

Sleep disturbance in cancer patients and caregivers who contact telephone-based help services

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Abstract

Purpose Insomnia is highly prevalent in people who are affected by cancer. However, options available to receive support for insomnia are limited. Telephone-based help services, such as cancer helplines, may be ideally placed to meet unmet needs regarding insomnia after cancer. The present study describes the prevalence and predictors of insomnia in patients and caregivers who call cancer helplines seeking support.

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Methods Participants ($N=500$ patients, $N=234$ caregivers) were recruited through an Australian state-based telephone-delivered cancer helpline. In addition to routine screening with the Distress Thermometer, participants were administered the Insomnia Severity Index.

Results Most participants were female, older than 50 years of age, and were three (caregivers) to four (patients) months post-diagnosis. Insomnia symptoms were reported by 59.4 % of patients and 62.9 % of caregivers, with moderate to severe levels of insomnia reported by 27 % of patients and 30 % of caregivers. Insomnia was predicted by distress level for both patients ($\beta=.31$, $p<.001$) and caregivers ($\beta=.32$, $p<.001$) and age for patients only ($\beta=-.13$, $p<.01$).

Conclusions Insomnia symptoms are common in patients and caregivers who call cancer helplines and appear to be related to distress. Telephone-based helplines have the potential to act as the first line of support in a stepped care approach addressing insomnia.

Keywords Insomnia · Sleep · Distress · Cancer

Introduction

A cancer diagnosis is a major life event negatively impacting not only the person diagnosed but also the people close to them. Cancer patients and caregivers can have a number of unmet needs that continue long after treatment has ended, influencing long-term cancer survivorship [3, 12, 13, 30]. Accessible information and self-management advice is crucial to helping individuals learn strategies to self-managed cancer-related problems [23]. The National Cancer Institute's Cancer Information Service (CIS) was established to provide telephone-based access to cancer information, and this type of service has since extended to many other countries often supported by non-government cancer control agencies [6, 23].

In Australia these services are delivered through cancer helplines located in each state that provide a low-intensity but high-volume service providing brief informational support [11, 15], as well as psychosocial support and referral [8, 16, 17]. As such, telephone-based services, such as cancer helplines, may have the capacity to provide support for other problems that patients and caregivers face after a diagnosis of cancer.

One concern that has recently been shown to impact post-diagnosis adjustment for people affected by cancer is sleep disturbance and/or insomnia [4, 20, 27]. Insomnia is characterised by a cluster of symptoms including sleep onset latency, frequent waking, waking too early and deficits in daytime functioning due to lack of sleep [2, 19]. The prevalence of insomnia has been shown to range from 19 to 63 % for cancer patients [19, 27] and 40 to 50 % for caregivers [7, 20]. These rates of insomnia in cancer patients are two to three times higher than that found in the general population [28]. For cancer patients, the post-diagnosis experience is marked by a series of stressors that can act as a trigger for insomnia. In particular, the period after initial surgery soon after diagnosis is associated with high levels of insomnia [28]. However, insomnia can continue to be a significant issue long after cancer treatments have ceased [27]. Factors associated with sleep disturbance in cancer patients include hospitalisation, physical discomfort and pain, treatment side effects and immune system and physiological changes [19]. For example, patients reporting post-chemotherapy nausea and vomiting report a higher rate of insomnia [25], and anti-estrogen treatments that aggravate menopausal symptoms can interfere with sleep [9]. Sleep disturbance is also associated with depression, anxiety and distress, with long-term negative impacts on quality of life [19]. Although studies investigating insomnia and sleep disturbances in caregivers of people diagnosed with cancer are scarce, the few studies that do exist suggest that moderate to severe sleep disturbance is highly prevalent and associated with a decreased quality of life [20]. Furthermore, the economic burden of untreated insomnia is high, with cost-effective treatments being considerably less costly than not treating this affliction [10].

In sum, insomnia is an important target for intervention with cancer patients and caregivers. Given cancer helplines have been shown to be an efficacious first point of contact in addressing cancer-related distress [17], a similar model may have a potential for identifying and treating insomnia in people affected by cancer. However, it is not yet known whether insomnia is a prevalent concern for the people who call cancer helplines. The primary aim of this study was to assess the prevalence of insomnia in patients and caregivers calling a cancer helpline, and the secondary aim to describe the predictors of insomnia.

Method

Participants and procedure

Ethical approval to conduct this study was obtained from the Human Research Ethics Committee at Griffith University (PSY/E2/12/HREC). Participants were recruited through the Cancer Council Queensland Cancer Helpline from 11th December 2012 to 26th March 2013. Eligible participants were callers to the cancer helpline who had been diagnosed with cancer or a caregiver of someone diagnosed with cancer and were at least 18 years of age. In total $N=500$ patients and $N=234$ caregivers agreed to participate from 1144 (43.71 %) patient and 809 (28.92 %) caregiver callers. Most patients and caregivers were female, older than 50 years of age, and had a high school education (Table 1). Median time since cancer diagnosis was 4 months for patients and 3 months for caregivers. Participant's reason for calling the cancer helpline were predominantly practical issues (54.8 % of patients, 36.8 % of caregivers), psychological/emotional support (17.0 % of patients, 32.1 % of caregivers), treatment and management (14.8 % of patients, 14.1 % of caregivers) or general information (8.8 % of patients, 10.7 % of caregivers).

Materials

Information regarding demographics, cancer-related factors and distress levels are routinely collected during all calls to the cancer helpline, including, age, gender, cancer type, stage of diagnosis (patients only), months since diagnosis, reason for call and level of distress using the Distress Thermometer [24]. In addition, participants were administered the Insomnia Severity Index during the helpline call [21].

Distress The single item Distress Thermometer (DT) [24] is routinely used in the cancer helpline in Queensland to screen callers' levels of distress. Participants are asked to rate how much distress they have been experiencing in the past week including the current day using a scale of 0 to 10. Higher scores are indicative of greater distress, with the DT showing good sensitivity and specificity for detecting heightened psychological distress with a cut-off point of ≥ 4 [18].

Insomnia severity The Insomnia Severity Index (ISI) is a seven-item measure of the nature, severity and impact of insomnia [2, 21, 29]. Participants are asked to consider the previous two weeks and rate their severity of 1) sleep onset, 2) sleep maintenance, 3) early morning awakening on a 5-point Likert scale (0=*not at all* to 4=*very severe*), 4) their level of sleep dissatisfaction on a 5-point Likert scale (0=*very satisfied* to 4=*very dissatisfied*), 5) the level of interference caused by sleep patterns on daily functioning, 6) noticeability of sleep problems by others and 7) distress caused by sleep patterns on

Table 1 Descriptive statistics for demographic, cancer-related and caller variables for patients ($N=500$) and caregivers ($N=234$)

		Patients N (%)	Caregivers N (%)
Gender	Female	380 (76.0)	197 (84.2)
	Male	120 (24.0)	37 (15.8)
Age (years)	20–29	9 (1.8)	4 (1.7)
	30–39	26 (5.2)	38 (16.2)
	40–49	65 (13.0)	44 (18.8)
	50–59	137 (27.4)	51 (21.8)
	60–69	137 (27.4)	63 (26.9)
	70–79	93 (18.6)	21 (9.0)
	80+	25 (5.0)	5 (2.1)
Education	High school	275 (55.0)	125 (53.5)
	Certificate/diploma	75 (15.0)	35 (14.9)
	Undergraduate university	54 (10.8)	39 (16.7)
	Postgraduate university	44 (8.8)	16 (6.9)
Disease stage	Remission/stable	40 (8.0)	–
	Early/localised	294 (58.8)	–
	Recurrence/second primary	38 (7.6)	–
	Metastasis/widespread/advanced/terminal	78 (15.6)	–
	Unknown	35 (7.0)	–
Cancer type	Breast	183 (36.6)	30 (12.8)
	Male urological	61 (12.2)	14 (6.0)
	Lower GI	42 (8.4)	26 (11.1)
	Gynaecological	36 (7.2)	16 (6.8)
	Respiratory	35 (7.0)	20 (8.5)
	CNS	26 (5.2)	24 (10.3)
	Other	117 (23.4)	62 (26.5)

Percentages do not always equal 100 % due to missing data

a 5-point Likert scale (0=*not at all* to 4=*very much*). The ISI is validated as both a screening and outcome measure, and categories are defined by 0–7=no clinically significant insomnia, 8–14=subthreshold insomnia, 15–21=clinical insomnia (moderate) and 22–28=clinical insomnia (severe) [21]. In this study internal reliability was excellent for this measure ($\alpha=.91$).

Statistical analysis

Descriptive statistics were calculated for demographic and cancer-related variables. Means and standard deviations were reported for normally distributed variables, with the exception of a median value reported for the highly skewed variable of time since diagnosis. Frequencies were examined for the levels of insomnia and levels of distress, with chi-square analyses determining potential differences between patients and caregivers as well as across cancer sites. Bivariate correlations were conducted to describe the relationships between predictor and outcome variables (Table 2). Hierarchical linear regression determined if insomnia was associated with

demographic characteristics (gender, age and level of education; step 1), disease stage (patients only; step 2) and level of distress (step 3). Categorical variables of gender, age, level of education and stage of disease were coded dichotomously for the analysis. Independent sample t -tests assessed potential differences between patients and caregivers on distress, ISI total score and ISI items.

Results

Prevalence of insomnia

The presence of insomnia symptoms was evident in 59.4 % of patients and 62.9 % of caregivers as defined by a score of 8 or above on the ISI. Moderate to severe levels of insomnia were reported by 27 % of patients and 30 % of caregivers as defined by a score of 15 or above on the ISI. Prevalence rates of insomnia levels did not differ between patients and caregivers, $\chi^2(3, N=734)=1.957, p=.581$. Scores of 4 and above on the

Table 2 Bivariate correlations among predictor and dependent variables for patients ($N=500$) and caregivers ($N=234$)

Variable	1	2	3	4	5	6
Gender ^a (0 male, 1 female)	–	.01	–.03	–	.00	.01
Age ^a (0 <60, 1 60+)	–.22**	–	–.27**	–	.13	–.08
Education level ^a (0 high school or less, 1 tertiary)	.08	–.14*	–	–	–.03	–.02
Disease stage ^a (0 early stage or remission, 1 recurrence or advanced)	.06	.01	–.01	–	–	–
Distress level	.12*	–.17**	.00	.04	–	0.31**
Insomnia level	.14*	–.23**	.07	–.01	.35**	–

Correlations for patients are below the diagonal. Higher scores indicate greater distress and insomnia. Disease stage was not collected for caregivers

^a Dichotomous measure

* $p < .01$; ** $p < .001$

DT were reported by 62 % of patients and 83 % of caregivers (see Table 3 for frequencies). Prevalence rates of high distress ($DT \geq 4$) were significantly different between patients and caregivers, $\chi^2(1, N=689)=31.668, p < .001$. When examining rates of insomnia levels and scores of 4 and above on the DT across cancer sites, prevalence rates only differed significantly between cancer sites for patients in relation to insomnia (Fisher's exact test, $p < .01$; Table 4). Post-hoc Fisher's exact tests with a Bonferroni correction revealed that the difference was between the insomnia levels of no clinically significant insomnia and subthreshold insomnia, where patients with prostate cancer were more likely to have no clinically significant insomnia compared to breast and other cancer patients ($p < .001$ and $p < .002$, respectively).

Predictors of insomnia

Table 2 presents bivariate correlations between predictor variables and insomnia level. Moderate positive correlations were found between distress level and insomnia level for both patients and caregivers, and modest positive correlations were found between insomnia level, gender and age for patients only.

Tables 5 and 6 present hierarchical multiple regressions for patients and caregivers, respectively. For patients, the combination of age, gender and education in step 1 of the hierarchical multiple regression explained 6 % of the variance in insomnia level, with patient age as the significant predictor. The inclusion of disease stage in step 2 did not increase the explained variance. In step 3, the level of distress contributed an additional 9 % to the explained variance in insomnia level. At this final step, being younger in age ($sr^2 = .02$) and reporting higher distress ($sr^2 = .09$) significantly predicted insomnia level for patients, with the total model explaining 14.8 % of the variance in insomnia level (Adj. $R^2 = .14$), $F(5, 365)=12.673, p < .001$.

For caregivers, the combination of age, gender and education in step 1 did not explain a significant proportion of variance in insomnia level. Inclusion of distress in step 2 of

the model increased the explained variance by 10.2 %, with distress emerging as the significant predictor. In the final model, the only significant predictor of a greater insomnia level for caregivers was higher distress ($sr^2 = .10$), with the total model explaining 11.1 % of the variance in insomnia level (Adj. $R^2 = .09$), $F(4, 197)=6.137, p < .001$.

Differences in distress and insomnia between patients and caregivers

Descriptive statistics for distress and insomnia scores, including individual ISI items, are presented in Table 7. Caregivers reported significantly higher levels of distress than patients ($p < .001$). No other significant differences between patients and caregivers were evident.

Discussion

Approximately 60 % of patients and caregivers who called the cancer helpline reported insomnia symptoms, with 28 % of patients and 32 % of caregivers indicating moderate to severe insomnia. Consistent with previous research, these rates are

Table 3 Frequencies of insomnia levels and distress for patients ($N=500$) and caregivers ($N=234$)

	Patients N (%)	Caregivers N (%)
Insomnia		
No clinically significant insomnia	203 (40.6)	87 (37.2)
Subthreshold insomnia	159 (31.8)	72 (30.8)
Clinical insomnia—moderate	99 (19.8)	51 (21.8)
Clinical insomnia—severe	39 (7.8)	24 (10.3)
Distress		
DT scores <4	176 (37.8)	37 (16.6)
DT scores ≥ 4	290 (62.2)	186 (83.4)

DT Distress Thermometer

Table 4 Frequencies of insomnia levels and distress for breast ($N=213$), prostate ($N=75$) and other cancers ($N=404$) for patients ($N=500$) and caregivers ($N=234$)

	Patients			Caregivers		
	Breast N (%)	Prostate N (%)	Other N (%)	Breast N (%)	Prostate N (%)	Other N (%)
Insomnia						
No clinically significant insomnia	62 (33.9)	37 (66.7)	104 (40.6)	11 (36.7)	7 (50.0)	55 (37.2)
Subthreshold insomnia	61 (33.3)	9 (14.8)	89 (34.8)	8 (26.7)	5 (35.7)	48 (32.4)
Clinical insomnia—moderate	44 (24.0)	13 (21.3)	42 (16.4)	9 (30.0)	1 (7.1)	31 (21.0)
Clinical insomnia—severe	16 (8.7)	2 (3.3)	21 (8.2)	2 (6.7)	1 (7.1)	14 (9.5)
Distress						
DT scores <4	66 (38.2)	29 (50.9)	81 (34.3)	7 (25.0)	4 (28.6)	20 (14.2)
DT scores \geq 4	107 (61.9)	28 (49.1)	155 (65.7)	21 (75.0)	10 (71.4)	121 (85.8)

DT Distress Thermometer

higher than those seen in the general population [5], highlighting an important concern for people calling cancer helplines. Insomnia has been shown to be a pervasive problem that can continue long after cancer treatment ends [27]. However, previous researchers have proposed that cancer patients may believe that their sleep difficulties are due to cancer treatment and will dissipate or may not be aware of existing services and therefore may not seek help [1]. As insomnia has been shown to reduce quality of life and increase psychological distress for a substantial number of people, a mechanism is needed to firstly identify and then treat this disorder.

In a review of the prevalence and non-pharmacological treatment of insomnia in cancer patients, Savard and Savard

[28] suggest a stepped care approach to overcoming insomnia, in which initial self-administered education material is the first level of care, with more intense levels of support provided by health professionals if needed [28]. The current study suggests that telephone-based cancer information and support services could potentially address insomnia applying a similar approach by providing self-management materials as a first step, with further referral for in depth insomnia intervention as needed. Specifically, cancer helplines and other related services available around the world could act as the initial point of contact and assessment in a stepped care framework for both distress and insomnia, a proposal that is further supported by findings that these problems appear to be interrelated [23].

Table 5 Hierarchical regression analyses predicting insomnia level for patients ($N=500$)

Insomnia level	ΔR^2	ΔF	df	B	SE	β
Step 1						
	.06	7.51**	3, 367			
Gender ^a (0 male, 1 female)				1.43	.88	.08
Age ^a (0 <60, 1 60+)				-2.72	.75	-.19**
Education level ^a (0 high school or less, 1 tertiary)				.91	.76	.06
Step 2						
	.00	.17	1, 366			
Gender ^a (0 male, 1 female)				1.45	.88	.09
Age ^a (0 <60, 1 60+)				-2.72	.75	-.19**
Education level ^a (0 high school or less, 1 tertiary)				.91	.76	.06
Disease stage ^a (0 early stage/remission, 1 recurrence/advanced)				-.35	.84	-.02
Step 3						
	.09	38.41**	1, 365			
Gender ^a (0 male, 1 female)				.86	.85	.05
Age ^a (0 <60, 1 60+)				-1.92	.73	-.13*
Education level ^a (0 high school or less, 1 tertiary)				1.09	.72	.07
Disease stage ^a (0 early stage/remission, 1 recurrence/advanced)				-.59	.80	-.04
Distress level				.80	.13	.31**

Higher scores indicate greater distress and insomnia

^a Dichotomous measure

* $p < .01$; ** $p < .001$

Table 6 Hierarchical regression analyses predicting insomnia level for caregivers (*N*=234)

Insomnia level	ΔR^2	ΔF	<i>df</i>	<i>B</i>	SE	β
Step 1	.01	.61	3, 198			
Gender ^a (0 male, 1 female)				.34	1.45	.02
Age ^a (0 <60, 1 60+)				-1.54	1.17	-.10
Education level ^a (0 high school or less, 1 tertiary)				-.64	1.15	-.04
Step 2	.11	22.53**	1, 197			
Gender ^a (0 male, 1 female)				.37	1.37	.02
Age ^a (0 <60, 1 60+)				-2.22	1.12	-.14
Education level ^a (0 high school or less, 1 tertiary)				-.73	1.09	-.05
Distress level				1.05	.22	.32**

Higher scores indicate greater distress and insomnia

^aDichotomous measure

p*<.01; *p*<.001

Strengths, limitations and implications

The present study demonstrates for the first time that insomnia is prevalent in patients and caregivers calling a cancer helpline. However, owing to study limitations, some caution is needed in generalising from these results. Specifically, we report a low recruitment rate, particularly for caregivers that reflects the challenges of recruiting for research in service-oriented environments. A further limitation may be that while the ISI [22] has been shown to be a reliable and valid tool for assessing the severity of insomnia, more detailed assessment methods such as sleep wake diaries and actigraphy were not possible [14], and we also were not able to assess in depth possible outcomes of sleep disturbance such as daytime sleepiness or fatigue. As well, the cross-sectional nature of the study means that causality cannot be inferred. These are areas for future research.

At present, there is limited evidence about the efficacy of insomnia interventions for people affected by cancer [20], although cognitive behavioural therapy has shown promise in this area [28]. In addition, it has been proposed that existing stress management interventions for cancer patients could be enhanced to treat insomnia through the addition of sleep and fatigue-specific content [31]. Problematically, accessibility of such programmes is limited, and further research is needed to examine ways to integrate interventions for insomnia into standard supportive care after cancer [28]. There may be a potential for insomnia interventions to be provided in a cost-effective manner through telephone-based or internet-based services [26], although we do acknowledge that telephone-based cancer information services may not be available in low resource settings. Finally, caregivers who are spouses of patients are susceptible to insomnia due to a shared sleeping environment, and this is also an area for future research [20].

Table 7 Descriptive statistics and significance values for *t*-tests on the Distress Thermometer and Insomnia Severity Index for patients (*N*=500) and caregivers (*N*=234)

In the last 2 weeks:	Scale or item range	Patients <i>M</i> (SD)	Caregivers <i>M</i> (SD)	<i>p</i>	<i>d</i> ^a
Distress Thermometer	0–10	4.50 (2.68)	5.71 (2.34)	<.001	.481
ISI—total score	0–28	10.06 (7.30)	10.62 (7.63)	.333	.075
Difficulty falling asleep	0–4	1.29 (1.33)	1.46 (1.37)	.121	.126
Difficulty staying asleep	0–4	1.73 (1.27)	1.66 (1.29)	.516	.055
Waking up too early	0–4	1.42 (1.35)	1.49 (1.39)	.521	.051
Dissatisfied with sleep pattern	0–4	1.92 (1.30)	1.97 (1.32)	.586	.038
Interfere with daily functioning	0–4	1.48 (1.35)	1.59 (1.38)	.313	.081
Noticeable to others	0–4	1.19 (1.31)	1.26 (1.26)	.487	.054
Worried/distressed about sleep	0–4	1.06 (1.25)	1.20 (1.29)	.171	.110

ISI Insomnia Severity Index

^a*d*, Cohen’s *d* effect size (small=.2, medium=.5, large=.8)

Conclusion

This study highlights the current concern of insomnia in patients and caregivers calling cancer helplines. The prevalence of insomnia after cancer appears to be higher than in the general population, indicating a burden that could be targeted with appropriate interventions. The association between insomnia and distress in these callers is a pressing issue, and telephone-based services have the potential to address both concerns through brief screening tools such as the Distress Thermometer [24] and Insomnia Severity Index [21] and then applying a stepped care approach [28]. Telephone help services for cancer patients and caregivers, such as those based in non-government organisations, could act as the first line of support for people affected by insomnia and provide a cost-effective approach alleviating already overburdened health services.

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Conflict of interest Dr Morris, Prof. Glozier, Prof. Dunn and Prof. Chambers have no conflict of interest. Prof. Chambers has full control of all the primary data and agrees to allow the journal to review it on request. Drs. Ritterband and Thorndike have equity ownership in BeHealth Solutions, LLC, a company disseminating online interventions, including one for insomnia. The terms of Drs. Ritterband and Thorndike's arrangement with BeHealth Solutions have been reviewed and approved by the University of Virginia in accordance with its conflict of interest policy.

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