Class, race and ethnicity and information avoidance among cancer survivors

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Background: Information seeking may increase cancer survivors' ability to make decisions and cope with the disease, but many also avoid cancer information after diagnosis. The social determinants and subsequent communication barriers that lead to avoidance have not been explored. The purpose of this study is to examine the influence of social determinants on information avoidance among cancer survivors.

Methods: We examined how health information avoidance is associated with structural and individual factors in a mail-based survey of 519 cancer survivors. Factor analysis was conducted to determine barriers to obtaining cancer information, and multivariable logistic regression models by gender were run to analyze social determinants of avoidance from an intersectional approach.

Results: Participants who were younger, female, had greater debt and lower income, and had difficulty finding suitable information were more likely to avoid information. The probability of information avoidance increased when survivors reported barriers to information use or comprehension.

Conclusion: These results indicate that survivors' information avoidance may be driven, in part, by social determinants, particularly among those at the intersection of multiple social status categories. Customized strategies are needed that maximize the likelihood that information will be used by vulnerable groups such as those from a lower socioeconomic position.

There are an estimated 13.7 million cancer survivors, a term considered by the National Cancer Institute to refer to people from the point of cancer diagnosis until the end of life (National Cancer Institute, 2009), living in the United States, with 5-year survival rates dramatically increasing over the last few decades (American Cancer Society, 2013). Given this improvement in cancer treatment and survival, the need for better cancer-related communication is growing. This need is particularly salient due to the shift to a healthcare climate of shared decision-making (Rimer et al, 2004), which assumes that most patients have access to cancer-related information and will enter the meeting with a physician with information that may help them to participate in decisions about their treatment and care (National Research Council, 2005). Despite this shift, communication inequalities based on education, income, race and ethnicity are likely to influence the availability,

accessibility and use of health information (Viswanath, 2005). Cancer survivors may be exposed to a bewildering array of confusing or contradictory advice, and those with higher education and access to resources may be better situated to discover, attend to, interpret and act on this information (Viswanath, 2005; Viswanath et al, 2007).

Among cancer survivors, acquiring cancer-related information has been found to reduce feelings of anxiety and uncertainty (Stark and House, 2000) and to increase participation in medical decision-making (Czaja et al, 2003). More informed patients have higher emotional, social, and cognitive functioning and lower reports of side effects (Schou et al, 2005). Information seeking also plays a critical role in cancer patients' efforts to cope with their illness, enhancing perceptions of competence in dealing with diagnosis and treatment (Arora et al, 2002).

However, not all of those diagnosed seek or accept information about cancer. 'Information avoiders,' defined as those who take steps to actively and purposefully avoid learning about or being exposed to information, are often found to be overwhelmed by health risks that are perceived as threatening and avoid potentially distressing information about their medical condition (Miller, 1995). Uncertainty Management Theory (Barbour *et al*, 2012) conceptualizes complex information behaviors such as avoidance as a process of interacting with or refraining from engaging with information in order to increase, maintain, or reduce uncertainty about their medical condition. Furthermore, Case *et al*, 2005 posit that people may limit unpleasant information that may cause mental discomfort. Avoidance may also occur due to fear (Rees and Bath, 2001; Case *et al*, 2005), negative views about cancer (Miles *et al*, 2008), a desire to maintain hope (Barbour *et al*, 2012), as a result of exposure to confusing or excessive information (Brashers *et al*, 2002; Barbour *et al*, 2012), and due to preferences to defer information gathering and decision making to their doctor (Czaja *et al*, 2003). Information avoiders may also choose whether or not to engage in health behaviors depending on how health information is presented and interpreted (Miller, 1996).

While many studies have explained information avoidance with a strong emphasis on psychosocial factors (Miller, 1995; Rees and Bath, 2001; Case *et al*, 2005; Smith-McLallen *et al*, 2011), few studies have focused primarily on the social determinants that may influence information avoidance. Previous research has demonstrated how *information seeking*, the counter-behavior to avoidance, may vary as a function of socioeconomic characteristics. Lower levels of education and income have been associated with information seeking or 'nonseeking' behavior (Ramanadhan and Viswanath 2006). Among cancer patients who actively look for information, socioeconomic status (SES) may drive the types of information sought. For example, post-treatment survivors who have a lower SES tend to look for information related to finances and employment rather than cancer specific information *per se* (Galarce *et al*, 2011). The Structural Influence Model (Viswanath *et al*, 2007) posits that health outcomes are partly determined by the influence of social determinants such as socioeconomic status on health communication behaviors. Structural antecedents such as SES influence both exposure to and ease of obtaining information, which may impact how information is accessed, accepted, processed, and used. Therefore, examining influences on avoidance as well as barriers to accessing cancer information in the context of social determinants could potentially explain disparities in outcomes among cancer patients (Viswanath *et al*, 2007).

While there is some information about how social factors relate to information avoidance, more work in this area is needed. Prior studies have been limited by a lack of focus and measurement of information avoidance (as opposed to measurement of seeking and non-seeking) and its social determinants. Information avoidance and seeking are deliberate actions, in contrast to the passive nature of non-seeking. Although SES has been examined in the context of information seeking, the exact drivers that influence information avoidance may differ. Past research indicates that patterns of information seeking may not remain constant along the illness trajectory (Butow *et al*, 1997; Leydon *et al*, 2000; Rees and Bath, 2001; McCaughan and McKenna, 2007; Eheman *et al*, 2009). For example, patients may avoid cancer-related information immediately after diagnosis but engage with information after some time has passed as they start to contemplate a life with cancer (McCaughan and McKenna, 2007). Information seeking behaviors may also vary by cancer type (Mayer *et al*, 2007; Nagler *et al*, 2010) or stage (Smith-McLallen *et al*, 2011). These patterns indicate that even among information seekers, there may be other factors that influence periods of avoidance. These nuances must be understood within the continuum of seeking behavior.

Moreover, some have contended that factors such as class or gender or age are not discrete categories but interact with each other to influence health outcomes (Williams *et al*, 2012). For example Blacks and Whites in the United States have comparable smoking rates though actual lung cancer death rates are higher for Black men than White men. In short, people who are at the intersection of multiple social categories such as poor and Black or less educated and male experience exposures and information differently from people who are rich and white or more educated and female. It is for this reason that an intersectional approach may yield different insights than using class or race or gender as discrete categories (Bowleg, 2012).

Some recent work has begun to document how social determinants are related to health communication behaviors including health information seeking (Viswanath, 2005; Galarce *et al*, 2011). This work clearly documented how factors such as race/ethnicity and social class may influence access to and use of information resulting in communication inequalities which in turn may result in disparities in health including cancer-related outcomes (Viswanath, 2005). If so, we contend that information avoidance is a dimension of communication inequality and may be subject to the influence of SES and race/ethnicity.

Study rationale. Examining the influence of social factors on cancer information avoidance can provide insights into the needs and practices of cancer survivors and inform the delivery of cancer-related messages when information may not be as readily accepted. Little is known about how information avoidance may be influenced by social determinants and barriers to accessing information. The purpose of this study is to examine the relationship between social factors, such as socioeconomic status and race and ethnicity, and information avoidance among a sample of cancer survivors and examine these differences using an intersectional approach.

MATERIALS AND METHODS

Study participants were recruited using a database of current and former patients at a major cancer hospital in the United States. Respondents were eligible to participate if they were diagnosed with cancer in the last 5 years (stage I, II, and III), had no evidence of tumor recurrence or metastatic disease, had no treatment (chemotherapy or radiation therapy) within the last 12 months, and spoke English or Spanish. Sampling and recruitment procedures complied with Health Insurance Portability and Accountability Act (HIPAA) standards and were approved by the Institutional Review Board of the cancer center. We oversampled minorities and poor (public insurance such as on Medicare and Medicaid).

Procedures. A random sample of 1000 survivors, stratified by race and socioeconomic status, were included in the sampling frame. Each potential participant's physician was sent an email describing the study and informing him/her of our intent to contact his/her patient. Unless requested not to do so by the physician, a copy of the survey was mailed to each survivor's home, with opportunities to respond by mail, via Internet, or over the phone. A letter detailing the project and providing staff contact information accompanied the survey. Participants indicated their consent by returning the completed survey. The packet also included a $5 gift card and an opt-out card. If the survey or opt-out card was not received after 2 weeks, a second copy of the survey was sent and we telephoned the patient to verify the receipt of the materials. The response rate for the survey was approximately 50% and the final sample was 519 respondents. The main reasons for doctor refusal was patient ineligibility ($n = 65$) or patients being lost to follow up ($n = 28$).

Survey instrument. The survey instrument was developed from a literature review and from results of six focus groups of 44 short and long-term cancer survivors from diverse ethnic, racial and

socioeconomic backgrounds (Galarce *et al*, 2011). The open-ended nature of the focus groups allowed us to probe in greater depth the reasons cancer survivors do or do not seek information and their communication experiences in multiple settings. Based on this data, a questionnaire was developed to assess information seeking among cancer patients and survivors more systematically. We conducted cognitive testing of the questionnaire with six cancer survivors. Survey items included questions on cancer information seeking behaviors, desired information topics and sources, symptoms and functional status, barriers to information access, SES, wealth and indebtedness. Based on focus group data, an emphasis was placed on information seeking barriers from internet-based resources. Two identical questionnaires were created in English and Spanish.

Measures. Information avoidance was measured by the question 'since you were diagnosed, was there *ever* a time when you purposefully avoided information about cancer?' with response options of yes or no.

We also measured the following independent variables:

Socioeconomic Status. We used three variables to measure SES. We asked respondents about their total annual household income before taxes, their level of debt (excluding home mortgage and car loans), and highest level of education, which was collapsed into categories of Less than High School, High School/Associate Degree, 4-year College Degree, Post Graduate Degree.

Cancer-related factors. Respondents were asked several characteristics about their cancer diagnosis and treatment. Respondents were asked the type of cancer and year of diagnosis, and then identified the length of illness. Health insurance status was collapsed into the following categories: Private insurance; Public (Medicare; Medicaid); or other. There were no uninsured individuals in the sample.

Barriers to obtaining cancer information. Health information-related factors were measured by the question 'People sometimes have a difficult time finding the information that they are looking for. Please tell us whether each of the following issues was a large problem, a small problem, or no problem at all in finding or getting the information you wanted about your cancer: difficulties in using a computer; difficulties using an on-line search tool or software; there was too much information; there was no way to tell if information was accurate; there was no way to tell if information was up-to-date; there was no way to tell if information was relevant to my situation; the available information used too many technical terms; I did not have enough access to a computer; I did not have enough access to the Internet.'

Sociodemographic factors. Respondents were asked their age, gender, race, and ethnicity.

Statistical procedures. We modeled cancer-related information avoidance in terms of intersectionality by running the models separately for each gender group. This is due to the fact that most previous studies found that women are much more likely to seek health information than are men (Rutten *et al*, 2006). First, descriptive statistics and frequencies were run for all variables. Second, univariate logistic analyses were run for each predictor variable to identify factors that were associated with avoiding cancer information. Barriers to obtaining cancer information were subjected to a factor analysis. Finally, we ran multivariable logistic regression models by gender with increasing significance values, retaining potential confounders (income, education, race, age, gender), until we reached a model where all additional predictors were significant at $P < 0.05$. We used the multiple imputation method in the process of replacing missing data. Statistical analyses were conducted by using SPSS v.17.0 (IBM SPSS Institute, Chicago, IL, USA).

RESULTS

The total number of respondents was 519 and was comprised of 73% women and 27% men (Table 1). Among the total surveyed, 55% respondents were age 50–69 and 10% were over 70 years of age. The majority of the sample was non-Hispanic white (82%), had a college degree or above (57%), earned more than $75 000 per year (54%), and had private health insurance (76%). Approximately 29% were burdened with debt in the amount of less than $2000. In regards to cancer-related factors, participants with breast cancer composed the largest subgroup (46%), and 26% of the sample had lived with the illness for less than 2 years. Given the amount of missing data on financial items, a sensitivity analysis was conducted. There were no significant differences between those who did and did not respond to these items.

Differences between information avoiding groups and non-avoiding groups. Within the sample, 34% of respondents reported having ever avoided cancer information. Several differences were observed between information avoiding groups and non-avoiding groups (Table 2). With respect to socio-demographic factors, compared to non-avoiders, a slightly higher proportion of women were likely to be avoiders ($P < 0.05$). Survivors younger than 49 were more likely to avoid ($P < 0.001$) compared to those older than 50. Avoiders had relatively higher debt ($P < 0.05$) and lower income ($P < 0.1$) compared to non-avoiders. There was no difference between the two groups in terms of cancer-related factors.

Table 1. General characteristics of the sample ($n = 519$)					
	%	**n**		**%**	**n**
Gender			**Education**		
Male	26.6	138	High school or less	15.2	79
Female	72.8	378	High school to associate	27.6	143
Missing	0.6	3	College	28.3	147
			Post-graduate	28.3	147
Age			Missing	0.6	3
⩽39	10.2	53	**Income**		
40–49	23.3	121			
50–59	28.5	148	⩽$29 999	10.8	56
60–69	26.8	139	$30 000–$49 999	8.1	42
⩾70	10.0	52	$50 000–$74 999	15.0	78
Missing	1.2	6	⩾$75 000	53.9	280
			Missing	12.1	63
Race					
			Debt		
Non-Hispanic white	81.7	424			
Hispanic	5.4	28	⩽$1999	29.1	151
Black/African American	7.1	37	$2000–$4999	10.2	53
Asian	3.1	16	$5000–$9999	8.9	46
Other	1.2	6	$10 000–$19 999	9.2	48
Missing	1.5	8	$20 000–$49 999	8.9	46
			⩾$50 000	14.5	75
Health Insurance			Missing	19.3	100
			Cancer Type		
Private Insurance	76.1	395			
Medicare/Medicaid	20.4	106	Breast cancer	46.1	239
Missing	3.5	18	Colon or rectal cancer	5.0	26
			Head and neck cancer	3.7	19
Period of Illness			Leukemia or blood cancer	3.1	16
			Lung cancer	4.4	23
Under 2 years	25.8	134	Prostate cancer	4.0	21
3 years	23.1	120	Other	33.7	175
4 years	25.6	133	Missing	0	0
Over 5 years	20.4	106			
Missing	5.0	26			

Table 2. Cancer information avoidance by social determinants and disease factors

	Non-avoider (n = 336)	Avoider (n = 176)	X²
	%	%	P-value
Gender			
Male	72.3	27.7	3.7
Female	63.2	36.8	<0.05
Race			
Non-Hispanic White	64.9	35.1	1.8
Hispanic	71.4	28.6	n.s.
Black/African American	64.9	35.1	
Asian/Other	77.3	22.7	
Age			
= <39	41.5	58.5	26
40–49	59.7	40.3	<0.001
50–59	65.3	34.7	
60–69	73.9	26.1	
> = 70	82.4	17.6	
Education			
High school or less	75.3	24.7	4.7
High school to associate	66.4	33.6	ns
College	61.1	38.9	
Post-graduate	63.9	36.1	
Income			
= <$29 999	62.5	37.5	7.4
$30 000–$49 999	78.6	21.4	<0.1
$50 000–$74 999	72.7	27.3	
> = $75 000	61.2	38.8	
Debt			
> = $1999	74.0	26.0	13.2
$2000–$4999	59.6	40.4	<0.05
$5000–$9999	56.5	43.5	
$10 000–$19 999	54.2	45.8	
$20 000–$49 999	65.2	34.8	
> = $50 000	54.1	45.9	
Cancer Type			
Breast Cancer	63.0	37.0	10.1
Colon or Rectal Cancer	65.4	34.6	ns
Head and Neck Cancer	78.9	21.1	
Leukemia or Blood Cancer	62.5	37.5	
Lung Cancer	52.2	47.8	
Prostate Cancer	90.5	9.5	
Other	67.2	32.8	
Health Insurance			
Private insurance	63.9	36.1	3.3
Medicare/Medicaid	73.3	26.7	<0.1
Period of Illness			
Under 2 yrs	65.7	34.3	0.8
3 yrs	67.8	32.2	ns
4 yrs	63.6	36.4	
Over 5 yrs	62.9	37.1	

Abbreviation: ns = non-significant.

Factor analysis: Barriers to Obtaining Cancer Information. We used factor analysis to assess the difficulties our respondents faced in obtaining cancer information (Table 3). The factors used to construct the information capacity index presented factor loadings, all of which were > 0.4 (Nunnally and Bernstein, 1994). The first factor, named *information access barriers*, accounted for 44% of the total variance (Cronbach's alpha = 0.932). This factor included four of the nine included variables: access to the Internet, access to a computer, use of a computer and an online search tool. A second factor, named *information utilization barriers*, explained 26% of the total variance (Cronbach's alpha = 0.826). This factor included five of the nine included variables: capacity to judge whether the information was accurate, is up-to-date, relevant, is overwhelming, and understandable. These two factors were modeled as continuous variables.

Influential factors on health-information avoidance behaviors by gender. As shown in Tables 4 and 5, health information-avoidant behaviors decreased as age increased. In other words, young people, both male and female, were more likely to avoid cancer information. In particular, young males clearly showed a tendency for avoiding information about cancer (Table 4, Model IV: OR = 0.418, 95% CI: 0.181–0.969). Among men, the probability of college graduates avoiding cancer information is lower than that of the reference group of participants with a high school degree or less (Table 4, Model IV: OR = 0.064, 95% CI: 0.005–0.758). Among women, although marginally significant, the probability of cancer information avoidance among patients who had an average yearly income in the range of $50 000—$74 999 is lower than that of the reference group who had an average yearly income of less than $29 999 (Table 5, Model IV: OR = 0.334, 95% CI: 0.109–1.028). There was a slight tendency for cancer information avoidance to decrease among those who had debt in the range of $2000—$4999 compared to the reference group who had debt of less than $2000,

Table 3. Principal components analyses: factor loadings for barriers to obtaining cancer information

	Factors	
Please tell us whether each of the following issues was a large problem, a small problem, or no problem at all in finding or getting the information you wanted about your cancer	Information Access Barriers	Information Utilization Barriers
I did not have enough access to the Internet	0.928	
I did not have enough access to a computer	0.920	
Difficulties in using a computer	0.867	
Difficulties using an on-line search tool or software	0.860	
There was no way to tell if information was accurate		0.876
There was no way to tell if information was up-to-date		0.855
There was no way to tell if information was relevant to my situation		0.804
There was too much information		0.682
The available information used too many technical terms		0.584

Note: Factor loadings for a promax oblique rotation. We presented factor loadings, all of which were > 0.4.

Table 4. Multivariable logistic regression model: influential factors on cancer survivors' cancer information avoiding behavior (male, $n = 138$)

Factors	Variables	Model I OR	Model I 95% CI Lower	Model I 95% CI Upper	Model II OR	Model II 95% CI Lower	Model II 95% CI Upper	Model III OR	Model III 95% CI Lower	Model III 95% CI Upper	Model IV OR	Model IV 95% CI Lower	Model IV 95% CI Upper
Sociodemographic Factors													
Age		0.561***	0.399	0.787	0.519**	0.333	0.808	0.443**	0.244	0.801	0.418*	0.181	0.969
Race	Non-Hispanic White (Ref.)												
	Other	2.271	0.809	6.375	1.424	0.302	6.719	1.017	0.147	7.047	0.509	0.026	9.889
Socioeconomic Factors													
Education	High school or less (Ref.)												
	High school to associate				0.873	0.197	3.868	0.607	0.112	3.288	0.138	0.011	1.746
	College				0.233†	0.046	1.174	0.121*	0.018	0.817	0.064*	0.005	0.758
	Post-graduate				0.850	0.243	2.974	0.639	0.157	2.599	0.348	0.056	2.152
Income	= <$29 999 (Ref.)												
	$30 000–$49 999				2.292	0.452	11.625	1.400	0.134	14.599	0.287	0.007	11.437
	$50 000–$74 999				1.795	0.203	15.893	0.399	0.024	6.684	0.398	0.015	10.779
	>= $75 000				0.487	0.113	2.097	0.542	0.105	2.805	0.443	0.049	4.006
Debt	Less than $2000 (Ref.)												
	$2000 to $4999				0.644	0.172	2.409	0.835	0.181	3.847	1.187	0.201	7.016
	$5000 to $9999				1.998	0.419	9.527	2.412	0.340	17.106	2.084	0.151	28.836
	$10 000 to $19 999				0.725	0.136	3.865	0.729	0.100	5.336	0.740	0.059	9.205
	$20 000 to $49 999				1.146	0.130	10.140	0.851	0.084	8.620	2.782	0.091	85.331
	$50 000 or more				1.068	0.189	6.018	1.055	0.166	6.702	2.447	0.266	22.480
Cancer Related Factors													
Cancer Type	Other (Ref.)												
	Colon or Rectal Cancer							3.917	0.323	47.562	10.133	0.412	249.212
	Head and Neck Cancer							6.414	0.275	149.685	22.598	0.324	1576.903
	Leukemia or Blood Cancer							0.186	54.983	4.595	0.107	198.081	
	Lung Cancer							7.395	0.268	204.399	100.868*	1.221	8335.396
	Prostate Cancer							25.238*	1.218	522.966	19.718	0.388	1002.290
Period of Illness								1.361	0.792	2.337	1.424	0.727	2.791
Insurance	Private (ref.)												
	Medicare/Medicaid							1.678	0.196	14.370	1.982	0.100	39.123
Barriers to obtaining cancer information													
	Information Access Barriers										0.780	0.254	2.397
	Information Utilization Barriers										5.515***	2.077	14.643
	Constant	1.950			4.429		3.199	0.860			0.412		
Fit Statistics													
	-2LL	147.926			112.710			92.374			67.275		
	NagelKerke R²	0.133			0.248			0.354			0.519		

†P<0.1, *P<0.05, **P<0.01, ***P<0.001.

Table 5. Multivariate logistic regression model: nested effect analyses of influential factors on cancer survivors' cancer information avoiding behavior (female, $n = 378$)

Factors	Variables	Model I OR	Model I 95% CI Lower	Model I 95% CI Upper	Model II OR	Model II 95% CI Lower	Model II 95% CI Upper	Model III OR	Model III 95% CI Lower	Model III 95% CI Upper	Model IV OR	Model IV 95% CI Lower	Model IV 95% CI Upper
Sociodemographic Factors													
Age		0.669***	0.547	0.818	0.748*	0.586	0.954	0.781†	0.593	1.029	0.846	0.631	1.134
Race	Non-Hispanic White (Ref.)												
	Hispanic	2.337	0.735	7.432	1.738	0.474	6.370	1.627	0.442	5.986	4.047	0.759	21.566
	Black/African American	1.317	0.284	6.113	0.738	0.112	4.855	0.468	0.060	3.626	1.518	0.143	16.089
	Asian/Other	1.598	0.399	6.396	1.238	0.239	6.415	1.289	0.227	7.321	3.317	0.429	25.635
Socioeconomic Factors													
Education	High school or less (Ref.)												
	High school to associate				0.417	0.138	1.259	0.531	0.164	1.725	0.490	0.139	1.726
	College				0.832	0.423	1.638	0.914	0.448	1.864	0.830	0.385	1.788
	Post-graduate				0.896	0.472	1.703	1.026	0.518	2.033	0.897	0.435	1.851
Income	= < $29 999 (Ref.)												
	$30 000–$49 999				1.321	0.558	3.125	1.284	0.466	3.544	1.795	0.579	5.567
	$50 000–$74 999				0.350*	0.127	0.967	0.338*	0.115	0.988	0.334†	0.109	1.028
	> = $75 000				0.778	0.369	1.640	0.673	0.299	1.516	0.765	0.316	1.851
Debt	Less than $2000 (Ref.)												
	$2000 to $4999				0.519†	0.244	1.103	0.523	0.234	1.166	0.473†	0.201	1.116
	$5000 to $9999				1.139	0.439	2.956	0.846	0.304	2.354	1.236	0.410	3.724
	$10 000 to $19 999				1.607	0.599	4.310	1.442	0.514	4.045	1.508	0.497	4.574
	$20 000 to $49 999				1.196	0.487	2.936	1.086	0.421	2.800	1.071	0.401	2.862
	$50 000 or more				0.741	0.288	1.907	0.757	0.271	2.112	0.723	0.236	2.213
Cancer Related Factors													
Cancer Type	Other (Ref.)												
	Breast Cancer							0.374	0.084	1.654	0.339	0.074	1.549
	Colon or Rectal Cancer							0.349	0.082	1.479	0.360	0.082	1.585
	Head and Neck Cancer							0.080†	0.006	1.097	0.110	0.008	1.557
	Leukemia or Blood Cancer							0.143	0.008	2.501	0.164	0.009	2.918
	Lung Cancer							1.016	0.121	8.511	0.818	0.081	8.230
Period of Illness													
Insurance	Private							0.902	0.706	1.151	0.883	0.673	1.158
	Medicare/Medicaid							0.897	0.354	2.273	0.636	0.210	1.926
Barriers to obtaining cancer information													
	Information Access Barriers										1.083	0.725	1.617
	Information Utilization Barriers										1.438*	1.053	1.964
	Constant	0.871			1.377			4.828			1.760		
Fit Statistics													
	-2LL	461.583			348.359			321.925			282.039		
	NagelKerke R²	0.070			0.143			0.155			0.178		

†$P < 0.1$, *$P < 0.05$, **$P < 0.01$, ***$P < 0.001$.

although this finding was not significant (Table 5, Model IV: OR = 0.473, 95% CI: 0.201–1.116). Male lung cancer patients also had a high likelihood of avoidance behavior. Length of illness and possession of health insurance, however, were not significantly related to cancer information avoidance.

The probability of information-avoidance behavior increased when both men and women had difficulty using or understanding cancer-related information. When respondents experienced difficulty in using or understanding cancer-related information, the probability of avoidance behavior was 5.515 times higher for males (Table 4, Model IV: 95% CI: 2.077–14.643) and 1.438 times higher for females (Table 5, Model IV: 95% CI: 1.053–1.964). These results were consistently significant after controlling for other related variables. The variance explained through the model was 51.9% for males (Nagelkerke, $R^2 = 0.519$) and 17.8% for females (Nagelkerke, $R^2 = 0.178$).

Cancer survivors, thus, were more likely to have avoided cancer-related information when they were young and experienced difficulty in using and understanding cancer information. At the same time, the statistical evidence showed a relationship between relatively highly educated men and high income-earning women and their information non-avoidance behavior. These separate models by gender support the argument for intersectional approach where multiple vulnerabilities may influence information seeking or avoiding behavior.

DISCUSSION

This study represents one of the first explorations of information avoidance from a social determinants perspective using an intersectional approach. Within the study, participants who were younger, female, had greater debt and lower income, and had difficulty using and understanding information were more likely to avoid information. When analyzing the results stratified by gender, the tendency for information avoidance was particularly pronounced in younger males with lower education. Male lung cancer patients also had a high likelihood of avoidance behavior. These findings may indicate that this group is more likely to avoid cancer-related information than men who have other types of cancer. However, these findings should be interpreted with caution given our small sample size. These results indicate significant associations between key social and individual factors that may influence cancer information avoidance, thus validating intersectional approach to examining information inequalities.

The findings in the current study indicate that in addition to individual factors, social determinants such as income, education, and debt may influence how survivors access, interact with, and process information. These associations have also been documented in studies on communication inequalities (Viswanath et al, 2007). Moreover, these pathways may differ by gender, arguing for a more nuanced understanding of information avoidance behavior. The finding that cancer survivors who have difficulty using and understanding cancer information were more likely to report information avoidance is supported in previous research. Miller 1995 states that information avoiders may become overwhelmed by health risks that are perceived as threatening; this may be exacerbated by overly complex information (Viswanath, 2005) in which risks of negative outcomes are not easy to interpret.

Identifying information avoiders may be an important step in creating a tailored approach to a patient's care and to understanding each particular patient's information needs. For example, providers may need to ask whether a patient would like to discuss specific cancer topics to ensure that they don't disclose information that the patient does not want to know. Alternatively, some survivors may avoid cancer-related information outside the medical encounter but would be open to discussing aspects of their care with their provider, particularly if their provider can give them relevant information in non-technical terms. Prior work has found that short, succinct messages in nonthreatening terms may increase positive health-related behaviors among information avoiders (Williams-Piehota et al, 2005). It is also critical for providers to try to identify when a patient has received 'too much' information or when their emotions may impair information processing so that conversations can be deferred to a time when the patient is able to more fully engage in care discussions. Cancer care providers must be aware that a steady stream of cancer information may not be received equally by all cancer survivors, or at all times.

Finally, although associations between debt, income, and avoidance are consistent with information non-seeking behaviors (Ramanadhan and Viswanath 2006), the current study also provides an important contrast to the non-seeking literature. Notably, among the respondents that indicated they had avoided information, 98% indicated that they have also looked for information from any source at some point in time. This suggests that information avoidance may be a distinctly different concept from information non-seeking, which has been suggested in previous literature (Lambert et al, 2009). For example, Barbour et al (2012) characterize information avoidance as an active behavior that is distinct from passively not seeking information. Additionally, research has shown that non-seekers are more likely to be older (Czaja et al, 2003; Mayer et al, 2007; Eheman et al, 2009) and male (Czaja et al, 2003; Mayer et al, 2007). In the current study, younger age and female gender were significant predictors for avoidance. It is plausible that cancer survivors may seek out and avoid cancer information at different points in their disease trajectory, suggesting that individuals operate with a fluid continuum of information engagement behaviors. It is also possible survivors readily seek out information related to certain topics while simultaneously avoiding information about other topics (e.g. treatment as compared to prognostic information). These findings suggest that more research is needed to fully tease out the factors that influence both information avoidance and information seeking at multiple points along the care continuum.

There are several limitations in this study. Given that our sample was predominantly female, white, from high socioeconomic groups, and drawn from one institution, the generalizability of our findings may be limited. Due to the small number of participants from minority groups, our study may not have sufficient power to detect differences among these groups. Furthermore, our avoidance dependent variable, while representing a first step to understanding this behavior, is unable to address some of the finer-tuned information about avoiding, including frequency and type of information avoided. The cross-sectional nature of this study also prevented from analyzing avoidance patterns over time or determining when in the illness experience they occurred.

CONCLUSION

This study found that social determinants and individual characteristics may play a role in understanding why cancer survivors avoid information. It also suggests that reasons for avoiding information may involve perceptions about the characteristics of the information itself, including information complexity and relevance. Understanding the impact of social- and communication-based influences on avoidance is critical for the medical encounter, as physicians and health educators must be aware of the factors that may lead patients to avoid information needed for treatment and survivorship. Future research should explore these issues in greater depth in a population with more diverse racial/ethnic and socioeconomic backgrounds to more fully capture the range of social determinants that may influence

information avoidance, paying particular attention to the intersectional nature of these relationships.

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