Documenting the Symptom Experience of Cancer Patients

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Abstract

BACKGROUND: Cancer patients experience symptoms associated with their disease, treatment, and comorbidities. Symptom experience is complicated, reflecting symptom prevalence, frequency, and severity. Symptom burden is associated with treatment tolerance as well as patients' quality of life (QOL).

OBJECTIVES: The purpose of this study was to document the symptom experience and QOL of patients with commonly diagnosed cancers. The relationship between symptoms and QOL was also explored.

METHODS: A convenience sample of patients with the five most common cancers at a comprehensive cancer center completed surveys assessing symptom experience (Memorial Symptom Assessment Survey) and QOL (Functional Assessment of Cancer Therapy). Patients completed surveys at baseline and at 3, 6, 9, and 12 months thereafter. This article describes the study's baseline findings.

RESULTS: Surveys were completed by 558 cancer patients with breast, colorectal, gynecologic, lung, or prostate cancer. Patients reported an average of 9.1 symptoms, with symptom experience varying by cancer type. The mean overall QOL for the total sample was 85.1, with results differing by cancer type. Prostate cancer patients reported the lowest symptom burden and the highest QOL.

LIMITATIONS: The sample was limited in terms of racial diversity. Because of the method of recruitment, baseline data were collected 6–8 months after diagnosis, meaning that participants were at various stages of treatment.

CONCLUSIONS: The symptom experience of cancer patients varies widely depending on cancer type. Nevertheless, most patients report symptoms, regardless of whether or not they are currently receiving treatment. Patients' QOL is inversely related to their symptom burden.

In 2010, the Centers for Disease Control and Prevention estimated that 12 million cancer survivors were living in the United States. With improvements in screening, detection, and treatment, more individuals diagnosed with cancer are surviving their disease,[1] thus affording the opportunity for researchers to examine patients' symptom experiences during and after treatment.[2–4] The Institute of Medicine's report "From Cancer Patient to Cancer Survivor: Lost in Transition" focused on adult cancer survivors and noted the substantial consequences of cancer and its treatment.[5] Patients with cancer experience multiple concurrent symptoms that affect their physical and psychosocial outcomes.[2,6] A National Institutes of Health State-of-the-Science Conference explored symptom management in cancer and recommended larger studies to provide more accurate estimates of the incidence of particular symptoms and to investigate the relationship between various symptoms and patient characteristics.[7]

The symptom experience of cancer patients has been studied widely, often with a focus on single symptoms or on single disease types.[8–10] In fact, patients rarely present with a single symptom. Researchers have found that most cancer patients experience multiple symptoms,[6,10,11] with the range of symptoms varying by type of treatment, sex, age, and cancer type. Previous studies have established the average number of symptoms reported by cancer survivors as ranging from 8 to 12.[6,11] The concept of symptom burden includes the prevalence, frequency, and severity of symptoms and the level of physical and emotional distress caused by symptoms that go untreated or unrelieved.[12–15] Tishelman and colleagues found that concordance among these aspects of symptoms varied by severity of illness, with greater concordance in patients closer to death.[13] The complexity of symptom experience poses challenges for successful treatment of patients over the long term. A recent study dem-

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onstrated that providing early symptom management through palliative care to metastatic lung cancer patients resulted in better quality of life (QOL), better mood, and longer survival.[16]

QOL is a multifactorial concept that has also been widely examined in a variety of disease types.[17–19] In the cancer arena, focus has centered on patients' perceptions of well-being in several domains: physical, psychological, social, and functional.[20] In cancer care, QOL has been recognized as important to the outcome of cancer treatment[3] and as a component of the symptom experience.[8,21] The number and type of symptoms cancer patients experience have been significantly related to impairment in performance status, psychological distress, and overall QOL.[6,8] Recently, several studies have demonstrated that pretreatment QOL is predictive of survival in patients with cancer of various types—advanced colorectal,[22] various stage esophageal,[23] advanced non-small cell lung,[24] and metastatic prostate.[25]

It is important for oncology clinicians to better understand the symptom experience of cancer survivors. Further research is needed to identify ways to minimize symptom persistence and relieve symptom burden and, thus, to improve patients' QOL. The primary aim of this study was to document the symptoms and QOL experienced by cancer survivors with commonly diagnosed cancers. This article describes the baseline findings of a longitudinal study.

Materials and Methods

This was a longitudinal (12-month) study using a repeated measures design involving a convenience sample of outpatients diagnosed with cancer at a large National Cancer Institute–designated comprehensive cancer center. The Protocol Review and Monitoring Committee of the cancer center and the Human Research Protection Office of the affiliated university approved the study.

PARTICIPANTS

Patients diagnosed with one of the top five cancers (breast, colorectal, gynecological, lung, and prostate) by volume at the cancer center and with stage I, II, or III disease were eligible for participation in this study. Patients with stage 0 disease were excluded because this stage is unusual outside of breast cancer. Patients with stage IV disease were excluded, to minimize attrition over the course of the longitudinal portion of the study (not described here) and because of the chronicity of treatment. Potential participants were identified through the cancer center's cancer registry.

PROCEDURES

New cases for the cancer center's tumor registry are entered into a database typically 6–8 months following initial diagnosis. Each month following study implementation, all eligible patients newly entered into the database received a letter informing them of the research study and inviting them to participate. The letter was accompanied by a consent document, which included the elements of informed consent and the assessment measures. The consent form included permission for the researchers to obtain the patient's clinical information from the tumor registry. Patients who returned completed assessment measures were considered to have consented to participate. Those who did not want to participate could return an opt-out card or could decline to return completed surveys from 2 consecutive mailings. If patients did not return the surveys from the first mailing, a follow-up phone call was made to determine whether they received the study packet and whether they had any questions about the study. Patients could decline to participate during the phone call or could request that the study packet be resent. If patients failed to return surveys from 1 mailing, they received one further mailing. If they failed to respond to 2 mailings, they were dropped from the study. All study measures were completed by patients at home and returned to the researchers by mail.

Patients who agreed to participate were asked to complete a set of surveys on their own at baseline and at 3, 6, 9, and 12 months.

Table 1

Patient Characteristics

VARIABLE	RESPONDERS (N = 558), N (%)	NONRESPONDERS (N = 1,036), N (%)
Currently receiving cancer treatment	189 (35%)	
Sex		
Female	298 (53%)	591 (57%)
Male	262 (47%)	443 (43%)
Age	X = 60.3, SD = 10.8	X = 60.6, SD = 12.4
Race[a]		
Minority	60 (11%)	253 (25%)
White	499 (89%)	780 (75%)
Cancer type		
Breast	164 (29%)	252 (24%)
Colorectal	34 (6%)	97 (9%)
Gynecological	96 (17%)	224 (22%)
Lung	44 (8%)	171 (17%)
Prostate	221 (40%)	290 (28%)
Cancer stage		
I	167 (30%)	382 (37%)
II	279 (50%)	435 (42%)
III	113 (20%)	217 (21%)
Comorbidity score[b]		
0	180 (32%)	288 (28%)
1	253 (45%)	424 (41%)
2	85 (15%)	181 (17%)
3	40 (7%)	141 (14%)
Number of symptoms		
Breast	X = 11.0, SD = 8.2	
Colorectal	X = 12.3, SD = 7.9	
Gynecologic	X = 11.6, SD = 8.3	
Lung	X = 11.1, SD = 6.8	
Prostate	X = 5.5, SD = 5.6	

[a] $P < .01$.
[b] $P < .001$.

Table 2

Top Symptoms from the MSAS for Those Reporting Symptoms

RANK AND SYMPTOM	OVERALL	BREAST	COLORECTAL	GYNECOLOGIC	LUNG	PROSTATE
Lack of energy						
Prevalence[a]	332 (60%)	115 (71%)	27 (79%)	68 (72%)	32 (74%)	90 (41%)
Frequency	2.6 (0.9)	2.5 (0.8)	2.7 (0.9)	2.8 (0.8)	2.9 (0.9)	2.4 (1.0)
Severity	2.0 (0.7)	1.9 (0.6)	2.4 (0.8)	2.0 (0.7)	2.2 (0.8)	1.9 (0.8)
Distress	2.3 (0.9)	2.3 (0.8)	2.7 (1.0)	2.5 (0.8)	2.5 (0.7)	2.1 (0.9)
Symptom score	2.3 (0.7)	2.3 (0.7)	2.6 (0.8)	2.4 (0.7)	2.6 (0.7)	2.1 (0.8)
Difficulty sleeping						
Prevalence	290 (52%)	96 (59%)	24 (71%)	60 (64%)	23 (55%)	87 (39%)
Frequency	2.5 (0.9)	2.4 (0.8)	2.5 (0.9)	2.6 (0.9)	2.4 (0.8)	2.5 (0.9)
Severity	2.1 (0.8)	1.9 (0.7)	2.3 (0.9)	2.2 (0.8)	2.3 (0.9)	2.1 (0.8)
Distress	2.4 (0.9)	2.2 (0.8)	2.7 (1.0)	2.5 (0.9)	2.5 (0.9)	2.3 (0.9)
Symptom score	2.3 (0.7)	2.2 (0.6)	2.5 (0.9)	2.4 (0.8)	2.4 (0.8)	2.3 (0.8)
Problems with sexual interest/activity						
Prevalence	282 (52%)	70 (43%)	10 (30%)	40 (44%)	12 (29%)	150 (69%)
Frequency	3.1 (1.0)	2.8 (1.0)	3.3 (0.8)	2.8 (1.0)	2.7 (1.1)	3.3 (0.9)
Severity	2.8 (1.0)	2.5 (1.0)	3.0 (1.1)	2.5 (1.1)	2.8 (1.3)	2.9 (1.0)
Distress	2.7 (1.0)	2.2 (1.0)	2.5 (1.4)	2.5 (1.1)	2.0 (0.7)	2.9 (0.9)
Symptom score	2.8 (0.9)	2.5 (0.8)	2.9 (1.1)	2.7 (1.0)	2.5 (0.7)	3.0 (0.8)
Pain						
Prevalence	250 (45%)	104 (64%)	18 (53%)	44 (48%)	26 (59%)	58 (26%)
Frequency	2.2 (0.9)	2.2 (0.9)	2.1 (0.8)	2.4 (0.9)	2.4 (0.9)	2.0 (0.9)
Severity	1.8 (0.7)	1.7 (0.8)	1.7 (0.8)	2.1 (0.8)	1.8 (0.7)	1.7 (0.6)
Distress	2.1 (0.8)	2.1 (0.9)	2.2 (0.6)	2.5 (0.9)	2.1 (1.0)	1.8 (0.7)
Symptom score	2.0 (0.7)	2.0 (0.8)	2.0 (0.6)	2.3 (0.8)	2.1 (0.8)	1.8 (0.6)
Feeling drowsy						
Prevalence	232 (42%)	84 (51%)	22 (65%)	52 (56%)	24 (56%)	50 (23%)
Frequency	2.2 (0.8)	2.2 (0.8)	2.5 (0.7)	2.3 (0.8)	2.3 (0.7)	2.0 (0.8)
Severity	1.8 (0.7)	1.7 (0.6)	2.1 (0.7)	1.8 (0.8)	1.8 (0.5)	1.7 (0.7)
Distress	1.9 (0.8)	1.9 (0.7)	2.1 (1.0)	1.9 (0.9)	1.7 (07)	1.7 (0.7)
Symptom score	2.0 (0.7)	2.0 (0.6)	2.2 (0.7)	2.0 (0.8)	1.9 (0.5)	1.8 (0.6)
Worrying						
Prevalence	229 (42%)	86 (53%)	13 (38%)	55 (59%)	16 (36%)	59 (27%)
Frequency	2.2 (0.9)	2.1 (0.8)	2.0 (0.7)	2.6 (1.0)	2.3 (1.0)	1.9 (0.7)
Severity	1.9 (0.9)	1.7 (0.7)	1.8 (0.8)	2.2 (1.0)	2.2 (1.0)	1.7 (0.8)
Distress	2.3 (0.9)	2.2 (0.7)	2.3 (0.7)	2.6 (1.0)	2.4 (1.0)	2.1 (0.8)
Symptom score	2.1 (0.8)	2.0 (0.7)	2.0 (0.7)	2.5 (0.9)	2.3 (0.9)	1.9 (0.7)
Feeling sad						
Prevalence	224 (40%)	81 (50%)	16 (47%)	57 (61%)	17 (39%)	53 (24%)
Frequency	2.1 (0.9)	2.1 (0.8)	2.0 (0.9)	2.2 (0.9)	2.3 (1.1)	1.9 (0.8)
Severity	1.8 (0.8)	1.8 (0.8)	1.9 (0.9)	1.7 (0.9)	1.9 (1.0)	1.9 (0.8)
Distress	2.2 (0.8)	2.2 (0.8)	2.2 (0.8)	2.2 (0.8)	2.2 (0.8)	2.1 (0.8)
Symptom score	2.0 (0.8)	2.0 (0.7)	2.1 (0.8)	2.0 (0.9)	2.1 (1.0)	2.0 (0.7)
Difficulty concentrating						
Prevalence	219 (40%)	85 (53%)	15 (44%)	46 (50%)	22 (50%)	51 (23%)
Frequency	2.0 (0.8)	2.1 (0.7)	1.9 (0.5)	2.0 (0.8)	1.9 (0.7)	1.7 (0.8)
Severity	1.6 (0.7)	1.6 (0.7)	1.5 (0.5)	1.6 (0.8)	1.5 (0.6)	1.6 (0.8)
Distress	2.2 (0.9)	2.2 (1.0)	2.5 (0.9)	2.5 (0.9)	2.0 (0.8)	1.9 (0.8)
Symptom score	1.8 (0.7)	1.9 (0.7)	1.7 (0.5)	1.8 (0.7)	1.7 (0.6)	1.7 (0.7)

Table continued on the following page

Table 2

Top Symptoms From the MSAS For Those Reporting Symptoms (*continued*)

RANK AND SYMPTOM	OVERALL	BREAST	COLORECTAL	GYNECOLOGIC	LUNG	PROSTATE
Numbness/tingling in hands/feet						
Prevalence	220 (40%)	77 (47%)	23 (68%)	51 (54%)	19 (43%)	50 (23%)
Frequency	2.6 (1.0)	2.6 (1.0)	3.0 (0.8)	2.9 (1.0)	2.3 (1.2)	2.2 (1.0)
Severity	1.9 (0.9)	1.9 (0.9)	2.2 (0.8)	2.1 (1.0)	1.6 (0.7)	1.8 (0.8)
Distress	2.2 (0.9)	2.2 (1.0)	2.5 (0.9)	2.5 (0.9)	2.0 (0.8)	1.9 (0.8)
Symptom score	2.3 (0.8)	2.3 (0.8)	2.6 (0.7)	2.5 (0.8)	2.0 (0.8)	2.0 (0.7)
Feeling irritable						
Prevalence	206 (37%)	82 (50%)	12 (36%)	44 (47%)	19 (43%)	49 (22%)
Frequency	2.0 (0.8)	1.8 (0.8)	2.3 (0.8)	2.2 (0.8)	2.0 (0.8)	1.9 (0.8)
Severity	1.7 (0.8)	1.6 (0.7)	1.7 (0.6)	1.9 (0.9)	1.7 (0.9)	1.9 (0.8)
Distress	2.1 (0.8)	2.0 (0.7)	2.2 (0.8)	2.1 (1.0)	2.0 (0.8)	2.2 (0.8)
Symptom score	1.9 (0.7)	1.8 (0.6)	2.1 (0.6)	2.1 (0.8)	1.9 (0.8)	2.0 (0.7)

[a] Prevalence scores reported as n (%) of those responding "yes" to the presence of this symptom. All other scores are reported as mean (SD). Frequency, severity, and distress scores calculated using only those participants reporting the given symptom.

The survey packet contained 2 measurement tools, the Memorial Symptom Assessment Scale and the Functional Assessment of Cancer Therapy–General Scale, and a demographic information form (including current treatment status). Clinical data, including comorbidity, disease type and stage, and treatment type (chemotherapy, surgery, radiation, hormonal therapy, or mixed), were captured from the tumor registry database. At baseline, survey packets were mailed to 1,594 patients, and 558 patients returned the completed surveys, yielding a participation rate of 35%. This article describes the baseline assessment results.

MEASURES

The Memorial Symptom Assessment Survey (MSAS)[26] is a 32-item measure and well-validated in oncology populations. The tool captures the multidimensional nature of symptoms (symptom presence, frequency, intensity, and symptom-related distress).[3,26,27] The MSAS has three subscales: the Physical Symptom Subscale (PHYS), the Psychological Symptom Subscale (PSYCH), and the Global Distress Index (GDI). The GDI was developed by Portenoy et al[26] as a clinically useful measure of global distress based on 10 selected psychological and physical items most likely to reflect a patient's clinical status. The Total MSAS is a summary measure of overall symptom burden, determined by both the number of symptoms experienced by a patient and the various ratings associated with each symptom. We computed a composite symptom score, which combined the patient's ratings (frequency, intensity, related distress) for each symptom, as a measure of burden associated with a particular symptom.[3,26,27] The alpha reliability score for the MSAS has been reported as ranging from 0.83 to 0.88[2,23] and in this study was 0.90. The MSAS takes approximately 10 minutes to complete.

The Functional Assessment of Cancer Therapy–General Scale (FACT-G)[20] is a 27-item measure of QOL. It is well validated and widely used with oncology patients. The instrument assesses 4 domains of well-being—Physical, Emotional, Social, and Functional—producing 4 subscale scores as well as a total summary QOL score. The alpha reliability score for the FACT-G has been reported as 0.89[17] and in this study was 0.92. The FACT-G takes approximately 5 minutes to complete.

Patient comorbidities were measured using the Adult Co-Morbidity Evaluation–27 (ACE-27), a comorbidity index developed for patients with cancer.[28] The ACE-27 was developed through modification of the Kaplan-Feinstein Comorbidity Index (KFI). After adjusting for TNM stage, the ACE-27 comorbidity score has been found to be an independent, statistically significant prognostic factor.[29] Comorbidities on the scale are measured from grade 1 through grade 3 (mild to severe) by body systems; therefore, higher scores represent greater comorbidity.

DATA ANALYSIS

Descriptive statistics were used to analyze the frequencies and means of demographic and clinical characteristics and scale measures for the study sample. Due to the data not having a normal distribution, the majority of continuous variables were compared with nonparametric methods (eg, Kruskal-Wallis test). Categorical variables were examined with χ^2 tests. Analysis of variance (ANOVA) was used to compare differences between cancer types on single dependent measures. Multivariate ANOVA (MANOVA) was used to examine differences between cancer types on multiple dependent variables. All tests were 2-sided, and the significance level was set at 0.05. The statistical package SAS 9.1 was used for all statistical calculations (SAS Institute, Cary, NC).

Results

We received baseline surveys from 558 patients. The distribution of cancer diagnoses was as follows: prostate = 220,

breast = 164, gynecologic = 96, lung = 45, and colorectal = 33. There were slightly more females (n = 298) than males (n = 262) in our sample. Most patients reported having stage II (n = 278) disease. Patient characteristics are presented in Table 1.

We compared responders with nonresponders on demographic and clinical variables. Race was the only demographic variable that distinguished the groups (χ^2 = 43.4, $P < .001$), with a higher response rate among whites than minorities. Among clinical variables, the groups differed by comorbidity (χ^2 = 15.52, P = .001), with nonresponders having higher comorbidity scores. The groups also differed by cancer stage (χ^2 = 10.03, P = .01), with nonresponders being more likely to have stage I disease and responders being more likely to have stage II disease. The groups also differed by cancer type (χ^2 = 45.72, $P < .001$), with more responders having breast and prostate cancers and more nonresponders having colorectal, gynecological, and lung cancers.

While 37 patients reported no symptoms at all, there was an average of 9.1 symptoms (range = 0–32) per patient on the MSAS. The number of symptoms varied by type of cancer, with prostate patients reporting an average of 5.6 symptoms and colorectal patients reporting an average of 12.3 symptoms. More than one symptom was reported by 85% of participants. Of the 36% of participants receiving active treatment at baseline, 94% reported more than 1 symptom, with the number of symptoms averaging 11.2 (SD = 7.7). Among those patients no longer receiving treatment at baseline, 81% reported more than 1 symptom, with the average number of symptoms being 7.8 (SD = 7.3).

Overall, the prevalence of symptoms varied by cancer type (see Table 2). The five most prevalent symptoms for all patients included lack of energy, difficulty sleeping, problems with sexual interest or activity, pain, and feeling drowsy. Lack of energy was among the top three symptoms for all cancer types—experienced by 79% of colorectal patients, 74% of lung patients, 72% of gynecologic patients, 71% of breast patients, and 41% of prostate patients. Among the 5 most prevalent symptoms for all patients, problems with sexual interest or activity had the highest mean individual symptom score (X = 2.9) in comparison with all other symptoms, followed by difficulty sleeping and lack of energy (X for both = 2.3).

The MSAS total scores were significantly different by cancer group ($P < .001$), with prostate cancer patients indicating less symptom burden (X = 0.3) than all other patient groups (see Table 3). Prostate cancer patients also reported fewer symptoms (X = 5.6) and lower GDI scores (X = 0.4) than all other cancer groups. The mean MSAS PHYS scores ranged between 0.23 (prostate) and 0.82 (colorectal). Prostate cancer patients had lower scores than all other groups. The mean MSAS PSYCH scores ranged between 0.45 (prostate) and 1.11 (gynecologic). MANOVA for the various subscale scores, total score, and number of symptoms demonstrated an overall effect by cancer type (F = 6.44, $P < .001$). Significant between-group differences indicated that prostate cancer patients differed from all other cancer types. In addition, breast cancer patients differed significantly from colorectal and lung cancer patients, and colorectal cancer patients differed significantly from gynecologic cancer patients.

Table 3

Mean MSAS Scores

CANCER TYPE	MSAS TOTAL*	TOTAL SYMPTOMS	GDI	PHYS	PSYCH
Breast	0.7	11.0	1.2	0.6	1.0
Colorectal	0.8	12.2	1.2	0.9	0.9
Gynecological	0.8	11.6	1.4	0.8	1.2
Lung	0.7	11.6	1.2	0.7	0.9
Prostate	0.4	5.5	0.6	0.3	0.5
Overall	0.59	9.1	1.0	0.5	0.8

*$P < .01$.

Table 4

FACT Scores

CANCER TYPE	EMOTIONAL	FUNCTIONAL	PHYSICAL	SOCIAL	TOTAL*
Breast	19.9	21.6	23.9	22.7	84.9
Colorectal	19.5	17.9	20.8	22.9	81.1
Gynecological	19.2	19.9	21.8	20.4	77.0
Lung	18.6	19.8	24.2	23.7	80.5
Prostate	22.2	23.7	25.9	21.7	90.0
Overall	20.6	21.8	24.2	22.0	85.1

*$P < .01$.

The QOL data are presented in Table 4. There was a significant difference among the diagnostic groups on the overall QOL score ($P < .001$). The mean overall QOL score (range = 0–108) for the entire sample was 85.1, with prostate patients reporting higher overall QOL (X = 90.24) than all other cancer groups. MANOVA for the various subscales demonstrated an overall effect by type of cancer (F = 8.86, $P < .001$). Significant between-group differences indicated that prostate cancer patients differed from all other cancer types. In addition, breast cancer patients differed significantly from colorectal, gynecologic, and lung cancer patients. Also, gynecologic patients differed significantly from colorectal and lung cancer patients.

There were significant negative correlations between overall QOL and the number of symptoms ($r = -0.61$, $P < .001$), the severity of symptoms ($r = -0.64$, $P < .001$), the GDI ($r = -0.69$, $P < .001$), and the MSAS total score ($r = -0.68$, $P < .001$). All symptom composite scores for the MSAS were significantly negatively correlated with overall QOL at $P <$ .01 or better. There were also significant correlations between comorbidity scores and both the MSAS total score (r = 0.12, P = .006) and overall QOL ($r = -0.11$, P = .01).

We compared the data from patients receiving treatment at the time of the assessment with data from patients not actively receiving treatment, using the Kruskal-Wallis test;

Table 5

Comparison of Patients by Treatment Status

ASSESSMENT MEASURE	CURRENTLY RECEIVING TREATMENT, MEAN (SD)	NOT RECEIVING TREATMENT, MEAN (SD)
FACT Emotional	19.6 (3.9)	19.6 (3.9)
FACT Functional**	19.9 (6.5)	21.4 (6.2)
FACT Physical***	21.8 (6.0)	24.4 (4.4)
FACT Social*	21.8 (6.0)	20.8 (6.2)
FACT Total	83.0 (17.7)	86.2 (15.9)
MSAS Total***	0.67 (0.55)	0.45 (0.45)
MSAS number of symptoms***	11.2 (7.7)	7.8 (7.3)
MSAS GDI***	0.88 (0.75)	0.62 (0.71)
MSAS Physical***	0.66 (0.62)	0.39 (0.50)
MSAS Psychological**	0.86 (0.77)	0.70 (0.81)

* $P < .05$, ** $P < .01$, *** $P < .001$.

these results are presented in Table 5. These groups differed on every MSAS subscale: PSYCH ($P < .01$), PHYS ($P < .001$), GDI ($P < .001$), and Total ($P < .001$). All of these results reflected higher symptom burden in those receiving treatment. Patients receiving treatment reported more symptoms than those not receiving treatment (X = 11.2 vs. X = 7.8, $P < .001$). We also examined differences in QOL between these groups. There was no significant difference between these groups on Overall QOL or Emotional QOL, but the groups were significantly different in terms of Physical QOL ($P < .001$), Social QOL ($P < .05$), and Functional QOL ($P < .01$). All of these results reflected poorer QOL in those patients receiving active treatment.

Discussion

This study highlights the varied symptom experience and QOL of a diverse sample of cancer survivors. The results revealed a high prevalence of symptoms among cancer survivors undergoing active treatment as well as those no longer receiving treatment. This is in concordance with previous research.[30–32] A systematic review of studies examining the symptoms of cancer patients undergoing treatment indicated that 40% of patients experienced more than one symptom.[30] This is in contrast to our rate of 93%. Our result is similar to the findings of the LIVESTRONG survey of 2,307 cancer survivors, in which 91% of respondents reported experiencing 1 or more physical concerns after the completion of treatment.[33] This difference may be due to the choice of instruments selected for symptom measurement. In a review of 18 published studies, researchers found that symptom-specific scales used in many studies offer valuable information on the multiple dimensions of a single symptom, while inventories such as the MSAS capture the occurrence, severity, and distress of multiple concurrent symptoms.[26] There is also variability in the number of symptoms measured in multisymptom inventories; for example, the MSAS assesses 32 symptoms, while the MD Anderson Symptom Inventory uses 13 items.

An important finding was the prevalence of symptoms among patients no longer receiving active treatment; specifically, in our sample, 80% of these patients reported multiple symptoms. This result raises concerns about the adequacy of current symptom assessment and management by oncology clinicians. This result also underscores the critical need for ongoing palliative care for cancer survivors, perhaps through the vehicle of survivorship clinics, as recommended by the Institute of Medicine report.[5]

We found differences by cancer type in the patient reports of their symptom experience and QOL. Prevalent symptoms by cancer type were clearly associated with the nature of the cancer. For example, shortness of breath was most prevalent among lung cancer patients, diarrhea among colorectal cancer patients, and difficulty urinating among prostate cancer patients. Prostate cancer patients had the lowest symptom scores altogether, with the lowest MSAS Total score, number of total symptoms, GDI, PHYS score, and PSYCH score. The only symptoms that were endorsed more highly by prostate cancer patients compared to patients with other cancer types were "problems with sexual interest/activity" (69%) and "problems urinating" (43%).

Prostate cancer patients endorsed the highest overall QOL scores and the highest QOL subscale scores except for Social Well-being. These results suggest that prostate cancer patients are faring better than the other 4 diagnostic groups after diagnosis of and treatment for their disease, perhaps indicating that treatment for prostate cancer is easier to tolerate or that this diagnosis is less distressing. Our data indicate that most prostate cancer patients do not receive chemotherapy, and this difference in treatment may impact the findings for symptom burden and QOL. The results also may reflect that this patient population is less likely to complain about symptoms, although the majority of this group endorsed problems with sexual interest and sexual functioning. Nevertheless, previous research has suggested that men are less likely to complain about symptoms they are experiencing compared to women.[34,35]

In terms of which diagnostic group did most poorly, the results are less clear. Colorectal and gynecologic cancer patients had equally high MSAS Total scores, reflecting worse overall symptom burden. However, colorectal cancer patients endorsed more physical difficulties, with the highest number of symptoms overall and the highest scores on the MSAS PHYS. Yet, gynecologic cancer patients endorsed more psychosocial difficulties, with the highest GDI and PSYCH scores. This same dichotomy was found in terms of QOL, with colorectal cancer patients reporting poorer Functional and Physical Well-being, but gynecologic patients reporting poorer Social Well-being and Overall QOL.

Study results indicate that the cancer experience, particularly in terms of symptom burden and QOL, varies depending on the specific cancer diagnosis, necessitating an individualized approach to symptom management and palliative care. When patients experience multiple symptoms caused by treatment, the result can be disruption of treatment or premature treatment termination, while

residual treatment-related symptoms can complicate posttreatment rehabilitation.[36] In general, it is clear that symptom burden is significantly related to patients' QOL and that these aspects of the patient's experience are intertwined. These findings suggest that attention to patients' symptom experience is important as one avenue for facilitating optimal QOL.

There are several limitations of this study that have implications for the generalizability of the results. First, the sample is fairly homogeneous from a racial standpoint, being primarily Caucasian. Second, data were collected via mailed questionnaires. Although the return rate was comparable to many survey studies, it is unclear whether this method of data collection instilled some systematic bias. Third, the MSAS is a complicated measure to complete. Examination of the returned surveys suggests that some patients had difficulty understanding how to complete the measure (eg, provided inconsistent answers). Fourth, because potential participants were identified from the cancer center's cancer registry, patients were not identified until 6–8 months after diagnosis, meaning that these results do not include a true baseline, collected at the time of diagnosis. Finally, because different patients and different cancer groups had different treatment regimens, the timeline for treatment was inconsistent across patients. This meant that data collection on a calendar-based timeline may have missed important clinical milestones (eg, changes in treatment regimen, end of treatment) for particular patients.

Conclusions

These results indicate that the symptom experience for patients varies widely depending on the type of cancer. Moreover, symptoms persist beyond treatment, suggesting that symptom burden is a long-term issue for cancer survivors. Our findings also underscore the strong connection between symptom experience and patients' QOL, suggesting that symptoms significantly negatively impact overall well-being of patients. These results lend weight to efforts to promote symptom reporting and symptom management throughout the continuum of oncology care.

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