



Persistent digital divide in health-related internet use among cancer survivors: findings from the Health Information National Trends Survey, 2003–2018

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Abstract

Purpose Prior research on the use of the internet among cancer survivors indicates a digital divide. The online landscape and patterns of information consumption, however, have notably changed over the past decade necessitating an updated examination of health-related internet use (HRIU) among cancer survivors.

Methods Using survey data from 2003, 2005, 2007, 2011, 2013, 2017, and 2018 Health Information National Trends Survey (HINTS) iterations, the objectives of this study were to report prevalence, trends, and user profiles in HRIU in terms of emailing doctors, buying medicine online, and support group participation. Descriptive analyses and weighted multivariate logistic regression analyses were performed.

Results Cancer survivors who reported not using the internet were more likely to be older, belong to ethnic minorities, be less educated, and reside in rural areas as compared with those who reported using the internet. Except for participation in online support groups, all other types of HRIU increased in prevalence across the years.

Conclusions Consistent with the increased penetration of the internet and the altered online health communication landscape, we found increased prevalence of HRIU among cancer survivors. However, the digital divide persists in terms of internet access. These findings can inform initiatives to bridge the gap among survivors of varying profiles in using the internet for their health needs.

Implications for Cancer Survivors There is increased reliance on online platforms to obtain and communicate health-related information. The risk with this approach is potential oversight of ensuring equity in terms of internet access and technology literacy among survivors.

Keywords Internet · Cancer survivors · Disparities · Health information · Information sources · Health communication · Health promotion

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Introduction

The 2010s have been marked by an altered online landscape. The internet has emerged as the primary resource for health-related information for an increasing percentage of the population [1]. The internet is considered a conduit for extensive information, convenient access to specific types of information, and interactive communication for real-time feedback [1–4]. Thirty-five percent of US adults reported going online to diagnose a medical condition either for themselves or for someone else. Of those diagnosing themselves online, 46% sought medical attention based on the information they found. Furthermore, 41% of those diagnosing themselves online claimed that their diagnoses were confirmed by a medical professional [3]. In a 2012 Pew survey, 26% of US adults reported having read about or watched another person's health experience and 16% reported going online to find others who shared their health concern [5]. The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 [6], incentivized payments to eligible providers to meet Meaningful Use mandates heralding a new era in how healthcare is delivered in the USA [6]. Health Information Technology (HIT) like electronic health records (EHRs) and technologies like mobile applications, social media, and video conferencing have been increasingly adopted since 2013 [7] effectively transforming the online health communication landscape over the last decade [8]. In 2018, social media overtook traditional print media as the primary source of news [9]. According to a 2019 Pew Research Center survey, nine out of 10 adults went online, 81% owned a smartphone, and 72% used social media [10]. As connectedness becomes the standard expectation of individuals in the broader community, the implications of internet use and the associated disparities are critical to our understanding of cancer survivorship.

The number of cancer survivors is projected to increase to 20 million by 2026 [11]. The internet as a source of information was second only to the healthcare provider for cancer survivors [12, 13]. Cancer survivors may use the internet for the following reasons: for information pertaining to disease management, complementary and alternative medicines, clinical trials and research, nutrition, personal rights, and medical language; for support in terms of advice on the cancer experience, emotional support, alleviation of isolation, and social interactions; and lastly, for practical reasons like communication with healthcare professionals, prescription refills, and scheduling. Reasons precluding cancer survivors from using the internet cited in the literature include lack of computer skills, lack of access to computers, concerns over privacy, and quality of information [14].

Chou and colleagues have documented an increasing trend in health-related internet use (HRIU) among cancer survivors, which they defined as emailing doctors, buying medicine online, online support group participation, and seeking cancer

information from the internet as the first source [15]. Notably, they found that cancer survivors not using the internet were more likely to be less educated, belong to racial/ethnic minorities, live in non-metropolitan areas, and report worse general health suggesting a digital divide—defined as the gulf between people who have and do not have access to information technologies [16].

Since the report on HRIU among cancer survivors by Chou and colleagues, the online landscape has considerably shifted, where 90% of Americans reported using the internet compared with the year 2000, when nearly half the American adult population did not use the internet, per a 2019 report from the Pew Research Center [17]. In the general US population, the use of the internet as the first source for health information has risen across the years [1, 18]. Upon examining the individual types of HRIU in cancer survivors, Chou and colleagues found a significant trend across the years for all types of HRIU except cancer information seeking. In their study on cancer survivors, while they did not examine cancer information seeking on the internet, Jiang and Liu reported a rising trend in Internet Health Information Seeking (IHIS), defined as having looked for medical information on the internet for oneself or someone else in the past 12 months [19]. Another recent study on online patient provider communication (OPPC), which includes emailing doctors, among cancer survivors reported a rising trend from 2008 to 2017 [8]. These reports suggest a shrinking, yet persistent, digital divide. Long-term cancer survivors reported a high prevalence of unmet information needs pertaining to side effects and symptoms, test and treatment, health promotion, interpersonal and emotional, insurance, and sexual functioning and fertility [20]. Engagement in HRIU was associated with psychological benefits for survivors and was positively associated with the patient-provider relationship [21–23]. Therefore, it is of vital importance to understand the factors associated with HRIU to identify user profiles for developing tailored health promotion and communication strategies.

The current landscape is characterized by use of personalized technology and the internet of things influencing the dissemination of health information, HIT, and how patients and providers interact [7] highlighting the importance of updated information on trends in internet usage in the cancer survivor population. Therefore, the objectives of this analysis were to replicate and update the findings by Chou and colleagues [15] using a pooled, cross-sectional analysis based on data over multiple Health Information National Trends Survey (HINTS) iterations to examine prevalence, trends in HRIU, and user profiles of cancer survivors across the years. To this end, we used a combined sample of survey data from HINTS corresponding to 2003, 2005, 2007, 2011, 2013, 2017, and 2018.

Methods

Data collection

This study used data obtained through HINTS [24] sponsored by the National Cancer Institute (NCI). HINTS is fielded to a representative sample of US civilian, non-institutionalized adults over 18 years of age. HINTS collects data about how respondents seek and use information about cancer, as well as cancer risk perception, cancer prevention behavior, and demographics. This study used data from HINTS 1 (2003), HINTS 2 (2005), HINTS 3 (2007), HINTS 4, cycles 1 (2011) and 3 (2013), and HINTS 5, cycles 1 (2017) and 2 (2018). The HINTS 1 and 2 surveys collected data by random-digit-dialing respondents to participate in a telephone interview, while HINTS 3 in 2007 used two modes: random-digit-dialing and also a mailed questionnaire. No differences were detected between survey administration modes based on chi-square comparison of key variables (i.e., age and gender), resulting in combining both telephone and mailed survey responses for HINTS 3. The fourth and fifth iterations of HINTS were administered by mail. The survey uses a stratified postal address frame to randomly sample residential addresses. HINTS is published with survey weights to allow the results to be more generalizable to the population [25]. The response rates for each year were HINTS 1 (33%), HINTS 2 (21%), HINTS 3 (21% telephone mode, 31% mail mode), HINTS 4 cycle 1 (40%), HINTS 4 cycle 3 (35%), HINTS 5 cycle 1 (32%), and HINTS 5 cycle 2 (33%).

To facilitate comparison with the findings identified by Chou et al. [15], Tables 2 and 4 have analyses by year. Following Chou's approach, analyses controlled for gender, age, race/ethnicity, education level, rural/urban status, insurance status, general health status, and time since cancer diagnosis. In contrast to Chou et al., distress was removed as a covariate, as this was not collected after HINTS 3 in 2007. In addition, the first source of cancer information was not asked after 2007 and was removed as a dependent variable.

Measures

The main population of interest was cancer survivors, consisting of those who answered "Yes" to the question "Have you ever been diagnosed as having cancer?" Sociodemographic and clinical characteristics used as covariates in this analysis included *gender* (male/female), *age* (18–49/50–64/65+), *race/ethnicity* (Hispanic/non-Hispanic White/non-Hispanic Black/Other), *education* (high school graduate or less/some college/bachelor's degree or more), *metropolitan status* (metro area/non-metro area), *general health* (excellent, very good, or good/fair or poor), *insurance status* (insured/uninsured), and *time since diagnosis* (1 year or less/2–5 years/6–10 years/11+ years).

Dependent variables used in this analysis include internet use, emailing doctors, buying medicine online, internet support groups, and seeking any cancer information. Internet use behavior was quantified by asking "Do you ever go on-line to access the Internet or World Wide Web, or to send and receive e-mail?" with responses of "Yes," or "No." If people responded "Yes" to using the internet at all, the ways people used the internet were assessed using the question "In the last 12 months, have you used the Internet for any of the following reasons?". Options included in this analysis were responses to the following: "used e-mail or the Internet to communicate with a doctor or a doctor's office" (emailing doctors), "bought medicine or vitamins online" (buying medicine online), and "participated in an online forum or support group for people with a similar health or medical issue" (support group). Finally, responses to the question "Have you ever looked for information about cancer from any source?" were included as a dependent variable in this analysis.

Statistical analysis

All analyses used survey weighting and jackknife variance estimations provided by HINTS to minimize sampling error [25]. Analyses were first performed using the data from 2003, 2005, and 2007 to replicate the findings from Chou et al. [15] to ensure model fidelity. These analyses were then extended to the 2011, 2013, 2017, and 2018 HINTS iterations.

Maintaining fidelity to the analyses conducted by Chou et al., the data was analyzed using the same demographic categories, excluding distress. Weighted descriptive statistics were analyzed for respondents who had a history of cancer and answered the question about internet use. Chi-square tests were used to test for associations between demographic characteristics and internet use. A weighted multivariable logistic regression model was created to explore the adjusted association between the dependent variables regarding HRIU, and the covariates gender, age, race/ethnicity, education, metro status, general health status, insurance status, and time since diagnosis among cancer survivors. Respondents excluded from regression analysis were those without any cancer history and/or those that did not answer the question regarding internet use. For the dependent variables pertaining to HRIU, the regression analysis excluded those who did not use the internet. Additionally, using the full sample of those who responded "Yes" to using the internet, we carried out Chi-square tests to test for associations between survey year and HRIU variables, and associations between cancer survivor status (cancer survivor, family with cancer but no personal history, and no history or family members with cancer) and HRIU variables. All analyses were completed using Stata version 14.2 (2015, StataCorp LP, College Station, Texas).

Results

Population

A population sample was obtained from the combined 2003, 2005, 2007, 2011, 2013, 2017, and 2018 HINTS data. The response rate in the combined sample was 28.4%. A total of 4756 respondents included in these analyses were cancer

survivors and answered positively to the question regarding internet use (Table 1). While 2857 of the survivors used the internet across the sample, 1887 responded “No” when asked if they went online for any reason. There were 12 respondents with a history of cancer that did not answer the internet use question (i.e., we used data from 4744 respondents for our analysis of HRIU among cancer survivors). Unadjusted, bivariate analyses produced significant associations between

Table 1 Demographic characteristics of cancer survivors overall and by internet use in the pooled sample

Characteristic	Total (<i>n</i> = 4756) ^a	Internet users (<i>n</i> = 2857)	Non-internet users (<i>n</i> = 1887)	<i>p</i> value
Age				< 0.001
18–49	654 (18.7)	526 (23.5)	128 (10.3)	
50–64	1467 (32.5)	1098 (39.3)	366 (20.7)	
65+	2562 (47.3)	1200 (35.8)	1354 (67.3)	
Missing	73 (1.5)	33 (1.4)	39 (1.8)	
Gender				0.876
Male	1749 (41.4)	1080 (41.1)	665 (42.0)	
Female	2962 (58.6)	1751 (58.9)	1204 (58.0)	
Race/ethnicity				< 0.001
Hispanic	252 (5.7)	125 (4.6)	126 (7.8)	
NH White	3629 (76.1)	2295 (80.2)	1328 (69.1)	
NH Black	330 (6.6)	170 (5.5)	160 (8.5)	
Other	196 (4.0)	106 (3.8)	88 (4.2)	
Missing	349 (7.6)	161 (6.0)	185 (10.4)	
Education				< 0.001
High school or less	1668 (40.0)	586 (25.7)	1077 (64.9)	
Some college	1349 (30.1)	888 (35.1)	457 (21.3)	
Bachelor’s or more	1631 (27.4)	1346 (37.8)	284 (9.4)	
Missing	108 (2.6)	37 (1.5)	69 (4.4)	
Metro status				< 0.001
Metro area	3857 (81.3)	2410 (84.3)	1436 (76.1)	
Non-metro area	899 (18.7)	447 (15.7)	451 (23.9)	
General health				< 0.001
Excellent/very good/good	3484 (72.0)	2306 (79.9)	1172 (58.4)	
Fair/poor	1186 (26.2)	519 (19.1)	662 (38.4)	
Missing	86 (1.8)	32 (1.0)	53 (3.2)	
Insurance				< 0.001
Insured	4443 (93.0)	2693 (94.4)	1740 (90.6)	
Not insured	213 (4.9)	120 (4.1)	92 (6.3)	
Missing	100 (2.1)	44 (1.5)	55 (3.2)	
Time since diagnosis				0.034
Less than 1 year	573 (13.0)	350 (12.8)	222 (13.3)	
2–5 years	1104 (23.8)	706 (25.3)	397 (21.2)	
6–10 years	902 (18.3)	544 (18.3)	357 (18.4)	
11 or more years	1988 (40.5)	1173 (40.0)	807 (41.1)	
Missing	189 (4.5)	84 (3.5)	104 (6.1)	

^a There were 12 cancer survivors who did not indicate whether or not they used the internet. Their results were only included in the total column

Table 2 Prevalence of different types of health-related internet use among cancer survivors for each survey year (*n* = 4744)

Activity	2003	2005	2007	2011	2013	2017	2018	<i>p</i> value
Internet use	49.5 (44.8, 54.1)	49.3 (45.2, 53.4)	56.9 (53.2, 60.5)	64.1 (58.5, 69.3)	72.8 (67.6, 77.3)	76.9 (71.6, 81.5)	76.4 (70.4, 81.5)	< 0.001
Emailing doctors	9.4 (6.6, 13.1)	14.6 (10.7, 19.6)	16.4 (13.0, 20.6)	23.8 (18.4, 30.2)	39.9 (31.2, 49.3)	38.8 (33.5, 44.4)	36.6 (30.9, 42.8)	< 0.001
Buying medicine online	11.4 (8.2, 15.7)	14.5 (10.6, 19.4)	22.3 (18.4, 26.7)	21.5 (16.3, 27.8)	20.5 (14.1, 29.0)	24.9 (19.9, 30.6)	20.2 (15.4, 26.1)	0.018
Support group	8.8 (5.4, 14.2)	3.5 (2.1, 5.8)	8.1 (5.2, 12.4)	5.1 (3.0, 8.5)	8.4 (4.1, 16.2)	7.7 (4.9, 11.8)	6.7 (4.4, 10.3)	0.399
Cancer info seeking	80.6 (75.3, 85.0)	80.0 (74.3, 84.6)	77.6 (73.3, 81.4)	81.8 (75.3, 86.9)	89.8 (84.0, 93.6)	88.5 (83.2, 92.2)	79.0 (72.9, 84.0)	0.003

internet use and seven of the weighted factors: age (X^2 (6) = 454.04, $p < 0.0001$), race (X^2 (8) = 101.64, $p < 0.0001$), education (X^2 (6) = 864.63, $p < 0.0001$), metro status (X^2 (2) = 49.82, $p < 0.0001$), general health status (X^2 (4) = 266.00, $p < 0.0001$), insurance status (X^2 (4) = 35.61, $p = 0.0007$), and time since diagnosis (X^2 (8) = 28.44, $p = 0.0339$).

Health-related internet use across years

There were significant associations between internet use, emailing doctors, buying medicine online, and seeking any cancer information and survey years (Table 2). All dependent variables increased in prevalence across survey years with the exception of online support group participation. The percent that answered “Yes” to internet use ranged from 49.3% in 2005 to 76.9% in 2017, emailing doctors ranged from 9.4% in 2003 to 39.9% in 2013, buying medicine online had a low of 11.4% in 2003 and a high of 24.9% in 2017, support group participation was at a low in 2005 of 3.5% and a high of 8.8% in 2003, and seeking cancer information from any source was 77.6% in 2007 and 89.8% in 2013.

Health-related internet use by cancer status

In the full sample that included all internet users (*n* = 31,491), there were significant associations between internet use, emailing doctors, online support group participation, and seeking any cancer information and cancer status (Table 3). Cancer survivors were the most likely to email doctors, be in online support groups, or seek cancer information online, while those with family who are survivors were most likely to use the internet. Those without a history of cancer or family members with cancer had the lowest prevalence of emailing doctors, buying medicine online, being in support groups, or seeking cancer info. Figures SF 1 to 5 in the supplementary document illustrate differences in responses between cancer survivors, those with family members with a history of cancer, and those with no history of cancer for the aforementioned HRIU questions over the study period.

Health-related internet use by cancer survivor demographics

Among cancer survivors, higher odds of internet use were associated with survey years 2007, 2011, 2013, 2017, and 2018 compared with 2003 (2007: OR 1.5, 95% CI 1.0–2.0; 2011: OR 2.3, 95% CI 1.6–3.1; 2013: OR 3.7, 95% CI 2.4–5.8; 2017: OR 7.5, 95% CI 5.0–11.2; and 2018: OR 4.8, 95% CI 2.8–8.2) (Table 4). Younger adults, non-Hispanic white respondents, those with higher education levels, those living in metro areas, and those reporting excellent, very good, or good general health were more likely to use the internet. Respondents were more likely to email doctors in all survey

Table 3 Internet use and health-related internet use by cancer status ($n = 31,491$)

	Cancer survivors	Family with cancer	No cancer and no family with cancer	<i>p</i> value
Internet use	63.5 (61.4, 65.6)	77.8 (76.9, 78.7)	69.4 (67.7, 71.0)	<0.001
Emailing doctors	28.7 (26.4, 31.1)	24.3 (23.1, 25.5)	22.8 (21.0, 24.7)	0.008
Buying medicine online	19.9 (18.0, 21.9)	17.9 (16.8, 19.1)	17.3 (15.5, 19.3)	0.264
Support group	6.9 (5.8, 8.3)	5.8 (5.2, 6.5)	4.4 (3.7, 5.3)	0.007
Cancer info seeking	82.9 (80.9, 84.8)	60.8 (59.7, 61.9)	38.9 (36.7, 41.0)	<0.001

years compared with 2003, and emailing doctors was also associated with being younger, higher education levels, and living in metropolitan areas. Buying medicine online was more likely in all survey years compared with 2003 and was associated with higher education levels and being insured. The odds of support group participation were significantly lower in 2005 (OR 0.4, 95% CI 0.2–0.9) and among those with excellent/very good/good general health, and the odds were higher among younger adults. Finally, among survivors who use the internet, seeking cancer information from any source had higher odds in 2013 and 2017 and among more educated adults, and lower odds among male survey respondents.

Discussion

This study sought to replicate and update the findings of Chou and colleagues [15], by reporting prevalence, trends, and user profiles of HRIU across the survey years from 2003 to 2018 using data from HINTS 1 through HINTS 5. We found that, despite the widespread availability of the internet, there were cancer survivors who did not utilize the internet. Our updated findings indicated that cancer survivors, who use the internet, were younger, white, college educated, metro-dwelling, and more likely to report better self-rated health. It is noteworthy that once online there were no race/ethnic differences in HRIU among cancer survivors. Overall, our findings are similar to those reported by Chou and colleagues suggesting a persistent digital divide despite the altered online health communication landscape.

We found that the proportion of cancer survivors reporting internet use increased across the years ranging from 49.5% in 2003 to 76.9% in 2017. Survivors not using the internet belonged to groups that were older, had a high school education, were from ethnic minorities, resided in non-metropolitan areas, and reported poor or fair self-rated health. As in the original study by Chou et al., the time since cancer diagnosis was not associated with internet use and any type of HRIU likely due to a healthy volunteer bias in the HINTS sample. In our multivariable models, the odds of internet use were higher in every year after 2005. With the exception of participation in online support groups, prevalence of all other types of HRIU

increased across the years from 2003 to 2018. In multivariable models, the odds of emailing doctors and buying medicines online were greater for all years in comparison with 2003. Our analysis found cancer survivors having college education or higher were more likely to engage in all types of HRIU except participation in online support groups.

In our study, the proportion of cancer survivors emailing their doctors increased from a mere 9.4% in 2003 to 39.9% in 2013. We also found that younger age, metropolitan residence, and college education were significantly associated with emailing doctors in all years as compared with the year 2003 in multivariable models. In contrast to the findings by Chou et al., we found that being 50–64 years old was a significant predictor of emailing doctors among cancer survivors. OPPC, of which emailing doctors is a subtype, has emerged as an alternative and a complement to traditional patient-provider communication [26]. OPPC has been associated with enhanced clinical management and self-care, decreased healthcare expenditure, increased accessibility to information, and reduced office visits/phone contacts [27, 28]. The increasing trend for emailing doctors found in our study of cancer survivors was also seen in the general US population. A recent study using HINTS data from 2003 to 2013 found that OPPC among US adults rose from 7% in 2003 to 30% in 2013 as well as a significant increase in the proportion of internet users communicating with their providers using email [29]. However, our findings also suggest a flatlining of the proportion of survivors emailing their doctors since 2013. This trend could be explained by the variety of other options available to patients like mobile applications, social media, video conferencing, and EHRs that have been increasingly adopted since 2013 [8], coincident with the Meaningful Use mandates of the HITECH Act [6, 30]. Indeed, 14% cancer survivors in 2017 reported using the secure messaging feature in the EHR and 18.5% used mobile-based applications to communicate with their healthcare providers [8]. In the same study, Jiang and colleagues examined the association of the dimensions of the digital divide with OPPC finding that physical internet access was significantly associated for all the years studied, cognitive access (health information overload, self-efficacy in health information seeking, and trust in online information) was not associated with OPPC, and the association with

Table 4 Multivariate logistic regression of factors associated with internet use and health-related internet use among cancer survivors (*n* = 4744)

	Internet use ^a OR (95% CI)	Emailing doctors ^b OR (95% CI)	Buying medicine online ^b OR (95% CI)	Support group participation ^b OR (95% CI)	Seeking cancer information ^b OR (95% CI)
Survey year					
2003	1.0	1.0	1.0	1.0	1.0
2005	1.0 (0.7–1.3)	1.7 (1.1–2.8)	1.4 (0.7–2.5)	0.4 (0.2–0.9)	1.0 (0.5–1.7)
2007	1.5 (1.0–2.0)	2.0 (1.2–3.4)	2.3 (1.4–4.0)	1.1 (0.5–2.5)	0.8 (0.5–1.2)
2011	2.3 (1.6–3.1)	3.2 (1.9–5.7)	2.0 (1.1–3.5)	0.7 (0.3–1.9)	1.0 (0.5–1.9)
2013	3.7 (2.4–5.8)	8.2 (4.8–14.1)	2.1 (1.0–4.4)	1.3 (0.4–4.1)	2.6 (1.4–5.0)
2017	7.5 (5.0–11.2)	11.3 (7.1–17.9)	3.5 (1.9–6.4)	1.6 (0.7–3.5)	1.8 (1.0–3.3)
2018	4.8 (2.8–8.2)	11.1 (6.7–18.4)	2.9 (1.5–5.4)	1.4 (0.6–3.2)	0.8 (0.5–1.5)
Age					
65+	1.0	1.0	1.0	1.0	1.0
50–64	4.9 (3.8–6.3)	1.9 (1.3–2.7)	1.1 (0.7–1.5)	2.3 (1.3–3.8)	1.4 (0.9–2.1)
18–49	8.8 (5.9–13.1)	2.1 (1.4–3.1)	1.2 (0.8–1.8)	4.2 (2.1–8.6)	1.2 (0.7–1.8)
Gender					
Female	1.0	1.0	1.0	1.0	1.0
Male	1.0 (0.8–1.2)	1.1 (0.8–1.6)	0.9 (0.6–1.2)	0.7 (0.4–1.2)	0.7 (0.5–1.0)
Race/ethnicity					
Hispanic	1.0	1.0	1.0	1.0	1.0
NH White	3.2 (1.6–6.5)	1.5 (0.8–3.0)	1.4 (0.8–2.7)	0.9 (0.2–3.8)	2.0 (0.8–4.7)
NH Black	1.4 (0.7–3.1)	1.2 (0.5–3.1)	0.9 (0.3–2.5)	0.5 (0.1–2.4)	1.7 (0.5–5.4)
Other	1.9 (0.8–4.4)	2.2 (0.8–5.8)	2.3 (0.8–7.1)	1.4 (0.2–9.3)	1.6 (0.4–6.5)
Education					
High school or less	1.0	1.0	1.0	1.0	1.0
Some college	3.2 (2.4–4.3)	2.7 (1.6–4.5)	1.8 (1.2–2.9)	1.5 (0.7–3.3)	2.3 (1.5–3.6)
Bachelor’s or more	7.6 (6.0–9.6)	3.2 (2.2–4.8)	1.7 (1.2–2.5)	1.2 (0.6–2.2)	3.0 (1.9–4.7)
Metro status					
Non-metro area	1.0	1.0	1.0	1.0	1.0
Metro area	1.5 (1.1–1.9)	1.8 (1.2–2.7)	1.1 (0.7–1.7)	1.0 (0.6–1.7)	1.0 (0.6–1.5)
General health					
Fair/poor	1.0	1.0	1.0	1.0	1.0
Excellent/very good/good	2.1 (1.6–2.7)	0.9 (0.6–1.4)	0.8 (0.6–1.2)	0.5 (0.3–0.8)	0.7 (0.4–1.0)
Insurance status					
Not insured	1.0	1.0	1.0	1.0	1.0
Insured	1.6 (0.9–2.7)	1.9 (0.8–4.7)	2.8 (1.1–7.5)	1.2 (0.3–4.4)	1.2 (0.7–2.3)
Time since diagnosis					
11+ years	1.0	1.0	1.0	1.0	1.0
6–10 years	1.0 (0.8–1.4)	1.1 (0.7–1.6)	1.2 (0.8–1.8)	1.2 (0.6–2.4)	1.4 (0.9–2.2)
2–5 years	1.1 (0.8–1.5)	1.1 (0.8–1.6)	1.0 (0.7–1.5)	1.0 (0.5–2.0)	1.5 (1.0–2.2)
Less than 1 year	1.1 (0.8–1.5)	1.4 (0.9–2.1)	1.1 (0.7–1.7)	0.7 (0.3–1.4)	1.3 (0.7–2.3)

^a Among cancer survivors

^b Among cancer survivors who used the internet

sociodemographic access (age, gender, race, household income, education, and health status) varied across the years.

Over the years, participation in support groups has consistently remained low compared with other types of HRIU. We did find that survivors younger than 65 were more likely to participate in online support groups than their older

counterparts. Sharing experiences online may affect a person’s health through finding information, feeling supported, maintaining relationships with others, affecting behavior, experiencing health services, learning to tell the story, and visualizing disease [31]. Research on social media participation, a contemporary platform for support groups, using

HINTS data arrived at a similar conclusion and highlighted the lack of popularity of this medium [32]. More research is needed to understand the evolution of this medium to gain a better understanding of how social media-type interventions can be used to target age-based diseases such as cancer and how social support is expressed via social media. Previous research has indicated that these platforms as a source of support for cancer may be too general and more emotionally oriented (as opposed to focused on resources/needs) [33]. Popular social media outlets such as Facebook may also provide information that needs to be appraised for quality to ensure that it is evidence based [34, 35]. Recent developments in online support group platforms include patient-generated health-data cohorts, where cancer survivors can report health data and experiences through their mobile and wearable health devices [36]. Information collected on such platforms is also used to develop a knowledge base that would help future cancer survivors.

The proportion of survivors buying medicines online has steadily risen from 11.4% in 2003 to 24.9% in 2017. There was no difference in the prevalence of buying medicines online by cancer status in our analysis. However, our results showed that cancer survivors who purchase medicines online were more likely to be insured after adjusting for sociodemographic factors and time since diagnosis. In a previous study, consumers of online pharmacies were more likely to be male, younger, white, married, more educated, and wealthier [37]. Buying medicine online offers several advantages: convenience to those who are housebound or disabled; privacy that encourages potentially embarrassing questions; variety; and affordable prices [38–40]. It also allows consumers to compare prices across internet pharmacies; for instance, a study showed that Americans can save nearly 24% per unit of drug if they purchase from an online Canadian pharmacy instead of an online US pharmacy [41].

In regard to cancer information seeking among cancer survivors, in contrast to Chou et al., we found that the frequency of cancer information seeking increased over time. It should be noted that the HINTS survey is altered and no longer asks the participant to distinguish cancer information seeking from the internet or any other source. Seeking cancer information online has been shown to be associated with engaging in protective behaviors like using sunscreen and increased adherence to screening guidelines [42]. In a survey of adult cancer patients at an academic medical center, 80% reported having internet access and 63% reported using the internet to search cancer-related information. Internet use to seek information about cancer differed by age, race, and education. The leading reason cited for an internet search was to develop questions to discuss with the provider. The top three types of information sought were treatment options, prognosis, and side effects. Results of the internet search influenced choice of treatment, choice of doctor, and enrollment in clinical trials [43]. A

recent study examining IHIS (i.e., having looked for medical information on the internet for oneself or someone else in the past 12 months) in cancer survivors using data from the 2011, 2013, and 2017 iterations of HINTS [19] reported a rising trend for IHIS from 53.5% in 2011 to 69.2% in 2017 mirroring the trends in the general US population [44]. Despite an increase in the proportion of cancer survivors engaging in IHIS, the study confirmed a digital divide and further examined the dimensions of the digital divide: mental access (trust in online information and self-efficacy in health information seeking), material access (ease of internet access), skill access (skill to seek information online), and usage access (online health-related activities like emailing doctors and buying medicines). There was a significant positive association between IHIS and material access, usage access, and mental access (trust in online information) across all 3 years [19].

Our study findings have important implications for clinicians, researchers, and public health practitioners in light of the increased adoption of technologies like personal health record portals [45, 46] and the paradigm shift underway in response to the COVID-19 pandemic necessitating and fast-tracking digital health solutions [47]. Evidence has shown that patient portals can foster patient engagement and improve health outcomes [48–51]. There is growing evidence of a digital divide in portal usage as younger, white cancer patients reportedly showed the heaviest use of patient portals [52]. Our updated results show that the persistent digital divide disproportionately affects vulnerable populations. Yet, while age, education, and residence were associated with HRIU, race and ethnic differences no longer exist among cancer survivors engaging in HRIU. As already emphasized by Chou et al., these findings underscore the importance of addressing the needs of a vulnerable population that is at risk of being further disenfranchised and potentially disengaged with their health and care [53].

Email has shown to be suited for questions about medications, health status updates, and medical questions [54], making it an important tool for patient-centered healthcare. Therefore, efforts should be made to encourage both patient and provider adoption of email and other types of OPPC. The slow and steady rise in buying medicine online offers several benefits to cancer survivors, such as, variety, better prices, and convenience. However, our findings suggest buying medicine online could contribute to disparities in health. The rising popularity of online pharmacies underscores a need to increase health literacy so consumers may make healthier choices and learn to recognize risks [55]. A systematic review of outcomes of online support and resources among cancer survivors showed a generally positive, albeit inconclusive, association [56]. Given the multitude of social media avenues available to people, the associated benefits, and the interactive nature of social media platforms, further research is needed to identify the profile of cancer survivors most likely to benefit

from this medium. Prior evidence showed that the desire for information and the desire for participation in care are independent. Cancer patients can be classified as those who are involved in seeking information and healthcare decisions; those who seek information, but defer to their providers to make decisions; and those who prefer to delegate both the information gathering and decision-making to their providers [57]. However, the rising trend in cancer information seeking brings into focus the role of healthcare providers in guiding their patients' HRIU. Patients have expressed a desire for guidance from their primary care providers regarding medical information on the internet [58]; moreover, over time, there has been an upward trend in guided versus spontaneous use of the internet among cancer patients [59].

Limitations and strengths

Some of the strengths of this study include an examination of all the years of data making the results comparable with previous reports. Moreover, the health communication landscape has considerably altered in the past decade influencing the dissemination of health information, HIT, and how patients and providers interact [7] highlighting the importance of updated information on trends in internet usage in the cancer survivor population. However, there are some notable limitations. First, the data are based on self-report and subject to recall bias. Second, the surveyed population is subject to selection bias as respondents with poor prognosis and serious disease are less likely to participate in the survey. Third, our analysis does not account for type of cancer, which has been shown to be associated with cancer information seeking behavior [60]. Fourth, the data are cross-sectional precluding any inference on causation highlighting the need for other types of studies to complement results from surveys, for example, patterns of information use can be gleaned using internet search data [4] and mined from social media platforms [61] to explore questions about the specific topics discussed, relation between promotional information and discussions, and the relationship of these patterns to survey results from HINTS. Lastly, the response rate in HINTS was low, but it was similar in other national surveys [62, 63]. HINTS administrators have taken steps to minimize bias arising from modality, coverage, and sampling [64, 65].

Implications

Our findings suggest a persistent digital divide in vulnerable segments of the population. Compared with the year 2000, when nearly half the American adult population did not use the internet, 10% of US adults were offline per a 2019 report from the Pew Research Center. The offline US adults were

more likely to be 65 and older, live in rural areas, and have a high school education [17]. Older adults in the general population have reported physical challenges in manipulating devices and a lack of confidence in using new technologies [66]. Trust in information and ease of searching for information were associated with adoption among older adults suggesting that this group might benefit from navigational assistance [67]. There is evidence showing significantly worse distress, depression, and overall health-related quality of life among Hispanic cancer patients [68]. In a recent study of online cancer prevention information seeking preferences in an ethnically diverse sample, older age, high school education, and being a Spanish speaker were associated with lower odds of seeking cancer prevention information online [69]. To avoid further exacerbating disparities, it is vital to gain an understanding of the perceptions of and barriers to internet access among older cancer survivors to inform the development of appropriate e-literacy interventions. However, it is noteworthy that once cancer survivors are online and engage in the different activities entailing HRIU, there were no significant race and ethnic differences highlighting the need to mitigate the barriers to internet access.

Conclusion

In summary, the current analysis using data from 5 iterations of HINTS showed increasing prevalence of HRIU among cancer survivors. Differences in internet use across key groups, particularly age, insurance status, and education, have implications for the design of health interventions and communication efforts.

Data availability This study uses publicly available data from the National Cancer Institute at hints.cancer.gov.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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