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## Insomnia among Cancer Caregivers: A Proposal for Tailored Cognitive Behavioral Therapy

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### Abstract

Caregivers are relatives, friends, or partners who have a significant relationship with and provide assistance (i.e., physical, emotional) to a patient with often life-threatening, serious illnesses. Between 40 and 76 percent of caregivers for people with cancer experience sleep disturbance. This is thought to be due, in part, to the unique responsibilities, stressors, and compensatory behaviors endemic to caregiving that serve as precipitating and perpetuating factors of insomnia. Sleep disturbances are associated with significant alterations in one's mental and physical health. Once chronic, insomnia does not remit naturally. Cognitive-behavioral therapy for insomnia (CBT-I) is well-suited to address the multifaceted contributing factors unique to caregivers' sleep disturbance, yet only one intervention has tested a CBT-I informed intervention among cancer caregivers. Toward the goal of developing effective, tailored treatments for insomnia in caregivers, we address the distinct presentation of insomnia among cancer caregivers and describe key modifications to standard CBT-I that address these specific needs and enhance sensitivity and feasibility, modeled in a demonstrative case vignette. Future research must seek to provide a wide range of effective treatment options for this population, including internet-based, dyadic, and alternative integrative medicine treatments. Applicability of key modifications for caregivers of patients with other chronic illnesses is discussed. Establishing empirically-supported interventions for insomnia among cancer caregivers has the potential to enhance their quality of life and care provided, lead to improved bereavement outcomes, and attenuate the notable mental and physical health disparities present in this vulnerable population.

### Keywords

Family Caregiver; Cancer; Cognitive Behavioral Therapy; Sleep Initiation and Maintenance Disorders; Integrative Medicine

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Sleep disturbances, primarily in the form of insomnia, are an especially important but frequently overlooked consequence of providing care to a loved one with chronic medical conditions. Informal caregivers are relatives, friends, or partners who have a significant

relationship with and provide assistance (i.e., physical, emotional) to a patient with often life-threatening, serious illnesses (National Alliance for Caregiving [NAC], 2015). Responsibilities, stressors, and compensatory behaviors endemic to the caregiving role can serve as precipitating and perpetuating factors of insomnia. Caregivers for patients with cancer show higher rates of clinically significant sleep disturbance than the general population (Schutte-Rodin, Broch, Buysse, Dorsey, & Sateia, 2008; Skalla, Smith, Li, & Gates, 2013), caregivers for patients with other severe illnesses (Happe, Berger, & Investigators, 2002; Lou et al., 2015), and even patients with cancer themselves (Morris et al., 2015). Sleep disturbance significantly contributes to caregivers' anxiety, depression, and decreased quality of life (QOL) (Carter, 2002; Carter, 2003; Carter & Chang, 2000; Morris et al., 2015), and can impair the normal grieving process and contribute to prolonged grief disorder (Ford & Cooper-Patrick, 2001).

Despite the pressing need to address sleep disturbance among cancer caregivers, only one study has examined an intervention to improve insomnia in this population (Carter, 2006). Given caregivers' unique psychosocial needs, preferences, and limitations in engaging supportive services, developing effective, tailored treatments for caregivers' insomnia represents a critical research priority for our field. Toward that goal, we discuss the distinct presentation of insomnia among cancer caregivers and describe key modifications to standard CBT-I to better meet these caregivers' specific needs.

## Caregiving for a Family Member with Cancer

Of the estimated 43.5 million American caregivers in 2016, cancer represented the fourth most frequent problem affecting care recipients, with roughly three million Americans providing care to a person with cancer (NAC, 2015, 2016). This figure is expected to rise, given the aging U.S. population and the shifting of cancer care from inpatient to outpatient settings (Gao et al., 2013; Higginson & Sen-Gupta, 2000). Cancer caregiving is uniquely challenging due to the combination of acute and chronic stressors (NAC, 2016; Kim & Schulz, 2008). A majority of cancer caregivers have high caregiving burden, spending 33 hours per week on average providing direct care and assisting with two to three activities of daily living (ADLs). The most frequent of these tasks include assisting with dressing, toileting, and mobility (NAC, 2016). Moreover, caregiving burden and complexity increases with the severity of illness (Applebaum, Bevans, et al., 2016; Applebaum, Kryza-Lacombe, et al., 2016). Beyond direct involvement in cancer care, caregivers also support patients by providing transportation to appointments, overseeing their day-to-day errands and chores, and serving as the emotional bedrock for the patient and their extended social networks. As such, it is unsurprising that many caregivers report feeling as though they are "on call" 24 hours per day, naturally causing disruption to their typical schedules and roles (Kim & Spillers, 2010).

These stressors associated with providing cancer care are known to place a toll on caregivers' own mental and physical health. Although most cancer caregivers adapt and cope effectively with their new role (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Pitceathly & Maguire, 2003), between 10 and 53 percent report clinically significant symptoms of depression and approximately 16 to 56 percent report clinically significant

symptoms of anxiety, rates that are higher than those reported among patients with cancer (Askari, Madgaonkar, & Rowell, 2012; Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Clavarino, Lowe, Carmont, & Balanda, 2002; Cliff & Macdonagh, 2000; Covinsky et al., 1994; Hudson, Thomas, Trauer, Remedios, & Clarke, 2011; Rhee et al., 2008). Caregivers also show premature physical health decline relative to demographically similar non-caregivers (Cora, Partinico, Munafò, & Palomba, 2012; Ji, Zöller, Sundquist, & Sundquist, 2012; Miller, Cohen, & Ritchey, 2002; Rohleder, Marin, Ma, & Miller, 2009), with distressed caregivers showing the most significant risk for morbidity (Kim, Carver, Shaffer, Gansler, & Cannady, 2015; Rohleder et al., 2009; Schulz & Beach, 1999).

## Sleep Disturbance among Caregivers for Patients with Cancer

Insomnia is perhaps the most common, distressing, and impairing psycho-physiological outcome experienced by cancer caregivers (Skalla et al., 2013), with between 40 and 76 percent reporting clinically significant sleep disturbance (Anand Dhruva et al., 2012; Carney et al., 2011; Lee, Yiin, Lu, & Chao, 2015; Morris et al., 2015). Such rates are higher than those reported among patients with cancer (Carney et al., 2011; Goren, Gilloteau, Lees, & Dacosta Dibonaventura, 2014; Langford, Lee, & Miaskowski, 2012) and the general population (Schutte-Rodin et al., 2008). Caregivers show several impaired sleep characteristics, including suboptimal sleep duration, lengthened sleep latency, frequent awakenings, daytime sleepiness, and poor self-rated sleep quality (Anand Dhruva et al., 2012; Carney et al., 2011; Lee et al., 2015; Pawl, Lee, Clark, & Sherwood, 2013).

Insomnia among cancer caregivers has been associated with aggravated psychological and physical health problems, including increased psychological distress (Morris et al., 2015), depression (Carter, 2003), poor QOL (Carter & Acton, 2006), and decreased immune functioning (Damjanovic et al., 2007). These cross-sectional findings align with longitudinal research among the general population, in which sleep disturbance has been found to play an important role in the onset and maintenance of depression (Baglioni et al., 2011; Bouwmans, Conradi, Bos, Oldehinkel, & De Jonge, 2017) and anxiety disorders (Alvaro, Roberts, & Harris, 2013; Neckelmann, Mykletun, & Dahl, 2007). Moreover, insomnia is prospectively associated with development of cardiovascular disease (Mallon, Broman, & Hetta, 2002; Phillips & Mannino, 2007), obesity (Buxton & Marcelli, 2010; Wu, Zhai, & Zhang, 2014), diabetes (Buxton & Marcelli, 2010; Gottlieb et al., 2005), and all-cause mortality (Cappuccio, D'elia, Strazzullo, & Miller, 2010; Dew et al., 2003; Gallicchio & Kalesan, 2009). As such, addressing cancer caregivers' sleep disturbance is critical to mitigating the notable mental and physical health disparities documented in this population.

Caregivers' sleep disturbance can also be interdependent with their loved ones' sleep disturbance during cancer treatment. Several large-scale epidemiological studies demonstrate that roughly 60 percent of people treated for cancer experience insomnia (Palesh et al., 2009; Savard, Ivers, Villa, Caplette-Gingras, & Morin, 2011). Importantly, patients' and caregivers' sleep parameters have been shown to be significantly interrelated. A study of women with breast cancer and their bed partners sought to understand sleep quality within the couple by using actigraphy, an objective measure that infers sleep based on the presence or absence of movement during the night. Researchers demonstrated that

both partners' sleep deteriorated across the course of adjuvant chemotherapy (Kotronoulas, Wengström, & Kearney, 2016). Bed partners' habits, attachment styles, and mental health are all associated with one's own sleep disturbance (Revenson, Marín-Chollom, Rundle, Wisnivesky, & Neugut, 2016; Rogojanski, Carney, & Monson, 2013; Troxel, Robles, Hall, & Buysse, 2007). Conversely, bed partners can also exert a positive effect on one's sleep, such as promoting healthy lifestyle behaviors (Fuller, 2010), consistent social routines (Carney, Edinger, Meyer, Lindman, & Istre, 2006; Larson, Crane, & Smith, 1991), and behavioral activation during the day (Carney et al., 2006; Monk, Petrie, Hayes, & Kupfer, 1994). Given that 39 percent of caregivers live with the individual with cancer and 16 percent are spouses (NAC, 2016), interventions efficacious in improving caregivers' sleep may also produce meaningful, indirect benefits to persons with cancer.

Importantly, once a chronic pattern has been established, the moderate to severe symptoms of insomnia reported by a large proportion of cancer caregivers do not remit naturally (Morris et al., 2015). Among the general population, over 80 percent of those with severe insomnia symptoms report no remission over time (Hohagen et al., 1994). Indeed, studies of bereaved caregivers highlight that severe insomnia symptoms present before the death of the patient, when left untreated, are still present five years later (Carlsson & Nilsson, 2007; Carter, 2005) and can contribute to prolonged grief disorder by impairing the normal grieving process (Ford & Cooper-Patrick, 2001).

The caregiving experience comes with responsibilities, stressors, and compensatory behaviors that serve as precipitating and perpetuating factors of insomnia (Carter, Mikan, & Simpson, 2009). The 4P model (Perlis, Ellis, Kloss, & Riemann, 2016), an extension of the traditional 3P behavioral model of Spielman and colleagues (Spielman, Caruso, & Glovinsky, 1987), demonstrates why cancer caregivers are at particular risk for severe and chronic insomnia as a result of their caregiving role. Caregivers, as with all people, vary in terms of *predisposing* risk factors for insomnia, such as genetic predisposition, neurobiological regulation of wakefulness, and propensity for rumination. Learning a loved one has been diagnosed with cancer, and the immediate transition into an often foreign and challenging role as a caregiver, is highly distressing, potentially traumatic, and often serves as the major *precipitating* event that initiates sleep disturbance. Disturbances to caregivers' sleep may also originate from the necessity to remain available for the patient in times of need, at any hour of the day or night. Indeed, a study of 176 advanced cancer caregivers found that the most frequent sleep disturbance was waking during the night to provide care to the patient (Lee et al., 2015).

As caregivers adjust to the shock of the cancer diagnosis, potentially maladaptive behavioral responses can develop in reaction to a caregiving-related sleep disturbance, which serve to *perpetuate* and exacerbate insomnia (Harvey, Inglis, & Espie, 2002; Morin & Barlow, 1993; Spielman, Caruso, et al., 1987). These include extending sleep opportunity by going to bed earlier, trying harder to sleep, taking over-the-counter or prescribed sleep medications, sleeping in or napping the next day to "make up" for lost sleep at night, and cancelling daytime activities because of poor sleep. In the study of 176 advanced cancer caregivers, for instance, many reported compensating for their evening sleep loss by napping during the day

(Lee, et al., 2015). This depletes their sleep drive and, if done outside the bedroom, further disassociates traditional sleep-stimuli from the process of sleep.

Caregivers' insomnia is also perpetuated by maladaptive cognitive processes, or dysfunctional sleep-related thoughts, such as planning, mental rehearsal, rumination, and worry about loss of sleep. Given the amount of responsibility placed on caregivers, it is not surprising that they may spend time in bed planning or rehearsing the next day's events in order to ensure that they meet all their obligations. Caregivers may worry about the negative impact of loss of sleep on their ability to meet the demands of caregiving and other responsibilities, or feel helpless to mitigate the physical and emotional consequences of sleep loss because of the demands placed on them by others (Lancee, Eisma, Van Zanten, & Topper, 2017). Another unique concern of caregivers is the potential risks associated with sleeping (i.e., sleep prevents attending to the patient and may heighten risk for a medical crisis when symptoms are not caught early). Repeated pairing of sleep-related stimuli (e.g., bed and bedroom) with unsuccessful sleep experiences, stress, and emotional and cognitive arousal leads to the development of classically (or *pavlovian*) conditioned wakefulness that serves to maintain insomnia. While caregiving-related precipitating and perpetuating factors are generally uncontrollable, maladaptive behavioral and cognitive responses that are amenable to change represent a logical point of intervention.

### Application to Other Caregiving Contexts

Caregivers for patients with cancer experience a unique caregiving trajectory compared to caregiving for other common chronic illnesses, one that is typically shorter in duration but more acutely stressful (Clipp & George, 1993; Kim & Schulz, 2008). Cancer caregivers for report having significantly more care responsibilities, requiring more time spent caregiving, than non-cancer caregivers (NAC, 2016), and also show higher rates of insomnia relative to caregivers for patients with other chronic medical illnesses (e.g., Alzheimer's disease [Lou et al., 2015], Parkinson's disease [Happe et al., 2002]). Although the course of caregiving may differ, and some precipitating factors of sleep disturbance may differ (e.g., problematic nocturnal care recipient behaviors common to dementia [McCurry, Logsdon, Teri, & Vitiello, 2007]), there is a high overlap in cognitive and behavioral perpetuating factors. CBT-informed interventions have been found efficacious in improving sleep and mood disturbance in caregivers for people with dementia (McCurry, Logsdon, Vitiello, & Teri, 1998) and other chronic disabling illnesses (McCrae, Tierney, & McNamara, 2006). As such, key modifications and future directions discussed here are widely applicable to caregivers across illnesses; however, understanding the unique caregiving challenges from the acute and variable trajectory of cancer will be important for clinicians to successfully and empathetically tailor CBT-I for cancer caregivers.

### Tailoring Insomnia Treatment for Caregivers

Despite the well-documented burden of insomnia experienced by cancer caregivers and multiple caregiving-specific risk factors for insomnia, there are no empirically supported treatments effectively tailored to the needs of this vulnerable group. Among the general population, primary treatments for insomnia fall into two major categories of

pharmacological or psychological treatments (Schutte-Rodin et al., 2008). Hypnotic medications offer effective short-term management of insomnia with minimal burden related to doctors' appointments or behavioral changes. Although this low-burden treatment might be ideal for cancer caregivers with already overburdened schedules, caregivers often express reticence to take these medications due to the risk of sedation preventing their ability to respond to their loved one in the event of a nighttime emergency (Carter, 2006). Moreover, hypnotic medications are not intended for long-term use, have been associated with increased mortality risk (Kripke, Langer, & Kline, 2012; Weich et al., 2014), and act as a perpetuating factor associated with chronic insomnia in caregivers.

Cognitive-behavioral therapy for insomnia (CBT-I), however, is well-suited to address etiological factors unique to caregivers' sleep disturbance. CBT-I treatment targets the factors perpetuating insomnia by combining behavioral techniques of stimulus control (i.e., developing a strong association between the bed and sleep), sleep restriction (i.e., matching time in bed to current sleep ability to increase homeostatic sleep pressure and facilitate deeper and more restorative sleep), and relaxation strategies (i.e., reduction of cognitive and physiological hyperarousal) with sleep hygiene education and cognitive restructuring of maladaptive beliefs about sleep (Morin, 1993; Perlis, Jungquist, Smith, & Posner, 2006; Schutte-Rodin et al., 2008). This treatment is recommended as a first-line treatment for insomnia (Schutte-Rodin et al., 2008). CBT-I has been shown to reduce sleep-onset latency, increase sleep efficiency, and increase slow-wave sleep more than hypnotic medications (Jacobs, Pace-Schott, Stickgold, & Otto, 2004; Sivertsen et al., 2006). Moreover, people seeking treatment for insomnia have been shown to prefer behavioral treatments over medications (Morin, Gaulier, Barry, & Kowatch, 1992; Vincent & Lionberg, 2001). Several reviews and meta-analyses of studies in patients with cancer (Garland, Johnson, et al., 2014; Johnson et al., 2016) and the general population (Edinger & Means, 2005; Okajima, Komada, & Inoue, 2011; Trauer, Qian, Doyle, Rajaratnam, & Cunnington, 2015) have concluded that CBT-I is a highly effective treatment that produces significant improvements in a variety of sleep components according to subjective and objective ratings.

Despite its strong efficacy data among cancer survivors and the general public, the efficacy and effectiveness of CBT-I among cancer caregivers has yet to be established. To date, only one study has tested an intervention tailored specifically to address sleep disturbance among cancer caregivers. Carter's (2006) CAregiver Sleep Intervention (CASI) was rooted in CBT-I strategies and administered in two 1-hour in-person sessions, with four brief follow-up phone calls. Topics covered at the in-person sessions were: "(1) discovering the importance of sleep and sleep myth busting; (2) stimulus control: how the environment affects your sleep; (3) sleep hygiene: planning for a good night's sleep; and (4) relaxation techniques: calming the mind and body to promote sleep." (p.97) Booster phone-calls were conducted primarily to collect follow-up data, but also included support for tailoring caregivers' sleep and relaxation goals. The program was found to be well-received by caregivers who reported appreciating its accommodation of their "energy and time constraints" (p.101), flexible scheduling of time and location, and goal setting to improve their confidence about sleep. Intervention participants demonstrated improved depressive symptoms and perceived sleep quality relative to attention-control participants. These findings suggest that behavioral



treatments for insomnia that are sensitive to cancer caregivers' complex schedules and role responsibilities are feasible and can improve psychological and sleep quality outcomes.

CASI participants did not, however, demonstrate reliable improvements to their sleep latency, duration, or efficiency, and the author noted that overall adherence to the intervention was limited due to "caregivers' willingness and ability" (p.101) to complete intervention assignments. This lack of effect may be also due in part to the absence of two of the most potent CBT-I treatment components: sleep restriction and tailored cognitive techniques to address cancer caregivers' maladaptive thoughts specifically associated with sleep and consequences to caregiving. These modifications will help to produce more rapid and lasting improvements in caregivers' sleep disturbance and address the primary challenge of the CASI intervention, namely treatment engagement. Balancing caregivers' scheduling and caregiving needs with adequate intervention time for a full dose of therapeutic strategies is difficult, but necessary to produce clinically significant and sustained improvements in cancer caregivers' sleep patterns.

### Key points of adaptation for CBT-I with caregivers

CBT-I, as with all educational, behavioral, and cognitive treatment components, should be made available to cancer caregivers presenting with insomnia, in a way that is tailored and sensitive to their unique needs and preferences in the following ways:

**Assessment**—Beyond the typical comprehensive assessment for insomnia (Howell et al., 2013; Morin & Benca, 2012; Schutte-Rodin et al., 2008), careful assessment of ways in which cancer has affected caregivers is needed. Understanding the disease status and treatment trajectory of patients will contextualize cancer caregivers' roles, responsibilities, daily routine, and worries. Asking caregivers to describe a typical day and night can help clarify their care tasks and schedule, which is important for tailoring sleep restriction plans. Sleep loss compensation strategies are common among caregivers (e.g., naps when help is available for the patient, caffeine, etc.; Lee et al., 2015), but are known to perpetuate sleep disturbance. As with any CBT-I treatment, ruling out safety concerns and setting a plan to monitor and prevent adverse events are critical. For example, ask whether the caregiver has ever fallen asleep at times when it would be dangerous (e.g., while driving) and set a safety plan to prevent future incidents.

**Psychoeducation**—CBT-I emphasizes comprehensive psychoeducation regarding factors that initiate and maintain insomnia, as well as the specific techniques oriented to counter these mechanisms. Having a solid foundation of knowledge about insomnia and treatment will be critical for caregivers' buy-in to techniques that may produce short-term daytime drowsiness, particularly sleep restriction. This technique matches the presenting caregivers' time spent in bed to their current sleep ability, and is effective as both a stand-alone and component of treatment (Harvey et al., 2002; Miller et al., 2014). As sleep efficiency increases, the prescribed sleep time is slowly expanded until the individual is able to achieve sleep of sufficient quantity and quality. This technique purposely induces mild sleep deprivation effects in order to enhance sleep drive, thus helping the person to fall asleep faster and sustain sleep to abolish conditioned arousal to sleep cues (Fernando, Arroll, &

Falloon, 2013; Spielman, Saskin, & Thorpy, 1987). Setting caregivers' expectations for short-term increases in daytime sleepiness to produce long-term benefits will help them initiate and maintain what can be a challenging element of CBT-I.

Managing expectations for overall treatment outcomes will also be important for practitioners. Treatment goals for CBT-I emphasize the importance of improved perceived sleep quality beyond increasing total sleep time in the initial stages of treatment (Schutte-Rodin et al., 2008). Although six or more hours of sleep is preferred, small, incremental increases in sleep may lead to meaningful improvements in caregivers' daily lives and sleep-related psychological distress. Lastly, cancer caregivers also often experience conflict engaging in self-care activities and tend to prioritize patient needs before meeting their own (Ramirez, Addington-Hall, & Richards, 1998; Shaw et al., 2013). Normalizing these concerns, as well as legitimizing and commending their attention to their own health needs, is important to encourage caregivers' adherence to treatment.

**Flexibility**—Assessment will reveal actual barriers that caregivers face in terms of scheduling weekly appointments and following rigid sleep schedules typical of CBT-I treatment. As with the CASI study and many other caregiver interventions (Applebaum & Breitbart, 2013), hectic schedules must be honored with flexible scheduling times, locations, and modes of treatment delivery. Although weekly 45-minute in-person sessions are typical, practitioners working with caregivers must be prepared to reschedule appointments, offer a variety of appointment times, and offer sessions by phone or other telehealth modalities (where allowable).

Flexibility must also be applied to the initiation of sleep restriction. Indeed, sleep restriction was excluded from the original CASI protocol given the rigidity with which the technique originally was applied, which is incompatible with cancer caregivers' often unpredictable care responsibility schedule (P. Carter, personal communication, January 30, 2017). Moreover, Carter found that many of the participating caregivers reported average sleep ability below the recommended time in bed threshold of 4.5 hours for formal sleep restriction (Spielman, Caruso, et al., 1987). Currently, more flexible and gradual variants of sleep restriction, such as sleep compression, have been examined among older adults with insomnia (Kyle et al., 2015) and may be more easily followed by caregivers.

**Problem solving**—Problem solving is an effective treatment component included in many caregiver interventions (Applebaum & Breitbart, 2013; Northouse, Williams, Given, & McCorkle, 2012; O'Toole, Zachariae, Renna, Mennin, & Applebaum, 2016). Infusing problem solving into sessions can help emphasize the spirit of flexibility and collaboration by encouraging practitioners and caregivers to think creatively about ways to fit sessions into their schedules and behavioral changes into their routines. Problem solving is also critical to securing caregivers' willingness to engage in sleep restriction or compression. Based on careful assessment of any nighttime care task or fears related to fatigue impairing caregiving responsibilities, problem solving to accommodate these tasks and ameliorate concerns related to short-term daytime sleepiness from sleep restriction is necessary to ensure caregivers' ability to fully participate in this important treatment component. Moreover, as caregivers will be asked to modify, reduce, or eliminate compensatory strategies such as



napping, identifying other pleasant and refreshing activities to replace these behaviors will be useful. Implementing regular relaxation exercises may be particularly beneficial for caregivers, given their frequently high levels of stress.

**Cognitive restructuring skills**—Beyond the typical CBT-I cognitive techniques to address maladaptive beliefs about sleep, caregivers' maladaptive thoughts specifically associated with sleep and consequences to caregiving must be targeted. Strategies such as automatic thought identification and downward arrow can be useful for pinpointing these maladaptive thoughts. For example, if a caregiver presents with significant worry about the effect of his/her fatigue on his/her ability to provide care, this worry must be addressed with problem solving and cognitive restructuring (e.g., decatastrophizing) before he/she may fully commit to completing behavioral strategies that frequently increase short-term daytime drowsiness.

**Case vignette**—We demonstrate use of these techniques with the case example of Anne, a single forty-seven year old woman living alone with her elderly mother, for whom she was providing care following a diagnosis of metastatic lung cancer approximately four months prior. In session one, we focused on assessment in order to formulate an impression of the unique precipitating and perpetuating factors related to Anne's insomnia and to build rapport. Anne was employed as a teacher's aide and typically worked from noon to 4 PM, having moved to a part-time position to allow her more time with her mother. Anne reported that prior to her mother's diagnosis, she had "no problem" falling and staying asleep and typically slept eight to nine hours per night. Since that time, however, she reported taking approximately 45 minutes per night to fall asleep due to worries about her mother's health and their finances. She also reported waking several times throughout the night to listen for, or attend to, her mother down the hall. When she woke during the night, she would look at the clock and calculate how much sleep she might be able to get, worrying about the effects of insufficient sleep on her functioning the next day. When Anne found it particularly difficult to fall back to sleep, she would often work on her computer in bed to pass the time. Although she had been going to bed later to accommodate completing both her work and caregiving responsibilities, Anne's sleep diaries showed that she maintained approximately a seven-hour sleep opportunity window, but she only slept about five hours per night. Anne reported frustration from significant fatigue throughout the day, difficulty concentrating, and increased irritability.

Anne described always providing care for her mother, who had suffered for a decade with mild congestive heart failure and arthritis, but her caregiving responsibilities increased exponentially four months ago following her diagnosis of metastatic lung cancer. Anne needed to provide more and more help with most of her mother's ADLs, given her mother's increasing dyspnea and pain from bone metastases, and it was becoming increasingly difficult for Anne to balance her mother's needs and her work schedule. Anne described a typical day as getting up at 6 AM and assisting her mother to the bathroom and dressing, before preparing their breakfast. She typically scheduled doctor's appointments for mornings, with either her or her sister, who lived locally, attending with her mother. When her sister took her mother to appointments, she reported typically napping on the couch for a

few hours. She spent evenings finishing work, cleaning the home, reading about her mother's condition, and preparing meals. She would often lose track of time and find herself rushing to be in bed by 11 PM, only to lay in bed awake with her mind spinning from the busyness of the day.

We spent the majority of session two providing psychoeducation about the 4P model of insomnia. We used Anne's own behavioral (e.g., napping, working in bed), cognitive (e.g., worry about consequences of lack of sleep, mother's health, finances), and caregiving-related (e.g., waking to listen for and assist her mother) factors to demonstrate how they perpetuate insomnia. This psychoeducation was used to support the rationale for sleep restriction. We collaboratively set a sleep window of 5.5 hours, using Anne's sleep diary data from the past two weeks to demonstrate the "mismatch" in her sleep ability versus opportunity.

In session three, we primarily addressed stimulus control with Anne, reviewing rationale for limiting time and sleep-incompatible behaviors (e.g., worrying, using the computer) in bed. Anne described feeling apprehensive about limiting her worry time in bed, expressing concern that she might forget an important task without this time mulling the day ahead. In response, she agreed to set a 30-minute worry time in the evenings to be completed at her desk, as well as keep a notepad on her bedside table to write down any thoughts that came to her in bed.

In session four, we used cognitive techniques and problem solving to address Anne's difficulty in adhering to the sleep restriction "prescription." Anne was enthusiastic about treatment to help improve her sleep, but she struggled with worry that she would sleep through her mother calling for her in the night. Using the downward arrow cognitive technique, it became clear that Anne believed if she slept through the night, she would miss her mother calling for help to get to the bathroom, and her mother would slip and critically injure herself upon attempting to go independently. Using the cognitive restructuring technique of examining the evidence for and against this thought demonstrated that her mother had only needed assistance in the evening three times in the past month, and each time Anne had woken up to her mother's call. Following the steps for problem solving, Anne agreed to discuss a back-up plan with her mother, who would use the phone to speed-dial Anne's cell phone in the event Anne did not respond to her verbal call. With these measures in place, Anne agreed to attempt sleep restriction.

By session five, Anne reported noticing that keeping to sleep restriction and stimulus control procedures helped reduce the time it took for her to fall asleep, and she woke fewer times at night knowing her mother could reach her in the event of an emergency. When she did wake during the night, she was able to eliminate the use of her computer and replace it with some imagery and relaxation techniques. However, it remained difficult for her to increase her window of sleep opportunity given the extent of her caregiving and work responsibilities. As such, we used problem solving to help increase her time in bed in order to meet her typical sleep need of eight to nine hours. We took inventory of her involvement in care tasks, and evaluated whether there were any tasks that could be done less frequently or by another person. We found that preparing meals nightly took approximately two hours, pushing back

her evenings. In discussing pros and cons of possible solutions, Anne discussed that she felt guilty thinking about not preparing fresh, healthy meals nightly for her mother, who had cooked for her family through her childhood. Upon further discussion and use of cognitive restructuring techniques, Anne acknowledged that her mother would want her to take care of herself and that her sister had offered to cook two nights per week. Accepting her sister's help, and planning to cook a large batch of food on Sunday afternoons, meant that Anne was able to move her bedtime earlier, as well as adding in time for a walk around the block for leisure.

In session six, we continued to discuss and troubleshoot adherence to sleep restriction and stimulus control procedures, and reviewed general sleep hygiene education. Given Anne's good application and comprehension of sleep restriction and stimulus control, we collaboratively agreed to one week off-treatment before the following appointment, allowing a trial for Anne to independently use the CBT-I skills. At the following session (i.e., session seven during week eight of treatment), Anne's sleep diaries showed an increase in her sleep time to an average of six hours per night and sleep efficacy of 85 percent. Moreover, she reported less daytime fatigue and worry about sleep, as well as greater ability to concentrate and overall feeling of wellbeing. We reviewed relapse prevention strategies, drawing on Anne's established knowledge of the 4P model of insomnia and CBT-I techniques of sleep restriction and stimulus control. Given her treatment gains and consistent use of CBT-I skills, we agreed to terminate treatment.

Anne's case demonstrates that cancer caregivers can experience both improved sleep quality and increased sleep quantity in CBT-I treatment that accommodates their unique schedules and responsibilities. Traditional CBT-I content was tailored to identify and address Anne's maladaptive thoughts about sleep pertaining to her caregiving role, and supplemented with problem solving, thus enabling her to benefit more fully from the therapy. Caregivers are experts in their own family structures and needs, yet gentle questioning of their strict rules about their roles as caregivers can illuminate opportunities for changes that may improve their QOL. Our group is currently piloting this tailored CBT-I treatment among cancer caregivers. Should our findings support CBT-I as an acceptable and feasible treatment that produces clinically meaningful effects on insomnia symptoms, we plan to conduct a fully-powered randomized controlled trial to determine the efficacy of CBT-I among cancer caregivers.

## Future Directions

Given the mismatch between the high proportion of cancer caregivers reporting sleep disturbance compared to the limited availability and utilization of psychosocial resources dedicated to this group, it is clear that additional modalities of delivering CBT-I to caregivers are needed. Internet-based CBT-I programs for the general population have been found both efficacious and acceptable (Farrell-Carnahan et al., 2010; Koffel et al., 2016; Ritterband et al., 2009). One web-based program, SHUTi, has shown strong effects on improving multiple sleep parameters (Ritterband et al., 2009), with effects maintained through a year post-treatment (Ritterband et al., 2016) and preliminary efficacy demonstrated among cancer patients (Ritterband et al., 2012). Moreover, this program has also been shown to attenuate

participants' depressive symptoms (Christensen et al., 2016), reduce anxiety, and improve QOL (Thorndike et al., 2013), secondary benefits that would be particularly relevant to addressing the mental health burdens associated with caregiving. Given cancer caregivers most frequently cite scheduling difficulty and limited time as barriers to accessing psychosocial (Applebaum, Farran, Marziliano, Pasternak, & Breitbart, 2014; Northouse, Katapodi, Song, Zhang, & Mood, 2010; Shaw et al., 2013; Waldron, Janke, Bechtel, Ramirez, & Cohen, 2013), online, self-directed CBT-I programs hold substantial promise to overcome these barriers and make the benefits of CBT-I more widely accessible to caregivers. Internet-based approaches are also scalable from a health systems perspective, given that they require little clinician time, which is also a significant barrier to implementing and sustaining caregiver interventions.

As sleep disturbance is known to be related between bed partners (Kotronoulas et al., 2016), dyadic interventions that target the couple as the unit of care may provide an opportunity to synergistically improve outcomes among co-sleeping caregivers and patients when both experience sleep problems. In individually-delivered CBT-I, patients' perceptions of their partners' support for their adherence to treatment was associated with improved sleep outcomes (Ellis, Deary, & Troxel, 2015). These findings were replicated among patients with cancer, with one study showing that greater social support was associated with treatment adherence and greater treatment effects from CBT-I (Kamen et al., 2017). Although theoretical models for integrating bed partners into a dyadic CBT-I treatment exist (Rogojanski et al., 2013; Troxel, 2010; Troxel et al., 2007), few systematic investigations of dyadic behavioral sleep treatments have been published. Early findings by Carter suggests a brief CBT-I intervention with co-residing cancer patients and caregivers is feasible and produces synergistic improvements in sleep disturbance among both partners by facilitating conversation and activating support for each other (Carter, Mikan, & Patt, 2015). Another study providing preliminary evidence for the efficacy and acceptability of dyadic sleep interventions demonstrated that a psychoeducational sleep intervention was efficacious in improving sleep among persons with dementia and their co-residing caregivers (McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2005). Even without a fully dyadic treatment, including bed partners in one or more sessions for individually-delivered CBT-I may facilitate identifying barriers and solutions to adherence and thus improve sleep. Capitalizing on the social support and dyadic coping of couples may exponentiate CBT-I treatment gains for caregivers and their loved ones.

Finally, although CBT-I remains the only behavioral treatment to be recommended as a first-line treatment for insomnia, ensuring that caregivers have a range of effective treatment options for managing their sleep disturbance is important. Other combination or stand-alone integrative insomnia treatments that are non-sedating have shown promise in the general public and among cancer patients, including yoga (Mustian et al., 2013), hypnosis (Becker, 2015; Picard et al., 2013), mindfulness-oriented therapies (Carlson & Garland, 2005; Garland, Carlson, et al., 2014) and acupuncture (Garland et al., 2017; Shergis et al., 2016; Yeung, Chung, Leung, Zhang, & Law, 2009). Given that cancer caregivers tend to underutilize available psychosocial services (Applebaum et al., 2014; Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005), research is needed to understand their beliefs

and barriers about utilizing these services as part of a patient-centered approach to tailor insomnia intervention delivery to meet individual caregivers' needs.

## Conclusions

Chronic insomnia is prevalent among cancer caregivers, is associated with significant psychosocial and physiological consequences, and does not remit naturally. As such, effective treatments for insomnia tailored to cancer caregivers' unique sleep disturbance presentation and etiology are needed. CBT-I tailored to be flexibly, yet rigorously provided in a way that respects caregivers' unique scheduling needs, accommodates their care responsibilities, and addresses their caregiving-related maladaptive thoughts about sleep will help alleviate caregivers' sleep disturbance. The establishment of empirically-supported interventions for insomnia among cancer caregivers has the potential to improve their QOL, enhance care provided by caregivers, lead to improved bereavement outcomes, and attenuate the notable mental and physical health disparities present in this vulnerable population.

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