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Preferences for Help With a Sleep Problem Before Starting Cancer Treatment

To the Editor

Being diagnosed with cancer can be overwhelming and is often associated with significant disruptions. Before beginning cancer treatment, many patients experience poor sleep. Disrupted sleep has meaningful clinical implications beyond "just" not feeling rested. Patients who sleep poorly prior may experience worse pain, fatigue, and depression during treatment.[1] Furthermore, sleep often gets worse as treatment progresses,[2] and chronic sleep problems are associated with major negative health consequences.[3,4] Unfortunately, patients are unlikely to seek treatment for sleep problems despite robust evidence supporting the effectiveness of interventions. These interventions are often disregarded in the oncology setting by patients and providers who consider them to be an expected problem after a cancer diagnosis.[5]

Cancer patients about to begin treatment are actively engaged with the medical system due to ongoing treatment and follow-up.[6] This provides an opportunity to screen for sleep disorders and provide affected patients with evidence-based treatments. Unfortunately, only a handful of reports have explored cancer patients' information preferences for learning about sleep treatment. It is critical to investigate help-seeking among cancer patients to improve the clinical management of sleep disorders at oncology centers. We sought to address this key gap by surveying a large cohort of newly diagnosed cancer patients across a range of diagnoses to understand their treatment interest and preferences as it relates to sleep.

Methods

As part of standard clinical care, outpatients at a comprehensive cancer center were asked to complete an electronic biopsychosocial distress screen[7] before they initiated cancer treatment at a routine medical appointment between 2009 and 2016. Patients were aged ≥18 years and completed the screening questionnaire in English, Spanish, or Chinese. This study was approved by the cancer center's Institutional Review Board.

Sample and Measures

The study sample comprised 5671 participants who had been diagnosed with one of eight cancers (hematological malignancy, gastrointestinal cancer, head/neck cancer, prostate cancer, gynecologic cancer, lung cancer, urinary cancer, or prostate cancer). Most patients were female (67.5%), were white (76.9%), had completed some college (71.7%), and had an annual household income of at least $40,000/year (56.0%).

The "*You, Your Family, and the City of Hope are a Team*" distress screen was developed following a literature review and input from patients, families, nurses, and physicians.[8] The distress screen first asks respondents to report on their level of bother specific to a list of 53 commonly experienced physical, psychological, and social problems. The question is presented as "How much of a problem is this for you: ___" and patients are provided five response options, ranging from "not a problem" to "very severe problem." Second, patients are asked "How can we best work with you on this problem?" and must select one of four options: 1) "provide written information"; 2) "talk with a member of the team"; 3) "written information and talk with a member of the team"; 4) "nothing needed at this time." In this study, we examined patient responses to the question about "sleeping." In addition, demographic characteristics were obtained from the survey and the patient's electronic medical record.

Data Analysis

We tabulated interest in receiving further information for their sleep problems in the entire sample and then by reported severity of sleep problems. Consistent with our prior study of sleep problem severity,[9] we classified a patient's sleep problems as being "high" if they endorsed "severe" or "very severe" to the question "How much of a problem is this for you: Sleep?". Conversely, they had "low" sleep problems if they responded "not a problem" or "mild" or "moderate." Univariate logistic regression analyses were performed to examine the association of cancer diagnosis and demographic variables with interest in information about sleep problems that was classified as "any sleep interest" (those who responded "provide written information" or "talk with a member of the team" or "written information and talk with a member of the team") versus those with "no sleep interest" (endorsed "nothing needed at this time"). Finally, we conducted a multivariate logistic regression model including the variables studied in the univariate analyses as predictors, with any interest in receiving further information about sleep problems as the dependent variable. We handled missing data using listwise deletion in all analyses. Statistics were calculated using SPSS 22.0 (IBM Corp, Armonk, NY) using a two-tailed P-value <0.05 to designate statistical significance.

Results

Overall, 34.2% of cancer patients indicated that they had interest in receiving some form of information about their sleep problems, with 14.6% indicating interest in talking with a provider, 9.9% expressing interest in receiving written information alone, and 9.6% wanting written information and also talking with a provider. Patients who were experiencing high sleep problems were statistically more likely than patients experiencing low sleep problems to report interest in receiving further information (66.7% vs. 15.4%; $P < 0.001$). Those experiencing high sleep problems expressed interest in receiving information that included a conversation with a provider (30.6% in talking with a provider, and 21.1% in talking with a provider and getting written information), with 15.0% interested in just receiving written information.

Univariate analyses indicated that compared to breast cancer patients, gastrointestinal cancer patients were more likely to be interested in some form of further information for their sleep problems (odds ratio [OR] = 1.21; $P < 0.05$), while prostate cancer patients were less likely (OR = 0.53; $P < 0.001$). Furthermore, when compared to patients with a high school diploma or less, those who had completed some college education or greater (ORs = 0.62 and 0.71; $P < 0.001$) were less likely to report interest in

further information. When compared to those with a household income $<\$40,000/year$, those with a household income of at least $\$40,000/year$ (ORs = 0.58 and 0.69; $P < 0.001$) were also less likely to report interest in further information. Finally, patients who were female (compared with males; OR = 1.19; $P < 0.001$), were married/had life partner (compared with not married; OR = 0.54; $P < 0.001$), or who self-identified as black (compared with white patients; OR = 1.68; $P < 0.001$) were more likely to be interested in receiving some form of further information for their sleep problems. A multivariate model including cancer diagnosis and demographic variables indicated cancer diagnosis, race, level of education, and annual household income all remained significant predictors of interest in receiving further information about sleep, after adjusting for the other variables (Table 1).

Comment

Before initiating cancer treatment, more than one of every three patients expressed interest in learning

Table 1
Multivariate Logistic Regression Model Incorporating Potential Covariates ($N = 3342$)

	No Sleep Interest, n (%)	Any Sleep Interest, n (%)	Odds Ratio
Diagnosis			
Breast	787 (23.5)	433 (13.0)	Ref
Hematological	172 (5.1)	71 (2.1)	0.79
Gastrointestinal	286 (8.6)	199 (6.0)	1.27
Head and neck	148 (4.4)	64 (1.9)	0.78
Prostate	213 (6.4)	60 (1.8)	0.59[a]
Gynecological	234 (7.0)	132 (3.9)	1.09
Lung	210 (6.3)	121 (3.6)	1.11
Urinary	143 (4.3)	69 (2.1)	0.95
Age			
18−39	135 (4.0)	70 (2.1)	Ref
40−64	1232 (36.9)	720 (21.5)	1.15
≥65	826 (24.7)	359 (10.7)	0.82
Gender			
Male	750 (22.4)	353 (10.6)	Ref
Female	1443 (43.2)	796 (23.8)	0.91
Race			
White	1751 (52.4)	887 (26.5)	Ref
Black	102 (3.1)	96 (2.9)	1.83[b]
Asian	340 (10.2)	166 (5.0)	0.88
Marital status			
Not married	791 (23.7)	431 (12.9)	Ref
Married/life partner	1402 (42.0)	718 (21.5)	1.17
Education			
≤High school diploma	500 (15.0)	361 (10.8)	Ref
Some college or four-year degree	1221 (36.5)	584 (17.5)	0.76[a]
>Four-year degree	472 (14.1)	204 (6.1)	0.81
Annual household income			
<$40,000	831 (24.9)	564 (16.9)	Ref
$40,000−$100,000	771 (23.1)	363 (10.9)	0.75[a]
>$100,000	591 (17.7)	222 (6.6)	0.60[b]

[a]$P < 0.01$.
[b]$P < 0.001$.

more about sleep problems. As expected, patients experiencing significant sleep problems were most eager to learn more, with 82.0% reporting interest in sleep information. In addition, multivariate analysis revealed that black patients were more likely to express this interest than others. By contrast, those diagnosed with prostate cancer and those with greater than a high school education or a household income of $40,000/year or more were less likely to express interest in sleep information.

This enthusiasm for further information about sleep problems is important. Patients may delay seeking medical advice for sleep problems owing to a lack of awareness about the importance of sleep in terms of overall health, a preference for nondrug treatments, or a belief that sleep problems are a natural response to life stressors (such as cancer) and will resolve itself over time. Clinicians have an opportunity to work with cancer patients during a potentially "teachable moment" and can promote overall health improvements that can meaningfully change the quality of patients' lives.

There are limitations of this research. First, findings are drawn from patients seen at a single cancer center and may not reflect the experiences of all cancer patients. Second, we studied a single, nonvalidated item capturing patients' interest in sleep-related information, which neither assessed details about the kind of information or interaction patients preferred (e.g., type of provider, in-person or telephone conversations) nor indicated whether patients accessed treatment. Third, we had limited access to cancer-specific information, such as patient's stage of disease or other health comorbidities. Finally, our data were cross-sectional and we cannot draw a conclusion about if or how the patient's desire for further sleep information might change over the course of their cancer treatment and into survivorship.

We hope that these findings draw greater attention to the significant role that oncology clinicians and other professionals can play in responding to the broad range of health issues that present after a cancer diagnosis. Many patients are interested in learning more about how to manage sleep problems, and although there may be limited expertise in sleep medicine at cancer centers,[10] it is important that these institutions develop evidence-based resources on the topic of sleep to provide to patients and establish a referral network of sleep specialists.

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Prognostication Using SCORTEN Severity of Illness Score in Patients With Stevens Johnson Syndrome and Toxic Epidermal Necrolysis

To the Editor:

Often in cases of severe injury or pathology, unclear prognosis and the lack of availability of concrete mortality measurements make goals-of-care (GOC) discussions with patients and their families difficult. Palliative care providers are sometimes involved in the care of patients with severe dermatological illnesses, such as Steven's Johnson syndrome (SJS) or toxic epidermal necrolysis (TEN), and knowledge of the prognostic tools used in these conditions is helpful. The incidence of SJS is estimated at 1−6 cases/million people, and the incidence of TEN is 0.4−1.2 cases/ million people; the mortality rates are 1%−5% and 25%−35%, respectively.[1] Because of the high mortality and other severe consequences of SJS/TEN, it is necessary to obtain a rapid diagnosis and evaluation of prognosis. Therefore, we describe a case to provide palliative care providers with the knowledge of the SCORTEN illness severity and in-hospital mortality calculator and demonstrate how having such a tool can aid in facilitating GOC discussion, leading to improved prognostication and patient end-of-life care.

Case Description

A 63-year-old woman with a history of myocardial infarction, cardiomyopathy, and hypertension presented to an outside hospital with fatigue and rash while undergoing treatment with doxycycline for a lower extremity cellulitis diagnosed a few days prior. On removal of the patient's clothes for physical examination, her skin sloughed off in sheets over multiple areas of her body. The patient was transferred to our institution's surgical ICU burn unit for suspected SJS and started on ceftaroline and IV fluids.

On arrival at our hospital, the patient was hypotensive, tachycardic, and complaining of 8/10 generalized body pain. Her radial and pedal pulses were absent bilaterally. She had a 1-inch hemostatic wound in the right inguinal region. Her skin examination was notable for diffuse lacy open skin sloughing, exposing raw, red skin on approximately 65% of her total body surface area including her chest, abdomen, groin, buttocks, and back as well as superficial ulcerations of the oral mucosa.

Based on the patient's skin findings in the context of recent exposure to doxycycline, she was diagnosed with TEN. The patient's SCORTEN score was calculated to be 5, receiving one point for each of the following: age >40 years, >10% total body surface area involvement, serum bicarbonate <20 mEq/L, serum BUN >28 mg/dL, and serum glucose >252 mg/dL. Her SCORTEN score of 5 correlated with a >90% chance of in-hospital mortality.

Unfortunately, despite interdisciplinary effort, the patient's clinical condition continued to worsen. Her last set of vital signs included a blood pressure of 40/30, despite maximum presser support, a temperature of 93.0 F, and staff were unable to obtain a pulse oximetry reading. Palliative care was consulted at this time, and a GOC discussion was held with the patient's family, the palliative care team, and the burn team. After review of the patient's clinical condition and prognosis via the SCORTEN assessment given, the patient's code status was changed to DNR and comfort care measures were ordered. Soon after this conversation, the patient developed ventricular tachycardia, asystole, and then expired, just over 24 hours from initial presentation, with her family at her bedside.

Comment

The SCORTEN severity of illness score was developed and validated to evaluate the risk of in-hospital death in patients diagnosed with TEN.[2] Though originally developed only for use in patients with TEN, it is now additionally used for burn victims and patients with other cutaneous drug reactions or exfoliative wounds.[3] It was developed using data from 165 patients and was then validated on an additional sample of 75 patients.[2] This score uses seven independent risk factors to aid in predicting in-hospital mortality in patients diagnosed with these severe skin reactions.[2] These risk factors are age above 40 years, presence of malignancy, tachycardia above 120 bpm, greater than 10% of epidermal detachment at admission, serum urea nitrogen level above 10 mmol/L, serum glucose level above 14 mmol/L, and bicarbonate level below 20 mmol/L. Patients get one point for each of these risk factors, and that score is correlated with a percentage of likely in-hospital mortality.[2] This score is quick and simple enough to calculate at the patient's bedside after initial venipuncture. This can then expedite and direct course of care for very sick patients.

Since the development of the SCORTEN scale, there have been several studies that have attempted