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The Symptom Experience of Patients with Cancer

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Introduction

There is little doubt that despite advances in supportive cancer care, unrelieved symptoms continue to be both prevalent and persistent in the cancer patient population whether in cancer centers or hospices.[1]The symptom experience of cancer patients remains an important area for nursing research and practice. The symptom experience consists of the perception and response to symptom occurrence and related symptom distress.[2] Persistent, unrelieved symptoms impair quality of life (QOL) including activities of daily living, engagement in social and emotional well being and relationships.[3] Symptom severity and symptom distress are aspects of the symptom experience that require assessment in order to fully understand the symptom experience. In some cases, symptom severity and symptom distress may not correlate with each other, and thus, the most severe symptoms may not present as the most distressing.[4] Careful symptom assessment that includes severity and distress are critical aspects of quality palliative care.

Review of Literature

Symptoms as a result of cancer disease and treatment are both pervasive and persistent despite cancer type, disease stage or treatment received.[1,5] Symptoms such as pain and fatigue represent two of the most common symptoms present in individuals undergoing cancer treatment. [6,7] Fatigue remains among the most commonly reported and distressing symptom experienced by persons with cancer, as it interferes with the individual's ability to perform daily activities.[5]

Prevalent and/or persistent symptoms cause distress by interference with activities of daily living and their ability to impair quality of life.[8] Despite advances in pain management, pain remains a common persistent symptom among persons with cancer. Estimates of pain prevalence among persons with cancer range from 14%-100%.[1] In a population-based study, vanden Beuken-van Everdingen et al. concluded that pain control remains inadequate in 42% of patients, especially among those receiving curative cancer therapies. [9] Given et al. found pain was most likely to occur within 40 days of receiving surgery, chemotherapy or radiation.[10] Patients presenting with pain tend to have more advanced disease and thus, more other symptoms.

Symptom severity and symptom distress represent unique aspects of quality of life. However, despite the advent of clinical guidelines, symptom experiences often remain difficult to characterize due to a relative lack of gold-standard assessments and few evidence-based interventions. Cancer-related pain is an example of a symptom perceived as having aspects that encompass both severity and distress and for which national clinical guidelines exist.[11] However, as noted above, despite clinical guidelines for addressing cancer-related pain, it remains poorly controlled.[9] In 2004, the National Institutes of Health issued a State of the Science Conference Statement concerning cancer-related pain, depression and fatigue that addressed the need for routine brief assessments of these symptoms, and implementation of evidence-based interventions.[1]

Symptom distress is defined as physical or mental upset, anguish or suffering reported as a result of specific symptoms.[2] In one study of cancer patients receiving home health-based hospice care, the lack of energy, dry mouth, pain, shortness of breath, feeling bloated and difficulty sleeping were the most distressing problems reported.[4] Furthermore, symptom distress was noted to be an important predictor of quality of life. In a cross-sectional, observational study of 180 patients with hematologic malignancies, the most distressing symptoms were difficulty sleeping, pain, constipation, difficulty swallowing, problems with urination, low libido, swelling in the extremities and hair loss. These symptoms were reported as causing quite a bit to very much distress in 40-50% of patients. Patients with refractory disease reported the highest number of symptoms (mean = 8.8) and highest levels of physical distress.[12] It is important to note that while symptom distress and symptom severity may be related they are not the same. There may be differing patterns of symptom prevalence, intensity and distress depending on the trajectory of the individual's illness. Due to the relatively high prevalence and persistence of multiple symptoms across the cancer continuum of care, routine, systematic assessment of symptom presence, severity and distress is needed.[12]

The purpose of this secondary analysis was to describe the symptom experience of patients with cancer. Specifically, we report:

1. Mean number of symptoms reported and which symptoms are most commonly occurring
2. Mean severity of symptoms and symptoms that have that highest severity
3. Mean distress of symptoms and symptoms that cause the most distress

Methods

Setting

H. Lee Moffitt Cancer Center & Research Institute is an NCI-designated comprehensive cancer center that sees more than 7,000 new patients annually with a variety of cancers. The outpatient clinics have approximately 220,000 patient visits annually, and the inpatient area has 205 beds. The Infusion Center has more than 40,000 patient visits annually, and radiation therapy department had 43,413 visits in 2010. Study participants were drawn from all outpatient clinics and the Infusion Center.

Sample

A sample of 393 patients with cancer was available in the database of a larger on-going NIH-funded study designed to evaluate an intervention for medication-induced constipation in persons with cancer. To be included, patients had to be receiving daily opioids for treatment of pain, receiving vinca alkaloids for treatment of their cancer, or be receiving both opioids and vinca alkaloids. Dose of medication was not an inclusion criterion. A total of 298 patients reporting pain were used in this analysis.

Patients with any type of cancer except a primary colorectal or gynecologic cancer, with any stage of disease, were included. Those on opioids were on stable doses for two days before the beginning of the study. Patients receiving vinca alklaloids had to have at least two scheduled doses of the vinca alkaloid medication remaining at the time of accrual. They had to be adults over 18 years, and able to consent, be alert, and able to read and understand English. Only persons who reported pain were included in this analysis.

Patients were excluded if they were excessively debilitated or deemed unlikely to survive for the eight weeks of the data collection period; if they were unable to read and understand English; if they had an ostomy that changed bowel function; if they had a current peritoneal catheter; if they had had abdominal surgery within the past six weeks; if they were currently having radiation therapy to the abdomen; if they had a history of chronic bowel disease (including irritable bowel syndrome, chronic constipation prior to cancer onset, Crohn's disease, ulcerative colitis or diarrhea as a result of radiation to the pelvis), a disease process suggestive of mechanical obstruction (tumor or adhesion), or reported chronic laxative use prior to cancer onset. Patients were excluded from the study if they appeared to have an impaction at the time baseline data were collected.

Instruments

1. Short Portable Mental Status Questionnaire

Because the data were self reported by patients, the 10-item Short Portable Mental Status Questionnaire (SPMSQ) was used as a screening instrument for cognitive impairment. While the SPMSQ is a brief instrument that may lack sensitivity to mild cognitive impairment, it has demonstrated validity in detecting moderate to severe cognitive impairment.[13]

2.Memorial Symptom Assessment Scale (MSAS)

2.Memorial Symptom Assessment Scale (MSAS) was used to help investigators better understand the full array of symptoms experienced by this group of patients and to help to better describe them. Several researchers have called for differentiating symptom distress from symptom intensity and frequency. [2,14,15,16] One expert defined symptom distress as "how bothered" the patients were by the symptom.[14] The MSAS was designed to differentiate among occurrence, intensity, and distress from symptoms and has 33 items reflecting symptoms commonly associated with cancer in 3 dimensions: (1) severity of the symptom; (2) frequency with which it occurs; and (3) the distress it produces. In the parent study, frequency (on a scale of 1= rarely experienced to 4 = almost constantly experienced) data was not collected; therefore, it was not included in our analysis. In addition, since our primary goal was to examine which symptoms were the most severe and which caused the most distress, we did not conduct subscale analysis.

Validity and reliability—Validity and reliability data for the MSAS have been strong when the tool was used with persons receiving active cancer therapy.[17] Factor analysis confirmed two factors that distinguished three major groups of symptoms. The three confirmed groups of symptoms were Psychological, High Prevalence and Low Prevalence Physical Symptoms.

3. Demographic Data

Standard demographic data was collected on patients to allow description of the sample. Data included: age; gender; education level; marital status; religious affiliation, type of cancer and stage of cancer.

Procedures

After approval was received from the Scientific Review Committee of the Cancer Center, the proposal was submitted to the Institutional Review Board for the University of South Florida. Data collection began after written approval was received.

Accrual

Patients in the outpatient clinics were screened using the computerized data system and patients who met study criteria were invited to participate in the study. The study was explained and questions answered by the research assistants. If the patient agreed and signed the consent, patients were screened with the SPMSQ to insure that they were able to self-report. Baseline data were collected during that regular outpatient visit.

Data Analysis

Demographic data were analyzed using descriptive statistics. The research aims were analyzed using means, standard deviations, frequencies and percentages. Only patients who endorsed a given symptom (such as fatigue or shortness of breath) were included in the analysis of that specific symptom.

Results

Sample

The sample consisted of 298 participants who were primarily white, non-Hispanic, married, Catholic or non-Catholic Christians, currently receiving some type of cancer treatment with either palliative or curative intent. More females than males were included in this sample (Table 1). Participants had a variety of solid tumors and hematologic malignancies, although the majority of the sample had breast cancer, lung cancer, or lymphoma (Table 2). Only 64 patients were receiving vinca alkaloids; the rest were admitted to the parent study because they were receiving opioids. Ages ranged from 21-84 with a mean of 54.2 years (SD=11.9).

Symptom Occurrence

Patients reported between 2 and 30 symptoms each with a mean of 14.1 (SD=5.5). Having pain was an inclusion criterion, so it was the most frequently reported symptom (n=298, 100%). Among the other symptoms, the most frequently endorsed symptoms were lack of energy/fatigue (n=272, 91.3%), feeling drowsy (n=199, 66.8%), difficulty with sleeping (n=196, 65.8%) and worrying (n=193, 64.8%) (Table 3).

Symptom Severity

Hair loss and problems with sexual activity or interest were the most severe symptoms (mean=2.6). To aid in interpretation of these means, since nurses are accustomed to using a 0-10 scale for symptom severity, we converted them from a 0 to 4 scale to a 0 to 10 scale. The most severe symptoms listed thus had scores of 6.5. These were followed by pain, lack of energy/fatigue and “I don't look like myself” with means of 2.5, or 6.25 on the 0 to 10 scale (Table 4). Problems with sexual activity or interest and hair loss were reported to be severe or very severe by at least 50% of participants who reported the symptom. Conversely, diarrhea, cough, and dizziness were severe or very severe in less than 20% of participants who reported the symptom (Table 5).

Symptom Distress

Again, for the distress scores, we converted this 0 to 4 scale to a 0 to10 scale and added those numbers to the table. Lack of energy/fatigue was reported by patients to be the most distressing symptom (mean = 2.8, or 7.0). This was followed by pain, difficulty sleeping (means both=2.7 or 6.8), worrying and constipation (means 2.5 or 6.3) (Table 6). Pain, difficulty sleeping, lack of energy/fatigue and “I don't look like myself” were reported to be “quite a bit” or “very distressing” by at least 50% of participants reporting the symptom. Weight loss, itching, and cough were reported as “quite a bit” or “very distressing” by less than 30% of participants reporting the symptom (Table 7).

Discussion

Sample

A strength of the study was the large sample size with patients having a variety of cancer diagnoses. As in earlier studies, the symptoms with the greatest severity were not necessarily the same as those that were the most distressing. For example, hair loss was reported to be severe or very severe by 52.5% of participants while being rated 4.3 on a scale of 0-10. There is a potential for distress among cancer patients beyond those symptoms related to pain and chemotherapy treatments. Individuals from a cultural minority represent less than 15% of the total participants in this study. While this percentage is typical of the population treated at tertiary cancer care centers, symptom distress among those from diverse cultures remains unclear. The majority of participants enrolled in this study are women; this is consistent with the tendency of more women than men to participate in research.[18] A limitation of this study is that the study participants come from a larger sample with inclusion criteria that restricted enrollment to only those who were receiving opiods, vinca alkyloids, or both. An additional limitation of this study is that 70% of the participants had more advanced disease.

Symptom Occurrence

A large number of symptoms occurring concurrently were reported by patients (Table 3). It should be noted that while pain was the most common symptom reported at 100%, this doubtless occurred because patients were accrued to a study of opioid-induced constipation. In earlier symptom studies of cancer patients, fatigue was the most commonly seen in more than 91% of the patients; this is consistent with earlier studies.[19, 20]

The next most frequently reported symptom was feeling drowsy. This result might have occurred due to the use of opioids, but the literature suggests that this is equally likely to be due to daytime napping.[21] Constipation was reported by 62% if the sample. This probably occurred because some clinicians are attending to the problem and others are not.

Symptom Severity

Symptoms with the greatest severity for this group of cancer patients were hair loss and impaired sexual activity; however, these problems were not the most distressing problems (Table 6). The *Look Good-Feel Better* program sponsored by the American Cancer Society provides a network for cancer patients that include information and access to support for a symptom such as hair loss.[22] However, in order for patients to know about and benefit from this program the nurse must make a referral; it is not known how often this type of referral is made.

Other high intensity symptoms included fatigue, pain and lack of appetite among the symptoms that were most distressing. There are evidence-based interventions for these problems; all could be better managed than they seem to have been for this group of patients.

Symptom Distress

The participants in this study reported significant symptom distress. With 100% of the patients reporting distress from pain and 91.3% with distress from lack of energy, worrying and constipation also were noted as distressing. The experience of continuous symptom distress has been shown to deplete the positive attitude that is essential to combating anxiety and depression among cancer patients.[23] While nurses often focus on symptom severity, there is still less of a focus on ameliorating symptom distress.

Conclusions

Despite prevalent and persistent energy and research spent on identifying and treating the distress patients experience from cancer-related symptoms, the problem persists. Generally, nurses are knowledgeable and skilled at evaluating symptom severity in cancer patients. In addition to having awareness and being knowledgeable about the symptoms that cause the most distress for cancer patients, nurses must also be aware of and knowledgeable about the resources that offer support to their patients. In addition to asking about the presence of symptoms patients may be experiencing, nurses must also inquire about the associated distress. Through the use of a 0-10 distress scale, in addition to the intensity ratings commonly used to assess symptom severity, nurses can assess the symptoms that are causing the most distress for their patients. This practice will assist nurses in prioritizing their care and providing the much needed support and education for this population. Assessing symptom distress experienced by the hospice or palliative care patient presents an opportunity for the nurse to develop a plan of care that is addresses the unique needs of the individual.

These important issues should be the focus of on-going research as well as nursing education both in service areas and in schools of nursing. Research is needed to develop and test interventions so that clinicians can implement evidence based interventions to improve symptom distress for their patients.

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Table 1

Frequency and Percent of Patients by Gender, Ethnicity, Marital status, Religious Affiliation, Stage of Cancer, and Stage of Treatment

Demographic Variable	Frequency	Percent
Gender: Female	172	57.7
Male	125	41.9
Missing	1	<1
Ethnicity		
White, non-Hispanic	254	85.2
Black, non-Hispanic	21	7.0
White, Hispanic	19	6.4
Black, Hispanic	1	<1
Asian-Pacific Islander	1	<1
Other	1	<1
Missing	1	<1
Marital Status		
Married	184	61.7
Single	57	19.1
Divorced	43	14.4
Widowed	14	4.7
Religious Affiliation		
Non-Catholic Christian	162	54.4
Catholic	68	22.8
None	43	14.4
Other	19	6.4
Jewish	5	1.7
Stage of Disease		
I	17	5.7
II	23	7.7
III	49	16.4
IV	104	34.9
Missing data	105	35.2
Stage of Treatment		
Newly diagnosed, not in treatment	1	<1
Curative treatment	89	29.6
Palliative treatment[a]	104	34.9
Symptom management only	10	3.4
In remission; pain management only		

[a] Includes chemotherapy, biotherapy, radiation therapy, or hormonal therapy

Table 2
Frequency and Percent of Patients by Primary Cancer

Type of Cancer	Frequency	Percent
Breast	56	18.8
Lung	55	18.5
Lymphoma	49	16.4
Leukemia	28	9.4
Multiple Myeloma	17	5.7
Melanoma	15	5.0
Non-melanoma skin cancer (Basal/Squamous cell)[a]	12	4.0
Pancreatic	10	3.4
Head and Neck	9	3.0
Prostate	8	2.7
Gastrointestinal	5	1.7
Other solid tumors	25	8.4
Missing	1	<1

[a] These were all deeply invasive skin cancers that had metastasized

Table 3
Frequency and Percent of Patients reporting Each Symptom on the MSAS

Symptom	Frequency	Percent
Pain	298	100
Lack of energy/fatigue	272	91.3
Feeling drowsy	199	66.8
Difficulty Sleeping	196	65.8
Worrying	193	64.8
Constipation	185	62.1
Numbness/tingling in hands or feet	167	56.0
Feeling sad	163	54.7
Dry Mouth	161	54.0
Feeling irritable	160	53.7
Change in taste	156	52.3
Difficulty Concentrating	151	50.7
Lack of appetite	151	50.7
“I don't look like myself”	146	49.0
Nausea	133	44.6
Hair loss	130	43.6
Feeling bloated	129	43.3
Shortness of breath	128	43.0
Feeling Nervous	127	42.6
Dizziness	112	37.6
Problem with sexual activity or interest	99	33.2
Weight loss	94	31.5
Cough	92	30.9
Swelling of arms and legs	92	30.9
Itching	82	27.5
Difficulty swallowing	71	23.8
Nightmares	64	21.5
Vomiting	63	21.1
Problems with urination	58	19.5
Mouth sores	49	16.4
Urinary accidents	44	14.8
Diarrhea	34	11.4

Table 4
Mean, Standard Deviation and Converted Score for Severity of Each Symptom

		Severity		Converted Score
Symptom	**n**	**Mean**	**SD**	**0-10**
Hair loss	130	**2.6**	1.3	6.5
Problem with sexual activity or interest	99	**2.6**	1.2	6.5
Pain	298	**2.5**	1.1	6.3
Lack of energy/fatigue	272	**2.5**	1.0	6.3
“I don't look like myself”	146	**2.5**	1.2	6.3
Difficulty Sleeping	196	2.4	1.1	6.0
Worrying	193	2.4	1.1	6.0
Constipation	185	2.4	1.1	6.0
Problems with urination	58	2.4	1.1	6.0
Numbness/tingling in hands or feet	167	2.3	1.1	5.8
Nightmares	64	2.3	1.3	5.8
Swelling of arms and legs	92	2.2	1.1	5.5
Change in taste	156	2.2	1.1	5.5
Lack of appetite	151	2.1	1.1	5.3
Feeling bloated	129	2.1	1.0	5.3
Dry Mouth	161	2.1	1.1	5.3
Feeling irritable	160	2.0	1.0	5.0
Feeling Nervous	127	2.0	1.0	5.0
Difficulty swallowing	71	2.0	1.1	5.0
Mouth sores	49	2.0	1.1	5.0
Nausea	133	2.0	1.0	5.0
Feeling drowsy	199	2.0	1.0	5.0
Feeling sad	163	1.9	1.1	4.8
Shortness of breath	128	1.9	1.1	4.8
Weight loss	94	1.9	1.1	4.8
Itching	82	1.9	1.1	4.8
Vomiting	63	1.9	1.1	4.8
Dizziness	112	1.8	0.9	4.5
Urinary accidents	44	1.8	1.1	4.5
Difficulty Concentrating	151	1.7	1.5	4.3
Cough	92	1.6	0.9	4.0
Diarrhea	34	1.6	1.1	4.0

Table 5

Frequency and percent of participants reporting each symptom as severe or very severe.

Symptom	n	Frequency	severe or very severe
Problem with sexual activity or interest	99	52	52.5
Hair loss	130	68	52.3
Pain	298	147	49.3
Lack of energy/fatigue	270	33	49.2
"I don't look like myself"	146	71	48.6
Constipation	185	79	43.7
Difficulty Sleeping	194	85	43.4
Nightmares	64	27	42.2
Worrying	193	81	42.0
Numbness/tingling in hands or feet	166	68	41.0
Swelling of arms and legs	92	37	40.2
Problems with urination	58	23	39.7
Change in taste	156	58	37.2
Dry Mouth	161	57	35.4
Lack of appetite	151	51	33.8
Mouth sores	49	16	32.7
Feeling bloated	129	41	31.8
Feeling drowsy	199	63	31.7
Difficulty swallowing	71	22	31.0
Nausea	132	40	30.3
Feeling irritable	159	44	27.7
Feeling nervous	127	35	27.6
Vomiting	62	17	27.4
Itching	82	22	26.8
Urinary accidents	44	11	25.0
Feeling sad	163	40	24.5
Shortness of breath	128	30	23.4
Weight loss	94	22	23.4
Dizziness	112	21	18.8
Difficulty Concentrating	151	28	18.6
Diarrhea	34	6	17.7
Cough	92	16	17.4

Table 6
Mean, Standard Deviation and Converted Score for Distress of Each Symptom

Symptom		**Distress**		**Converted Score**
	n	**Mean**	**SD**	**0-10**
Lack of energy/fatigue	272	**2.8**	1.1	7.0
Pain	298	**2.7**	1.2	6.8
Difficulty Sleeping	196	**2.7**	1.2	6.8
Constipation	185	**2.5**	1.3	6.3
Worrying	193	**2.5**	1.2	6.3
Problems with urination	58	2.4	1.3	6.0
Problem with sexual activity or interest	99	2.4	1.5	6.0
Swelling of arms and legs	92	2.4	1.3	6.0
“I don't look like myself”	146	2.4	1.4	6.0
Numbness/tingling in hands or feet	167	2.3	1.3	5.8
Nausea	133	2.3	1.3	5.8
Feeling Nervous	127	2.3	1.3	5.8
Nightmares	64	2.3	1.4	5.8
Mouth sores	49	2.3	1.3	5.8
Urinary accidents	44	2.3	1.4	5.8
Feeling sad	163	2.2	1.2	5.5
Vomiting	63	2.2	1.4	5.5
Shortness of breath	128	2.2	1.2	5.5
Feeling bloated	129	2.2	1.2	5.5
Feeling irritable	160	2.1	1.3	5.3
Change in taste	156	2.1	1.3	5.3
Difficulty Concentrating	151	2.1	1.4	5.3
Difficulty swallowing	71	2.0	1.2	5.0
Lack of appetite	151	1.9	1.3	4.8
Dry Mouth	161	1.9	1.3	4.8
Itching	82	1.9	1.2	4.8
Dizziness	112	1.9	1.2	4.8
Feeling drowsy	199	1.9	1.3	4.8
Hair loss	130	1.7	1.5	4.3
Cough	92	1.6	1.2	4.0
Diarrhea	34	1.6	1.3	4.0
Weight loss	94	1.4	1.4	3.5

Table 7

Frequency and percent of participants reporting each symptom as quite a bit or very bothersome.

Symptom	n	Frequency	Percent
Pain	296	174	58.8
Difficulty Sleeping	194	110	56.7
Lack of energy/fatigue	269	168	56.3
“I don't look like myself”	144	72	50.0
Constipation	184	90	48.9
Problem with sexual activity or interest	99	48	48.5
Feeling nervous	126	60	47.6
Mouth sores	49	23	46.9
Urinary accidents	43	20	46.5
Worrying	192	89	46.4
Swelling of arms and legs	92	42	45.7
Nightmares	64	29	45.3
Numbness/tingling in hands or feet	166	73	44.2
Problems with urination	57	25	43.9
Feeling bloated	128	56	43.8
Nausea	130	54	41.5
Vomiting	62	26	41.9
Difficulty Concentrating	149	59	39.6
Change in taste	155	59	38.1
Lack of appetite	150	55	36.7
Shortness of breath	128	47	36.7
Difficulty swallowing	70	25	35.7
Feeling drowsy	197	69	35.0
Feeling irritable	159	55	34.6
Hair loss	128	42	32.8
Dry Mouth	161	52	32.3
Dizziness	111	35	31.5
Feeling sad	163	61	31.4
Itching	82	21	25.6
Cough	92	22	23.9
Diarrhea	34	8	23.5
Weight loss	94	22	23.4