



# Oncology patients' perceptions of and experiences with COVID-19

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## Abstract

**Purpose** No information is available on cancer patients' knowledge of and experiences with COVID-19. We undertook an evaluation of differences in COVID-19 symptom occurrence rates, COVID-19 testing rates, clinical care activities, knowledge of COVID-19, and use of mitigation procedures between patients who were and were not receiving active cancer treatment.

**Methods** Patients enrolled were  $\geq 18$  years of age; had a diagnosis of cancer; and were able to complete the emailed study survey online.

**Results** Of the 174 patients who participated, 27.6% ( $n = 48$ ) were receiving active treatment, 13.6% were unemployed because of COVID-19, 12.2% had been tested for COVID-19, and 0.6% had been hospitalized for COVID-19. Patients who were not on active treatment reported a higher mean number of COVID-19 symptoms ( $3.1 (\pm 4.2)$  versus  $1.9 (\pm 2.6)$ ), and patients who reported a higher number of COVID-19 symptoms were more likely to be tested. Over 55% of the patients were confident that their primary care provider could diagnose COVID-19, and the majority of the patients had high levels of adherence with the use of precautionary measures (e.g., social distancing, use of face coverings).

**Conclusion** The high level of COVID-19 symptoms and the significant overlap of COVID-19 and cancer-related symptoms pose challenges for clinicians who are assessing and triaging oncology patients for COVID-19 testing. For patients on active treatment, clinicians face challenges with how to assess and manage symptoms that, prior to COVID-19, would be ascribed to acute toxicities associated with cancer treatments or persistent symptoms in cancer survivors.

**Keywords** COVID-19 · Cancer · Perceptions · Fears · Mitigation procedures · Symptoms

## Introduction

The emergence of the novel coronavirus SARS-CoV-2 in December 2019, in Wuhan, China [1], dramatically changed the care of oncology patients. While limited data are available on the occurrence of the coronavirus disease 2019 (COVID-

19) in cancer patients [2, 3], one study from China reported a history of cancer in 18 of 1590 confirmed cases of COVID-19 [4]. In this study, after adjusting for age, sex, and comorbidities, a cancer diagnosis was associated with an increased risk of developing severe sequelae of COVID-19 (i.e., need for mechanical ventilation, death). In two recent consortium studies of cancer patients with confirmed cases of COVID-19, 13 [5] to 28% [6] of patients died. Risk factors associated with increased mortality included older age [5, 6], being male [6], presence of comorbidities [5, 6], being a former smoker [5], and having a poorer performance status [5].

The first known case of COVID-19 transmitted by community spread in the USA was reported in Northern California on February 28, 2020 [7]. Given that COVID-19 is transmitted primarily through person-to-person contact [8], public health orders were issued to limit person-to-person interaction [9] and to institute mitigation procedures [10]. On March 17, a "shelter in place order" went into effect in San Francisco and five other Bay Area counties [11]. With the issuance of the

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“shelter in place order,” for oncology patients, diagnostic and surgical procedures were delayed, treatment plans were altered to minimize visits to the clinic, and routine follow-up visits were postponed.

Evidence from the general population is beginning to emerge on individuals’ experiences with and knowledge of COVID-19, as well as on the use of various mitigation procedures. In a study of the general population in China ( $n = 1210$ ) [12], 0.9% had undergone COVID-19 testing; 60.5% agreed that COVID-19 was an airborne virus; 46.5% were very confident in their doctor’s ability to diagnose COVID-19; and 59.8% always wore masks. In another population-based study in the USA ( $n = 2402$ ) based on the data collected in early May many from individuals in New York City, Los Angeles, and a nationwide cohort [13], most of the participants supported stay-at-home orders and nonessential business closures (~82.6%). In addition, the majority reported always or often wearing face coverings in public areas (~84.5%) and believed that their state’s restrictions achieved the right balance (~66.3%) or were not restrictive enough (~18.0%). The authors of both studies noted the importance of evaluating additional groups of individual’s knowledge of and experiences with COVID-19. This information can be used to determine patients’ educational and clinical needs and to plan appropriate public health interventions.

To date, no information is available on oncology patients’ knowledge of and experiences with COVID-19. Given the potential increased risk for serious adverse events associated with COVID-19 infection in oncology patients [14, 15] and the changes in clinical practice as a result of the various “shelter in place” orders, we undertook an evaluation of differences in COVID-19 symptom occurrence rates, COVID-19 testing rates, clinical care activities, knowledge of COVID-19, and use of mitigation procedures between patients who were ( $n = 48$ ) and were not ( $n = 126$ ) receiving active cancer treatment.

## Methods

### Sample and settings

Oncology patients were recruited from a registry of individuals who participated in our previous National Cancer Institute–funded symptom management studies (CA187160, CA212064, CA151692) and gave permission to be re-contacted for future studies. Potential participants received an email with a brief explanation of the study and a link that directed them to the study’s enrollment page. This enrollment page explained the purpose of the study, the timeframe for survey completion, and information about participating in research. This study was exempt from requiring written informed consent by the Institutional Review Board at the University of California, San Francisco (UCSF). Patients were

included if they were  $\geq 18$  years of age; were able to read, write, and understand English; had a diagnosis of cancer; and were able to complete the study questionnaires online and by completing the survey consented to participate. A total of 627 emails were sent, 250 patients began the survey, and 174 completed the information that is presented in this paper (27.8% response rate).

### Recruitment and survey administration

Emails were sent to potential participants beginning May 27, 2020. Patients who received the survey link were asked to complete the survey within 2 weeks. After 14 days, one email reminder was sent to the patients who did not respond to the initial request to complete the survey. Responses as of June 19, 2020, are presented in this paper.

Patients were asked to answer all of the survey questions in relationship to their experiences in the past 14 days. The entire survey took ~60 min to complete. Patients were advised that doing the survey in one sitting was preferable but to take as many breaks as needed. All of the instruments were completed online using Research Electronic Data Capture (REDCap™) [16, 17].

### Instruments

*Demographic and clinical characteristics*—Patients completed a demographic questionnaire (e.g., age, marital status, living arrangements), the Karnofsky Performance Status (KPS) scale [18], and the Self-Administered Comorbidity Questionnaire (SCQ) [19]. In addition, they responded to questions about their cancer diagnosis, previous and current cancer treatments, and presence of metastatic disease.

*COVID-19 questionnaire*—This investigator-developed questionnaire was modeled after the survey that was used to evaluate symptoms of COVID-19, knowledge of COVID-19, use of precautionary measures for COVID-19, and health care utilization in the general population in China [12].

### Data analysis

Survey responses reside on a UCSF secure server. Data were downloaded from REDCap [16, 17] into the Statistical Package for the Social Sciences (SPSS) Version 27 (IBM Corporation, Armonk, NY) for subsequent analyses. Descriptive statistics for sample characteristics and study measures were calculated and reported as means and standard deviations for quantitative variables and percentages and frequencies for categorical variables. Differences between groups were evaluated using independent sample  $t$  tests, chi-square analyses, and Mann-Whitney  $U$  tests. A  $p$  value of  $< 0.05$  was considered statistically significant.

## Results

### Differences in demographic and clinical characteristics

Of the 174 patients who participated in this study, 27.6% ( $n = 48$ ) were receiving active treatment (Table 1). No differences were found in any demographic characteristics between patients who were and were not receiving active treatment. The total sample was 98.3% female, with a mean age of 63.3 ( $\pm 11.0$ ) years. The majority of the sample was White (82.2%), lived in a private home or apartment (98.8%), was married/partnered (59.8%), and had a college degree (77.4%). In terms of employment status, 40.2% of the patients were currently employed and 13.6% were unemployed because of COVID-19.

No differences were found in the majority of the clinical characteristics between patients who were and were not receiving active treatment (Table 1). The majority of the patients had breast cancer (79.6%) and 25.9% reported metastatic disease. Compared with the patients who were not receiving active treatment, patients on active treatment had a significantly lower KPS score, a higher level of comorbidity, and a longer time since their cancer diagnosis (all,  $p < 0.05$ ).

### Differences in COVID-19 symptoms and COVID-19 testing

In response to the question “During the past 14 days, have you had any of the following symptoms?” on the COVID-19 questionnaire, as shown in Table 2, compared with patients receiving active treatment, patients not on active treatment reported significantly higher occurrence rates for persistent fever, repeated shaking chills, severe chest pain, and ringing in your ears. No differences were found between the two groups in the rates of COVID-19 testing for the patient themselves or individuals who lived with the patient. Only 12.2% of the sample was tested for COVID-19.

As shown in Table 3, compared with patients who were not tested, patients who were tested reported significantly higher occurrence of rates for persistent fever, chills, repeated shaking with chills, muscle aches, difficulty breathing, dizziness, loss of sense of taste, loss of sense of smell, and severe chest pain. Compared with patients who were not tested, patients who were tested had a significantly higher number of COVID-19 symptoms ( $p = 0.021$ ).

### Differences in clinical care

Patients’ responses to the question “During the past 14 days, have you done any of the following activities?” are listed in Table 2. In the total sample, 20.3% called their primary care provider, 10.4% called their oncologist, and 7.0% had a video

appointment with their oncologist. Compared with the patients who were not receiving active treatment, a significantly higher percentage of patients on active treatment saw their oncologist in the clinic (i.e., 4.0% versus 14.6%,  $p = 0.021$ ).

### Knowledge of COVID-19

Because no differences were found between the two groups for any of the questions on Table 4, data for the total sample are reported. In terms of viral transmission, while 98.9% of the patients agreed that COVID-19 was transmitted as droplets when individuals cough or sneeze, only 85.0% agreed that COVID-19 is an airborne virus. The majority obtained their health information from the Internet (78.7%) and/or television (67.2%). The majority were very (36.3%) or somewhat (47.7%) satisfied with the amount of health information that is available about COVID-19. The majority (55.2%) were very confident in their primary care provider’s ability to recognize and diagnose COVID-19. Thirty-five percent of the sample indicated that they were very (3.4%) or somewhat (30.6%) likely to contract COVID-19 and 33.5% indicated that they were very likely to survive if infected with the virus. In terms of worries, 19.5% and 54.6% were very worried or somewhat worried, respectively, that family members would become infected with COVID-19.

### Use of precautionary measures

Because no differences were found between the two groups on the use of any of the precautionary measures listed on Table 5, data for the total sample are reported. The majority of the patients reported that they always did the following behaviors: covering mouth when coughing and sneezing; avoiding sharing utensils during meals; washing hands with soap and water; washing hands immediately after coughing, rubbing nose, and/or sneezing; wearing a mask; maintaining social distancing, and washing hands after touching objects that may be contaminated. On average, in the past 14 days, patients stayed at home 18.0 ( $\pm 6.8$ ) hours.

## Discussion

This study is the first to report on oncology patients’ experiences with and perceptions of COVID-19 in terms of COVID-19 symptom occurrence rates, COVID-19 testing rates, clinical care activities, knowledge of COVID-19, and use of mitigation procedures. While one may have hypothesized that a large number of differences would be found in the experiences and perceptions of oncology patients who were and were not receiving active treatment, very few differences were identified. As of June 19, 2020, 3.2 million (8.1%) of California’s population of 39.5 million were tested for COVID-19 (<https://>

**Table 1** Differences in patients' demographic and clinical characteristics based on treatment status

Characteristic	Total sample <i>n</i> = 174	Not on current treatment <i>n</i> = 126 72.4%	Receiving treatment <i>n</i> = 48 27.6%	Statistics
<b>Demographic characteristics</b>				
Age (years, mean, SD)	63.3 (11.0)	64.2 (11.2)	60.9 (10.1)	$t = 1.79, p = 0.076$
Female (% , <i>n</i> )	98.3 (171)	99.2 (125)	95.8 (46)	FE, $p = 0.185$
Living arrangements (% , <i>n</i> )				
Private home or apartment	98.8 (172)	99.2 (125)	97.9 (47)	$\chi^2 = 3.01, p = 0.222$
Assisted living facility	0.6 (1)	0.8 (1)	0.0 (0)	
Other	0.6 (1)	0.0 (0)	2.1 (1)	
Lives alone (% yes, <i>n</i> )	31.6 (55)	33.3 (42)	27.1 (13)	FE, $p = 0.470$
Married/partnered (% yes, <i>n</i> )	59.8 (104)	58.7 (74)	62.5 (30)	FE, $p = 0.730$
Number of people in your household including yourself (mean, SD)	1.9 (0.9)	1.8 (0.9)	2.1 (0.9)	$t = 1.45, p = 0.150$
Race/ethnicity				
White	82.2 (143)	85.6 (108)	72.9 (35)	$\chi^2 = 9.48, p = 0.050$
Black or African American	1.1 (2)	1.6 (2)	0.0 (0)	
Asian or Pacific Islander	6.9 (12)	4.8 (6)	12.5 (6)	
Hispanic	4.6 (8)	2.4 (3)	10.4 (5)	
Mixed ethnic background and other	5.2 (9)	5.6 (7)	4.2 (2)	
Highest level of education				
High school	2.9 (5)	3.2 (4)	2.1 (1)	$U, p = 0.818$
Some college	19.7 (34)	19.2 (24)	20.8 (10)	
College graduate	24.3 (42)	24.0 (30)	25.0 (12)	
Some graduate school	15.6 (27)	15.2 (19)	16.7 (8)	
Advanced degree	37.5 (65)	38.4 (48)	35.4 (17)	
Annual household income				
< \$20,000	5.5 (8)	6.6 (7)	2.5 (1)	$U, p = 0.379$
\$20,000 to \$59,000	26.0 (38)	27.4 (29)	22.5 (9)	
\$60,000 to \$100,000	21.9 (32)	20.8 (22)	25.0 (10)	
> \$100,000	46.6 (68)	45.2 (48)	50.0 (20)	
Currently employed (% yes, <i>n</i> )	40.2 (70)	39.7 (20)	41.7 (20)	FE, $p = 0.863$
Unemployed because of COVID-19 (% yes, <i>n</i> )	13.6 (14)	15.8 (12)	7.4 (2)	FE, $p = 0.346$
<b>Clinical characteristics</b>				
Body mass index (kg/m <sup>2</sup> , mean, SD)	26.6 (5.4)	26.1 (4.8)	27.8 (6.7)	$t = 1.55, p = 0.126$
Karnofsky Performance Status score (mean, SD)	92.4 (9.3)	93.5 (8.4)	89.6 (10.7)	$t = 2.54, p = 0.012$
Number of comorbidities (mean, SD)	1.6 (1.4)	1.5 (1.4)	1.9 (1.4)	$t = -1.35, p = 0.179$
Self-Administered Comorbidity Questionnaire score (mean, SD)	3.3 (3.0)	3.0 (2.9)	4.1 (3.3)	$t = -2.14, p = 0.034$
Chronic conditions (% , <i>n</i> )				
Heart disease	7.0 (12)	8.0 (10)	4.3 (2)	FE, $p = 0.518$
High blood pressure	29.7 (51)	32.3 (40)	22.9 (11)	FE, $p = 0.267$
Lung disease	5.9 (10)	6.4 (8)	4.4 (2)	FE, $p = 1.000$
Diabetes	4.1 (7)	3.2 (4)	6.5 (3)	FE, $p = 0.390$
Ulcer or stomach disease	3.5 (6)	3.2 (4)	4.3 (2)	FE, $p = 0.662$
Kidney disease	1.8 (3)	2.4 (3)	0.0 (3)	FE, $p = 0.568$
Liver disease	1.8 (3)	0.8 (1)	4.4 (2)	FE, $p = 0.177$
Anemia or blood disease	2.4 (4)	1.6 (2)	4.5 (2)	FE, $p = 0.286$
Depression	26.6 (45)	23.8 (29)	34.0 (16)	FE, $p = 0.180$
Osteoarthritis, degenerative arthritis	28.7 (49)	26.2 (33)	35.6 (16)	FE, $p = 0.253$
Back pain	32.4 (55)	32.5 (40)	31.9 (15)	FE, $p = 1.000$
Rheumatoid arthritis	4.3 (7)	5.0 (6)	2.3 (1)	FE, $p = 0.675$
Cancer diagnosis (% , <i>n</i> )				
Breast cancer	79.6 (137)	75.2 (94)	91.5 (43)	FE, $p = 0.111$
Gastrointestinal	3.5 (6)	4.0 (5)	2.1 (1)	
Lung	0.6 (1)	0.8 (1)	0.0 (0)	
Malignant melanoma	0.6 (1)	0.8 (1)	0.0 (0)	
Gynecological	5.2 (9)	7.2 (9)	0.0 (0)	
Prostate	0.6 (1)	0.0 (0)	2.1 (1)	
Multiple cancer diagnoses or other	9.9 (17)	12.0 (15)	4.3 (2)	
Presence of metastatic disease (% yes, <i>n</i> )	25.9 (44)	23.6 (29)	31.9 (15)	FE, $p = 0.328$
Time since cancer diagnosis (years, mean, SD)	9.5 (6.7)	11.0 (7.1)	5.3 (3.0)	$t = 7.28, p < 0.001$
Number of previous cancer treatments (mean, SD)	3.0 (1.0)	2.9 (0.9)	3.3 (1.2)	$t = -1.85, p = 0.068$
Number of current cancer treatments (mean, SD)	---	---	1.04 (0.4)	---
Receiving cancer treatments currently (% , <i>n</i> )	27.6 (48)			
Types of current treatments (for <i>n</i> = 48; % , <i>n</i> )				
Radiation therapy	4.2 (2)			
Chemotherapy	14.6 (7)			
Hormonal therapy	81.3 (39)			
Immunotherapy	4.2 (2)			
Targeted therapy	0.0 (0)			

FE Fisher's Exact test, kg kilograms, m<sup>2</sup> meters squared, SD standard deviation, U Mann-Whitney U test

[covidtracking.com/data/state/california#historical](https://covidtracking.com/data/state/california#historical)). In our study, a slightly higher percentage (12.2%) of the patients were tested and only one patient (0.6%) reported being hospitalized for the infection.

While in a recent report of 350 patients in the USA who tested positive for the infection [20] the median number of symptoms out of 17 was 7 (range 4–10), in our sample, the median number of symptoms out of 15 was 2.0 (range 0 to 15). However, for four of the fifteen COVID-19 symptoms evaluated (i.e., persistent fever, repeated shaking chills, severe chest pain, ringing in your ears), patients not on active treatment reported higher occurrence rates. Equally noteworthy is the relatively high occurrence rates for many of the COVID-19-related symptoms among the total sample. For example, symptoms like headache, muscle aches, severe fatigue or tiredness, and difficulty with word finding that are on the list of COVID-19-related symptoms are common symptoms associated with cancer and its treatment [21, 22]. This significant overlap of COVID-19 and cancer-related symptoms poses challenges for clinicians who are assessing and triaging oncology patients for COVID-19 testing. Moreover, for patients on active treatment, clinicians face challenges with how to assess and manage symptoms that, prior to COVID-19, would be ascribed to acute toxicities associated with cancer treatments or persistent symptoms in cancer survivors.

Not surprising, patients in our sample who were tested for COVID-19 reported a higher median number of symptoms (i.e., 3; range 0 to 15). Symptoms with occurrence rates above 70% in the tested group included persistent fever, chills, repeated shaking chills, loss of sense of taste, and severe chest pain. Again, while only one case of COVID-19 was diagnosed in the 21 patients who were tested, this list of symptoms often suggests the occurrence of an infection or sepsis in an oncology patient that warrants emergency management.

While the number of telehealth visits has increased during the pandemic [23] and international oncology guidelines suggest that telemedicine needs to be considered to support patients and reduce oncology patients' exposure to COVID-19 [24], little is known about how oncology patients have accessed healthcare during the pandemic. As shown in Table 2, only 20.3% of our sample contacted their primary care provider and only 10.4% contacted their oncologist. Except for a higher rate of oncology-related clinic visits in the active treatment group, no differences were found between the treatment groups in the utilization of other clinical care services. As routine healthcare services begin to resume, clinicians will need to consider how they can provide primary care and oncology services to patients in the safest and most cost effective manner [25].

In terms of oncology patients' knowledge and feelings regarding COVID-19 (Table 4), the only comparative data are from a study of the general population in China [12]. While 58.2% of the Chinese participants were college students, their

responses are very similar to our cancer patients. A few findings warrant consideration as public health programs are planned and implemented to improve patients' knowledge and decrease fears regarding the pandemic. While 60.5% of Chinese participants agreed with the statement that COVID-19 is an airborne virus, 85% of our patients endorsed this statement. This difference may be attributable to when the questionnaires were administered as dissemination of information about the pandemic increases over time.

In contrast to 93.5% of Chinese participants who obtained health information about the pandemic from the Internet, our patients used multiple sources for information (e.g., Internet, television). It should be noted that the majority of our patients, as well as the Chinese participants, were satisfied with the amount of health information available and confident in their primary care provider's ability to recognize and diagnose the infection. However, over a third of the participants in both studies expressed concerns about themselves or a family member contracting COVID-19. Given the added stress associated with social distancing and other mitigation procedures initiated during the pandemic, clinicians need to be mindful of oncology patients' fears and concerns about COVID-19 as well as plans to monitor and manage their cancer [26] and plan to discuss these concerns during telehealth or in person visits. In addition, given that our patients were well educated, future studies need to evaluate gaps in knowledge and optimal educational approaches for individuals with lower levels of education.

Consistent with the previous reports [12, 13], our patients reported high levels of adherence with the precautionary measures listed on Table 5. These high levels of adherence may be related to the issuance of an executive order in the State of California regarding shelter in place on March 19, 2020 (<https://www.gov.ca.gov/2020/03/19/governor-gavin-newsom-issues-stay-at-home-order/>), and recommendations by the California Department of Health on the use of face coverings on April 1, 2020 (<https://www.cdph.ca.gov/Programs/CID/DCDC/Pages/Face-Coverings-Guidance.aspx>). In addition, these high levels of adherence may be related to oncology patients' concerns about increased risk for adverse events associated with COVID-19 infection.

While this study provides the first information on oncology patients experiences with COVID-19, several limitations warrant consideration. Given that the majority of the patients were well-educated, White women with breast cancer, our findings may not generalize to men, to different racial/ethnic groups, patients with other types of cancer, and/or patients with a lower socioeconomic status. In addition, given that only 27.6% of the patients were receiving active treatment at the time they completed the survey,

**Table 2** Differences in COVID-19 symptoms and cancer and non-cancer treatments based on treatment status

Characteristic	Total sample <i>n</i> = 174  % ( <i>n</i> )	Not on current treatment <i>n</i> = 126 72.4%  % ( <i>n</i> )	Receiving treatment <i>n</i> = 48 27.6%  % ( <i>n</i> )	Statistics
COVID-19 symptoms—During the past 14 days, have you had any of the following symptoms? (% yes)				
Persistent fever (> 38 °C of 100.4 °F) for at least one day	9.2 (16)	12.0 (15)	2.1 (1)	FE, <i>p</i> = 0.044
Chills	9.9 (17)	12.1 (15)	4.2 (2)	FE, <i>p</i> = 0.158
Repeated shaking with chills	9.8 (17)	12.8 (16)	2.1 (1)	FE, <i>p</i> = 0.043
Headache	30.6 (53)	32.8 (41)	25.0 (12)	FE, <i>p</i> = 0.361
Muscle aches	33.5 (58)	32.0 (40)	37.5 (18)	FE, <i>p</i> = 0.590
Cough	23.7 (41)	25.6 (32)	18.8 (9)	FE, <i>p</i> = 0.426
Difficulty breathing	13.8 (24)	16.7 (21)	6.3 (3)	FE, <i>p</i> = 0.088
Dizziness	20.2 (35)	21.6 (27)	16.7 (8)	FE, <i>p</i> = 0.532
Sore throat	17.5 (30)	21.0 (26)	8.5 (4)	FE, <i>p</i> = 0.071
Loss of sense of taste	11.6 (20)	13.7 (17)	6.3 (3)	FE, <i>p</i> = 0.197
Loss of sense of smell	12.8 (22)	15.2 (19)	6.4 (3)	FE, <i>p</i> = 0.198
Severe fatigue or tiredness	24.4 (42)	25.6 (32)	21.3 (10)	FE, <i>p</i> = 0.691
Severe chest pain	9.8 (17)	12.8 (16)	2.1 (1)	FE, <i>p</i> = 0.043
Difficulty finding the right words in a conversation	24.0 (41)	26.0 (32)	18.8 (9)	FE, <i>p</i> = 0.426
Ringing in your ears	29.4 (50)	35.2 (43)	14.6 (7)	FE, <i>p</i> = 0.009
Number of COVID-19 symptoms (mean, SD)	2.8 (3.8)	3.1 (4.2)	1.9 (2.6)	U, <i>p</i> = 0.174
Median number of COVID-19 symptoms	2.0	2.0	1.0	
COVID-19 testing				
Have you been tested for COVID-19?				
No	87.8 (152)	87.3 (110)	89.4 (42)	$\chi^2 = 0.44, p = 0.804$
Yes and tested negative	11.6 (20)	11.9 (15)	10.6 (5)	
Yes and tested positive	0.0 (0)	0.0 (0)	0.0 (0)	
Yes and prefer not to report my test results	0.6 (1)	0.8 (1)	0.0 (0)	
Has anyone you live with been tested for COVID-19?				
No	83.9 (146)	84.1 (106)	83.3 (40)	$\chi^2 = 0.97, p = 0.616$
Yes and tested negative	4.0 (7)	3.2 (4)	6.3 (3)	
Yes and tested positive	0.0 (0)	0.0 (0)	0.0 (0)	
Yes and prefer not to report my test results	0.0 (0)	0.0 (0)	0.0 (0)	
I live alone	12.1 (21)	12.7 (16)	10.4 (5)	
Clinical care—During the past 14 days, have you done any of the following activities? (% yes)				
Called your primary care provider	20.3 (35)	22.4 (28)	14.9 (7)	FE, <i>p</i> = 0.395
Seen your primary care provider in the clinic	6.4 (11)	4.9 (6)	10.4 (5)	FE, <i>p</i> = 0.295
Had a video appointment with your primary care provider	12.1 (21)	11.1 (14)	14.9 (7)	FE, <i>p</i> = 0.601
Called your oncologist	10.4 (18)	10.3 (13)	10.6 (5)	FE, <i>p</i> = 1.000
Seen your oncologist in the clinic	6.9 (12)	4.0 (5)	14.6 (7)	FE, <i>p</i> = 0.021
Had a video appointment with your oncologist	7.0 (12)	4.8 (6)	13.0 (6)	FE, <i>p</i> = 0.088
Received supportive care (e.g., blood transfusion)	2.9 (5)	1.6 (2)	6.4 (3)	FE, <i>p</i> = 0.128
Received treatment for symptoms (e.g., pain, nausea)	6.4 (11)	4.0 (5)	12.8 (6)	FE, <i>p</i> = 0.072
Had a nurse visit your home	1.7 (3)	1.6 (2)	2.1 (1)	FE, <i>p</i> = 1.000
Had an aid care for you in your home	1.2 (2)	0.8 (1)	2.1 (1)	FE, <i>p</i> = 0.473
Been hospitalized for COVID-19	0.6 (1)	0.8 (1)	0.0 (0)	FE, <i>p</i> = 1.000
Been hospitalized for cancer care	0.6 (1)	0.8 (1)	0.0 (0)	FE, <i>p</i> = 1.000
Have you had medical insurance coverage during the last 14 days	97.7 (169)	96.8 (121)	100.0 (48)	FE, <i>p</i> = 0.577

FE Fisher's Exact test, SD standard deviation, U Mann-Whitney U test

**Table 3** Relationship between COVID-19 symptoms and COVID-19 testing

COVID-19 symptoms – during the past 14 days have you had any of the following symptoms?	Not tested % (n)	Tested % (n)	<i>p</i> value*
Persistent fever (> 38 °C of 100.4 °F) for at least 1 day			
No	92.7 (140)	76.2 (16)	0.030
Yes	7.3 (11)	23.8 (5)	
Chills			
No	92.7 (139)	71.4 (15)	0.009
Yes	7.3 (11)	28.6 (6)	
Repeated shaking with chills			
No	92.1 (139)	76.2 (16)	0.039
Yes	7.9 (12)	23.8 (5)	
Headache			
No	70.9 (107)	57.1 (12)	0.215
Yes	29.1 (44)	42.9 (9)	
Muscle aches			
No	69.5 (105)	42.9 (9)	0.025
Yes	30.5 (46)	57.1 (12)	
Cough			
No	77.5 (117)	66.7 (14)	0.282
Yes	22.5 (34)	33.3 (7)	
Difficulty breathing			
No	89.5 (136)	61.9 (13)	0.003
Yes	10.5 (16)	38.1 (8)	
Dizziness			
No	83.4 (126)	52.4 (11)	0.002
Yes	16.6 (25)	47.6 (10)	
Sore throat			
No	4.6 (126)	66.7 (14)	0.063
Yes	15.4 (23)	33.3 (7)	
Loss of sense of taste			
No	90.7 (136)	71.4 (15)	0.021
Yes	9.3 (14)	28.6 (6)	
Loss of sense of smell			
No	90.1 (136)	65.0 (13)	0.006
Yes	9.9 (15)	35.0 (7)	
Severe fatigue or tiredness			
No	78.0 (117)	57.1 (12)	0.055
Yes	22.0 (33)	42.9 (9)	
Severe chest pain			
No	92.7 (140)	71.4 (15)	0.008
Yes	7.3 (11)	28.6 (6)	
Difficulty finding the right words in a conversation			
No	76.7 (115)	70.0 (14)	0.579
Yes	23.2 (35)	30.0 (6)	
Ringing in your ears			
No	72.3 (107)	57.1 (12)	0.201
Yes	27.7 (41)	42.9 (9)	
Number of COVID-19 symptoms (mean, SD)	2.4 (3.4)	5.3 (5.6)	0.021 <sup>+</sup>
Median number of COVID-19 symptoms	1.5	3.0	

\*Fisher's Exact test

<sup>+</sup> Mann-Whitney *U* test*SD* standard deviation

**Table 4** Knowledge and feelings regarding COVID-19 (*n* = 174)

Questions	%
COVID-19 is transmitted as droplets when individuals cough or sneeze	
Agree	98.9
Disagree	0.0
Don't know	1.1
COVID-19 is transmitted by contaminated objects	
Agree	75.8
Disagree	7.5
Don't know	16.7
COVID-19 is an airborne virus	
Agree	85.0
Disagree	8.7
Don't know	6.4
Have you kept track of the number of individuals in the United States who are infected with COVID-19? (% yes)	84.4
Have you kept track of the number of individuals in the United States who have died from COVID-19? (% yes)	86.8
Have you heard that the number of individuals who have recovered from COVID-19 has increased? (% yes)	76.2
What is your main source of health information? (check all that apply)	
Internet	78.7
Television	67.2
Radio	24.1
Family members	23.6
Other	27.6
What is your level of satisfaction with the amount of health information that is available about COVID-19?	
Very satisfied	36.3
Somewhat satisfied	47.7
Not very satisfied	10.9
Not satisfied at all	3.4
Do not know	1.7
What is your level of confidence in your primary care provider's ability to recognize and diagnosis COVID-19?	
Very confident	55.2
Somewhat confident	23.0
Not very confident	4.0
Not confident at all	1.1
Do not know	16.7
What do you think is your likelihood of contracting COVID-19 during the current outbreak?	
Very likely	3.4
Somewhat likely	30.6
Not very likely	51.1
Not at all likely	8.6
Do not know	6.3
What do you think is your likelihood of surviving if infected with COVID-19?	
Very likely	33.5
Somewhat likely	37.0
Not very likely	15.6
Not at all likely	2.9
Do not know	11.0
How worried are you that members of your family will become infected with COVID-19?	
Very worried	19.5
Somewhat worried	54.6
Not very worried	23.6
Not worried at all	2.3
Do not know	0.0
How worried are you that your children or grandchildren younger than 16 years of age will become infected with COVID-19?	
Very worried	8.0
Somewhat worried	21.3
Not very worried	16.7
Not worried at all	3.4
Do not know	0.6
I do not have children or grandchildren younger than 16 years of age	50.0

additional research is needed to evaluate the impact of the pandemic on the receipt of primary and cancer care services. Equally important is a need to understand why the

patients not receiving active treatment reported more symptoms than the patients on active treatment and why the testing rates were relatively low in this sample. Qualitative



**Table 5** Use of precautionary measures ( $n = 174$ )

How often have you used each of the precautionary measures in the past 14 days?	Never %	Occasionally %	Sometimes %	Most of the time %	Always %
Covering mouth when coughing and sneezing	0.0	0.0	0.6	14.4	85.0
Avoiding sharing utensils during meals	5.2	1.7	4.6	17.2	71.3
Washing hands with soap and water	0.0	0.0	1.2	11.0	87.8
Washing hands immediately after coughing, rubbing nose, and/or sneezing	2.3	3.5	14.0	27.3	52.9
Wearing a mask outside regardless of the presence or absence of symptoms	1.7	1.2	7.5	21.4	68.2
Maintaining social distancing of at least 6 ft	0.0	0.0	1.2	28.9	69.9
Washing hands after touching objects that may be contaminated	0.6	0.0	2.9	17.9	78.6
Wearing gloves when shopping	48.5	8.2	15.8	5.8	21.7
Feeling that too much unnecessary worrying has occurred as a result of the COVID-19 pandemic	47.7	20.3	19.8	8.1	4.1
Over the past 14 days, please let us know the average number of hours per day you have stayed at home to avoid COVID-19 (mean, SD)	18.0 (6.8)				

*SD* standard deviation

studies are warranted to understand these findings. Given the study's cross-sectional design, future studies need to evaluate for changes in patients' experiences with COVID-19 and cancer care in the context of the evolving pandemic. Equally important and is currently being undertaken by our research team, regional variations in patients' experiences with COVID-19 and cancer care warrant investigation.

Despite these limitations, this study provides information that clinicians can use to educate oncology patients regarding the mechanisms of viral transmission and the need for mitigation procedures, as well as begin discussions about their concerns regarding the likelihood of viral infection, how to assess and report symptoms during and after treatment, and how to re-engage in their care in the safest way possible. In addition, detailed information needs to be provided to oncology patients on multiple platforms (e.g., Internet, television) about the relationships between the risks associated with COVID-19 and cancer screening, treatments, and ongoing surveillance.

**Availability of data** Data will be provided to the publisher after they obtain a material transfer agreement from the University of California, San Francisco. Individuals who would like a copy of the survey can contact the corresponding author.

**Authors' contributions** All of the authors participated in the revisions to this paper, the interpretation of the results, and approved the final paper.

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### Compliance with ethical standards

**Conflicts of interest** The authors declare that they have no conflicts of interest.

**Ethics approval** This study was approved by the Committee on Human Research at the University of California.

**Consent to participate** This study was exempted from written informed consent.

**Consent for publication** All of the authors read the final version of the paper and approved its submission for publication.

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