Patient-Provider Communications and Mental Health among Cancer Survivors in the United States: Health Disparities during COVID Compared to Pre-COVID

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Patient-Provider Communications and Mental Health among Cancer Survivors in the United States: Health Disparities during COVID Compared to Pre-COVID

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Table of Contents

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Patient-Provider Communications and Mental Health among Cancer Survivors in the United States: Health Disparities during COVID Compared to Pre-COVID

Abstract

Background

Patient-Provider Communications play important roles in cancer survivors' self-care and mental health management. However, the use and associations of perceived patient-centeredness and online-based communications with mental health outcomes among cancer survivors during SARS/COVID-19 (COVID) have been understudied.

Objective

This dissertation examines the prevalence of and associated factors with optimal patient-centered communications (PCC), online patient-provider communications (OPPC) use, and poor mental health among cancer survivors during COVID in comparison with pre-COVID and those without a history of cancer.

Methods

Nationally representative cross-sectional survey data (Health Information National Trends Survey, HINTS 5 2017-2020) were used for three studies among cancer survivors (n=2,579) and individuals without a history of cancer (n=13,292) during COVID (HINTS 5 2020) vs. pre-COVID (HINTS 5 1-3, 2017-2019). To assess the prevalence of optimal PCC (always perceiving PCC), OPPC use (email/internet, tablet/smartphone, electronic health records (EHR) use to communicate with providers), and poor mental health (depression as a chronic condition or depressive/anxiety symptoms in the past 2 weeks), weighted descriptive analyses were conducted to obtain frequency (n) and weighted percentage (%) with standard errors (SE). To investigate the associations of sociodemographic and health status factors with optimal PCC, OPPC use, and poor mental health, multivariable-weighted logistic regression models were developed to obtain odds ratios (ORs) and 95% confidence intervals (95% CIs).

Results

During COVID vs. pre-COVID, the prevalence of optimal PCC was lower (OR=0.73, 95% CI 0.54-0.98), and OPPC use was higher (ORs=1.61-1.92 in email/internet, EHR) among cancer survivors. However, the prevalence of poor mental health did not change significantly among cancer survivors from pre-COVID to COVID. Cancer survivors who had no usual source of care, were the oldest (≥75 years), or had poor mental health were less likely to have both optimal PCC and OPPC use. Income, race/ethnicity, marital status, health insurance type, and general health status were found to be associated with either optimal PCC or OPPC use. The COVID pandemic and a history of cancer were not associated with mental health. When adjusted for PCC and OPPC with other sociodemographic and health status factors, individuals who had low income, had low education, had a poor general health condition, or who were younger, were females, were non-Hispanic Whites, were significantly more likely to have poor mental health.

Conclusions

Our findings could inform tailored interventions to prevent further inequities in this population. Raising awareness of PCC roles among healthcare providers and patients through early-stage clinician training or collaborating with patient advocate groups for patient education may improve perceived PCC. Efforts to increase the coverage of virtual visits, enhance eHealth literacy, or improve health technology access might help those with low OPPC use. Furthermore, partnering with public health programs to reach target populations and providing life skills-based training and support could also help people with poor mental health.

Introduction

Patient-provider communication is an essential element of cancer care[1]. It has been found to be associated with the improvement of patients' disease management ability and treatment adherence, as well as health outcomes (e.g., reduced mortality and better mental health)[2–5]. As a particular skill set of patient-provider communication, patient-centered communication (PCC) is defined as communications between patients and healthcare providers that can help patients address concerns and allow healthcare providers to properly respond to the patients' needs[6]. The National Cancer Institute designated six primary PCC domains that could play roles in health outcomes in 2007 (Figure 1)[7]. It outlined the suggested key functions of patient-provider communications, including exchanging information, responding to emotions, making decisions, enabling self-management, fostering healing relationships, and managing uncertainty. The Institute of Medicine (IOM) construed PCC as a crucial component of patient-centered cancer care[8]. Quality PCC practice showed a beneficial impact on cancer survivors' perception of cancer care quality and satisfaction[9]. Moreover, cancer survivors who experienced PCC presented better self-efficacy, emotional well-being, and health-related quality of life[10,11].

Online patient-provider communication (OPPC) is defined as patient-provider communication through online-based tools, broadly including the internet or email, using digital devices (e.g., computers, mobile phones, tablets)[12]. With the recent development and wide implementation of online health-related services and platforms (e.g., online patient portal, electronic health records system), OPPC has become an important part of modern healthcare[13]. In recent studies, OPPC showed commensurate benefits with face-to-face patient-provider communications[13]. Further advantages of OPPC among cancer survivors include improved access to health information, involvement in health decision-making, and self-care capability[14,15].

Poor mental health negatively influences cancer survivors' quality of life and health-related outcomes, including mortality[16]. Depression and anxiety, common types of poor mental health, have been known to be more prevalent among cancer survivors than those without a history of cancer[17]. Approximately 25-40% of individuals with cancer experienced depression and anxiety in the U.S. in 2019[18]. During the SARS/COVID-19 pandemic, elevated poor mental health was reported among cancer survivors[19], potentially because of a higher level of stress due to the disturbed cancer care and additional fear of COVID infection due to their compromised health condition[20]. Under the unprecedented Stay at Home Order declaration in the U.S. in 2020, healthcare office visits were extremely restrained, which might have hindered the use of optimal PCC [21]. However, the limited availability of in-person-based office visits increased the necessity and facilitated opportunities for online-based platforms for the patients to connect with the health providers during this time[22].

However, little is known about the use of PCC and OPPC among cancer survivors during the early pandemic and what roles optimal PCC and OPPC use played in cancer survivors' mental health. Moreover, identifying subgroups of cancer survivors who need resources and support to improve PCC and OPPC practices in the context of mental health during the pandemic has been understudied. Therefore, the three studies aimed to investigate the prevalence of optimal PCC, OPPC use, and poor mental health among cancer survivors compared to adults without a history of cancer during COVID to see how these changed from the pre-COVID years. Furthermore, the following studies intended to identify factors associated with optimal PCC, OPPC use, and poor mental health among cancer survivors during COVID in comparison with pre-COVID. We hypothesized that the prevalence of optimal PCC decreased, yet the prevalence of OPPC use and poor mental health increased during COVID. In addition, the subgroups with sub-optimal PCC, low OPPC use, and poor mental health would differ during COVID compared to pre-COVID. The information generated by these studies will contribute to advancing our knowledge and preparing targeted interventions to prevent further inequities and enhance optimal PCC and OPPC use and, eventually, mental health among cancer survivors.

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Chapter 1.

Title: Cancer Survivors with Sub-Optimal Patient-Centered Communication Prior to and During the Early COVID Pandemic.

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Abstract

Objectives

Patient-Centered Communication (PCC) is an essential element of patient-centered cancer care. However, the prevalence of optimal PCC and factors associated with optimal PCC among cancer survivors during the SARS/COVID-19 (COVID) is less studied.

Methods

We used national survey data (Health Information National Trends Survey) among cancer survivors (n=2,579) to calculate the prevalence (%) of optimal PCC in all 6 PCC domains and overall (mean) by time (pre-COVID, 2017-19 vs. COVID, 2020). Multivariable logistic regressions were performed to estimate the odds ratio (OR) and 95% confidence intervals of optimal PCC by sociodemographic (age, birth gender, race/ethnicity, income, education, usual source of care), and health status (general health, depression/anxiety symptoms, time since diagnosis, cancer type) factors.

Results

The prevalence of optimal PCC decreased during COVID up to 7.3%. Those with no usual source of care (ORs=1.53-2.29), poor general health (ORs=1.40-1.66), depression/anxiety symptoms

(ORs=1.73-2.17) were less likely to have optimal PCC in most domains and overall PCC assessments.

Conclusions

We identified subgroups of cancer survivors with sub-optimal PCC during COVID.

Practice implications

To improve PCC among those vulnerable cancer survivors, educational programs and guidelines/ policies for both healthcare providers and patients are suggested to raise awareness of PCC roles.

Introduction

Patient Centered Communication (PCC) is defined as interactions and communications between patients and providers to meet patients' needs and respond to their preferences [1]. The National Cancer Institute (NCI) outlined six core domains of PCC that could influence patients' essential health outcomes: exchanging information, responding to emotions, making decisions, enabling self-management, fostering healing relationships, and managing uncertainty [2].

PCC allows patients to have time with providers to ask questions and receive the relevant information to care for themselves, acquire support from the providers for health decision-making, and help to express emotions and deal with uncertainty and anxiety [3–6]. The Institute of Medicine (IOM) identified PCC as an essential element of patient-centered care in 2013 [7]. People who experienced PCC reported benefits from mental distress management [2, 8]. They also showed higher cancer care quality, treatment adherence, emotional well-being, and health-related quality of life [9–11].

During the early SARS/COVID-19 pandemic in 2020, cancer survivors faced disrupted cancer care (e.g., delayed cancer care, changed treatment plans) and fear of disease progression [12–

14]. In addition, cancer survivors experienced additional fear of COVID infection because those with chronic medical conditions, including cancer, showed worse COVID infection outcomes [13, 15]. After the unprecedented Stay Home Order in March 2020 in United States (U.S.), in-person clinic visits were extremely limited. A study reported that physicians' responsiveness to patients' negative emotions during conversations was associated with mental health status during COVID [16], highlighting the importance of PCC.

Prior studies have found PCC disparities by sociodemographic and health status factors among cancer survivors in the U.S. Cancer survivors who were racial/ethnic minorities, were more educated, had low income, had no usual source of care, or had poor physical or mental health reported lower perceived PCC [17–20], while age showed inconsistent associations. For example, older cancer survivors had higher perceived PCC in HINTS 4 (2011-2013) [19], yet age was not related among newly diagnosed colon or rectal cancer patients [20]. However, a systematic evaluation of all six PCC domains among cancer survivors during the early pandemic has not been conducted, limiting our ability to identify subgroups with sub-optimal PCC.

Therefore, this study used the nationally representative HINTS data (2017 to 2020) to assess the prevalence of optimal PCC, defined as always having perceived PCC [19], among cancer survivors during COVID compared to those in pre-COVID years. This study also investigated sociodemographic and health status characteristics associated with optimal PCC during COVID to identify subgroups of cancer survivors who would need support to have optimal PCC.

We hypothesized that the prevalence of optimal PCC would decrease during the pandemic and the subgroups of cancer survivors with sub-optimal PCC would differ during COVID than pre-COVID. Findings from this study can inform targeted interventions to support those in need. Furthermore, the knowledge could also contribute to improving PCC during telehealth visits that became rapidly and widely implemented during COVID [21].

Methods

Data source

We used nationally representative survey data from Health Information National Trends Survey (HINTS) for this study [22]. HINTS is a self-administered, publicly available, cross-sectional survey data distributed and collected by National Cancer Institute (NCI) [23]. This study used the HINTS 5 data, Cycles 1-3 (2017-2019) for pre-COVID and Cycle 4 (2020) for COVID. Of note, the COVID sample was collected from February to June 2020. The survey questionnaires were administered to non-institutionalized civilians 18 years and older in the United States. We followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines to accurately report recommended items for an observational study [24]. The total number of survey responses in HINTS 5 Cycles 1-4 was 16,092 and the average response rate was 33% [25]. Among the total responses, those with a history of cancer diagnosis were designated as cancer survivors' responses (n=2,579) in this study as we followed the NCI definition of cancer survivor, a person with cancer from the time of diagnosis until the end of life [26]. We examined the variables of our interest before we combined 4 survey cycles if those were different across the cycles and the survey mode (mailed, push-to-web with a paper return, push-to-web with web return). We used the HINTS Data Merging Code Tool that the HINTS provides to merge the data of HINTS 5 Cycle 1 to Cycle 4 [27]. We obtained 200 replicate weights and used those to calculate standard errors. The full-sample weights were applied for the data to be nationally representative, intending to account for household-level base weight, non-response, and person-level initial weight [28].

Outcomes

PCC was defined by the NCI framework [2] and measured using the following questions: "In your communication with all doctors, nurses, or other health professionals in the past 12 months, how often did they 1) give you a chance to ask health questions? (Exchanging information), 2) had the attention you needed to your feelings and emotions? (Responding to emotions), 3) involve you in decisions about your health care as much as you wanted? (Making decisions), 4) make sure you understood the things you needed to do to take care of your health? (Enabling self-management), 5) explain things in a way you could understand? (Enabling self-management), 6) spend enough time with you? (Fostering healing relationships), 7) help you deal with uncertain feelings about your health or health care? (Managing uncertainty)." Responses for each question were measured on a Likert scale (1=always, 2=usually, 3=sometimes, 4=never). Responses were combined and recoded using the Likert scale numbers to generate a new continuous PCC outcome variable, ranging from score 0 (the most optimal, when all 6 domains were scored "always") to score 100 (the least optimal, when all 6 domains were scored "never") [19]. The overall PCC was analyzed as a dichotomous outcome when when all 6 domains were "always" for optimal PCC. Given this stringent cut-off, the overall PCC was also analyzed as a continuous outcome to allow for comparison to prior studies where the overall PCC was reported as a continuous outcome [18]. Furthermore, we dichotomized response options of each of the 6 domains as optimal (always) vs. sub-optimal (usually, sometimes, never) for our analysis and a sensitivity analysis was done to assess if the different cut-points [optimal (always/usually) vs. sub-optimal (sometimes/never)] would affect the associations, as done previously with HINTS data [18].

Covariates

Sociodemographic characteristics

We chose sociodemographic factors as independent variables of this study based on the social determinants of health conceptual framework from the Healthy People 2030 [29]: age (18 to 34, 35 to 49, 50 to 64, 65 to 74, 75 years or older), birth gender (male, female), race/ethnicity (non-Hispanic White, Non-Hispanic Black/African American, Hispanic, non-Hispanic Asian, Other), household income (< $20,000, $20,000 to <$35,000, $35,000 to < $50,000, $50,000 to < $75,000, ≥$75,000), educational attainment (less than high school, high school graduate, some college, college graduate or more), marital status (married or living with a romantic partner as a married vs. not married including divorced, widowed, separated, single/never been married), employment status (employed vs. unemployed including homemaker, student, retired, disabled), health insurance type (insured by employment, private insurance, Medicaid, Medicare, Tricare, Veterans Affairs, Indian Health Services, others), usual source of care (yes, no), and rurality of residence (metropolitan, micropolitan, small town, rural). HINTS used Urban Rural Commuting Area (RUCA) to designate the rurality of residence of the survey respondents, which categorized census tracts using population density, urbanization, and commuting patterns developed by the United States Department of Agriculture [30].

Health status characteristics

Health status factors included general health status (excellent, very good, good, fair, poor), chronic medical conditions (diabetes, high blood pressure, heart disease, lung disease, depression), time since cancer diagnosis (less than a year, 2-5 years, 6-10 years, more than 11 years), cancer type (breast, cervical, prostate, colon, lung, skin cancer, melanoma, other cancer, or multiple cancer), and measures of psychological distress (little interest, hopelessness, nervousness, worrying). The psychological distress measurements were converted to depression or anxiety symptoms (past 2 weeks) using Patient-Health Questionnaire-4 (PHQ-4), and following its clinical cut-off (score ≥3, then symptom presents) [31].

Statistical analysis

Weighted descriptive analyses [percentage with standard error (SE)] were performed to describe cancer survivors' sociodemographic and health status characteristics. To assess the prevalence of optimal PCC for each of the 6 domains and overall [dichotomized response (optimal = the response was ‘always’)] by time period (pre-COVID and COVID), we performed the weighted descriptive analyses to obtain weighted percentage (%) with SE. Additionally, to examine the perceived PCC by sociodemographic and health status factors over the entire study period and in pre-COVID and COVID time periods, we conducted the weighted descriptive analyses to calculate the overall mean PCC and SE.

To investigate the factors associated with optimal PCC (optimal=the responses of each domain was ‘always’), multivariable-adjusted weighted logistic regression models were developed to estimate the odds ratio (OR) and 95% confidence intervals (95% CI) of optimal PCC using dichotomized response for each domain. The same model was applied for a dichotomous overall PCC (optimal=the responses of all 6 domains were ‘always’). To explore the factors associated with a continuous overall PCC score, a multivariable-adjusted weighted linear regression model was developed to obtain coefficients (β) with SE. Sociodemographic and health status variables for the logistic and linear regression models, included age, gender, race/ethnicity, education, income, usual source of care, general health status, depression or anxiety symptoms, time since diagnosis, and cancer type. These variables were retained in the final model because they were considered as confounders (e.g., the covariate effect estimate changed by more than 10%), significantly associated with the outcome in univariable models ($P<0.05$) or were associated with PCC in prior studies [18, 19, 32]. To investigate whether the prevalence of optimal PCC differed during COVID than pre-COVID, we assessed the associations of time period with 6 PCC domains, a dichotomous and a continuous overall PCC using the multivariable weighted logistic and linear regression models, respectively, adjusting for the same covariates above. Sensitivity analysis was conducted with [optimal (always/usually) vs. sub-optimal (sometimes/never)] to investigate the associated factors further by domain, as done previously [18].

We assessed the interactions of selected sociodemographic and health status factors (age, income, gender, usual source of care, race/ethnicity, and depression/anxiety symptoms) with time period (pre-COVID vs. COVID) with overall PCC score. For these interaction assessments, we included interaction terms in multivariable weighted linear regression models. We performed hot deck imputation, which the HINTS used to account for the non-response [28], to account for the missing data in the covariates, which ranged from 1.0% to 13.3% (see footnotes of Table 1). For all descriptive and regression analyses, the imputed data were used in SAS 9.4 (SAS studio 3.8, Cary, NC, USA). The statistical significance was determined at a $P < 0.05$.

Results

Cancer survivor characteristics

In HINTS 5 2017-2020, there were 2,579 cancer survivors, 75% during pre-COVID (n=1,953) and 25% during COVID (n=626) time periods (Table 1.1). About half (51%) were older adults (≥65 years), non-Hispanic Whites were the majority (80%), 66% had some college education or more, more than half (53%) reported $50,000 or more income, 57% had public/government-supported insurance, 84% had a regular provider, and 75% rated their health status as excellent/good. High blood pressure (54%) was the most common co-morbid chronic condition, followed by diabetes (24%) and depression (23%). Nearly one in three cancer survivors reported depression or anxiety symptoms in the past 2 weeks (33%). Almost half have been cancer survivors for more than 11 years (47%). There were no significant differences in population characteristics of cancer survivors between pre-COVID and COVID (Supplemental Table 1.1).

Table 1.1. Sociodemographic and health status characteristics of cancer survivors, HINTS 5 Cycles 1-4 (2017-2020)

	Frequency (N) N=2,579*	Weighted % (SE)
Time period		

Pre-COVID (2017-19)	1953	74.8 (0.4)
COVID (2020)	626	25.2 (0.4)
Age (years)		
18-34	37	4.1 (1.1)
35-49	172	12.0 (1.2)
50-64	742	33.0 (1.5)
65-74	850	25.9 (1.1)
≥ 75	778	25.0 (1.0)
Gender		
Female	1500	56.6 (1.5)
Male	1079	43.4 (1.5)
Race/Ethnicity		
Non-Hispanic White	2003	79.1 (1.3)
Non-Hispanic Black/African	243	8.3 (1.0)
Hispanic	203	8.7 (1.0)
Non-Hispanic Asian	50	1.6 (0.3)
Others	80	2.3 (0.4)
Education		
Less Than High School	155	6.8 (1.0)
High School Graduate	550	27.0 (1.4)
Some College	805	38.3 (1.4)
College Graduate or More	1069	27.9 (1.2)
Household income		
<$20,000	460	16.6 (1.2)
$20,000 to <$35,000	411	14.3 (1.1)
$35,000 to <$50,000	366	15.3 (1.4)
$50,000 to <$75,000	489	19.3 (1.3)
≥$75,000	853	34.5 (1.5)
Employment[**]		
Employed	507	35.9 (1.8)
Unemployed	1163	64.1 (1.8)
Marital status		
Married	1345	61.9 (1.5)
Not married	1234	38.1 (1.5)
Rurality		
Metropolitan	2186	81.9 (1.1)
Micropolitan	212	10.3 (0.9)
Small town	98	3.9 (0.6)
Rural	83	3.9 (0.6)
Health insurance type		
Private or employment-based	668	33.8 (1.5)
Medicare	1039	33.4 (1.2)
Medicaid	282	14.0 (1.3)

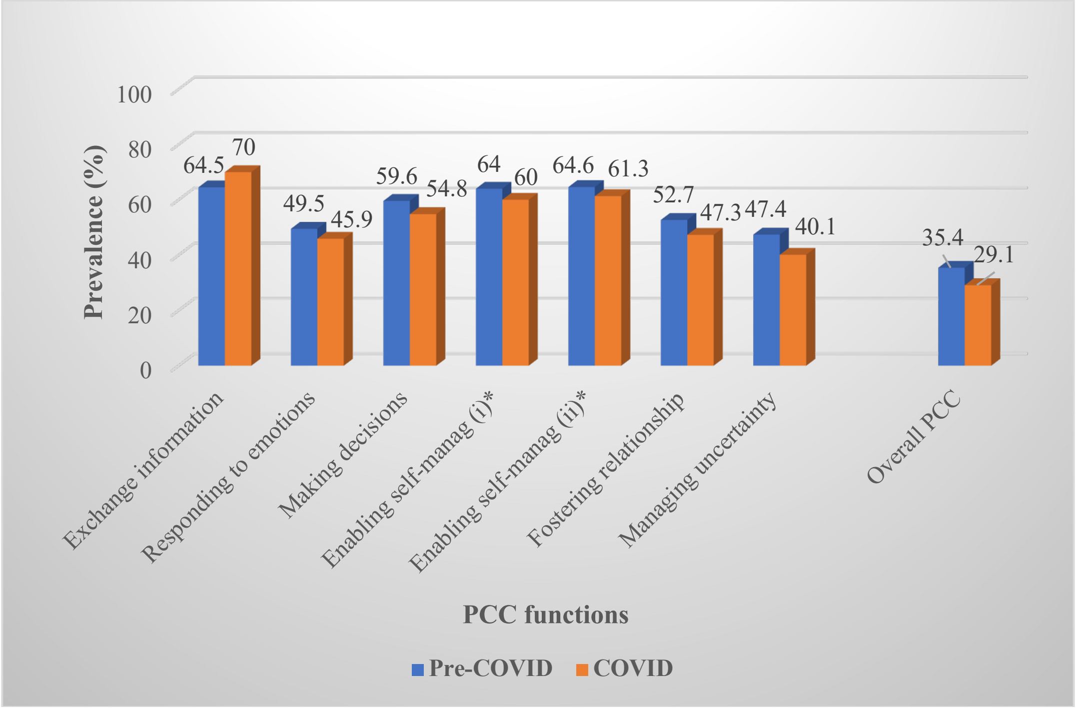
Tricare/ VA/ IHS	301	9.4 (0.8)
Others	289	9.4 (0.8)
Usual source of care		
Yes	2189	84.1 (1.1)
No	390	15.9 (1.1)
General health status		
Excellent/good	1947	74.7 (1.4)
Fair/poor	632	25.3 (1.4)
Chronic medical condition		
Diabetes	693	24.3 (1.4)
High blood pressure	1492	54.4 (1.5)
Heart disease	409	15.1 (1.1)
Lung disease	461	16.7 (1.0)
Depression	598	23.2 (1.2)
Depression/Anxiety symptoms+ (past 2 weeks)		
Yes	717	30.2 (1.6)
No	1862	69.8 (1.6)
Time since diagnosis		
<1 year	330	13.9 (1.2)
2-5 years	533	20.3 (1.2)
6-10 years	485	19.0 (1.4)
≥ 11 years	1231	46.8 (1.6)
Cancer type++		
Breast	374	13.2 (1.0)
Cervical	136	6.9 (0.9)
Prostate	237	6.5 (0.6)
Colon	108	3.9 (0.5)
Lung	49	1.8 (0.4)
Skin	646	24.8 (1.3)
Melanoma	124	5.1 (0.7)
Multiple cancers	441	16.4 (1.0)
Others	464	21.3 (1.6)

*Missingness of covariates: age 2.1 %, gender 1.0%, race/ethnicity 11.6%, education 2.1%, income 13.1%, marital status 2.1%, health insurance type 4.0%, usual source of care 2.0%, general health status 1.4%, diabetes 2.2%, high blood pressure 1.9%, heart disease 1.3%, lung disease 1.5%, depression 2.1%, little interest 2.1%, hopelessness 2.4%, nervousness 2.1%, worrying 2.1%, time since diagnosis 6.0 %, cancer type1.7%. Covariates with any missing values were imputed in Table 1 (Frequency and Weighted %). ** Employment data are not reported in Cycle 3, n=909; + 4 Psychological distress items (little interest, nervousness, hopelessness, worrying) were converted to PHQ-4 to represent depression or anxiety symptoms; ++ Less prevalent cancer types were recoded as Others (bladder, bone, endometrial, head and neck, leukemia/blood, liver, lymphoma, oral, ovarian, pancreatic, pharyngeal, rectal, renal, stomach cancer, and unknown cancer); Abbreviations: VA (Veterans Affairs), IHS (Indian Health Services)

Prevalence of optimal PCC: pre-COVID vs. COVID

Figure 1.1 describes the prevalence of optimal PCC in pre-COVID and COVID by 6 PCC domains and overall. The prevalence of optimal PCC decreased during COVID in most domains, except for exchanging information. The largest decrease of 7.3% was observed for managing uncertainty. In both periods, exchanging information was the domain with the highest prevalence of optimal PCC (64.5% and 70%; pre-COVID and COVID) while managing uncertainty was the domain with the lowest prevalence of optimal PCC (47.4% and 40.1%).

Figure 1.1 The prevalence of optimal PCC+ among cancer survivors in pre-COVID (2017-19) and COVID (2020)



+ Optimal PCC: When the response was ‘always’ for each domain and when all six domains were ‘always’ for the overall PCC; * Enabling self-management (i) : Understood the next steps; Enabling self-management (ii) : Providers explained things clearly

Table 1.2 shows the mean PCC by sociodemographic and health status factors over the entire study period and in pre-COVID and COVID. The PCC mean score significantly differed in some sociodemographic subgroups by time. The PCC mean score decreased in non-Hispanic

Black/African Americans during COVID (better PCC) while PCC mean score increased during COVID (poorer PCC) compared to pre-COVID. Within each time period, those who were aged 18-49 years, were male, of Hispanic race/ethnicity, were least educated, had the lowest income (<$20,000), or did not have a usual source of care had higher than average mean PCC (poorer PCC) in both time periods. In addition, those who had generally poor physical health, a chronic medical condition (lung disease, depression) or depression or anxiety symptoms were found to have higher than the average mean PCC (poorer PCC).

Table 1.2. Mean (SE) PCC^{+} by sociodemographic and health status factors among cancer survivors

	Pre-COVID$^{\#}$	**COVID$^{\#}$**	**Overall period**
	Weighted m (SE) N=1,673^{++}	**Weighted m (SE) N=571^{++}**	**Weighted m (SE) N=2,244^{++}**
Total	19.1 (0.9)	20.7 (1.3)	19.5 (0.7)
Age (years)			
18-34	*28.9 (11.5)*	*23.6 (7.5)*	27.3 (9.0)
35-49	*22.1 (3.0)*	*28.5 (5.3)*	24.1 (2.7)
50-64	19.0 (1.4)	18.6 (1.9)	19.1 (1.2)
65-74	16.0 (1.1)	19.0 (1.8)	16.8 (0.9)
≥75	19.1 (1.7)	20.2 (2.1)	19.3 (1.3)
Gender			
Female	18.2 (1.1)	20.5 (2.0)	18.8 (1.0)
Male	*20.2 (1.4)*	*20.9 (2.2)*	20.4 (1.2)
Race/Ethnicity			
Non-Hispanic White	18.0 (0.8)	*21.1 (1.5)*	18.7 (0.7)
Non-Hispanic Black/AfricanAmerican	*24.1 (5.5)**	13.0 (2.4)*	22.0 (4.2)
Hispanic	*21.2 (5.0)*	*25.4 (4.2)*	22.4 (3.9)
Non-Hispanic Asian	*24.1 (5.0)*	15.1 (4.6)	21.4 (4.0)
Others	*23.9 (6.1)*	18.8 (10.9)	24.1 (5.4)
Education			
< High School	*31.3 (6.9)*	*27.3 (7.8)*	30.5 (7.0)
High School Grad	17.3 (1.4)	*21.9 (3.6)*	36.6 (3.6)
Some College	17.7 (1.2)	18.7 (1.9)	35.9 (2.7)
≥College Grad	*19.4 (1.1)*	*20.9 (1.3)*	29.1 (2.2)
Household income			
<$20,000	*22.9 (2.8)*	*24.5 (4.0)*	23.8 (2.3)

$20,000 to <$35,000	18.6 (2.0)	16.6 (2.7)	17.7 (1.7)
$35,000 to <$50,000	*20.9 (3.7)*	18.2 (3.0)	20.2 (2.7)
$50,000 to <$75,000	18.7 (1.5)*	*27.0 (3.6)**	21.9 (1.5)
≥$75,000	17.1 (1.1)	17.3 (1.6)	16.5 (0.9)
Marital status			
Married	18.8 (0.9)	*20.9 (1.9)*	19.4 (0.9)
Unmarried	*19.5 (1.9)*	20.2 (1.9)	19.6 (1.5)
Employment			
Employed	*19.8 (1.7)*	18.8 (2.2)	19.4 (1.3)
Unemployed	18.5 (1.2)	*21.6 (1.9)*	19.6 (1.0)
Rurality			
Metropolitan	18.7 (0.9)	*20.9 (1.6)*	19.3 (0.8)
Micropolitan	*21.4 (3.4)*	19.0 (4.7)	20.7 (2.8)
Small town	17.9 (6.0)	*22.5 (7.7)*	19.0 (4.8)
Rural	*20.3 (4.2)*	20.4 (4.3)	20.3 (3.1)
Health insurance			
Private/employment	18.6 (1.4)	*22.0 (2.5)*	19.3 (1.2)
Medicare	16.6 (0.9)	19.8 (1.6)	17.5 (0.8)
Medicaid	*23.5 (4.1)*	19.9 (4.5)	22.2 (3.2)
Tricare/VA/IHS	*21.0 (2.1)*	19.2 (3.2)	22.3 (2.4)
Others	*20.3 (2.6)*	*21.0 (4.4)*	20.5 (2.2)
Usual source of care			
Yes	17.8 (0.9)	19.9 (1.5)	18.3 (0.7)
No	*27.3 (3.2)*	*26.4 (3.6)*	27.1 (2.6)
General health status			
Excellent/good	17.5 (1.0)	19.3 (1.5)	18.0 (0.8)
Fair/poor	*23.3 (1.8)*	*25.0 (2.6)*	23.8 (1.5)
Chronic medical condition			
Diabetes	*19.2 (1.9)*	18.7 (2.4)	19.0 (1.5)
High blood pressure	*19.7 (1.2)*	20.0 (2.1)	19.8 (1.0)
Heart disease	*21.5 (2.8)*	19.7 (2.7)	21.1 (2.3)
Lung disease	*25.8 (2.6)*	*22.1 (2.8)*	24.6 (2.1)
Depression	*21.7 (1.7)*	*22.6 (2.5)*	21.9 (1.4)
Depression/Anxiety symptoms (past 2 weeks)			
Yes	*23.9 (2.0)*	*29.1 (3.4)*	25.6 (1.7)
No	16.9 (0.9)	17.2 (1.3)	16.8 (0.7)
Time since diagnosis			
< 1 year	*20.7 (2.7)*	18.7 (2.4)	22.1 (2.8)
2-5 years	18.0 (1.5)	*21.5 (2.6)*	18.3 (1.4)
6-10 years	*19.9 (2.0)*	*22.6 (4.2)*	20.6 (1.9)
≥11 years	18.7 (1.3)	20.2 (1.7)	18.7 (0.9)

Cancer type			
Breast	18.9 (1.9)	*22.5 (5.1)*	19.5 (2.0)
Cervical	*21.1 (5.0)*	*23.5 (4.0)*	20.8 (3.8)
Prostate	17.7 (2.6)	17.9 (5.9)	18.1 (2.5)
Colon	17.5 (2.9)	*21.2 (7.0)*	18.3 (2.7)
Lung	*20.3 (5.4)*	20.4 (13.5)	19.6 (5.1)
Skin	*20.8 (1.7)*	19.8 (2.3)	21.1 (1.4)
Melanoma	18.2 (4.6)	*27.2 (4.4)*	22.2 (3.1)
Multiple cancers	15.8 (1.4)	20.0 (2.1)	16.5 (1.2)
Others	*19.8 (2.5)*	17.9 (2.8)	19.3 (2.0)

Pre-COVID (HINTS 5 Cycles 1-3, 2017-2019), COVID (HINTS 5 Cycle 4, 2020); +Overall PCC score ranged from 0 (optimal) to 100 (sub-optimal), the lower score means better PCC; ++ Total cancer survivors, N = 1,956 (pre-COVID), 626 (COVID), and 2,579 (overall study period); Abbreviations: private/employment (private or employment-based insurance), VA (Veterans Affairs), IHS (Indian Health Services); Mean PCC was compared between pre-COVID and COVID by each sociodemographic and health status subgroup using t-tests (*P<0.05); in italics, if PCC mean is higher than the average (poorer PCC) within each time period.

Impact of COVID

We did not observe interactions between COVID time period and sociodemographic or health status factors with overall PCC score. Thus, associations of sociodemographic and health status factors with optimal PCC in pre-COVID and COVID were combined in Table 1.3 and Supplemental Table 1.2.

Factors associated with optimal PCC in each domain and overall

Cancer survivors during COVID (2020) were less likely to have optimal PCC than those in pre-COVID (2017-2019) in managing uncertainty (OR=0.74, 95% CI 0.55-0.99) and overall (OR=0.73, 0.54-0.98) (Table 1.3). Cancer survivors who had a usual source of care were 1.5-2 times as likely to have optimal PCC than those without it in most domains (ORs=1.64-2.29) and overall (OR=1.53, 1.04-2.25). Similarly, cancer survivors who had excellent/good general health, or had no depression or anxiety symptoms had approximately 1.5-2 times the odds of having optimal PCC than their counterparts who had poor general or mental health in most PCC domains and overall.

The second oldest group (ORs=1.37-1.61, 65-74 years) were more likely to have optimal PCC than the oldest (≥75 years) in making decisions and enabling self-management domains (Table 3). Females were more likely to have optimal PCC in exchanging information, enabling self-management, and fostering healing relationship compared to males. Hispanic cancer survivors approximately 2 times as likely to have optimal PCC than White counterparts in exchanging information and enabling self-management (ORs=1.71-1.89). Cancer survivors with middle income ($50,000 to <$75,000) were less likely to have optimal PCC compared to those with the lowest income (<$20,000) in responding to emotions, fostering healing relationship, or managing uncertainty domains (ORs=0.51-0.61). Individuals diagnosed with cancer 2-5 years ago had higher odds of having optimal PCC (ORs=1.51-1.53) in exchanging information or enabling self-management than those diagnosed 11 years ago.

In the linear regression models considering overall PCC score, most associations were similar to optimal PCC, with exception that COVID time period was not significantly related to overall PCC score (Supplemental Table 2). Sensitivity analysis revealed that the associations remained the same for most sociodemographic and health status factors, except for gender. Gender was not associated with PCC outcomes when 'always/usually' were treated as optimal PCC.

Table 1.3. Associations of sociodemographic and health status factors with optimal PCC[#] among cancer survivors[##]

	Exchanging information	Responding to emotion	Making decisions	Enabling self-mng (i)[+]	Enabling self-mng (ii)[+]	Fostering healing relationship	Managing uncertainty	Overall PCC
	aOR[++] (95%CI) N=2,264	aOR[++] (95%CI) N=2,243	aOR[++] (95%CI) N=2,258	aOR[++] (95%CI) N=2,259	aOR[++] (95% CI) N=2,257	aOR[++] (95% CI) N=2,253	aOR[++] (95% CI) N=2,233	aOR[++] (95% CI) N=2,244
Time period[@]								
COVID	1.24 (0.91-1.69)	0.85 (0.65-1.11)	0.84 (0.63-1.10)	0.84 (0.64-1.09)	0.86 (0.65-1.12)	0.80 (0.62-1.05)	0.74* (0.55-0.99)	0.73 (0.54-0.98)*
Pre-COVID	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference

Age (years)								
18-34	1.10 (0.39-3.14)	0.99 (0.33-2.96)	1.10 (0.33-3.62)	0.55 (0.20-1.45)	1.22 (0.40-3.74)	1.43 (0.45-4.48)	0.62 (0.15-2.54)	0.41 (0.12-1.36)
35-49	0.83 (0.48-1.45)	0.83 (0.49-1.44)	1.03 (0.60-1.77)	0.91 (0.54-1.53)	1.20 (0.73-1.99)	0.78 (0.46-1.31)	0.81 (0.48-1.35)	0.93 (0.52-1.68)
50-64	0.90 (0.62-1.30)	0.82 (0.60-1.13)	1.03 (0.74-1.44)	1.11 (0.79-1.56)	1.32 (0.92-1.90)	0.92 (0.67-1.27)	0.84 (0.60-1.16)	1.05 (0.76-1.46)
65-74	1.31 (0.94-1.82)	1.11 (0.81-1.51)	1.37* (1.01-1.86)	1.61* (1.14-2.25)	1.55* (1.13-2.11)	1.16 (0.87-1.54)	1.13 (0.84-1.52)	1.20 (0.88-1.64)
≥75	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
Gender								
Female	1.54* (1.13-2.08)	1.27 (0.93-1.74)	1.32 (0.97-1.80)	1.11 (0.83-1.50)	1.63* (1.18-2.77)	1.48* (1.08-2.03)	1.25 (0.90-1.72)	1.25 (0.91-1.72)
Male	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
Race/Ethnicity								
NH White	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
NH Black/ African American	0.96 (0.52-1.78)	0.90 (0.51-1.59)	0.68 (0.39-1.18)	1.08 (0.60-1.96)	0.91 (0.50-1.66)	0.95 (0.55-1.64)	0.86 (0.50-1.46)	0.97 (0.58-1.64)
Hispanic	1.76* (1.06-2.93)	1.16 (0.65-2.06)	1.53 (0.95-2.45)	1.89* (1.13-3.15)	1.71* (1.05-2.78)	1.58 (0.98-2.54)	1.53 (0.87-2.70)	1.38 (0.74-2.56)
NH Asian	0.46 (0.21-1.01)	1.11 (0.51-2.44)	0.79 (0.36-1.73)	0.86 (0.40-1.81)	1.27 (0.56-2.89)	0.72 (0.32-1.58)	0.66 (0.29-1.51)	0.69 (0.30-1.62)
Others	0.51 (0.23-1.13)	0.37* (0.17-0.79)	0.58 (0.27-1.25)	0.50 (0.22-1.15)	0.79 (0.33-1.86)	0.91 (0.41-2.05)	0.60 (0.28-1.26)	0.72 (0.34-1.49)
Education								
< High School	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
High School Grad	2.53* (1.28-5.00)	1.61 (0.80-3.24)	1.54 (0.81-2.95)	1.25 (0.66-2.38)	1.19 (0.62-2.28)	1.47 (0.74-2.94)	1.09 (0.55-2.18)	1.05 (0.56-1.97)
Some College	1.77 (0.93-3.39)	1.00 (0.51-1.94)	1.56 (0.83-2.93)	1.45 (0.77-2.73)	1.44 (0.75-2.76)	1.26 (0.65-2.45)	0.90 (0.47-1.72)	0.88 (0.47-1.67)
College Grad/more	1.53 (0.77-3.03)	0.81 (0.41-1.61)	1.35 (0.70-2.63)	0.86 (0.46-1.64)	1.17 (0.60-2.28)	0.93 (0.47-1.86)	0.67 (0.34-1.35)	0.58 (0.30-1.09)
Household income								
<$20,000	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
$20,000 to <$35,000	1.08 (0.68-1.71)	0.81 (0.51-1.30)	1.43 (0.91-2.24)	1.25 (0.78-2.01)	0.98 (0.62-1.55)	0.99 (0.64-1.53)	0.96 (0.61-1.52)	0.98 (0.63-1.54)
$35,000 to <$50,000	0.90 (0.54-1.50)	0.84 (0.51-1.40)	1.17 (0.71-1.92)	1.36 (0.83-2.23)	1.12 (0.68-1.83)	0.98 (0.58-1.66)	1.14 (0.68-1.89)	1.10 (0.68-1.79)
$50,000 to <$75,000	0.78 (0.48-1.28)	0.51* (0.32-0.82)	0.78 (0.48-1.25)	0.89 (0.54-1.49)	0.83 (0.53-1.32)	0.61* (0.38-0.99)	0.55* (0.34-0.89)	0.68 (0.43-1.09)
≥$75,000	1.54 (0.95-2.50)	1.11 (0.63-1.65)	1.19 (0.76-1.87)	1.48 (0.94-2.36)	1.44 (0.91-2.26)	1.13 (0.71-1.81)	0.99 (0.62-1.59)	1.13 (0.69-1.83)
Usual source of care								
Yes	2.29* (1.57-3.33)	1.64* (1.13-2.39)	1.70* (1.20-2.42)	1.79* (1.22-2.63)	1.76* (1.21-2.56)	1.72* (1.18-2.52)	1.34 (0.94-1.89)	1.53* (1.04-2.25)
No	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
Health status								
Excellent/good	1.21 (0.87-1.69)	1.49* (1.09-2.03)	1.48* (1.07-2.05)	1.40* (1.01-1.93)	1.33 (0.98-1.81)	1.41* (1.01-1.98)	1.56* (1.14-2.14)	1.66* (1.17-2.35)

Fair/poor	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
Depression/Anxiety symptoms (past 2 weeks)								
No	1.73* (1.25-2.39)	0.67* (0.46-0.99)	2.17* (1.60-2.95)	1.92* (1.42-2.59)	2.10* (1.56-2.83)	2.13* (1.58-2.88)	1.75* (1.30-2.34)	1.77* (1.30-2.40)
Yes	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
Time since diagnosis								
< 1 year	1.46 (0.98-2.16)	1.11 (0.73-1.67)	1.45 (0.98-2.15)	1.27 (0.88-1.83)	0.93 (0.63-1.37)	1.28 (0.83-1.96)	0.89 (0.56-1.41)	1.03 (0.67-1.61)
2-5 years	1.51* (1.03-2.21)	1.17 (0.83-1.65)	1.36 (0.97-1.92)	1.53* (1.07-2.19)	1.30 (0.90-1.87)	1.14 (0.81-1.60)	0.97 (0.68-1.39)	0.99 (0.71-1.39)
6-10 years	1.10 (0.76-1.58)	0.95 (0.67-1.35)	0.89 (0.63-1.26)	0.91 (0.66-1.26)	0.70* (0.51-0.98)	0.91 (0.64-1.29)	0.79 (0.55-1.15)	0.92 (0.62-1.38)
≥11 years	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
Cancer type								
Breast	0.95 (0.60-1.51)	0.91 (0.59-1.41)	1.04 (0.68-1.61)	1.14 (0.73-1.78)	0.93 (0.61-1.43)	0.84 (0.55-1.28)	1.08 (0.72-1.62)	0.98 (0.63-1.52)
Cervical	1.05 (0.52-2.15)	1.57 (0.81-3.05)	1.48 (0.73-2.99)	1.96 (0.95-4.07)	1.45 (0.69-3.06)	1.32 (0.67-2.58)	1.44 (0.74-2.80)	1.76 (0.89-3.51)
Prostate	1.64 (0.93-2.90)	1.90* (1.13-3.19)	1.53 (0.88-2.65)	0.94 (0.57-1.57)	1.48 (0.86-2.57)	1.67 (0.99-2.80)	1.51 (0.92-2.49)	1.69* (1.03-2.77)
Colon	1.55 (0.75-3.20)	0.95 (0.47-1.90)	2.03 (1.00-4.12)	2.17 (0.99-4.72)	1.57 (0.75-3.27)	1.06 (0.53-2.12)	1.24 (0.62-2.47)	1.25 (0.61-2.59)
Lung	0.94 (0.38-2.35)	1.65 (0.67-4.08)	2.09 (0.81-5.41)	0.96 (0.38-2.46)	1.01 (0.43-2.38)	1.61 (0.66-3.89)	2.53 (0.95-6.72)	1.57 (0.66-3.71)
Skin	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
Melanoma	1.47 (0.69-3.12)	0.80 (0.46-1.38)	1.05 (0.58-1.89)	1.24 (0.62-2.45)	1.12 (0.55-2.27)	1.14 (0.62-2.11)	0.94 (0.52-1.70)	0.95 (0.51-1.78)
Multiple cancers	1.27 (0.85-1.91)	1.17 (0.80-1.73)	1.91* (1.32-2.75)	1.54* (1.01-2.33)	1.42 (0.96-2.11)	1.31 (0.92-1.87)	1.60* (1.11-2.32)	1.26 (0.85-1.85)
Other cancers	1.14 (0.77-1.69)	1.21 (0.81-1.78)	1.40 (0.95-2.05)	1.24 (0.83-1.86)	1.28 (0.84-1.93)	1.00 (0.68-1.47)	1.34 (0.90-2.00)	1.32 (0.87-2.01)

Optimal PCC: for each domain (when the response for the domain was 'always') and for the overall PCC (when the responses for 6 domains were all 'always'): ## Total cancer survivors, N=2,579; + Enabling self-management (i): Understood next steps, Enabling self-management (ii): Provider explained things clearly; ++ Adjusted for all variables in the table; @ Pre-COVID (HINTS 5 Cycles 1-3, 2017-2019), COVID (HINTS 5 Cycle 4, 2020); Abbreviations: NH White (Non-Hispanic White), NH Black/African American (Non-Hispanic Black/African American), NH Asian (Non-Hispanic Asian); *$P<0.05$

Discussion and conclusions

Discussion

We found sociodemographic and health status factors associated with optimal PCC among cancer survivors in recent years, including during the initial SARS/COVID-19 pandemic, using nationally representative survey data. The prevalence of optimal PCC decreased in most domains and overall during the early COVID compared to pre-COVID. Cancer survivors least likely to have optimal PCC in most domains were those without a usual source of care, with depression or anxiety symptoms or poor general health status. Additionally, older, male, non-Hispanic White and middle-income cancer survivors were less likely to have optimal PCC in some PCC domains. More efforts need to be focused on improving PCC among cancer survivors, particularly those identified in this study. Multifaceted approaches may be required to enhance the perception of PCC as well as actual PCC quality through patient education and clinician training.

We observed that the overall optimal PCC prevalence was lower (6.3% lower) during COVID compared to pre-COVID among cancer survivors, particularly for responding to emotions (3.6% lower) and managing uncertainty (7.3% lower) domains. Notably, the prevalence of optimal PCC during COVID was lower than estimated from a study during 2008-2013 [18]. Cancer survivors during COVID were less likely to have optimal PCC overall and in managing uncertainty than those in pre-COVID in our study. Efforts to enhance the quality of PCC have been put into the practice[33], including educational PCC training for healthcare providers (e.g., family physician residents, nursing students) [34, 35] and attempts to improve PCC assessment tools (e.g., standardization and validation of PCC check list, engagement of patient advocate to improve PCC design and content) [36, 37]. Despite these previous efforts, the prevalence of optimal PCC has decreased over time, highlighting the need to focus more attention and resources on promoting PCC.

We observed that having depression or anxiety symptoms or poor general health status were consistently associated with sub-optimal PCC in most PCC domains among cancer survivors, findings aligned with previous reports [17–19]. While PCC is ideal at all times, under the situations like COVID pandemic, when individuals with compromised health conditions, including cancer patients, experienced additional fear, its role is particularly crucial as a channel to address those uncertainties and receive necessary care and support. Because we cannot confirm the directions of associations in our cross-sectional study, our interpretations are limited as to whether poor health status hinders optimal PCC or vice versa. However, our findings highlight the importance of preparing targeted approaches for those with poor physical or mental health to improve PCC, which has been found to be positively related to better health-related outcomes, including disease outcomes, quality of life, and mental health [9, 11, 38].

In our study, those without a usual source of care were less likely to have optimal PCC in most domains, as found previously [18]. This finding may relate to these patients lacking consistent or frequent medical encounters that enable quality patient-physician relationships that could positively affect optimal PCC [32, 39]. Previously, cancer survivors with low-income were less likely to have optimal PCC, and had a higher rate of discontinuation of treatment or disease care [40–42], which may relate to inconsistent or less frequent office visits due to financial barriers. However, in our study, those with middle income range ($50,000 to <$75,000) had lower likelihood of having optimal PCC than those with the lowest income in responding to emotion, fostering healing relationship, and managing uncertainty domains. It is notable that 16% of cancer survivors did not have a usual source of care and 18% were low income in our study.

Cancer survivors 75 years of age and older had a lower likelihood of optimal PCC than 65-74 year-olds in enabling self-management and making decisions domains. Although age was not associated with optimal PCC among cancer survivors in a previous study [18], older age has been found to be associated with optimal PCC in the U.S. adult populations [19, 32]. More than half of cancer survivors (53%) were age 70 or older in the U.S. in 2022, and it is projected to be growing [43]. Thus, our findings indicate that more resources will need to be put into the oldest group to support them to achieve optimal PCC. Perhaps, national efforts for healthy aging could potentially incorporate opportunities to inform and educate older adults to improve PCC [44, 45].

Male cancer survivors were consistently less likely to have optimal PCC than females in most domains. It aligns with the previous literature, which reported that male cancer survivors experienced sub-optimal PCC in managing uncertainty [18]. This may reflect gender differences in communicational styles, as women are more likely to share their issues or concerns with providers than men [33, 46]. Typically, care providers can be more informative and supportive when they better understand patients' issues [47]. Given the gender gap in optimal PCC widened in recent years, further investigations to understand the underlying reasons for PCC differences are warranted.

Practice implications

To improve PCC among the vulnerable cancer survivors identified in this study, educational programs and guidelines/ policies for both healthcare providers and patients are suggested to raise awareness of PCC roles for both groups and guide them to practice PCC in clinical settings [48–50]. Although there is no one simple solution, extensions of previous efforts could be considered [34, 35, 37]. For example, early-stage trainings could be offered to health professionals on performing PCC and identifying vulnerable subgroups, particularly those with poor general health or depression or anxiety symptoms. Moreover, patient advocate groups for the older or male cancer survivors could play roles in tailored patient education regarding PCC. In addition, further specifics will need to be considered, including doctors' philosophy in care [51], patients' communication style [52], and physician-patient racial/ethnic concordance [53]. Some doctors prioritize biomedical issues and physician control in care, while others value shared-decision making and patients' perspectives [39]. Also, healthcare providers are usually more responsive to the patients who ask questions and request, and share concerns, like any other social interactions [52]. Additionally, there is evidence that racial/ethnic provider-patient concordance could facilitate positive interactions and relationship [54]. Lastly, exploring opportunities to enhance optimal PCC through online opportunities (e.g., communications using Electronic Health Record to increase chances of patients engagement) are timely with the widespread use of digital devices [55, 56]. Online platforms could reach broad populations, including those without a usual source of care. Furthermore, given the rapid adoption and wide dissemination of telehealth during the pandemic, efforts may need to focus on engaging clinicians with PCC in telehealth services [21, 57].

Limitations

Some limitations need to be acknowledged. First, the present study used self-report survey data. Although the HINTS is a nationally representative, high-quality dataset, there is the possibility of reporting bias (e.g., some PCC responses could be reported subjectively, including ‘spending enough time with you’ question because the same amount of time could be enough for some and not for others). Second, the possibility of selection bias needs to be acknowledged due to not high overall response rate (33%, 2017-2020). Third, because they are cross-sectional data, we were not able to determine the direction of the associations. Fourth, the COVID data were collected from February to June 2020, during the early COVID pandemic. Hence, the findings should be interpreted in the early COVID pandemic context, and the findings may differ in later or post COVID period. Despite the limitations, this study has strengths, including the comprehensive investigations of the prevalence and associations by sociodemographic and health status factors with the optimal PCC by domains as well as the overall PCC with recent data, including in the context of the SARS/COVID-19 pandemic on a population level. This information contributes to our knowledge base of the PCC performance of vulnerable populations with chronic conditions, like cancer, during COVID.

Conclusions

Our findings highlight that cancer survivors without a usual source of care, with depression or anxiety symptoms or with poor general health status, or those who were older, males, non-Hispanic Whites, or had middle-income require additional support to achieve optimal PCC during the extended COVID pandemic. Raising awareness of PCC roles among both providers and cancer survivors and guiding them to practice it are suggested strategies to improve PCC. The knowledge generated by this study informs related stakeholders, including healthcare professionals, public health professionals and policymakers, of the subgroups of cancer survivors to target with approaches to improve PCC performance and potentially prevent further disparities in health outcomes in these vulnerable populations.

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Appendix

Supplemental Table 1.1. Sociodemographic and health status characteristics of cancer survivors during pre-COVID (2017-19, HINTS 5 Cycles 1-3) and COVID (2020, HINTS 5 Cycle 4)

	Pre-COVID (2017-19)		COVID (2020)	
	N=1,953		N=626	
	Frequency, N	weighted % (SE)	Frequency, N	weighted % (SE)
Sociodemographic characteristics				
Age (years)				
18-34	26	4.4 (1.5)	12	3.1 (1.2)
35-49	128	11.2 (1.3)	47	16.0 (3.0)
50-64	578	33.8 (1.7)	173	32.5 (3.2)
65-74	632	25.4 (1.3)	209	24.7 (2.3)
≥ 75	589	25.1 (1.2)	185	23.6 (1.9)

Gender				
Female	1120	56.9 (1.7)	370	57.0 (3.2)
Male	809	43.1 (1.7)	256	43.0 (3.2)
Race/Ethnicity				
Non-Hispanic White	1527	78.9 (1.6)	472	80.9 (2.3)
Non-Hispanic Black/African American	181	8.2 (1.3)	62	8.9 (1.8)
Hispanic	150	9.0 (1.2)	62	7.3 (1.7)
Non-Hispanic Asian	34	1.5 (0.3)	15	1.9 (0.6)
Others	61	2.3 (0.5)	15	1.0 (0.4)
Education				
Less Than High School	109	7.0 (1.2)	44	5.7 (1.3)
High School Graduate	410	26.5 (1.6)	138	29.0 (2.4)
Some College	627	38.2 (1.7)	176	36.9 (2.6)
College Graduate or More	807	28.2 (1.3)	268	28.4 (2.6)
Household income				
<$20,000	338	15.5 (1.3)	115	19.1 (2.5)
$20,000 to <$35,000	320	15.5 (1.3)	86	11.1 (2.0)
$35,000 to <$50,000	283	15.5 (1.8)	100	16.4 (2.2)
$50,000 to <$75,000	366	18.6 (1.4)	118	20.2 (2.8)
≥$75,000	646	34.9 (1.7)	207	33.1 (2.7)
Employment[c]				
Employed	325	36.3 (2.2)	182	35.3 (2.9)
Unemployed	721	63.7 (2.2)	442	64.7 (2.9)
Marital status				
Married	1016	61.2 (1.7)	322	62.6 (2.9)
Not married	937	38.8 (1.7)	304	37.4 (2.9)
Rurality				
Metropolitan	1655	82.9 (1.3)	531	78.8 (2.1)
Micropolitan	166	9.9 (1.0)	46	11.3 (2.0)
Small town	75	3.6 (0.6)	23	4.9 (1.6)
Rural	57	3.6 (0.6)	26	5.0 (1.1)
Health insurance type				
Employment and private	478	32.9 (1.8)	156	36.1 (3.0)
Medicare	751	32.4 (1.5)	252	36.6 (2.6)
Medicaid	195	14.4 (1.7)	72	13.3 (2.0)
Tricare, VA, IHS	236	10.5 (1.0)	59	6.1 (1.1)
Others	213	9.8 (0.9)	65	8.0 (1.7)
Usual source of care				
Yes	1653	83.6 (1.3)	534	84.1 (2.4)
No	300	16.4 (1.3)	92	15.9 (2.4)
General health status				
Excellent/good	1473	74.0 (1.6)	463	76.2 (2.5)

Fair/poor	480	26.0 (1.6)	163	23.8 (2.5)
Chronic medical condition				
Diabetes	517	23.9 (1.6)	176	25.6 (2.5)
High blood pressure	1139	54.5 (1.7)	377	54.5 (3.1)
Heart disease	318	15.8 (1.4)	91	13.0 (1.7)
Lung disease	320	16.2 (1.2)	132	17.9 (2.4)
Depression	438	21.8 (1.4)	152	24.8 (2.6)
Psychological distress				
Little Interest	665	36.5 (1.6)	212	35.1 (3.2)
Hopelessness	554	29.7 (1.6)	179	30.7 (3.1)
Nervousness	663	37.0 (1.7)	228	40.2 93.5)
Worrying	568	32.8 (1.8)	185	32.7 (3.5)
Time since diagnosis				
<1 year	248	13.7 (1.3)	90	14.8 (2.4)
2-5 years	421	21.9 (1.4)	118	16.9 (2.4)
6-10 years	360	18.2 (1.3)	119	19.3 (2.3)
≥ 11 years	924	46.2 (1.7)	299	49.0 (3.3)
Cancer type				
Breast	287	12.6 (1.0)	92	15.1 (2.5)
Cervical	98	6.7 (1.0)	37	7.2 (1.9)
Prostate	174	6.4 (0.7)	62	6.7 (1.2)
Colon	80	3.9 (0.7)	26	3.5 (0.6)
Lung	38	2.1 (0.5)	12	1.0 (0.4)
Skin	489	25.7 (1.6)	157	22.5 (2.2)
Melanoma	86	3.8 (0.6)	35	8.5 (2.0)
Multiple cancers	354	17.6 (1.2)	91	13.4 (1.8)
Other cancers	347	21.2 (1.9)	114	22.1 (2.6)

Missingness of covariates: pre-COVID (age 2.4 %, gender 1.2%, race/ethnicity 11.5%, education 1.6%, income 13.3%, marital status 1.8%, health insurance type 4.1%, usual source of care 1.8%, general health status 1.6%, diabetes 2.4%, high blood pressure 2.1%, heart disease 1.3%, lung disease 1.5%, depression 2.5%, little interest 2.0%, hopelessness 2.2%, nervousness 2.0%, worrying 1.9%, time since diagnosis 5.9%, cancer type1.4%); COVID (age 1.3 %, gender 0.5%, race/ethnicity 11.7%, education 3.5%, income 12.5%, marital status 2.9%, health insurance type 3.5%, usual source of care 2.7%, general health status 0.6%, diabetes 1.6%, high blood pressure 1.3%, heart disease 1.3%, lung disease 1.3%, depression 1.1%, little interest 2.4%, hopelessness 3.0%, nervousness 2.4%, worrying 2.7%, time since diagnosis 6.2%, cancer type 2.6%)

Supplemental Table 1.2. Associations of sociodemographic and health status factors with overall PCC score[+] among cancer survivors

	Overall PCC	
	Beta (SE)[++] N=2,244[#]	P value

Time period##		
COVID	1.62 (1.34)	0.228
Pre-COVID	Reference	
Age (years)		
18-34	2.68 (6.47)	0.679
35-49	2.41 (2.87)	0.401
50-64	0.47 (1.76)	0.791
65-74	-2.62 (1.59)	0.099
≥75	Reference	
Gender		
Female	-3.14 (1.46)	0.032*
Male	Reference	
Race/Ethnicity		
Non-Hispanic White	Reference	
Non-Hispanic Black/African American	0.44 (3.11)	0.888
Hispanic	-0.53 (2.92)	0.857
Non-Hispanic Asian	1.70 (3.24)	0.600
Others	7.18 (4.92)	0.145
Education		
< High School	Reference	
High School Grad	-8.49 (4.73)	0.073
Some College	-7.46 (4.54)	0.101
College Grad or more	-4.50 (4.59)	0.327
Household income		
<$20,000	Reference	
$20,000 to <$35,000	-1.74 (2.56)	0.498
$35,000 to <$50,000	-1.64 (2.94)	0.578
$50,000 to <$75,000	1.87 (2.59)	0.471
≥$75,000	-3.43 (2.44)	0.161
Health status		
Excellent/good	-4.10 (1.74)	0.019*
Fair/poor	Reference	
Time since diagnosis		
< 1 year	0.03 (2.09)	0.990
2-5 years	-1.80 (1.59)	0.258
6-10 years	2.11 (1.79)	0.240
≥11 years	Reference	
Cancer type		

Breast	0.04 (2.24)	0.987
Cervical	-3.40 (3.73)	0.362
Prostate	-3.99 (2.88)	0.167
Colon	-4.66 (3.28)	0.156
Lung	-2.12 (4.34)	0.625
Skin	Reference	
Melanoma	0.89 (3.14)	0.776
Multiple cancers	-5.38 (1.80)	0.003*
Other cancers	-2.99 (1.97)	0.129
Usual source of care		
Yes	-8.36 (2.35)	<0.001*
No	Reference	
Depression/Anxiety symptoms (past 2 weeks)		
No	-7.24 (1.74)	<0.001*
Yes	Reference	

+ Overall PCC score ranged from 0 (optimal) to 100 (suboptimal), the lower score means better PCC; ++ Adjusted for all the variables in the table; # Total cancer survivors, N=2,579; ## Pre-COVID (HINTS 5 Cycles 1-3, 2017-2019), COVID (HINTS 5 Cycle 4, 2020);* P<0.05

Chapter 2.

Factors Associated with Online Patient-Provider Communications Among Cancer Survivors in the United States during COVID: A Cross-Sectional Study.

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Abstract

Background

Online Patient-Provider Communication (OPPC) is crucial in enhancing access to health information, self-care, and related health outcomes among cancer survivors. The necessity of OPPC increased during SARS/COVID-19 (COVID), yet investigations in vulnerable subgroups have been limited.

Objective

Thus, this study aimed to assess the prevalence of OPPC and sociodemographic and clinical characteristics associated with OPPC among cancer survivors and adults without a history of cancer during COVID vs. pre-COVID.

Methods

Nationally representative cross-sectional survey data (Health Information National Trends Survey, HINTS 5 2017-2020) was used among cancer survivors (n= 1,900) and adults without a history of cancer (n= 13, 292). COVID included data from February to June 2020. We calculated the prevalence of three types of OPPC, defined as using email/internet, tablet/smartphone, or Electronic Health Records (EHR) for patient-provider communication, in the past 12 months. To investigate the associations of sociodemographic and clinical factors with OPPC, multivariable-adjusted weighted logistic regression was performed to obtain odds ratios (OR) and 95% confidence intervals (95% CI).

Results

The average prevalence of OPPC increased from pre-COVID to COVID among cancer survivors (39.7% vs. 49.7%, email/internet; 32.2% vs. 37.9%, tablet/smartphone; 19.0% vs. 30.0%, EHR). Cancer survivors (OR=1.32, 95% CI 1.06-1.63) were slightly more likely to use email/internet communications than adults without a history of cancer prior to COVID. Among cancer survivors, email/internet (OR=1.61, 1.08-2.40) and EHR (OR=1.92, 1.22-3.02) were more likely to be used during COVID than pre-COVID. During COVID, subgroups of cancer survivors, including Hispanics (OR=0.26, 0.09-0.71 vs. non-Hispanic Whites), or those with the lowest income (OR=6.14, 1.99-18.92 $50,000 to <$75,000; OR=0.42, 1.56-11.28 ≥ $75,000 vs. <$20,000), with no usual source of care (OR=6.17, 2.12-17.99), or reporting depression (OR=0.33, 0.14-0.78) were less likely to use email/internet and those who were the oldest (OR=9.33, 2.18-40.01 age 35-49; OR=3.58, 1.20-10.70 age 50-64; OR=3.09, 1.09-8.76 age 65-74 vs. ≥ 75), unmarried (OR=2.26, 1.06-4.86) or had public/no health insurance (ORs=0.19-0.21 Medicare, Medicaid, or Other, vs. private) were less likely to use tablet/smartphone to communicate with providers. Cancer survivors with a usual source of care (OR=6.23, 1.66-23.39) or healthcare office visits within a year (ORs=7.55-8.25) were significantly more likely to use EHR to communicate. While not observed in cancer survivors, lower education level was associated with lower OPPC among adults without a history of cancer during COVID.

Conclusions

Our findings identified vulnerable subgroups of cancer survivors who were left behind in online patient-provider communications which are becoming an increasing part of healthcare. Those

vulnerable subgroups of cancer survivors with lower OPPC should be helped through multidimensional interventions to prevent further inequities.

Introduction

Online patient-provider communication (OPPC) refers to using online-based tools, including email/internet, tablets/smartphones, and mobile apps, for patient-provider communication [1]. Patient-provider communication is an essential element of cancer care and is associated with improved disease management, treatment adherence and quality, better health outcomes (e.g., reduced mortality and mental distress), and superior health-related quality of life among cancer survivors [2–6]. Optimal OPPC has been found to have comparable benefits to face-to-face patient-provider communications among cancer survivors [7]. In addition, further benefits of OPPC among cancer survivors included increased access to health information, enhanced self-care ability, and increased chance to be involved in health-related decision-making [8–10].

During the SARS/COVID-19 (COVID) pandemic, the prevalence of poor mental health increased among cancer survivors [11–14]. Cancer survivors may have experienced a higher level of stress, fear, and psychological distress (e.g., nervousness, worrying) due to delayed cancer care, fear of COVID infection and poor health outcomes, or worry for cancer progression during COVID than those without cancer [11, 15–17]. Their unique situations would have required timely care and active communications with health providers to address health concerns and discuss care plans. Online-based health care became widely available in various health sectors during the early pandemic when in-person clinic visits were extremely limited owing to the pandemic [18–26]. Moreover, online-based care and communications will likely remain post-pandemic for those who have medical conditions because it became a major part of health care over the pandemic [27].

However, we do not know much about the adoption of online-based communications among cancer survivors during the early COVID pandemic, although internet or digital device use behaviors in general U.S. populations were assessed [28]. Given that OPPC use could also be a proxy of online-based care (e.g., telehealth), which is only starting to be reported in some populations (e.g., Medicare beneficiaries) [29, 30], it is important to investigate subgroups who had low OPPC practice.

Previously, only few studies identified subgroups of cancer survivors that were vulnerable to OPPC before COVID [7, 31, 32] and none, to our knowledge, during the pandemic.

Before the COVID pandemic, adoption and access to technology-based communication with providers was found to differ by some socioeconomic characteristics among cancer survivors. In a study by Jiang et al, using the national survey data (Health Information National Trends Survey, HINTS 2008-2017), income, education, age, and health status were associated with OPPC via email, mobile platforms, and electronic health records (EHR) among cancer survivors, yet the associations were inconsistent by year [7]. Two other studies, using HINTS (2003-2008 [31] and 2003-2018 [32]), found that young, highly educated, and metropolitan residing cancer survivors were more likely to email healthcare professionals. However, knowledge gaps still exist in OPPC practice among cancer survivors during COVID compared to pre-COVID. Moreover, no studies have compared OPPC use in cancer survivors to the general population in prevalence and associations. Therefore, this study aimed to evaluate whether OPPC was higher among cancer survivors during COVID than pre-COVID and identify subgroups of cancer survivors with lower adoption of OPPC compared to those without a history of cancer during COVID.

Methods

Data source

The current study used nationally representative survey data from Health Information National Trends Survey (HINTS) [33]. HINTS is a publicly available, self-administered, cross-sectional data collected by National Cancer Institute (NCI). HINTS 5 Cycles 1,2,3, and 4 data from 2017 to 2020 were used for this study. HINTS 5 Cycles 1,2, and 4 are single-mode mailed surveys that used a two-stage sampling design, yet HINTS 5 Cycle 3 is a double-mode design with a pilot push-to web survey in addition to the mailed survey. Remediated HINTS 5 Cycle 3 data was released in March 2021, and this study used the updated data. The survey questionnaires were distributed to non-institutionalized civilians aged 18 years and older in the United States. HINTS 5 applied two stratified geographic addresses with the areas of high concentration of minority population or low concentration of minority population except for HINTS 5 Cycle 1. Cycle 1 employed three stratified geographic addresses, adding the counties of Central Appalachia. The present study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines [34]. The total number of survey respondents in HINTS 5 Cycles 1-4 was 16,092 (3,285 in Cycle 1; 3,504 in Cycle 2; 5,438 in Cycle 3; 3,865 in Cycle 4). The 4-year average response rate was approximately 33% (32.4 % in Cycle 1; 32.4 % in Cycle 2; 30.3 % in Cycle 3; 36.7 % in Cycle 4) [35]. Because we needed to combine the data from 4 survey cycles, we evaluated differences in variables across the cycles and the survey mode (mailed, push-to-web with a paper return, push-to-web with web return) prior to merging the data. Because no critical discrepancies were identified in the variables of our interest by the cycle, we merged the data from 4 cycles, following the recommended analytic process provided by the HINTS. We obtained 200 replicate weights, which were used to calculate standard errors. Full sampling weights were applied for the sample to be nationally representative. The full-sample weight is intended to account for household-level base weight, non-response, person-level initial weight, and other biases [36]. Among the total respondents, excluding those who were missing questions on a history of cancer (n=221), those who reported that they had ever been diagnosed with cancer were considered as cancer survivor after further excluding those with non-melanoma skin cancer (n=1,900) and the remaining (n=13,292) were considered as adults without a history of cancer.

Outcomes

Online patient-provider communication (OPPC) was measured by 3 types of communication behaviors, including email/internet, tablet/smartphone, and EHR, as done previously [7]. Although the three types of OPPC might not be mutually exclusive, we used the following questions to measure different types and levels of participants' behaviors in technology-based patient-provider communications; 1) "In the past 12 months, have you used an email or the internet to communicate with a doctor or doctor's office?", which required basic level of technology literacy (email) and technology enabling environment (internet connection), 2) "Has your tablet or smartphone helped you in discussions with your healthcare provider?", which demanded advanced level of technology literacy (e.g., live chatting, video visits) and digital device ownership (tablet, smartphone) , 3) "In the past 12 months, have you used your online medical record to securely message health care providers and staff?", which additionally required some degree of engagement with healthcare system. The responses were either "Yes" or "No," and those who answered "Yes" to the question were considered to practice OPPC. The tablet/smartphone and EHR questions were only asked to those who owned tablet computers/smartphones or used EHR at least once in the past 12 months. In this study, those who did not have tablet/smartphone or use EHR once in the past 12 months were included in the no OPPC groups using tablet/smartphone or EHR.

Covariates

Sociodemographic characteristics

We employed the social determinants of health conceptual framework from the Healthy People 2030[37] to choose sociodemographic factors as independent variables of this study: Age (18 to 34, 35 to 49, 50 to 64, 65 to 74, 75 years or older), birth gender (male, female), race/ethnicity (non-Hispanic White, non-Hispanic Black/African American, Hispanic, non-Hispanic Asian, Other), household income (< $20,000, $20,000 to <$35,000, $35,000 to < $50,000, $50,000 to < $75,000, ≥$75,000), educational attainment (less than high school, high school graduate, some college, college graduate or more), marital status (married or living with a romantic partner as a married vs. not married including divorced, widowed, separated, single/never been married), employment status (employed vs. unemployed including homemaker, student, retired, disabled), health insurance type (insured by employment, private insurance, Medicaid, Medicare, Tricare, Veterans Affairs, Indian Health Services), a usual source of care (yes, no), number of healthcare office visits (none, 1-4 times, 5-9 times), rurality of residence (metropolitan, micropolitan, small town, rural). HINTS used the Urban-Rural Commuting Area (RUCA), which categorizes census tracts based on population density, urbanization, and commuting patterns developed by the United States Department of Agriculture to determine the rurality of residence of the respondents [38].

Clinical characteristics

Clinical characteristics included general health status (excellent/very good/good, fair/poor), chronic medical conditions (diabetes, high blood pressure, heart disease, lung disease, depression), time since cancer diagnosis (less than a year, 2-5 years, 6-10 years, more than 11 years), psychological distress (little interest, hopelessness, nervousness, worrying), and cancer type the respondents were diagnosed with, including breast, cervical, prostate, colon, lung, melanoma, bladder, bone, endometrial, head and neck, leukemia/blood, liver, lymphoma (Hodgkin and non-Hodgkin), oral, ovarian, pancreatic, pharyngeal, rectal, renal, stomach, and multiple cancer. We re-coded unknown and less prevalent cancer types, including bladder, bone, endometrial, head and neck, leukemia/blood, liver, lymphoma, oral, ovarian, pancreatic, pharyngeal, rectal, renal, and stomach cancer, as other cancer.

Statistical analysis

We conducted survey-weighted descriptive analyses to demonstrate sociodemographic and clinical characteristics of cancer survivors with frequency (n) and weighted percentage (%) during COVID (HINTS 5 Cycle 4, 2020) and pre-COVID (HINTS 5 Cycles 1-3, 2017-2019) eras. Of note, the Cycle 4 questionnaires were collected from February to June 2020. Survey weighted descriptive analyses were also performed to report the prevalence of three OPPC outcomes by sociodemographic and clinical factors among cancer survivors during pre-COVID and COVID. We used multivariable-adjusted weighted logistic regression to obtain odds ratios (ORs) and associated 95% confidence intervals (95% CIs) to examine the associations of sociodemographic factors and clinical predictors with each OPPC outcome. The psychological distress measurements were converted to depression (little interest and hopelessness) or anxiety (nervousness and worrying) symptoms using Patient-Health Questionnaire-2 (PHQ-2) or General Anxiety Disorder-2 (GAD-2) scales, respectively, and following their clinical cut-off (score ≥3, then symptom presents) [39]. Cancer survivors and adults without a history of cancer were analyzed in one model to compare the association of being a cancer survivor on each OPPC outcome after controlling for age, race/ethnicity, education, income, marital status, health insurance type, having a usual source of care, number of office visits, general health condition, chronic health condition (depression), mental health (depression or anxiety symptoms). Because being a cancer survivor was associated with OPPC outcome (email/internet use to communicate with providers, *P*=.035), we stratified cancer survivors and adults without a history of cancer to investigate the associations with sociodemographic and clinical factors. Six multivariable-adjusted weighted logistic regression models were developed for three OPPC outcomes during COVID and pre-COVID among cancer survivors. Separately, six models were developed for adults without a history of cancer (Supplemental table 1). Sociodemographic and clinical variables were included in a final model only if they were significantly associated with the outcome in univariable analyses (*P*<.05) or if they were considered a confounder for another covariate (e.g., when the covariate effect estimate changed by more than 10%). Employment status was not reported in cycle 3, so it was not included in the models due to a huge portion of data unavailability (35%). For other covariates, the range of missingness varied from 0% to 13.3%, yet mostly less than 4.5% (see footnotes of Table 1). To account for this missing data, which was considered suitable to impute, we applied a hot deck imputation method, which the HINTS used to account for the non-response [36]. Adjustments for multiple testing were not performed because the current study is not a confirmatory by design and we intended to avoid potential risk of increasing type II error [40, 41]. The statistical significance was determined at a $P < .05$ in SAS 9.4 (SAS studio 3.8, Cary, NC, USA).

Ethical considerations

This study used the publicly available national survey data, Health Information National Trends Survey (HINTS). The current study was a secondary analysis of survey data, and the human subject was not involved as well as identifiable information was not included. Given that the data are deidentified, this was deemed exempt from review by the Institutional Review Board at the University of California, Davis.

Results

Description of cancer survivors

Among 1,900 cancer survivors, 1,444 were surveyed pre-COVID (2017-2019), and 456 were surveyed during the COVID pandemic (2020). There were no significant differences between the characteristics of the cancer survivors in pre-COVID and COVID eras (Table 2.1). Nearly half (48%) were aged 65 years or older, 59% were female, 79% were non-Hispanic White race/ethnicity, 63% had some college education or more, 63% were married, 62% had public/government-aided health insurance, 84% had a usual source of care, and 91% had healthcare office visits at least once within a year. Clinically, 73% reported that their general health status was good, while 56% reported high blood pressure, 28% had diabetes, 24% had depression, and 12% and 13% reported that they had depressive and anxiety symptoms in the past two weeks, respectively. Nearly half of cancer survivors (46%) were 11 years or more from cancer diagnosis (Table 2.1).

Table 2.1. Sociodemographic and clinical characteristics of cancer survivors during pre-COVID (2017-19, HINTS 5 Cycles 1-3) and COVID (2020, HINTS 5 Cycle 4)

	Pre-COVID (2017-19)[a]		COVID (2020)[a]	
	N=1,444[b]		N=456[b]	
	Frequency, N	Weighted % (SE)	Frequency, N	Weighted % (SE)
Sociodemographic characteristics				
Age (years)				
18-34	22	5.7 (2.0)	9	2.3 (0.8)
35-49	99	11.8 (1.6)	31	17.5 (3.7)
50-64	412	31.8 (1.9)	127	32.8 (4.0)
65-74	477	25.5 (1.6)	155	25.5 (2.6)
≥ 75	434	25.2 (1.6)	134	22.0 (2.3)
Gender				
Female	875	59.5 (2.0)	272	58.8 (4.0)
Male	569	40.5 (2.0)	184	41.2 (4.0)
Race/Ethnicity				
Non-Hispanic White	1057	73.8 (2.0)	329	79.3 (2.6)
Non-Hispanic Black/African American	179	11.0 (1.7)	53	8.3 (1.5)
Hispanic	120	10.2 (1.5)	53	9.0 (2.2)
Non-Hispanic Asian	33	2.0 (0.5)	10	1.5 (0.6)
Others	55	3.1 (0.7)	11	1.8 (1.0)
Education				
Less Than High School	88	7.5 (1.6)	39	7.0 (1.7)
High School Graduate	315	26.9 (2.0)	104	30.0 (3.1)
Some College	481	40.1 (2.0)	137	39.9 (3.3)
College Graduate or More	560	25.6 (1.5)	176	23.1 (2.9)
Household income				
<$20,000	284	16.9 (1.7)	100	21.9 (3.0)
$20,000 to <$35,000	242	15.9 (1.4)	73	12.5 (2.2)
$35,000 to <$50,000	194	14.9 (2.3)	72	16.3 (2.6)
$50,000 to <$75,000	285	19.4 (1.7)	78	19.0 (3.1)
≥$75,000	439	32.8 (2.0)	133	30.2 (2.9)
Employment[c]				
Employed	228	36.2 (2.5)	126	34.8 (3.7)
Unemployed	535	63.8 (2.5)	328	65.2 (3.7)
Marital status				

Married	729	59.6 (2.1)	228	63.3 (3.4)
Not married	715	40.4 (2.1)	228	36.7 (3.4)
Rurality				
Metropolitan	1221	83.6 (1.5)	386	78.7 (2.6)
Micropolitan	127	9.9 (1.2)	33	10.9 (2.6)
Small town	56	3.1 (0.6)	18	5.6 (2.1)
Rural	40	3.4 (0.7)	19	4.7 (1.5)
Health insurance type				
Employment and private	359	31.6 (2.1)	118	37.9 (3.7)
Medicare	570	31.9 (1.7)	179	32.4 (2.9)
Medicaid	174	16.6 (2.2)	70	16.7 (2.5)
Tricare, VA, IHS	173	9.9 (1.2)	40	4.9 (1.1)
Others	168	10.1 (1.0)	49	8.0 (2.1)
Usual source of care				
Yes	1205	82.9 (1.4)	392	83.7 (3.2)
No	239	17.1 (1.4)	64	16.3 (3.2)
Number of office visits (year)				
None	86	7.4 (1.3)	36	9.5 (2.7)
1-4 times	791	56.9 (2.5)	234	50.6 (4.0)
5-9 times	567	35.8 (2.2)	186	39.9 (3.7)
Clinical characteristics				
General health status				
Excellent/good	1073	72.6 (1.9)	322	73.1 (3.0)
Fair/poor	371	27.4 (1.9)	134	26.9 (3.0)
Chronic medical condition (Ever told)				
Diabetes	415	24.9 (1.8)	149	27.7 (3.0)
High blood pressure	860	54.5 (2.1)	283	55.5 (3.5)
Heart disease	248	15.6 (1.5)	66	11.6 (1.9)
Lung disease	243	16.1 (1.2)	106	20.2 (2.9)
Depression	332	22.7 (1.7)	111	24.0 (2.8)
Mental health (past 2 weeks)				
Depression symptom	203	16.0 (1.9)	62	11.6 (2.0)
Anxiety symptom	168	12.6 (1.4)	60	13.4 (2.2)
Time since diagnosis				
<1 year	177	13.3 (1.5)	67	16.1 (3.1)
2-5 years	313	21.5(1.8)	87	18.2 (2.9)
6-10 years	268	16.6 (1.4)	91	19.6 (2.4)
≥ 11 years	686	48.7 (2.0)	211	46.0 (3.7)
Cancer type				
Breast	282	17.0 (1.4)	88	19.2 (3.3)
Cervical	96	8.9 (1.4)	36	9.4 (2.5)
Prostate	173	8.6 (1.0)	61	8.8 (1.5)

Colon	80	5.4 (0.9)	26	4.6 (0.9)
Lung	37	2.8 (0.6)	12	1.3 (0.5)
Melanoma	85	5.1 (0.9)	33	10.9 (2.6)
Multiple cancers	348	23.7 (1.6)	90	17.4 (2.4)
Other cancers	343	28.5 (2.4)	110	28.4 (3.5)

a. Missingness of covariates: pre-COVID (age 2.1 %, gender 1.0%, race/ethnicity 11.9%, education 1.5%, income 13.0%, marital status 1.7%, health insurance type 4.4%, usual source of care 1.8%, general health status 1.5%, diabetes 2.8%, high blood pressure 2.4%, heart disease 1.6%, lung disease 1.7%, depression 2.6%, time since diagnosis 4.8%, cancer type 1.9%); COVID (age 1.3 %, gender 0.7%, race/ethnicity 12.5%, education 3.9%, income 11.0%, marital status 2.9%, health insurance type 3.7%, usual source of care 3.3%, general health status 0.7%, diabetes 1.8%, high blood pressure 1.3%, heart disease 1.5%, lung disease 1.8%, depression 1.3, time since diagnosis 4.4%, cancer type 3.5%); b. Covariates with any missing values were imputed in Table 1; c. Employment data is not reported in Cycle 3, n=681 unavailable; Abbreviations (VA: Veterans Affairs; IHS: Indian Health Services)

Prevalence of OPPC among cancer survivors compared to adults without a history of cancer

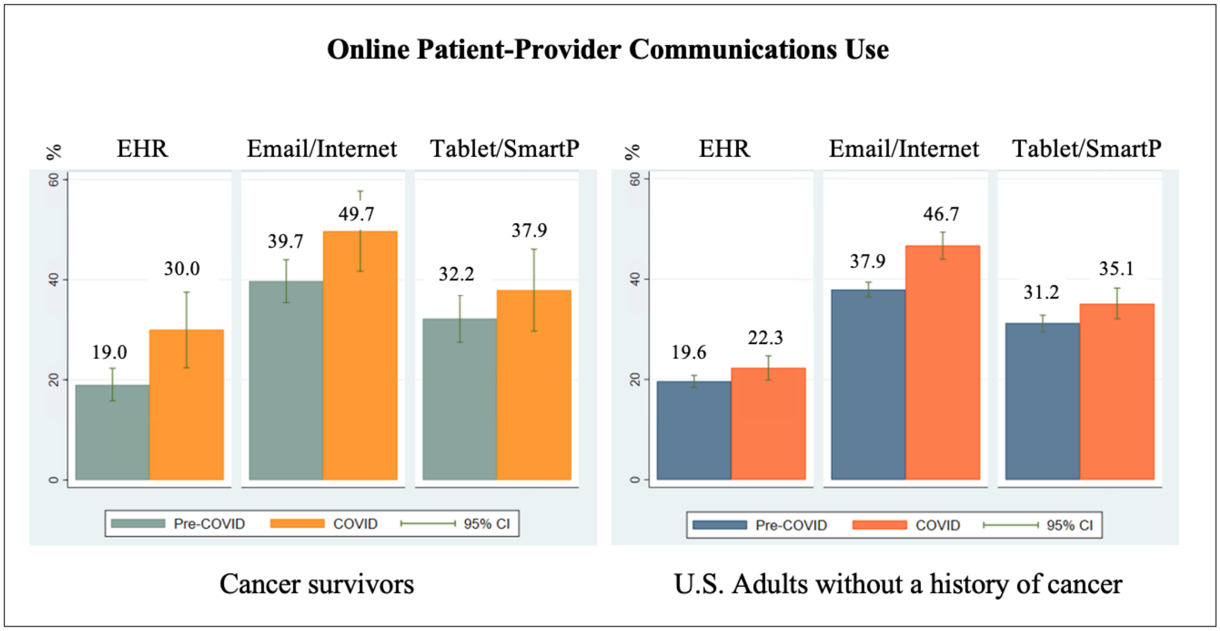
The average prevalence of OPPC increased pre-COVID to COVID among cancer survivors (39.7% to 49.7% for email/internet use for communications with provider/office, 32.2% to 37.9% for tablet/smartphone use for discussions with providers, and 19.0% to 30.0% for EHR use for messaging providers during pre-COVID) (Figure 2.1). The average prevalence of OPPC among cancer survivors was similar to adults without a history of cancer in pre-COVID (29%), but higher among cancer survivors during COVID. In multivariable models, cancer survivors were approximately1.3 times as likely to use email/internet in pre-COVID than adults without a history of cancer (Table 2.2).

Table 2.2. Associations of a history of cancer with OPPC outcomes

History of cancer	pre-COVID (2017-2019)^{a}			COVID (2020)^{a}		
	Email/Internet aOR^{b}(95%CI) N=11,351	Tablet/SmartP aOR^{b} (95%CI) N=10,759	EHR aOR^{b} (95%CI) N=9,751	Email/Internet aOR^{b}(95%CI) N=3,568	Tablet/SmartP aOR^{b}(95%CI) N=3,554	EHR aOR^{b}(95%CI) N=3,541
Yes	1.32 (1.06-1.63)*	1.21 (0.95-1.54)	0.98 (0.78-1.23)	1.28 (0.87-1.88)	1.20 (0.86-1.70)	1.39 (0.92-2.12)
No	Reference	Reference	Reference	Reference	Reference	Reference

a. Total sample size: pre-COVID (N=11,718), COVID (N=3,695); b. Adjusted by age, race/ethnicity, education, income, marital status, health insurance type, having a usual source of care, number of office visits, general health condition, chronic medical condition (depression), mental health (depression or anxiety symptoms); *P <.05; Abbreviations (SmartP: smartphone, EHR: Electronic Health Record)

Figure 2.1. Prevalence of OPPC during pre-COVID (2017-19) and COVID (2020)



Prevalence of OPPC was presented as weighted %; Cancer survivor (N=1,900) and U.S. Adults without a history of cancer (N=13,292); EHR=EHR use to send messages to the providers or clinic staffs; Email/Internet=Email or internet use to communicate with providers or offices; Tablet/SmartP=Tablet or smartphone use to discuss with providers

Prevalence of OPPC by sociodemographic and clinical factors during pre-COVID and COVID

Table 2.3 shows the prevalence of OPPC by sociodemographic and clinical factors among cancer survivors before and during COVID. In general, cancer survivors who were younger than 65 years, more educated (some college or more education), with high income ($50,000 or more), married, employed, metropolitan residents, holding private/employment-based insurance, had a usual source of care or healthcare office visits, those with good general health status and chronic medical conditions (e.g., depression), recently diagnosed (less than 6 years) or diagnosed with breast cancer showed a high prevalence of OPPC than the average in both periods. While the prevalence of OPPC was similar between pre-COVID and COVID for most sociodemographic and clinical subgroups, there were some noticeable differences during COVID. Cancer survivors of non-Hispanic White race/ethnicity had higher than the average prevalence in all three types of OPPC during COVID, while non-Hispanic Asians had higher OPPC before COVID.

Table 2.3. Prevalence of online patient-provider communication by sociodemographic factors among cancer survivors

	pre-COVID			COVID		
	Email/Internet Weighted % (SE)	Tab/SmartP Weighted % (SE)	EHR Weighted % (SE)	Email/Internet Weighted % (SE)	Tab/SmartP Weighted % (SE)	EHR Weighted % (SE)
Average prevalence, %	39.7 (2.2)	32.2 (2.4)	19.0 (1.6)	49.7 (4.0)	37.9 (4.1)	30.0 (3.8)
Age (years)						
18-34	*53.0 (21.8)*	*56.8 (22.1)*	7.7 (5.2)	*67.8 (23.9)*	*40.6 (24.5)*	6.3 (7.0)
35-49	*50.5 (6.4)*	*36.4 (7.4)*	*31.4 (6.1)*	*58.8 (13.9)*	*69.8 (13.2)*	21.5 (9.3)
50-64	*46.4 (4.1)*	*35.7 (3.9)*	*19.9 (2.6)*	*57.2 (7.1)*	*50.0 (6.3)*	*45.3 (7.5)*
65-74	39.1 (3.3)	*35.0 (3.2)*	*20.3 (2.8)*	40.8 (5.2)	23.7 (5.1)	25.0 (4.9)
≥ 75	23.2 (3.1)	15.6 (2.5)	12.9 (2.4)	39.0 (6.6)	9.9 (3.1)	21.0 (6.6)
Gender						
Female	37.1 (2.6)	29.7 (2.5)	*19.5 (2.1)*	46.2 (6.0)	*41.6 (5.5)*	27.2 (4.6)
Male	*43.6 (4.0)*	*35.8 (4.1)*	18.4 (2.8)	*54.8 (4.5)*	33.0 (6.3)	*34.0 (5.2)*
Race/Ethnicity						
Non-Hispanic White	*40.3 (2.2)*	29.0 (2.1)	*20.6 (1.8)*	*53.5 (4.4)*	*38.3 (4.7)*	*31.4 (4.3)*
Non-Hispanic Black/African American	*44.5 (10.8)*	*43.9 (11.9)*	10.7 (3.7)	30.6 (7.8)	27.8 (8.1)	26.6 (7.9)
Hispanic	28.7 (7.0)	*36.8 (8.4)*	14.4 (6.7)	35.2 (11.8)	*43.5 (10.8)*	24.4 (11.6)
Non-Hispanic Asian	*50.2 (11.9)*	*50.3 (12.3)*	*36.5 (15.6)*	35.0 (18.3)	35.2 (18.7)	18.1 (14.2)
Others	38.8 (14.3)	*43.7 (15.6)*	16.1 (7.8)	*59.6 (30.0)*	*47.8 (35.7)*	17.2 (13.9)
Education						
< High School	29.9 (18.5)	*36.4 (20.0)*	3.8 (3.0)	30.2 (13.0)	11.2 (6.3)	20.9 (12.0)
High School Grad	25.8 (3.7)	24.4 (4.0)	11.8 (2.7)	44.2 (7.9)	37.2 (8.5)	19.0 (6.6)
Some College	*42.5 (3.7)*	*33.8 (3.6)*	17.2 (2.8)	46.2 (6.6)	*38.7 (6.6)*	28.8 (5.7)
College Grad/ More	*52.4 (3.1)*	*36.2 (2.9)*	*32.7 (3.2)*	*69.8 (4.2)*	*46.1 (7.0)*	*50.0 (7.2)*
Household income						
< $20,000	17.9 (3.2)	20.4 (4.2)	8.2 (2.1)	27.7 (6.7)	30.7 (8.8)	16.0 (5.5)
$20,000 to <$35,000	29.4 (4.4)	26.3 (4.7)	15.2 (3.3)	30.2 (9.3)	21.5 (6.8)	15.7 (4.8)
$35,000 to <$50,000	*42.3 (7.2)*	*35.4 (10.6)*	17.9 (5.0)	48.7 (8.9)	28.2 (6.6)	28.5 (7.7)
$50,000 to <$75,000	*44.6 (4.8)*	*37.7 (4.7)*	*20.8 (3.7)*	*65.1 (8.8)*	*45.9 (10.4)*	29.3 (7.9)
$75,000 and more	*51.8 (3.5)*	*35.8 (3.7)*	*25.4 (3.0)*	*63.5 (7.1)*	*48.7 (7.4)*	*47.3 (8.5)*
Marital status						

Married	*44.1 (2.4)*	*34.0 (2.7)*	*20.9 (2.1)*	*54.1 (5.2)*	*44.8 (5.5)*	*34.7 (5.5)*
Not married	33.3 (4.0)	29.5 (4.2)	16.2 (2.4)	42.0 (6.4)	24.8 (4.2)	21.6 (4.9)
Employment						
Employed	*49.4 (4.8)*	*33.8 (4.8)*	*21.8 (4.0)*	*65.6 (7.4)*	*59.7 (6.8)*	*39.3 (8.0)*
Unemployed	31.0 (3.3)	31.0 (3.7)	16.1 (2.7)	41.1 (4.1)	26.3 (4.6)	24.9 (2.9)
Rurality						
Metropolitan	*42.5 (2.4)*	*34.0 (2.6)*	*19.7 (1.9)*	*51.2 (4.5)*	*38.6 (4.5)*	*30.7 (4.0)*
Micropolitan	28.0 (5.2)	20.4 (5.5)	16.9 (4.8)	*51.1 (14.7)*	35.2 (17.3)	*43.5 (16.4)*
Small town	26.6 (7.2)	30.4 (8.7)	14.7 (6.8)	10.7 (10.9)	34.5 (33.4)	10.5 (11.8)
Rural	16.2 (7.8)	23.8 (9.7)	12.7 (7.0)	*68.2 (18.0)*	36.9 (19.5)	8.5 (5.6)
Health insurance						
Employment/private	*55.9 (4.2)*	*36.8 (4.2)*	*23.8 (3.1)*	*64.9 (7.3)*	*65.6 (6.0)*	*43.6 (8.0)*
Medicare	34.2 (2.8)	27.0 (2.7)	*20.5 (2.5)*	39.2 (5.3)	17.2 (3.7)	22.6 (4.2)
Medicaid	31.4 (8.9)	*37.5 (9.5)*	13.4 (4.3)	40.8 (10.7)	26.0 (7.7)	17.0 (6.8)
Tricare, VA, IHS	29.0 (5.3)	30.3 (5.2)	13.4 (4.4)	*60.1 (12.9)*	29.8 (9.3)	*32.0 (11.0)*
Others	30.3 (4.5)	26.7 (5.0)	14.7 (3.9)	35.1 (7.8)	18.9 (4.9)	23.2 (6.1)
Usual source of care						
Yes	*42.3 (2.5)*	*34.8 (2.7)*	*20.9 (2.0)*	*53.6 (4.1)*	37.8 (4.7)	*34.2 (4.0)*
No	27.5 (4.5)	20.0 (4.0)	8.9 (2.4)	26.6 (11.8)	*38.6 (14.9)*	5.7 (2.9)
Number of office visits						
None	20.6 (6.6)	10.7 (4.9)	7.9 (6.3)	43.9 (16.3)	30.3 (19.5)	3.9 (2.7)
1-4 times	*39.8 (2.9)*	30.5 (3.3)	16.0 (2.0)	47.7 (5.2)	37.6 (6.1)	*31.9 (4.7)*
5-9 times	*43.6 (3.4)*	*39.7 (3.7)*	*25.7 (3.1)*	*53.7 (6.7)*	*39.9 (6.8)*	*33.5 (5.6)*
Health status						
Excellent/good	*42.6 (2.5)*	30.9 (2.8)	*19.5 (2.0)*	*54.9 (4.5)*	*43.5 (4.5)*	*32.0 (4.4)*
Fair/poor	31.9 (3.8)	*35.9 (4.4)*	17.9 (3.0)	35.4 (6.4)	23.0 (5.4)	24.7 (5.9)
Chronic condition (Ever diagnosed)						
Diabetes	35.5 (4.0)	29.1 (4.1)	18.4 (3.3)	47.7 (7.3)	32.6 (6.9)	*32.5 (7.7)*
High blood pressure	37.2 (2.6)	30.7 (2.4)	*19.5 (2.2)*	*51.6 (4.4)*	33.2 (5.7)	*33.1 (5.1)*
Heart disease	36.7 (4.9)	*33.2 (5.1)*	*20.1 (4.3)*	37.5 (8.4)	27.6 (7.4)	23.1 (6.3)
Lung disease	32.9 (4.6)	30.2 (4.9)	18.2 (4.0)	43.6 (6.2)	33.6 (7.6)	30.0 (5.6)
Depression	*44.4 (3.9)*	*38.1 (4.6)*	*23.9 (4.0)*	38.4 (7.3)	*38.9 (7.5)*	26.3 (5.9)
Mental Health (Past 2 weeks)						
Depression symptom	*41.2 (8.1)*	*38.3 (8.9)*	15.7 (4.4)	40.1 (9.3)	27.3 (10.0)	21.1 (7.8)
Anxiety symptom	*42.3 (5.8)*	*36.0 (5.8)*	*20.4 (5.1)*	46.0 (9.5)	36.0 (9.7)	28.4 (8.4)
Time since diagnosis						
Less than 1 year	*43.9 (6.2)*	*36.4 (6.6)*	*19.4 (4.9)*	*63.8 (10.2)*	*54.8 (12.1)*	*32.7 (10.1)*
2-5 years	*49.5 (5.5)*	*43.7 (6.2)*	*25.0 (4.3)*	47.2 (8.8)	35.0 (8.6)	*30.2 (8.2)*

6-10 years	39.4 (4.2)	29.0 (3.9)	*22.5 (4.1)*	38.9 (9.3)	32.4 (9.4)	19.0 (5.3)
More than 11 years	34.3 (3.1)	27.0 (2.7)	14.9 (2.1)	*50.3 (5.7)*	35.3 (5.4)	*33.2 (5.9)*
Cancer type						
Breast	*39.9 (4.0)*	*36.8 (4.5)*	*23.6 (3.9)*	*55.8 (9.1)*	*52.2 (9.1)*	*32.3 (8.1)*
Cervical	*41.7 (7.9)*	31.1 (7.8)	*22.9 (7.0)*	49.7 (16.4)	*39.4 (15.1)*	27.2 (13.8)
Prostate	34.1 (5.2)	29.3 (4.9)	12.6 (3.5)	48.4 (11.3)	18.9 (7.1)	*35.2 (10.3)*
Colon	*42.2 (10.9)*	*50.2 (11.2)*	10.6 (8.1)	45.0 (12.9)	26.8 (10.7)	24.6 (10.0)
Lung	19.8 (8.5)	11.2 (6.8)	7.0 (3.6)	38.2 (22.2)	*41.4 (21.5)*	7.6 (6.3)
Melanoma	*45.5 (8.9)*	20.8 (5.9)	*23.6 (7.9)*	*52.8 (14.1)*	*40.0 (17.0)*	*31.3 (14.0)*
Multiple cancers	*43.0 (4.5)*	31.5 (3.7)	*22.0 (3.5)*	49.3 (9.7)	20.8 (5.6)	29.6 (7.8)
Other cancers	38.6 (5.2)	*32.4 (5.6)*	16.5 (2.8)	46.2 (8.2)	*45.0 (9.3)*	29.3 (7.3)

Abbreviations (SmartP: smartphone, EHR: Electronic Health Record, VA: Veterans Affairs, IHS: Indian Health Services); *Italics*: Prevalence is higher than the average

Sociodemographic and clinical factors associated with OPPC among cancer survivors during pre-COVID vs. COVID

Email/internet and EHR-based communications were 1.5-2 times as likely to be used during COVID than pre-COVID (OR=1.61, 95% CI 1.08-2.40 email/internet; OR=1.92, 1.22-3.02 EHR). In pre-COVID, younger age groups (18-74 years old) had nearly 2-9 times the odds of using email/internet, tablet/smartphone, or EHR to communicate with the providers compared to those 75 years or older (Table 4). Cancer survivors with a higher annual income ($20,000 or more) were 2-3.5 times as likely to communicate electronically with the providers via email/internet, tablet/smartphone, or EHR than those with less than $20,000 of income. Those insured by private or employment-based plans had 2 times the odds of using email/internet for communications than those with public/government-supported insurance (ORs=0.41-0.49 Medicaid, Tricare/VA/IHS, Other). Those who were recently diagnosed with cancer (2-5 years) were nearly 2 times as likely to use email/internet, tablet/smartphone, or EHR for communications with provider/office as those diagnosed more than 10 years ago (OR=2.02, 95% CI 1.23-3.33; OR=1.86, 1.14-3.03; OR=2.30, 1.29-4.11, respectively). Those with a usual source of healthcare had 2.5 times (OR=2.55, 1.21-5.38) the odds of using EHR and had healthcare office visits at least once had 4-6 times (ORs=4.46-5.91) the odds of using tablet/smartphone to communicate with providers compared to those without a usual source of care or office visits. Breast cancer survivors were more likely to use tablet/smartphone and EHR than lung cancer survivors to communicate with providers.

During COVID, cancer survivors with a usual source of care had 6 times the odds of using email/internet (OR=6.17, 2.12-17.99) or EHR (OR=6.23, 1.66-23.39) to communicate with provider/office (Table 2.4). Moreover, those who had healthcare office visits at least once within a year were 8 times as likely to use EHR to send messages to the provider (OR=8.25, 1.61-42.18 1-4 times; OR=7.55, 1.56-36.60 5-9 times) than those without any office visits. Hispanic cancer survivors (OR=0.26, 0.09-0.71) were significantly less likely to use email/internet to communicate with provider/office than non-Hispanic White counterparts. Cancer survivors with more income (≥$50,000 vs. <$20,000) had 4-6 times the odds of using email/internet for communications with provider/office. Cancer survivors reporting a history of depression diagnosis were less likely to use email/internet to communicate with provider/office (OR=0.33, 0.14-0.78). The oldest individuals (≥75 years) were significantly less likely to use tablet/smartphone to discuss with providers than younger counterparts (ORs=3.09-9.33, 35-74 years). Married cancer survivors were 2 times as likely to use tablet/smartphone for communications (OR=2.26, 1.06-4.86). Cancer survivors insured by Medicare (OR=0.21, 0.08-0.54), Medicaid (OR=0.19, 0.06-0.61), or other types of health plans (OR=0.20, 0.07-0.58) were significantly less likely to discuss with providers via tablet/smartphone than those with private or employment-based insurance.

Table 2.4. Associations of sociodemographic and clinical factors with OPPC among cancer survivors pre-COVID (2017-2019) and COVID (2020)

	Email/Internet	Tablet/SmartP	EHR
Time period	aOR[b] (95%CI)	aOR[b] (95%CI)	aOR[b] (95%CI)
COVID	1.61 (1.08-2.40)*	1.40 (0.90-2.20)	1.92 (1.22-3.02)*
Pre-COVID	Reference	Reference	Reference

	pre-COVID (2017-2019)[a]	COVID[a]

	Email/Internet	Tablet/Smart P	EHR	Email/Internet	Tablet/Smart P	EHR
	aOR^b (95%CI)	aOR^b (95%CI)	aOR^b (95%CI)	aOR^b (95%CI)	aOR^b (95%CI)	aOR^b (95%CI)
	N=1,411	N=1,307	N=1,229	N=446	N=441	N=444
Age (years)						
18-34	7.43 (2.47-22.29)*	9.59 (3.03-30.35)*	0.87 (0.21-3.65)	5.38 (0.65-44.88)	1.04 (0.03-39.71)	0.40 (0.01-11.97)
35-49	2.52 (1.18-5.39)*	2.85 (1.26-6.46)*	2.52 (1.03-6.19)*	3.53 (0.55-22.47)	9.33 (2.18-40.01)*	1.13 (0.18-7.14)
50-64	2.30 (1.30-4.06)*	2.85 (1.62-5.01)*	1.47 (0.69-3.11)	1.74 (0.43-7.10)	3.58 (1.20-10.70)*	1.94 (0.38-9.82)
65-74	2.16 (1.36-3.43)*	2.91 (1.81-4.66)*	1.53 (0.86-2.73)	1.25 (0.45-3.43)	3.09 (1.09-8.76)*	1.31 (0.42-4.13)
≥75	Reference	Reference	Reference	Reference	Reference	Reference
Race/Ethnicity						
Non-Hispanic White	Reference	Reference	Reference	Reference	Reference	Reference
Non-Hispanic Black/African	1.37 (0.72-2.63)	1.87 (0.98-3.57)	0.58 (0.25-1.33)	0.64 (0.24-1.69)	1.16 (0.46-2.92)	1.04 (0.32-3.38)
Hispanic	0.60 (0.29-1.27)	2.67 (0.49-2.79)	0.83 (0.28-2.43)	0.26 (0.09-0.71)*	1.14 (0.32-4.05)	0.47 (0.16-1.39)
Non-Hispanic Asian	1.27 (0.51-3.13)	2.67 (0.93-7.64)	2.11 (0.66-6.70)	0.32 (0.07-1.40)	1.33 (0.17-10.78)	0.47 (0.07-3.31)
Others	0.78 (0.34-1.82)	1.09 (0.38-3.11)	0.98 (0.30-3.23)	1.62 (0.30-8.89)	1.39 (0.17-11.41)	0.47 (0.08-2.62)
Education						
Less Than High School	Reference	Reference	Reference	Reference	Reference	Reference
High School Graduate	0.99 (0.41-2.38)	0.65 (0.25-1.74)	2.37 (0.45-12.57)	0.67 (0.13-3.61)	2.54 (0.35-18.35)	0.48 (0.07-3.46)
Some College	1.64 (0.71-3.78)	0.96 (0.41-2.24)	2.93 (0.59-14.65)	0.90 (0.18-4.60)	2.61 (0.33-20.58)	0.80 (0.12-5.37)
College Grad or More	1.94 (0.78-4.81)	1.00 (0.41-2.47)	6.24 (1.22-32.05)*	1.75 (0.40-7.62)	2.88 (0.34-24.23)	1.76 (0.27-11.38)
Income						
< $20,000	Reference	Reference	Reference	Reference	Reference	Reference
$20,000 to < $35,000	2.03 (1.00-4.11)*	2.41 (1.07-5.40)*	1.79 (0.76-4.23)	2.08 (0.61-7.07)	1.04 (0.31-3.55)	0.79 (0.21-2.91)
$35,000 to < $50,000	3.40 (1.70-6.82)*	2.88 (1.22-6.80)*	2.14 (0.94-4.91)	2.69 (0.77-9.38)	0.66 (0.20-2.16)	1.51 (0.38-6.03)
$50,000 to < $75,000	3.26 (1.69-6.29)*	3.22 (1.56-6.66)*	2.20 (1.06-4.56)*	6.14 (1.99-18.92)*	2.07 (0.34-3.33)	1.67 (0.53-5.23)
≥$75,000	3.55 (1.82-6.90)*	3.03 (1.46-6.28)*	2.36 (1.05-5.31)*	4.20 (1.56-11.28)*	0.99 (0.32-3.09)	1.59 (0.52-4.85)
Marital status						
Married	1.10	1.20	0.83	0.88	2.26	1.09

	(0.72-1.69)	(0.80-1.81)	(0.52-1.32)	(0.46-1.67)	(1.06-4.86)*	(0.54-2.20)
Not married	Reference	Reference	Reference	Reference	Reference	Reference
Health insurance						
Private or by employment	Reference	Reference	Reference	Reference	Reference	Reference
Medicare	0.65 (0.38-1.10)	0.99 (0.54-1.83)	1.19 (0.58-2.43)	0.47 (0.16-1.35)	0.21 (0.08-0.54)*	0.41 (0.13-1.35)
Medicaid	0.48 (0.25-0.91)*	1.01 (0.49-2.11)	0.88 (0.37-2.11)	0.83 (0.24-2.90)	0.19 (0.06-0.61)*	0.36 (0.11-1.21)
Tricare/VA/IHS	0.41 (0.21-0.80)*	1.05 (0.53-2.09)	0.61 (0.26-1.44)	1.42 (0.39-5.26)	0.69 (0.21-2.29)	0.89 (0.21-3.78)
Others	0.49 (0.27-0.89)*	0.88 (0.43-1.79)	0.71 (0.29-1.75)	0.34 (0.09-1.37)	0.20 (0.07-0.58)*	0.34 (0.010-1.21)
Usual source of care						
Yes	1.58 (0.88-2.84)	1.58 (0.91-2.76)	2.55 (1.21-5.38)*	6.17 (2.12-17.99)*	0.98 (0.26-3.69)	6.23 (1.66-23.39)*
No	Reference	Reference	Reference	Reference	Reference	Reference
Number of office visits (year)						
None	Reference	Reference	Reference	Reference	Reference	Reference
1-4 times	2.05 (0.73-5.77)	4.46 (1.49-13.37)*	1.98 (0.51-7.60)	0.83 (0.26-2.63)	2.15 (0.50-9.25)	8.25 (1.61-42.18)*
5-9 times	2.55 (0.90-7.22)	5.91 (1.94-17.97)*	2.85 (0.67-12.02)	1.18 (0.35-3.97)	2.32 (0.52-10.34)	7.55 (1.56-36.60)*
Health status						
Excellent/good	1.36 (0.87-2.12)	0.79 (0.49-1.28)	0.81 (0.45-1.48)	1.52 (0.64-3.63)	1.94 (0.82-4.60)	0.84 (0.35-2.00)
Fair/poor	Reference	Reference	Reference	Reference	Reference	Reference
Chronic condition						
Depression	1.46 (0.93-2.29)	1.43 (0.88-2.32)	1.43 (0.80-2.57)	0.33 (0.14-0.78)*	1.59 (0.55-4.55)	0.73 (0.32-1.70)
No depression	Reference	Reference	Reference	Reference	Reference	Reference
Mental health (Past 2 weeks)						
Depression symptoms	1.35 (0.69-2.66)	1.10 (0.56-2.17)	0.87 (0.39-1.92)	0.99 (0.24-4.10)	0.52 (0.14-2.00)	0.41 (0.07-2.29)
No symptoms	Reference	Reference	Reference	Reference	Reference	Reference
Anxiety symptoms	1.23 (0.61-2.48)	1.10 (0.54-2.23)	1.24 (0.53-2.88)	2.21 (0.51-9.61)	1.52 (0.29-7.93)	2.14 (0.53-8.62)
No symptoms	Reference	Reference	Reference	Reference	Reference	Reference
Time since diagnosis						
< 1 year	1.56 (0.88-2.77)	1.49 (0.81-2.74)	1.36 (0.65-2.84)	1.26 (0.47-3.40)	2.15 (0.69-6.69)	0.88 (0.24-3.15)

2-5 years	2.02 (1.23-3.33)*	1.86 (1.14-3.03)*	2.30 (1.29-4.11)*	0.97 (0.40-2.39)	0.54 (0.18-1.63)	1.17 (0.50-2.70)
6-10 years	1.21 (0.76-1.92)	0.99 (0.60-1.61)	1.83 (0.97-3.43)	0.47 (0.20-1.09)	0.59 (0.26-1.35)	0.42 (0.15-1.18)
>11 years	Reference	Reference	Reference	Reference	Reference	Reference
Cancer type						
Breast	Reference	Reference	Reference	Reference	Reference	Reference
Cervical	0.94 (0.40-2.21)	0.61 (0.26-1.43)	1.28 (0.51-3.22)	0.90 (0.26-3.10)	0.41 (0.13-1.30)	1.58 (0.31-8.22)
Prostate	1.01 (0.51-1.97)	0.79 (0.41-1.53)	0.43 (0.17-1.09)	1.17 (0.38-3.57)	0.26 (0.09-0.77)*	1.65 (0.48-5.69)
Colon	1.08 (0.45-2.57)	1.47 (0.60-3.59)	0.40 (0.10-1.66)	1.74 (0.42-7.21)	0.0.87 (0.22-3.45)	1.60 (0.36-7.01)
Lung	0.41 (0.14-1.20)	0.14 (0.04-0.47)*	0.26 (0.08-0.86)*	1.68 (0.25-11.27)	3.21 (0.59-17.42)	0.26 (0.02-2.92)
Melanoma	0.99 (0.39-2.49)	0.41 (0.17-1.00)	0.85 (0.31-2.33)	0.97 (0.24-3.92)	0.39 (0.08-1.98)	0.82 (0.18-3.71)
Multiple cancers	1.81 (0.97-3.36)	0.99 (0.56-1.78)	1.18 (0.63-2.22)	1.07 (0.32-3.65)	0.42 (0.14-1.28)	1.14 (0.31-4.20)
Other cancers	0.88 (0.48-1.59)	0.62 (0.35-1.07)	0.72 (0.38-1.36)	0.90 (0.32-2.53)	0.61 (0.24-1.58)	1.26 (0.38-4.18)

a. Total sample size: pre-COVID (N=1,444), COVID (N=456); b. Adjusted for all the variables in the Table; **P* < .05; Abbreviations (SmartP: smartphone, EHR: Electronic Health Record, VA: Veterans Affairs, IHS: Indian Health Services)

Cancer survivors vs. adults without a history of cancer

Among cancer survivors (Table 2.4) and adults without a history of cancer (Supplemental table 2.1), those with a usual source of care were 2-6 times as likely to do OPPC than those without the source in pre-COVID and COVID. Among those without a history of cancer in both periods, those who were more educated were 2-6 times and those who reported depression were 1.5-2 times as likely to use OPPC (Supplemental table 2.1). However, among cancer survivors, we did not observe associations with education and found that depression was inversely associated with OPPC.

Discussion

Principal results

Using nationally representative survey data in the U.S. from 2017 to 2020, we identified that having a usual source of care or healthcare office visits were strongly associated with three types of OPPC and different sociodemographic and clinical characteristics were associated with OPPC among cancer survivors and adults without a history of cancer during pre-COVID and COVID eras. Cancer survivors were more likely to use email/internet to communicate with the providers than those without a history of cancer prior to COVID pandemic, yet no difference was found during the early pandemic. However, the OPPC uses were higher during COVID than pre-COVID among cancer survivors. During COVID, subgroups of cancer survivors were less likely to use OPPC, including cancer survivors with the oldest age (≥ 75 years), who were of Hispanic race/ethnicity, with the lowest income, who were unmarried, with no usual source of care or no visits to the health providers, who had public/no health insurance, or who reported having depression. On the other hand, lower education level was associated with lower OPPC among adults without a history of cancer during COVID. Our findings identified vulnerable subgroups of cancer survivors who were left behind in OPPC, communications which are becoming an increasing part of healthcare [19–21, 24].

During COVID, but not prior to the pandemic, cancer survivors who were not married or had Medicare, Medicaid, or other health plans, including no insurance, were significantly less likely to use a tablet/smartphone to communicate with providers. Our marital status findings are consistent with prior studies that found individuals living with a spouse or partner were more likely to perform healthy behaviors (e.g., a higher success rate of quitting tobacco [42, 43]). Differences by health insurance could be related to the surge of telehealth use among those with private/employment-based insurance when major insurance companies started reimbursement for telehealth services in early 2020 [44]. The CMS also expanded healthcare professionals to provide telemedicine to increase telehealth access and increased its use including telephone/audio-only or e-visit [45–47]. However, CMS's effort to create enabling environment for telehealth use might not have been enough for cancer survivors with Medicare or Medicaid to increase their use of mobile devices (e.g., tablets/smartphones) for communications with providers compared to those with private/employment-based insurance.

While racial/ethnic differences were not observed among cancer survivors prior to COVID in this study and previously [7, 31, 32], we observed that Hispanic cancer survivors were significantly less likely to have online communications with providers/offices via email/internet than their non-Hispanic White counterparts during COVID. Early in the pandemic, Hispanic populations had higher rates of COVID-related hospitalization, Intensive Care Unit admission or in-hospital death[48, 49], which could have related to a higher prevalence of chronic diseases [50] or having more unmet healthcare needs [51]. In our study, chronic disease prevalence was not significantly different between racial/ethnic groups, but we were unable to account for unmet health care needs, other than lacking a usual source of care, that could have resulted in less use of online tools to communicate with providers.

Before COVID, cancer survivors ≥75 years were least likely to practice OPPC via email, internet, tablet, smartphone. This was also observed among adults without a history of cancer in this study, which aligned with the previous literature [28]. Prior studies suggest that adults 65 years and older had less interest in exchanging medical information online with providers [52], less frequently used social media for health communication [53], and less frequently used the internet to search for health information [54] compared to younger generations. This could be potentially due to lower eHealth literacy or higher computer stress among the oldest (≥ 70 years) compared with younger individuals [55–57]. Older individuals had poorer COVID outcomes [58] and a higher level of fear of COVID [59], hence their demands of OPPC might have been high to avoid possible exposures during our study period, yet barriers noted above could have limited their uses. In addition, low income was significantly associated with lower OPPC among cancer survivors before COVID, consistent with low income being strongly associated with low health technology use in the general population [52, 55]. Specifically, low-income older adults designated a lack of financial resources as a barrier to technology access and ownership [60]. However, these strong associations with low income in OPPC were less evident among cancer survivors during COVID, suggesting that lacking financial resources was less of a barrier to OPPC use in the early COVID pandemic period. Because older age and low income have been associated with eHealth activities, including OPPC, further investigations are warranted to confirm if they remain in the extended COVID period.

Notably, we observed different associations between depression and education with use of OPPC among cancer survivors compared to adults without a cancer history. In our study, cancer survivors reporting depression as a chronic condition were less likely to use email/internet to communicate with providers than their counterparts during COVID. Prior studies either did not find associations [31] or did not assess associations of depression with OPPC [7, 32]. However, depression was associated with use of all three types of OPPC among adults without a history of cancer in pre-COVID and COVID. The differing associations with OPPC among cancer survivors will need to be further investigated to determine whether our findings were specific to conditions in the early pandemic period that generated extreme mental distress. In addition, even though less educated adults without a history of cancer were less likely to use OPPC during COVID and pre-COVID, these associations were not observed among cancer survivors in our study. In contrast to our findings, two prior studies (2003-2008 [31] and 2003-2018 [32]) reported that highly educated cancer survivors were more likely to email providers [7]. Given the widespread use of email/internet, education-level may impact OPPC use less compared to other factors, such as access or eHealth literacy that have been found to impact use more recently [55]. Therefore, our findings suggest that education level might not be a barrier to cancer survivors' OPPC.

In this study, 16% of cancer survivors and 36% of U.S. adults without a history of cancer reported no usual source of care, which was consistently associated with lower OPPC use among both cancer survivors and adults without a history of cancer before and during COVID. The likelihood of OPPC use among cancer survivors with a usual source of care appeared to be stronger during COVID. In addition, visiting the health provider's office was strongly associated with EHR-based communications during the pandemic. One potential explanation could be that it would have been easier for those who had a usual source of care or had recent office visits to connect with providers online than those without it, particularly when in-person office visits were extremely limited under the Stay Home Order in 2020. Previous studies have not considered usual source of care when assessing OPPC among cancer survivors [7, 31, 32]. However, it has been associated with OPPC in the general population [61]. To increase usual source of care among cancer survivors, enhancing insurance coverage (e.g., Medicaid expansion [51]) will need to be prioritized to improve healthcare access in underserved populations [62]. In addition, improving perceived quality of care and physician trust [63, 64] could improve healthcare seeking behaviors [65, 66].

Given that OPPC is a combination of health technology use and healthcare-seeking behavior, it requires a multi-faceted approach to support it among cancer survivors. Prior studies have identified that health technology use is impacted by low digital device ownership, internet access, and lack of technical assistance [29, 67, 68] and healthcare-seeking is lower among racial/ethnic minority populations and those with poor patient-provider relationship [63, 69]. Our study adds to this knowledge base by identifying vulnerable subgroups in OPPC. Interventions to improve OPPC should incorporate comprehensive and consistent health policies to cover diverse tele-visits (e.g., audio only calls, video conferences), enhancing eHealth literacy, and increasing access to digital devices. Given OPPC is technology-based communications, an effort to improve eHealth literacy among the targeted groups (e.g., low-SES) is recommended along with creating a technology-enabling environment [54]. One example of improving health literacy was done through a nation-wide Adult Basic Education (ABE) network collaborated with community health organizations [70, 71] by raising awareness of health literacy among ABE registered low-literate individuals and implementing pilot projects into the targeted population via peers (e.g., peer language navigators [72]). In addition, qualitative studies are suggested for a deeper understanding of barriers and facilitators of OPPC in the vulnerable subgroups identified in this study.

Limitations

This study has some limitations. First, because we used cross-sectional survey data, we cannot determine the prospective and longitudinal associations with OPPC. Second, although the data used in this study was high-quality national survey data, it carries inevitable weakness originating from self-reporting, the possibilities of reporting bias (e.g., communicated with providers via EHR more than 12 months ago, but reported it as within 12 months, intentionally or unintentionally). Third, due to the questionnaire time frame (In the past 12 months), it is possible that our outcome measurements during COVID could have captured respondents' behaviors before COVID. Fourth, the overall response rate of an average 33% during the study period could result in selection bias. However, HINTS applied full sample weights and conducted imputation to minimize non-response. Fifth, the COVID sample size was smaller than the pre-COVID sample size (2017-19) since the year 2020 was the only available data for COVID. Further, the HINTS 5 Cycle 4 questionnaires were administered and collected in the first half year of 2020 (February through June). Hence, we need to interpret the findings of this study from the context of the early COVID pandemic period.

Conclusions

Our findings suggest that cancer survivors who were older, had no usual source of care or healthcare office visits, were low income, had public or no health insurance, were of Hispanic ethnicity, were unmarried, or reported depression were less likely to use OPPC during COVID, findings that differed from associations in adults without a history of cancer. As OPPC are becoming an increasing part of healthcare, we will need to continue to evaluate disparities in utilization in the extended COVID period. Strategies to increase use of OPPC include improvement in health policies to cover virtual-visits, interventions to enhance eHealth literacy, and community-based or nationwide efforts to expand health technology access. Our findings identify vulnerable subgroups of cancer survivors with lower OPPC that can be targeted through multidimensional interventions to prevent further inequities.

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Appendix

Supplemental table 2.1. Associations of sociodemographic and clinical factors with OPPC among non-cancer populations pre-COVID (2017-2019) and COVID (2020)

	pre-COVID (2017-2019)[a]			COVID[a]		
	Email/Internet	Tablet/Smart P	EHR	Email/Internet	Tablet/Smart P	EHR
	aOR[b] (95%CI)	aOR[b] (95%CI)	aOR[b] (95%CI)	aOR[b] (95%CI)	aOR[b] (95%CI)	aOR[b] (95%CI)
	N=9,940	N=9,452	N=8,522	N=3,122	N=3.113	N=3,097
Age (years)						
18-34	2.77 (1.96-3.91)*	2.56 (1.79-3.66)*	2.25 (1.38-3.69)*	3.28 (2.08-5.20)*	3.20 (1.51-6.78)*	2.37 (1.12-5.05)*
35-49	2.83 (2.05-3.89)*	2.50 (1.81-3.46)*	2.36 (1.48-3.75)*	3.66 (2.26-5.95)*	3.75 (1.76-8.02)*	2.66 (1.39-5.10)*
50-64	2.17 (1.58-2.97)*	1.86 (1.40-2.48)*	1.76 (1.12-2.76)*	2.43 (1.57-3.77)*	2.61 (1.36-5.01)*	2.11 (1.11-4.01)*
65-74	1.54 (1.16-2.05)*	1.52 (1.14-2.03)*	1.73 (1.18-2.53)*	2.24 (1.48-3.40)*	2.34 (1.28-4.29)*	2.06 (1.19-3.57)*
≥75	Reference	Reference	Reference	Reference	Reference	Reference

Race/Ethnicity						
Non-Hispanic White	Reference	Reference	Reference	Reference	Reference	Reference
Non-Hispanic Black/African	1.06 (0.84-1.33)	1.22 (0.96-1.55)	1.13 (0.83-1.54)	1.26 (0.78-2.04)	2.27 (1.54-3.34)*	1.45 (0.96-2.18)
Hispanic	0.93 (0.75-1.16)	0.98 (0.80-1.21)	0.90 (0.69-1.17)	1.38 (0.93-2.03)	1.16 (0.80-1.66)	0.90 (0.61-1.33)
Non-Hispanic Asian	1.37 (0.95-1.96)	1.40 (1.01-1.95)*	1.13 (0.77-1.66)	0.92 (0.54-1.56)	1.65 (0.99-2.74)	2.46 (1.31-4.63)*
Others	1.22 (0.80-1.86)	1.06 (0.66-1.71)	1.70 (0.96-3.03)	1.85 (0.83-4.13)	0.97 (0.55-1.71)	0.56 (0.25-1.27)
Education						
Less Than High School	Reference	Reference	Reference	Reference	Reference	Reference
High School Graduate	1.76 (1.14-2.73)*	1.94 (1.31-2.87)*	1.52 (0.73-3.17)	0.94 (0.41-2.15)	1.26 (0.69-2.29)	3.49 (1.39-8.74)*
Some College	3.31 (2.18-5.03)*	2.87 (1.95-4.22)*	2.42 (1.17-5.01)*	1.50 (0.69-3.26)	1.80 (1.03-3.13)*	3.59 (1.43-8.98)*
College Grad or More	4.76 (3.08-7.33)*	3.72 (2.54-5.45)*	3.14 (1.50-6.56)*	3.26 (1.53-6.98)*	2.65 (1.46-4.80)*	6.47 (2.60-16.09)*
Income						
< $20,000	Reference	Reference	Reference	Reference	Reference	Reference
$20,000 to < $35,000	1.01 (0.71-1.44)	1.15 (0.79-1.66)	1.03 (0.64-1.66)	1.21 (0.76-1.94)	0.99 (0.59-1.67)	1.07 (0.52-2.18)
$35,000 to < $50,000	1.38 (1.00-1.91)*	1.16 (0.81-1.65)	0.98 (0.61-1.57)	1.38 (0.86-2.21)	1.20 (0.70-2.06)	2.04 (0.95-4.38)
$50,000 to < $75,000	1.82 (1.29-2.56)*	1.33 (0.94-1.89)	1.64 (1.02-2.64)*	1.55 (0.91-2.65)	1.47 (0.87-2.47)	1.68 (0.82-3.44)
≥$75,000	2.60 (1.88-3.59)*	1.37 (0.98-1.92)	1.76 (1.12-2.78)*	1.71 (1.09-2.68)*	1.37 (0.80-2.33)	1.81 (0.94-3.47)
Marital status						
Married	1.10 (0.96-1.26)	1.19 (1.01-1.40)*	1.13 (0.93-1.38)	1.20 (0.92-1.57)	1.61 (1.18-2.20)*	1.40 (1.05-1.86)*
Not married	Reference	Reference	Reference	Reference	Reference	Reference
Health insurance						
Private or by employment	Reference	Reference	Reference	Reference	Reference	Reference
Medicare	1.00 (0.76-1.33)	0.75 (0.57-1.00)	0.90 (0.61-1.33)	0.93 (0.58-1.47)	0.81 (0.47-1.39)	0.96 (0.54-1.68)
Medicaid	0.86 (0.63-1.18)	1.03 (0.75-1.43)	0.84 (0.56-1.25)	0.98 (0.66-1.44)	1.50 (1.01-2.21)*	0.70 (0.40-1.21)
Tricare/VA/IHS	1.14 (0.78-1.66)	0.93 (0.65-1.31)	1.02 (0.69-1.53)	0.92 (0.60-1.42)	1.11 (0.65-1.91)	0.93 (0.54-1.63)
Others	0.99 (0.73-1.34)	1.00 (0.74-1.35)	0.95 (0.61-1.49)	0.51 (0.33-0.80)*	1.06 (0.64-1.77)	0.62 (0.34-1.11)
Regular provider						

Yes	1.66 (1.35-2.04)*	1.58 (1.26-1.97)*	2.33 (1.83-2.95)*	1.76 (1.30-2.39)*	1.68 (1.24-2.29)*	2.29 (1.50-3.50)*
No	Reference	Reference	Reference	Reference	Reference	Reference
Number of office visits (yearly)						
None	Reference	Reference	Reference	Reference	Reference	Reference
1-4 times	2.09 (1.64-1.66)*	1.70 (1.34-2.17)*	3.15 (2.12-4.68)*	2.52 (1.67-3.81)*	1.97 (1.35-2.86)*	3.46 (1.85-6.48)*
5-9 times	3.18 (2.40-4.23)*	2.60 (1.93-3.50)*	4.16 (2.70-6.40)*	4.62 (2.88-7.39)*	3.57 (2.09-6.08)*	6.30 (3.36-11.80)*
Health status						
Excellent/good	1.49 (1.16-1.91)*	1.07 (0.84-1.36)	1.06 (0.81-1.39)	1.26 (0.81-1.98)	1.10 (0.73-1.65)	0.90 (0.55-1.46)
Fair/poor	Reference	Reference	Reference	Reference	Reference	Reference
Medical condition						
Depression	1.42 (1.17-1.74)*	1.33 (1.07-1.65)*	1.54 (1.23-1.92)*	2.15 (1.55-2.98)*	2.24 (1.57-3.21)*	2.32 (1.52-3.55)*
No depression	Reference	Reference	Reference	Reference	Reference	Reference
Mental health (past 2 weeks)						
Depression symptom	1.06 (0.77-1.46)	1.16 (0.82-1.64)	1.00 (0.71-1.42)	0.95 (0.61-1.47)	0.84 (0.54-1.30)	0.94 (0.61-1.46)
No symptom	Reference	Reference	Reference	Reference	Reference	Reference
Anxiety symptom	1.12 (0.83-1.50)	1.30 (0.91-1.86)	0.86 (0.8-1.36)	1.00 (0.57-1.73)	0.73 (0.43-1.25)	0.83 (0.51-1.36)
No symptom	Reference	Reference	Reference	Reference	Reference	Reference

a. Total sample size: pre-COVID (N=10,124), COVID (N=3,168); b. Adjusted for all the variables in the Table; *P-value < 0.05; Abbreviations (SmartP: smartphone, EHR: Electronic Health Record, VA: Veterans Affairs, IHS: Indian Health Services)

Chapter 3.

Mental Health Among Cancer Survivors and Adults Without a History of Cancer in the United States Prior to and During Early SARS/COVID-19 Pandemic

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Abstract

Background

Poor mental health has been found to be more common among cancer survivors compared to those without a history of cancer. However, prior studies, to our knowledge, have not examined the impact of SARS/COVID-19 (COVID) on mental health, encompassing depression/anxiety and psychological distress, among cancer survivors compared to U.S. adults without a history of cancer using the same study population.

Objectives

This study aimed to assess the association of sociodemographic factors, health status characteristics, and patient-provider communication practices with poor mental health among cancer survivors and adults without a history of cancer during COVID compared to pre-COVID.

Methods

Nationally representative cross-sectional data (Health Information National Trends Survey, HINTS 5 2017-2020) was used for those with cancer (n=2,579) and without cancer (n=13,292) in pre-COVID (2017-2019) and COVID (2020). We calculated the prevalence of poor mental health through weighted descriptive analyses and evaluated differences between cancer survivors and those without a history of cancer by time period using Differences-In-Differences (D-I-D). To obtain odds ratios (ORs) and 95% confidence intervals (95% CIs) of online patient-provider communications (OPPC), sociodemographic factors and health status characteristics with poor mental health, we developed multivariable weighted logistic regression models.

Results

The prevalence of poor mental health increased during COVID, with a similar prevalence observed for both cancer survivors (41.9%) and adults without a history of cancer (40.2%) during COVID. D-I-D analyses revealed that changes in poor mental health prior to and during COVID among cancer survivors compared to adults without a history of cancer were not significantly different. In multivariable models, individuals who had OPPC use (OR=1.39 95% CI 1.20-1.60 email/internet/tablet/smartphone), were young (ORs=1.98-3.25 18-64 years vs. ≥75 years), were females (OR=1.59, 1.39-1.80), were non-Hispanic Whites (vs. Hispanics, non-Hispanic Black/African Americans and Asians), were least educated (vs. college graduate OR=0.72, 0.56-0.94), had lowest income (vs. ≥$20,000 ORs=0.37-0.63), and had poor general health (vs. excellent health OR=0.31, 0.26-0.37) were more likely to have poor mental health. History of cancer and the early COVID pandemic were not associated with poor mental health.

Conclusions

The prevalence of poor mental health was high during the early COVID pandemic. We identified subgroups of adults with poor mental health, including those with OPPC use, with low socioeconomic status or who were younger. Our findings highlight the importance of targeted approaches for these vulnerable subgroups, such as through partnering with communities or local governments, involving related stakeholders, or applying life skills training.

Introduction

Poor mental health, including anxiety, depression, and psychological distress, affects individuals' well-being and quality of life[1]. Poor mental health has been found to be more common among cancer survivors than those without a history of cancer due to the disease-related concerns, including cancer recurrence, modified body image, or challenges in long-term healthcare needs[2]. It has been reported to negatively impact treatment adherence, self-management, and mortality among cancer survivors[3–6]. Approximately 25% to 40% of cancer survivors experienced poor mental health in 2019[7]. Previously, cancer survivors of Black/African American race/ethnicity, who were unmarried, with lower income, with lower education, who live in a rural residence, or have low health literacy were reported to have poorer mental health[8–13]. As communications with healthcare providers play an important role in psychological distress management, optimal quality of patient centered communication (PCC) style[14,15] and online-based communications with providers[16–19] have shown to benefit managing poor mental health.

Under the unprecedented SARS/COVID-19 pandemic, psychosocial distress or depression increased in the general population[20–22] as well as among cancer survivors[23–25] worldwide. However, studies in the U.S. have observed mixed findings. Health Information National Trends Survey (HINTS) cross-sectional data reported that the prevalence of depression/anxiety slightly decreased among cancer survivors in the U.S. during COVID (2019 vs. 2020), but did not compare estimates to adults without a history of cancer[26]. Alternatively, the COVID-19 Impact Study using 2020 cross-sectional data reported that cancer survivors had more mental health symptoms, including feeling nervous, anxious, hopeless, lonely, and depressed, than their non-cancer counterparts during COVID[27]. Last, a study using longitudinal data of 5 U.S. regions (Thinking and Living With Cancer) found that depression and anxiety worsened to a similar extent between breast cancer survivors ≥ 60 years of age and those without cancer during the pandemic[28]. Prior studies, to our knowledge, have not examined the impact of COVID on mental health, encompassing depression/anxiety and psychological distress, among cancer survivors compared to U.S. adults without a history of cancer using the same study population. Additionally, chronic medical conditions have not been assessed for potential associations with poor mental health previously among cancer survivors during COVID[26]. Moreover, during the pandemic, PCC was significantly associated with cancer survivors' mental health[29], and online patient-provider communication (OPPC) became an essential channel to address psychological distress[30–32]. However, no studies have investigated the associations of PCC and OPPC with mental health accounting for sociodemographic and clinical factors.

Therefore, this study used HINTS data to assess changes in mental health before (2017-2019) and during COVID (2020), in cancer survivors compared to adults without a history of cancer. In addition, we examined the associations of the quality of PCC and OPPC with mental health after accounting for sociodemographic and clinical factors. The findings of our study will identify those with poor mental health and inform targeted approaches to improve mental health outcomes.

Methods

Data source

Health Information National Trends Survey (HINTS), a nationally representative survey distributed and collected by the National Cancer Institute (NCI) was used for the study. HINTS is a self-administered, publicly available, cross-sectional survey. The present study used HINTS 5 Cycles 1, 2, 3, and 4 (2017-2020). Of note, the COVID sample (2020) was collected from January to June 2020. The respondents of the survey questionnaires were non-institutionalized civilians 18 years and older in the United States. HINTS 5 Cycles 2, 3, and 4 have two geographic stratum: areas with low and high minority concentrations. HINTS 5 Cycle 1 had one more geographic stratum: area in the Central Appalachia. HINTS 5 was single-mode mailed surveys with a two-stage sampling design in Cycles 1, 2, and 4 and a double-mode design with a pilot push-to web survey in addition to the mailed survey in Cycle 3. HINTS 5 Cycle 3 was remediated and updated in March, 2021 and we used the most recent version of HINTS data. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines[33]. The total number of respondents in HINTS 5 Cycles 1-4 was 16,092. The average response rate was 33% (32.4% in Cycle 1 [n=3,285]; 32.4% in Cycle 2 [n=3,504]; 30.3% in Cycle 3 [n=5,438]; 36.7% in Cycle 4 [n=3,865])[34]. Among the total respondents, those who reported a history of cancer diagnosis were designated as cancer survivors (n=2,579) and the rest were considered as adults without a history of cancer (n=13,292) after excluding those who missed reporting their history of cancer information (n=221). We merged the four iterations (HINTS 5 Cycles 1-4) and obtained 200 replicate weights following the analytic suggestions from HINTS after confirming that there were no significant differences between variables of each iteration. The full-sample weights were applied to account for household-level base weight, non-response, and person-level initial weight[35].

Outcome

Mental health was measured by depression/anxiety diagnosis and psychological distress symptoms. To determine depression/anxiety diagnosis status, the question "Has a doctor or other healthcare professional ever told you that you had depression or anxiety disorder?" was used with the responses of “yes,” or “no.” To define psychological distress symptoms, the question “Over the past two weeks, how often have you been bothered by any of the following problems? 1) little interest in doing things, 2) feeling down, depressed, hopeless, 3) feeling nervous or anxious, 4) not being able to stop or control worrying” was used. These four questions were the same as those on the Patient Health Questionnaire (PHQ-4), a brief form commonly used to assess mental health[36,37]. The responses were measured by a Likert scale (1=always, 2=usually, 3=sometimes, 4=never). The scores from the four questions were summed to compute a total score, ranging from 4 (the worst) to 16 (the best). This total score was recoded as 'yes' for the score of 4-13 (mild/moderate/severe) and 'no' for the score of 14-16 (normal), following the PHQ-4's cut-off approach[36] to represent psychological distress. As a last step, we created a new mental health variable with depression/anxiety and total psychological distress score. If either depression/anxiety or the new psychological distress was 'yes,' then it was coded as poor mental health.

<u>*Covariates*</u>

Patient-Centered Communications (PCC)

PCC was measured by the following seven questions that represent the main PCC functions that affect health outcomes, defined by the National Cancer Institute (NCI)[38]. "In your communication with all doctors, nurses, or other health professionals in the past 12 months, how often did they 1) give you the chance to ask health questions, 2) had the attention you needed to your feelings and emotions, 3) involve you in decisions about your health care as much as you wanted, 4) make sure you understood the things you needed to do to take care of your health, 5) explain things in a way you could understand, 6) spend enough time with you, 7) help you deal with uncertain feelings about your health or health care?"[38] Responses for each question were measured on a Likert scale (1=always, 2=usually, 3=sometimes, 4=never). Responses to the seven questions were combined and recoded using the Likert scale numbers to generate a new continuous PCC outcome, ranging from score 0 (the least optimal, when all 7 questions were scored "never") to score 100 (the most optimal, when all 7 questions were scored "always")[39]. We also created a binary PCC variable with categories for optimal (when all 7 responses were 'always') and sub-optimal (any response of usually, sometimes or never).

Online Patient-Provider Communications (OPPC)

OPPC was measured by 3 types of communication behaviors, as done previously[40], using the following questions; 1) “In the past 12 months, have you used an email or the internet to communicate with a doctor or doctor's office?”, 2) "Has your tablet or smartphone helped you in discussions with your healthcare provider?", 3)"In the past 12 months, have you used your online medical record to securely message health care providers and staff?". The response to each question was either “yes” or “no.” The tablet/smartphone and EHR questions were only asked to those who owned tablet computers/smartphones or used EHR at least once in the past 12 months. In this study, those who did not have tablet/smartphone or use EHR once in the past 12 months were included in the no digital device use groups.

Sociodemographic and clinical characteristics

We chose sociodemographic factors as independent variables of this study based on the social determinants of health conceptual framework from the Healthy People 2030[41]: Age, birth gender, race/ethnicity, household income, educational attainment, marital status, employment status, health insurance type, a usual source of care, and rurality of residence. HINTS used Urban Rural Commuting Area (RUCA) to designate the rurality of residence of the survey respondents, which categorized census tracts using population density, urbanization, and commuting patterns developed by the United States Department of Agriculture [42]. Clinical factors included general health status, chronic medical conditions (diabetes, high blood pressure, heart disease, lung disease), time since cancer diagnosis, psychological distress, and diagnosed cancer type among survivors.

Statistical analysis

We conducted descriptive analyses to present sociodemographic and clinical characteristics of cancer survivors and adults without a history of cancer prior to and during COVID using means with standard errors (SE) or weighted percentages (%) with SE. The prevalence of poor mental health was estimated using weighted percentage (%) with SE by sociodemographic and clinical characteristics. The mean PCC score with SE was estimated among cancer survivors and those without a history of cancer in pre-COVID and COVID.

We conducted Differences-In-Differences (D-I-D) analysis in a weighted logistic regression model to identify the differences in the odds of poor mental health from pre- to during COVID, among cancer survivors compared to those without a history of cancer. The D-I-D of the odds of poor mental health were reported as an odds ratio (OR) with 95% confidence interval (95% CI). D-I-D analyses were adjusted for age, gender, race/ethnicity, education, household income, general health status, and the chronic medical condition of lung disease because these variables were associated with mental health in prior studies[8,12,22,26] or were confounders in our analyses (i.e., changed covariate estimates by more than 10%). Additionally, we stratified the D-I-D analysis by PCC quality (optimal vs. sub-optimal) and OPPC (yes vs. no for Email/Internet communication, Tablet/Smartphone for discussion, EHR message) to identify changes in poor mental health by time-period and patient communication status adjusting for the same covariates.

In addition, we developed a multivariable-adjusted weighted logistic regression model to examine the associations of history of cancer, COVID time period, PCC and OPPC with mental health after accounting for sociodemographic and clinical factors. We assessed the interactions of PCC (composite score) and three digital device use measures with both time-period and history of cancer. For these interaction assessments, we included interaction terms in multivariable logistic regression models. As above, variables included in the final models were associated with mental health in prior studies[8,12,22,26] or were a potential confounder in our analyses. We performed imputation for any covariates with missingness, ranging from 0.9% to 21.4% (see footnotes of Table 3.1). Hot deck imputation was applied to account for missingness, which was also used for non-response by HINTS. As Cycle 3 did not contain employment status, it was not included in the model due to its large missingness (35% in employment status). Imputed data were used for all descriptive and regression analyses in SAS 9.4 (SAS studio 3.8, Cary, NC, USA). The statistical significance was determined at *P*< 0.05.

Results

<u>Sociodemographic and clinical characteristics of study population</u>

Table 3.1 shows population characteristics of cancer survivors and adults without a history of cancer, before and during COVID. Cancer survivors were older, with 51% of cancer survivors aged 65 or older compared to 17% of adults without a history of cancer. Among cancer survivors, 36% were employed (vs. 58% in those without a history of cancer), 33% had private or employment-based insurance (vs. 54%), 84% had a usual source of care (vs. 63%), 25% reported poor general health status (vs. 14%), and 15-54% had chronic health conditions (vs. 7-35%). All three types of OPPC were similar between groups, yet differed by time, use was lower during COVID. PCC score was higher among cancer survivors (mean 70 vs. 62). There were no differences by time period by gender, race/ethnicity, or education.

Table 3.1. Sociodemographic and clinical characteristics of cancer survivors and adults without a history of cancer by pre-COVID and early COVID time period (HINTS 5 2017-2020).

	Cancer survivors		Adults without a history of cancer	
	Pre-COVID N=1,953[a]	COVID N=626[a]	Pre-COVID N=10,124[a]	COVID N=3,168[a]
	Weighted % (SE)	Weighted % (SE)	Weighted % (SE)	Weighted % (SE)
Sociodemographic characteristics				
Age (years)				
18-34	4.8 (1.5)	3.1 (1.2)	24.6 (0.8)	28.3 (1.1)
35-49	10.8 (1.2)	16.2 (2.9)	27.9 (0.8)	26.4 (1.2)
50-64	33.2 (1.7)	32.1 (3.1)	30.2 (0.6)	27.4 (1.0)
65-74	25.6 (1.3)	24.6 (2.3)	10.4 (0.2)	10.7 (0.3)
≥ 75	25.6 (1.2)	24.0 (2.0)	7.0 (0.2)	7.3 (0.2)

Gender				
Female	57.2 (1.7)	56.9 (3.2)	50.6 (0.2)	50.8 (0.4)
Male	42.8 (1.7)	43.1 (3.2)	49.4 (0.2)	49.2 (0.4)
Race/Ethnicity				
Non-Hispanic White	79.0 (1.6)	82.1 (2.1)	64.8 (0.3)	62.6 (0.5)
Non-Hispanic Black/African American	8.0 (1.3)	8.4 (1.7)	10.7 (0.2)	11.0 (0.4)
Hispanic	9.0 (1.2)	6.5 (1.6)	16.2 (0.2)	17.3 (0.2)
Non-Hispanic Asian	1.7 (0.4)	1.4 (0.5)	5.3 (0.2)	5.5 (0.3)
Others	2.4 (0.5)	1.7 (0.8)	3.0 (0.2)	3.6 (0.3)
Education				
Less Than High School	7.1 (1.2)	6.0 (1.4)	8.3 (0.5)	8.1 (0.9)
High School Graduate	26.6 (1.6)	28.9 (2.5)	22.4 (0.5)	21.7 (1.0)
Some College	38.5 (1.7)	36.0 (2.5)	37.7 (0.5)	39.1 (1.0)
College Graduate or More	27.8 (1.3)	29.1 (2.7)	31.7 (0.2)	31.1 (0.5)
Household income				
<$20,000	15.4 (1.4)	19.3 (2.6)	17.3 (0.7)	14.4 (0.9)
$20,000 to <$35,000	15.5 (1.3)	11.3 (2.0)	11.5 (0.6)	11.3 (0.8)
$35,000 to <$50,000	15.1 (1.8)	15.0 (2.1)	13.4 (0.6)	12.1 (0.9)
$50,000 to <$75,000	19.6 (1.5)	19.2 (2.7)	18.5 (0.7)	18.3 (1.5)
≥$75,000	34.5 (1.7)	35.2 (2.6)	39.2 (0.8)	44.0 (1.7)
Marital status[b]				
Married	61.2 (1.7)	63.6 (2.8)	54.0 (0.4)	54.5 (0.6)
Not married	38.8 (1.7)	36.4 (2.8)	46.0 (0.4)	45.3 (1.3)
Rurality				
Metropolitan	82.9 (1.3)	78.8 (2.1)	84.8 (0.6)	88.1 (0.8)
Micropolitan	9.9 (1.0)	11.3 (2.0)	9.1 (0.5)	7.4 (0.9)
Small town	3.6 (0.6)	4.9 (1.6)	3.3 (0.3)	3.1 (0.5)
Rural	3.6 (0.6)	5.0 (1.1)	2.9 (0.3)	1.4 (0.3)
Health insurance type				
Employment and private	33.0 (1.8)	35.2 (3.0)	54.3 (0.8)	54.5 (1.4)
Medicare	32.9 (1.4)	36.6 (2.6)	14.8 (0.5)	14.9 (0.8)
Medicaid	14.3 (1.7)	14.8 (2.3)	16.4 (0.7)	15.2 (0.9)
Tricare, VA, IHS	10.3 (1.0)	5.7 (1.1)	6.0 (0.4)	6.6 (0.5)
Others	9.6 (0.9)	7.8 (1.7)	8.5 (0.5)	8.9 (0.8)
Usual source of care				
Yes	83.8 (1.2)	85.7 (2.2)	63.8 (0.8)	60.6 (1.3)
No	16.2 (1.2)	14.3 (2.2)	36.2 (0.8)	39.4 (1.3)
Clinical characteristics				
General health status				
Excellent/good	74.1 (1.6)	76.3 (2.5)	85.3 (0.6)	86.8 (0.9)
Fair/poor	25.9 (1.6)	23.7 (2.5)	14.7 (0.6)	13.2 (0.9)
Chronic medical condition				

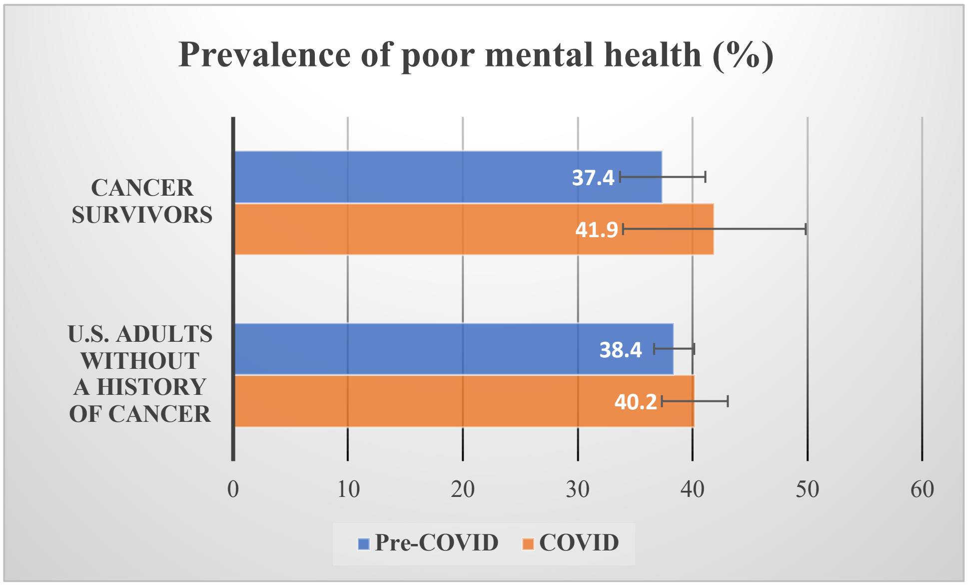
Diabetes	23.9 (1.6)	25.3 (2.5)	16.5 (0.6)	17.4 (1.1)
High blood pressure	54.4 (1.7)	54.7 (3.1)	35.0 (0.7)	34.5 (1.0
Heart disease	15.8 (1.4)	12.9 (1.7)	6.9 (0.3)	7.8 (0.7)
Lung disease	16.3 (1.1)	18.8 (2.3)	11.1 (0.4)	12.1 (0.7)
Time since diagnosis				
<1 year	13.3 (1.3)	15.6 (2.6)	N/A	N/A
2-5 years	21.5 (1.3)	17.5 (2.3)	N/A	N/A
6-10 years	18.4 (1.4)	19.8 (2.2)	N/A	N/A
≥ 11 years	46.8 (1.9)	48.1 (3.0)	N/A	N/A
Cancer type[c]				
Breast	12.7 (1.1)	14.9 (2.6)	N/A	N/A
Cervical	6.6 (1.0)	7.2 (1.9)	N/A	N/A
Prostate	6.3 (0.7)	6.7 (1.2)	N/A	N/A
Colon	3.9 (0.7)	3.7 (0.7)	N/A	N/A
Lung	2.1 (0.5)	1.0 (0.4)	N/A	N/A
Skin	25.5 (1.6)	22.6 (2.2)	N/A	N/A
Melanoma	3.8 (0.6)	8.3 (2.0)	N/A	N/A
Multiple cancers	17.5 (1.2)	13.4 (1.8)	N/A	N/A
Other cancers	21.6 (1.9)	22.2 (2.7)	N/A	N/A
Online PPC				
Email/Internet communication	60.6 (1.8)	48.7 (3.1)	61.7 (0.8)	53.1 (1.3)
Tablet/Smartphone for discussion	69.9 (1.8)	60.8 (3.2)	69.0 (0.8)	64.9 (1.5)
EHR message	80.5 (1.3)	69.9 (3.1)	79.2 (0.6)	77.8 (1.2)
PCC composite score[d]				
Mean (SE)	70.2 (1.1)	71.0 (2.0)	60.6 (0.7)	64.3 (1.2)

a. Missingness of covariates ranged from 0.48% to 22.84%. Covariates with any missing values were imputed in Table 1; b. Marital status (married or living with a romantic partner as a married vs. not married including divorced, widowed, separated, single/never been married); c. Less prevalent cancer types were recoded as Others (bladder, bone, endometrial, head and neck, leukemia/blood, liver, lymphoma, oral, ovarian, pancreatic, pharyngeal, rectal, renal, stomach cancer, and unknown cancer); d. PCC score ranges from 0 (sub-optimal) to 100 (optimal), higher is better; Abbreviations (VA: Veterans Affairs; IHS: Indian Health Services)

Prevalence of poor mental health

The prevalence of poor mental health increased from pre-COVID to during COVID in both cancer survivors (by 4.5%) and adults without a history of cancer (by 1.8%) (Figure 3.1). During COVID, the prevalence of poor mental health during COVID was similar for cancer survivors (41.9%) and adults without a history of cancer (40.2%). Table 3.2 describes the prevalence of poor mental health by sociodemographic and clinical characteristics. Younger adults (35-49 years), females, least educated (less than high school), unmarried, those with low income (<$50,000), had Medicaid, had fair/poor health condition, had chronic disease (high blood pressure, heart disease, lung disease), or used a tablet/smartphone to communicate with providers had higher than the average prevalence of poor mental health in both groups and time periods. However, the prevalence of poor mental health did not differ by PCC scores in cancer survivors and those without a history of cancer by time period.

Figure 3.1. Prevalence of poor mental health in pre-COVID (2017-2019) and COVID (2020)



Poor mental health was determined by either having depression/anxiety or psychological distress. Described in weighted percent (%) with 95% CI (error bars) among cancer survivors (N=2,449) and U.S. adults without a history of cancer (N=12,791).

Table 3.2. The prevalence of poor mental health among cancer survivors and U.S. adults without a history of cancer in pre-COVID (2017-19) and COVID (2020).

	Cancer survivors		Adults without a history of cancer	
	Pre-COVID N=1,953	COVID N=626	Pre-COVID N=10,124	COVID N=3,168

	Weighted % (SE)	Weighted % (SE)	Weighted % (SE)	Weighted % (SE)
Average prevalence (%)^a	37.4	41.9	38.4	40.2
Age (years)				
18-34	**71.5 (15.3)**	32.2 (20.7)	**45.1 (2.1)**	**47.0 (3.7)**
35-49	**50.4 (6.0)**	**65.5 (10.4)**	**39.2 (1.6)**	**44.4 (2.8)**
50-64	35.8 (3.0)	**43.9 (7.1)**	37.9 (1.4)	37.0 (2.7)
65-74	32.1 (2.8)	34.7 (4.9)	28.7 (1.4)	27.6 (2.5)
≥75	33.1 (2.9)	31.5 (4.9)	26.0 (1.8)	27.2 (4.0)
Gender				
Female	**42.5 (2.4)**	**50.2 (4.4)**	**44.2 (1.0)**	**44.9 (2.2)**
Male	30.6 (3.1)	31.1 (5.6)	32.7 (1.5)	35.4 (2.3)
Race/Ethnicity				
Non-Hispanic White	35.5 (2.0)	**43.9 (4.2)**	**40.1 (1.2)**	40.0 (2.1)
Non-Hispanic Black/African American	**55.2 (9.0)**	28.3 (9.4)	35.3 (2.3)	39.6 (3.7)
Hispanic	**44.1 (7.6)**	37.8 (13.0)	36.2 (2.0)	**42.8 (2.9)**
Non-Hispanic Asian	9.6 (5.9)	33.2 (18.0)	33.0 (3.8)	22.2 (5.2)
Others	29.1 (9.5)	24.9 (19.5)	**38.6 (4.6)**	**60.6 (7.4)**
Education				
Less Than High School	**69.4 (8.6)**	**66.1 (13.1)**	**48.2 (3.2)**	**42.8 (5.5)**
High School Graduate	**42.2 (3.8)**	**43.9 (7.6)**	36.9 (1.8)	**43.3 (3.7)**
Some College	34.6 (2.8)	**41.4 (6.3)**	**40.4 (1.6)**	**40.9 (2.8)**
College Grad or More	29.2 (2.3)	36.0 (5.5)	34.7 (1.1)	36.6 (2.0)
Household income				
< $20,000	**59.2 (4.8)**	**54.9 (7.6)**	**54.1 (2.4)**	**59.4 (3.1)**
$20,000 to < $35,000	**45.4 (4.2)**	37.8 (9.7)	**41.5 (2.4)**	**44.2 (4.3)**
$35,000 to < $50,000	**41.4 (6.6)**	**45.3 (9.9)**	**44.5 (2.9)**	38.6 (4.9)
$50,000 to < $75,000	31.4 (4.0)	38.3 (6.8)	33.7 (2.2)	37.3 (4.0)
≥ $75,000	25.8 (2.2)	36.9 (5.6)	30.5 (1.2)	34.6 (2.1)
Marital status				
Married	31.4 (2.1)	37.9 (4.7)	32.2 (1.0)	34.1 (1.6)
Unmarried	**47.3 (3.2)**	**49.2 (5.6)**	**45.8 (1.6)**	**47.4 (2.7)**
Health insurance				
Private/employment	32.8 (3.3)	40.9 (6.0)	36.0 (1.1)	37.5 (2.0)
Medicare	30.5 (2.3)	29.7 (4.9)	28.7 (1.6)	32.5 (3.7)
Medicaid	**60.3 (6.1)**	**79.4 (7.0)**	**51.6 (2.0)**	**49.7 (3.0)**

Tricare, VA, IHS	**37.6 (5.6)**	37.5 (8.8)	37.1 (3.6)	**45.5 (5.2)**
Others	**40.7 (5.1)**	39.0 (8.6)	**44.4 (2.9)**	**50.1 (5.1)**
Rurality of residence				
Metropolitan	37.2 (2.1)	39.9 (4.1)	37.8 (1.0)	**40.5 (1.5)**
Micropolitan	31.6 (4.7)	39.8 (12.0)	**45.7 (3.3)**	34.9 (6.0)
Small town	**49.4 (8.3)**	**69.4 (14.8)**	34.2 (3.7)	**46.1 (8.6)**
Rural	**44.9 (9.6)**	**50.9 (13.0)**	**40.7 (3.9)**	38.7 (11.7)
General health status				
Excellent/great	29.0 (1.9)	37.5 (4.6)	33.9 (0.9)	36.8 (1.7)
Fair/poor	**62.3 (3.6)**	**56.4 (6.4)**	**65.1 (2.0)**	**63.2 (4.0)**
Chronic medical condition				
Diabetes	**44.0 (3.8)**	36.4 (5.9)	**47.0 (1.9)**	**46.8 (3.4)**
No diabetes	35.3 (2.1)	**43.5 (4.1)**	36.8 (1.0)	38.8 (1.6)
High blood pressure	**41.8 (2.4)**	**44.7 (4.9)**	**41.3 (1.3)**	**44.6 (2.5)**
No high blood pressure	32.2 (3.1)	38.6 (5.7)	36.9 (1.1)	38.0 (1.8)
Heart disease	**40.4 (5.0)**	**58.4 (8.0)**	**44.5 (2.9)**	**41.0 (4.3)**
No heart disease	36.8 (2.0)	39.5 (4.1)	38.0 (0.9)	40.1 (1.6)
Lung Disease	**54.8 (4.1)**	**55.8 (7.5)**	**56.6 (2.2)**	**53.9 (3.6)**
No lung disease	33.9 (2.1)	38.9 (4.5)	36.2 (0.9)	38.3 (1.7)
Time since diagnosis				
Less than 1 year	**43.4 (7.2)**	**44.2 (7.2)**	N/A	N/A
2-5 Years	37.3 (3.4)	30.8 (7.3)	N/A	N/A
6-10 Years	35.0 (4.1)	**44.7 (7.7)**	N/A	N/A
11 Years or more	36.5 (2.7)	**43.9 (5.9)**	N/A	N/A
Digital device use				
Email/Internet communication	37.7 (3.2)	**40.4 (5.2)**	**42.3 (1.4)**	**45.9 (2.2)**
No Email/Internet communication	**37.1 (2.3)**	**43.6 (4.6)**	36.0 (1.1)	35.1 (2.0)
Tablet/Smartphone for discussion	**44.4 (3.9)**	**46.5 (6.6)**	**45.2 (1.5)**	**46.6 (2.7)**
No Tablet/Smartphone for discussion	**34.3 (2.1)**	39.0 (4.3)	35.4 (1.1)	36.7 (1.8)
EHR message	**39.8 (3.1)**	34.3 (5.9)	**40.5 (2.0)**	**46.9 (2.7)**
No EHR message	**36.8 (2.1)**	**45.4 (4.1)**	37.9 (1.0)	38.2 (1.5)
	Cancer survivors		Adults without a history of cancer	
	Pre-COVID	COVID	Pre-COVID	COVID
PCC[b]	**Mean (SE)**	**Mean (SE)**	**Mean (SE)**	**Mean (SE)**

Composite score	81.0 (0.9)	79.3 (1.3)	79.9 (0.4)	79.8 (0.8)

a. Poor mental health outcome was determined if either having depression/anxiety or psychological distress. The prevalence is presented by each group; b. PCC score ranges from 0 (sub-optimal) to 100 (optimal), higher is better; Abbreviations (VA: Veterans Affairs; IHS: Indian Health Services)

Impact of early COVID on mental health

The D-I-D analysis revealed that the changes in poor mental health prior to and during COVID among cancer survivors compared to adults without a history of cancer were not significantly different (Table 3.3), overall or stratified by PCC or online PPC. When we stratified by PPC (optimal vs. sub-optimal), we observed that the odds of poor mental health significantly increased from pre-COVID to during COVID in adults without a history of cancer among those who had optimal PCC (OR = 1.32, 95% CI 1.00-1.15). Among cancer survivors, there was also an increase among adults with optimal PCC, but it was not statistically significant (OR=1.31, 95% CI 0.76-2.25).

Table 3.3. Changes in poor mental health prior to (2017-2019) and during COVID (2020) among cancer survivors by PCC quality and Online PPC

	Cancer survivors			**U.S. Adults without a history of cancer**				
	Pre-COVID (Odds)	COVID (Odds)	Difference (aOR, 95% CI)	Pre-COVID (Odds)	COVID (Odds)	Difference (aOR, 95% CI)	Difference-In-Difference[a] (aOR, 95% CI)	P-value
Overall[b]	0.93	1.13	1.21 (0.83-1.76)	0.87	0.98	1.14 (0.97-1.33)	1.07 (0.71-1.60)	0.76
PCC[c]								
Optimal	0.79	1.03	1.31 (0.76-2.25)	0.68	0.90	1.32 (1.00-1.15)*	0.99 (0.53-1.81)	0.96
Sup-optimal	0.99	1.13	1.14 (0.73-1.79)	0.99	1.03	1.04 (0.87-1.24)	1.10 (0.68-1.77)	0.71
Online PPC								
Email/Internet communication	1.03	1.16	1.13 (0.67-1.92)	1.06	1.20	1.13 (0.91-1.41)	1.00 (0.57-1.75)	0.99
No Email/ Internet communication	0.85	1.06	1.26 (0.82-1.93)	0.79	0.86	1.09 (0.89-1.34)	1.15 (0.71-1.86)	0.56
Tablet/ Smartphone for discussion	1.21	1.40	1.15 (0.61-2.18)	1.12	1.23	1.10 (0.85-1.41)	1.05 (0.52-2.11)	0.88

No Tablet/ Smartphone for discussion	0.84	0.99	1.17 (0.78-1.77)	0.83	0.95	1.14 (0.94-1.38)	1.03 (0.66-1.62)	0.90
EHR message	0.76	0.65	0.85 (0.46-1.57)	0.70	0.87	1.24 (0.94-1.65)	0.68 (0.35-1.32)	0.25
No EHR message	0.97	1.33	1.38 (0.94-2.03)	0.92	1.00	1.09 (0.91-1.31)	1.26 (0.83-1.93)	0.28

a. Refers to changes of the odds of poor mental health among cancer survivors compared to those with without a history of cancer during the early COVID pandemic in generalized linear model using inverse link function to estimate the differences in differences of log odds, adjusting for a history of cancer, time period, age, birth gender, education, race/ethnicity, household income, general health status, and chronic disease (lung disease); b. total n=15,240; c. Optimal PCC= When all 7 PCC questions were answered 'always'; *Statistically significant (P<0.05); aOR, adjusted odds ratio; CI, confidence interval

Factors associated with poor mental health

We did not observe interactions of PCC or digital device use measures with either history of cancer or time period. Therefore, Table 3.4 shows factors associated with poor mental health in a multivariable model with cancer survivors and adults without cancer during both time periods. In multivariable models, individuals who used email/internet (OR=1.39, 1.20-1.60) or tablet/smartphones (OR=1.39, 1.21-1.59) to communicate with providers were more likely to have poor mental health. The odds of poor mental health was not associated with EHR message use or PCC composite score. In addition, history of cancer (OR=1.04, 0.88-1.23 vs. no) and the early COVID pandemic (OR=1.09, 0.94-1.27 vs. pre-COVID 2017-2019) were not associated with poor mental health. However, other health conditions were associated with poor mental health. Those with excellent/good general health status (vs. fair poor) were less likely to have poor mental health. Adults with chronic lung disease (OR=1.72, 1.47-2.02) were 1.7 times as likely to have poor mental health than those without chronic lung disease.

Demographic factors associated with poor mental health included younger populations (ORs=1.98-3.25; 18-64 vs. ≥ 75 years years) and females (OR=1.59, 1.39-1.80). Non-Hispanic Black/African Americans (OR=0.62, 0.51-0.75), Hispanics (OR=0.68, 0.56-0.82) and non-Hispanic Asians (OR=0.54, 0.39-0.75) were less likely to have poor mental health than non-

Hispanic White populations. More educated individuals (OR=0.72, 0.56-0.94 college graduate or more vs. less than high school) were less likely to have poor mental health. Individuals with the lowest income (<$20,000) were approximately 2-3 times as likely to have poor mental health than those with higher incomes.

Table 3.4. Factors associated with poor mental health in cancer survivors and adults without a history of cancer (HINTS 2017-2020)

	aOR[a] (95% CI) N=15,240	P-value
History of cancer		0.66
Yes	1.04 (0.88-1.23)	
No	Reference	
Time period		0.23
COVID (2020)	1.09 (0.94-1.27)	
Pre-COVID (2019-17)	Reference	
PCC[b]		
Per 10-unit composite score	1.00 (0.99-1.02)	0.75
Online PPC		
Email	1.39 (1.20-1.60)*	<0.0001
No Email	Reference	
Tablet	1.39 (1.21-1.59)*	<0.0001
No Tablet	Reference	
EHR	1.01 (0.87-1.17)	0.88
No EHR	Reference	
Age (years)		
18-34	3.25 (2.56-4.11)*	<0.0001
35-49	2.58 (2.08-3.21)*	<0.0001
50-64	1.98 (1.64-2.39)*	<0.0001
65-74	1.16 (0.96-1.40)	0.14
≥75	Reference	
Gender		
Female	1.59 (1.40-1.80)*	<0.0001
Male	Reference	
Race/Ethnicity		
Non-Hispanic White	Reference	

Non-Hispanic Black/ African American	0.62 (0.51-0.75)*	<0.0001
Hispanic	0.68 (0.56-0.82)*	<0.0001
Non-Hispanic Asian	0.54 (0.39-0.76)*	0.0003
Others	0.88 (0.60-1.28)	0.49
Education		
<High School	Reference	
High School Graduate	0.78 (0.59-1.02)	0.06
Some College	0.82 (0.63-1.06)	0.13
College Grad or More	0.72 (0.56-0.94)*	0.02
Household income		
<\$20,000	Reference	
\$20,000 to <\$35,000	0.63 (0.49-0.79)*	0.0001
\$35,000 to <\$50,000	0.57 (0.45-0.72)*	<0.0001
\$50,000 to <\$75,000	0.42 (0.34-0.52)*	<0.0001
≥\$75,000	0.37 (0.30-0.45)*	<0.0001
General health status		
Excellent/good	0.31 (0.26-0.37)*	<0.0001
Fair/poor	Reference	
Chronic medical condition		
Lung Disease	1.72 (1.47-2.02)*	<0.0001
No lung disease	Reference	

a. Adjusted for all variables in the table; b. PCC score ranges from 0 (sub-optimal) to 100 (optimal), higher is better.

Discussion

We examined the prevalence of poor mental health and found factors associated with poor mental health among cancer survivors and U.S. adults without a history of cancer prior to and during early SARS/COVID-19 pandemic using nationally representative survey data. The prevalence of poor mental health increased to a similar extent in both those with and without a history of cancer pre-COVID to the early COVID pandemic, where the prevalence was high at approximately 40%. Overall, we found that email/internet and tablet/smartphone use for communications with providers was associated with poor mental health, suggesting that active digital device users might be the ones who need mental health supports. In addition, our study identified subgroups of adults, defined by sociodemographic (younger age, females, lower income/education) and clinical (chronic lung disease or poor general health) factors, who were more likely to experience poor mental health. Our findings shed light on populations more likely to experience poor mental health and opportunities for targeted interventions to prevent further mental health inequities in the U.S.

Our findings showed that the prevalence of poor mental health increased during COVID to a similar degree among cancer survivors and those without a history of cancer. Our findings of an increase in poor mental health aligned with the longitudinal study (2014-2020) among breast cancer survivors 60 years and older and adults without a history of cancer from 5 U.S. regions[28]. Despite the previous concerns that COVID-related situations (e.g., delayed cancer care, fear of disease progression) would disproportionately impact the mental health status of cancer survivors during COVID[43,44], the prevalence did not differ between cancer survivors and those without a history of cancer. Our findings of a high prevalence of poor mental health among U.S. adults during the early pandemic align with the findings of a national survey in April 2020 that observed 52% had mild or severe depression[22]. Thus, our findings contribute to the evidence of the unusually high prevalence of poor mental health during the early pandemic that will need to be carefully monitored post-pandemic.

In our study, communication through email/internet and tablet/smartphone with health providers was associated with poor mental health after accounting for PCC quality and sociodemographic and clinical factors. The three types of digital devices we considered involve different levels of digital fluency and experience. Specifically, email/internet communications could refer to a lower and general level of digital fluency, whereas discussions with tablet/smartphone requires a higher level of digital fluency. On the other hand, messaging via EHR, which was not associated with mental health, demands being digitally engaged to the healthcare system. In previous literature, those with poor mental health were more likely to seek online activities for health (e.g., participate in online health discussion forums, watch health-related videos)[45]. Given OPPC could be a part of online activity, it is possible that those with existing poor mental health were engaged more in OPPC. However, this interpretation needs caution as it is also possible that heavy online activities, which could have increased OPPC as well, led to the poor mental health[46]. While PCC quality was not associated with poor mental health in our study, this association was found previously among cancer survivors during COVID[29]. Although we cannot confirm the directions of associations observed in this cross-sectional study, our findings signaled that digital device-based communications could be a tool and provide additional opportunities to care for individuals with mental distress. Suggested interventions could include related stakeholders (e.g., healthcare clinics and public health practitioners) widely informing the public about the available digital device-based communication channels for those with mental distress[47]. Potentially, social media could also play a role in the dissemination of relevant information and online communication options[45].

Consistent with prior studies[22,26,27,48,49], we also found that lower education level and income were associated with poor mental health. Overall wealth also has been associated with resilience during COVID, with those with resilience having a lower odds of depression and anxiety in a longitudinal study[50]. In addition, COVID pandemic-related loss of employment income was associated with worsened mental health[51]. Multifaceted approaches will need to be considered to relieve the poor mental health of those with low SES and address the root cause of the issue in the long-term[48]. Approaches could include partnering with already available community programs (e.g., Special Supplemental Nutrition Program for Women, Infants, and Children, WIC) or local governments (e.g., State Employment Development Department, EDD) to reach out to those in need, including low-income families or those who experienced unemployment during the pandemic, to gauge the mental health care needs and design tailored mental health care interventions[52,53].

We also found that younger individuals and females were more likely to have with poor mental health, which aligned with the previous literature[12,26,27]. These consistent associations highlight the need for targeted interventions for younger individuals and females. A prior study found that younger individuals had a lower level of resilience and poor sleep quality, mediators for depression and anxiety symptoms, and were more vulnerable to perceived stress, which was strongly associated with depression and anxiety symptoms during COVID[54]. Evidence-based life skills training (e.g., support for stress management, resilience training, sleep quality improvement) may need to be considered. Moreover, we observed that non-Hispanic Whites were more likely to experience poor mental health than non-Hispanic Black/African Americans, Asians, and Hispanics. This is in contrast to prior findings that found Black/African Americans to have poorer mental health[13,55]. Previously, stressful life events, including health, financial, or job problems in the past 30 days, had stronger associations with depression among non-Hispanic White men than non-Hispanic Black/African Americans in a national survey[56]. Thus, it is possible that non-Hispanic Whites were more vulnerable to poor mental health during the early COVID pandemic, although further investigations in the extended and post-pandemic period are warranted to determine whether these differences persist.

Last, those who had chronic lung disease were more likely to have poor mental health, a finding that has been reported previously and is likely related to the poor quality of life among those with chronic lung disease[57,58]. Similarly, we also observed that those with poor general health status were more likely to have poor mental health, which is consistent with a previous report that considered depression and anxiety among cancer survivors[26]. Given that SARS/COVID-19 is a respiratory infectious disease, which disproportionately affected those with compromised health status, our finding highlights a vulnerable group to target for improving mental health.

Limitations

Our study has some limitations. First, we were not able to confirm the direction of associations with factors in mental health as we used cross-sectional survey data. Second, even though HINTS data are high-quality and national, they might have some inevitable weaknesses originated from self-reporting, including reporting bias. For example, people might not report mental distress intentionally (hesitancy) or unintentionally (lack of awareness or knowledge). Third, the COVID (2020) sample size was smaller than the pre-COVID (2017-2019) sample size, as 2020 was the only available COVID data from the HINTS. Fourth, COVID data were collected from February to June 2020, hence the findings will need to be interpreted in context of the early pandemic. Despite these limitations, this study is among the first studies, to our knowledge, that examined and compared poor mental health prevalence for those with and without a history of cancer before and during COVID with the same study population data. Last, the associations of PCC quality and digital device use for patient-provider communications with mental health have been rarely known in spite of its potential role in online mental health care.

Conclusion

A high proportion of adults in our study experienced poor mental health and this did not differ for those with and without a history of cancer or by time period that included the early COVID pandemic. We also identified subgroups of adults who were more likely to experience poor mental health, including those with lower income or education, who used email/internet or tablet/smartphone for communication and had chronic lung disease or poor general health status. Our findings highlight the importance of targeted approaches for these vulnerable subgroups, such as through partnering with communities or local governments, involving related stakeholders, or applying life skills training.

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Conclusion

Using the nationally representative survey data (Health Information National Survey, HINTS 5 2017-2020), this dissertation examined the prevalence of and factors associated with optimal PCC, OPPC use, and poor mental health among cancer survivors during COVID in comparison to pre-COVID and those without a history of cancer. As hypothesized, the prevalence of optimal PCC decreased and OPPC use (communications with the providers through email, internet, or EHR) increased among cancer survivors during COVID. Cancer survivors' sub-optimal PCC and OPPC use were associated with sociodemographic and health status characteristics during COVID. Although we observed that the subgroups with low OPPC use during COVID were different from pre-COVID, the subgroups with sub-optimal PCC were consistent over time. Having no usual source of care, being ≥75 years, or having poor mental health was related to both sub-optimal PCC and low OPPC use among cancer survivors during COVID, while sociodemographic characteristics, including race/ethnicity, birth gender, marital status, health insurance type, and income, were associated with optimal PCC or OPPC use. When we compared OPPC use among those with and without a history of cancer, lower education was only associated with OPPC use among those without a history of cancer. Optimal PCC was similar between those with and without a history of cancer.

Contrary to our hypothesis, the prevalence of poor mental health, which included depression as a chronic medical condition and depressive or anxiety symptoms within the past 2 weeks, did not significantly increase from pre-COVID among cancer survivors and were similar to those without a history of cancer. However, when accounting for PCC and OPPC, low socioeconomic status (e.g., low income and low education) was strongly associated with poor mental health in cancer survivors and those without a history of cancer.

Raising awareness of PCC roles among healthcare providers and patients through suggested interventions, including early-stage clinician training or collaborating with patient advocate groups for patient education, is recommended so as to guide them to practice PCC and improve perceived PCC. Efforts to increase the coverage of virtual visits, enhance eHealth literacy, or improve community- and national-level health technology access might help those with low OPPC use. Furthermore, partnering with local government programs to reach target populations and providing life skills-based training and support could also help people with poor mental health.

Our findings and recommendations could inform the related stakeholders, including public health professionals, clinicians, or policymakers, to prepare tailored interventions to prevent further inequities in this population.