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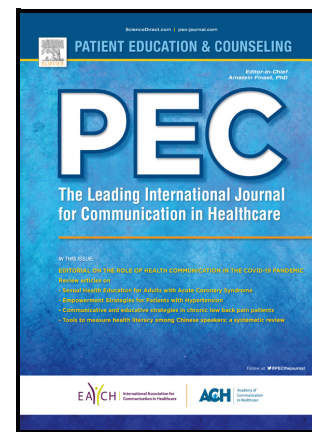


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Cancer Survivors with Sub-Optimal Patient-Centered Communication Before and During the Early COVID-19 Pandemic.

Jiyeong Kim, Nathan P. Fairman, Melanie S. Dove, Jeffrey S. Hoch, Theresa H. Keegan



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Statement & Declaration

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- **Conflict of interests**

The authors declared no potential conflicts of interest.

- **Author contributions**

Jiyeong Kim: Conceptualization of study, Writing, Data analysis, Editing, Reviewing final submission. Nathan P. Fairman: Writing, Editing, Reviewing final submission. Melanie S. Dove: Writing, Data analysis, Editing, Reviewing final submission. Jeffrey S. Hoch: Writing, Editing, Reviewing final submission. Theresa H. Keegan: Conceptualization of study, Writing, Data analysis, Editing, Reviewing final submission.

- **Data availability**

Current study used publicly available national survey data (Health Information National Trends Survey, HINTS 5 2017-2020). The raw data required to reproduce the above findings are available to download from <https://hints.cancer.gov/data/download-data.aspx> The processed data required to reproduce the above findings will be made available upon request.

- **Ethics approval**

This study was a secondary data analysis. Human subject was not involved, and identifiable information was not included. Thus, this was deemed exempt for review by the Institutional Review Board at University of California, Davis

- **Acknowledgement**

N/A

Abstract

Objectives

Patient-Centered Communication (PCC) is an essential element of patient-centered cancer care. Thus, this study aimed to examine the prevalence of and factors associated with optimal PCC among cancer survivors during COVID-19, which has been less studied.

Methods

We used national survey (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 (before COVID-19, 2017-19 vs. COVID-19, 2020). Multivariable logistic regressions were performed to explore the associations of 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 with optimal PCC.

Results

The prevalence of optimal PCC decreased during COVID-19 overall, with the greatest decrease in managing uncertainty (7.3%). Those with no usual source of care (odd ratios, 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.

Conclusions

We observed that the decreased prevalence of optimal PCC, and identified those with suboptimal PCC during COVID-19.

Practice implications

More efforts to raise awareness and improve PCC are suggested, including education and guidelines, given the decreased prevalence during this public health emergency.

Keywords

Patient-Centered Communication (PCC), cancer survivors, patient-provider communication, psychological distress, COVID-19

1. 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 COVID-19 pandemic in 2020, cancer survivors faced disrupted cancer care (e.g., delayed cancer care, changed treatment plans) and fear of disease progression [12–15]. After the unprecedented Stay At Home Order in March 2020 in United States (U.S.), in-person clinic visits were extremely limited. In addition, cancer survivors experienced additional fear of COVID-19 infection because those with chronic medical conditions, including cancer, showed worse COVID-19 infection outcomes [13, 16]. The restricted in-person patient-provider interactions due to Stay At Home Order might have hindered optimal PCC during this time. In addition to this actual limitation of providers' communicational capacity (e.g., closed health care facility, lack of health providers), patients' perceived distance from providers due to the interaction-discouraged atmosphere during this unique time might have been also at play in preventing optimal PCC performance [13, 15, 17]. A study reported that physicians' responsiveness to patients during conversations to help address uncertain and difficult emotions was associated with better health and coping and less psychological distress during COVID-19 [17], 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 [18–21], while age showed inconsistent associations. For example, older cancer survivors had higher perceived PCC in HINTS 4 (2011-2013) [20], yet age

was not related among newly diagnosed colon or rectal cancer patients [21]. Previously, Blanch-Hartigan et al. assessed the trends in cancer survivors' PCC experience using HINTS 2007-2013 [19]. However, a systematic evaluation of all six PCC domains among cancer survivors during the early pandemic has not been conducted, limiting our ability to examine the impact of COVID-19 pandemic overall PCC performance and across the subgroups.

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 [20], among cancer survivors during COVID-19 compared to those before COVID-19. This study also investigated sociodemographic and health status characteristics associated with optimal PCC during COVID-19 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-19 than before COVID-19. 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-19 [22].

2. Methods

2.1. Data source

We used nationally representative survey data from Health Information National Trends Survey (HINTS) for this study [23]. HINTS is a self-administered, publicly available, cross-sectional survey data distributed and collected by National Cancer Institute (NCI) [24]. This study used the HINTS 5 data, Cycles 1-3 (2017-2019) for before COVID-19 and Cycle 4 (2020) for during COVID-19. Of note, the COVID-19 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 report for an observational study [25] (Supplemental Table 1). The total number of survey responses in HINTS 5 Cycles 1-4 was 16,092 and the average response rate was 33% [26]. 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 [27]. The HINTS reconciled the data from the different survey modes (mailed, push-to-web with a paper return, push-to-web with web return). We examined our variables of interest before combining 4 survey cycles to make sure the variable names and

codes were consistent across the cycles. We used the HINTS Data Merging Code Tool that the HINTS provides to merge the data of HINTS 5 Cycle 1 to Cycle 4 [28]. 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 [29].

2.2. 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). As done previously with HINTS data [19, 20], overall PCC was analyzed as a dichotomous outcome when all 6 domains were "always" for optimal PCC. Given this stringent cut-off, responses were combined and recoded using the Likert scale numbers to generate a new continuous PCC outcome variable, ranging from score 0 (the least optimal, when all 6 domains were scored "never") to score 100 (the most optimal, when all 6 domains were scored "always") to allow for comparisons to prior studies [19, 20]. 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, consistent with prior work [19].

2.3. Covariates

2.3.1. 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 [30]: age, birth gender, race/ethnicity, household income, educational attainment, 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, usual source of care, 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 [31].

2.3.2. 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) [32].

2.4. Statistical analysis

Weighted descriptive analyses [percentage with standard error (SE)] was conducted 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 (before and during COVID-19), we calculated the weighted percentage (%) with SE. Additionally, to examine the overall continuous PCC by sociodemographic and health status factors over the entire study period and in before and during COVID-19 time periods, we calculated 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 [19, 20, 33]. To investigate whether the PCC differed during COVID-19 compared with before COVID-19, we assessed the associations between selected sociodemographic and health status factors (age, income, gender, usual source of care, race/ethnicity, and depression/anxiety symptoms) and time period (before vs. during COVID-19) in each model. Sensitivity analysis was conducted with [optimal (always/usually) vs. sub-optimal (sometimes/never)] to investigate the associated factors further by domain, as done previously [19].

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 (before vs. during COVID-19) 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 [29], 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 $P < 0.05$.

3. Results

3.1. Cancer survivor characteristics

In HINTS 5 2017-2020, there were 2,579 cancer survivors, 75% before ($n=1,953$) and 25% during COVID-19 ($n=626$) time periods (Table 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 before and during COVID-19 (Supplemental Table 2).

Table 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		
Before COVID-19 (2017-19)	1953	74.8 (0.4)
COVID-19 (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)

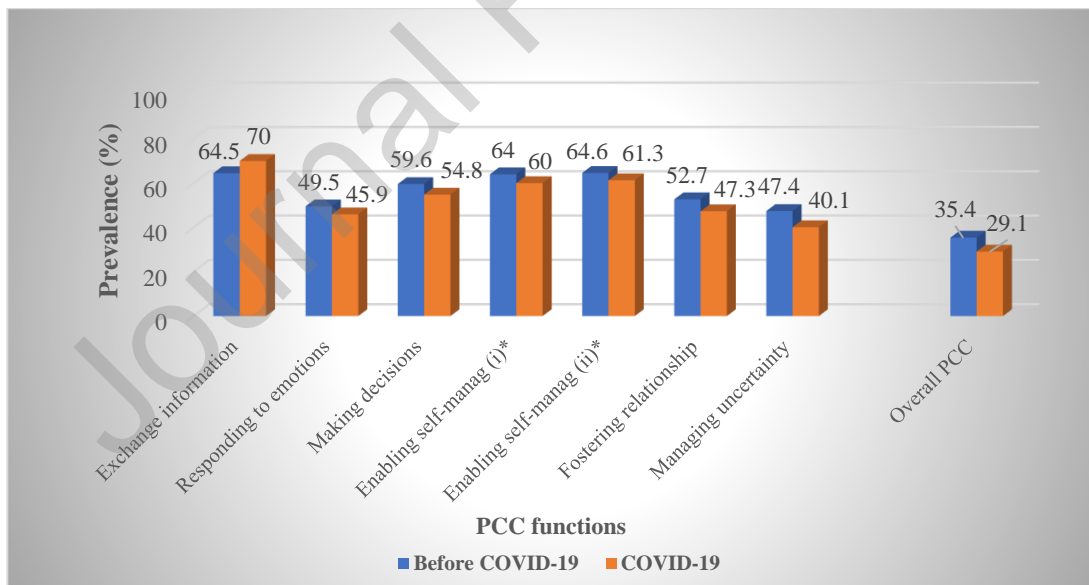
*Missingness of covariates: age 2.1 %, gender 1.0%, race/ethnicity 11.6%, education 2.1%, income 13.1%, marital status 2.1%, health insurance type 4.0%, usual source of care 2.0%, general health status 1.4%, diabetes 2.2%, high blood pressure 1.9%, heart disease 1.3%, lung disease 1.5%, depression 2.1%, little interest 2.1%, hopelessness 2.4%,

nervousness 2.1%, worrying 2.1%, time since diagnosis 6.0 %, cancer type 1.7%. 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)

3.2. Prevalence of optimal PCC: before vs. during COVID-19

Figure 1 describes the prevalence of optimal PCC before and during COVID-19 by 6 PCC domains and overall. The prevalence of optimal PCC decreased during COVID-19 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% before and 70% during COVID-19) while managing uncertainty was the domain with the lowest prevalence of optimal PCC (47.4% before and 40.1% during COVID-19). However, none of these differences were statistically significant.

Figure 1. The prevalence of optimal PCC⁺ among cancer survivors in before (2017-19) and during COVID-19 (2020)



+ Optimal PCC: When the response was ‘always’ for each domain and when all six domains were ‘always’ for the overall PCC; Difference of overall PCC: unadjusted prevalence before and during COVID-19 (35.4% vs. 29.1%, respectively) did not differ, $p > 0.05$); * Enabling self-management (i) : Understood the next steps; Enabling self-management (ii) : Providers explained things clearly

Table 2 shows the mean PCC by sociodemographic and health status factors over the entire study period and before and during COVID-19 (higher score refers to better PCC). The PCC mean score significantly differed in some sociodemographic subgroups by time. From before to during COVID-19, the PCC mean score increased in non-Hispanic Black/African Americans and decreased in those in the middle-income bracket (\$50,000 to < \$75,000).

Table 2. Mean (SE) overall continuous PCC⁺ score by sociodemographic and health status factors among cancer survivors

	Before COVID-19[#]	COVID-19[#]	Overall period
	Weighted m (SE) N=1,673⁺⁺	Weighted m (SE) N=571⁺⁺	Weighted m (SE) N=2,244⁺⁺
Total	81.0 (0.9)	79.3 (1.3)	80.5 (0.7)
Age (years)			
18-34	71.2 (11.2)	76.4 (7.5)	72.1 (9.2)
35-49	77.3 (3.2)	71.1 (5.2)	75.9 (2.7)
50-64	81.2 (1.4)	81.4 (1.9)	81.0 (1.2)
65-74	83.9 (1.1)	81.0 (1.8)	83.2 (0.9)
≥75	81.0 (1.6)	80.1 (2.1)	80.7 (1.3)
Gender			
Female	81.8 (1.1)	79.5 (2.0)	79.7 (1.2)
Male	79.9 (1.4)	79.1 (2.2)	81.2 (1.0)
Race/Ethnicity			
Non-Hispanic White	82.3 (0.8)	78.8 (1.5)	81.1 (0.7)
Non-Hispanic Black/African American	73.6 (5.2)*	87.6 (2.4)*	78.1 (4.3)
Hispanic	79.0 (5.1)	74.7 (4.1)	79.4 (3.9)
Non-Hispanic Asian	74.4 (5.6)	84.9 (4.6)	79.2 (3.8)
Others	73.5 (6.3)	80.5 (11.4)	74.5 (5.2)
Education			
< High School	68.5 (6.8)	73.0 (7.8)	69.2 (5.6)
High School Grad	82.8 (1.4)	78.1 (3.6)	81.5 (1.4)
Some College	82.1 (1.2)	81.4 (1.9)	82.1 (1.0)
≥College Grad	80.9 (1.1)	79.0 (1.3)	80.1 (0.9)
Household income			
<\$20,000	77.1 (2.9)	75.1 (3.9)	77.0 (2.3)
\$20,000 to <\$35,000	81.4 (1.9)	83.4 (2.5)	81.5 (1.6)
\$35,000 to <\$50,000	80.4 (3.6)	81.2 (2.9)	80.1 (2.8)
\$50,000 to <\$75,000	80.2 (1.5)*	71.8 (3.8)*	78.4 (1.5)
≥\$75,000	83.1 (1.2)	83.4 (1.6)	83.2 (1.0)
Marital status			

Married	81.1 (0.9)	79.1 (1.9)	80.6 (0.9)
Unmarried	80.8 (1.9)	79.7 (1.9)	80.4 (1.5)
Employment			
Employed	80.2 (1.7)	81.2 (2.2)	80.6 (1.3)
Unemployed	81.5 (1.2)	78.4 (1.9)	80.4 (1.0)
Rurality			
Metropolitan	81.3 (0.9)	79.1 (1.6)	80.7 (0.8)
Micropolitan	78.6 (3.4)	81.0 (4.7)	79.3 (2.8)
Small town	82.1 (6.0)	77.5 (7.7)	81.0 (4.8)
Rural	79.7 (4.2)	79.6 (4.3)	79.7 (3.1)
Health insurance			
Private/employment	81.3 (1.4)	78.1 (2.5)	80.9 (1.2)
Medicare	83.6 (0.9)	79.4 (1.7)	82.4 (0.9)
Medicaid	76.7 (4.0)	82.0 (4.1)	77.7 (3.2)
Tricare/VA/IHS	78.9 (2.1)	81.7 (3.2)	78.1 (2.0)
Others	79.6 (2.6)	78.7 (4.0)	79.3 (2.2)
Usual source of care			
Yes	82.2 (0.9)	80.0 (1.5)	81.7 (0.7)
No	72.7 (3.2)	73.8 (3.7)	72.8 (2.6)
General health status			
Excellent/good	82.5 (1.0)	80.7 (1.5)	82.0 (0.8)
Fair/poor	76.7 (1.8)	74.9 (2.6)	76.2 (1.5)
Chronic medical condition			
Diabetes	80.8 (1.9)	81.3 (2.4)	81.0 (1.5)
High blood pressure	80.3 (1.2)	80.0 (2.1)	80.2 (1.0)
Heart disease	78.5 (2.8)	80.3 (2.7)	78.9 (2.3)
Lung disease	74.1 (2.6)	77.8 (2.8)	75.5 (2.0)
Depression	78.3 (1.7)	77.4 (2.5)	78.2 (1.4)
Depression/Anxiety symptoms (past 2 weeks)			
Yes	76.1 (2.0)	70.9 (3.4)	74.4 (1.7)
No	83.1 (0.9)	82.8 (1.3)	83.2 (0.7)
Time since diagnosis			
< 1 year	78.3 (2.6)	81.1 (2.4)	79.7 (2.0)
2-5 years	80.3 (2.3)	78.0 (2.7)	81.9 (1.4)
6-10 years	80.5 (2.2)	77.7 (4.2)	77.9 (2.3)
≥11 years	82.3 (1.0)	79.9 (1.7)	81.2 (0.9)
Cancer type			
Breast	81.7 (1.9)	77.9 (5.2)	80.3 (2.0)
Cervical	79.6 (5.0)	76.3 (4.1)	79.8 (3.8)
Prostate	82.3 (2.6)	82.2 (5.9)	82.0 (2.5)
Colon	82.5 (2.9)	77.0 (6.2)	81.7 (2.6)

Lung	80.5 (5.8)	79.6 (13.5)	80.1 (5.2)
Skin	79.0 (1.7)	79.9 (2.2)	79.3 (1.4)
Melanoma	81.8 (4.6)	73.0 (4.4)	76.2 (3.3)
Multiple cancers	84.5 (1.4)	80.0 (2.2)	83.4 (1.2)
Others	79.6 (2.5)	82.4 (2.9)	80.5 (2.0)

Before COVID-19 (HINTS 5 Cycles 1-3, 2017-2019), COVID-19 (HINTS 5 Cycle 4, 2020); +Overall continuous PCC score ranged from 0 (sub-optimal) to 100 (optimal), the higher score means better PCC; ++ Total cancer survivors, N = 1,956 (before COVID-19), 626 (COVID-19), 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 before COVID-19 and COVID-19 by each sociodemographic and health status subgroup using t-tests (*P<0.05); in italics, if PCC mean is lower than the average (poorer PCC) within each time period.

3.3. Impact of COVID-19

We did not observe interactions between COVID-19 time period and sociodemographic or health status factors with overall PCC score. Thus, associations of sociodemographic and health status factors with optimal PCC before and during COVID-19 were combined in Table 3 and Supplemental Table 3.

3.4. Factors associated with optimal PCC in each domain and overall

Compared with the time before COVID-19, cancer survivors during COVID-19 were less likely to have optimal PCC overall (OR=0.73, 95% CI 0.54-0.98) and in the domain of managing uncertainty (OR=0.74, 0.55-0.99) (Table 3). However, other PCC functions did not differ between the two time periods. Cancer survivors who had a usual source of care were 1.5-2 times as likely to have optimal PCC than those without it overall (OR=1.53, 1.04-2.25) and in all domains (ORs=1.64-2.29), except for managing uncertainty. Similarly, cancer survivors who had no depression or anxiety symptoms had 1.62-2.17 times the odds of having optimal PCC overall and each domain, compared with those with anxiety or depression symptoms. Cancer survivors with excellent/good general health had 1.40-1.66 times the odds of having optimal PCC overall and in the domains of responding to emotion, making decisions, enabling self-management, and fostering healing relationships.

The second oldest age group (ORs=1.37-1.61, 65-74 years) was 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 were approximately 2 times as likely to have optimal PCC compared with Whites in

exchanging information and enabling self-management (ORs=1.71-1.89). Compared to those with the lowest income (<\$20,000), cancer survivors in the middle-income group (\$50,000 to <\$75,000) were less likely to have optimal PCC in the responding to emotions, fostering healing relationship, and managing uncertainty domains (ORs=0.51-0.61). Individuals diagnosed with cancer more recently (2-5 years ago) had a higher odds of having optimal PCC (ORs=1.51-1.53) in exchanging information and 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 the exception that the COVID-19 time period was not significantly related to the overall PCC score (Supplemental Table 3). 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 3. Associations of sociodemographic and health status factors with optimal PCC[#], overall and by domain, 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-19	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)
Before COVID-19	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)	1.62* (1.20-2.19)	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; @ Before COVID-19 (HINTS 5 Cycles 1-3, 2017-2019), COVID-19 (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); * $P < 0.05$

4. Discussion and conclusions

4.1. Discussion

We found that cancer survivors were less likely to have optimal PCC overall and in the managing uncertainty domain during the early COVID-19 period compared to before COVID-19, using nationally representative survey data. We identified sociodemographic and health status factors associated with optimal PCC among cancer survivors in recent years, including during the initial COVID-19 pandemic. 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 focus on improving PCC among cancer survivors, particularly those identified in this study. Multifaceted approaches may be required to enhance the perception of PCC through patient education and clinician training.

We observed that the overall optimal PCC prevalence was lower (6.3% lower) during COVID-19 compared to before the pandemic among cancer survivors, particularly for responding to emotions (3.6% lower) and managing uncertainty

(7.3% lower) domains, yet this unadjusted prevalence did not significantly differ. However, in the fully adjusted model, cancer survivors during COVID-19 were less likely to have optimal PCC overall and in managing uncertainty than cancer survivors before pandemic. Substantially limited interactions with providers (actual restriction) and pervasive social distancing policies (perceived distance from providers) might have prevented them from having quality communications for managing uncertainty despite their elevated fear and uncertainties. Before COVID-19, several efforts to enhance the quality of PCC have been put into the practice [34], including educational PCC training for healthcare providers (e.g., family physician residents, nursing students) [35, 36] and attempts to improve PCC assessment tools (e.g., standardization and validation of PCC check list, engagement of patient advocates to improve PCC design and content) [37, 38]. However, systematic PCC practice guidelines and evaluations for clinicians, and consistent and broadly available education for patients are still lacking. Despite those previous efforts, the prevalence of optimal PCC and some domains have decreased over time, even lower than estimated from a study during 2008-2013 [19], 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, which aligns with previous reports [18–20]. While PCC is ideal at all times, under the situations like COVID-19 pandemic, when individuals with compromised health conditions, including cancer patients, experienced additional fear due to COVID-19, the PCC's role is crucial as a channel to address those uncertainties and receive necessary care and support. It is possible that those with poor health status were less likely to be engaged in the communications with providers (e.g., disinterested or unable to), and the providers were also less likely to be patient-centered for those less attentive during the communication [20, 21]. 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, 39].

In our study, those without a usual source of care were less likely to have optimal PCC in most domains, as found previously [19]. This finding may relate to consistent medical encounters enabling quality patient-physician relationships and positively impacting optimal PCC [33, 40]. 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 [41–43], which may

relate to inconsistent or less frequent office visits due to financial barriers. However, in our study, those in the middle-income bracket (\$50,000 to <\$75,000) had a lower likelihood of having optimal PCC, compared with those with the lowest income in the emotion, relationship, and uncertainty domains. We also observed that the overall PCC score significantly worsened in this middle-income bracket during COVID-19 compared to before the pandemic. Further investigations, including qualitative approaches, are warranted to understand the underlying dynamics in this observation. It is notable that 16% of cancer survivors did not have a usual source of care and 19% were middle income in our study.

Cancer survivors 65-74 years-old had a higher likelihood of optimal PCC than those 75 years of age and older in the enabling self-management and making decisions domains. The 75+ group may prefer to have strong control in care, asking direct questions, refusing some treatment options, or valuing 'being understood' during the communication [33, 44]. Demanding more quality in care among the oldest could potentially contribute to less satisfactory PCC in these patient involvement related domains. 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 [45]. 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 [46, 47].

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 [19]. This may reflect gender differences in communicational styles, as women are more likely to share their issues or concerns with providers than men [34, 48]. Typically, care providers can be more informative and supportive when they better understand patients' issues [49]. Given the gender gap in optimal PCC widened in recent years, further investigations to understand the underlying reasons for PCC differences are warranted.

4.2. 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 [50–52]. 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 mental health symptoms [35, 36, 38]. Moreover, patient advocate groups for the older or male cancer survivors could play roles in tailored patient education. Also, healthcare providers are usually more responsive to the patients who ask questions and share concerns, like other social interactions [53]. Additionally, there is evidence that racial/ethnic provider-patient concordance could facilitate positive interactions and relationships [54]. Last, exploring opportunities to enhance optimal PCC through online platforms (e.g., communications using Electronic Health Record to increase 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 [22, 57, 58].

4.3. Limitations

Some limitations need to be acknowledged. First, the present study used self-reported 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 the ‘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 low overall response rate (33%, 2017-2020). Third, because the data are cross-sectional, we were not able to determine the prospective and longitudinal associations with optimal PCC. Fourth, the COVID-19 data were collected from February to June 2020, during the early COVID-19 pandemic. Hence, the findings should be interpreted in the early COVID-19 pandemic context, and the findings may differ in later or post COVID-19 periods. 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 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-19.

4.4. 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-19 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.

Statement & Declaration

- **Funding**

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- **Data availability**

Current study used publicly available national survey data (Health Information National Trends Survey, HINTS 5 2017-2020). The raw data required to reproduce the above findings are available to download from <https://hints.cancer.gov/data/download-data.aspx>. The processed data required to reproduce the above findings will be made available upon request.

- **Ethics approval**

This study was a secondary data analysis. Human subject was not involved, and identifiable information was not included. Thus, this was deemed exempt for review by the Institutional Review Board at University of California, Davis

- **Acknowledgement**

N/A

Reference

1. Crossing the Quality Chasm: A New Health System for the 21st Century. 2001. doi:10.17226/10027.
2. Nci, DCCPS, Arp. PATIENT CENTERED COMMUNICATION IN CANCER CARE PATIENT-CENTERED COMMUNICATION IN CANCER CARE Promoting Healing and Reducing Suffering.
3. Street RL, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Educ Couns*. 2009;74:295–301. doi:10.1016/J.PEC.2008.11.015.
4. Street RL. How clinician-patient communication contributes to health improvement: modeling pathways from talk to outcome. *Patient Educ Couns*. 2013;92:286–91. doi:10.1016/J.PEC.2013.05.004.
5. Gattellari M, Butow PN, Tattersall MHN. Sharing decisions in cancer care. *Soc Sci Med*. 2001;52:1865–78. doi:10.1016/S0277-9536(00)00303-8.
6. Liang W, Burnett CB, Rowland JH, Meropol NJ, Eggert L, Hwang Y-T, et al. Communication between physicians and older women with localized breast cancer: implications for treatment and patient satisfaction. *J Clin Oncol*. 2002;20:1008–16. doi:10.1200/JCO.2002.20.4.1008.
7. Levit LA, Balogh EP, Nass SJ, Ganz PA. Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis. *Deliv High-Quality Cancer Care Charting a New Course a Syst Cris*. 2013;:1–412. doi:10.17226/18359.
8. Zachariae R, Pedersen CG, Jensen AB, Ehrnrooth E, Rossen PB, Von Der Maase H. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. *Br J Cancer*. 2003;88:658. doi:10.1038/SJ.BJC.6600798.
9. Mazor KM, Beard RL, Alexander GL, Arora NK, Firneno C, Gaglio B, et al. Patients' and family members' views on patient-centered communication during cancer care. *Psychooncology*. 2013;22:2487–95. doi:10.1002/PON.3317.
10. Gilligan T, Coyle N, Frankel RM, Berry DL, Bohlke K, Epstein RM, et al. Patient-Clinician Communication: American Society of Clinical Oncology Consensus Guideline. *J Clin Oncol*. 2017;35:3618–32. doi:10.1200/JCO.2017.75.2311.
11. Arora NK. Importance of patient-centered care in enhancing patient well-being: a cancer survivor's perspective. *Qual Life Res*. 2009;18:1–4. doi:10.1007/S11136-008-9415-5.
12. Chen G, Wu Q, Jiang H, Zhang H, Peng J, Hu J, et al. Fear of disease progression and psychological stress in cancer patients under the outbreak of COVID-19. *Psychooncology*. 2020;29:1395–8. doi:10.1002/PON.5451.
13. Young AM, Ashbury FD, Schapira L, Scotté F, Ripamonti CI, Olver IN. Uncertainty upon uncertainty: supportive Care for Cancer and COVID-19. *Support Care Cancer*. 2020;28:4001. doi:10.1007/S00520-020-05604-9.
14. Soriano EC, Perndorfer C, Otto AK, Fenech AL, Siegel SD, Dickson-Witmer D, et al. Psychosocial Impact of Cancer Care Disruptions in Women With Breast Cancer During the COVID-19 Pandemic. *Front Psychol*. 2021;12. doi:10.3389/FPSYG.2021.662339.
15. Patt D, Gordan L, Diaz M, Okon T, Grady L, Harmison M, et al. Impact of COVID-19 on Cancer Care: How the Pandemic Is Delaying Cancer Diagnosis and Treatment for American Seniors. *JCO Clin cancer informatics*. 2020;4:1059–71. doi:10.1200/CCI.20.00134.
16. Poortmans PM, Guarneri V, Cardoso MJ. Cancer and COVID-19: what do we really know? *Lancet (London, England)*. 2020;395:1884–5. doi:10.1016/S0140-6736(20)31240-X.
17. Street RL, Treiman K, Wu Q, Kranzler EC, Moultrie R, Mack N, et al. Managing uncertainty and responding to difficult emotions: Cancer patients' perspectives on clinician response during the COVID-19 pandemic. *Patient Educ Couns*. 2022;105:2137–44. doi:10.1016/J.PEC.2022.03.029.
18. Ayanian JZ, Zaslavsky AM, Arora NK, Kahn KL, Malin JL, Ganz PA, et al. Patients' experiences with care for lung cancer and colorectal cancer: findings from the Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol*. 2010;28:4154–61. doi:10.1200/JCO.2009.27.3268.
19. Blanch-Hartigan D, Chawla N, Moser RP, Finney Rutten LJ, Hesse BW, Arora NK. Trends in cancer survivors' experience of patient-centered communication: results from the Health Information National

- Trends Survey (HINTS). *J Cancer Surviv.* 2016;10:1067–77. doi:10.1007/S11764-016-0550-7/TABLES/4.
20. Spooner KK, Salemi JL, Salihu HM, Zoorob RJ. Disparities in perceived patient-provider communication quality in the United States: Trends and correlates. *Patient Educ Couns.* 2016;99:844–54. doi:10.1016/J.PEC.2015.12.007.
21. Treiman K, McCormack L, Wagner L, Roach N, Moultrie R, Sanoff H, et al. Factors affecting the communication experiences of newly diagnosed colorectal cancer patients. *Patient Educ Couns.* 2018;101:1585–93. doi:10.1016/J.PEC.2018.04.016.
22. Street RL, Treiman K, Kranzler EC, Moultrie R, Arena L, Mack N, et al. Oncology patients' communication experiences during COVID-19: comparing telehealth consultations to in-person visits. 1:3. doi:10.1007/s00520-022-06897-8.
23. Health Information National Trends Survey | HINTS. <https://hints.cancer.gov/>. Accessed 20 Mar 2023.
24. Winston S. Health Information National Trends Survey (HINTS.gov). <https://doi.org/101080/0276386920211912575>. 2021;40:215–23. doi:10.1080/02763869.2021.1912575.
25. E von E, DG A, M E, SJ P, PC G, JP V. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Ann Intern Med.* 2007;147:573–7. doi:10.7326/0003-4819-147-8-200710160-00010.
26. Survey Instruments | HINTS. <https://hints.cancer.gov/data/survey-instruments.aspx>. Accessed 23 Aug 2021.
27. Definition of survivor - NCI Dictionary of Cancer Terms - National Cancer Institute. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivor>. Accessed 20 Jan 2022.
28. HINTS Data merging code tool.
29. Westat. Health Information National Trends Survey 5 (HINTS 5) Cycle 4 Methodology Report. 2020.
30. Social Determinants of Health - Healthy People 2030 | health.gov. <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>. Accessed 23 Aug 2021.
31. Cohen SA, Kunicki ZJ, Nash CC, Drohan MM, Greaney ML. Rural-Urban Differences in Caregiver Burden Due to the COVID-19 Pandemic among a National Sample of Informal Caregivers. *Gerontol Geriatr Med.* 2021;7. doi:10.1177/23337214211025124.
32. Kroenke K, Spitzer RL, Williams JBW, Löwe B. An Ultra-Brief Screening Scale for Anxiety and Depression: The PHQ–4. *Psychosomatics.* 2009;50:613–21.
33. Trivedi N, Moser RP, Breslau ES, Chou WYS. Predictors of Patient-Centered Communication among U.S. Adults: Analysis of the 2017-2018 Health Information National Trends Survey (HINTS). <https://doi.org/101080/1081073020211878400>. 2021;26:57–64. doi:10.1080/10810730.2021.1878400.
34. Street RL, Gordon H, Haidet P. Physicians' communication and perceptions of patients: Is it how they look, how they talk, or is it just the doctor? *Soc Sci Med.* 2007;65:586–98.
35. Gutiérrez-Puertas L, Márquez-Hernández V V., Gutiérrez-Puertas V, Granados-Gámez G, Aguilera-Manrique G. Educational Interventions for Nursing Students to Develop Communication Skills with Patients: A Systematic Review. *Int J Environ Res Public Health.* 2020;17. doi:10.3390/IJERPH17072241.
36. Adam P, Murphy CF, Dierich M, Hager KD. Seven Years of Teaching Communication With the Patient-Centered Observation Form. *Fam Med.* 2018;50:132–7. doi:10.22454/FAMMED.2018.516713.
37. Talisman NW, Hurtado-de-Mendoza A, Saunders PA, Green BL. Validation of a Standardized Patient Checklist for Patient-Centered Communication: The G-PACER. *Med Sci Educ.* 2018;28:367–73. doi:10.1007/S40670-018-0558-X.
38. Treiman K, McCormack L, Olmsted M, Roach N, Reeve BB, Martens CE, et al. Engaging Patient Advocates and Other Stakeholders to Design Measures of Patient-Centered Communication in Cancer Care. *Patient.* 2017;10:93–103. doi:10.1007/S40271-016-0188-6.
39. Epstein R, Jr RS. Patient-centered communication in cancer care: promoting healing and reducing suffering. 2007. <https://psycnet.apa.org/record/481972008-001>. Accessed 13 Sep 2022.
40. Zandbelt LC, Smets EMA, Oort FJ, Godfried MH, de Haes HCJM. Determinants of physicians' patient-centred behaviour in the medical specialist encounter. *Soc Sci Med.* 2006;63:899–910.

41. Bickell NA, Wang JJ, Oluwole S, Schrag D, Godfrey H, Hiotis K, et al. Missed opportunities: racial disparities in adjuvant breast cancer treatment. *J Clin Oncol*. 2006;24:1357–62. doi:10.1200/JCO.2005.04.5799.
42. Hershman D, McBride R, Jacobson JS, Lamerato L, Roberts K, Grann VR, et al. Racial disparities in treatment and survival among women with early-stage breast cancer. *J Clin Oncol*. 2005;23:6639–46. doi:10.1200/JCO.2005.12.633.
43. Liu Y, Malin JL, Diamant AL, Thind A, Maly RC. Adherence to adjuvant hormone therapy in low-income women with breast cancer: the role of provider-patient communication.
44. Teh CF, Karp JF, Kleinman A, Reynolds CF, Weiner DK, Cleary PD. Older People’s Experiences of Patient-Centered Treatment for Chronic Pain: A Qualitative Study. *Pain Med*. 2009;10:521. doi:10.1111/J.1526-4637.2008.00556.X.
45. Miller KD, Nogueira L, Devasia T, Mariotto AB, Yabroff KR, Jemal A, et al. Cancer treatment and survivorship statistics, 2022. *CA Cancer J Clin*. 2022;72:409–36. doi:10.3322/CAAC.21731.
46. Healthy aging | National Institute on Aging. <https://www.nia.nih.gov/health/topics/healthy-aging?page=1>. Accessed 27 Jan 2023.
47. Bluethmann SM, Coa KI, Alfano CM, Hesse BW. Electronic Health Information Exchange Opportunities for Self-management of Care: Responses from Older Adults With and Without Cancer History in the United States. *Curr Oncol Rep*. 2018;20. doi:10.1007/S11912-018-0674-1.
48. Street RL, Gordon HS, Ward MM, Krupat E, Kravitz RL. Patient participation in medical consultations: Why some patients are more involved than others. *Med Care*. 2005;43:960–9. doi:10.1097/01.MLR.0000178172.40344.70.
49. Gordon HS, Street RL, Sharf BF, Soucek J. Racial differences in doctors’ information-giving and patients’ participation. *Cancer*. 2006;107:1313–20.
50. MM I, J I, H S-S, T Ø, GS T, S S, et al. Effect of a telemedicine intervention for diabetes-related foot ulcers on health, well-being and quality of life: secondary outcomes from a cluster randomized controlled trial (DiaFOTo). *BMC Endocr Disord*. 2020;20. doi:10.1186/S12902-020-00637-X.
51. LeBlanc TW, Baile WF, Eggly S, Bylund CL, Kurtin S, Khurana M, et al. Review of the patient-centered communication landscape in multiple myeloma and other hematologic malignancies. *Patient Educ Couns*. 2019;102:1602–12. doi:10.1016/J.PEC.2019.04.028.
52. Levinson W, Lesser CS, Epstein RM. Developing Physician Communication Skills For Patient-Centered Care. <https://doi.org/101377/hlthaff20090450>. 2017;29:1310–8.
53. Street RL, Millay B. Analyzing patient participation in medical encounters. *Health Commun*. 2001;13:61–73.
54. Burgess DJ, Fu SS, Van Ryn M. Why do providers contribute to disparities and what can be done about it? *J Gen Intern Med* 2004 1911. 2004;19:1154–9. doi:10.1111/J.1525-1497.2004.30227.X.
55. Tai-Seale M, Rosen R, Ruo B, Hogarth M, Longhurst CA, Lander L, et al. Implementation of Patient Engagement Tools in Electronic Health Records to Enhance Patient-Centered Communication: Protocol for Feasibility Evaluation and Preliminary Results. *JMIR Res Protoc*. 2021;10. doi:10.2196/30431.
56. Rathert C, Mittler JN, Banerjee S, McDaniel J. Patient-centered communication in the era of electronic health records: What does the evidence say? *Patient Educ Couns*. 2017;100:50–64.
57. Bailey JE, Gurgol C, Pan E, Njie S, Emmett S, Gatwood J, et al. Early Patient-Centered Outcomes Research Experience With the Use of Telehealth to Address Disparities: Scoping Review. doi:10.2196/28503.
58. Street, RL, Finset A. Two years with COVID-19: New - and old - challenges for health communication research. *Patient Educ Couns*. 2022;105:261. doi:10.1016/J.PEC.2022.01.006.

Conflict of interests

The authors declared no potential conflicts of interest.

CRediT Author Statement

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Highlights for Patient Education and Counseling

- Patient-centered communication (PCC) was suboptimal in cancer survivor during COVID-19
- Cancer survivors with poor mental health were less likely to have optimal PCC
- Cancer survivors without a usual source of care were less likely to have optimal PCC
- Male cancer survivors were less likely to have optimal PCC