




# When Cancer Centers Snooze, Patients Lose: It is Time to Make Insomnia a Priority for Survivors

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## INSOMNIA CAN NO LONGER BE OVERLOOKED

Cancer survivors consistently report poor sleep as one of the most problematic issues impairing quality of life. The prevalence of poor sleep can be as high as 59%.<sup>1,2</sup> Racial/ethnic minorities and those from a lower socioeconomic background are at even greater risk for sleep problems.<sup>3</sup> Poor sleep is more prevalent among cancer populations than in the general population because they are exposed to many factors that can disrupt sleep (eg, pain after surgery, hospitalizations disturb circadian rhythms, side effects of steroid medications).

The most common sleep disorder among cancer survivors is insomnia.<sup>4</sup> It is characterized by  $\geq 3$  months of difficulty in falling and/or staying asleep. If untreated, sequelae include increased anxiety, depression, fatigue, and cognitive disturbances.<sup>5</sup> More troubling, both objectively and subjectively measured insomnia outcomes have been linked with an increased risk for the development of cancer,<sup>6</sup> disease progression, and mortality.<sup>7</sup>

## INSOMNIA REMAINS A BLIND SPOT

The National Comprehensive Cancer Network's (NCCN) Survivorship Guidelines provide clear direction on how to identify sleep disorders, such as insomnia.<sup>8</sup> Unfortunately, <50% of survivorship programs in National Cancer Institute–designated comprehensive cancer centers routinely screen for sleep disorders among survivors.<sup>9</sup> The lack of sleep disorder screening stems from barriers at the patient, provider, and institutional levels. Patients and providers understandably prioritize cancer-directed treatments, followed by concerns related to acute discomfort (eg, pain). In addition, both patients and providers tend to mistakenly perceive insomnia as an inevitable consequence of cancer, which is of limited consequence and will self-resolve. In addition, without sufficient knowledge about nonpharmacologic treatment options for sleep disorders, many providers are hesitant to bring up sleep; one in three oncologists and 58% of oncology nurses report that they never ask their patients about sleep after a cancer diagnosis.<sup>10,11</sup> This lack of attention to insomnia feeds into the patient's perception that it is simply not important enough to be on the agenda during follow-up visits.<sup>12</sup> Consequently, fewer than one in five patients with cancer struggling with their sleep will bring this issue up with their oncology team.<sup>10</sup> At the institutional level, key barriers include administrative issues such as lack of familiarity with insurance coverage for sleep services and the need for prioritizing resources such as clinical space.<sup>12</sup>

One treatment barrier for a patient with insomnia is having to seek care in another setting (eg, an affiliated hospital or with a community-based provider), rather than within the same institution. As cancer survivors place a great deal of trust in the providers and institution that they view as having saved their lives, it is important that cancer centers implement more consistent screening practices and offer on-site treatment access for their cancer survivors with insomnia.

## EVIDENCE-BASED TREATMENTS FOR INSOMNIA EXIST, BUT ARE WIDELY UNAVAILABLE

Cognitive-behavioral therapy for insomnia (CBT-I) is a multicomponent treatment that has been consistently supported by randomized trials to be an effective and durable treatment for insomnia in the general population and cancer survivors.<sup>13</sup> It comprises sleep restriction, stimulus control, cognitive therapy, sleep hygiene, and relaxation training. Because cancer



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survivors may experience sleep-related challenges that are different from the general population (eg, treatment late effects), it may be beneficial to tailor standard CBT-I strategies for the cancer care setting.<sup>14</sup>

In addition to improved sleep, treatment with CBT-I also improves anxiety, depression, fatigue, and quality of life among cancer survivors with insomnia. NCCN Survivorship Guidelines recommend CBT-I as the preferred treatment for cancer survivors with insomnia disorder, consistent with the general population guidelines from the American Academy of Sleep Medicine (AASM).<sup>15</sup> Unfortunately, when a cancer survivor presents with insomnia disorder, they are typically offered sleep hygiene education and/or sleep medications, rather than CBT-I. Sleep hygiene describes behavioral and environmental changes that can support sleep, with common recommendations including the reduction of caffeine intake, sleeping in a dark bedroom, and limiting electronics use in the evening. However, while useful as part of CBT-I, sleep hygiene has been demonstrated to be ineffective when used alone. The AASM advises *against* its use for insomnia disorder because it can potentially discourage patients from seeking evidence-based care.<sup>15</sup>

In addition to CBT-I, there is a developing evidence base for other integrative therapies for insomnia among cancer survivors. These include meditative (eg, mindfulness-based interventions, yoga, qigong/tai chi) and body-based therapies (eg, acupuncture, acupressure, massage, reflexology).<sup>16</sup>

In the late 1980s, the use of psychotropic medications for oncology patients increased significantly because of their ability to improve mental health and to manage co-occurring symptoms of cancer-directed therapy (eg, lorazepam is beneficial for anxiety and can help reduce nausea). While prescription sleep aids play an important role after diagnosis and during treatment, concerns remain regarding long-term use in cancer survivors, including medication side effects and an increased risk of fractures, and the possibility of developing tolerance to or dependence on these medications.

## A FEASIBLE APPROACH TO INTRODUCE INSOMNIA CARE

To bring our current model of care for insomnia in cancer survivors into alignment with the NCCN Survivorship Guidelines will require a thoughtful approach to ensure its sustainability. Below, we describe our efforts to develop and maintain a program designed to treat cancer survivors with insomnia disorder, in hopes that these experiences can support the introduction of better care for insomnia among cancer survivors at other institutions.

### Identify a Sleep Champion

Identifying a champion, often an existing provider at the institution with a strong interest in and commitment to a particular domain, has been advised for supportive care services for cancer survivors to promote quality palliative

care treatment and clinical trial enrollment in oncology. At our institution, a study author (E.S.Z.) was trained in both cancer survivorship and behavioral sleep medicine. His efforts to systematically address deficits in insomnia care for survivors were supported by program leaders in childhood (C.J.R.) and adult (A.H.P.) cancer survivorship. At your institution, a starting point may be to determine whether there is currently a faculty member with a training background or with clinical research interests in behavioral sleep medicine. This will often be someone with a background in mental health (eg, clinical psychologists, social workers, and psychiatrists).

### Find a Program Home

Although many cancer centers are organized by disease center (eg, breast), insomnia cuts across all diagnoses and requires leadership in different programs to work together. The structure of sleep services embedded within a program home will likely depend on the size of the institution and its patient base, as well as the preferences of the oncology treatment teams for the provision of supportive care services. Depending on the sleep champion's program affiliation, it may be most reasonable to start by providing services to that program's patients, before considering an expansion to other disease groups. It may also be helpful to consult with other services, such as palliative care or nutrition, whose work also cuts across disease centers to understand their internal processes for care provision for the broader patient population. At our center, we found a natural home in the Adult Survivorship Program at the Dana-Farber Cancer Institute as it was designed to not only help survivors manage the risk of morbidity and mortality after cancer and its treatment but also to understand and remedy the long-term effects of treatment, including their social and psychological concerns. This program comprises a multidisciplinary team, and the pre-existing diversity of this team's expertise made the introduction of a new subspecialty (behavioral sleep medicine) an easier process.

### Demonstrate Prevalence and a Desire for Evidence-Based Treatment

Screening for insomnia should occur at routine intervals (eg, at the patient's first visit to establish a baseline and then every 6 months thereafter) as insomnia symptoms can evolve over time.<sup>1</sup> This can be accomplished with tools like the Insomnia Severity Index (ISI),<sup>17</sup> a seven-item self-report measure that we have validated among cancer survivors. If an even briefer scale is desired, a three-item version of the ISI may be adequate.<sup>18</sup> With hospitals more broadly implementing electronic screening, there are potential opportunities to evaluate for sleep disturbances in a more consistent manner.<sup>3</sup> Notably, insomnia is one of the symptoms of the Patient-Reported Outcomes of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)<sup>19</sup> and could be included in an institutional symptom screening and management program, if the ISI is not desired. Should a survivor

suffer from a sleep-related impairment, it is clear that the majority do not want their cancer center to ignore the issue: 82% of survivors struggling with their sleep wanted more information on the subject.<sup>20</sup> Institutional leaders may be more likely to be influenced by reports that survivors at their center expect to have access to evidence-based insomnia care. Demonstrating this by asking about preferences for insomnia treatment in a convenience sample of survivors receiving care at a survivorship clinic or including insomnia as part of an institution's overall screening program could be an important step toward receiving a financial commitment to establish a sleep clinic. Finally, it is important to acknowledge that while insomnia disorder is the most common sleep disorder among cancer survivors, other sleep disorders (eg, sleep apnea) do routinely present in survivor populations and can be screened for with other self-report measures.<sup>21</sup>

### Providing Proof of Efficacy

While positive results from many randomized trials for CBT-I have been published over the past 15 years,<sup>13</sup> the inclusion of sleep-related services in an oncology setting is relatively novel. It may be that hospital leaders wish to see proof that treatments for sleep disorders, such as insomnia, are effective at their center. If one of the institutional barriers is the extent of the clinical resources that need to be dedicated to delivering standard CBT-I (six sessions), there are alternatives that can be considered. In testing novel CBT-I delivery strategies at our center, we have found that interventionist-led programs of varying intensities were all efficacious among cancer survivors. These programs ranged from a single education session to three-session individual protocols that were delivered via telehealth, in a group setting, and via a stepped care approach. Similar work, with similar outcomes, has been conducted at other institutions.<sup>22,23</sup> While fully automated computer interventions are efficacious, treatment completion rates may be an issue<sup>24</sup>; thus, they are not advised as the sole program offering at the present time. However, as researchers refine and improve user engagement with computer/app-based health interventions, the role of digital insomnia treatment programs as part of survivorship care could increase in the future.

### Identify Trusted Collaborative Providers

#### *Behavioral Sleep Medicine Expert*

The core provider of an insomnia clinic should be an individual with expertise in behavioral sleep medicine. To support the cancer center-based behavioral medicine expert, collaborators in psychiatry and sleep medicine are needed to optimize care for patients with insomnia. As more than 40% of cancer survivors receive a prescription for a

sleeping medication after their cancer diagnosis, cancer survivors are likely to benefit from the expertise of psychiatrist who specializes in psycho-oncology to evaluate their need for sleep medicines. Similarly, board-certified sleep medicine providers with expertise in interpreting sleep studies will be useful for patients who present with sleep disorders such as obstructive sleep apnea, which should be treated in conjunction with their insomnia therapy. While psychiatry and sleep medicine collaborators need not be on site at the cancer center, providers within the same medical system may be preferred as they likely share a common electronic medical record. This will increase the likelihood that a patient's oncology providers will be able to see records of these appointments and also eliminate a barrier to the patient seeking appropriate follow-up care.

### Planning for Reimbursement

Fully understanding insurance reimbursement for sleep-related services is vital for its viability as a patient service, especially at centers that are not highly resourced. In particular, it will be important for administrators to determine how well mental health services are reimbursed at their institution. This is because insomnia disorder (F51.01) is considered a mental health code, and the behavioral sleep medicine expert is often a clinical psychologist. Favorable agreements negotiated with private insurance payers are key to financial viability and are especially crucial as public reimbursement rates (eg, Medicare) for mental health services have declined over the past several decades after adjusting for inflation. A good starting point for these conversations is with the department that processes insurance billing for mental health services. The billing partner can work with administrators to explore reimbursement and denial rates. There are often a great deal of variability and lack of clear explanation in the reimbursement/denial process, so understanding total financial recovery could be essential for some centers to assess the financial feasibility of hiring a clinician with sleep-related expertise. As reimbursement rates for the same billing codes change over time, administrators should routinely track reimbursement rates by billing code and diagnosis code across individual insurers.<sup>25</sup>

In conclusion, insomnia has a profound impact on the overall health of cancer survivors. It should be prioritized throughout the cancer treatment trajectory and into survivorship care to insure their long-term well-being. With growing public awareness of the importance of sleep, cancer survivors will likely come to expect a sleep expert be a part of their survivorship care team. It is encouraged that cancer centers across the United States begin to consider what steps should be taken within their individual setting so that they can prioritize sleep health of their cancer survivors.

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