

## **Perceptions, Skills, and Knowledge of Sleep-Related Difficulties and Their Treatment in a Cancer Psychosocial Workforce**

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*Sleep is a basic human need under the influence of and influenced by mind and body processes. Optimal sleep is critical at times of increased load, such as during growth, illness, or healing. Sleep problems among patients with cancer are strongly associated with physical and psychological distress and reduced quality of life. Patients frequently report sleep concerns from the time of diagnosis into the survivorship period. Despite this, clinicians may not have access to the knowledge, skills, and resources needed to support optimal sleep in this group. A survey was conducted with a nationwide psychosocial cancer support service comprising psychologists and social workers (52% response rate). Most participants reported having received some education about normal sleep and sleep problems, and 68% felt competent to screen for sleep difficulties. Less than half of the participants reported feeling competent, skilled, or qualified to complete sleep assessment or treatment, and few used standardised measures for assessment or outcome tracking. Almost all participants endorsed the need for more sleep-related knowledge, skills, and resources, including continuing education and patient-focused resources. The development and provision of such resources could enhance workforce capacity and positively impact the distress of cancer sufferers beyond their immediate medical prognosis and treatment.*

### **Introduction**

Sleep problems in patients with cancer have been strongly associated with increased pain and emotional distress (Sharma et al., 2012), and diminished quality of life (Fleming, Gillespie, & Espie, 2010). Analysis of data from 1,205 outpatients with cancer collected using the National Comprehensive Cancer Network's (NCCN) Distress Thermometer ranked sleep among the top five risk factors associated with patient distress (VanHoose et al., 2015). Difficulty with sleep is frequently reported as a symptom of concern by patients with cancer. Estimates suggest at least one-third of active patients with cancer and 28% of cancer survivors report sleep problems (Sharma et al., 2012). Prevalence estimates for insomnia among women affected by breast cancer are higher, with up to 70% of women reporting difficulty falling asleep, staying asleep, and reduced sleep duration (Fiorentino & Ancoli-Israel, 2006). Sleep problems in this population often appear as part of a cluster of symptoms including pain, fatigue, and emotional distress (Fiorentino, Rissling, Liu, & Ancoli-Israel, 2011). While each symptom can be linked to cancer and its treatment, the symptoms are also linked in a negative feedback loop where one symptom exacerbates another. This means that each symptom domain is a potential intervention point.

Improving sleep in patients with cancer is likely to be of great benefit. Sleep duration has been associated with survivorship in patients with advanced cancer, with both very long and very short sleep associated with increased mortality (Collins et al., 2017). It has also been shown in animal studies that changes to the timing and quantity of sleep are linked to alterations in hormones regulating the immune system, and that suppression of immune activity is related to cancer tumour growth (De Lorenzo, de Oliveira Marchioro, Greco, & Suchecki, 2015). For example, exposure to light at night (when humans are biologically evolved to be sleeping) has downstream effects on the production of melatonin (suppressing this powerful anti-oxidant and influencer of sleep timing), with flow-on impediments to its role in repressing oestrogen

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synthesis among other processes. Since elevated levels of ovarian hormones are related to the incidence of breast cancer, this pathway has robust support as a mechanism contributing to an increased risk for breast cancer in shift-working nurses (Samuelsson, Bovbjerg, Roecklein, & Hall, 2018). At the same time, a growing body of research is considering how to harness the power of the body's clock or 'circadian' system to optimise the timing of treatments such as chemotherapy, with a goal of minimising treatment toxicity and maximising efficacy; an approach known as chronotherapy (Truong, Lam, Grandner, Sasseon, & Malhotra, 2016).

Well-established and scientifically-validated non-pharmacological interventions for insomnia have existed for decades, and are now strongly recommended as first-line treatment in both primary care and oncology settings (Johnson et al., 2016; Qaseem et al., 2016). Despite this, health professionals are unlikely to be trained in these approaches (Kathol & Arnedt, 2016), leaving patients with cancer with few options (other than hypnotic medication) to cope with sleep problems such as insomnia.

New Zealand has one of the highest per capita rates of cancer in the world, with over 23,000 new cases recorded in 2015 among a population of 4.6 million (Ministry of Health, 2017; Statistics NZ, 2015). Based on these statistics, New Zealand is ranked among the Organisation for Economic Co-operation and Development member countries (Melaku et al., 2018) for its age-standardised cancer incidence rate. However, in recent years, its age-standardised incidence rate places it second only after Australia (Bray et al., in press).

Diagnosis and treatment of cancer in New Zealand is provided under universal healthcare. In general, patients with cancer do not bear the direct financial burden of diagnosis and treatment. Most of these activities occur within the publicly funded setting, although some private services exist for those with premium insurance cover or who choose and can afford to pay out-of-pocket. A 2010 national review of care available to individuals affected by cancer identified gaps in the provision of supportive care, highlighting the need for psychological and social support (Ministry of Health, 2010). Following this review, the Ministry of Health established a psychosocial support service focused on adults with cancer who also have high or complex psychosocial needs, patients from communities where services may be difficult to access, and patients with a cancer diagnosis typically associated with fewer supports or higher levels of distress.

This study aimed to assess the level of knowledge and skills related to sleep difficulties in a cancer psychosocial workforce. From this, potential opportunities may be identified for education, skill enhancement, and resource development aimed at health professionals to improve current practice and patient experiences.

## Methods

This study was evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by a university human ethics committee. Participation in the survey was voluntary and implied consent was given by proceeding past an information and consent page on electronic survey.

## Participants

The Cancer Psychological and Social Support Initiative is a discrete sector of the New Zealand oncology workforce, employing social workers and psychologists. Sixty employees of this service were eligible to participate in this study. All 60 employees were sent an invitation to participate.

## Measures

A 31-item online survey aimed at psychosocial support providers was developed for this study. Demographic information including gender, age range, and ethnicity (New Zealand Census question) was collected, as well as professional information such as field, experience, and workload. The questionnaire investigated providers' knowledge and beliefs about the role of sleep in their clients. Additional items focused on training and skills in screening, assessing, and treating sleep issues. Questions were generated based on current literature and guidelines about sleep difficulties in oncology populations, as well as the researchers' experience working with clients affected by sleep difficulties. The questionnaire was refined following feedback from the National Lead of the service and several healthcare professional test users. Question and response formats varied throughout the survey, and included: closed response items (e.g., "I have received formal education on normal sleep/assessment of sleep difficulties/treatment of sleep difficulties"; yes/no/not applicable); open response items (e.g., "When do you refer patients on for sleep issues?"); and multi-option items (e.g., "Have you used any of these standardised sleep related screening or assessment tools in the last year?"). For the listed measures, response options were yes/no/don't know/never heard of this. The listed measures included the NCCN Distress Thermometer (National Comprehensive Cancer Network, 2019), NCCN 3 question screen (Berger, Matthews, & Kenkel, 2017), Auckland Sleep Questionnaire (Arroll, Fernando III, Falloon, Warman, & Goodyear-Smith, 2011), Insomnia Severity Index (Morin, 1993), and the Pittsburgh Sleep Quality Index, (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989).

## Procedure

An email inviting participation in the survey was distributed to eligible participants by the national service leader. The email contained an internet link to the questionnaire, which was completed anonymously in Qualtrics. At the end of the questionnaire, participants were asked to supply an email address (through a separate linked questionnaire) if they wished to be included in: a) a draw for one of two NZD50 prize cards, and b) a database for future research. Reminder emails were sent at weekly intervals, with the final reminder advising a 2-week extension to the survey completion closing date. Data collection lasted 4 weeks, from 21 May to 18 June 2018.

## Data Management and Analyses

Data were exported to SPSS for analysis. In total, 60 practitioners were exposed to the survey, of which 31 submitted completed surveys and two submitted partially completed surveys. Only completed surveys were included in analyses. Descriptive statistics were generated.

## Results

Thirty-one participants (52%) completed the online survey. The majority of participants identified as female (84%; male 16%), and of New Zealand/European ethnicity (64.5%), with 20% identifying as Māori. The median age range was 35–44 years. More than half of the participants reported general clinical experience of  $\geq 10$  years, with 57% reporting their experience in the oncology setting as  $\leq 3$  years. Professional roles were predominately psychologists (55%) or social workers (45%), with several participants holding dual discipline status (e.g., social worker/counsellor). Half of the participants worked full-time (40 hours/week) and the minimum hours worked in this setting was 8 hours/week. Participants reported seeing 2–25 clients per week (mean = 9.3, standard deviation = 5.5).

All participants reported that they had contact with patients during early and ongoing treatment stages, and 90% had contact with patients around the time of diagnosis. Patients were less involved in the service during recovery or survivorship phases (39%). It was common in this

setting for patients to have whanau attend with them for face-to-face contact (77% sometimes, 16% often).

Patients in the service commonly reported sleep problems. Participants responded that almost all patients (97%) reported sleep difficulties, with half (52%) reporting these often. Participating health professionals screened for sleep difficulties regularly, with 68% doing so often. Fewer participants completed assessment of sleep difficulties, with 45% reporting they often did so. Patients were more likely to report fatigue often (77%), with participants reporting the perception that fatigue was most likely related to both sleep and cancer difficulties (52%) or cancer difficulties alone (45%), as opposed to solely due to sleep problems.

### **Knowledge/training**

Most participants reported that they had received at least some formal education about normal sleep (61%), assessment of sleep problems (68%), and sleep treatment (65%). For most participants, this education was ≤4 hours in duration (range 2–30 hours, median 5.5 hours).

### **Skills**

In general, participants felt competent, skilled, and qualified to screen for sleep difficulties (68%), with fewer reporting the same skill level in relation to assessment (48%) and treatment (42%) of sleep difficulties in this population. No participants reported that they maintained their sleep-related knowledge and practice skills through supervision or continuing education. Participants were asked how they went about screening for sleep difficulties. Most reported that this occurred through a general question or ad hoc discussion (90%). Some information was also derived from client self-report on a patient assessment form (32%), with the least common method being use of a standardised questionnaire or set of questions (13%). Most commonly, screening covered insomnia (71%), excessive daytime sleepiness (52%), and regularity of sleep patterns (42%). Other sleep disorders, including restless legs syndrome, were infrequently screened.

The majority of participants who undertook sleep assessments reported that they did this through a clinical interview (77%) or by taking a sleep history (42%). A few used standardised sleep-related measures such as the Insomnia Severity Index (Bastien, Vallières, & Morin, 2001), Epworth Sleepiness Scale (Johns, 1991), or the Pittsburgh Sleep Quality Index (Buysse et al., 1989); 26% reported using a sleep diary of varying duration (from 3 nights to 2 weeks). Use and awareness of standardised sleep- and fatigue-related measures are shown in Figure 1.

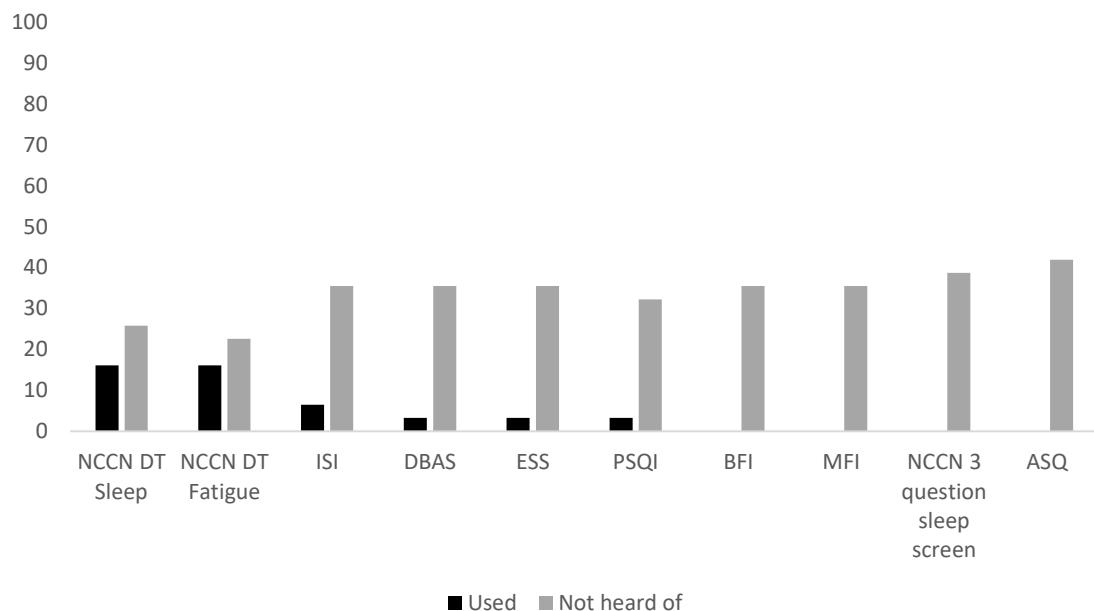


Figure 1. Percentage of participants who used or have not heard of specific sleep and fatigue screening and assessment tools.

NCCN DT: National Comprehensive Cancer Network Distress Thermometer; NCCN 3: 3 questionnaire screen from NCCN DT; DBAS: Dysfunctional Beliefs and Attitudes about Sleep Questionnaire; ESS: Epworth Sleepiness Scale; ISI: Insomnia Severity Index; PSQI: Pittsburgh Sleep Quality Index; ASQ: Auckland Sleep Questionnaire; NCCN DT Fatigue: fatigue screen from NCCN DT; BFI: Brief Fatigue Inventory; MFI: Multidimensional Fatigue Inventory.

Participants indicated which of a range of common sleep-related treatments and interventions they recommend or provided to patients, and which they felt comfortable to provide or give guidance on (Figure 2). For each approach endorsed, they were also asked to indicate what, if any, training they had received and whether this training was sufficient (Table 1).

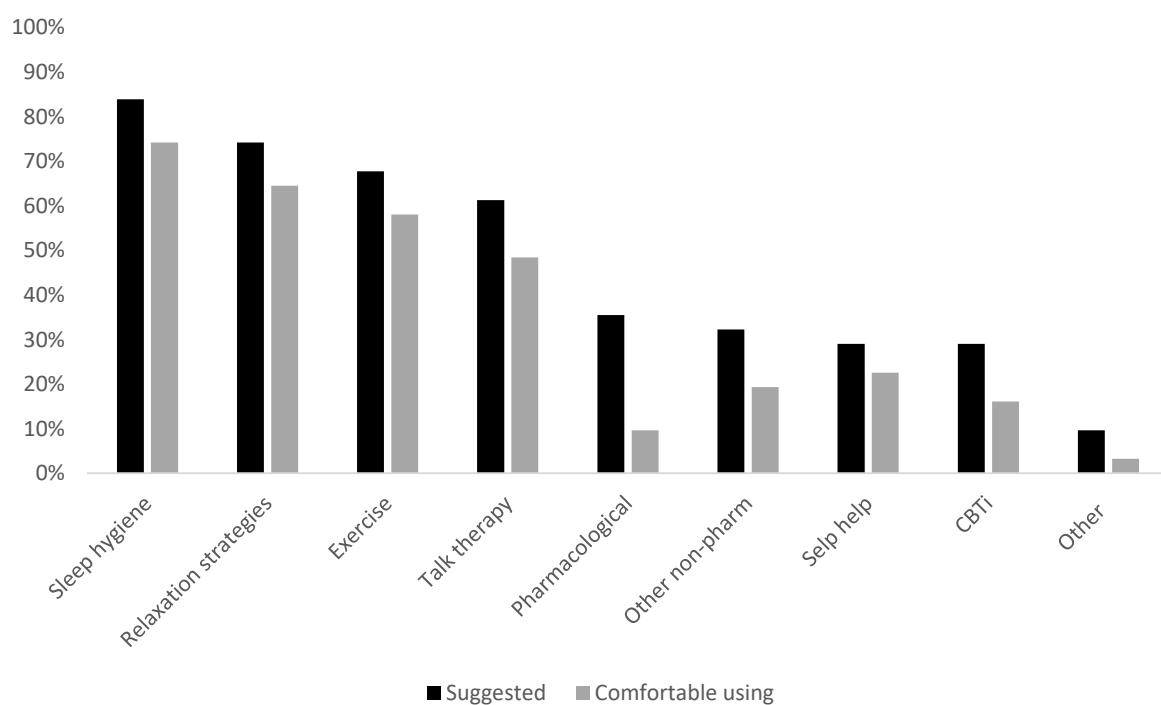


Figure 2. Percentage of respondents who suggested sleep-related treatment/interventions and those who felt comfortable to provide or give guidance on the suggested approaches.

*Table 1. Number of Participants Reporting Training Received for Sleep Related Interventions or Treatments*

	No formal training	Part of basic training	Self-trained course	Online training	In-person training	In-person practice	Supervised practice	Training was sufficient <sup>a</sup>
					<1 day	≥1 day		
Sleep hygiene	4	13	12	1	5	6	4	82%
Relaxation	1	13	13	3	3	9	9	77%
Exercise	3	9	8	1	4	3	2	78%
Talk therapy <sup>b</sup>	3	9	5	2	1	10	8	75%
CBT-i <sup>c</sup>	1	1	3	1	3	3	3	71%
Self -help <sup>e</sup>	2	2	4	1	0	1	3	71%
Pharmacological <sup>f</sup>	1	3	1	0	2	1	1	38%
Non-pharmacological <sup>d</sup>	3	3	4	0	1	1	1	33%

Note: <sup>a</sup>percentage of participants who reported the training they received was sufficient; <sup>b</sup>for example cognitive behavioural therapy, mindfulness-based stress reduction; <sup>c</sup>cognitive behavioural therapy for insomnia; <sup>d</sup>other non-pharmacological approaches, for example herbal or nutritional supplements; <sup>e</sup>for example books, online programs, mobile apps; <sup>f</sup>participants in this study were unlikely to be prescribers.

Of those who indicated they referred patients to specialist sleep services (42%), the most common referral reason was suspected obstructive sleep apnoea. Referrals were also made when there were long-standing sleep disorders, sleep did not improve despite trying strategies such as sleep hygiene, or when the sleep difficulties or support required were judged to be beyond the scope of the service. Approximately half of the participants indicated they referred patients to local sleep services, one indicated there was no such service in their area, and the remaining participants were unsure if there were local sleep services.

When asked about barriers to helping patients with sleep problems, the most common response was that patients' other clinical issues took precedence (52%), followed by insufficient experience to help patients who reported sleep difficulties (36%). Participants also selected time constraints (23%) and a lack of referral services as barriers to helping patients (16%). Only 10% selected cost as a barrier to helping patients with their sleep.

To determine the need for more sleep-related knowledge, skills, and resources, we asked participants if they thought they would benefit from provision of a range of offerings. These were: in-person training for health professionals (94% agreed, 61% strongly agreed); continuing education resources (94% agreed, 65% strongly agreed); patient-focused resources (97% agreed, 77% strongly agreed); screening tools (87% agreed, 65% strongly agreed); and assessment tools (90% agreed, 65% strongly agreed).

## **Discussion**

In this study, members of a cancer psychosocial service workforce completed questionnaires about their knowledge and skills related to sleep difficulties for patients in that setting. Participants reported limited formal sleep education, consistent with healthcare training in New Zealand. The responses indicated that almost all patients reported sleep difficulties at some point during treatment; however, only two-thirds of participants felt sufficiently skilled to screen for sleep difficulties. Less than half of the participants reported confidence in completing a sleep assessment or providing treatment for sleep difficulties.

Participants most often referred patients for respiratory sleep disorders, such as sleep apnoea, which made sense given the clinical context. No government funding is provided for behavioural treatment of sleep disorders in New Zealand, and referral to a DHB sleep clinic for investigation of insomnia is unlikely to be accepted. Even if an individual presents with severe and/or chronic insomnia beyond the scope of the psychosocial service, there is nowhere to refer, as insomnia treatment is not provided for in public funds beyond pharmacological intervention. A 2011 economic analysis of insomnia treatment in New Zealand identified a lack of both a systematic treatment pathway and public funding to effectively treat insomnia; this situation remains unchanged (Scott, Scott, O'Keeffe, & Gander, 2011).

Previously, Sharma et al. (2012) observed that one-third of outpatient attendees with cancer reported problems with their sleep. In the same sample (2,862 outpatients), sleep problems were more prevalent among those who also reported higher levels of pain and emotional distress. Other studies have reported a mismatch between cancer healthcare providers' and patients' assessments of symptoms, with nurses and physicians underestimating the intensity of symptoms including pain, fatigue, and gastric and sleep disturbances (Laugsand et al., 2010). In the present sample, the perception of health practitioners surveyed was that almost all patients experienced sleep disturbance. This high estimation likely reflects the complex presentations of those attending the service, and may also be a function of social workers and psychologists in this setting having more time during consultations (compared with medical staff) to go beyond the most pressing clinical cancer-related symptoms, treatment plans, and side-effects.

Patients with cancer with insomnia commonly report onset around the time of diagnosis, with comorbid symptoms of fatigue and sleep difficulty intensified by active treatment; evidence indicates that these effects persist long after active treatment is finished (Fleming et al., 2010; Schieber et al., 2019; van Leeuwen et al., 2018). Our data suggested unmet needs in relation to sleep problems among patients with cancer because of other clinical problems taking precedence or health practitioners not feeling skilled to address sleep issues. Patients may be receptive to

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supportive care for sleep before commencing treatment, which is a time when they are actively engaged in medical oversight and treatment (Zhou, Clark, Recklitis, Obenchain, & Loscalzo, 2018), and also a time when distress levels may be at their highest (Cutillo et al., 2017).

Limitations of this research included canvassing the perceptions of health practitioners in a single government-funded clinical service. Further, this service was established relatively recently (2014), rolled out progressively across the nation, and is still evolving in terms of any standardisation of services and approach. Not included in this survey were oncology social workers, counsellors and psychologists working outside of the public health system, including in not-for profit cancer-focused organisations. These organisations are more likely to work with individuals and families affected by cancer through all phases of the cancer pathway, including survivorship. They are also more likely to work with a wider range of presentations, not just individuals assessed as having complex needs in this setting. Data collected represent the perceptions and estimates of responders; the response rate was also low, resulting in a relatively small sample size. Our questionnaire was long and we relied on the goodwill of individuals to respond in an already busy context.

In contrast, this study was strengthened through the engagement of the National Lead for the service who supported the study and its aims, and facilitated face-to-face access to a meeting of Regional Leads, where one of the research team was able to explain the purpose and process of the study.

These results highlight needs for sleep support, knowledge, and skills in both patient and workforce populations. Our findings could be extended by eliciting the experiences of patients directly, as well as experiences of the wider oncology workforce including nurses, physicians, and support workers. A more pressing agenda may be the identification, development, implementation, and evaluation of specific resources to support these needs. Service users' voices should inform such work. Obtaining accurate data on the prevalence across the spectrum of sleep disorders in this population is also a gap in the current literature (Otte et al., 2015).

## Conclusion

Our findings are consistent with extant literature on the experiences of patients with cancer with sleep difficulties. These findings give strength to the need for behavioural sleep support and training to be met in the oncology setting. The situation in New Zealand is not unique (Berger et al., 2017; Schieber et al., 2019; van Leeuwen et al., 2018). Sleep may be a modifiable factor in the pathway for patients with cancer. Behavioural approaches to sleep problems are not only likely to improve sleep in the short-term but also offer the individual strategies throughout treatment, recovery, and survivorship. Improvements in sleep and self-efficacy around sleep are also likely to positively impact other cancer-related distress. Psychologists, social workers, and counsellors in the oncology setting are in an ideal position to provide sleep interventions and support.

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