

Symptom Distress and Quality of Life in Patients With Cancer Newly Admitted to Hospice Home Care

Susan C. McMillan, PhD, ARNP, FAAN, and Brent J. Small, PhD

Purpose/Objectives: To evaluate the relationships between quality of life (QOL) and symptom distress, pain intensity, dyspnea intensity, and constipation intensity in people with advanced cancer who were newly admitted to hospice home care.

Design: Descriptive and correlational.

Setting: A large hospice that provides primarily home care.

Sample: 178 adult hospice homecare patients with cancer who were accrued to a clinical trial funded by the National Institutes of Health focusing on symptom management and QOL. Patients were excluded if they received a score lower than seven on the Short Portable Mental Status Questionnaire.

Method: The patients were invited to participate in the clinical trial within 48 hours of admission to hospice home care. Among the questionnaires they completed were a QOL index and a distress scale. Scales measuring present intensity of pain, dyspnea, and constipation also were administered.

Main Research Variables: QOL, symptom distress, pain intensity, dyspnea intensity, and constipation intensity.

Findings: The most frequently reported symptoms among the sample were lack of energy, pain, dry mouth, and shortness of breath. Lack of energy caused the greatest distress, followed closely by dry mouth and pain. The results of the regression analysis indicated that total distress score, pain intensity, dyspnea intensity, and constipation intensity were related to QOL at the univariate level. When all predictors were considered simultaneously, only the total distress score remained a significant predictor of QOL ($p < 0.001$), accounting for about 35% of variance.

Conclusions: QOL was affected by symptom distress in people with advanced cancer near the end of life.

Implications for Nursing: The symptoms most commonly reported and those that cause the greatest patient distress should be addressed first by hospice nurses. Continued effort is needed in the important area of symptom management.

Key Points . . .

- Fatigue, pain, dyspnea, and dry mouth are symptoms reported frequently by people with cancer who were newly admitted to hospice home care.
- Pain, dyspnea, and constipation intensity are related negatively to quality of life.
- Symptom distress is the strongest predictor of overall quality of life in people with advanced cancer.

by an interdisciplinary team and is designed to relieve distress from symptoms and promote overall quality of life (QOL) for patients and their families. Although QOL is multifaceted (Cella, 1995), uncontrolled symptoms clearly have a negative impact on all aspects of QOL, including emotional and spiritual well-being, social relationships, and functional abilities (Kurtz, Kurtz, Given, & Given, 1993; McMillan & Weitzner, 1998).

Rhodes, McDaniel, and Matthews (1998) wrote that a patient's symptom experience may be defined as the person's perception and response to symptom occurrence and symptom distress. Symptom occurrence is said to include the frequency and severity with which the symptom occurs and the duration or persistence of the symptom. Symptom distress refers to the amount or level of physical or mental upset, anguish, or suffering experienced by a person with a specific symptom.

Limited research is available about the distress caused by symptoms experienced by hospice patients and the impact of the distress on their QOL. The purpose of this study was to describe and evaluate, in people with advanced cancer

The American Cancer Society (ACS) (2002) estimates that 1.2 million new cancer cases are diagnosed annually, and, although many cases are cured or controlled, more than 550,500 people die from cancer each year (ACS). As people with advanced cancer approach death, they often need symptom relief and may be admitted to hospice care near the end of their lives. Hospice care is provided

Susan C. McMillan, PhD, ARNP, FAAN, is a professor in the College of Nursing, and Brent J. Small, PhD, is an associate professor in the Department of Gerontology, both at the University of South Florida in Tampa. This research was funded, in part, by a grant from the National Cancer Institute and the National Institute for Nursing Research. (Submitted October 2001. Accepted for publication March 4, 2002.)

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who were newly admitted to hospice home care, the relationships between QOL and several independent variables: symptom distress, pain intensity, dyspnea intensity, and constipation intensity. The study addressed the following questions.

- What are the most frequently reported symptoms among people with cancer receiving hospice home care?
- Does a significant relationship exist between total symptom distress and total QOL in people with cancer receiving home care?
- Do significant relationships exist between total QOL and the intensity of pain, constipation, and dyspnea in people with cancer receiving home care?

Background Literature

Symptom Distress

Patients with cancer experience a variety of unpleasant symptoms because of the disease and its treatment. Research has shown that fatigue, pain, dyspnea, and constipation are among the most common symptoms experienced by patients with cancer receiving hospice care (Donnelly, Walsh, & Rybicki, 1994; Weitzner, Moody, & McMillan, 1997).

Fatigue is one of the most common side effects of cancer and its treatment. Although recognized for decades, it has only recently become the focus of clinical research (Dean et al., 1995; Kurtz et al., 1993). Carpenito (1992) differentiated between fatigue and the ordinary experience of feeling tired by focusing on severity and duration. Tiredness is transitory, but fatigue is pervasive and not relieved by rest. Distress is associated with fatigue and may be the critical issue for many patients (Holley, 2000). In a cross-section of people ($n = 218$) with cancers of the prostate, colon, breast, or ovary, fatigue was found to have an overall prevalence of 73% (Portenoy et al., 1994).

Pain has been found to require treatment in 82%–88% of patients with cancer (Donnelly et al., 1994). Although pain is a common problem among patients with cancer, the literature suggests that it is not effectively managed and patients often are undermedicated (Brescia, Portenoy, Ryan, Krasnoff, & Gray, 1992; Donovan & Dillon, 1987; Gaston-Johansson, Franco, & Zimmerman, 1992; Paice, Mahon, & Faut-Callahan, 1991; Short, Burnett, Egbert, & Parks, 1990). Pain relief is a major goal of hospice care, yet a prospective study (McMillan & Tittle, 1995) of pain among hospice patients with cancer ($n = 25$) found that during a 24-hour period, patients continued to have pain despite pain-management regimens, with some patients reporting average daily pain to range as high as 96.7 on a 0–100 visual analogue scale. A follow-up study (McMillan, 1996a) included hospice patients with cancer ($n = 118$) who were asked how bad their pain was at its worst (1–10) and how much pain relief they were getting (1–10). Pain relief, even after three weeks of hospice care, was not optimal, with 42% of patients reporting pain relief at a level of 5 or less. Pain relief was found to be related to overall QOL ($r = 0.41$; $p < 0.001$) and elements of QOL, including sleeping ($r = 0.34$, $p < 0.002$) and fatigue ($r = 0.29$, $p < 0.01$).

Constipation also is a common problem in hospice patients with cancer (Donnelly et al., 1994), not only because of the narcotics needed to manage pain but also because of the limited food and fluid intake and lack of activity. A

study of hospice patients with cancer assessed constipation by asking patients about symptoms (McMillan & Tittle, 1995). The study found that 84% of hospice patients had some degree of constipation, but it was recorded as a problem on only 29% of these patients' charts. A recent chart audit at a hospice indicated that 51% of patients with cancer were being treated for constipation (Weitzner et al., 1997). If all patients with constipation were receiving some nursing intervention, 51% would be an impressive number; however, earlier research has suggested that the number of patients suffering from constipation is much higher than 51%; therefore, the problem probably was unrecognized and untreated.

Dyspnea is one of the most frequent and distressing symptoms occurring in hospice patients with advanced cancer and end-stage lung and heart disease. Current research indicates that dyspnea is the fourth most common symptom of patients who present to the emergency department with advanced cancer, and it is thought to be a clinical marker for the terminal phase of their disease (Escalante et al., 1996). A recent survey of hospice patients found dyspnea to be the second most common physical symptom, with 59% of patients needing nursing intervention (Weitzner et al., 1997). Strategies to reduce and manage dyspnea in hospice patients have been tested only minimally. Patients, healthcare providers, and caregivers often are frustrated and left with feelings of helplessness in coping with severe, chronic dyspnea. Fewer than 20% of those suffering from chronic dyspnea obtain relief through treatment (Moody, Fraser, & Yarandi, 1993). Moody, McCormick, and Williams (1990) found that in patients with chronic lung disease, dyspnea severity directly affected functional status and QOL. The problems of dyspnea assessment and management also are of clinical importance for QOL of hospice patients. Few intervention studies have been conducted to demonstrate which methods of treating dyspnea work best in patients with advanced cancer or end-stage cardiorespiratory disease.

After pain, nausea and vomiting are the problems most commonly associated with cancer in the minds of the lay public. Although nausea and vomiting generally are associated with chemotherapy administration, narcotics also may cause the problem. Disease-related causes of nausea and vomiting include hypercalcemia, increased intracranial pressure, or intestinal obstruction (Kinzel, 1988). Although great progress has been made in controlling nausea and vomiting, they remain problems for many patients. A retrospective chart review of hospice charts found nausea and vomiting in 27% of patient records (Weitzner et al., 1997).

Other physical problems identified by researchers and clinicians include drowsiness, dry mouth, anorexia, feeling bloated, changes in taste, weight loss, diarrhea, numbness and tingling, cough, alopecia, and dizziness. Although these symptoms are distressing, they were found in fewer than 50% of people with cancer (Portenoy et al., 1994) and seldom have been the subject of research.

A number of emotional problems have been identified in people with cancer. Portenoy et al. (1994) reported the following prevalences: worrying (73%), feeling sad (67%), feeling nervous (62%), difficulty sleeping (53%), feeling irritable (47%), and difficulty concentrating (40%).

More severe psychological problems also have been reported. Clinical depression has been reported in 25% of

people with cancer, with prevalence increasing to 77% for those with advanced disease (Bukberg, Penman, & Holland, 1984). Patients experiencing pain are twice as likely to develop psychiatric complications as patients without pain (Derogatis et al., 1983).

Although symptoms have been a focus of hospice research, the authors found no studies that assessed symptom distress in hospice settings. However, a study by Bruera, Kuehn, Miller, Selmsler, and MacMillan (1991) used the Edmonton Symptom Assessment Scale (ESAS) in a group of patients admitted to a palliative care unit. For the ESAS, symptom distress is defined as the sum of the symptom intensity scores for eight symptoms. Chang, Hwang, and Feuerman (2000) challenged its use as a measure of symptom distress and recommended that it be used as a measure of symptom intensity. The authors of the current study found no studies that evaluated symptom distress in relation to QOL of hospice patients with cancer.

Summary

QOL has been described as a multidimensional concept that must be reported by the person experiencing it (Cella, 1995). It has been conceptualized to include physical, psychological, functional, social, and spiritual well-being (McMillan & Weitzner, 1998). Symptom distress has been defined as the amount of physical or mental upset, anguish, or suffering caused by specific symptoms (Rhodes et al., 1998). Because few studies have demonstrated a link (McMillan, 1996b), this study aimed to test whether symptom intensity and distress are significantly associated with patient QOL.

Methods

Sample

The sample consisted of 178 adult hospice homecare patients with cancer who were accrued to a clinical trial funded by the National Institutes of Health that focused on symptom management and QOL. Patients had to have family caregivers and at least two of the following problems: pain, dyspnea, or constipation. Patients were excluded if they received a score lower than seven on the Short Portable Mental Status Questionnaire and if they were comatose, excessively debilitated, or actively dying.

Instruments

Among the questionnaires patients completed were the Hospice Quality of Life Index (HQLI), the Symptom Distress Subscale of the Memorial Symptom Assessment Scale (MSAS), numeric rating scales (NRSs) for pain and dyspnea, and the Constipation Assessment Scale (CAS). In addition, patients provided demographic data.

The **HQLI** is a 28-item, self-report tool that includes three aspects of overall QOL: psychophysiologic well-being, functional well-being, and social and spiritual well-being. Each item is a numeric rating scale (0–10), and total scores may range from 0–280 (McMillan & Weitzner, 1998).

Evidence of validity was provided by the ability of the HQLI to differentiate between homecare hospice patients and apparently healthy controls using both discriminate analysis ($p < 0.001$) and comparison of means ($p < 0.001$). The finding that HQLI scores correlated at the expected level ($r = 0.26$; $p < 0.01$) with functional status scores provided further evi-

dence of validity. Finally, factor analysis confirmed the factor structure of the HQLI (McMillan & Weitzner, 1998).

Reliability of the HQLI was provided by generation of coefficient alphas for both total scale scores and subscale scores (McMillan & Weitzner, 1998). Subscale alphas all were 0.84, and the total scale alpha was high ($r = 0.88$).

The **MSAS** lists 32 symptoms commonly experienced by people with cancer. The tool measures the presence, frequency, intensity, and distress caused by each of the symptoms (Portenoy et al., 1994). Validity and reliability data have been strong when the tool was used with people receiving active cancer therapy. Factor analysis confirmed two factors that distinguished three major groups of symptoms. The three confirmed groups of symptoms were psychological, high prevalence physical symptoms, and low prevalence physical symptoms. Reliability coefficients indicated strong internal consistency for the psychological and high prevalence physical subscales (alpha = 0.83–0.88), but a somewhat lower reliability estimate in the low prevalence physical subscale (Portenoy et al.).

A slightly revised MSAS was used in the current study to reduce response burden on the debilitated patients. The revised MSAS includes a list of 24 symptoms commonly experienced by hospice patients with cancer. The tool measures the presence and distress caused by each symptom. Each symptom was assessed on a 0–4 scale, with 4 representing the greatest distress for that symptom. Total distress scores could range from 0 (no distress) to 96 (greatest possible distress).

Pain intensity was assessed using an 11-point **pain NRS**, with scores ranging from 0–10. Patients were asked to respond orally with a number between 0 (no pain) and 10 (worst pain) to rate pain intensity at that moment (McGuire, 1984; Stewart, 1977). One advantage of the NRS is its ease of use by patients who are debilitated. Investigators have found that patients prefer the 0–10 NRS over other pain rating scales (Downie et al., 1978; Kremer, Atkinson, & Ignelzi, 1981). The NRS is simple to administer and score, and the scaling is understandable to patients. This is a brief, simple tool that provides a relatively sensitive measure of pain intensity. Previous research indicates that the NRS is valid and reliable. The NRS correlates well ($r = 0.59$ – 0.86) with other measures of pain intensity (Kremer et al.). A comparison among the NRS, a visual analog scale, a box scale, a behavioral rating scale, a four-point verbal rating scale, and a five-point verbal rating scale resulted in similar results in the number of subjects who responded correctly and the predictive value of each measure. The NRS was found to be more sensitive than the other scales (Jensen, Karoly, & Braver, 1986).

Among patients with severe dyspnea and fatigue, an 11-point **dyspnea rating scale** to assess dyspnea intensity is preferred because of ease of administration and accuracy (Moody, Lowry, Yarandi, & Voss, 1997; Silvestri & Mahler, 1993). Reliability and validity of the one-item numeric rating scales have been supported by a number of studies (McCord & Cronin-Stubbs, 1992; Silvestri & Mahler). Test-retest reliability ranged from 0.89–0.92, and concurrent validity with other measures was 0.88–0.94 (Moody et al., 1997).

The **CAS** is an eight-item, three-point, Likert-type scale that measures the presence and intensity of constipation. Each item is a symptom of constipation and rated by the respondent as no problem, some problem, or severe problem. Scores may range from 0 (no constipation) to 16 (worst possible constipation).

Validity and reliability data have been strong. A significant difference ($p = 0.0001$) between CAS scores of 32 working adults and 32 patients receiving treatment with either morphine or vinca alkaloids supported the validity of the CAS. A further analysis compared the CAS scores of the patients receiving significant doses of morphine with the CAS scores of patients who had received vinca alkaloids three weeks previously. The significant difference between these two groups ($p < 0.01$) supports the sensitivity of the CAS to differentiate between moderate and severe symptoms of constipation. Test-retest with brief delay provided strong evidence of reliability ($r = 0.98$). Alpha coefficients ($r = 0.70$ – 0.78) were very acceptable for such a short scale (McMillan & Williams, 1989).

Demographic data were collected to describe the sample. Data included gender, age, ethnicity, years of education, type of cancer, months since diagnosis, and length of stay in the hospice recorded in days.

Procedures

The clinical trial was approved by the hospice bioethics committee and the university institutional review board for the protection of human subjects before data collection. The patients were identified through hospice admission records and were invited to participate in the clinical trial within 48 hours of admission to hospice. After having the study explained and giving consent, the patients filled out the questionnaires at home in the presence of a trained data collector. Each form was checked for completeness before the data collector left the home.

Data Analysis

The MSAS items were examined with percentage affected to determine which symptom was most prevalent among the participants. In addition, means and standard deviations of each scale were examined to quantify the self-rating impact of each factor. To examine the relationship between QOL and symptom distress, two sets of analyses were computed. In the first, correlations were calculated between QOL scores, the four intensity and distress items (i.e., MSAS total score, pain score, breathlessness score, CAS), as well as demographic characteristics (i.e., age, gender, years of education, marital status). Finally, univariate and multivariate regression analyses were computed on the data with QOL as the dependent variable and the intensity and distress scores as the independent variables.

Results

Sample

The 178 hospice homecare patients in the sample were predominantly male, married, and Caucasian (see Table 1). Their mean age was 71 years, with a range of 37–95 years. They reported from 1–25 years of formal education, with a mean of 12 years. Their average time since cancer diagnosis was 29 months, with a range of one week to 30 years, and their length of stay in the hospice averaged 59 days, with a range of 1–354 days.

Scores: Prevalence and Distress

The most frequently reported symptoms were lack of energy (89%), pain (83%), dry mouth (78%), and shortness of breath (70%). Other symptoms reported by more than half of the patients included lack of appetite and cough (see Table 2).

Table 1. Demographic Variables

Variable	n	%
Gender		
Male	106	60
Female	72	40
Marital status		
Married	126	71
Widowed	24	14
Divorced	19	11
Never married	6	3
Separated	2	1
No response	1	1
Ethnicity		
Caucasian	150	84
African American	14	8
Hispanic	12	7
Asian/Pacific Islander	1	1
No response	1	1

N = 178

Note. Because of rounding, percentages may not total 100.

The mean symptom distress item scores were used to identify problems that caused the patients the greatest distress. Lack of energy ($\bar{X} = 2.7$, $SD = 1.2$) caused the greatest distress, followed closely by dry mouth ($\bar{X} = 2.5$, $SD = 1.1$) and pain ($\bar{X} = 2.4$, $SD = 1.1$).

The HQLI scores varied widely among the 178 hospice patients, with scores ranging from 100–276 (see Table 3); the

Table 2. Most Common Problems Identified by Patients With Cancer on Admission

MSAS Item/Variable	n	%	\bar{X} (SD)
Lack of energy	159	89	2.7 (1.2)
Pain	148	83	2.4 (1.1)
Dry mouth	138	78	2.5 (1.1)
Shortness of breath	124	70	2.1 (1.2)
Lack of appetite	102	57	1.9 (1.3)
Cough	101	57	1.7 (0.9)
Feeling nervous	80	45	1.9 (1.0)
Worrying	78	44	1.9 (1.1)
Drowsy	78	44	1.1 (1.2)
Feeling sad	74	42	2.0 (1.1)
Feeling bloated	70	39	2.2 (1.1)
Numbness or tingling	69	39	1.8 (1.2)
Nausea	67	38	1.9 (1.1)
Dizziness	66	37	1.4 (0.8)
Difficulty sleeping	66	37	2.2 (1.2)
Feeling irritable	63	35	1.4 (0.9)
Difficulty concentrating	61	34	1.6 (0.9)
Itching	53	30	1.7 (1.1)
Sweats	51	29	2.0 (1.2)
Difficulty swallowing	41	23	1.9 (1.2)
Problems with urination	37	21	1.9 (1.2)
Vomiting	38	21	1.8 (1.1)
Diarrhea	32	18	1.8 (1.2)
Sexual problems	9	5	1.8 (1.8)

N = 178

MSAS—Memorial Symptom Assessment Scale

Table 3. Quality of Life, Pain, Dyspnea, Constipation, and Symptom Distress

Variable	\bar{x}	SD	Possible Range	Actual Range
Quality of life	209.46	35.76	0–280	100–276
Pain	2.95	2.86	0–10	0–10
Dyspnea	3.08	2.92	0–10	0–10
Constipation	3.13	3.03	0–16	1–13
Symptom distress	21.74	11.70	0–96	1–67

N = 178

mean for the group was 209.46 (SD = 35.76). Total symptom distress scores ranged from 1–67, with a mean score of 21.74 (SD = 11.70). For the pain intensity scores on the numeric rating scale, the mean was 2.95 (SD = 2.86; range = 0–10). The dyspnea intensity scores on the numeric rating scale also ranged from 0–10, with a mean of 3.08 (SD = 2.92). The average intensity score on the CAS was 3.13 (SD = 3.03), with a range of 1–13.

Intercorrelations Among Symptom Distress, Quality of Life, and Demographic Covariates

The correlations among the items of interest are shown in Table 4. A number of significant correlations were observed. Age was positively related to ratings; older patients had higher QOL scores. All of the physical correlates (i.e., symptom distress, pain, breathlessness, constipation) were significantly related to QOL. In all cases, the correlations were negative, indicating that higher ratings of distress or intensity were related to lower QOL scores. In addition, age was negatively correlated with symptom distress; older adults reported less distress.

A number of significant correlations were observed between gender and other measures. For example, gender and symptom distress were positively correlated, indicating that women expressed more distress than men. A negative correlation between distress and gender suggested that women had lower ratings of overall breathlessness. All of the physical predictors were positively related among themselves.

Table 4. Variable Intercorrelations

Variable	1	2	3	4	5	6	7	8	9	10
1. Age	–	–	–	–	–	–	–	–	–	–
2. Gender	–0.08	–	–	–	–	–	–	–	–	–
3. Race	–0.09	–0.07	–	–	–	–	–	–	–	–
4. Marital status	–0.02	0.31***	–0.03	–	–	–	–	–	–	–
5. Years of education	–0.17*	0.01	–0.13	–0.04	–	–	–	–	–	–
6. Time since diagnosis (months)	0.15*	0.03	0.08	0.05	–0.03	–	–	–	–	–
7. MSAS symptom distress	–0.31***	0.21**	–0.09	0.08	0.09	0.00	–	–	–	–
8. Constipation assessment scale	–0.12	0.07	–0.02	0.09	–0.03	0.14	0.53***	–	–	–
9. Self-rating of pain	–0.15*	–0.09	0.10	–0.01	–0.20**	0.12	0.21**	0.34***	–	–
10. Self-rating of breathlessness	–0.09	–0.20**	–0.10	–0.11	0.01	–0.08	0.26***	0.14	0.21**	–
11. Hospice quality of life	0.36***	–0.04	0.13	0.09	–0.14	0.02	–0.67***	–0.38***	–0.20**	–0.27***

* $p < .05$

** $p < .01$

*** $p < .001$

MSAS—Memorial Symptom Assessment Scale

Regression Analysis Predicting Quality of Life

Table 5 displays the results of regression analyses predicting QOL from the physical correlates at both the univariate and multivariate levels. Based on the significant bivariate relationship between age and QOL, age was entered on the first step of all models to control for potential age confounds. At the univariate level, all four predictors were significantly related to QOL. In all cases, the direction was negative, indicating that higher intensity and distress were associated with lower QOL. However, a comparison across the predictors revealed that the MSAS symptom distress scale was the strongest predictor, accounting for more than 34% of variance.

The results of the multivariate regression model also are shown in Table 5. All four distress variables were entered in a single block after controlling for age. This block of variables accounted for more than 35% of variance in QOL scores. However, among the individual predictors, only MSAS symptom distress was statistically significant.

Discussion

Sample

The sample consisted of 178 homecare patients with advanced cancer who were alert and able to self-report symptom distress and QOL. The fact that the patients were well enough to self-report biases the results to some extent because these patients did not represent all hospice patients with cancer, only those who had the best functional status. The slight bias toward male patients is consistent with the patient numbers in the large hospice, and their length of stay was representative of all patients. The community from which the patients were drawn is about 12% African American and 11% Hispanic; these groups were under-represented in the sample.

Symptom Prevalence

Among the symptoms most commonly experienced by patients were lack of energy, pain, and shortness of breath. The literature supports that these symptoms are the ones most commonly experienced by people with cancer at the end of life. Interestingly, dry mouth was near the top in both incidence and distress. The problem has not been studied

Table 5. Univariate and Multivariate Regression Analyses Predicting Hospice Quality of Life

Model ^a	b	ΔR ²	Δp
Univariate			
MSAS symptom distress	-0.62***	0.34	< 0.001
Self-rating of pain	-0.15*	0.02	< 0.05
Self-rating of breathlessness	-0.24***	0.06	0.001
Constipation Assessment Scale	-0.34***	0.11	< 0.001
Multivariate			
MSAS symptom distress	-0.57***	–	–
Self-rating of pain	-0.02	–	–
Self-rating of breathlessness	-0.10	–	–
Constipation Assessment Scale	-0.04	0.35	< 0.001

^a Effects are independent of age ($\beta = .36$; $\Delta R^2 = .13$, $\Delta p < .001$).

* $p < .05$

** $p < .01$

*** $p < .001$

MSAS—Memorial Symptom Assessment Scale; Δ—change

extensively and, in previous studies, was found in fewer than half of patients. Perhaps dry mouth deserves more careful scrutiny. Chart reviews showed that nurses did not develop care plans for the most common symptom, lack of energy (Weitzner et al., 1997). Although interest in lack of energy as a problem for chronically ill people has grown, little help can be found in the scientific literature about empirically based methods to help hospice patients manage the problem.

The problem of pain was the second most prevalent in the sample. Unlike fatigue and dry mouth, great effort is made to manage pain. Evidence has been published that a focus on pain management has improved pain outcomes (Holzheimer, McMillan & Weitzner, 1999).

Dyspnea, a very distressing problem for many patients, is reported in the literature to be the second or third biggest problem among patients with cancer at the end of life (Weitzner et al., 1997). One study showed that dyspnea in patients with cancer seen in the emergency room was a predictor of impending death (Escalante et al., 1996). The current study supported that dyspnea is near the top of the list of most commonly seen problems. However, dyspnea management now appears to be at the stage that pain management was in the early 1990s. Few standardized measures for dyspnea exist, and the ones that are available seldom are used. Increased emphasis on this important problem is needed.

Comparison of Hospice and Active Treatment Patients

Because the MSAS has been used primarily with patients with cancer during active treatment, the researchers decided to compare the prevalence of problems between this study's hospice patients and patients being treated actively, based on results of a study by Portenoy et al. (1994). They found many similarities in terms of which problems were most common in each group (see Table 6). However, the hospice patients generally had a much higher prevalence of many of the problems than the actively treated patients. Specifically, the average prevalence rating in this study was 47%, with a median rating of 43. In the study by Portenoy et al., the av-

Table 6. Prevalence of Problems Identified by Patients With Cancer on Admission to Hospice Compared to Patients Undergoing Active Treatment

MSAS Item/Variable	Hospice Home Care	Active Treatment
	%	%
Lack of energy	89	73
Pain	83	63
Shortness of breath	75	22
Dry mouth	75	55
Drowsy	72	60
Lack of appetite	70	44
Cough	62	29
Worrying	50	72
Numbness or tingling	50	36
Feeling nervous	47	62
Feeling sad	45	67
Feeling bloated	43	39
Feeling irritable	42	47
Difficulty sleeping	41	53
Difficulty concentrating	41	40
Dizziness	39	23
Nausea	35	45
Itching	34	27
Sweats	33	–
Problems with urination	26	16
Difficulty swallowing	22	11
Diarrhea	20	24
Vomiting	18	21
Sexual problems	8	23

MSAS—Memorial Symptom Assessment Scale

erage prevalence across 23 items was 41%, with a median of 40.

The higher prevalence of many of the problems in the hospice patients was expected because their cancers were in stage IV, or very advanced. Some notable differences in the two groups did emerge. Shortness of breath was much more prevalent in the hospice group. Again, this was expected in a group of patients with more advanced disease and, doubtless, a much higher incidence of metastasis to the lungs. However, worrying, feeling sad, and feeling nervous were much more prevalent in the actively treated patients. One possible explanation might be that when patients are admitted to hospice, their fates are sealed. Patients under active treatment have much to worry and feel nervous about, not the least of which is the uncertainty of whether the treatment they are undergoing will be effective. That issue is settled for hospice patients, and the uncertainty is much less. A death-and-dying theorist might hypothesize that the hospice patients had come to some degree of acceptance of their situations.

Quality of Life

The mean QOL score was slightly higher (209.46) than scores found in an earlier study. McMillan and Weitzner (1998), using the same scale with a different sample of hospice patients with cancer, found a mean of 191.3. The reason for this difference might be the strict accrual criteria required by the study; patients in the current study were expected to

survive at least 30 days, and this was not the case in the earlier study. The patients in the current sample showed a wide range of QOL scores. Interestingly, the highest score in the group was within 4 points of a perfect score of 280. This result would seem to suggest that, although patients were near the end of life, their self-perceived QOL remained relatively high.

Symptom Distress

Total symptom distress scores on the MSAS can range from 0–96, with 0 being no distress and 96 being the worst possible distress. Although some patients reported higher distress scores, the mean distress score was in the low range (21.74).

Pain

Pain was assessed using a single-item 0–10 scale. Although pain intensity scores ranged from 0–10 (none to worst pain imaginable), the mean of just less than 3 suggests that, in general, pain was not severe in these patients. However, when compared with the data from the MSAS, pain caused one of the highest levels of distress. This result might have occurred because of the continuous nature of the pain. Even at a low level, pain can be distressing if it is unrelenting. However, further research is needed to evaluate this issue.

Dyspnea

Mean dyspnea scores were based on a 0–10 scale. These scores also ranged from none (0) to the worst dyspnea imaginable (10), but a mean score of about 3 suggests a relatively low level of dyspnea. Although this was a relatively low intensity of shortness of breath, in combination with the MSAS distress scores, the patients found it to be among the most distressing problems they experienced.

Constipation

Constipation was assessed with an eight-item, self-report tool. Mean scores were relatively low at about 3, but scores reached as high as 13 on a 0–16 scale. A score of 3 might be interpreted to mean that a patient has at least two, possibly three, symptoms of constipation. No constipation item was included on the version of the MSAS used in this project, so the researchers could not assess the extent to which constipation caused distress among the patients. However, a significant negative correlation was found between constipation and total distress scores ($r = 0.38$, $p < 0.001$).

Intercorrelations Among Quality of Life, Symptoms, and Demographic Covariates

The finding that age was significantly correlated with QOL supports earlier research (McMillan & Mahon, 1994). The current study also found that age was negatively correlated with symptom distress, indicating that older patients reported less symptom distress. Why older patients perceived themselves to have better QOL and less symptom distress in hospice care was unclear; perhaps it was related to expectations. Younger patients may expect to live pain and symptom free, but older patients, having a longer life perspective, may be more tolerant of such symptoms. Because of this expected finding, age was covaried in the remainder of the analyses.

All three problems that were assessed with symptom intensity scales (i.e., pain, dyspnea, and constipation) were significantly negatively correlated with QOL. This supports findings of earlier studies (McMillan, 1996a). Greater symptom intensity was expected to have a greater negative impact on QOL. Improved QOL continues to be the most valued outcome of hospice services. This result suggests that healthcare providers should focus on symptom management as an important way to improve QOL.

Regression Analysis Predicting Patient Quality of Life

With variance caused by age partialled out, pain, dyspnea, constipation intensity, and overall symptom distress were significantly related to QOL. The negative correlations confirm that higher symptom intensity and symptom distress are associated with lower QOL. In these univariate relationships, symptom distress clearly has the strongest relationship with QOL ($r = 0.67$, $p < 0.001$). This stronger relationship was confirmed in the multivariate analyses, which clearly showed symptom distress to be the most important predictor of patient QOL. Measures of individual symptoms cannot compete with it. Therefore, although relieving symptoms is the goal of hospice care, the continued focus on interdisciplinary approaches to relieve distress from all causes continues to be paramount.

Validity of the Memorial Symptom Assessment Scale

The MSAS had not been validated previously for use with hospice homecare patients; thus, current findings may be used to support discriminant validity. A moderately strong negative correlation was found between MSAS symptom distress scores and QOL. The correlation was negative, indicating that as symptom distress increased, QOL decreased. This correlation was expected. QOL has been documented to relate to symptom severity and distress (McMillan, 1996b; Portenoy et al., 1994). This finding reconfirms the relationship in a somewhat different population of patients.

The moderately strong correlation indicates that the two variables are related. However, the lack of a very strong or perfect relationship clarifies that the two tools are measuring different constructs. The MSAS has not been validated for use with hospice patients. Thus, the predicted correlation supports the construct validity of the MSAS for use with patients with cancer at the end of life.

Conclusions

Although pain intensity, dyspnea severity, and constipation intensity all are predictors of QOL, the strongest predictor in people with advanced cancer is symptom distress. The most commonly reported symptoms, and those that cause the greatest patient distress, should be addressed first by hospice interdisciplinary teams. Continued effort is needed in the important area of symptom management, and research in this area should continue.

Author Contact: Susan C. McMillan, PhD, ARNP, FAAN, can be reached at Smcmilla@hsc.usf.edu, with copy to editor at rose_mary@earthlink.net.

References

- American Cancer Society. (2002). *Cancer facts and figures 2002*. Atlanta, GA: Author.
- Brescia, F.J., Portenoy, R.K., Ryan, M., Krasnoff, L., & Gray, G. (1992). Pain, opioid use, and survival in hospitalized patients with advanced cancer. *Journal of Clinical Oncology*, 10, 149–155.
- Bruera, E., Kuehn, N., Miller, M.J., Selmser, P., & MacMillan, K. (1991). The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *Journal of Palliative Care*, 7(2), 6–9.
- Bukberg, J., Penman, D., & Holland, J.C. (1984). Depression in hospitalized cancer patients. *Psychosomatic Medicine*, 46, 199–212.
- Carpenito, L.J. (1992). *Nursing diagnosis: Application to practice* (4th ed.). Philadelphia: Lippincott.
- Cella, D.F. (1995). Measuring quality of life in palliative care. *Seminars in Oncology*, 22(Suppl. 3), 73–81.
- Chang, V.T., Hwang, S.S., & Feuerman, M. (2000). Validation of the Edmonton Symptom Assessment Scale. *Cancer*, 88, 2164–2171.
- Dean, G.E., Spears, L., Ferrell, B.R., Quan, W.D., Groshon, S., & Mitchell, M.S. (1995). Fatigue in patients with cancer receiving interferon alpha. *Cancer Practice*, 3, 164–172.
- Derogatis, L.R., Morrow, G.R., Fetting, J., Penman, D., Piasetsky, S., Schmale, A.M., et al. (1983). The prevalence of psychiatric disorders among cancer patients. *JAMA*, 249, 751–757.
- Donnelly, S., Walsh, D., & Rybicki, L. (1994). The symptoms of advanced cancer in 1,000 patients. *Journal of Palliative Care*, 10(1), 57.
- Donovan, M.I., & Dillon, P. (1987). Incidence and characteristics of pain in a sample of hospitalized cancer patients. *Cancer Nursing*, 10, 85–92.
- Downie, W.W., Leatham, P.A., Rhind, V.M., Wright, V., Branco, J.A., & Anderson, J.A. (1978). Studies with pain rating scales. *Annals of the Rheumatic Diseases*, 37, 378–381.
- Escalante, C.P., Martin, C.G., Elting, L.S., Cantor, S.B., Harle, T.S., Price, S., et al. (1996). Dyspnea in cancer patients: Etiology, resource utilization, and survival-implications in a managed care world. *Cancer*, 78, 1314–1319.
- Gaston-Johansson, F., Franco, T., & Zimmerman, L. (1992). Pain and psychological distress in patients undergoing autologous bone marrow transplantation. *Oncology Nursing Forum*, 19, 41–48.
- Holley, S. (2000). Cancer-related fatigue: Suffering a different fatigue. *Cancer Practice*, 8, 87–95.
- Holzheimer, A., McMillan, S.C., & Weitzner, M. (1999). Improving pain outcomes of hospice patients with cancer. *Oncology Nursing Forum*, 26, 1499–1504.
- Jensen, M.P., Karoly, P., & Braver, S. (1986). The measurement of clinical pain intensity: A comparison of six methods. *Pain*, 27, 117–126.
- Kinzel, T. (1988). Symptom control in geriatric patients with terminal cancer: Pain, nausea, and vomiting. *Geriatrics*, 43(6), 83–84, 87–89.
- Kremer, E., Atkinson, J.H., & Ignelzi, R.J. (1981). Measurement of pain: Patient preference does not confound pain measurement. *Pain*, 10, 241–248.
- Kurtz, M.E., Kurtz, J.C., Given, C.W., & Given, B. (1993). Loss of physical functioning among patients with cancer: A longitudinal review. *Cancer Practice*, 1, 275–281.
- McCord, M., & Cronin-Stubbs, D. (1992). Operationalizing dyspnea: Focus on measurement. *Heart and Lung*, 21, 167–179.
- McGuire, D.B. (1984). Measurement of clinical pain. *Nursing Research*, 33, 152–156.
- McMillan, S.C. (1996a). Pain and pain relief experienced by hospice patients with cancer. *Cancer Nursing*, 19, 298–307.
- McMillan, S.C. (1996b). The quality of life of patients with cancer receiving hospice care. *Oncology Nursing Forum*, 23, 1221–1228.
- McMillan, S.C., & Mahon, M. (1994). Measuring quality of life in hospice patients using a newly developed Hospice Quality of Life Index. *Quality of Life Research*, 3, 437–447.
- McMillan, S.C., & Tittle, M. (1995). A descriptive study of the management of pain and pain-related side effects in a cancer center and a hospice. *The Hospice Journal*, 10, 89–107.
- McMillan, S.C., & Weitzner, M. (1998). Quality of life in cancer patients: Use of a revised Hospice Index. *Cancer Practice*, 6, 282–288.
- McMillan, S.C., & Williams, F.A. (1989). Validity and reliability of the Constipation Assessment Scale. *Cancer Nursing*, 12, 183–188.
- Moody, L., McCormick, K., & Williams, A. (1990). Disease and symptom severity, functional status, and quality of life in chronic bronchitis and emphysema (CBE). *Journal of Behavioral Medicine*, 3, 297–306.
- Moody, L.E., Fraser, M., & Yarandi, H. (1993). Effects of guided imagery in patients with chronic bronchitis and emphysema. *Clinical Nursing Research*, 2, 478–486.
- Moody, L.E., Lowry, L., Yarandi, H., & Voss, A. (1997). Psychologic predictors of weaning from mechanical ventilation in chronic bronchitis and emphysema. *Clinical Nursing Research*, 6, 311–333.
- Paice, J.A., Mahon, S.M., & Faut-Callahan, M. (1991). Factors associated with adequate pain control in hospitalized postsurgical patients diagnosed with cancer. *Cancer Nursing*, 14, 298–305.
- Portenoy, R.K., Thaler, H.T., Kornblith, A.B., Lepore, J.M., Friedlander-Klar, H., Kiyasu, F., et al. (1994). The Memorial Symptom Assessment Scale: An instrument for the evaluation of symptom prevalence, characteristics and distress. *European Journal of Cancer*, 30A, 1326–1336.
- Rhodes, V.A., McDaniel, R.W., & Matthews, C.A. (1998). Hospice patients' and nurses' perceptions of self-care deficits based on symptom experience. *Cancer Nursing*, 21, 312–319.
- Short, L.M., Burnett, M.L., Egbert, A.M., & Parks, L.H. (1990). Medicating the postoperative elderly: How do nurses make their decisions? *Journal of Gerontological Nursing*, 16(7), 12–17.
- Silvestri, G.A., & Mahler, D.A. (1993). Evaluation of dyspnea in the elderly patient. *Clinics in Chest Medicine*, 14, 393–404.
- Stewart, M.L. (1977). Measurement of clinical pain. In A. Jacox (Ed.), *Pain: A source book for nurses and other health professionals* (pp. 107–136). Boston: Little, Brown.
- Weitzner, M.A., Moody, L.N., & McMillan, S.C. (1997). Symptom management issues in hospice care. *American Journal of Hospice and Palliative Care*, 14, 190–195.

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