# NEEDS AND PREFERENCES OF CANCER SURVIVORS IN AN INSOMNIA TREATMENT SMARTPHONE APP

by © Samlau Kutana

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#### Abstract

**Background:** Insomnia affects cancer survivors at a higher rate than the general population, impacting quality of life and physical health. Cognitive behavioural therapy for insomnia (CBT-I), the first-line recommended treatment for insomnia, is effective when delivered digitally through a smartphone app. However, no digital CBT-I program has been developed that addresses the unique needs of cancer survivors. The objective of this study was to understand the experiences of cancer survivors with regards to insomnia and insomnia treatment, while assessing their needs in an insomnia treatment smartphone app.

**Methods:** Cancer survivors meeting criteria for current or past insomnia responded to a digital questionnaire assessing demographic information, and cancer diagnosis and treatment history. Survivors then participated in one-on-one semi-structured interviews about their experiences with insomnia, smartphone use, and needs in an insomnia treatment app. Interviews were recorded and transcribed, and recurrent themes were identified using a process of thematic analysis.

**Results:** Twenty interviews were analyzed. All participants reported incidence or worsening of insomnia following cancer diagnosis or treatment. Smartphone CBT-I was considered acceptable by cancer survivors. Primary needs identified by cancer survivors for an insomnia treatment app included user friendliness, privacy and data security, and evidential basis.

**Conclusion:** Our results suggest that smartphone CBT-I is acceptable to cancer survivors, holding potential to greatly increase access to evidence-based insomnia treatment.

Keywords: insomnia, cancer, mHealth, cognitive behavioral therapy for insomnia

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# **General Summary**

Cancer survivors commonly face problems getting enough sleep, which can affect quality of life and limit recovery. Cognitive behavioural therapy for insomnia (CBT-I) is the best-known treatment for insomnia and can be delivered through a smartphone app, however there are currently no apps delivering CBT-I that were developed for the unique needs of cancer survivors. The objective of this study is to interview cancer survivors to understand their experiences with insomnia and insomnia treatment, and assess the needs and preferences of this patient group for CBT-I smartphone app. Twenty cancer survivors completed questionnaires and were interviewed about their experience with insomnia as well as their smartphone use and needs in a CBT-I app. Interviews were analyzed and common ideas identified between participants. The results showed that all participants' sleep was negatively impacted by their cancer diagnosis or treatment. Most cancer survivors owned a smartphone, had experience using smartphone apps, and found a CBT-I app to be an acceptable form of treatment. Primary needs identified by participants in a CBT-I app included user friendliness, privacy, and evidential basis.

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# **Cancer Prevalence and Impact in Canada**

Recent estimates rank cancer as the second leading cause of death globally, behind only ischemic heart disease (Hulvat, 2020). In Canada, cancer is the leading cause of death causing over 1 million estimated potential years of life lost between 2018 and 2020 (Canadian Cancer Society, 2023). Despite its high death toll, trends in cancer incidence and mortality are improving, with recent advances in screening, early detection, prevention, and treatment improving survival rates significantly. While the absolute number of cancer incidents in Canada is expected to rise due to a growing and aging population, public health initiatives such as anti-smoking campaigns and the vaccine for Human Papillomavirus have worked to reduce incidence rates (Hulvat, 2020). Since their peak in 1988, cancer death rates have decreased by 39% in males and 26% in females, and the 5-year survival rate for all cancers has increased from 55% in the early 1990s to 64% in 2023 (Canadian Cancer Society, 2023). This substantial and growing number of people who are living with and beyond their cancer diagnosis are likely to have unique medical and mental healthcare needs for the rest of their lives (Savard et al., 2011).

# **Psychosocial Impact of Cancer**

Cancer survivors face many unique challenges to their physical and mental health (Weaver et al., 2012), as well as their social, familial, and occupational functioning, which may endure throughout a patient's lifetime (Reynolds-Cowie & Fleming, 2021). These challenges, in addition to the need for ongoing monitoring for cancer recurrence, require cancer survivorship to be thought of as a chronic condition requiring long term care (Miller et al., 2015).

Mental health problems are nearly twice as common in cancer survivors compared to the general population (Hewitt et al., 2003; Weaver et al., 2012). A systematic review of 60 studies examining risk of adverse mental health outcomes in over 15,000 breast cancer survivors

concluded that these patients face elevated risks of depression, anxiety, suicide, neurocognitive dysfunction, and sexual dysfunction compared to women with no prior cancer (Carreira et al., 2018). A 2016 survey of 1,294 disease-free survivors of breast, colorectal, and prostate cancer found high levels of cancer-related fatigue affecting about one-third of survivors and persisting for several years beyond cancer remission that was associated with high levels of disability (Jones et al., 2016).

In addition to reducing quality of life, there is some evidence that mental health issues in cancer survivors can have negative impacts on health outcomes, potentially leading to maladaptive health behaviours and even poorer overall survival. A large prospective study of 3,080 Dutch cancer patients found that clinically elevated depression symptoms (HADS >= 8) were twice as prevalent among those who died (38%) than among survivors (19%) even after adjusting for major clinical predictors (Mols et al., 2013). These findings suggest that cancer survivors face increased risks of mental health challenges that reduce quality of life and negatively impact long-term survival rates. One particularly important comorbidity that affects many cancer survivors and produces both of these negative outcomes is Insomnia Disorder (Olfson et al., 2018; Parthasarathy et al., 2015).

# **Insomnia in Cancer Survivors**

Insomnia is characterized by difficulty initiating and/or maintaining sleep, with frequent nighttime awakenings or difficulty returning to sleep after awakenings (American Psychiatric Association, 2013). Clinically, insomnia disorder is typically defined by the frequency, duration, and severity of sleep disturbance, as well as whether there are consequences to daytime functioning (American Psychiatric Association, 2013). To be diagnosed as insomnia disorder,

sleep disturbances must occur at least 3 times per week, for a period of at least 3 months, with daytime impairment (American Psychiatric Association, 2013).

# Prevalence

Insomnia is highly prevalent in cancer survivors, affecting up to 60% of people treated for cancer, which is two to three times the rate found in the general population (Palesh et al., 2010; J. Savard et al., 2011; J. Savard & Savard, 2013). Insomnia is an often-overlooked consequence of cancer diagnosis and treatment. There are several cancer-specific factors that may elicit the onset of sleep disturbances, such as hospitalization, surgery, adjuvant treatments, or symptoms like hot flashes, pain, and fatigue (J. Savard & Savard, 2013). A qualitative examination of the factors that drive development and maintenance of insomnia found that cancer survivors commonly report their insomnia either started or, if they already had trouble sleeping, worsened during the time of their cancer diagnosis (Garland et al., 2019). These findings suggest that the time of initial diagnosis is a critical time for most cancer survivors regarding the development of sleeping issues. An 18-month longitudinal study investigating the course of insomnia in 962 patients newly diagnosed with nonmetastatic cancer found high baseline rates of insomnia symptoms (59%) and insomnia disorder (28%) (J. Savard et al., 2011). While these rates did decline over the 18-month follow-up period, a large proportion of the sample was still experiencing insomnia symptoms (36%), and some still suffering from insomnia disorder (15%) (J. Savard et al., 2011). Individuals with insomnia symptoms who did not meet criteria for insomnia disorder had a greater likelihood of going into insomnia remission during the 18-month follow-up period (42.0% - 51.3%) than individuals who met criteria for insomnia disorder (10.8% - 14.9%). These findings taken together suggest that early sleep-focused

intervention for newly diagnosed cancer patients may prevent or reduce the development of insomnia disorder.

# Course of Cancer-Related Insomnia

Even if an individual's insomnia is precipitated by their initial cancer diagnosis and treatment, there is no guarantee that the sleep issue will disappear following full remission of cancer (Schieber et al., 2019). A prospective longitudinal study was conducted that assessed the course of cancer-related insomnia over 12 months in a sample of 405 German adult cancer patients (Schieber et al., 2019). This study also found the rate of insomnia symptoms to decline only slightly over the 12-month follow-up period, despite improvements in both depression and anxiety, and the fact that 80% of the sample were in cancer remission with no evidence of disease (Schieber et al., 2019). While the proportion of men reporting insomnia symptoms dropped from baseline (47.2%) to the 12-month follow up (39.3%), the proportion of women reporting insomnia symptoms actually *rose* during the same time period, from 51.1% at baseline to 53.3% at 12-months (Schieber et al., 2019). Due to this, women were significantly more likely to experience persistent or recurring insomnia at the 12-month period (Schieber et al., 2019). These results suggest that the conditions necessary for perpetuation of insomnia are present in a significant subset of cancer patients, perhaps particularly in women, which may lead to years of sleep disturbance following cancer remission.

#### Impact of Insomnia in Cancer Survivors

As the importance of regular sleep to the maintenance of mental and physical health becomes better understood, our understanding of the negative consequences of sleep

disturbances is also improving. Despite not seeming as threatening as active cancer, insomnia is far from just an inconvenience in cancer patients. Insomnia in cancer survivors is associated with a wide range of negative symptoms, including physical, psychological, and economic consequences. Insomnia disorder is correlated with mental health conditions such as depression (Li et al., 2016), anxiety (Staner, 2003), cognitive impairment (Liou et al., 2019), and fatigue (Theorell-Haglöw et al., 2006).

In 2021, researchers recruited 27 cancer survivors to participate in focus group discussions designed to explore their lived experience with persistent insomnia (Reynolds-Cowie & Fleming, 2021). The researchers found that insomnia had significant negative effects on participants' lives across several domains such as physical and psychological wellbeing, sociability, relationships, cognitive function, and temperament (Reynolds-Cowie & Fleming, 2021). Recently, researchers have begun exploring the impact that treating cancer survivors' insomnia has on other psychological conditions such as fatigue (Heckler et al., 2016) and perceived cognitive impairment (Garland, Savard, et al., 2021). Ultimately, it is clear that insomnia in cancer survivors may be predictive of a host of challenges and negative outcomes across several domains, including psychological, physical, social, and economic consequences.

# Insomnia and other Psychological Comorbidities

One challenge faced by cancer survivors with insomnia is an increased risk of psychological comorbidities including anxiety, depression, and/or impaired cognition due to disrupted sleep (Haque et al., 2021; Hoang et al., 2020; Liou et al., 2019). These symptoms go hand-in-hand with insomnia and contribute to the reduced quality of life experienced by cancer survivors with insomnia (Lis et al., 2008).

**Anxiety.** A recent cross-sectional survey of 213 patients undergoing chemotherapy found 42.8% of participants reported insomnia, with 31.9% of this group experiencing severe insomnia (Hoang et al., 2020). Insomnia occurrence and severity were found to correlate with participants' anxiety and depression scores, and principal components analysis revealed that insomnia, anxiety, and depression seemed to form one symptom cluster (Hoang et al., 2020). Anxiety, characterized by cognitive arousal, may lead to rumination and a failure to de-arouse and cognitively disengage, leading to the experience of "racing thoughts" endorsed by many insomnia sufferers (Espie, 2023). This state of arousal can lead to a bout of acute insomnia which may develop into chronic insomnia in the presence of perpetuating factors.

**Depression.** Insomnia and depression tend to exhibit a bidirectional relationship in which the presence of one increases subsequent risk of developing the other (Khurshid, 2018). Chang and colleagues (1997) conducted a longitudinal, prospective trial to determine predictors of future psychological distress. The researchers assessed the sleep habits of 1053 medical students and continued to follow up with these participants over the next several decades. Participants who reported insomnia in medical school had a higher relative risk (RR = 2.0, 95% CI: [0.9-2.3]) of developing clinical depression during the follow up period (Chang et al., 1997). These results indicate that prior insomnia may predispose individuals to experiencing a future incidence of clinical depression, or perhaps that the two disorders share a common underlying vulnerability. While there exists no such prospective research of this kind among cancer survivors, the high prevalence of sleep disturbance in this population combined with cancer-specific stressors likely compounds this relationship (Irwin, 2013).

Supporting this, Haque and colleagues (2021) conducted a cross-sectional analysis of the relationship between insomnia, depressive symptoms, and fatigue in a sample of 315 breast cancer survivors who did not meet criteria for major depressive disorder. Women with insomnia symptoms were found to have much greater odds of also having depressive symptoms (OR = 5.98) and moderate fatigue (OR = 5.02). Moreover, use of antidepressants or hypnotic medications post-breast cancer diagnosis was unrelated to odds of depressive symptoms or fatigue (Haque et al., 2021).

Insomnia has also been shown to increase risk of suicidality, and individuals experiencing suicidal ideation have been shown to have higher rates of poor sleep and insomnia (Franzen & Buysse, 2008; Khurshid, 2018). Insomnia is one of the most commonly endorsed symptoms of depression, and while there are debates about which condition precedes which, what is clear is that insomnia does not always remit following treatment of depression (Nierenberg et al., 1999).

**Perceived Cognitive Impairment.** In addition to depression and anxiety, insomnia in cancer patients and survivors is often associated with perceived cognitive impairment. Liou and colleagues (2019) surveyed 1072 breast cancer patients receiving aromatase inhibitor therapy and found an association between insomnia and cognitive impairment, in which cognitive impairment increases as insomnia severity increases. Caplette-Gingras and colleagues (2013) assessed the relationship between insomnia and both objective and subjective cognitive impairment among 63 women treated for nonmetastatic breast cancer and found significant differences in objectively assessed verbal episodic memory and executive functioning between women with insomnia and good sleepers. Moreover, women with insomnia in the study scored

significantly lower on the Actual State Scale, a subjective measure of many aspects of cognitive functioning. Older age and higher education were associated with greater deficits in cognitive functioning.

**Quality of Life.** Insomnia is associated with a significant reduction in quality of life, as sufferers deal with the daytime consequences of lost sleep. There are several different ways of assessing quality of life in the literature, with most methods assessing health symptoms (e.g., pain, fatigue, etc.) and level of functioning across several domains (e.g., physical, social, role, etc.) through self-report. Lis and colleagues (2008) explored the association between insomnia and quality of life using a case series of 954 patients being treated for various types of cancer. In this study, patients reporting higher levels of insomnia reported lower quality of life across several domains, particularly with regards to physical health and psychological/spiritual quality of life (Lis et al., 2008).

More recently in 2018, researchers analyzed data from 34712 US adults who participated in the National Epidemiologic Survey on Alcohol and Related Conditions-III (2012–2013) to determine the annual population-level burden of insomnia (Olfson et al., 2018). Insomnia was found to be highly prevalent, with 27.3% of the sample meeting criteria for the disorder in the last 12-months. Insomnia resulted in an annual loss of 5.6 million Quality-adjusted life years (a measure assessing both quality and quantity of life), which was significantly greater than any of the other 18 medical conditions analyzed, including hypertension, arthritis, and depression (Olfson et al., 2018). Analyses conducted within samples of cancer survivors show much the same picture. Ross and colleagues (2020) conducted a prospective analysis of the relationship between self-reported insomnia symptoms, medications, and quality of life in 894 Australian women with ovarian cancer in the first three years following their initial diagnosis. Insomnia was found to be highly prevalent, and one quarter of women reported clinical insomnia within three years, with an additional 13% regularly using sleeping medications. Women with clinical insomnia had significantly lower quality of life at baseline and at three month follow up.

Reynolds-Cowie and Fleming (2021) conducted a qualitative analysis of the lived experience of insomnia disorder and its management amongst a sample of 27 cancer survivors with persistent insomnia who participated in focus groups. The impact of insomnia was significant for all participants, affecting key domains such as temperament, sociability, physical and psychological well-being, cognitive functioning, and relationships. These results show that insomnia's harmful impact on cancer survivors' quality of life can persist long after cancer has been treated.

#### **Physical Comorbidities of Insomnia**

Due to the critical role played by sleep in maintaining homeostasis of several physiological systems, disrupted sleep can have widespread negative consequences across several domains of health and functioning. While insomnia's negative effects of daytime cognitive functioning and nighttime wellbeing are well-studied and understood, its effects on other bodily systems such as pain perception, the cardiovascular system, and the endocrine system are becoming increasingly recognized and studied (Yun & Jo, 2021).

**Pain.** Pain is one of the most common comorbidities associated with insomnia in cancer patients. It can exacerbate insomnia by disrupting sleep onset and maintenance. The loss of restorative capacity caused by missed sleep may even cause the pain to intensify (Cheatle et al.,

2016; Ostovar-Kermani et al., 2020; Sivertsen et al., 2015). Indeed, the ability of sleep loss to elicit hyperalgesia has been shown in multiple experimental trials of healthy participants. For instance, fourteen such participants who were subjected to one night of total sleep deprivation developed an increased sensitivity to pain from heat, cold, blunt pressure, and pinprick stimulation the following day (Schuh-Hofer et al., 2013). More recently, Staffe and colleagues (2019) subjected 24 healthy volunteers to 24 hours of total sleep deprivation to investigate the association between sleep deprivation and central pain mechanisms. The researchers found that pain sensitivity was significantly increased following a night of total sleep deprivation compared to a night of normal sleep, supporting the results from Schuh-Hofer and colleagues (2013) and suggesting that loss of sleep can itself cause an increase in pain symptoms.

This assertion is further supported by a study in cancer patients being treated with radiation therapy which found that women with pre-treatment sleep disturbances had significantly greater post-treatment pain (Peoples et al., 2021). Thus, while interventions that specifically target pain in insomnia patients are effective and necessary to provide acute relief clinical improvements, treatment of insomnia in these patients may have longer-term benefits in reducing pain as well.

**Cardiovascular System.** Insomnia's impact on circadian rhythm function and misalignment has been implicated in its negative effects on cardiovascular functioning (Khan et al., 2020). A meta analysis of seven large prospective studies involving over half a million participants found that insomnia symptoms of difficulty initiating sleep, difficulty maintaining sleep, and nonrestorative sleep were associated with a 22%, 14%, and 16% increased risk of adverse cardiovascular events such as heart attack or stroke, respectively (Hu et al., 2021).

Another meta-analysis of 21 observational studies that included data from over 2.5 million individuals compared risk for cardiovascular disease incidence and mortality between individuals with insomnia and good sleepers, finding relative risk for cardiovascular mortality, myocardial infarction, cardiovascular disease, and all-cause mortality were significantly higher in the insomnia group (Ali et al., 2023). These studies provide convincing evidence that individuals with insomnia have impaired cardiovascular functioning compared with good sleepers. While insomnia is well known for reducing quality of life, it is less commonly associated with mortality. However, given that diseases of the heart are the second leading cause of death in Canada (Government of Canada, 2023), insomnia's association with negative cardiovascular outcomes implicate it as a risk factor for development of serious, life-threatening medical complications.

**Metabolism.** Sleep health has also been shown to be closely tied to metabolic health and functioning, as sleep and circadian rhythm have several downstream effects on the body's ability to hormonally regulate energy metabolism and caloric intake (Broussard et al., 2016; Cain et al., 2015; Hogenkamp et al., 2013; Zhang et al., 2021). Multiple studies have shown alterations in appetite regulating hormones such as ghrelin following experimentally induced periods of sleep restriction or sleep deprivation. For example, Broussard and colleagues (2016) used a randomized crossover trial to examine circulating appetite hormones and caloric intake in nineteen lean, adult men after a night of normal sleep and a night of sleep restriction. Allowed to eat freely from a buffet-style selection of food items, the sleep restricted participants ate an average of 328 additional calories in a 24-hour period than they did after a night of normal sleep.

Moreover, their circulating ghrelin levels were found to be significantly higher when sleep restricted, with no differences in leptin profiles (Broussard et al., 2016).

Similar research has shown that individuals show a greater preference for calorically dense foods (Cain et al., 2015), choose larger portions, and report greater subjective hunger following a night of sleep deprivation or restriction than after a night of normal sleep (Hogenkamp et al., 2013). If one night of sleep restriction can have such an effect on hormones and caloric intake, then it is reasonable to expect problems with diet regulation and weight gain in the long term among chronically sleep restricted individuals, such as those with insomnia. As a result of these and similar findings, insomnia has been implicated as a risk factor in metabolic conditions such as type 2 diabetes and obesity (Cain et al., 2015; Duan et al., 2023; Hogenkamp et al., 2013).

According to a systematic review and meta-analysis of 12 studies involving over 150,000 individuals, risk of insomnia is also increased among individuals with metabolic syndrome (including obesity, hypertension, and hyperglycemia), hinting at a possible positive feedback effect between disrupted sleep and disrupted energy metabolism (Zhang et al., 2021). Further complicating this relationship is the association between weight gain and increased risk for obstructive sleep apnea, a distinct sleep disorder from insomnia that has similar negative effects on metabolic function (Wolk et al., 2003). Considering how intertwined sleep and metabolism seem to be, optimization of sleep health can be expected to improve metabolic function and health for many individuals.

# Economic Consequences of Insomnia

Beyond its detrimental effects to patient health and quality of life, insomnia is also associated with a set of negative economic consequences that affect patients, their employers, and the larger healthcare system simultaneously. Daley and colleagues (2009) categorized 1362 adult participants from Quebec, Canada into 3 groups based on insomnia status, including 1) good sleepers, 2) individuals endorsing subclinical insomnia symptoms, and 3) individuals meeting criteria for insomnia disorder. Surveys assessing mental and physical health, subjective work productivity, and healthcare utilisation were completed by participants, and supplemented by objective data about healthcare utilisation and hospitalisation obtained from databases maintained by the Quebec Ministry of Health and Social Services. This study found that individuals with insomnia disorder had significantly more health problems and higher morbidity compared to the other two groups. In addition, insomnia was also associated with increased utilization of healthcare services as well as higher levels of work presenteeism (inability to function at full capacity while at work) and absenteeism (missing work entirely; Daley, Morin, LeBlanc, Grégoire, Savard, et al., 2009). The total annual economic burden of insomnia in the province of Quebec has been estimated to be as high as \$6.6 billion CAD, the vast majority of which (5.97 billion CAD) stems from insomnia-related absenteeism and lost productivity due to presenteeism (Daley, Morin, LeBlanc, Grégoire, & Savard, 2009).

Extending this line of research to cancer populations, Gonzalez and colleagues (2018) investigated how sleep disturbances affect the impact of cancer on health expenditures and work absenteeism using data from 9488 employees who participated in the Kansas State employee wellness program in the US. Sleep difficulties were found to significantly mediate the impact of cancer on healthcare expenditure and absenteeism (Gonzalez et al., 2018). Ultimately, these findings suggest that insomnia is associated with a host of negative economic consequences, the

effects of which are felt not only by the individual, but by their employer and the broader healthcare system as well.

#### **Treating Insomnia in Cancer Survivors**

# Cognitive-Behavioral Therapy for Insomnia

Cognitive-behavioral therapy for insomnia (CBT-I) is currently the first-line recommended treatment for adults presenting with chronic insomnia according to the American Academy of Sleep Medicine and the American College of Physicians (Qaseem et al., 2016). CBT-I is a manualized, multicomponent intervention that is typically delivered in person over a period of 6-8 weeks by a trained behavioural sleep medicine practitioner. While the specific components may vary slightly from patient to patient or between practitioners, CBT-I is a combination of cognitive techniques (e.g., cognitive therapy, relaxation techniques) and behavioural strategies (e.g., sleep restriction, stimulus control, sleep hygiene) that help individuals take advantage of the circadian and homeostatic sleep regulating systems (Rossman, 2019).

**Sleep Restriction Therapy.** Individuals with insomnia typically respond to a perceived lack of sleep by increasing their time in bed to recoup the loss (M. L. Perlis et al., 2019). However, considering the two-process model of sleep regulation, this "sleep extension" strategy can perpetuate insomnia by limiting the buildup of sleep drive as individuals may end up spending a significant amount of time awake in bed rather than asleep. The primary goal of sleep restriction therapy is to reduce the mismatch between an individual's time in bed and time spent

actually sleeping, so as to increase homeostatic sleep drive and make falling and staying asleep easier (Spielman et al., 1987). Sleep restriction therapy first involves determining an individual's habitual nightly sleep duration through the collection of daily sleep diaries over a one to twoweek period. Once this is determined, the patient is prescribed a nightly sleep window equal to their average nightly sleep duration + 15-30 minutes. The prescribed sleep window can then be increased or decreased incrementally depending on the level of consolidation of the patient's sleep. If sleep efficiency remains lower than 85%, the prescribed sleep window is decreased by 15-30 minutes. If sleep efficiency rises above 90%, the prescribed sleep window is instead increased by 15-30 minutes. Adjustments to the sleep schedule are made weekly based on the previous week's sleep diary entries.

Stimulus Control Therapy. Based in behavioural principles and the idea that a stimulus may elicit a variety of conditioned responses, stimulus control therapy seeks to ensure that the bed and bedroom environment become and remain associated with sleep and behaviours conducive to sleep (Bootzin et al., 2010). Many insomnia patients suffer from conditioned arousal, where the bed and bedroom environment become mentally associated with wakefulness as well as various non-sleep behaviours such as reading, watching television, or ruminating, reducing the patient's propensity to sleep at the desired time and place. Stimulus control therapy recommendations are as follows, 1) lie down in bed only when sleepy, 2) only use the bed for sleeping and sex, 3) if unable to sleep for >15 minutes, get out of bed and do a non-stimulating activity (e.g., reading) until you feel sleepy enough to return to bed (Bootzin et al., 2010).

**Cognitive Therapy.** Individuals with insomnia often hold beliefs about sleep that perpetuate insomnia by causing pre-sleep arousal or eliciting maladaptive compensatory behaviours (Carney & Edinger, 2006). For example, the thought "I won't be able to function at work tomorrow if I cannot sleep tonight" may increase pre-sleep arousal, while the belief that "I need 8 hours of sleep every night" might lead a person to increase their time in bed by sleeping in or going to bed early, which paradoxically limits their sleep debt accumulation and makes sleep even more elusive. Research has shown that these unhelpful beliefs discriminate between people with insomnia and good sleepers, and that changes in these beliefs following cognitive therapy are associated with clinical improvement in insomnia (Carney & Edinger, 2006). The focus of the cognitive therapy component of CBT-I is to identify and challenge the attentional biases and unhelpful beliefs that patients hold, ultimately replacing them with more helpful and adaptive sleep-promoting beliefs.

**Relaxation Techniques.** Relaxation techniques help to quiet racing thoughts and calm the body, reducing pre-sleep arousal and promoting a peaceful mindset conducive to sleep (Lichstein et al., 2011). These techniques can take a variety of forms including breathing exercises, mindfulness practices, progressive relaxation, and meditation, and can be taught to patients for use at their own discretion (Lichstein et al., 2011).

**Sleep Hygiene.** Sleep Hygiene education is designed to promote improved sleep practices by providing information about behaviours that can influence sleep. Sleep hygiene recommendations typically include a list of various habitual and environmental factors that can be strategically modified to improve sleep and reduce the risk of sleep disturbances (e.g., limiting alcohol and caffeine intake in the hours before bed, limiting lights and noises in the bedroom environment, regular exercise, etc).

# **Treating Insomnia**

Cancer survivors with insomnia typically present with unique physical and psychological health issues which may worsen insomnia and interfere with CBT-I treatment, however these issues can be mitigated if they are anticipated and specifically addressed (Garland et al., 2014; Zhou et al., 2017). For example, due to the high prevalence of fatigue in cancer survivors, treatments that incorporate a discussion around fatigue and provide strategies for reducing its impact may provide additional benefit to these patients (Zhou et al., 2017).

Despite these challenges, evidence supports the use of CBT-I as a first-line treatment for insomnia in cancer survivors. Squires and colleagues (2022) conducted a systematic review and meta analysis of 22 high-quality randomized controlled trials (RCTs) investigating CBT-I in a total of 1,461 adults with a diagnosis of cancer who met criteria for clinically relevant insomnia. The researchers found that CBT-I is associated with significant posttreatment improvements in insomnia severity (g = 0.78), sleep quality (g = 0.70), fatigue (g = 0.35), quality of life (g = 0.31), depression (g = 0.31) and anxiety (g = 0.42) and 6 (g = 0.33) month follow up, suggesting that CBT-I is capable of producing durable improvements in sleep (Squires et al., 2022). Given these large, consistent, and durable treatment effects across multiple indices, and lack of serious risk for adverse events, CBT-I is an effective first-line option for treating insomnia in cancer survivors.

# Improving Insomnia Comorbidities with CBT-I

Because so many bodily functions require sleep for optimal function, it is reasonable to expect that CBT-I treatment of insomnia might lead to broader health improvements across a variety of domains, particularly those involved in common insomnia symptoms and comorbidities. While outcomes such as pain, daytime functioning, anxiety, and depression are often studied as secondary outcomes in CBT-I trials compared to improvement in insomnia, there is still a significant body of research showing that CBT-I treatment is associated with improvement in comorbid conditions (Lau et al., 2022; Selvanathan et al., 2021; Taylor & Pruiksma, 2014).

Pain. Studies of patients with comorbid pain and insomnia report that while CBT-I treatment is not associated with acute reductions in pain severity at the end of treatment, the treatment is associated with a delayed improvement in pain severity after 3 to 6 months (Jungquist et al., 2010; Yang et al., 2021). Yang and colleagues (2021) compared the effects of CBT-I and acupuncture on pain severity in 35 cancer survivors with insomnia and moderate to severe pain, finding that only acupuncture was effective in significantly reducing average pain severity by week 8. While there was no significant difference in average pain severity between baseline and week 8 in the CBT-I group, there was a significant reduction in average pain severity between the two treatments were found (Yang et al., 2021). Moreover, Yang and colleagues (2021) found that CBT-I "responders" (patients who responded to CBT-I treatment with clinically significant reductions in insomnia symptoms) showed clinically meaningful reductions

in pain severity compared to CBT-I "non-responders", suggesting insomnia improvement is a prerequisite to improvements in pain in patients receiving CBT-I.

**Daytime Functioning.** Apart from the time spent fruitlessly tossing and turning in bed, one of the most salient symptoms of insomnia for sufferers is daytime dysfunction. These symptoms range from fatigue and sleepiness to social and cognitive impairment, and are not addressed by hypnotic medications. In fact, daytime symptoms in individuals taking hypnotics may be worsened by carryover sedation effects (Kripke, 2000). By enhancing the body's own ability to produce sleep effectively without relying on external sedation, CBT-I is a promising solution to improving daytime symptoms of insomnia.

Heckler and colleagues (Heckler et al., 2016) investigated whether CBT-I, a stimulant medication (armodafinil), or a combined therapy would be effective in improving sleep and daytime function in a group of 96 cancer survivors with insomnia. Fatigue was measured using two separate scales: the Brief Fatigue Inventory (BFI), and the Functional Assessment of Chronic Illness Therapy – Fatigue (FACIT-Fatigue). Results of this trial showed that CBT-I was associated with significant improvements on both measures of fatigue at posttreatment (BFI: p = 0.002, effect size (ES) = 0.46; FACIT-Fatigue: p < 0.001, ES = 0.64), while armodafinil was unrelated to improvements in fatigue and did not influence the effectiveness of CBT-I (Heckler et al., 2016).

A systematic review and network meta-analysis conducted in 2020 reviewed 86 studies involving 15,578 individuals to investigate the impact of various delivery methods of CBT-I treatment on a range of daytime insomnia symptoms (Benz et al., 2020). The researchers found that internet-delivered CBT-I was associated with small to medium effect size improvements in

several daytime insomnia symptoms such as sleepiness (d = -0.38, 95%CI: [-0.66, -0.11]), fatigue (d = -0.49, 95%CI: [-0.70, -0.28]), and daytime and social functioning (d = 0.74, 95%CI: [0.41, 1.06]) (Benz et al., 2020). These results provide promising evidence that beneficial effects of CBT-I treatment on daytime function are not lost when treatment is delivered via internet.

In a recent study investigating the effects of CBT-I on perceived cognitive impairment, Garland and colleagues (2024) randomly assigned 132 Canadian cancer survivors to either receive 7 weekly sessions of virtual CBT-I or a waitlist control group. The treatment group not only showed significantly greater improvement in insomnia symptoms relative to the waitlist group, they also showed significantly improvement in perceived cognitive impairment (p < .001; d = 0.75), cognitive abilities (p < .001; d = 0.92), and impact on quality of life (p < .001; d = 1.01) at post treatment, which were fully mediated by improvement in insomnia symptoms (Garland et al., 2024). Taken together, these research findings provide evidence that improvement of insomnia via treatment with internet-delivered CBT-I in cancer survivors can be expected to improve symptoms of daytime functioning such as fatigue, sleepiness, and perceived cognitive function.

**Anxiety.** Anxiety is a common comorbidity with insomnia, and vice-versa. Individuals with anxiety often report struggling with insomnia, and individuals with insomnia often struggle with anxiety, racing thoughts, pre-sleep worry, and hyperarousal. This interrelation between anxiety and insomnia suggests that improvement or deterioration on one dimension may affect the same change in the other, and indeed, there is some evidence that improvement in sleep following CBT-I treatment can lead to reductions in anxiety.

A meta analysis of 50 studies involving a total of 2690 participants with chronic insomnia assessed the impact of CBT-I on comorbid anxiety, finding that CBT-I was associated with moderate effect-sized improvements in anxiety (Belleville et al., 2011). Moreover, inclusion of anxiety management strategies did not influence the effect of CBT-I on anxiety symptoms, suggesting that anxiety may be improved following treatment of insomnia, even if treatment is not specifically focused on reducing anxiety (Belleville et al., 2011).

A more recent study examined the impact of a digital CBT-I program on symptoms of anxiety and insomnia in 991 individuals with chronic insomnia (C. Morin et al., 2023). The researchers found that digital CBT-I treatment was associated with significant improvement in both insomnia and anxiety symptoms at post-treatment and at 6-month follow up, particularly in those with more severe symptoms at baseline (Morin et al., 2023). These findings highlight the utility of CBT-I in the treatment of insomnia and comorbid anxiety, showing that a digital CBT-I program can effectively alleviate symptoms of anxiety without inclusion of any specific anxiety management strategies or techniques.

**Depression.** Cancer diagnosis and treatment are associated with a significant negative psychological impact, which may exacerbate or elicit depression in certain individuals. While the presence of insomnia can compound this risk, increasing the likelihood and severity of co-occurring depression, there is promising evidence that effective CBT-I treatment can lead to significant improvements in symptoms of depression.

Carney and colleagues (2017) recruited 107 participants with comorbid insomnia and major depression to determine the effects of 1) CBT-I treatment alone, 2) antidepressant medication alone, or 3) a combination of CBT-I and antidepressant medication on symptoms of insomnia and depression. Participants were randomized to one of the three groups, and placebo

treatments (placebo pill and sleep hygiene control therapy) were used to blind participants to their study condition so that each participant received therapy and a pill. The researchers found depression was significantly improved in all three groups at post treatment with no group differences (F = 37.86, p = 1.0), despite the fact that one condition did not have any depressionfocused treatments (CBT-I + placebo pill). While all three groups self-reported improved sleep, the group that received antidepressant medications and sleep hygiene education showed worsened objective sleep indices. This study highlights the potential antidepressant effects of CBT-I, as depression in the CBT-I group improved despite the lack of tailored treatment (Carney et al., 2017).

Cheng and colleagues (2019) extended this line of inquiry to digitally delivered CBT-I, randomizing 1358 individuals with insomnia to receive either 1) digital CBT-I or 2) sleep education, in order to determine the effects of digital CBT-I on insomnia and depressive symptoms. Compared with the sleep education group, the group receiving digital CBT-I showed greater improvements in insomnia (ISI:  $-10 \pm 5.7$  vs.  $-4.4 \pm 4.2$ ) and depressive symptoms (Quick Inventory of Depressive Symptomatology:  $-4.1 \pm 4.7$  vs.  $-1.6 \pm 3.7$ ) (Cheng et al., 2019). While this study's limitations include lack of an active control treatment and a sample that did not have clinically significant depression, it provides some evidence that digitally delivered CBT-I can improve symptoms of depression in individuals with insomnia.

#### **Challenges Implementing CBT-I**

Despite the large empirical evidence base and increasing clinical popularity, in-person CBT-I approaches have not been able to make a meaningful dent in the high volume of insomnia patient care. One primary reason for this is a lack of patient access to the treatment resulting

from a shortage of appropriately trained providers (Garland, Trevino, et al., 2021; Thomas et al., 2016). While in-person CBT-I is very effective at treating insomnia, it puts a heavy demand on limited clinical resources such as clinician time and treatment space.

Lack of access to appropriate first-line treatments for insomnia results in many patients receiving no care at all or receiving treatments with less empirical support. Davy and colleagues (2015) conducted interviews and focus groups with a purposive sample of patients and health professionals to determine their experiences and perspectives on primary care insomnia treatment. Practitioners in this study described providing a form of stepped care for insomnia, however this did not include CBT-I; instead, it typically consisted of a printed sleep hygiene information sheet followed by consideration of pharmaceutical options (Davy et al., 2015). While sleep hygiene is considered a component of CBT-I, evidence supporting its use as a standalone treatment for insomnia is poor (Edinger et al., 2021).

When sleep hygiene recommendations are not sufficient, many practitioners will consider pharmaceutical approaches for managing poor sleep in cancer survivors. Casault and colleagues (2012) conducted a survey of 1,984 patients who had been treated for breast, prostate, colorectal, or lung cancer at L'Hôtel-Dieu de Québec to determine prevalence of hypnotic medication use among cancer survivors and associated risk factors. The survey revealed that 40.8% of the participants had been prescribed hypnotic medications, of which 22.6% of the sample reported using at least once per week (Casault et al., 2012). Prescriptions were primarily for benzodiazepines (78.5%) with sedative properties (e.g., lorazepam). Risk factors for hypnotic medication use included past chemotherapy (OR = 1.71), current (OR = 2.28) or past (OR = 1.98) psychological comorbidity, and increased insomnia severity (OR = 1.89) (Casault et al., 2012). More recently in 2020, researchers analyzed data from a nationwide survey of 1,903

American cancer survivors at an average of 9 years post-diagnosis, finding sleep medication use reported by 28% of the sample (Strollo et al., 2020).

Pharmaceutical treatments for insomnia can be effective in improving certain sleep indices such as SOL, although they carry a higher risk for adverse events and may not actually work to improve patient QoL at all. Investigating the effects of insomnia and sleeping medication use on physical and mental health related QoL, Sasai and colleagues (2010) found that use of sleep medications was associated with significantly lower physical and mental health related QoL regardless of whether the participants had insomnia or were good sleepers. A study of physician attitudes and preferences regarding pharmaceutical insomnia treatment revealed that frontline providers have reservations about prescribing certain hypnotic medications such as benzodiazepines for routine insomnia care (Sorscher & Siddiqui, 2016). Interviewing cancer survivors with insomnia, Garland and colleagues (2019) found that use of sleep medications was a common insomnia-perpetuating factor. Participants were reluctant to use sleep medications due to concerns about side effects and efficacy, but felt they had few options (Garland et al., 2019).

With their primary treatment options remaining largely insufficient or inaccessible, cancer survivors with insomnia deserve more options that are accessible and have evidence for their effectiveness that are supported by research evidence. As mentioned, while CBT-I treatment has a large body of evidence to support its effectiveness, it remains very difficult for most patients to access due to a lack of trained providers (Thomas et al., 2016).

#### mHealth for Insomnia Treatment

Some researchers have begun to explore mHealth as a means of increasing access to evidence-based insomnia care. The term "mHealth" refers to the use of information and

communications technology (e.g., internet, smartphones) to support and improve health research, treatments and outcomes. In theory, internet-delivered sleep therapies may represent an improvement over face-to-face treatments when it comes to cost and accessibility. Internet delivered therapies can be administered widely and cheaply to any patient who owns a smartphone and is able to access the internet. Fully-automated treatments can be scaled infinitely with little to no additional investment cost, while partially automated treatments that require a degree of therapist support may allow therapists to spend their time more efficiently, servicing a greater number of clients in a given amount of time. Because treatment is delivered via the internet, both parties save costs involved with in-person appointments, such as those reserved for renting a treatment space, travel costs, missed work, and childcare arrangements.

One obvious concern with internet and smartphone delivered sleep therapies is that these treatments may be unsuitable for patients who lack access to the internet, do not own a smartphone capable of displaying mobile apps, or lack the technological skill necessary to engage with an app. Raghunathan and colleagues (2018) conducted a survey of 631 cancer patients to determine the prevalence of mobile technology use and interest in smartphone applications for supportive care. Of these participants, 466 (74%) reported regular use of smartphones and mobile technology, and 242 (39%) reported an interest in smartphone applications for supportive care. Participants under 45 were more likely to use mobile technology compared with older participants. Non-white participants and participants under 45 were more interested in receiving information through smartphone apps (Raghunathan et al., 2018).

More recently, Potdar and colleagues (2020) conducted interviews with 151 cancer patients at a medical center in the United States to understand participants' perceptions of the barriers and facilitators of current and desired use of technology in healthcare. The strongest

predictor of health app utilization was access to the technology (e.g., internet, smartphone), with the researchers finding that 73.5% of participants had daily access to the internet, while 68.2% owned a smartphone capable of displaying applications (Potdar et al., 2020). Utilization of a daily mHealth app was higher in college educated participants (OR; 2.78, p<0.01), and lower in older participants (OR; 0.05, p<0.01). Given that trends in smartphone ownership and internet access are increasing, this data shows that internet and smartphone delivered treatments are accessible to a large and growing proportion of cancer survivors.

Another concern with internet and smartphone delivered sleep therapies is that remote or automated treatments may not be as effective as those delivered in person by a trained practitioner. Zachariae and colleagues (2016) conducted a systematic review and meta-analysis of 11 randomized controlled trials involving 1460 participants that investigated the efficacy of internet-delivered CBT-I on insomnia severity, sleep efficiency, and other sleep indices. The researchers found that internet delivered CBT-I was associated with significant posttreatment improvements in insomnia severity (*Hedges* ' g=1.09) and sleep efficiency (g=.58), as well as SOL (g=0.34), wake after sleep onset (g=0.45), number of nocturnal awakenings (g=0.24), total sleep time (g=0.29), and subjective sleep quality (g=0.49; Zachariae et al., 2016). Treatment effect sizes for the primary outcomes insomnia severity and sleep efficiency were comparable to those obtained by face-to-face CBT-I, and remained significant at follow up (4-48 weeks; Zachariae et al., 2016). These results show that internet delivery of CBT-I is a viable delivery option capable of producing significant improvements in insomnia symptoms.

# Sleep Apps Available for Download

Despite this clear advantage in accessibility, mobile app repositories are inundated with a preponderance of official and unofficial apps for every imaginable purpose, with little oversight regarding quality of content. Finding an evidence-based sleep app on the app store is a task akin to finding a needle in a haystack. While there exists a preponderance of apps available for download that purport to help users with their sleep, a majority of these apps were not built according to evidence-based treatment guidelines.

Choi and colleagues (2018) identified over 2,000 apps across four app stores that were potentially related to sleep self-management, although the vast majority of these apps were little more than alarms or white noise generators. The review ultimately concluded that few sleep selfmanagement apps meet acceptable criteria for content quality or functionality (Choi et al., 2018). Cancer survivors seeking sleep self-management apps through these channels are likely to be presented with an overwhelming array of options, most of which are unsupported by evidence.

**Evidence-Based Apps Delivering CBT-I.** The abundance of sleep apps available for download implies a large demand for internet-delivered sleep therapies. Recognizing this demand, sleep researchers have developed and disseminated a number of evidence-based sleep self-management apps in the past several years (Kuhn et al., 2022; Ritterband et al., 2022; Zhou et al., 2022), although none of these apps were developed with the unique needs of cancer patients and survivors in mind.

*Insomnia Coach.* Kuhn and colleagues (2022) recruited 50 US veterans with moderate insomnia symptoms to receive self-management CBT-I through the Insomnia Coach mobile app to examine the feasibility, acceptability, and potential efficacy of the app. Participants were randomized to 1) receive 6 weeks of CBT-I through Insomnia Coach, or 2) a wait-list control condition. The app was found to be feasible to use, with 75% of participants engaging with

active elements for the duration of the 6 weeks, as well as highly acceptable to participants based on self-report and interview responses (Kuhn et al., 2022). Findings also provided preliminary evidence of efficacy in treating insomnia, with a larger proportion of participants in the Insomnia Coach arm (28%) than wait-list arm (4%) achieving clinically significant improvement at posttreatment (p = .049), as well as significant treatment effects for insomnia severity (d = -1.1, p = .001), SOL (d = -0.6, p = .021), sleep quality (d = -0.9, p = .002), and depression symptoms (d = -0.8, p = .012; Kuhn et al., 2022). Ultimately, these findings provide preliminary evidence that a CBT-I based self-management app is feasible and acceptable for veterans with moderate insomnia and shows promise with regards to efficacy in improving insomnia severity.

*SHUTi.* Similarly, Nazem and colleagues (2023) randomized 231 USA veterans with insomnia to receive a self-guided internet-delivered CBT-I program (SHUTi; Sleep Healthy Using the Internet) or an Insomnia Education Website (IEW) providing non-tailored insomnia information to evaluate the efficacy of unguided internet CBT-I in this population. Participants completed online assessments at baseline, posttreatment, 6 months posttreatment, and 1 year posttreatment. Compared with the IEW group, the group receiving SHUTi reported significantly greater improvements in ISI scores at baseline (-3.47, 95%CI:[-4.78, -2.16]), 6 months (-3.80 95%CI:[-5.34, -2.27]), and 1 year (-3.42, 95%CI:[-4.97, 1.88]; Nazem et al., 2023). These results show that CBT-I delivered through the SHUTi program was associated with both short-and long-term improvements in insomnia severity, further demonstrating the ability of mHealth solutions to effectively address unmet insomnia treatment demands in vulnerable populations.

# Tailoring Insomnia Treatment to Cancer Survivors

While preliminary trial results for CBT-I based mHealth insomnia interventions are promising, none of the aforementioned apps has been designed with the unique experiences, challenges, and roadblocks faced by cancer survivors in mind. Moreover, with the exception of CBT-I Coach which is maintained by the US department of Veterans Affairs, evidence-based CBT-I apps have been made accessible exclusively through research or referral, and are not available to the general public. Cancer patients face specific challenges related to their cancer such as pain, fatigue, and anxiety, and may benefit from an accessible, tailored treatment approach that addresses these issues (Zhou et al., 2017).

**Technology Acceptance Model (TAM).** When developing new technology-based tools and medical solutions, it is important to follow best established practices to maximize adoption of and engagement with the novel intervention. According to the Technology Acceptance Model (TAM), developed to describe the factors influencing adoption of novel technologies, the primary factors that predict attitudes toward a given technology are its perceived usefulness (individual's belief that using a system would be beneficial) and its perceived ease of use (individual's belief that using a system would be free of effort; Davis, 1985). The TAM has been used widely as a theory of information technology adoption in numerous fields including healthcare, where it is considered an accepted theory of technology adoption (Holden & Karsh, 2010).

**User-Centered Design (UCD)**. In order to engage potential users and increase the likelihood of effectiveness, novel mHealth applications should be developed following a user-centered design process. User-centered design (UCD) is an evidence-based approach for the

development of new technological applications that considers the needs, preferences, and understanding of a specific group of target end-users. Many health apps are designed based on existing healthcare constructs, without appropriate consideration for their new context; these apps may not be as effective as those that involve the end-user in the design process (McCurdie et al., 2012). Designers may have assumptions that are not validated by primary end-user input, leading to designs which may lack key components, compromising the effectiveness of the intervention and its evaluation (McCurdie et al., 2012). With UCD, target end-users are involved and engaged at all design stages: informing decisions about the scope and features of the application, testing and refining the user interface, and ultimately assessing the usability and effectiveness of the final product. Inclusion of end-user feedback throughout the intervention design process is a way to ensure inclusion of key features and functionality, maximize the perceived usefulness and usability of the final app, and ultimately ensure successful evaluations of its efficacy.

# iCANSleep

iCANSleep is an evidence-based insomnia treatment smartphone app based on CBT-I that is tailored to the unique needs and preferences of cancer survivors. iCANSleep was developed to address the aforementioned gaps in sleep-focused survivorship care by providing an easily accessible and affordable drug-free insomnia treatment.

iCANSleep will implement an established CBT-I protocol, tailored to the needs and preferences of cancer survivors identified from the user needs assessment. Core components of CBT-I intervention, including education, sleep restriction, stimulus control, and cognitive restructuring, will be supplemented with optional modules included to address common comorbidities of cancer patients (i.e., pain). The primary functions of iCANSleep will
include: 1) Daily sleep diary with the option to link a consumer device (e.g. fitbit); 2) Sleep and symptom self-assessment; 3) Personalized electronic feedback (delivered via chatbot) based on sleep diaries and self-assessment.

# **Objectives**

The primary objective of this study is to collect qualitative information about the experience of insomnia in cancer survivors and its impact on their quality of life, including their physical and psychological health, social and occupational functioning. A secondary objective is to gather qualitative information about the needs and preferences of cancer survivors regarding a self-guided insomnia treatment smartphone app.

#### Methods

# **Participants**

Participants in this study were considered eligible if they had been diagnosed with cancer at any point in their lives and also previously or currently experience insomnia. Participants with past or current insomnia (as defined by an ISI score >= 8) were eligible for participation. All recruitment materials were produced and distributed in English, and participants were required to speak English to enroll in the study. A target sample size of about 20 participants was selected based on past studies performing needs assessments through semi-structured interviews, as samples of this size often achieve adequate thematic saturation, in which further interviews provide limited novel information and simply reinforce findings from previous interviews (Hennink et al., 2017; Radcliffe & Lester, 2003). Cancer survivors were recruited through multiple channels for this study. Participants in past studies with the Sleep, Health, and Wellness Laboratory at Memorial University of Newfoundland who had agreed to be contacted for future research opportunities were sent information about the study and offered an opportunity to participate. Other participants responded to advertisements on social media or on a bulletin board in a cancer treatment center in St. John's, NL. Information about the study was also shared with community groups such as Hope Cope and Cancer Chat Canada who disseminated it within their networks. Interested participants contacted the lab by email or phone and were screened for eligibility by telephone before enrolling.

## Measures

#### **Demographic Questionnaire**

Participants self-reported demographic information as well as information pertaining to their history with cancer and cancer treatments. The demographic information that was collected included gender, age, number of years and highest level of education, employment status, household income, province of residence, relationship status, and number of children. The cancer-related items asked participants to report the type, site, and stage of their cancer at its initial diagnosis, their current treatment/disease status, and to list the cancer treatments they had received. Lastly, participants reported the model of their currently owned mobile phone, and whether they considered this device to be a "smartphone."

### Insomnia Severity Index

The Insomnia Severity Index (ISI) is a 7-item scale used to screen participants for the presence and severity of insomnia symptoms. ISI items are scored on a 5-point scale, with higher scores representing greater symptom severity. Low scores ranging from 0 to 7 indicate no presence of insomnia, while scores in the range of 8 to 14 indicate the presence of subthreshold insomnia. Scores of 15 to 22 indicate moderate clinical insomnia, while scores in the 22 to 28 range indicate severe clinical insomnia. The ISI has been validated among cancer patients, provides strong internal consistency and temporal stability, correlates well with various measures of sleep quality, and is sensitive to therapeutic changes (Michaud et al., 2021; M.-H. Savard et al., 2005).

# Smartphone Self-Efficacy Scale

The Smartphone Self Efficacy Scale (SSES) was used to assess participant comfort and familiarity with smartphone technology (Aktay, 2018). The original SSES is a 20-item Likert scale that assesses an individual's belief in their own capacity to accomplish tasks using a smartphone. Each item is scored on a 5-point scale from 1 (Strongly Agree) to 5 (Strongly Disagree), with lower scores indicating higher smartphone self-efficacy. The scale was developed in Turkish, though the English translated version was used in this study. Item 12, "I can share internet-based mobile on my smartphone with other wireless devices" was identified as having confusing wording (perhaps referring to the practice of 'hotspotting', and intended to read as 'mobile-based internet') and was subsequently removed from the scale, leaving a final total of 19 items.

#### Semi-Structured Interviews

Semi-structured interviews were conducted by the author remotely with participants primarily over Webex videoconferencing software, lasting roughly 30 minutes each. Two interviews were completed by telephone due to technical issues. Interview topics (See Appendix A) comprised participants' experiences with insomnia and insomnia treatment, their ownership and use of smartphones and mobile applications, as well as their specific needs and preferences in an insomnia-treatment mobile app. Participants who completed the interview were compensated for their time and contribution with a \$15 digital gift card.

# Data Handling

Interviews were recorded using the Webex record meeting function. Recordings of interviews were then transcribed using NVivo transcription software, and the transcriptions were cleaned and reviewed manually by the author to ensure accuracy and consistency with audio recordings. The two interviews that took place over the telephone were unable to be transcribed as the recording quality was too poor to be coherent.

## Transcript Data Analysis

Interview transcripts were analyzed and recurrent themes were identified through a process of thematic analysis. Thematic analysis is a form of qualitative data analysis that is used in psychology and a range of disciplines to analyze patterns in the data and organize them into overarching themes (Clarke & Braun, 2017). This process involves interpreting, identifying, and categorizing the major ideas and concepts in a passage (codes), and noticing which ideas and concepts are repeated or more central to the experience of interest. Codes are the smallest units of analysis capturing important features of the data, ranging from a single sentence or phrase to a

paragraph in length. These codes are then further organized categorized into overarching core ideas, known as themes. This process requires multiple reflexive iterations of transcript review, as categories are refined and restructured as more data is analyzed. Additionally, the process is non-linear as codes may be established and later updated or refined to fit with a new interpretation of the data.

The first step in the process of thematic analysis for the qualitative interviews was for digitally generated transcripts to be manually cleaned and reviewed for accuracy. To accomplish this, the author manually reviewed each interview recording alongside the transcript and edited any mistakes. To conserve time, transcripts were refined with the objective of preserving the meaning and intent of the speaker, rather than create a verbatim record of all utterances. On occasion, filler words ("umm", "uhhh", repeated words, etc) were left out, and specific rules for punctuation (quotation marks, question marks, exclamation marks, etc.) were corrected only when deemed essential.

After the transcripts had been cleaned and manually reviewed, a first round of coding was conducted which consisted of identifying meaningful passages and categorizing them. For example, a participant speaking about how a nurse told them to keep their bedroom environment cool might be coded as "advised to keep bedroom cool," while a comment about their concerns being brushed off by their oncologist might be recorded as "sleep concerns minimized by professional." The purpose of the first round of coding is to familiarize oneself with the data and identify the major ideas and concepts being expressed, ultimately ending up with a tentative list of codes.

The next step was to refine and reorganize the codes into themes which involved both categorizing codes into larger themes and defining these themes, but also returning to the

transcripts to reinterpret and revise the original codes to fit the new thematic organization. This step proceeds reflexively in a non-linear manner until all the codes have been categorized into themes and all the themes have been defined in relation to the research question. For example, the code "advised to keep bedroom cool" might be revised to "given sleep hygiene recommendations" to fit in the same category as other passages from other transcripts that described a similar but distinct recommendation (e.g., no caffeine after noon). Additionally, the code "sleep concerns minimized by professional" might be further categorised under the theme "Professional help sought for insomnia," which includes other instances of participants speaking about their interactions with healthcare professionals related to insomnia. Other codes under this umbrella might include "prescribed hypnotic medications," "referred to sleep specialist," or "given sleep hygiene recommendations."

# Results

## **Participants**

A total of 22 eligible participants responded to recruitment materials and were enrolled in the study. Two participants were successfully interviewed, however technical issues with the audio recordings of these interviews rendered the transcripts unusable, and these participants were excluded from the final dataset. The final sample of 20 participants ( $M_{age} = 58.65 \pm 15.68$ ) included 14 female and 6 male participants.

### **Demographics**

**Residence.** Participants resided primarily in Newfoundland (35%), Nova Scotia (30%), and New Brunswick (20%), with a couple residing in British Columbia (10%) and one in Ontario (5%). The majority of the sample reported living in an urban area (60%), while a minority described their residence as rural (40%).

**Highest Level of Education.** Half (50%) of the sample reported a postsecondary certificate as their highest level of education. One participant (5%) reported having a doctorate degree, while 25% reported a master's degree as their highest level of education. Finally, the remaining 20% of the sample reported receiving some postsecondary education.

**Employment Status.** The majority of the sample was retired (55%), followed by those working in full-time positions (35%). Lastly, 2 participants reported being in receipt of disability benefits (10%).

**Relationship Status.** The vast majority of participants reported being "married" (80%) or in a "committed long-term relationship" (10%). One participant reported being "widowed" (5%), while the final participant reported their relationship status as "other" (5%).

# **Cancer History**

Participants reported several different types of cancer diagnosis including breast (35%), melanoma (10%), kidney (5%), lung (5%), blood (5%), thyroid (5%), ovarian (5%), abdomen (5%), lymph node (5%), and multiple initial diagnoses (15%). The most common cancer stage at diagnosis was stage II (35%), followed by stage III (20%), stage I (15%), unknown (15%), stage IV (10%), and finally stage 0 (5%). Most of the sample reported having completed cancer treatments and having no evidence of disease (80%), while 10% reported actively receiving cancer treatments, and 10% reported living with active metastatic disease. Participants received several treatments to manage their cancer (with some participants receiving multiple forms),

including surgical excision (85%), radiation therapy (70%), chemotherapy (55%), hormonal treatments (20%), and other treatments (45%).

#### **CBT-I** History

Of the final sample of 20 participants, 50% reported receiving some form of CBT-I in the past, while the remaining 50% reported no experience with sleep-focused talk therapy.

#### Smartphone Ownership

The majority of participants in this study reported owning a smartphone (85%), with 10% being unsure, and 5% reporting that they do not own a smartphone. The most common phone model was the iPhone (60%), followed by Android (25%), and landline (15%).

#### Smartphone Self Efficacy

Participants scored an average of 28.5 (range=[19-59]; SD=12.66) on the SSES, with six scoring a 19, the lowest possible score indicating the maximum level of smartphone self-efficacy. No item on the scale received less than 70% "Agree" or "Strongly Agree" responses, indicating that most cancer survivors felt confident completing each task. The results did reveal a small minority of cancer survivors (15%; 3/20) who were less confident in their smartphone skills, responding "Neither Agree nor Disagree", "Disagree", or "Strongly Disagree" to 50% or more of the items. Overall, the results showed that cancer survivors as a group were confident in their ability to complete tasks using smartphones, although there is a small proportion of survivors with much less confidence in their skills. Response frequencies by item and by participant can be found in Appendix B.

# Table 1.

Demographic Questionnaire Results

Gender	Ν	%
Female	14	70
Male	6	30
Age	N	%
18-29	3	15
30-49	2	10
50-59	2	10
60-69	7	35
70+	6	30
Province	N	%
NL	7	35
NS	6	30
NB	5	20
BC	2	10
ON	1	5
Highest Level of		• •
Education	Ν	%
Doctorate Degree	1	5
Master's Degree	5	25
Postsecondary Certificate	10	50
Some Postsecondary		
Education	4	20
Employment Status	Ν	%
Retired	11	55
Working Full-Time	7	35
On Disability	2	10
Relationship Status	Ν	%

Married	16	80
In a Committed Long-	2	10
	2	
vvidowed	1	5
Other	1	5
Rural / Urban Status	Ν	%
Rural	8	40
Urban	12	60
Cancer Type	Ν	%
Breast	7	35
Melanoma	2	10
Kidney	1	5
Lung	1	5
Blood	1	5
Thyroid	1	5
Ovarian	1	5
Abdomen	1	5
Lymph Node	1	5
Multiple	3	15
Cancer Stage at		0/
Diagnosis	n	%
Stage 0	1	5
Stage I	3	15
Stage II	7	35
Stage III	4	20
Stage IV	2	10
Current Disease Status	N	%
Completed		
Treatments with no evidence of disease	16	80
Actively Receiving	2	10

# Treatment

Living with Metastatic Disease	2	10
Cancer Treatment History	N	%
Surgery	17	85
Radiation Therapy	14	70
Chemotherapy	11	55
Hormone Therapy	4	20
Other	9	45
Insomnia Treatment History	Ν	%
Received CBT-I in the past	10	50
Never received CBT-I	10	50
Smartphone Ownership	N	%
Owns Smartphone	17	85
Does not Own		
Smartphone	1	5
Unsure	2	10
Phone Model	Ν	%
iPhone	12	60
Android	5	25
Landline	3	15
Gender	N	%
Female	14	70
Male	6	30
Age	N	%
18-29	3	15
30-49	2	10
50-59	2	10
60-69	7	35
70+	6	30
Province	N	%

NL	7	35
NS	6	30
NB	5	20
BC	2	10
ON	1	5
Highest Level of Education	N	%
Doctorate Degree	1	5
Master's Degree	5	25
Postsecondary Certificate	10	50
Some Postsecondary Education	4	20
Employment Status	Ν	%
Retired	11	55
Working Full-Time	7	35
On Disability	2	10
<b>Relationship Status</b>	Ν	%
Married	16	80
In a Committed Long- Term Relationship	2	10
Widowed	1	5
Other	1	5
Rural / Urban Status	N	%
Rural	8	40
Urban	12	60
Cancer Type	N	%
Breast	7	35
Melanoma	2	10
Kidney	1	5
Lung	1	5
Blood	1	5
Thyroid	1	5
Ovarian	1	5
Abdomen	1	5
Lymph Node	1	5
Multiple	3	15
Cancer Stage at Diagnosis	n	%
Stage 0	1	5
Stage I	3	15

Stage II	7	35
Stage III	1	20
		10
Current Disease Status	N	%
Completed Treatments with no evidence of disease	16	80
Actively Receiving Treatment	2	10
Living with Metastatic Disease	2	10
Cancer Treatment History	N	%
Surgery	17	85
Radiation Therapy	14	70
Chemotherapy	11	55
Hormone Therapy	4	20
Other	9	45
Insomnia Treatment History	N	%
Received CBT-I in the past	10	50
Never received CBT-I	10	50
Smartphone Ownership	N	%
Owns Smartphone	17	85
Does not Own Smartphone	1	5
Unsure	2	10
Phone Model	N	%
iPhone	12	60
Android	5	25
Landline	3	15

# Semi-Structured Interviews

Semi-structured virtual interviews were conducted and recorded during the spring of 2022 using Webex videoconferencing software. On two occasions, technical difficulties

prevented participants from being able to join the Webex videoconference, and the interview was instead completed over the telephone. Recordings were transcribed using NVivo transcription services and were manually compared against the recordings for accuracy (See Appendix A for the interview guide).

# Cancer Survivors' Experiences of Insomnia

Theme 1: Precipitants of Insomnia. Cancer survivors with insomnia described a variety of precipitating events and situations that led to their initial bouts of insomnia, the majority of which (75%) were related in some way to cancer. A quarter (5/20) of the sample reported experiencing lifelong difficulties with insomnia, though these participants found that their insomnia did worsen after their cancer diagnosis. According to 45% (9/20) of the participants, their insomnia was precipitated by a stressful event or a period of increased stress and anxiety. Stressors related to cancer (e.g., receiving a diagnosis, ruminating about future health and finances, etc.) were identified as the primary insomnia precipitating stressor by 8 participants. A quarter of participants (5/20) also identified stressors that were unrelated to cancer (e.g., births/deaths in the family, menopause, etc.), often in conjunction with cancer-related stressors. Lastly, about a third of participants listed side effects from cancer treatments (e.g., pain from surgery, hot flashes from hormone therapy) as the cause of their initial bout of insomnia.

Subtheme 1: Pre-Existing Insomnia. For 25% (5/20) of participants, insomnia has been a lifelong issue that they have dealt with since childhood. These participants felt that their sleeping difficulties 'ran in the family' or were an otherwise normal part of life. "I think I've had

some trouble sleeping throughout my life, but I think most people do, " described one survivor. "I don't know that it's highly abnormal or where it falls in that range, but certainly within the past few years, it worsened in that (...) I think some of it started with menopause, but I think it got worse recently. Since cancer treatments." While these participants report that their insomnia worsened slightly in response to life stressors such as menopause, cancer diagnosis, or cancer treatments, they felt strongly that their sleeping difficulties preceded the stressful events.

Subtheme 2: Anxiety & Stress. Forty five percent (9/20) of participants reported their insomnia began after a stressful event or a period of increased stress and anxiety. Participants described precipitating stressors specifically related to their diagnosis of cancer, as well as non-cancer related stressors such as the death of a family member or the birth of a child. "There was a lot of stress at that particular time," said one participant, recalling her first sleepless nights early in her recovery journey. "I was diagnosed with cancer. A lot of stress in the family with children." Like this survivor, most participants' cancer diagnoses caused added stress on top of the normal stresses of everyday life, compounding the issue.

Subtheme 2a: Related to Cancer Diagnosis. 40% (8/20) of participants reported that their insomnia was initially precipitated by the stress related to receiving a diagnosis of cancer and the uncertainty regarding its effects on their health, family, and finances. Participants reported experiencing rumination, anxiety, and a sense of losing control over their lives, which interfered with sleep. "...*The anxiety is definitely related to my cancer diagnosis with that sense* of kind of losing that sense of control and having kind of like the worst outcome." explained one participant, describing the effects that their cancer diagnosis had on their mental state. "Having been presented with an issue and then having the worst outcome of that issue kind of happen at the time... I definitely struggle with a sense of kind of catastrophizing things in my brain, which is generally what happens when it comes to going down to sleep is that I just can't shut my brain off of the things that I'm worrying about.

Like this participant, 25% (2/8) of cancer survivors whose insomnia was precipitated by cancer diagnosis and/or treatment did not initially attribute their trouble sleeping to the cancer, and only retrospectively made the connection when reflecting on their experiences with insomnia and cancer. Making matters worse for these previously good sleepers, their issues with insomnia were unlikely to remit after completion of cancer treatment. "*I thought it would be like a temporary thing, you know, with the added stress and whatnot,*" remembered one survivor. "*But it did went on for like, you know, probably a couple of years after I was finished treatment and everything.*"

Subtheme 2b: Unrelated to Cancer. Participants also reported insomnia precipitating stressors that were not related cancer, although these were less common, reported by only 25% (5/20) of participants, and often reported in conjunction with cancer-related stressors. Non-cancer related stressors that participants attributed their insomnia to included family stress (births, deaths, and family health concerns), menopause, and occupational stress, especially rotating shift work.

*Subtheme 3: Treatment Side Effects.* 35% (7/20) of the cancer survivors interviewed in this study attributed their initial bouts of insomnia primarily to the effects of treatments they had received to address their cancer. Treatments that participants identified as sleep interfering or

insomnia-precipitating included chemotherapy, radiation therapy, hormone therapy, immunotherapy, and surgery.

Because participants were receiving cancer treatments during a stressful period in their life, many participants were unclear as to the specific stressors causing their insomnia. One participant was not completely sure whether their insomnia was in part related to post-diagnosis stress, or due entirely to treatment with chemotherapy and surgery. Another participant reported feeling the need to get more sleep following her radiation treatment, but only made the connection between insomnia and cancer treatment after enrolling in the study and learning that insomnia is common among survivors. As a third participant describes, the cancer diagnosis did not have much of an effect on her sleep, but she began experiencing multiple disruptions and nighttime awakenings following chemotherapy. Others described sleeping normally following the diagnosis, but experiencing sleep disturbances after starting cancer treatments. "I didn't notice a whole lot of sleep effect of [cancer] until about six or seven months after I was diagnosed," reported one participant who had been diagnosed with stage II breast cancer. "So I started chemotherapy May of 2015, and around that time I did actually find that my sleep was interrupted. So prior to cancer, I- I'd go to bed and I'd sleep solid definitely, 8-10 hours. And then, like I said, May to June was when I really started to notice that I'd wake up several times during the night." Like this participant, several cancer survivors were confident that their insomnia was precipitated by the cancer treatment itself, and not stress related to diagnosis or in other areas of their life. For example, one participant similarly reported sleeping well immediately following their diagnosis with cancer, and only several months later upon starting chemotherapy did she notice a decline in sleep quality.

Another participant had a negative experience taking the hormone therapy drug Letrozole, an aromatase inhibitor used to treat breast cancer. "Well, they put me on this five year pill Letrozole, and the moment I went on that one, my sleep was just gone," she remembered. "Like I used to wake up with hot flashes all the time, and thank God, I went off it in January... And now I find say, like, I'm sleeping better since I went off it, like it totally wrecked my sleep, eh?" For this participant, one significant side effect of hormone therapy was frequent sleepinterfering hot flashes. Following cessation of the medication, the hot flashes stopped occurring, and her sleep subsequently improved.

Theme 2: Impact of Insomnia on Daytime Functioning. Insomnia had a significant and negative impact on participants' daytime functioning. In addition to reporting impaired physical functioning (feeling sick, loss of strength, etc.), participants described significant difficulties with perceived cognitive impairment (e.g., brain fog, memory loss). Cancer survivors also described being unable to participate in social activities because of their insomnia or their aforementioned physical or social impairment.

*Subtheme 1: Physical Impairment.* Cancer survivors described several negative effects that insomnia had on their physical functioning. These included feeling weak (10%), having no energy or motivation to exercise or do activities (10%), needing to take additional or earlier naps than usual (5%), and even feeling physically sick (10%). One participant reported noticing a connection between missing sleep and developing a sore throat a few days later. *"[Insomnia] has a big impact,"* another participant explained, *"I just can't. I get to the point where I'm almost* 

physically sick because I'm so tired that I just can't do anything. You know, it really does have an impact."

Subtheme 2: Cognitive Impairment. Perceived cognitive impairment was a common complaint from cancer survivors suffering from insomnia and was described in several ways. Most commonly, participants complained of "brain fog," or an inability to concentrate or think clearly (35%; 7/20). Complaints of excessive daytime sleepiness (25%; 5/20), fatigue (20%; 4/20), irritability (15%; 3/20), and poor memory (10%; 2/20) were common and distressing to cancer survivors. While many participants described their cognitive difficulties in terms of difficulties meeting their occupational demands, two participants (10%) were forced to stop working or go on a leave of absence due to their cognitive impairment. "The impact on my life is that I am quite tired at times," explained one participant, describing the effects that her insomnia had on her ability to work and participate in her normal activities. "I won't say I'm not involved in much as I used to be, I am, but I'm not putting the… I'm not giving the output that I used to give. I would say a lot of it is due to being tired."

Subtheme 3: Social Impairment. Three participants described significant negative effects of insomnia on their social life. One participant detailed how he was forced to structure his life, including social events, according to his sleep medication schedule, as he became impaired after taking the medication and would be unable to drive for several hours, limiting his ability to make flexible social plans. "Once you take the pill, to me, it's like you shouldn't be driving, you shouldn't be doing anything like that. You're going to go to sleep then." Another participant described her difficulties making plans to meet with friends as her inability to sleep well

combined with her early work schedule made late-night hangouts untenable. One final participant reported that her insomnia and subsequent "gloomy" mood made her much less sociable than she was before, lacking the energy to engage in social activities the way she used to.

**Theme 3: Experiences of help-seeking for their insomnia.** While 30% (6/20) of the cancer survivors in this study reported never having sought help for their insomnia for several reasons, the remaining 70% (14/20) reported contacting various health professionals with a variety of outcomes. These participants sought help with their sleep from oncologists, primary care doctors, nurse practitioners, and nurses, and received several forms of treatment, referral, and advice, with varying levels of success. The most common outcome from this discussion was a form of pharmacotherapy which occurred in more than half the cases (57%; 8/14), followed by talk therapy including CBT-I (50%; 7/14), advice or behavioural recommendations that were ultimately perceived as ineffective (29%; 4/14), or minimization and dismissal of the issue as important (29% 4/14).

*Subtheme 1: Pharmacotherapy.* Among the participants who sought professional help for insomnia, 57% (8/14) received some form of pharmaceutical medication. One participant was advised to take over the counter painkillers (e.g., acetaminophen) to manage sleep-interfering pain. While not all participants who were prescribed a "sleeping pill" were able to recall the name of the medication, drug names that were mentioned included benzodiazepines (lorazepam), tricyclic antidepressants (doxepin, amitriptyline), and nonbenzodiazepine sedative-hypnotics (zopiclone). Remarkably, all 7 participants who were prescribed a "sleeping pill" reported one or more negative side effects that required tapering (14%; 1/7) or cessation (86%; 6/7) of the medication. These negative side effects included tolerance (requiring higher doses to achieve the same effect), dependence (relying on the medication in order to get any sleep), carryover effects such as drowsiness and cognitive impairment, and an inability to get restful sleep. *"[Sleep medicine] worked for a while and then that started, you know, not working,"* described one participant. *"So then you go back into this whole cycle again of you're now dependent on something that's not working, but you can't sleep without it."* 

Many participants had similar experiences with sleeping pills, where the initial relief from insomnia provided by the medication quickly diminishes as tolerance to the medication builds, and soon the participant faces the same insomnia symptoms as before with the added complication of being dependent on the medication. "*My doctor started me on lorazepam just to help kind of reduce the stress and help me sleep. And at first it worked*," reported another participant, describing the diminishing returns brought by the benzodiazepine over time. "So, *you know, I started on lorazepam and I've got about five hours of sleep and and within a month, month or so, I'll just kind of back to four and a half hours. And I was to four hours and stayed on lorazepam much longer than I should have, really. So I end up getting an addiction to it. So it wasn't doing anything for me, but if I didn't take it, geez, I would only sleep about two hours and I would wake up.*"

As the positive effects of the sleeping medication begin to wane, participants were back to square one, with some participants resorting to taking higher doses of the drug to achieve the same effect. "*And then, so then what I was doing is I was taking, like many zopiclone,*" described one participant, recounting the events that lead to her doctor recommending cessation. "*Like, three, four zopiclone. My doctor said 'Oh good god, no.*""

In addition to difficulties with tolerance, dependence, and addiction, many cancer survivors complained that sleeping pills did not help them achieve a restful sleep. "*I couldn't sleep basically without the pill and I was kind of tired of taking the pill*," expressed one participant. "*I felt better when I wasn't on the pill for about three months or more and I felt rested when I got up. With the pill, you don't feel rested. You did sleep, but you don't feel rested... You get up just as tired as you went, but you did have five or six hours sleep.*"

Subtheme 2: Psychotherapy. Fifty percent (7/14) of cancer survivors seeking professional help for their insomnia were referred to receive some form of evidence-based psychotherapy. These included both insomnia focused CBT-I (71%; 5/7), and CBT for anxiety and depression related to cancer (29%; 2/7). Of the 5 participants who received CBT-I, two reported finding it very beneficial. "I did do a sleep therapy thing and, you know, went through the process of getting up through the night and reading when I couldn't sleep and trying not to watch the clock, which I prayed I still do," reported another participant, one of two who found CBT-I to be only temporarily beneficial. "It helped for a while, but it didn't help for that much." The last participant to receive CBT-I perceived a mismatch between her own goals and the goals of the therapy, which led to her finding it ultimately unhelpful. "I've sought therapy to help, but it wasn't super helpful at all, to be honest," she described. "I don't think their choice of therapy and advice aligned with what I wanted... their advice is actually to get up when I wake up in the middle of the night at like two o'clock morning, do a few hours work and go back to sleep again. But that wasn't at all what I wanted to do."

Of the two participants who received CBT for cancer-related distress, only one reported finding it beneficial. Participants who found either form of therapy beneficial described learning

strategies to manage stress or specific situations related to insomnia such as meditation techniques or stimulus-control which they continue to find useful.

Subtheme 3: Ineffective Recommendations. Four cancer survivors who discussed their sleeping difficulties with their medical practitioners did not receive any treatment or specialist referrals and were merely offered advice that was ultimately perceived as insufficient or ineffective. "I've tried to seek treatment through primary care physicians as well, and things are generally kind of pushed aside and being like just the generic treatments," said one participant, describing her disappointment. "Don't use your phone before bed or, you know, just relax, take a bath before bed, but again. They're like, that's what you can Google."

Most recommended were aspects of sleep hygiene (75%; 3/4), which included things like avoiding caffeine and alcohol, limiting screen time before bed, and maintaining a dark, quiet sleep environment. Another participant who was told not to drink caffeine less than eight hours before bedtime and to exercise regularly, expressed her frustration at the paucity of these recommendations, saying "*I think it's common sense that I had already*." Participants followed these directives but felt that they were ultimately "common sense" recommendations that did little to address the root of their sleeping difficulties. One participant was advised to supplement with an over-the-counter melatonin supplement which they did not find to be effective.

*Subtheme 4: Minimization and Dismissal.* Troublingly, four cancer survivors who did discuss their sleeping difficulties with a medical practitioner did not receive any treatments or referrals, and instead had their experiences minimized or dismissed. Two were told that their sleeping difficulties were a normal part of undergoing chemotherapy or menopause and were not

offered any solutions beyond this explanation. "Oh, I mean, they just said that was just part of part of chemo," recalled one participant. "Part of what I was experiencing. Part of menopause. And there was nothing that could be done. Frustrating!"

Another participant who never had any issues sleeping before cancer but had family with sleeping difficulties was told his insomnia was likely genetic. Lastly, one participant was told that her sleeping problems and subsequent bodily discomfort should be attributed to aging. "*I'm exhausted, I'm tired,*" she remembers telling her oncologist. "*You know, all this thing is going on with me, my whole body aches and stuff.*' The oncologists' response was dismissive. "*You'll never, ever be 100 percent,*" she was told. "*You'll always have that 80 percent.* You're always going to feel only 80 percent."

Subtheme 5: Did Not Seek Professional Help. Thirty percent (6/20) of cancer survivors interviewed did not seek professional help to manage their insomnia. One participant recalled believing their insomnia would resolve itself after she finished her cancer treatment, deciding against seeking specific treatment for sleep. "I think because I thought it was going to be a temporary thing," she explained. "I thought once I get all these appointments over with that, then it would go back to normal, but it didn't."

Other participants felt it was not a serious enough issue to warrant medical attention. One participant who never reached out to his doctor, said *"I just kind of accepted that I just kind of had to live with it." "I didn't ask,"* said a third participant who struggled with sleep during the COVID19 pandemic. She went on to describe how social distancing and the disruptions to everyday life during that time limited her ability to seek help. "*You know, we were, we're in the* 

COVID thing and. Everything was just. Insane at that time, everything. Sleep, family life, work life like everything was chaotic for me then."

Lastly, one participant described the difficulty of seeking routine medical care for perceived "minor" issues while living in a rural community. "I live in a rural community herethere's not much, much here to do. Maybe if I lived in St John's somewhere I'd have checked into it further like that."

Theme 4: Self-directed efforts to resolve insomnia. Ninety percent (18/20) of participants reported taking one or more self-directed actions in an attempt to improve or resolve their insomnia. Half (10/20) of participants described making small to moderate changes in their behaviour that correspond to isolated CBT-I components. On the other hand, 25% (5/20) of participants described only implementing sleep hygiene recommendations, and a further 20% (4/20) of participants described engaging in counterproductive strategies that are known to perpetuate insomnia. Twenty percent (4/20) of participants also reported using a variety of mobile apps to help relax and wind down in the evening time before bed. Lastly, 25% (4/20) participants described implementing eclectic home remedies with no empirical basis.

Subtheme 1: Isolated CBT-I Components. Half of participants described implementing isolated CBT-I components as single-behaviour changes in an attempt to improve their sleep. Of these participants, 50% (5/10) reported implementing stimulus-control by leaving the bed when unable to sleep and engaging in a quiet activity such as reading. Thirty percent (3/10) described increasing their daytime activity level and avoiding daytime naps in order to increase their sleep drive at night. "I try not to sleep during the day because I find on the occasion that I do, say,

have a nap during the day, It's even more difficult to fall asleep at night, "described one participant. "So I think that's probably the only thing I've done is make sure of that, and I try to keep busy because of course, the more active I am, the more tired I am, I guess, and it's a little easier to sleep."

Another 30% (3/10) described reducing their time spent awake in bed by waiting until they were very sleepy to enter the bed and leaving the bed immediately upon their final morning awakening, also in an attempt to increase nighttime sleep drive. Lastly, 20% (2/10) of participants who implemented isolated CBT-I components reported using some form of relaxation technique, such as meditation or breathing exercises.

Subtheme 2: Sleep Hygiene. One fifth (4/20) of the sample reported only small making behavioural changes that correspond to sleep hygiene recommendations. Of these participants, 75% (3/4) described strict daily adherence to a bedtime/risetime schedule, 50% (2/4) described limiting their evening screen time, and one participant each reported avoiding alcohol, avoiding caffeine, and ensuring that bedroom temperature remains low. "*I'm pretty religious about trying to be in bed by 9:30 and get up at 5:30 a.m.*," said one survivor describing her nightly routine. "*I've been trying to reduce my screen time before I go to bed, reading instead. Sometimes works, sometimes doesn't. I love just being able to put my book that I'm reading on my tablet down and roll over and go to sleep.*"

Subtheme 3: Maladaptive Strategies. Concerningly, 20% (4/20) of participants reported taking directed action to improve their sleep that evidence shows may actually be counterproductive in that they act to perpetuate sleep system dysfunction. The most common

counterproductive strategy adopted by 15% (3/20) cancer survivors was to increase their nighttime sleep window, either by going to bed a little earlier, or by sleeping in in the mornings. As one survivor recalls, "*I said*, "*Well*, *I'll just start going to bed a little earlier*," so I go to bed at 10 o'clock and then I was waking up at one o'clock."

Other maladaptive strategies included napping during the day (5%; 1/20), and use of alcohol as a sleep aid (5%; 1/20). "*I tried drinking a lot*," admitted one participant detailing her unsuccessful attempts to use both alcohol and sleeping medications to find relief. "*I tried drinking, you know, one glass of wine, two glass of wine, three glasses of wine. And the same as zopiclone. You knock out, you wake up. You don't know how you got to where you were."* 

*Subtheme 4: Mobile Apps.* One fifth (4/20) of cancer survivors interviewed reported using or having used a mobile app for the purpose of improving their sleep. No participants reported using an evidence-based sleep app or a CBT-I based sleep app; instead, participants described using apps to play prerecorded audio for calming purposes. Cancer survivors used apps for guided meditations (10%; 2/20), relaxing audio such as "rainforest sounds" or white noise (10%; 2/20) and to listen to podcasts (5%; 1/20). "*I think the most helpful things that I've found is another app. I used the Calm app and their sleep stories,*" reported one participant. The "Calm" app by Calm.com Inc, advertised as an app for "meditation and sleep", was the most popular app listed by name (10%; 2/20). "*So when I wake up I turn on a sleep story and I find that actually is one of the best things that I can do in terms of going right back to sleep.*"

Subtheme 5: Home Remedies. Lastly, 20% (4/20) participants described implementing some form of home remedy with no empirical support or plausible mechanism of action. These

strategies were each uniquely pursued by one participant, and included applying mint oil to the feet, ingesting cbd oil, nighttime fasting, and taking hot showers in the hour before bedtime. "*I did actually do a couple of things*," one survivor recalls, "*like I did try to do some breathing exercises when I'd settle in bed. I did put some, like mint oil on my feet. You know, I did. I did a bit of like, you know, searching around the internet to see if some things would work.*"

While none of the home remedies were perceived by participants as beneficial for improving sleep, a common sentiment shared among the survivors was the willingness to try just about anything to find relief. As another describes, "...*it was pharmaceuticals, it was trying CBD oil, it was yoga like, I mean, I've tried so much and it's just taken up so much because without proper sleep, you can't do anything else like your your cognitive functions are completely off and stuff.*"

# Cancer Survivors' Recommendations for mHealth-based Insomnia Treatment

Theme 1: Defining Characteristics, Features, and Functionality of an Insomnia Treatment Smartphone App.

Subtheme 1: User Friendliness. User friendliness was the most common characteristic recommended by cancer survivors in an insomnia-treatment smartphone app. Simplicity and ease of use were highly valued by cancer survivors as they reported not wanting to spend too much time "figuring out" the app, many having discarded apps in the past that were perceived as difficult or annoying after only a few uses. Participants with no history of receiving CBT-I wanted an insomnia treatment app to be simple and easy to navigate and use. Easy navigation

included having a few large, clear buttons with apparent functions. These participants saw the primary advantage of a smartphone app for insomnia treatment to be in its ability to be easily accessed from anywhere at any time, where professional or evidence-based sleep help is usually quite difficult to access, and rarely available on demand. Easy access to the app also meant not having to spend time signing in by manually entering a username and password each time. CBT-I naïve participants had mixed feelings about the user-friendliness of in-app reminders such as badges, sounds, and push notifications. While they did recognize the advantages of receiving timely reminders to complete certain tasks, they noted that overuse of these notification would be perceived as annoying and would discourage long term use of the app.

A colorful, easy to understand data visualization was favoured by CBT-I naïve participants, particularly one that included information on the displayed variables and their relevance to sleep and insomnia. Lastly, these participants liked the prospect of being able to connect a consumer wearable device such as a fitbit or Garmin watch with the app to collect activity data as well.

Participants who had experienced CBT-I treatment in the past similarly found simplicity and ease of use to be one of the most important qualities in an insomnia treatment app. Ease of use to these participants meant being free from frustration or concerted effort. Similarly to CBT-I naïve participants, these participants found apps with fewer, larger buttons with clear functions to be more navigable, and raised aspects of apps they did not like (e.g., not having an in-app video be pausable, requiring one to start over from the beginning if they had to leave the app for any reason while it was playing). Having past experience with the task of filling out of daily sleep diaries, these participants noted that the task would be more easily completed on a smartphone than using paper and pencils or by desktop computer. Moreover, electronic data

collection carries the additional advantage of being able to digitally display the data over several different timescales. Participants also noted that the digital data display would be easier to understand at a glance than paper diaries, and that this could be augmented through the thoughtful use of display colors, flags, and info bubbles. These participants also liked the ability to connect a consumer wearable device to the app for automatic data collection.

Accessibility was another facet of ease of use that was highlighted by participants with past experience of CBT-I. These participants saw the one of the main advantages of a smartphone app for insomnia treatment to be its accessibility relative to other forms of professional or evidence-based sleep care. Being able to download the app from the app store onto a personal device for no cost, and then access the app at any time of day from almost any geographical location were cited as the main benefits to accessibility.

The final facet of ease of use that was identified by participants with past CBT-I experience was that the app would consolidate several functions that they already used or wanted to use as part of an insomnia treatment app. These participants saw the app as a convenient onestop-shop for receiving bed and rise time routine recommendations, tracking sleep diary indices as well as unique circumstances (events, stressors, subjective sleep quality), seeking evidencebased information and resources on sleep, and receiving peer support through an anonymous forum.

Cancer survivors with and without past CBT-I experience also spoke about aspects of smartphone apps that they did not find contributed to the user friendliness of the apps. These characteristics included aspects of apps that impose upon one's life, aspects that make apps more difficult to understand and navigate, and issues related to configurability. Crucially, these

characteristics also lead participants to discontinue use of the offending apps. One survivor put it simply, "*If I don't like it, I don't usually stay, stick on it for very long.*"

Participants found that many apps they had used in the past imposed upon their daily life through various unwelcome means, including irrelevant suggested content, an endless scrolling feature, excessive notifications, and intrusive advertising. These apps were perceived as annoying or even exploitative, and were not favoured by cancer survivors.

Several issues hindered the navigability of apps that cancer survivors had used in the past, which negatively affected their usability. Apps making heavy use of medical and technical jargon were considered difficult to understand and therefore less usable; this extended to apps that displayed data awkwardly or without explaining what the variables mean or how to understand the data display. *"I bought a new one, and it does a much more comprehensive job of measuring things and and but it's almost too complex to help,"* described one participant, expressing his frustration over the data display given by his smart watch. *"What does HRV, what does heart rate variability really mean in the context of sleep? I don't have any explanation for that. I've read their explanation. It doesn't really make sense to me."* 

Website based apps that lacked specific mobile formatting were deemed less usable by cancer survivors than those that were properly formatted. Lastly, participants found frequent app updates and user interface changes to be upsetting and confusing, and preferred apps that maintained a consistent look and feel.

*Subtheme 2: Evidence-Based.* Being evidence-based was another important quality in an insomnia treatment app that was valued by cancer survivors, who reported being much more likely to use an app that is endorsed by the medical community and/or their local cancer center.

Participants liked that the content of the app is designed by insomnia specialists and that it delivers the frontline recommended treatment for insomnia according to clinical practice guidelines.

Cancer survivors who had no experience with CBT-I highly valued the ability to track their sleep within the app and receive individualized behavioural recommendations (e.g., bed and rise time assignments) tailored to their own sleep data. This sentiment was echoed by participants who had experiences CBT-I in the past, who also appreciated the ability to access curated evidence-based educational materials and resources within the app, rather than searching for similar information on the web where it would be intertwined with information from unverifiable sources.

Subtheme 3: Security, Privacy, Data Ownership. Cancer survivors expressed concerns regarding the privacy and security of the app, and desired secure ownership over any personal health information as well as all of the data that they would be generating in the app. Participants expressed distrust in the privacy and security of most apps, noting that many apps earn revenue through selling of user data, and even those that do not explicitly sell user data are still vulnerable to unintentional data breaches. As a result, participants with and without past CBT-I experience both desired an insomnia treatment app that could be used while maintaining full anonymity and privacy. This was especially important regarding certain potential app features, such as sleep tracking and a peer support forum, where data privacy and anonymity are respectively crucial.

Participants with no past CBT-I experience highlighted the importance of owning their own sleep data, both for privacy reasons as well as the ability to bring this easily understood

information to another healthcare provider to augment the visit. "...virtual whole medicine has just made these things so easy," noted one participant. "All I would have had to do was send her a file. Let her look at it. And she could have had a 15-minute or 10-minute Zoom conversation with me, given me the feedback and the information of an expert. And to me that opens up huge realms of opportunity. Just that that kind of ability to get expert advice very quickly, very easily based on real data. That, those two things, I think are really, really valuable"

Subtheme 4: Desired Functionality. Cancer survivors with and without past CBT-I experience agreed on several desired functions in an insomnia treatment app, including the ability to receive peer support, the ability to connect a consumer wearable device, and the ability to receive feedback and encouragement from the app. Participants spoke about the importance of peer support on their journeys with cancer treatment, and liked the idea of being able to give and receive peer support through an in-app forum, noting that anonymity of this forum would increase their odds of participating actively. "I'm really interested in the peer support group type thing, right?" one participant said. "On an app, I would do that," he clarified, "whereas I would never say go to a meeting, I wouldn't do that, but I could handle, you know, I can handle that."

Some participants also expressed the desire to be able to connect their various wearable devices (e.g., fitbit, smartwatch) to the app to consolidate their activity data in one location. Others wished to use the 'objective' sleep data collected from their device to augment the manual entry of subjective sleep diary data. Most participants agreed that the app's ability to provide feedback and praise when certain tasks are completed or goals achieved through badges, streaks, and other gamification features would augment their experience of the app and encourage its use.

Participants with no CBT-I experience desired an insomnia treatment app that included guided meditations, calming sounds, and sleep stories to listen to while falling asleep to manage pre-sleep stress and anxiety.

Participants who had experienced CBT-I in the past found that the digital sleep diary was an attractive feature of an insomnia treatment app as it would eliminate the need for paper and pencil sleep diaries that needed to be printed weekly and would greatly increase their ability to quickly understand the relevance of their sleep diary data.

Theme 2: Advantages of receiving Insomnia Treatment via mobile App. Cancer survivors identified multiple advantages to receiving insomnia treatment through a smartphone app compared to in person sessions. These advantages served to lower barriers to treatment and reduce participants' investment of time, money, and other resources needed to avail of treatment, and included increased accessibility of treatment, anonymity in receiving treatment, and simplicity of app use.

Subtheme 1: Accessibility. The primary advantage identified by cancer survivors to receiving insomnia treatment through a smartphone app was increased accessibility. Participants liked how an app for insomnia treatment could be accessed around the clock, without the need for scheduling of appointments at a predetermined hour. Furthermore, the app could be accessed from any location, allowing treatment access when away from home such as on vacation, and eliminating costs associated with travel to appointments such as gas, parking, and childcare. "I've always got my phone on me," said one participant, "so it doesn't matter where I am if I'm camping or home or whatever. If I'm having trouble, I have techniques, I'll have tools."

As cost is often a major barrier to treatment, cancer survivors considered an insomnia treatment app that is available for free download to be highly advantageous compared to standard treatment channels. Further advantages in an insomnia treatment app's accessibility that were identified by participants included being contactless, thus eliminating the risk of COVID or other communicable disease transfer, and not requiring a referral to use. "Something that's actually accessible to people like a smartphone app makes it a lot easier for people to actually access care that they wouldn't necessarily otherwise be able to access." Expressed one participant, speaking of the many ways an app would be more accessible for her. "I think anything that gets it in the hands of people that doesn't require a referral, doesn't require, you know, \$120 every time you go see them. Things like that becomes a lot more... people are, just more people are going to use it."

Subtheme 2: Anonymity. Anonymity in accessing insomnia treatment was important to some cancer survivors, who felt this was a major advantage of receiving treatment through an app rather than a face-to-face provider. These participants spoke about the difficulty of finding a new therapist who is a good fit, and how this could encompass an emotionally draining ordeal of several appointments over a period of weeks to months, and several hundred dollars in treatment costs, with no guarantee of a finding positive therapeutic relationship. According to one participant, the ordeal of seeking out a new mental health professional was a big step to take. "… To finally go and see someone about it … it's difficult when you go and you see a therapist three times and realize we're not going to mesh," she explained. "Like this isn't going to work. And then the thought of having to go and repeat yourself all over again to another person and

you know, that cycle. If there was an option of having an app that I could try, what's the harm in trying?"

Subtheme 3: Simplicity. Another major advantage raised by cancer survivors about receiving insomnia treatment through a smartphone app instead of a face-to-face therapist was simplicity. Participants felt that a properly designed smartphone app would simplify the daily process of filling out the sleep diary, eliminating the need for a printer or office supplies such as paper & pencils. "*It's so much easier,*" explained one participant, speaking of the advantages of a digital diary over the paper and pencil version. "*You know, like especially where our phones are pretty much, for the most part, next for beds, so you can quickly type it in... First thing we do, I check my email. I can easily plug in the numbers. Boom, it's done. I'm not having to go anywhere else to put that information, input that information. It's right there at my fingertips, literally."* 

Moreover, the data display simplifies the process of understanding the entered sleep data, as the program automatically calculates the variables of interest from the entered data and display them along with past data in an easy-to-understand, color-coded format. Participants also noted that the data display facilitates the process of identifying trends in their own data, and would even simplify in-person appointments with care providers as they could easily present their sleep data to the clinician.

Theme 3: Disadvantages with receiving insomnia treatment via a mobile app. Cancer survivors identified several disadvantages with receiving insomnia treatment through a smartphone app. These disadvantages were mostly related to losing certain beneficial aspects of
a face-to-face visit, such as a personal/therapeutic relationship with a provider and a sense of accountability to engage in care. Other disadvantages that were raised were common to health apps or apps in general and related to issues of reliance on technology that occasionally malfunctions or is at risk of exploitation by cyber criminals.

Subtheme 1: Absence of therapeutic relationship. Cancer survivors were concerned that by receiving insomnia treatment through a smartphone app, they would miss out on the benefits of having a therapeutic relationship with a trained care professional. Participants viewed an insomnia treatment app as more impersonal than insomnia treatment with a face-to-face provider, and worried that they would not receive insomnia care tailored to their specific needs and circumstances. The ability to raise concerns or ask questions and receive answers from an experienced clinician was important to several participants, who highlighted the app's relative lack of individual tailoring as a weakness. Some participants felt that the app's ability to deliver cognitive therapy would be limited, and were looking for a treatment that did more to 'analyze' the causes and precipitants of their insomnia, rather than simply provide psychoeducation and behavioural recommendations. *"I like face to face,"* said one survivor, *"it's a personal preference. It's- I think it allows me to ask questions that I can get answered as opposed to just putting in and they, the app, giving me back the information they think I want."* 

*Subtheme 2: Lack of accountability.* Some participants found that accountability to another human helped them remain engaged in past treatments, and worried that engagement with an insomnia treatment app would therefore be more difficult to maintain. These participants noted that the onus would be on the app user to engage with the app and maintain the daily sleep

diary entries, and felt that it would be easier to forget to complete the diaries or ignore any push notification reminders if there was no other human involved to keep them accountable. "If I didn't feel like it worked right away, I sometimes I have a tendency to give up early," admitted one participant. "It was helpful in the study because I felt like I had an obligation to the researchers to keep going when it wasn't going well at the beginning," she explained, "whereas it might be easier to quit on an app because it's an app and there's nobody to disappoint."

Subtheme 3: Reliance on technology. Potential disadvantages with mHealth mediated insomnia treatments include limited access, risk of technological failure, and even potential security risks. An important bottleneck inherent to mHealth applications is that of reliance on mobile technology such as internet/WIFI, cellphone service, and smartphone ownership. Cancer survivors noted several disadvantages of an insomnia treatment app that related to reliance on mobile technology. First, treatment would only be explicitly available to people who own smartphones, and are located in a region with cell service. While no participants felt that this would specifically exclude them from taking advantage of mobile insomnia treatment, some raised concerns that older participants or participants located in more rural areas would be unable to access the app. "There are people that because of where they live, don't have the best reception with their phones and their apps," noted one participant. "There are still a lot of places here in Newfoundland that are rural and don't have the best reception." Participants also noted that certain events or circumstances might limit access to treatment, such as adverse weather conditions causing power or service outages. Some participants did own smartphones, but expressed concerns that they were not familiar enough with the phone or with using apps to be confident in using an insomnia treatment app. "I'm not that old," insisted one such participant. "I mean, my husband is in his early 80s. I'm going to be 75... I don't feel I don't feel old in any way, except when I pick up one of these [smartphones] and then or this [laptop computer] and then I feel old."

Lastly, concerns were raised about stewardship of patient data and how personal health information would be protected from accidental or malicious data breaches. Participants were particularly wary about their data being sold or shared with employers, preferring their engagement with the app to remain completely anonymous.

### Table 2.

Themes: Cancer Survivors' Experiences with Insomnia and Preferences for an Insomnia Treatment App

Domain	Theme	Subtheme
Cancer Survivor' Experiences of Insomnia	1. Precipitants of Insomnia	1. Pre-Existing
		Insomnia
		2. Anxiety & Stress
		2a Related to Cancer
		Diagnosis
		2b Unrelated to
		Cancer
		3. Treatment Side
		Effects
	2. Impact of Insomnia on Daytime	1. Physical Impairment

	Functioning	2. Cognitive
		Impairment
		3. Social Impairment
	3. Experience of Help-Seeking for Their Insomnia	1. Pharmacotherapy
		2. Psychotherapy
		3. Ineffective
		Recommendations
		4. Minimization and
		Dismissal
		5. Did Not Seek
		Professional Help
	4. Self-Directed Efforts to Resolve	1. Isolated CBT-I
		Components
		2. Sleep Hygiene
		3. Maladaptive
	msonnia	Strategies
		4. Mobile Apps
		5. Home Remedies
Cancer Survivors'	1. Defining Characteristics, Features,	1. User Friendliness
Recommendation for mHealth-	and Functionality of an Insomnia	2. Evidence-Based
based Insomnia Treatment	Treatment Smartphone App	3. Security, Privacy,

	Data Ownership
	4. Desired
	Functionality
2. Advantages of Insomnia Treatment via Mobile App	1. Accessibility
	2. Anonymity
	3. Simplicity
	1. Absence of
	therapeutic relationship
3. Disadvantages with Receiving an	2. Lack of
Insomnia Treatment App	Accountability
	3. Reliance on
	Technology

## Discussion

# **Experiences of Insomnia**

Our findings show that cancer survivors are highly motivated to take action to improve their sleep, as 90% of the participants in our study reported taking one or more actions to resolve their insomnia. While some of the more common actions taken do have a basis in evidence (e.g., increasing daytime activity to increase sleep drive), other common actions lack evidence (e.g., sleep hygiene, home remedies, CBD) and can actually be maladaptive/counterproductive (e.g., sleeping in/increasing time in bed). Mobile apps geared towards relaxation or improving sleep did receive some attention from a subset of the cancer survivors interviewed. These apps were not designed to deliver evidence-based treatments for insomnia, and primarily served to play calming audio such as rainforest sounds or guided meditations. This finding aligns with the investigation by Choi and colleagues (2018) that reviewed nearly 2,500 smartphone apps for sleep, concluding that the vast majority of sleep apps listed for download on common app stores fail to meet acceptable criteria for content, quality, or functionality in sleep self-management. To the untrained eye, finding an evidence-based sleep app through a simple search is thus a task akin to finding a needle in a haystack. Accordingly, there is a major opportunity for an evidence-based app geared towards insomnia treatment with the legitimacy/backing of a health authority or governmental body.

The results from this study align with past research identifying several insomniaprecipitating stressors among aspects of the experience of newly diagnosed cancer patients, from direct effects of treatment to anxiety and worry (Savard & Savard, 2013). Similar to past qualitative examinations of insomnia incidence among cancer survivors (e.g., Garland et al., 2019), all participants in this study reported insomnia either starting or worsening around the time of or in response to their cancer diagnosis and treatment. While many of the insomnia precipitating stressors reported by participants are directly related to their cancer diagnosis or treatments (e.g., death anxiety, financial stress), participants also reported a number of non cancer-related stressors that further negatively impacted sleep such as the death of a loved one.

Slightly more than one-third of the sample attributed their initial incidence of insomnia to side effects of treatments they had received to address their cancer, including chemotherapy, radiation therapy, hormone therapy, immunotherapy, and surgery. These treatments resulted in symptoms such as pain, discomfort, and hot flashes that significantly interfered with sleep.

Given the prevalence of physical and psychological factors that can harm sleep for newly diagnosed cancer patients, routine insomnia screening should be implemented early and often among this patient group. When insomnia is detected, patients should be referred to qualified sleep specialists and be offered first-line recommended treatments such as CBT-I. In some cases, additional psychological treatment may be warranted to address symptoms of depression or anxiety surrounding the battle with cancer.

#### **Impact of Insomnia**

While insomnia in cancer patients may seem like the "lesser of two evils," our study is consistent with past research indicating that insomnia is a serious concern for health (e.g., Hu et al., 2021; Peoples et al., 2021) and wellbeing (e.g., Lis et al., 2008; Olfson et al., 2018; Ross et al., 2020). Participants in this study described the significant negative impact that insomnia had on their quality of life and ability to function during normal activities. Many participants attributed some physical impairment to their insomnia, reporting feeling weak and fatigued, having little energy or motivation to participate in activities, needing to take frequent daytime naps, and even feeling physically sick. Moreover, many participants had complaints of perceived cognitive impairment in addition to their physical symptoms, congruent with previous research revealing significant perceived cognitive impairment among cancer patients experiencing insomnia (Caplette-Gingras et al., 2013; Liou et al., 2019). The psychological toll of insomnia on these patients was reported as very distressing and included excessive daytime sleepiness, fatigue, inability to concentrate (e.g., "brain fog"), irritability, and poor memory.

Past research has shown that insomnia is associated with several negative economic consequences to society through missed work and increased healthcare expenditure (Daley,

Morin, LeBlanc, Grégoire, & Savard, 2009; Daley, Morin, LeBlanc, Grégoire, Savard, et al., 2009), and that sleep mediates the impact of cancer on both missed work and healthcare expenditure (Gonzalez et al., 2018). In this study, participants' symptoms occasionally interfered with their ability to work and function in their day-to-day life, which had both economic and social consequences. While the majority of this sample was retired (55%), many participants reported their cognitive symptoms interfered with their ability to work, and two participants were forced to stop working or go on a leave of absence as a result.

Finally, some participants described the negative impact that insomnia had on their social life at a time when social support is critical to their recovery from cancer. Cancer survivors with insomnia not only felt they lacked the energy and motivation to engage in social activities, they also felt they had to structure their lives around getting proper sleep, which limited their ability to flexibly make social plans. This observation may have important implications for potential wellness/resilience consequences likely associated with deficits in social support and a sense of loneliness. While beyond the scope of this study, the role social factors might play in the prevalence, impact and management of insomnia among cancer survivors is worthy of assessment in future investigations.

Considering the significant negative physical, cognitive, economic, and social impacts that insomnia has on cancer patients, medical practitioners must recognize the seriousness of this diagnosis and treat it accordingly. Insomnia is not just "part of" cancer treatment or menopause, it is a serious condition with profound negative impacts across several domains of life.

### **Experiences Seeking Help for Insomnia**

Participants in this study approached a variety of medical professionals for help improving their insomnia, including oncologists, primary care doctors, nurse practitioners, and nurses. Past research has shown that many practitioners have reservations about prescribing benzodiazepines and other strong medications for routine insomnia care (Sorscher & Siddiqui, 2016); despite this, nearly half of patients ultimately receive some form of prescription hypnotic medication (Casault et al., 2012). This was true for the current study, in which the most common treatment received was a form of "sleeping pill", which included benzodiazepines (lorazepam), tricyclic antidepressants (doxepin, amitriptyline), and nonbenzodiazepine sedative hypnotics (zopiclone). Troublingly, all seven participants reported a negative experience with their sleeping pill that required cessation or tapering of the dose. Common issues with the sleeping pills included tolerance and dependence, dangerous impairment, and waking after a long sleep but still not feeling well rested. Participants typically reported an increase in negative side effects as duration of use of the medication increased. These findings align with past research (e.g., Garland et al., 2019; Sasai et al., 2010) showing the limited utility and high risk of hypnotic medications in treating chronic insomnia.

Half of the participants interviewed in this study had received some form of evidencebased psychotherapy, which included CBT-I as well as CBT for anxiety and depression related to cancer. It should be noted that this study may not reflect an accurate proportion of cancer patients with insomnia who receive CBT-I as the sample was partially recruited from a pool of potential participants who had participated in a past CBT-I trial with our lab. This likely resulted in a large proportion of the sample having experience receiving CBT-I relative to the population of cancer survivors with insomnia. While patient perceptions of the effectiveness of both forms of therapy were mixed, most participants did describe therapy as somewhat beneficial to

improving their sleep, and most reported learning a skill or strategy to manage stress or specific situations that they found helpful and still use.

Slightly less than one-third of the cancer survivors in this study never sought help for their sleeping difficulties from a medical professional. While this was occasionally due to the COVID-19 pandemic or living in a rural area, in some cases it was because participants believed their insomnia was normal or believed that nothing could be done. As these patients still reported significant negative effects of insomnia on their lives, it is important to spend time with cancer patients to educate them about potential difficulties and roadblocks along the way, such as insomnia, and increase awareness about care options that exist.

Unfortunately, many cancer survivors who did approach their healthcare providers with concerns about their sleep were met with either ineffective recommendations for improving sleep, or had their problems minimized or even outright dismissed. Participants were commonly given sleep hygiene recommendations, or told to supplement melatonin, neither of which are sufficient interventions for treating insomnia disorder. More concerning, some patients who had sought help from a medical professional were told that their insomnia was genetic, or a normal part of cancer, aging, or menopause, and were not offered any further solution. The experiences of patients in this study align with past research showing that physicians typically manage insomnia by first providing sleep hygiene recommendations, and when those are insufficient, prescribing hypnotic medications (Davy et al., 2015).

Medical professionals overlooking the detrimental effects of insomnia in their patients is extremely concerning, and efforts should be directed to raising awareness among frontline medical professionals of both the seriousness of insomnia as well as the range of evidence-based treatment options that exist. Insomnia treatment options with evidence for effectiveness include

the first-line recommended treatment for insomnia, CBT-I, as well as certain hypnotic medications medications. However, caution should be exercised when prescribing hypnotic medications as the risk for negative side effects is very high (Morin et al., 2020), and the evidence supporting their effectiveness for improving quality of life is tenuous (Sasai et al., 2010). All participants in this study who took hypnotic medications reported one or more negative side effects, and most voluntarily discontinued the medication in search of a different solution to their sleeping problem. Providers should ideally focus on referring patients to receive CBT-I treatment where it exists as an option. Development of evidence-based self-help CBT-I apps such as iCANSleep will serve to provide such an option for cancer survivors who may not currently have access to CBT-I treatment.

#### **Insomnia Self-Help**

In addition to seeking professional help, participants in this study made several selfdirected attempts to improve their sleep. While many of these changes resemble isolated components of evidence-based CBT-I treatment, such as increasing daytime activity levels or only going to bed when sleepy, participants also described a number of strategies that lack evidence (e.g., sleep hygiene, home remedies) or were actively counterproductive (e.g., going to bed early or sleeping in, using alcohol as a sleep aid).

While the effects of these individual efforts may be mixed, they demonstrate that cancer survivors with insomnia are motivated to take self-directed action to address their insomnia, increasing the likelihood that iCANSleep will be an acceptable form of treatment for this group. Twenty percent of the sample had already searched for a mobile app that could help with their efforts to improve their sleep. None of the apps used by participants were or claimed to be

evidence-based, though participants valued apps that were evidence-based. This reflects the limited availability of evidence-based sleep apps and the preponderance of "junk" sleep apps identified by Choi and colleagues (2018). It is likely that an evidence-based insomnia treatment app that was readily available on app stores and endorsed by the medical community would engage a significant portion of cancer survivors with insomnia.

#### Features and Functionality of iCANSleep

Important features and functions that cancer survivors reported wanting to see in their ideal insomnia app differed slightly between participants with past CBT-I experience and those without. Participants with no CBT-I experience described generally user-friendly features of apps they had used in the past, requesting features like guided meditations and sleep sounds. Participants who had undergone CBT-I in the past had a more concrete idea of what the treatment entailed, speaking more about how digital delivery would improve their experience, increasing accessibility and streamlining treatment processes such as completing the daily sleep diary. Though their specific demands differed slightly, participants with and without CBT-I experience agreed on three main features: 1) user friendliness, 2) evidence-based, 3) secure and anonymous.

Significant to both groups was that the iCANSleep app be both user friendly and evidence based, findings congruent with the TAM (Davis, 1985; Holden & Karsh, 2010) in that app upkeep depends on perceived ease of use (e.g., user friendliness) and perceived utility (iCANSleep is evidence-based). Uptake and subsequent effectiveness of iCANSleep can be maximized by ensuring the app has a smooth, simple, and well-formatted user interface that users find to be free from effort and frustration.

Importantly, many participants also had reservations about app security and data privacy, with participants preferring to interact with the app anonymously, and wanting assurance that personal health information would not be lost or sold to any outside parties. Therefore, iCANSleep must be developed and maintained to be as secure as possible, where patients can interact anonymously, and personal health information is kept both confidential and encrypted.

In addition to providing an evidence-based treatment for insomnia, participants requested a number of features for iCANSleep that can plausibly be implemented depending on development budget. Firstly, participants requested that the app contain a repository of scientifically curated information about sleep, insomnia, and its relation to health, cancer, and recovery. Inclusion of curated articles would give cancer survivors a place to find easy-tounderstand, evidence-based information within the app, allowing them to avoid searching online where good health information is indistinguishable from misinformation or advertising to the untrained eye. Second, participants requested a peer support forum where they could interact anonymously, providing and receiving advice and support from other cancer survivors dealing with insomnia. Lastly, several participants wanted the ability to connect wearable devices such as Fitbits or Garmin watches to the app to augment data collection.

### **Advantages of Insomnia Treatment App**

Three major themes emerged from discussions with cancer survivors about the advantages of receiving insomnia treatment through a smartphone app: Accessibility, Anonymity, and Simplicity. The major advantage noted by every participant to the smartphone app treatment was its accessibility. An insomnia treatment smartphone app was found to be far more accessible than face-to-face treatment. Not only is the app available on-demand 24/7 from

any location within reach of cell phone towers, it also carries a lower cost and time investment than face to face options typically do. Participants also appreciated that the app would be contactless (limiting risk of COVID-19 infection) and hoped that a professional referral would not be necessary in order to download the app. Given the difficulties that many patients with insomnia have accessing evidence-based sleep care (Garland et al., 2021; Thomas et al., 2016), ensuring that iCANSleep is accessible to as many cancer survivors as possible will be critical to increasing its impact.

Another perceived advantage of a smartphone app for insomnia treatment is that participants can engage with it anonymously. Many participants wanted to keep their insomnia treatment private from outside parties such as employers, while others simply felt the process of finding a good match among face-to-face providers to be draining and not guaranteed. Lastly, participants found that delivering an insomnia treatment via a smartphone app would streamline treatment processes and simplify tasks like completing sleep diaries.

#### **Disadvantages of Insomnia Tx App**

Cancer survivors highlighted some areas where they perceived a disadvantage to receiving insomnia treatment through a smartphone app. These included a lack of a therapeutic relationship between patient and clinician, a lack of accountability, and a reliance on technology. Some participants felt that an insomnia treatment app would miss certain aspects of face-to-face treatments, such as individual tailoring and the ability to ask questions. This is a reasonable concern, and the exact trade-off between cost and effectiveness when it comes to therapist guidance vs. automation of sleep therapies is currently being debated (Kutana et al., 2023).

Despite past research showing increasing treatment effect sizes in therapies that include more intense therapist involvement (Zachariae et al., 2016), other research has shown that automating aspects of treatments can make them much more cost-efficient in producing improvements in sleep (Baka et al., 2022). While iCANSleep will have a Frequently Asked Questions page as well as a repository of informational articles, it will not have the ability to flexibly answer individual inquiries, or alter treatment based on specific personal circumstances. Moreover, the app might be able to provide some feedback and encouragement through gamification features (e.g., badges, streaks), but an in-person clinician may be able to provide more personalized feedback. Participants also noted that there would be no clinician to hold them accountable, and the onus would be on themselves to engage with the app and follow its advice.

Lastly, participants recognized the potential for technological issues to arise that would disrupt their ability to avail of the digital therapeutic. Not only is access limited to those currently owning a smartphone who are serviced by cell phone towers, but a failure in any link of the chain (phone, power, internet service, data) may cause the entire system to be inaccessible for a time. In addition to potential accessibility issues, reliance on technology also leaves patients open to digital risks such as accidental breach of data, although these risks exist at varying levels for in-person treatments as well.

### Limitations

Due to the method of participant recruitment, there may have been a selection bias against participants who are less comfortable using technology. Participants were recruited through past interaction or participation in studies with our lab, but also by responding to social media advertisements posted on Twitter (now X.com). Moreover, the study took place entirely

remotely, with participants contacting the lab through email or telephone, completing questionnaires online, and being interviewed virtually via Webex. The barrier for participation in this study may have been relatively high for people with less confidence in their ability to use technology like social media and videoconferencing software, and as a result the final sample is likely more comfortable using technology that the true population. Further exacerbating this effect, two participants were recruited and completed questionnaires but were not able to figure out how to use Webex for the interview. While these participants were interviewed by telephone, the recordings of these sessions were not clear enough to be transcribed, and the data was thus excluded from analysis. Participation in this study was limited to English speaking Canadians, which may have resulted in the exclusion of primarily French-speaking communities, specifically in Quebec and New Brunswick.

Due to the flexibility of language and necessity of interpreting context when determining the meaning of words, qualitative analysis is an inherently subjective process. When conducting thematic analysis, there is always a risk of a top-down interpretive bias. It is impossible for the interpreter to completely remove their own bias as it is inevitable that their knowledge of the research question and preconceived ideas about the research population will color their analysis of the data. Moreover, all data analysis was conducted by a single coder and lacked a process for establishing inter-rater reliability, leaving open the possibility that different raters might interpret the findings differently.

### **Future Directions**

Future steps in the development and deployment of iCANSleep are currently underway. This process, spanning from app development to efficacy testing, will proceed with input from

patient stakeholders and will be informed by the needs and preferences of this patient group established in this study. First, a low-fidelity wireframe version of the app will be constructed that can be used for the first round of usability testing. At this stage, the wireframe is nothing more than a slideshow of app screens that is used to establish the design, format, and flow of the app without expending resources to actually build the app. In the first round of usability testing, this slideshow is presented to a target user who will be walked through the flow of a typical inapp session as they ask questions and provide active feedback. Results from this round of usability testing will inform any design changes that need to be made before the following step.

Once the feedback from the first round of testing has been integrated and the app's design has crystallized, a fully functioning prototype can be developed. The second (high fidelity) round of usability testing takes place with this prototype and may take place in person or virtually. Target users will be given access to the functioning app and asked to explore the app and complete several tasks while thinking aloud and providing feedback. Results from the second round of usability testing will be integrated into the final design of iCANSleep.

Once the design is finalized and the app is functional, the final step to demonstrate the value of the app is to test its effectiveness as an insomnia treatment in a randomized controlled trial. If deemed effective, the last challenge will be finding a way to disseminate the app to be accessible to as many patients as possible. Given the ubiquity of sleeping problems experienced by newly diagnosed cancer patients and patients undergoing cancer treatment, cancer centers may be a good place to engage patients about sleeping problems and provide access to therapeutic tools like iCANSleep. Not only would this prime cancer patients to be aware of their sleep and understand the seriousness of insomnia as well as their own susceptibility to it, but it would also provide them with awareness of an effective, first-line self-help treatment option.

While doing so across a province or a country's healthcare system would represent a significant investment in sleep=focused digital therapeutics, the potential benefit to patient health and quality of life as well as reduced burden on the medical system is large.

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## Appendix A

# iCANSleep Structured Interview Guide:

## Insomnia & Treatment History

Thinking back about your personal experience with insomnia...

- When did you first begin to have trouble sleeping?
- What do you think caused your difficulty sleeping?
- What impact did insomnia have on your life?
- What did you do or try to do to resolve your insomnia?
- What professional help or support was offered to you for your insomnia?

Thinking about your experience with cancer and cancer treatment...

• In what ways were your cancer diagnosis or treatment affected by your sleep?

# General Mobile Apps

- What do you currently use your phone for?
- What experience do you have using mobile apps?
  - Of the mobile apps that you use, what aspects do you find very helpful?
  - Of the mobile apps that you use, what aspects do you dislike?

# Health Apps

- What experience, if any, do you have using mobile apps for health purposes?
  - What did you like/dislike about that experience?

# Mobile App for Insomnia

- What do you see as the advantage(s) of receiving insomnia treatment through a mobile app?
- What do you see as the disadvantage(s) of receiving insomnia treatment through a mobile app?
- What are you currently doing to manage or improve your sleep that an app could help you with?
- What would you like the tone of the app to be? Professional? Supportive? Entertaining?

If an app like iCANSleep had been available when you first started experiencing your sleep difficulty...

- Would you have used it?
  - o Yes
    - What is attractive to you about an app for insomnia treatment?
    - Can you think of anything that would have discouraged you from using iCANSleep?
  - o No
    - What would have stopped you from using the app?
    - What could have made the app more attractive to you?

Often, cancer survivors with insomnia have other conditions such as anxiety, pain, or hot flashes that they feel interfere with sleep.

- What other conditions, ailments, or symptoms would you like iCANSleep to address?
- How specific to the experiences of cancer survivors should the app be?

One advantage of a mobile app is the ability to include many different features; for example, iCANSleep could be designed to include things such as symptom tracking, peer support forums, information directories, "test your knowledge" quizzes, and more.

• What additional functions or features would you find helpful to include in iCANSleep?

# General/Wrap Up

- Is there anything else you would like to add to our understanding of your insomnia and how it affects your life?
- Is there anything else you would like to say about using smartphone apps as healthcare tools?
- Do you have any questions or further comments?
## Appendix B



