysis

Frequency distributions were calculated for each categorical variable. Means and standard deviations were calculated for each quantitative variable. To compare Latina with non-Latina respondents, Chi-square tests were performed for qualitative variables; the two-sample *t*-test was performed for quantitative variables when the data were normally distributed and the Wilcoxon rank sum test was performed when the data departed from normality (Table 1). To investigate patterns of use of information sources, percentages were calculated for each information source, and for each of Longo's model's five stages of use (Table 2).

To further investigate active information-seeking behaviour, the percentage of respondents who reported they were aware of the information sources and actively tried to access them was calculated ($n = 156$). To determine if there was an association between information-seeking behaviour and ethnic background, this percentage was calculated by ethnicity, and then the Chi-squared test was performed to determine whether active information-seeking behaviour is independent of ethnicity (Table 3).

The percentage of respondents was calculated who reported they were aware of information sources, actively tried to access them, and also received information from sources they did not actively seek (passive receipt of information) ($n = 118$). The Chi-squared test was used to determine if passive information-receipt was independent of ethnicity (Table 4).

The percentage of respondents for each stage of information use was calculated for three populations relative to their information-seeking behaviour (Table 5).

To examine potential factors that predict information-seeking behaviour, three new variables, which represent the behaviour characteristics of information-seeking, were created as dependent variables for the predicting model. The three new dependent variables were 'use of website' (whether patients used any website to seek information), 'only source of information was doctors or nurses' and 'both active seekers and passive receivers of information' (whether patients both actively sought and passively received information). All demographic characteristic variables, including age, cancer stage, treatment phase, ethnic background, marital status, language and educational level, were considered as potential predictors. As the dependent variables were dichotomous, logistic regression models were used to determine variables associated with the three dependent variables. Initially all potential predictors were included in the models and stepwise selection procedures were used to identify a set of predictors. The final sets of predictors were selected for each model.

RESULTS

Demographic characteristics of study subjects are shown in Table 1. Summaries of subjects' responses to questions regarding stages of awareness and use of various

Table 2: Information sources cited by subjects*

Information source	Active seeking								Passive receipt								Use of information			
	(1) Were you *aware* that information about breast cancer is available from this source?				(2) If you were aware of this source, did you *actively try to access or find it?*				(3) Did you *come across this source by chance* when you were not actively seeking it?				(4) If you answered 'yes' in column (2) or (3), were you *able to use* this source?				(5) If you used this source, did it *influence your decisions about your own healthcare?*			
	Yes		No		Yes		No		Yes		No		Yes		No		Yes		No	
	n	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)
American Cancer Society website	74	92.5	6	7.5	70	46.1	82	53.9	2	1.3	155	98.7	69	97.2	2	2.8	35	50.7	34	49.3
National Cancer Institute website	52	85.2	9	14.8	50	33.8	98	66.2	1	0.6	154	99.4	51	100.0	0	0.0	31	60.8	20	39.2
WEB MD website	34	75.6	11	24.4	33	22.6	113	77.4	0	0.0	155	100.0	33	100.0	0	0.0	16	48.5	17	51.5
Susan Love MD website	29	72.5	11	27.5	28	19.0	119	81.0	0	0.0	155	100.0	28	100.0	0	0.0	15	53.6	13	46.4
Susan G. Komen Foundation website	40	80.0	10	20.0	39	26.5	108	73.5	0	0.0	154	100.0	39	100.0	0	0.0	22	56.4	17	43.6
Other website(s) (specify)	25	73.5	9	26.5	24	16.3	123	83.7	0	0.0	155	100.0	24	100.0	0	0.0	7	29.2	17	70.8
Book(s)	112	95.7	5	4.3	110	71.9	43	28.1	1	0.6	154	99.4	110	99.1	1	0.9	78	70.9	32	29.1
Family and/or friends	124	96.1	5	3.9	123	80.9	29	19.1	2	1.3	154	98.7	124	100.0	0	0.0	88	71.0	36	29.0
Other women with breast cancer and/or support groups	125	97.7	3	2.3	120	77.9	34	22.1	2	1.3	154	98.7	120	99.2	1	0.8	100	83.3	20	16.7
Personal physician (primary care or specialist)	142	98.6	2	1.4	142	91.0	14	9.0	1	0.6	156	99.4	142	100.0	0	0.0	108	76.1	34	23.9
Doctor's office nurse	113	98.3	2	1.7	110	71.0	45	29.0	1	0.6	155	99.4	111	100.0	0	0.0	91	82.0	20	18.0
Newspaper articles	6	50.0	6	50.0	3	2.0	149	98.0	80	51.6	75	48.4	79	96.3	3	3.7	19	24.0	60	76.0
Magazine(s)	10	76.9	3	23.1	6	3.9	146	96.1	99	64.7	54	35.3	102	99.0	1	1.0	50	51.0	52	49.0
Professional literature†	2	n/a		n/a	2			n/a	n/a			n/a	2			n/a	2			n/a
Radio	6	50.0	6	50.0	2	1.3	150	98.7	43	27.9	111	72.1	43	95.6	2	4.4	13	30.2	30	69.8
Television	9	75.0	3	25.0	5	3.3	148	96.7	79	50.6	77	49.4	81	98.8	1	1.2	31	38.3	50	61.7
Other (specify)	36	90.0	4	10.0	35	23.3	115	76.7	1	0.6	153	99.4	34	97.1	1	2.9	26	76.5	8	23.5

*Percentages are calculated from total responses. If totals do not equal 158, this reflects missing values.

†These were handwritten responses. Number is shown but percentage is not calculated.

Table 3: Active information–seeking behaviour: subjects who reported they were aware of information sources and actively tried to access or find them, by information source*

| Information source | Latina (n = 38) | | | | Non-Latina (n = 118) | | | | p-value† |
| | Yes | | No | | Yes | | No | | |
	n	(%)	n	(%)	n	(%)	n	(%)	
American Cancer Society website	11	32.4	23	67.6	59	50.0	59	50.0	0.0689
National Cancer Institute website	5	16.7	25	83.3	45	38.1	73	61.9	0.0264
WEB MD website	1	3.6	27	96.4	32	27.1	86	72.9	0.0074
Susan Love MD website	2	6.9	27	93.1	26	22.0	92	78.0	0.0629
Susan G. Komen Foundation website	3	10.3	26	89.7	36	30.5	82	69.5	0.0276
Other websites	4	13.8	25	86.2	20	16.9	98	83.1	0.7862
Mayo Clinic website‡	n/a	n/a			1	n/a			
MD Anderson website‡	n/a	n/a			1	n/a			
Medline‡	n/a	n/a			1	n/a			
National Library of Medicine website‡	n/a	n/a			1	n/a			
National Institutes of Health website‡	n/a	n/a			2	n/a			
Sloan Kettering website‡	1	n/a			n/a	n/a			
Books	21	60.0	14	40.0	89	75.4	29	24.6	0.0746
Family and/or friends	22	64.7	12	35.3	101	85.6	17	14.4	0.0063
Other women with breast cancer and/or support groups	21	58.3	15	41.7	99	83.9	19	16.1	0.0012
Personal physician	35	92.1	3	7.9	107	90.7	11	9.3	1.0000
Doctor's office nurse	25	67.6	12	32.4	85	72.0	33	28.0	0.6015
Newspaper articles	3	8.8	31	91.2	0	0.0	118	100.0	0.0104
Magazines	5	13.9	31	86.1	1	0.9	115	99.1	0.0028
Professional literature§	n/a	n/a			2	n/a			
Radio	2	5.9	32	94.1	0	0.0	118	100.0	0.0489
Television	5	14.3	30	85.7	0	0.0	118	100.0	<0.0001
Other	6	18.7	26	81.3	29	24.6	89	75.4	0.4895

*Percentages are calculated from total **responses**. If totals do not equal 156, this reflects missing values.
†Chi–squared test.
‡Selected handwritten responses specifying 'other websites.' Number is shown but percentage is not calculated.
§Handwritten responses. Number is shown but percentage is not calculated. Two of the 158 study subjects indicated they were not aware of any information sources, therefore only 156 subjects could be further classified by type of information seeking and stage of information use.

information sources are in Table 2. Note that the model assumes that awareness precedes active seeking of information, and that active seeking and/or passive receipt precede use of the source and use of the information to make healthcare decisions.

Interpersonal sources

Results indicate interpersonal com–munication, especially with doctors and other health professionals, is the primary information source. Nearly all patients (99 per cent) indicated awareness of their physicians as information sources and the vast majority sought information from their physicians (91 per cent); these individuals all indicated they were able to use it, and most (76 per cent) used it in making healthcare decisions. Doctor's office nurses were a very important source of information, with 98 per cent of

Table 4: Active information-seeking behaviour and passive receipt of information: subjects who reported they were aware of information sources, actively tried to access or find them, and also received information from sources they did not actively seek, by information source★

| | Latina (n = 38) | | | | Non-Latina (n = 118) | | | | |
| | Yes | | No | | Yes | | No | | |
Information source	n	(%)	n	(%)	n	(%)	n	(%)	p-value†
American Cancer Society website	8	33.3	16	66.7	51	55.4	41	44.6	0.0538
National Cancer Institute website	3	15.0	17	85.0	41	44.6	51	55.4	0.0141
WEB MD website	1	5.3	18	94.7	28	30.4	64	69.6	0.0225
Susan Love MD website	2	10.0	18	90.0	23	25.0	69	75.0	0.2348
Susan G. Komen Foundation website	3	15.0	17	85.0	33	35.9	59	64.1	0.0701
Other websites	2	10.0	18	90.0	18	19.6	74	80.4	0.5196
Mayo Clinic website‡	n/a	n/a			1	n/a			
MD Anderson website‡	n/a	n/a			1	n/a			
Medline‡	n/a	n/a			1	n/a			
National Library of Medicine website‡	n/a	n/a			1	n/a			
National Institutes of Health website‡	n/a	n/a			2	n/a			
Sloan Kettering website‡	n/a	n/a			n/a	n/a			
Books	18	75.0	6	25.0	82	89.1	10	10.9	0.0960
Family and/or friends	18	75.0	6	25.0	85	92.4	7	7.6	0.0266
Other women with breast cancer and/or support groups	16	66.7	8	33.3	85	92.4	7	7.6	0.0027
Personal physician	24	92.3	2	7.7	86	93.5	6	6.5	1.0000
Doctor's office nurse	16	64.0	9	36.0	75	81.5	17	18.5	0.0617
Newspaper articles	1	4.5	21	95.5	0	0.0	92	100.0	0.1930
Magazines	3	12.5	21	87.5	1	1.1	91	98.9	0.0275
Professional literature§	n/a	n/a			2	n/a			
Radio	0	0.0	22	100.0	0	0.0	92	100.0	n/a
Television	3	13.0	20	87.0	0	0.0	92	100.0	0.0072
Other	6	26.1	17	73.9	25	27.2	67	72.8	0.1628

★Percentages are calculated from total responses. If totals do not equal 118, this reflects missing values.

† Chi-squared test.

‡Selected handwritten responses specifying 'other websites.' Number is shown but percentage is not calculated.

§Handwritten responses. Number is shown but percentage is not calculated. Two of the 158 study subjects indicated they were not aware of any information sources, therefore only 156 subjects could be further classified by type of information seeking and stage of information use. Of the 156, who were aware and reported active seeking, 118 also reported passive receipt of information; responses from those 118 subjects are shown in this table.

respondents aware and 71 per cent actively seeking information; all of those who received information were able to use it, and 82 per cent used it to make healthcare decisions.

Other breast-cancer patients and/or support groups ranked almost evenly with medical professionals as sources of informa-tion (98 per cent aware, 78 per cent actively seeking information). Almost all respon-dents who sought or received information from other patients or support groups were able to use it, and 83 per cent used it to make healthcare decisions.

Family members and/or friends also played a prominent role, with 96 per cent

Table 5: Stages of information use by subjects with breast cancer*

Population and stage	Latina		Non-Latina		
	n	(%)	n	(%)	p-value
Active information seekers (*n* = 156)					
1. Aware	40	100.0	116	100.0	
2. Aware, but does not attempt to access	0	0.0	0	0.0	
3. Aware, attempts to access	40	100.0	116	100.0	
4. Accesses, but is not able to use	0	0.0	0	0.0	
5. Accesses, is able to use	40	100.0	116	100.0	
6. Uses, but does not use to make healthcare decisions	7	18.4	6	5.1	0.0166
7. Uses to make healthcare decisions	31	81.6	112	94.92	
Active seekers and additional passive receipt of information (*n* = 118)					
1. Does not passively receive information	36	100.0	92	100.0	
2. Passively receives information	0	0.0	0	0.0	
3. Receives information, but does not use	36	100.0	92	100.0	
4. Receives information and uses	0	0.0	0	0.0	
5. Uses, but does not use to make healthcare decisions	2	7.7	2	2.8	0.2104
6. Uses to make healthcare decisions	24	92.3	90	97.8	
Source of information was only physician or nurse (*n* = 9)					
1. Information provided	4	100.0	5	100.0	
2. Information provided but not used	0	0.0	0	0.0	
3. Information provided but not used to make healthcare decisions	2	50.0	1	20.0	0.5238
4. Uses to make healthcare decisions	2	50.0	4	80.0	

*Because subjects identified a variety of different information sources, as well as active information seeking, and active and passive, there are no mutually exclusive categories. No subjects reported only passive information receipt.

†Two of the 158 study subjects indicated they were not aware of any information sources, therefore only 156 subjects could be further classified by type of information seeking and stage of information use.

of respondents aware of these people as information sources, and 81 per cent stating they actively sought information. All who sought or received information from family and friends indicated they were able to use it, and 71 per cent used it to make healthcare decisions.

Website use

Five major websites were among sources for which subjects were asked to indicate their awareness and use; they were also asked about use of other websites and asked to specify which sites they had used. The majority of respondents were aware of the five major sites, and a large proportion actively tried to access one or more of these sites. The American Cancer Society (ACS) and National Cancer Institute (NCI) websites ranked first and second, respectively, on both awareness and use, with 93 per cent and 85 per cent, respectively, of respondents indicating they were aware of these sites; 46 per cent and 34 per cent, respectively, reported they actively sought information from these sites. The next most frequently cited websites were the Susan G. Komen

Foundation (80 per cent aware, 27 per cent sought to access); WEB MD (76 per cent aware, 23 per cent sought to access), and Susan Love, MD, website (73 per cent aware, 19 per cent sought to access). About half of those who obtained information from these five websites indicated they used it in making healthcare decisions, with the NCI site being the highest ranked for decision-making usefulness (61 per cent).

A variety of 'other' websites were cited, with 16 per cent of respondents indicating they actively sought information from one or more of these. Examples include government sites (eg National Library of Medicine, National Institutes of Health), universities and medical centres, organisations (eg Imaginis, friendsinneed.com, Y-Me); search sites (eg Medline, Association of Cancer Online Resources) and alternative medicine sites.

Information from books

A vast majority of respondents (96 per cent) were aware of information in books; a higher percentage than those aware of the websites, and 72 per cent actively tried to access this information. Most importantly, an overwhelming majority (99 per cent) reported using this information, with 71 per cent using it to make healthcare decisions.

Traditional mass media

Among traditional mass media, magazines were most frequently cited in terms of awareness (77 per cent), and respondents indicated magazines were both actively sought and passively received. Interestingly, nearly all respondents who sought or received information from magazines reported they were able to use it (99 per cent), with 51 per cent indicating they used it to make healthcare decisions. Some respondents also indicated that they were aware of and used medical profes-

sional journals, but this was the exception rather than the rule.

Some respondents reported television (75 per cent), newspapers (50 per cent), and radio (50 per cent) as sources of information, but fewer used it in making healthcare decisions (38 per cent, 24 per cent, and 30 per cent, respectively). Information from these sources was more typically passively received through leisure viewing/reading/listening or 'channel surfing', rather than actively sought.

Influence of race/ethnicity

Tables 3 and 4 display results of comparisons of information-use patterns by race/ethnicity. Data were included for all study subjects (Table 3) who actively sought information ($n = 156$) from one or more source(s). In Table 4, only those subjects who both actively sought and passively received information ($n = 118$) are reported. In both the 'active' and 'active and passive' groups, non-Latina women were more likely to seek information from family and/or friends ($p = 0.0063$ for 'active', $p = 0.0266$ for 'active and passive'), and from others with breast cancer and/or support groups ($p = 0.0012$ for 'active', $p = 0.0027$ for 'active and passive').

Among the larger group of active information seekers (Table 3), Non-Latina women were more likely than Latina women to actively seek information from websites; this difference was statistically significant for the NCI ($p = 0.0264$), WEB MD ($p = 0.0074$), and Susan Komen ($p = 0.0276$) websites. A similar pattern was observed for the subset of women who both actively sought and passively received information, although the difference was significant for only the NCI ($p = 0.0141$) and WEB MD ($p = 0.0225$) websites.

Table 5 stages respondents according to

model categories. Of the 156 patients who could be classified as active seekers of information, all stated that they were aware of one or more information source(s), and were able to access and use this information. Nearly all (92 per cent) indicated that they used one or more of these information source(s) to make healthcare decisions. Of the 118 patients classified as both active seekers and passive receivers of information, all indicated they were able to use the information they received, and 97 per cent used it to make healthcare decisions. Among active information seekers ($n = 156$), non-Latinas were more likely to use information to make decisions ($p = 0.0166$). For respondents who both actively and passively received information, there were no statistically significant differences between Latinas and non-Latinas. No respondents reported only passive receipt of information.

Nine patients (see Table 5) reported receiving information only from their physician and/or nurse; five of those received information from both their doctor and nurse. While these patients were initially classified as 'active information seekers' based on their taking the initiative to seek physician consultation, in reality there is insufficient information to definitively classify them into active or passive categories. It is possible that while these patients sought care, they did not actively seek any information other than what was offered by the doctor or nurse in the clinical encounter.

Logistic regression results (not shown in tables) indicated that English-speaking or bilingual patients are more likely to use websites than those who speak Spanish only (OR = 4.17; CI = 1.34–13.04, $p = 0.0139$). Younger women are more likely to use websites (OR = 1.83; CI = 1.28–2.62, $p = 0.0009$), and older women are more likely to rely on their doctor or nurse as their only source of information about breast cancer (OR = 2.56; CI = 1.40–4.69; $p = 0.0023$). English-speaking or bilingual patients are more likely than those who speak Spanish only to receive information both actively and passively (OR = 3.16; CI = 1.24–8.05; $p = 0.0162$).

DISCUSSION

This study is one of the first to assess the combination of both passive and active information receipt, and explicitly follows the revised Longo conceptual model that takes into account health literacy and cross-cultural communication concerns; further it evaluates the influence and importance of the internet as a cancer information source in the 21st century. While most women were found to be active information seekers, many were also passive receivers. While the internet was an important source of information for patients, physicians remain the primary source of information. This pilot study provides insight into patients' use of health information to make more informed health decisions, and it supports Little and colleagues' finding that patients strongly prefer a patient-centred approach.[57] It is likely that dissemination of these findings to oncologists and others who treat these patients may change clinical practice and/or thinking about what information is provided or recommended to patients.

The implications of this study may perhaps best be discussed in light of the National Cancer Institute's 'Making Health Communication Programs Work'[58] and the four stages it proposes.

Planning and strategy development

Effective communication programmes must be based on an understanding of the needs as well as perceptions of the

intended audience. Despite the widely-held belief regarding the internet as a major source of information, interpersonal communication (doctors, nurses, other patients, family, and friends) was far more often cited as a source of information than either the internet or traditional print and broadcast media. The data showed websites to be an important source of breast-cancer information, but — contrary to perceptions in some of the literature[59–63] — the internet has not replaced, but likely supplements, traditional sources of information such as doctor and nurse, family and friends, books and other printed resources, and broadcast media. Future communication programmes must take into account the strategic role the healthcare provider still plays despite the explosion of the internet and other communication avenues.

Developing and pretesting concepts, messages and materials

This study, as others, indicates that patients may also lack the health literacy necessary to understand and use medical information.[64] Differing levels of literacy span across racial and ethnic groups, with language barriers playing a major role. Findings indicate that higher internet use is associated with younger age and with English-speaking and bilingual (English/Spanish) patients, compared to Spanish-speaking only. Thus, effective communication programmes aimed at these target populations must develop relevant and meaningful messages, and plan and pre-test these with the target population in mind. For example, this study found that magazines were cited frequently as a passively received information source. It is important for healthcare providers to develop communication strategies which recognise that during the course of daily activities such as leisure reading, patients may come across pertinent medical information that may influence their healthcare decisions. This is especially true for breast cancer, given the current level of proactive awareness efforts in many popular magazines (eg *Redbook*, *Self*, *Good Housekeeping*). This step is critical in identifying vital communication avenues that health professionals may overlook or neglect, yet patients may greatly rely upon.

Implementing the programme

While the findings do not directly address this fourth step in the NCI strategy, they do emphasise the vital role of keeping current with and understanding patient perspectives in the aggregate as well as subpopulations of patients; this is key to the success of any communication strategy. This is seen in the observed differences between the Latina and non-Latina populations where 'one size does not fit all'.

Assessing effectiveness and making refinements

This is the fourth step in the NCI model and is best reflected in the necessity for the present investigation to revise its conceptual model from that initially proposed in *Health Communications* to explicitly take into account health literacy as well as related cross-cultural communication issues. For example, as the overall design of this study examined differences between Latinas and non-Latinas it was possible to explicitly examine and identify important cross-cultural differences; these differences would have been lost had the initial study to examine the information needs of women with breast cancer not been refined to the more specific approach taken in the present study.

Limitations

This study is based on self-reported data and may be affected by information recall

bias. Future studies should include more extensive follow-up questions, supplemented by in-depth interviews and/or direct observation of physician-patient encounters, to further explore the degree to which information-seeking in doctor/patient, nurse/patient encounters is active versus passive. As some subject recruitment was done through breast-cancer support groups, some results may be skewed regarding information receipt and use from friends and support groups. More work is needed to determine whether patients who indicated they were not able to use given sources of information did so because of issues related to use of the medium (eg lack of access to a computer), versus the information itself (eg doubts about credibility, information not applicable to patient's situation). Further work with larger samples in the USA and international sites, as well as further survey instrument refinement will also help determine the generalisability of these pilot findings.

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APPENDIX: PATIENT HEALTH COMMUNICATION AND INFORMATION SURVEY

Participant ID number _____

1. How long has it been since you were first diagnosed with breast cancer?	__ Less than 1 year __ 1 year or more, but less than 2 years __ 2 years or more, but less than 3 years __ 3 years or more, but less than 4 years __ 4 years or more, but less than 5 years __ 5 years or more

2. To the best of your knowledge, what was the stage of your breast cancer at diagnosis?

__ **Stage 0**: Also known as ductal carcinoma in situ or lobular carcinoma in situ, which means the cancer cells are located within a duct and have not invaded the surrounding fatty breast tissue or that the abnormal cells grow within the lobules or milk-producing glands, but they do not penetrate through the wall of these lobules.

__ **Stage I**: The tumor is 2 cm or less in diameter and has not spread to lymph nodes or anywhere else.

__ **Stage II**: The tumor is between 2 cm and 5 cm in diameter or it has spread to 1-3 underarm lymph nodes on the same side as the breast cancer. Both of these can be present also. The tumor may also be larger than 5 cm but has not spread to lymph nodes.

__ **Stage III**: The tumor is either smaller than 5 cm in diameter and has spread to 4-9 underarm lymph nodes, larger than 5 cm and has spread to 1–9 underarm nodes, the tumor has grown into the chest wall or skin and 0–9 nodes are involved, or the tumor is any size has spread to 10 or more nodes in the underarm or to lymph nodes under the clavicle (infraclavicular) or above the clavicle (supraclavicular) or to lymph nodes in the chest near the breast bone (internal mammary). Patients with stage III cancer show no signs that the cancer has spread to distant organs or bones. Inflammatory breast cancer is classified as stage III, unless it has spread to distant organs or lymph nodes that are not near the breast, in which case it would be stage IV.

__ **Stage IV**: The cancer, regardless of its size, has metastasized to distant organs such as bones or lungs or to lymph nodes not near the breast.

__ **I don't know**.

3. To the best of your knowledge, what best describes the phase of breast cancer treatment you are in now?

__ **Phase 2** - you have had an abnormal mammogram or breast exam, and your doctor plans to evaluate you and diagnose the problem

__ **Phase 3** - you are currently undergoing treatment (surgery, chemotherapy, or radiation) for breast cancer

__ **Phase 4** - you have completed the treatment of your breast cancer, and you are either in remission (there is no longer evidence of cancer in your body), or the breast cancer has reoccurred

__ **Phase 5** - you have long-term breast cancer and may or may not be undergoing comfort care

4. At the time of your diagnosis, did you seek additional information about breast cancer, other than that provided through your doctor's office?	__ yes	__ no
5. Do you have access to a computer with internet connection?	__ yes	__ no
6. Do you have access to a public library or school/university library?	__ yes	__ no
9. Do you read a newspaper on a regular basis?	__ yes	__ no
10. Do you read popular magazines on a regular basis?	__ yes	__ no

Before continuing, please read:

The questions on the following pages will help us better understand how you and other women with breast cancer receive and use information on topics such as the symptoms, causes, diagnosis and prognosis of breast cancer; available breast cancer treatments and services; the cost and quality of health care services and providers; and the quality of the health care plan or insurance that pays for your care. We define "information" broadly, to include any information you may have received, through traditional mass media, the internet, online discussion groups, or personal interactions with health care professionals, friends, family, or other women with breast cancer. You may have intentionally sought this information (***active information seeking***), or you may have come across it when you were not actively seeking it, for instance, while watching television, reading a popular magazine, or visiting with a friend (***passive information receipt***).

11. For each source of information in the following list, please circle your answer, yes or no, to the five questions regarding your awareness and use of these sources.

INFORMATION SOURCE	ACTIVE SEEKING		PASSIVE RECEIPT	USE OF INFORMATION	
	(1) Were you ***aware*** that information is available from this source?	**(2)** If you were aware of this source, did *you **actively try to access or find it***?	**(3)** Did you ***come across this source by chance*** when you were not actively seeking it?	**(4)** If you answered "yes" in column (2) or (3), were you ***able to use*** this source?	**(5)** If you used this source, did it ***influence your decisions about your own health care***?
American Cancer Society website	yes no	yes no	yes no	yes no	yes no
National Cancer Institute website	yes no	yes no	yes no	yes no	yes no
WEB MD website	yes no	yes no	yes no	yes no	yes no
Susan Love MD website	yes no	yes no	yes no	yes no	yes no
Susan G. Komen Foundation website	yes no	yes no	yes no	yes no	yes no
Other website(s) (specify)	yes no	yes no	yes no	yes no	yes no
_____ _____ _____ _____ _____					
Newspaper articles	yes no	yes no	yes no	yes no	yes no
Book(s)	yes no	yes no	yes no	yes no	yes no
Magazine(s)	yes no	yes no	yes no	yes no	yes no
Radio	yes no	yes no	yes no	yes no	yes no
Television	yes no	yes no	yes no	yes no	yes no
Hospital or clinic booklet(s), brochure(s) or similar information piece(s)	yes no	yes no	yes no	yes no	yes no
Family and/or friends	yes no	yes no	yes no	yes no	yes no
Other women with breast cancer and/or support groups	yes no	yes no	yes no	yes no	yes no
Personal physician (primary care or specialist)	yes no	yes no	yes no	yes no	yes no
Doctor's office nurse	yes no	yes no	yes no	yes no	yes no
Other (specify)	yes no	yes no	yes no	yes no	yes no
_____ _____ _____ _____ _____					

12. In the following list, please **rate the credibility of each source** <u>that you used</u> to find information on breast cancer. By "credible," we mean information that you (1) have the skills to access, evaluate, and use; and also (2) have found to be believable and useful in your breast cancer decision-making and self-care. Circle only one rating for each source. If you did not use a particular source of information, circle the X under "Did not use."

INFORMATION SOURCE	Did not use	Rate the credibility of this source:				
		Poor	Fair	Average	Good	Excellent
American Cancer Society website	X	1	2	3	4	5
National Cancer Institute website	X	1	2	3	4	5
WEB MD website	X	1	2	3	4	5
Susan Love MD website	X	1	2	3	4	5
Susan G. Komen Foundation website	X	1	2	3	4	5
Other website(s) (specify)	X	1	2	3	4	5

_____
_____
_____
_____
_____

INFORMATION SOURCE	Did not use	Poor	Fair	Average	Good	Excellent
Newspaper articles	X	1	2	3	4	5
Book(s)	X	1	2	3	4	5
Magazine(s)	X	1	2	3	4	5
Radio	X	1	2	3	4	5
Television	X	1	2	3	4	5
Hospital or clinic booklet(s), brochure(s) or similar information piece(s)	X	1	2	3	4	5
Family and/or friends	X	1	2	3	4	5
Other women with breast cancer and/or support groups	X	1	2	3	4	5
Personal physician (primary care or specialist)	X	1	2	3	4	5
Doctor's office nurse	X	1	2	3	4	5
Other (specify)	X	1	2	3	4	5

_____
_____
_____
_____
_____

13. Please read each of the following statements and circle the number below the response which reflects how much you agree or disagree with the statement. (Circle one number for each statement.)

	Very strongly disagree	Strongly disagree	Disagree	Agree	Strongly agree	Very strongly agree
13a. I got all the information I needed to understand **treatment options for my breast cancer** from my physician and her/his office staff.	0	1	2	3	4	5
13b. I got all the information I needed to **make decisions about treatment for my breast cancer** from my physician and her/his staff.	0	1	2	3	4	5
13c. I got all the information I needed to **cope with my breast cancer** from my physician and her/his office staff.	0	1	2	3	4	5

Your answers to the questions below will help us to better understand the relationship of factors such as age, gender and socioeconomic status to the way breast cancer patients access and use information. Your individual information will be kept confidential.

14. What is your age? _____

15. What is your gender?   __ male   __female

16. What best describes your ethnic/racial background?
__ African American/Black
__ American Indian/Aleut/Eskimo
__ Asian/Pacific Islander
__ Caucasian/White
__ Hispanic/Latino
__ Other (specify) _____

17. Is English your primary language?   __ yes   __ no

18. What is your current marital status?
__ Married/living as married
__ Divorced
__ Separated
__ Widowed
__ Single, never married

19. What is the highest grade or level of education you have completed? (Mark only one answer.)
__ 8th grade or less
__ Some high school (grade 9-12)
__ High school diploma or GED
__ Vocational school or some college
__ College degree
__ Professional or graduate school experience

20. What is your estimated annual household income?
__ Less than $15,000
__ $15,000 to $29,999
__ $30,000 to $49,999
__ $50,000 to $74,999
__ $75,000 or more