

RESEARCH ARTICLE

In Whom Do Cancer Survivors Trust Online and Offline?

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Abstract

Background: In order to design effective educational intervention for cancer survivors, it is necessary to identify most-trusted sources for health-related information and the amount of attention paid to each source. **Objective:** The objective of our study was to explore the sources of health information used by cancer survivors according to their access to the internet and levels of trust in and attention to those information sources. **Materials and Methods:** We analyzed sources of health information among cancer survivors using selected questions adapted from the 2012 Health Information National Trends Survey (HINTS). **Results:** Of 357 participants, 239 (67%) had internet access (online survivors) while 118 (33%) did not (offline survivors). Online survivors were younger ($p<0.001$), more educated ($p<0.001$), more non-Hispanic whites ($p<0.001$), had higher income ($p<0.001$), had more populated households ($p<0.001$) and better quality of life ($p<0.001$) compared to offline survivors. Prevalence of some disabilities was higher among offline survivors including serious difficulties with walking or climbing stairs ($p<0.001$), being blind or having severe visual impairment ($p=0.001$), problems with making decisions ($p<0.001$), doing errands alone ($p=0.001$) and dressing or bathing ($p=0.001$). After adjusting for socio-demographic status, cancer survivors who were non-Hispanic whites (OR= 3.49, $p<0.01$), younger (OR=4.10, $p<0.01$), more educated (OR= 2.29, $p=0.02$), with greater income (OR=4.43, $p<0.01$), and with very good to excellent quality of life (OR=2.60, $p=0.01$) had higher probability of having access to the internet, while those living in Midwest were less likely to have access (OR= 0.177, $p<0.01$). Doctors (95.5%) were the most and radio (27.8%) was the least trusted health related information source among all cancer survivors. Online survivors trusted internet much more compared to those without access ($p<0.001$) while offline cancer survivors trusted health-related information from religious groups and radio more than those with internet access ($p<0.001$ and $p=0.008$). Cancer survivors paid the most attention to health information on newsletters (63.8%) and internet (60.2%) and the least to radio (19.6%). More online survivors paid attention to internet than those without access (68.5% vs 39.1%, $p<0.001$) while more offline survivors paid attention to radio compared to those with access (26.8% vs 16.5%, $p=0.03$). **Conclusions:** Our findings emphasize the importance of improving the access and empowering the different sources of information. Considering that the internet and web technologies are continuing to develop, more attention should be paid to improve access to the internet, provide guidance and maintain the quality of accredited health information websites. Those without internet access should continue to receive health-related information via their most trusted sources.

Keywords: Cancer survivors - information sources - internet access - trust - health information national trends survey

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Introduction

Cancer is the second most common cause of death, accounting for nearly 1 of every 4 deaths in the United States (American Cancer Society, 2014). According to the American Cancer Society (ACS) in 2014, about 1,665,540 Americans are expected to receive a new diagnosis of invasive cancer, and about 585,720 are expected to die of this disease (American Cancer Society, 2014). However, the overall cancer death rate is continuing the decline as the 5-year survival rate is now 68% up from 49% in 1970s. With advances in cancer control, there are approximately 13.7 million cancer survivors in the United States currently (American Cancer Society, 2014). Given the rise seen in

number of survivors of cancer, their health and its related issues have been of increasing concern to medical and public health professionals (Jung, Ramanadhan, and Viswanath 2013).

When faced with a potentially life threatening disease like cancer, gathering information may be a method of coping (Carlsson 2000, Rutten et al., 2005). The majority of cancer survivors prefer to receive as much information as possible about their disease (Cassileth et al., 1980, James et al., 1999, Kav et al., 2012). Patients diagnosed with cancer desire information about different aspects including diagnosis, treatment options and goals, side effects and impact on quality of life (Bennenbroek et al., 2002, Mayer et al., 2007).

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Patients receive most of the information about their disease from health care professionals (James et al., 2007) but they also obtain information from non-medical sources (e.g. internet, newspapers, television) (Tian and Robinson 2008). Obviously, internet has significantly changed the way cancer patients meet their health-related information needs (Hesse et al., 2005).

To improve effectiveness of interventions, it is important to identify the way cancer patients obtain health information and the level of trust on different information channels. Previous studies have investigated the patterns of information seeking behaviors among cancer survivors (Miller 1995, Carlsson 2000, Bennenbroek et al., 2002), however, research on the level of trust on different information sources are lacking (Pearson and Raeke 2000, Hesse et al., 2005, Waters et al., 2010).

The aim of this study was to examine the demographic and medical characteristics of cancer survivors with or without access to the internet (online and offline survivors) and their level of trust in different health information sources.

Materials and Methods

The Health Information National Trends Survey (HINTS) is a biennial, cross-sectional survey of American adults (Nelson et al., 2004) which collects nationally representative data about the American public's use of cancer-related information, cancer-relevant behavior, knowledge, and attitudes (Cantor et al., 2005).

For the current study we have analyzed the 2012 database (National Cancer Institute, 2012). The survey has questions on socio-demographic characteristics (age, gender, income, education, race, household size, and region). Moreover it includes assessment of quality of life, disabilities and previous cancer treatment. Inquiring about trust in various sources, the survey asked respondents

to rate their level of trust (a lot, some, a little or not at all) on TV, religious groups, radio, magazine, internet, government, family, doctor and charity organizations for health-related information. For the purpose of this study, the answers were categorized into two groups; respondents who trusted health-related information from one source a lot or some versus a little or not at all. Furthermore, the survey asked respondents about the level of attention they pay to health-related information from various sources. Similar to questions on trust, respondents were able to rate their level of attention as a lot, some, a little or not at all. These responses were categorized into two groups: a lot or some attention versus a little attention or not at all.

Statistical analysis

For continuous and categorical variables, two-sample t-test and chi-square analysis were used respectively. Pearson correlation was used for bi-variate correlation between each factor and clinical trial awareness. Coefficient and logistic regression were utilized for the multivariate analysis. A p-value less than 0.05 was considered as statistically significant. The statistical analysis was performed using SPSS software (version 15, Chicago, IL, USA).

Results

As reported in table 1, of the 357 cancer survivors, 42.9% were younger than 65, 58.3% were female, 65.4% had education more than a high-school diploma, 58.9% earned over \$35,000 annually, 64.1% had a household size of more than 1, 38.1% were living in South region of the United States of America, only 35.7% had very good to excellent self-reported quality of life, and 67.2% were non-Hispanic whites. Socio-demographic characteristics of study subjects stratified by internet access are shown in table 1. As reported, 239 (67%) out of 357 participants

Table 1. Socio-Demographic and Performance Status of Cancer Survivors

		Total cohort (N=357)	Online survivors N=239 (67%)	Offline survivors N=118 (33%)	p value
Age	< 65	42.90%	50.20%	28%	<0.001
Gender	Female	58.30%	56.50%	62.10%	0.32
Education	More than high school diploma	65.40%	76.50%	42.70%	<0.001
Income	> 35 K annually	58.90%	71.60%	27.40%	<0.001
Number of people in household	More than 1 person	64.10%	70.80%	50%	<0.001
Region	Northeast	17.90%	18.40%	16.90%	0.01
	Midwest	21.30%	17.20%	29.70%	
	South	38.10%	37.70%	39%	
	West	22.70%	26.80%	14.40%	
Quality of Life	Very good to excellent	35.70%	43.70%	19.30%	<0.001
Race	Non-Hispanic White	67.20%	74.90%	51.70%	<0.001
Received any treatment for cancer		91.30%	93.30%	87.30%	0.06
Still receiving or less than 5 years since completion of treatment		44.80%	44.30%	45.80%	0.8
Surgery		79.60%	82.20%	74.00%	0.09
Chemotherapy		30.40%	33.80%	23%	0.05
Radiation therapy		36.70%	35.20%	40%	0.4
Other types of treatment		13.60%	12.60%	15.60%	0.48
Deaf or severely hard of hearing		15%	12.70%	20%	0.08
Blind or severely visually impaired		6.60%	3.50%	13.30%	0.001
Difficulty making decisions because of physical, mental or emotional conditions		10.50%	6.20%	19.80%	<0.001
Serious difficulty walking or climbing stairs		25.70%	18.80%	40.60%	<0.001
Difficulty dressing or bathing		7.80%	4.40%	15.20%	0.001
Difficulty doing errands alone		10.70%	7%	18.70%	0.001

had internet access while 118 (33%) did not. Half of cancer survivors with internet access were younger than 65 compared to 28% of those without access ($p<0.001$). Gender distribution was almost similar between those with and without access (56.5% vs 62.1%, $p=0.32$). Those with internet access were more educated as 76.5% of those with access had more than a high school diploma compared to 42.7% of those without access ($p<0.001$). The difference between income of two groups were striking as 71.6% of those with access earned over \$35,000 per year while this

was true for only 27.4% of those without access ($p<0.001$). Those living with at least another person were more likely to have access to internet as 70.8% of cancer survivors with access had household size of more than 1 compared to 50% of those without access ($p<0.001$). Among those without internet access, about 30% were living in Midwest and 14.4% in West compared to 17.2% and 26.8% of those with internet access, respectively ($p=0.01$). Those with internet access had significantly better quality of life compared to those without access. Among those with access, 43.7% rated their quality of life as very good to excellent compared to only 19.3% of those without access ($p<0.001$). Race was also significantly different between groups. About half of cancer survivors without access were from races other than non-Hispanic whites compared to only 25% of those with access ($p<0.001$).

The groups didn't differ in receiving cancer treatment and type of cancer treatment. However, significant differences were noted in prevalence of disabilities among two groups. In general the group without internet access had more disabilities and specifically they were more likely to have serious difficulty with walking or climbing stairs (40.6% vs 18.8%, $p<0.001$), being blind or having severe visual impairment (13.3% vs 3.5%, $p=0.001$), have difficulty making decisions (19.8% vs 6.2%, $p<0.001$),

Table 2. Univariate Analysis: Correlation between Socio-Demographic Factors and Internet Access

Characteristics	Odds ratio	95%CI	p value
Age <65 ^a	2.597	1.615-4.178	<0.001
Male ^b	1.261	0.801-1.985	0.32
> high school diploma ^c	4.355	2.713-6.990	<0.001
> 35K annual income ^d	6.698	3.801-11.802	<0.001
> 1 person in household ^e	2.42	1.521-3.852	<0.001
Region ^f			
Midwest	0.518	0.256-1.046	0.07
South	0.865	0.453-1.650	0.66
West	1.663	0.778-3.557	0.19
Very good to excellent quality of life ^g	3.249	1.907-5.536	<0.001
Non-Hispanic White ^h	2.778	1.752-4.436	<0.001

^a vs Age > 65, ^b vs Female, ^c vs ≤High school diploma, ^d vs < than 35K annual income, ^e vs 1 person in household, ^f vs Northeast, ^g vs Good to poor quality of life, ^h vs Other races

Table 3. Multivariate Analysis: Socio-Demographic Factors and Internet Access

Characteristics	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I for EXP(B)	
							Lower	Upper
Age < 65 ^a	1.413	0.374	14.255	1	<0.01	4.108	1.973	8.554
Male ^b	-0.447	0.359	1.549	1	0.21	0.64	0.317	1.293
> High School diploma ^c	0.829	0.347	5.718	1	0.02	2.29	1.161	4.517
> 35 K annual income ^d	1.489	0.354	17.664	1	<0.01	4.434	2.214	8.881
> 1 person in household ^e	0.365	0.356	1.051	1	0.31	1.44	0.717	2.893
Region ^f								
Midwest	-1.729	0.615	7.916	1	<0.01	0.177	0.053	0.592
South	-0.782	0.573	1.863	1	0.17	0.457	0.149	1.407
West	-0.509	0.609	0.697	1	0.4	0.601	0.182	1.985
Very good to excellent QoL ^g	0.971	0.395	6.029	1	0.01	2.64	1.216	5.728
non-Hispanic white ^h	1.253	0.364	11.82	1	<0.01	3.499	1.713	7.147
Constant	0.321	0.738	0.189	1	0.66	1.379		

^a vs Age > 65, ^b vs Female, ^c vs ≤ High school diploma, ^d vs < 35K annual income, ^e vs 1 person in household, ^f vs Northeast, ^g vs Good to poor quality of life, ^h vs Other races

Table 4. Multivariate Analysis: Socio-Demographic, Performance Status and Internet Access

Characteristics	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Age < 65 ^a	1.202	0.36	11.144	1	<0.01	3.328	1.643	6.742
Male ^b	0.455	0.36	1.601	1	0.21	1.577	0.779	3.194
> High School diploma ^c	0.85	0.356	5.717	1	0.02	2.34	1.166	4.699
> 35 K annual income ^d	1.603	0.369	18.898	1	<0.01	4.967	2.411	10.233
> 1 person in household ^e	0.148	0.36	0.168	1	0.68	1.159	0.572	2.348
Region ^f								
Midwest	-1.3	0.481	7.306	1	<0.01	0.273	0.106	0.7
South	-0.32	0.432	0.548	1	0.46	0.726	0.311	1.694
West	0.407	0.618	0.434	1	0.51	1.503	0.447	5.048
Very good to excellent QoL ^g	1.059	0.424	6.226	1	0.01	2.883	1.255	6.625
non-Hispanic white ^h	1.288	0.387	11.105	1	<0.01	3.626	1.7	7.734
Blind or severely visually impaired	-0.456	0.64	0.508	1	0.48	0.634	0.181	2.222
Difficulty with decision making	0.717	0.559	1.642	1	0.2	2.047	0.684	6.127
Difficulty walking	-0.41	0.433	0.898	1	0.34	0.663	0.284	1.55
Difficulty dressing	0.755	0.692	1.19	1	0.27	2.127	0.548	8.254
Difficulty doing errands	-0.331	0.631	0.275	1	0.6	0.718	0.208	2.476
Constant	-1.726	0.788	4.796	1	0.03	0.178		

^a vs Age > 65, ^b vs Female, ^c vs ≤ High school diploma, ^d vs < 35K annual income, ^e vs 1 person in household, ^f vs Northeast, ^g vs Good to poor quality of life, ^h vs Other races

doing errands alone (18.7% vs 7%, $p=0.001$) and dressing or bathing (15.2% vs 4.4%, $p=0.001$).

In the univariate analysis, six socio-demographic variables were significantly associated with having access to the internet. Cancer survivors with internet access were more likely to be younger than 65 years of age (OR (odds ratio)=2.59 [95%CI (confidence interval)=1.61-4.17]), having higher education than high-school diploma (OR=4.35, [95%CI=2.71-6.99]), having higher income (OR=6.69, [95%CI=3.8-11.8]), having household with at least 2 members (OR=2.42, [95%CI=1.52-3.85]), having a very good to excellent quality of life (OR=3.24, [95%CI=1.9-5.53]) and being a non-Hispanic white (OR=2.77, [95%CI=1.75-4.43]) (Table 2).

After adjusting for socio-demographic status, cancer survivors who are non-Hispanic whites (OR= 3.49, $p<0.01$), younger (OR=4.10, $p<0.01$), more educated (OR= 2.29, $p=0.02$), with greater income (OR=4.43, $p<0.01$), and with very good to excellent quality of life (OR=2.60, $p=0.01$) had higher probability of having access to the internet, while those living in Midwest were less likely to have access (OR= 0.177, $p<0.01$) (table 3).

Addition of performance status characteristics of cancer survivors did not lead to any significant change on the impact of socio-demographic status on internet access. Moreover, none of performance status characteristics were significantly associated with internet access (Table 4).

We further examined the level of trust (table 5) and attention (table 6) to health related information that cancer survivors accessed from various sources. As shown in table 5, the most and least trusted health related information sources among all study subjects were doctors (95.5%) and radio (27.8%), respectively. Other trusted

Table 5. Level of Cancer Survivors' Trust on Various Sources for Health-Related Information

A lot or some trust for health-related information from				
	Whole cohort	Online survivors	Offline survivors	p value
Doctor	95.50%	96.20%	94%	0.35
Government	70.40%	71%	69%	0.72
Internet	68.60%	74.90%	52.70%	<.001
Charity	51.20%	53.20%	46.40%	0.26
Family	49.30%	47.60%	52.90%	0.37
TV	44.10%	43.20%	46.20%	0.62
Magazines	42.50%	41.10%	45.50%	0.45
Religious groups	33.20%	27.50%	46.50%	0.001
Radio	27.80%	23.50%	37.80%	0.008

Table 6. Level of Cancer Survivors' Attention to Health-Related Information from Various Sources

Paying a lot or some attention for health-related information from				
	Whole cohort	Online survivors	Offline survivors	p value
Newsletter	63.80%	66%	59.30%	0.23
Internet	60.20%	68.50%	39.10%	<0.001
National TV	43.50%	41.90%	47.10%	0.37
Local TV	38.80%	36%	45.20%	0.11
Print news	34.40%	35.90%	31%	0.39
Online news	27.40%	29.80%	21.60%	0.13
Radio	19.60%	16.50%	26.80%	0.03

sources for the cohort were Government (70.4%), internet (68.6%), charity organization (51.2%), family (49.3%), TV (44.1%), magazines (42.5%), and religious groups (33.2%). The groups with and without internet access differed on their level of trust on various sources. Those with internet access, trusted internet much more compared to those without access (74.9% vs 52.7%, $p<0.001$). On the other hand cancer survivors without access to internet trusted health-related information from religious groups and radio more than those with internet access (46.5% vs 27.5%, $p<0.001$ and 37.8% vs 23.5%, $p=0.008$).

The level of attention cancer survivors pay to the health information from various sources is of significant importance. More cancer survivors paid more attention to health information on newsletters (63.8%) and internet (60.2%) while only 19.6% paid attention to radio. The groups with and without access did differ in their level of attention to health-related information from various sources. More people without access paid attention to radio (26.8%) compared to those with access (16.5%) and this was significant ($p=0.03$), while significantly more people with internet access paid attention to internet than those without access (68.5% vs 39.1%, $p<0.001$).

Discussion

The increased availability and development of various sources of medical information including internet has obvious influence on patients' decisions and behaviors regarding their health. As a result, establishing the patterns of use and trust among cancer survivors may help to tailor the services and special interventions for their special needs in the future. This study examined the socio-demographic and medical factors associated with health related internet usage and the trend of trust on information sources among cancer survivors based on their access to the internet.

When comparing socio-demographic characteristics of the patients with and without internet access, significant differences were found in terms of age, race, education, quality of life, income, living region and number of household members. Survivors with internet access were younger which is consistent with other studies' results (Smith et al., 2003, Cotten and Gupta 2004, Lea, Lockwood, and Ringash 2005, Hesse et al., 2005, van de Poll-Franse and van Eenbergen 2008, Carlsson 2009, Marrie et al., 2013, Jung 2013) and probably reflects earlier exposure in life to this new technology. Survivors with access were more likely to be non-Hispanic whites. This is in contrast to the results obtained by the other studies which did not find any significant racial/ethnic differences between the patients (Chou et al., 2009, Chou et al., 2011). Cancer survivors with internet access were more educated than the group without access which is consistent with the results of other research (Smith et al., 2003, Cotten and Gupta 2004, Lea, Lockwood, and Ringash 2005, van de Poll-Franse and van Eenbergen 2008, Carlsson 2009). Survivors who had internet access reported overall better quality of life (Eakin and Strycker 2001, Cotten and Gupta 2004) and higher income (Cotten and Gupta 2004, Hesse et al., 2005, Marrie et al., 2013). They also were more located

in the West of the United States compared to the other group who were more located in Midwest of the country. Survivors with internet access had greater household size. We did not obtain any significant gender related difference between the two groups which was not consistent with previous studies' results showing that women are more active health related internet users (Rogers et al., 2012, Bianco et al., 2013, Jung 2014).

Our results showed that prevalence of disabilities was more common among survivors without internet access than survivors with access to the internet (Marrie et al., 2013). This data further implicates the need for improving the accessibility to the internet and expanding other sources of health information to provide equal access for all patients.

After adjusting for socio-demographic status, survivors who were younger, non-Hispanic whites, with higher level of income, education and quality of life had higher probability of having access to the internet, while those living in Midwest were less likely to have access. Multivariate data analysis results were consistent with many other preceding studies mentioned before.

We found that the doctors were the most trusted health related information source among the whole study subjects; this finding is consistent with results of previous studies (Hesse et al., 2005, Donohue et al., 2009, Ye 2011, Dugandžija et al., 2012, Marrie et al., 2013, Sait et al., 2014). Survivors with internet access, trusted internet much more compared to those without access (Carlsson 2009). While, survivors without access trusted the religious groups and radio more than those with internet access. Furthermore, more cancer survivors paid the more attention to health information on newsletters and internet while the least attention was paid to radio. These findings further emphasize the importance of improving the access and empowering the different sources of information (Mohammadzadeh, Safdari, and Rahimi 2013, Lin et al., 2014).

One of the limitations of this study was reliance on self-reported data. Second, this data was obtained at a highly ranked center therefore the results might be different from the whole picture. Also, the study population may represent the healthier group among survivors diagnosed with cancer.

Considering the different sources of health information used by patients, the need for designing and developing different health promotion interventions via different sources is being felt. Also, given that the Internet and web technologies are continuing to develop, health care professionals and policy makers should pay more attention to developing use of internet based health services. They also need to improve access to the internet, provide guidance and maintain the quality of accredited health information websites.

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