Effectiveness of a Clinical Intervention to Eliminate Barriers to Pain and Fatigue Management in Oncology

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Abstract

Background: Pain and fatigue are recognized as critical symptoms that impact quality of life (QOL) in cancer, particularly in palliative care settings. Barriers to pain and fatigue relief have been classified into three categories: patient, professional, and system barriers. The overall objective of this study was to test the effects of a clinical intervention on reducing barriers to pain and fatigue management in oncology.

Methods: This longitudinal, three-group, quasi-experimental study was conducted in three phases: phase 1 (usual care), phase 2 (intervention), and phase 3 (dissemination). A sample of 280 patients with breast, lung, colon, or prostate cancers, stage III and IV disease (80%), and a pain and/or fatigue of 4 or more (moderate to severe) were recruited. The intervention group received four educational sessions on pain/fatigue assessment and management, whereas the control group received usual care. Pain and fatigue barriers and patient knowledge were measured at baseline, 1 month, and 3 months post-accrual for all phases. A 3×2 repeated measures statistical design was utilized to derive *a priori* tests of immediate effects (baseline to 1 month) and sustained effects (baseline or 1 month to 3 months) for each major outcome variable, subscale, and/or scale score.

Results: There were significant immediate and sustained effects of the intervention on pain and fatigue barriers as well as knowledge. Measurable improvements in QOL were found in physical and psychological well-being only.

Conclusion: A clinical intervention was effective in reducing patient barriers to pain and fatigue management, increasing patient knowledge regarding pain and fatigue, and is feasible and acceptable to patients.

Introduction

MAJOR DEFICIENCIES in the treatment of cancer symptoms have been documented over the past two decades. Efforts to provide optimal symptom management in cancer are hampered by barriers related to patient, professional, and system issues. Suffering from uncontrolled pain is one of the greatest fears of cancer patients.^{1,2} Patients are reluctant to report their pain due to fear of side effects, fatalism about the possibility of achieving pain control, fear of distracting physicians from treating the cancer, and belief that pain is indicative of progressive disease.^{3–13} Physicians, nurses, and other members of the interdisciplinary team often fail to adequately assess pain or to recognize patient barriers.^{14–18} Professionals lack knowledge of the principles of pain relief, side effect management, or understanding of key concepts such as ad-

diction, tolerance, dosing, and communication.^{19–22} System barriers include reimbursement and regulatory constraints, and lack of referrals to pain specialists and supportive care services.^{10,23,24}

Cancer-related fatigue (CRF) is one of the most common symptoms experienced by patients with cancer.^{25,26} Patient-related barriers to fatigue include reluctance to report fatigue, and beliefs that fatigue is inevitable, unimportant, and untreatable.^{27–32} Professionals are unaware of the principles of fatigue assessment and management, and may be unwilling to initiate discussion about fatigue with patients.^{30,33–39} Documentation of fatigue assessment and management in the medical record is lacking in most clinical settings. Lack of health care reimbursement for fatigue affects the availability of medications, prescription practices, and referral patterns to supportive care services.²⁸

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After decades of efforts to advance symptom management, sources have documented that reducing these barriers requires more than publication of guidelines or staff education.^{40,41} Model programs have emphasized patient teaching interventions including the use of pain assessment tools, strategies to dispel misconceptions, and patient coaching regarding the reporting and documenting of their symptoms.^{42,43} The "Passport to Comfort" intervention was designed and implemented in response to the overwhelming evidence of the impact of these barriers on symptom management, and the intent to move beyond descriptive studies to test innovative models that would eliminate these barriers in palliative care settings.

Methods

This longitudinal, three-group, quasi-experimental study was designed in three phases. Phase 1 assessed patient pain and fatigue management in usual care to describe the current status of pain and fatigue management in the sample population and setting. In phase 2, all patients were offered the intervention. This included structured patient education and systems change efforts carried out by the research team. During phase 3, the intervention was disseminated within the institution so that it can be sustained for continued practice.

Sample

Patients with cancer recruited for the study met the following eligibility criteria for enrollment: (1) diagnosis of breast, colon, lung, or prostate cancer; (2) time since diagnosis of at least 1 month; (3) an expected prognosis of at least 6 months; and (4) subjective pain and/or fatigue rating of 4 or greater (moderate to severe pain) on a numeric scale of 0–10 (0 = none; 10 = worst imaginable). Stratification was conducted to reflect a sample of the four diagnoses that were proportional to the cancer center population. Participants were recruited from the ambulatory clinic of one National Cancer Institute (NCI)-designated comprehensive cancer center in Southern California. The Institutional Review Board approved the study protocol and monitored study progress.

Procedure

Potential participants were screened at the ambulatory clinics, and once eligibility was determined, study purpose and procedures were introduced. Written informed consent was obtained from all participants prior to enrollment. For phase 1 (usual care), all participants completed questionnaires at baseline, 1 month, and 3 months. For phase 2 (intervention), baseline questionnaires were completed prior to the intervention. The intervention was delivered by trained advanced practice nurses (APN) through four education sessions. At each session, information pertaining to pain assessment, pain management, fatigue assessment, and fatigue management was provided. A teaching material packet was also provided, and it included the National Comprehensive Cancer Network (NCCN) guidelines for patients on pain and fatigue and "tip sheets," which were 1-page education sheets on nutrition, sleep disturbance, emotional issues, and exercise. Questionnaires were then repeated at 1 and 3 months. Beginning at 1 month, all participants were supported through phone calls made every 2 weeks. Length of intervention was tailored to

the patient's needs and was approximately 60 minutes in length. For phase 3 (dissemination), participants completed questionnaires only at baseline, 1, and 3 months, and received phone calls every 2 weeks. In this phase, the APN role was less involved in direct professional and patient education. Her main role was to facilitate the intervention as it was implemented into the existing systems in order to sustain improved pain and fatigue management after the conclusion of the project.

Instruments

The Demographic and Treatment Data Tool was designed by the investigators to capture key disease and treatment variables of importance in describing the population and for analysis of influencing variables. Demographic and treatment data such as age, gender, disease type, stage of disease, treatments, and performance status using the Karnofsky Performance Scale (KPS)⁴⁴ were collected at baseline.

The Barriers Questionnaire (BQ II) was developed by Gunnarsdottir and colleagues⁴⁵ to measure patient-reported barriers to pain management. Significant ($t = -2.16, p < 0.05$) construct validity and a factor analysis revealed four factors: (1) physiologic effects, (2) fatalism, (3) communication and (4) harmful effects. The BQ-II total has an internal consistency reliability coefficient α of 0.89 ($n = 134$), and a range of 0.75–0.85 for the subscales.

The Patient Pain Knowledge Tool was developed by the investigators based on the NCCN Pain Guidelines.⁴⁶ This 15-item questionnaire was used as an assessment of patients' knowledge and beliefs. The questions were based on content from the NCCN pain guidelines and were in a true or false format. This tool was written at a low literacy level and to be less burdensome for subjects to complete. Internal consistency reliability analysis was performed, and Cronbach α was 0.67.

The Piper Fatigue Scale (PFS) is a 22-item, self-report scale that measures four dimensions of subjective fatigue (behavioral/severity [6 items], sensory [5 items], cognitive/mood [6 items], and affective meaning [5 items]) confirmed by principal axes factor analysis.⁴⁷ Internal consistency (Cronbach α) reliabilities were strong (0.83–0.97) for the PFS and its subscales across various cultures, languages, and diagnostic groups and were 0.89–0.97 in this sample. Each item is measured on a 0–10 numeric rating scale, and higher scores indicate more fatigue. Mild (1–3), moderate (4–6), and severe (7–10) levels have been validated with declines in physical functioning (MOS-SF-36 Physical Functioning subscale and PFS-Total scores). Five additional items, not included in the scale's scoring, assess perceived causes, relief measures, additional fatigue descriptors, presence of other symptoms, and duration of fatigue.⁴⁷

The Fatigue Barriers Scale (FBS) is an investigator-developed 13-item scale designed to elicit patient beliefs and attitudes that might serve as barriers to effective fatigue assessment and management. It was developed based on an extensive literature review and clinical experience. In this study, the reliability estimates for the subscales were: Beliefs/Attitudes ($r = 0.30$), Good Patient ($r = 0.65$), and Fatalism ($r = 0.54$). For the total scale ($r = 0.73$) the reliability coefficient indicated good reliability for a new scale.

The Patient Fatigue Knowledge Tool is an investigator-developed scale that contains 15 true and false statements

TABLE 1. DEMOGRAPHICS AND TREATMENT DATA (N = 280)

	n	%
Age	Mean = 60.4	
Gender		
Male	109	(38.9)
Female	171	(61.1)
Race/Ethnicity		
Caucasian	180	(64.3)
African American	27	(9.6)
Hispanic/Latino	41	(14.7)
Other	32	(11.4)
Education		
Graduate	56	(20)
College	122	(43.4)
High school or less	102	(36.6)
Marital Status		
Married	174	(62.1)
Other	106	(37.9)
Type of Cancer		
Breast	109	(38.9)
Colon	56	(20)
Lung	72	(25.7)
Prostate	43	(15.4)
Stage		
I-II	56	(20.3)
III	82	(29.7)
IV	138	(50)
Disease status		
Recently diagnosed and undergoing rx	141	(50.9)
Recurrence and undergoing rx	84	(30.3)
Completed rx, NED	20	(7.2)
Other	32	(11.6)
Symptom Clusters		
Pain only	27	(9.7)
Fatigue Only	167	(59.6)
Pain & Fatigue	86	(30.7)

KPS range = 80–70 at baseline.

about fatigue designed to assess a patient's knowledge about what fatigue is, and how it can be assessed, measured and treated. It was developed based on the NCCN fatigue guidelines, and was designed to capture key patient-related knowledge barriers.

Statistical analysis

Sample size was planned based on preliminary power analysis. There were 83 patients in usual care, 104 in intense intervention, and 93 in the dissemination phase. Eligible subjects were recruited and consented until the accrual goal

of 100 patients per phase was reached. Data were audited for accuracy and scored according to the guidelines for each instrument. A missing values analysis was conducted and values were found to be missing at random (MAR), and therefore were imputed using the estimation-maximization method. A total of 280 patients were included in the final analysis. After examining initial results indicating no significant differences between intensive intervention and dissemination, the phase 2 and phase 3 groups were collapsed, and a 3×2 repeated measures statistical design was utilized to derive *a priori* tests of immediate effects (baseline to 1 month) and sustained effects (baseline or 1 month to 3 months) for each major outcome variable, subscale, and/or scale score. Patients achieving the criterion of having pain at study baseline, a single item pain score of 4 or greater on a 0–10 point scale, ($n = 113$) were included in all analyses of pain variables, while patients achieving the criterion of having fatigue at baseline, a single item fatigue score of 4 or greater on a 0–10 point scale, ($n = 251$) were included in all analyses of fatigue barriers. Patients who met the criteria for having pain and fatigue at baseline ($n = 86$) were included in both sets of analyses. All patients were included in the description of study demographics and the QOL item and subscale/scale scores. Association between group and categorical demographic variables was tested using the χ^2 statistic or Fisher's exact test, as appropriate. α for this study was set at 0.05, two-tailed, and when indicated a Bonferroni adjustment factor was used to control for inflation of experimentwise error.

Results

Study recruitment began November 17, 2005 to July 24, 2009. Final sample sizes by study phase (including participants with complete, evaluable data) were as follows: 83 for phase 1, 104 for phase 2, and 93 for phase 3. The demographics of study patients are presented in Table 1. Importantly, over one third of the patients were racial or ethnic minorities and a quarter of the patients each had colon or lung cancer. Few patients were receiving supportive services. The usual care group was significantly more likely to be experiencing a recurrence (42%) whereas the intervention group was more likely to have a recent diagnosis (44%) ($p = 0.005$). Usual care patients were significantly more likely to be diagnosed at stage III and intervention patients at stage IV ($p = 0.006$).

Single-item pain and fatigue scores over time are shown in Table 2. In the usual care group there was a significant immediate effect, but this improvement was not sustained. There was a significant immediate and sustained effect on

TABLE 2. PAIN AND FATIGUE SCORES X (95% CI) FROM SINGLE ITEM SCALES

	Baseline	1 month	3 month	Immediate effect	Sustained or delayed effect
Pain scores for patients with pain					
Usual care	5.5 (5.0, 6.0)	4.0 (3.2, 4.8)	5.1 (4.2, 6.1)	$p = 0.007$	$p = 0.013$
Intervention	5.5 (5.1, 5.9)	3.9 (3.3, 4.5)	4.0 (3.4, 4.7)	$p < 0.001$	$p = 0.001$
Fatigue scores for patients with fatigue					
Usual care	6.2 (5.8, 6.6)	3.5 (3.0, 4.1)	4.0 (3.4, 4.5)	$p < 0.001$	$p < 0.001$
Intervention	5.9 (5.7, 6.2)	5.2 (4.9, 5.6)	4.5 (4.2, 4.9)	$p < 0.001$	$p = 0.001$

0–10 scale: 0 = none, 10 = worse.

TABLE 3. BARRIERS TO PAIN X (95% CI) FROM THE BQ-II

	Baseline	1 month	3 month	Immediate Effect (Baseline to 1 Month)	Sustained or delayed effect (Baseline 1 Month to 3 Months)
Physiologic subscales					
Usual Care	2.3 (2.0, 2.6)	2.4 (2.1, 2.8)	2.1 (1.8, 2.5)	p = 0.001	p = 0.037
Intervention	1.8 (1.7, 2.1)	1.4 (1.2, 1.6)	1.4 (1.2, 1.6)		p = 0.001
Fatalism subscale					
Usual care	1.3 (1.0, 1.7)	1.7 (1.4, 2.1)	1.2 (0.9, 1.5)	p = 0.006	p = 0.010
Intervention	1.3 (1.0, 1.5)	0.88 (0.6, 1.1)	0.81 (0.6, 1.0)		p = 0.002
Communication subscale					
Usual care	1.2 (0.9, 1.6)	1.5 (1.2, 1.9)	0.96 (0.7, 1.2)		
Intervention	1.2 (0.9, 1.4)	0.92 (0.7, 1.2)	0.87 (0.6, 1.1)		
Harmful subscale					
Usual care	2.5 (2.1, 2.9)	2.5 (2.1, 2.9)	2.3 (1.9, 2.7)	p < 0.001	p < 0.001
Intervention	2.1 (1.8, 2.4)	1.4 (1.1, 1.7)	1.3 (1.1, 1.7)		
Total score					
Usual care	2.0 (1.7, 2.2)	2.2 (1.9, 2.5)	1.8 (1.5, 2.1)	p < 0.001	p = 0.003
Intervention	1.7 (1.5, 1.9)	1.2 (1.0, 1.4)	1.2 (1.0, 1.4)		p < 0.001

1–5 scale: 1 = low barriers, 5 = high barriers.

BQ-II, Barriers Questionnaire II.

pain for patients in the intervention group. The same pattern was demonstrated for fatigue.

Impact of intervention on barriers to pain and fatigue management

There were significant immediate and sustained effects of the intervention on all BQII subscales except for the Communication subscale, and on the Total score (Table 3). Fatalism as a barrier to pain management actually increased in the usual care group at one month, and returned significantly to baseline at 3 months.

There was a significant immediate effect of the intervention on the Sensory and Cognitive subscales and for the Total Piper Fatigue Scale (PFS) score, as shown in Table 4. The p value for the Affective subscale's immediate effect did not achieve the required criterion of $p = 0.0125$ to control for inflation of α . Significant delayed improvements were shown in the

usual care group for the Sensory, Affective, and Behavioral subscales and the Total score. Significant sustained effects were observed in the intervention group for the Sensory, Affective, Cognitive, and Behavioral subscales and the Total score. Significant immediate and sustained effects were shown on the Fatigue Barriers Scale (FBS) for the intervention group, as shown in Table 5. Persistent barriers to fatigue management are also listed in Table 5, as are four beliefs that were significantly improved.

Impact of intervention on knowledge of pain and fatigue management

There was a significant immediate and sustained effect on knowledge of pain for the intervention group ($p < 0.001$), with no significant change in knowledge of pain in the usual care group. Table 6 lists the knowledge items with persistently low scores that indicate areas of need for teaching reinforcement.

TABLE 4. PIPER FATIGUE SCALE X (95% CI)

	Baseline	1 Month	3 Month	Immediate effect	Sustained or delayed effect
Sensory subscale					
Usual care	6.4 (5.8, 6.9)	6.2 (5.6, 6.7)	5.1 (4.5, 5.7)	$p < 0.001$	$p < 0.001$
Intervention	6.2 (5.9, 6.5)	5.6 (5.2, 5.9)	4.9 (4.5, 5.2)		$p = 0.002$
Affective subscale					
Usual care	6.0 (5.4, 6.5)	5.7 (5.1, 6.2)	4.9 (4.3, 5.4)	$p = 0.049$	$p = 0.005$
Intervention	5.8 (5.4, 6.1)	5.3 (4.9, 5.6)	4.9 (4.5, 5.2)		$p < 0.001$
Cognitive subscale					
Usual care	4.9 (4.4, 5.4)	4.9 (4.4, 5.4)	4.3 (3.8, 4.8)	$p = 0.004$	$p = 0.001$
Intervention	4.9 (4.6, 5.2)	4.4 (4.1, 4.7)	4.2 (3.9, 4.5)		
Behavioral subscale					
Usual care	6.0 (5.4, 6.6)	5.7 (5.1, 6.4)	4.9 (4.3, 5.5)		$p = 0.01$
Intervention	5.4 (5.0, 5.8)	5.0 (4.6, 5.4)	4.5 (4.1, 4.9)		$p = 0.033$
Total score					
Usual care	5.8 (5.3, 6.3)	5.6 (5.1, 6.1)	4.8 (4.3, 5.3)	$p = 0.006$	$p = 0.002$
Intervention	5.5 (5.2, 5.8)	5.0 (4.7, 5.4)	4.5 (4.3, 4.9)		$p = 0.001$

Range, 0–10; 0 = none, 10 = worse.

TABLE 5. BARRIERS TO FATIGUE X (95% CI) FROM THE FATIGUE BARRIERS SCALE (FBS)

	Baseline	1 month	3 month	Immediate effect	Sustained or delayed effect
Total score					
Usual care	28.1 (24.9, 31.3)	28.4 (25.6, 31.3)	27.5 (24.9, 30.1)		
Intervention	27.5 (25.6, 29.5)	23.9 (22.2, 25.6)	23.8 (22.3, 25.4)	$p = 0.001$	$p = 0.001$
Items with persistent barriers to fatigue (>3, range 0–5)					
Fatigue is inevitable result of cancer					
If fatigue is important, my MD will bring up the subject					
Items with lower barriers to fatigue (<1, range 0–5)					
If I complain, my MD won't want to treat me					
MD think of fatigue only as a psychological problem					
Talking about fatigue is as important as having my vital signs taken					
MD is too busy to worry about my fatigue					

15 items on a 0–5 scale. Scale range = 0–75; 0 = no barriers, 75 = maximum barriers.

ment with patients. There are also four items that appear to have been successfully taught to patients, indicating that progress is being made in overcoming these barriers.

The intervention group demonstrated an immediate and sustained significant effect on knowledge of fatigue and its management ($p < 0.001$, $p = 0.002$, respectively) whereas there was no significant change in knowledge for the usual care group. Table 6 lists the knowledge items with persistently low scores indicating continued need to teach and reinforce with patients. There are also three items that appear to have been successfully taught to patients, indicating that patients had some increased knowledge of fatigue.

Impact of intervention on quality of life

Table 7 summarizes the four-dimensional COH-QOL tool results for the study patients. There was a significant immediate drop in Psychological QOL for the usual care group, while there were sustained improvements in Physical, Psychological, Social, and Total QOL in that group. The intervention group demonstrated a significant delayed effect in Physical QOL. Descriptively, the intervention group tended to maintain baseline levels of QOL throughout the study, or to show mild improvements (as in Physical QOL) when we would normally expect a decrease in QOL. Overall, QOL was about mid-range for these patients (5–6 on a 0–10 scale). The most frequent QOL concerns were sleep, sexuality, appetite, constipation, nausea, anxiety, depression, and isolation.

Discussion

In this study, we tested the "Passport to Comfort" intervention that targeted patient, professional, and system-related barriers to improve pain and fatigue management in an ambulatory care setting with primarily palliative care patients. Study results underscore the importance of integrating quality palliative care into routine care in order to impact symptom and QOL for patients with incurable cancer. Not only was the intervention innovative and feasible, but study results suggests that significant improvements were seen in barriers and knowledge of pain and fatigue, and that the effect was sustained over time. Although significant differences

were seen on QOL measures, these differences were small, with only mild improvements observed.

The intervention was able to reduce common patient-related barriers to pain, as demonstrated by the immediate and sustained effect seen in all but one subscale score. For pain knowledge, we saw significant improvements in several communication items, including the importance to discuss pain with M.D./R.N. and the use of the pain rating scale to communicate pain intensity. Although improvements were seen in patient's willingness to discuss pain issues with health care professionals, more efforts may be needed for the importance of symptom communication between patient and provider. We also found that addiction persists as an important barrier to optimal pain management for patients with cancer. This finding indicates that aggressive education and counseling to dispel the myth of pain medication addiction

TABLE 6. PATIENT KNOWLEDGE OF PAIN

Overall Score = 74% to 85% correct
Items with low scores (< 60% correct)
Cancer is most common cause of pain
Taking opioids leads to addiction
Items with high scores (>90% correct)
Pain is divided into 2 types: acute and chronic
It is important for MDs and RNs to know about your pain
Pain scale is used to describe how much pain you are feeling
Fluids, exercise, fiber, and laxatives can prevent constipation as a side effect of pain medications
Patient knowledge of fatigue
Overall score = 87% to 91% correct
Items with low scores (<60% correct)
Exercise requires more energy and leads to more effort to do activities
Items with high scores (>90% correct)
Fatigue can be described using 0–10 scale
If fatigue is severe, MD should be notified
It is important to talk to MD about pain, nausea, or depression because they make fatigue worse

TABLE 7. QUALITY OF LIFE X (95% CI)

	Baseline	1 month	3 month	Immediate effect	Sustained or delayed Effect
Physical					
Usual care	5.9 (5.6, 6.2)	5.9 (5.5, 6.2)	6.6 (6.2, 6.9)		$p = 0.001$
Intervention	6.2 (6.0, 6.4)	6.4 (6.1, 6.6)	6.7 (6.5, 6.9)		$p = 0.005$
Psychologic					
Usual care	5.0 (4.6, 5.4)	4.5 (4.2, 4.9)	5.5 (5.1, 5.8)	$p = .005$	$p < 0.001$
Intervention	5.2 (4.9, 5.4)	5.1 (4.8, 5.3)	5.2 (5.0, 5.5)		
Social					
Usual care	5.0 (4.5, 5.4)	5.1 (4.6, 5.5)	5.9 (5.5, 6.3)		$p = 0.014$
Intervention	5.0 (4.7, 5.2)	5.0 (4.6, 5.2)	5.1 (4.8, 5.3)		
Spiritual					
Usual care	6.1 (5.6, 6.6)	5.9 (5.5, 6.4)	5.6 (5.1, 6.0)		$p = 0.014$
Intervention	6.2 (5.9, 6.5)	6.1 (5.8, 6.4)	6.1 (5.8, 6.4)		
Total QOL					
Usual care	5.4 (5.1, 5.7)	5.3 (5.0, 5.6)	5.8 (5.5, 6.1)		$p < 0.001$
Intervention	5.5 (5.3, 5.7)	5.5 (5.3, 5.7)	5.6 (5.5, 5.8)		

Range, 0–10; 0 = poor QOL, 10 = best QOL.

Items with low QOL scores: initial diagnosis distress, distress from treatment, family distress, uncertainty.

QOL, quality of life.

may not be enough to eliminate this barrier. Future studies may need to focus on other factors that impact patient's beliefs and attitudes about pain medication. In terms of fatigue, approximately 50% of our patients reported experiencing moderate to severe fatigue. This finding validates existing evidence that fatigue is one of the most common symptoms experienced by cancer patients.⁴⁸ We were able to improve knowledge on several communication items, indicating that patients are aware of the importance of discussing fatigue issues with their providers. However, patients are unaware of

the importance of exercise in managing CRF. We found that patients believed that exercise expenses rather than increases energy. This belief is not supported by the current evidence that physical activity, including exercise, is an effective strategy for managing CRF.^{49–53} Future studies need to address this important misconception.

We had anticipated that the intervention would result in significant improvements in overall QOL for our patients. Although we were able to detect some positive changes, these changes were mild. This may not be surprising given that our

TABLE 8. PATIENT/PROFESSIONAL/SYSTEM CHANGES AT CITY OF HOPE RESULTING FROM THE BARRIERS STUDY

Patient	Professional	System
1. Patient education materials developed for pain (pain assessment and management, constipation) and fatigue (fatigue assessment and management, sleep, nutrition, energy conservation, exercise)	1. Pain and fatigue education provided to physicians, nursing, pharmacy, rehabilitation, nutrition, case management (total of 38 in-services)	1. Routine fatigue assessment added to outpatient clinic vital sign flow sheet.
2. All patient education materials translated in Spanish by COH Patient-Family Education Department. Available at: http://prc.coh.org/pt-familyEd.asp	2. Pain and fatigue education presented at key meetings:—Medical Oncology Staff-11—Medical Grand Rounds-1—Psycho-Oncology Grand Rounds-2—Science of Caring Lecture-1	2. Internal Advisory Board meeting held quarterly to coordinate institution-wide efforts to improve pain and fatigue management. Average attendance per meeting 12–15 people from 10 departments.
3. All patient education materials placed on COH employee internet website to be accessed by all staff and all clinics. Above efforts resulted in distribution of 1055 patient education cards throughout COH over two years.	3. Clinical feedback reports completed for 118 patients and provided to MDs and NPs based on chart audits with specific suggestions for pain and fatigue management.	3. Increased referrals to supportive care departments for pain and fatigue including nutrition, rehabilitation and pain/palliative care.
4. Advocacy posters for pain and fatigue posted in every clinic room, in the hallways, and on the walls of the MedOnc outpatient clinic. Also posted in the hematology outpatient clinics.		

COH, City of Hope.

FIG. 1. Longitudinal quality of life (QOL).

sample consisted primarily of palliative care cancer patients with advanced disease. The evidence on QOL in advanced disease suggests that it is common to see gradual and sometimes dramatic QOL decline, referred to as the "terminal drop."⁵⁴ Based on these observations, some investigators proposed the "longitudinal terminal decline QOL model." In the model, slow and steady changes in symptom distress, functional status, and QOL dimensions can occur.⁵⁵ This gradual decline was also observed in our sample population, with mild

improvements seen for the intervention group. Although this mild improvement in QOL may not be significant, we were able to detect improvements in our sample of patients with advanced disease where QOL decline is expected. This indicates that our intervention did have a positive impact on overall QOL.

There are several strengths and limitations of this study. Our sample consisted of four solid tumor diagnoses, which makes the study findings generalizable to more than one cancer diagnosis population. We were also able to recruit 36% ethnic

minorities for study participation. Our recruitment strategy was to enroll patients who had symptomatic pain and fatigue that is moderate to severe. Therefore, our findings may not be generalizable for patients who are less symptomatic.

It is relevant to discuss how the "Passport to Comfort" intervention can be integrated into routine clinical practice. The study design incorporated a third phase, where dissemination of the intervention into routine care was undertaken at the study institution. Phase 3 dissemination incorporated strategies for systems-related changes to facilitate further improvements in pain and fatigue management (Table 8). Patient education materials used in the intervention were refined and translated into Spanish. Patient education materials were made available system-wide through the employee Intranet (available to the public at <http://prc.coh.org/>). Advocacy posters were posted in ambulatory clinics and waiting rooms as a reminder to both patient and provider to discuss pain and fatigue-related issues. The 0–10 numeric analogue scale was added to the ambulatory clinic vital sign flow sheet to assess fatigue.

Finally, plans are underway to disseminate the intervention into other community cancer centers. The National Institutes of Health (NIH) and NCI have long emphasized the importance of disseminating evidence-based interventions into routine clinical practice, and federal funding mechanisms have been established to encourage and solicit hypothesis-driven proposals to test the dissemination process of evidence-based interventions. The investigators have submitted a proposal to test the dissemination process of the "Passport to Comfort" intervention, and if funded, our evidence-based clinical intervention to reduce barriers to pain and fatigue management can be successfully integrated into routine palliative care.

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