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Evaluation and treatment of insomnia in adult cancer survivorship programs

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Abstract

Purpose—Insomnia is commonly experienced by cancer survivors. Chronic insomnia is associated with significant physical and psychosocial consequences if not properly treated. Both the National Cancer Institute (NCI) and the National Comprehensive Cancer Network (NCCN) recommend the evaluation of sleep disturbances and evidence-based treatment of insomnia during routine survivorship care. To better understand current clinical practices, we conducted a survey of major cancer centers across the United States (US).

Methods—Adult survivorship programs at the 25 US cancer centers that are both NCI-designated comprehensive cancer centers and NCCN member institutions were surveyed about the evaluation and treatment of insomnia in their hospital.

Results—All institutions responded to the survey. Thirteen centers (56 %) reported screening <25 % of survivors for sleep disorders, and few clinicians providing survivorship care were well-prepared to conduct a proper sleep evaluation. Insomnia was most commonly treated with sleep hygiene, or pharmacotherapy, rather than cognitive-behavioral therapy. No program reported that >50 % of their survivors were receiving optimal insomnia-related care. A variety of methods to improve insomnia care were endorsed by respondents.

Conclusions—There is a clear need to improve the evaluation and treatment of insomnia for cancer survivors at institutions across the country. Cancer centers deemed a number of modalities relevant for improving provider confidence in addressing sleep challenges.

Implications for cancer survivors—To improve the quality of insomnia care for survivors, systematic interventions to increase standardized screening for sleep disorders, providing additional sleep medicine training for survivorship clinicians, and optimizing the role of sleep medicine specialists in the oncology setting should be considered.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval This article does not contain any studies with human participants or animals performed by any of the authors.

Keywords

Insomnia; Sleep disorders; Cancer survivorship; Oncology; Evaluation and treatment

Introduction

A cancer diagnosis and subsequent treatment are known to exacerbate pre-existing sleep problems and to precipitate new sleep disturbances [1–4]. Prevalence estimates of insomnia symptoms (characterized by difficulty with falling or staying asleep and/or poor sleep quality [5]) in cancer survivors range from 18 to 68 % [6–9]. Without proper treatment, insomnia often becomes chronic [10, 11] and has been associated with a range of physical and psychosocial consequences (e.g., fatigue, pain, depression, etc.) in a population already at high risk for health comorbidities [12–18].

As there are significant health consequences related to untreated insomnia, both the National Cancer Institute (NCI) and the National Comprehensive Cancer Network (NCCN) encourage cancer survivors to discuss chronic sleep disruptions with their medical team during the course of routine survivorship care [19]. Further, the NCCN provides survivorship care guidelines for evaluating sleep disorders and encourages the use of evidence-based therapy in the treatment of insomnia [20]. Specifically, cognitive-behavioral therapy for insomnia (CBT-Insomnia) is encouraged due to the convincing body of evidence demonstrating its efficacy in cancer populations [21–26]. NCCN guidelines supporting the use of CBT-Insomnia are in line with the American College of Physicians, which strongly “recommends that all adult patients receive CBT-I as the *initial* treatment for chronic insomnia disorder” [27]. However, it is possible that adherence to these carefully designed guidelines may not be occurring in practice, with evidence suggesting that sleep problems are frequently overlooked by both cancer survivors and their medical team [28] as they often see insomnia “as a temporary reaction to the cancer diagnosis or treatment” [9].

We sought to better understand current clinical practice for evaluating and treating insomnia at cancer centers in the United States (US). To accomplish this, we examined available sleep-related patient care at institutions where both NCI and NCCN guidelines would be most likely to be routinely disseminated as part of the routine survivorship care. Specifically, we evaluated the available resources and clinical practices for the evaluation and treatment of insomnia at cancer centers that have received NCI designation as a comprehensive cancer center and are an NCCN member institution.

Methods

A total of 45 NCI-designated comprehensive cancer centers and 26 NCCN member institutions were identified upon review of their respective websites in October 2015 (NCI, <http://www.cancer.gov/research/nci-role/cancer-centers/find>; NCCN, <http://www.nccn.org/members/network.aspx>). Of these, 25 centers located across 19 states were concurrently NCI-designated comprehensive cancer centers and NCCN member institutions (Table 1). The contact information for the Program Director of the Adult Survivorship Program at each

center was acquired through the hospital's website or a telephone call to the hospital's primary phone number.

A 6-item survey was developed by the current study authors to better understand the availability of resources and standard practice for the evaluation and treatment of sleep disorders, with a focus on insomnia (Table 2). Recognizing that individual clinician practices may vary considerably, the survey was sent to the Adult Survivorship Program Director at each institution in order to collect a broad view of current practice. S/he was asked to report their best estimate of screening practices for sleep disorders, availability of providers specializing in sleep medicine, treatment practices for patients reporting insomnia symptoms, and how their cancer center could improve the care that adult cancer survivors were receiving for sleep-related problems. If the Program Director were not confident in their knowledge of practice at their respective institution, they were asked to nominate another individual at their center with sufficient awareness to accurately complete the survey. This occurred at one institution, with a patient navigator affiliated with the center's survivorship resource program assisting the Program Director in survey completion. This study was approved by the IRB at the first author's cancer center.

A paper copy of the survey was initially mailed to each Program Director in November 2015, with a total of nine centers responding. A second mailing was made to non-responding centers 1 month later, resulting in seven additional returned surveys. One month after the second mailing, a link to a Qualtrics online survey was emailed to the remaining non-responders, with email reminders sent approximately every 2 weeks thereafter until all remaining surveys were completed 3 months after the initial survey mailing (February 2016). Data from the returned questionnaires were de-identified and analyzed in Microsoft Excel.

Results

Overall

All 25 centers responded to the survey. Overall, there was not a single cancer center which reported that at least 50 % of their cancer survivors were receiving optimal treatment for their insomnia (question 5, Table 2). Further, almost two thirds (64 %) reported that fewer than 25 % of their survivors were receiving optimal treatment (Table 2).

Screening practices, provider confidence, and access to sleep specialists

Thirteen survivorship programs (56 %) screened less than 25 % of their patients, and seven programs (30 %) routinely screened fewer than 10 % (question 1, Table 2). The majority of the centers (18, 72 %) lacked on-site access to a provider specializing in the treatment of sleep disorders (question 4, Table 2) and were not confident that medical providers at their center were prepared to conduct a full sleep evaluation (12, 48 %, question 2, Table 2). If a survivor reported insomnia symptoms, four respondents (16 %) believed typical survivorship providers at their institution were well-prepared to treat the insomnia (question 2, Table 2). The most common treatments provided to a survivor with insomnia were sleep hygiene or prescription of sleep medications. In 11 survivorship programs (46 %), patients were treated

with sleep hygiene at least 50 % of the time; in 10 survivorship programs (43 %), patients received pharmacotherapy as treatment more than half of the time (question 3, Table 2). Despite the reported availability of trained providers at 14 of 22 (64 %) cancer centers (question 4, Table 2), only 13 % of centers referred to CBT-Insomnia more than half of the time (question 3, Table 2).

Improving provider confidence

A variety of methods were viewed as being potentially helpful for improving the medical team's confidence in the assessment and treatment for sleep disorders (question 6, Table 2). The vast majority of centers indicated that it would be somewhat helpful or very helpful for their medical team to develop patient education materials (80 %) or a web page with information about sleep disorders and treatment (76 %), offer an in service for providers focused on the evaluation and treatment of sleep disorders (72 %), access to an on-site consult service providing pharmacotherapy for sleep disorders (68 %), and access to an on-site consult service providing cognitive-behavioral treatment for sleep disorders (88 %) or an online intervention providing treatment for sleep disorders (80 %).

Discussion

Insomnia is one of the most common long-term sequelae of a cancer diagnosis and subsequent treatment, with significant and detrimental health consequences if it is not properly addressed. Our survey indicates that insomnia in cancer survivors is not being adequately identified and treated during survivorship care. It was striking that there was not a single cancer survivorship program which believed that even half of their survivors were receiving optimal treatment for their insomnia. This finding is less surprising given that most centers reported medical providers at their institution are not well-prepared to conduct a sleep evaluation or provide informed treatment for insomnia. Limitations in provider knowledge and experience may explain why most patients with insomnia in these clinics received treatments that are ineffective as monotherapy (sleep hygiene [29, 30]) or are more appropriate as a short-term solution (pharmacotherapy [31, 32]) rather than empirically supported treatments recommended by NCCN survivorship care guidelines and the American College of Physicians as front-line therapy (CBT-Insomnia [27]).

Oncology providers caring for cancer survivors with insomnia are placed in a challenging position. Not only is it unlikely that a cancer survivor will initiate discussion of insomnia [28, 33] but these providers are asked to treat a sleep disorder that they may not have been fully trained to evaluate or care for [34, 35]. This presents a crucial opportunity for intervention, and across the country, survivorship programs viewed multiple systematic intervention opportunities, requiring a minor investment of time and expense, as being potentially helpful ways to appreciably improve their providers' level of confidence to screen for sleep disorders and to refer to appropriate treatment resources (e.g., development of websites/handouts that educate clinicians about sleep disorders and provider in-service/grand rounds). Evidence from other medical specialty areas indicates brief trainings in sleep medicine can be very effective at improving provider knowledge and subsequent clinical practice [36–38]. Such trainings could be adapted to the specific needs of those caring for

cancer survivor, and highlighting the many negative consequences of sleep difficulties for patients would likely increase a provider's awareness of the importance of properly treating insomnia. This may help to address the notable gap that exists between the reported availability of an on-site CBT-Insomnia specialist at many cancer centers with the few survivors who ultimately are referred to these providers. Novel methods to deliver CBT-Insomnia in cancer populations via group, self-help, video, and telehealth approaches may further address this issue [24, 25, 39–41].

There are limitations to the current study which are acknowledged. Twenty-five institutions where we believed NCI and NCCN care guidelines most likely to be disseminated were surveyed. Further, one individual in a leadership position at each institution responded to the survey, and they were asked to provide global and retrospective information. Their responses may be influenced by a social desirability and a recall bias, and thus, our findings may not reflect the current practice at every cancer center in the US, nor the individual practice of every survivorship provider. However, we note that the surveyed cancer centers are some of the better-resourced institutions and the respondents are likely to view their colleagues and home institutions favorably. Therefore, the findings are compelling and may represent the tip of the iceberg with respect to how many survivorship programs in the US may be struggling with consistently evaluating and treating sleep disorders in clinical practice. Future research should consider surveying “frontline” medical and mental health providers to determine their experiences in delivering sleep-related services in the context of survivorship care at a range of institutions and also examine the impact of delivering interventions focused on improving a survivorship provider's knowledge about sleep-related issues on the quality of patient care for insomnia.

As the short- and long-term side effects of cancer often play a fundamental role in the development and/or persistence of insomnia, cancer survivorship programs must pay greater attention to this important health issue [42, 43]. In order to deliver the highest quality survivorship care, many institutions would benefit from developing core resources for their providers with information about sleep disorders and highlighting sleep consult referrals and delivering routine trainings about the evaluation and treatment of common sleep disorders in cancer populations.

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Table 1

Institutions surveyed for their treatment of insomnia

Institution	City	State
University of Alabama at Birmingham Comprehensive Cancer Center	Birmingham	AL
City of Hope Comprehensive Cancer Center	Duarte	CA
UC San Diego Moores Cancer Center	San Diego	CA
UC San Francisco Helen Diller Family Comprehensive Cancer Center	San Francisco	CA
Stanford Cancer Institute	Stanford	CA
University of Colorado Cancer Center	Aurora	CO
Yale Cancer Center	New Haven	CT
Moffitt Cancer Center	Tampa	FL
Robert H. Lurie Comprehensive Cancer Center of Northwestern University	Chicago	IL
Dana-Farber/Brigham and Women's Cancer Center	Boston	MA
Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins	Baltimore	MD
University of Michigan Comprehensive Cancer Center	Ann Arbor	MI
Mayo Clinic Cancer Center	Rochester	MN
Siteman Cancer Center at Washington University School of Medicine	St. Louis	MO
Duke Cancer Institute	Durham	NC
Roswell Park Cancer Institute	Buffalo	NY
Memorial Sloan Kettering Cancer Center	New York	NY
Case Comprehensive Cancer Center/Seidman Cancer Center	Cleveland	OH
The Ohio State University Comprehensive Cancer Center	Columbus	OH
Fox Chase Cancer Center	Philadelphia	PA
St. Jude Children's/University of Tennessee Health Science Center	Memphis	TN
Vanderbilt-Ingram Cancer Center	Nashville	TN
University of Texas MD Anderson Cancer Center	Houston	TX
Huntsman Cancer Institute at the University of Utah	Salt Lake City	UT
Fred Hutchinson Cancer Research Center	Seattle	WA

Table 2

Evaluation and treatment of insomnia in cancer survivorship programs

Question	Number of programs	Percent
1. As part of routine clinical care, what percentages of survivors are routinely screened for sleep disorders? (<i>n</i> = 23)		
Less than 10 %	7	30.4
10–25 %	6	26.1
26–50 %	0	0.0 line up numbers
51–75 %	0	0.0 line up numbers
More than 75 %	10	43.5
2. When a survivor reports insomnia symptoms, how prepared would the typical medical provider at your cancer center feel to: (<i>n</i> = 25)		
<i>To conduct sleep evaluation</i>		
Not at all prepared	12	48.0
A little prepared	3	12.0
Somewhat prepared	8	32.0
Very prepared	2	8.0
<i>To treat insomnia</i>		
Not at all prepared	2	8.0
A little prepared	11	44.0
Somewhat prepared	8	32.0
Very prepared	4	16.0
3. When a survivor reports insomnia symptoms during a visit, what proportion of these patients will receive:		
<i>Prescription sleep medication (n = 23)</i>		
Less than 10 %	4	17.4
10–25 %	3	13.0
26–50 %	6	26.1
51–75 %	7	30.4
More than 75 %	3	13.0
<i>Sleep hygiene discussion (n = 24)</i>		
Less than 10 %	5	20.8
10–25 %	4	16.7
26–50 %	4	16.7
51–75 %	5	20.8
More than 75 %	6	25.0
<i>Referral to cognitive-behavioral treatment for insomnia (n = 24)</i>		
Less than 10 %	7	29.2
10–25 %	11	45.8
26–50 %	3	12.5
51–75 %	2	8.3
More than 75 %	1	4.2
<i>Referral to a psychiatrist (n = 22)</i>		
Less than 10 %	14	63.6
10–25 %	6	27.3

Question	Number of programs	Percent
26–50 %	1	4.5
51–75 %	1	4.5
More than 75 %	0	0.0
<i>Referral to a primary care provider (n = 24)</i>		
Less than 10 %	4	16.7
10–25 %	8	33.3
26–50 %	3	12.5
51–75 %	6	25.0
More than 75 %	3	12.5
<i>Referral for a sleep study (n = 22)</i>		
Less than 10 %	12	54.5
10–25 %	5	22.7
26–50 %	4	18.2
51–75 %	1	4.5
More than 75 %	0	0.0
4. Do medical providers at your cancer center have access to a provider that specializes in:		
<i>Treatment of sleep disorders (n = 25)</i>		
Cancer center	8	32.0
Affiliated hospital	11	44.0
Community referral	4	16.0
Not available	3	12.0
<i>Cognitive-behavioral treatment for insomnia (n = 22)</i>		
Cancer center	14	63.6
Affiliated hospital	3	13.6
Community referral	2	9.1
Not available	3	13.6
5. What percentages of survivors at your cancer center are receiving what you consider to be optimal treatment for their insomnia? (n = 22)		
Less than 10 %	3	13.6
10–25 %	11	50.0
26–50 %	8	36.4
51–75 %	0	0.0
More than 75 %	0	0.0
6. To improve your medical team's confidence in discussing sleep-related issues with cancer survivors, how helpful would ___ be? (n = 25)		
<i>Patient education materials</i>		
Not helpful	1	4.0
A little helpful	4	16.0
Somewhat helpful	8	32.0
Very helpful	12	48.0
<i>Informational web page</i>		
Not helpful	1	4.0
A little helpful	5	20.0
Somewhat helpful	8	32.0

Question	Number of programs	Percent
Very helpful	11	44.0
<i>In-service/grand rounds</i>		
Not helpful	3	12.0
A little helpful	4	16.0
Somewhat helpful	8	32.0
Very helpful	10	40.0
<i>On-site pharmacotherapy consult service</i>		
Not helpful	3	12.0
A little helpful	5	20.0
Somewhat helpful	8	32.0
Very helpful	9	36.0
<i>On-site cognitive-behavioral treatment consult service</i>		
Not helpful	1	4.0
A little helpful	2	8.0
Somewhat helpful	11	44.0
Very helpful	11	44.0
<i>Online intervention</i>		
Not helpful	2	8.0
A little helpful	3	12.0
Somewhat helpful	12	48.0
Very helpful	8	32.0