



Living with persistent insomnia after cancer: A qualitative analysis of impact and management

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Objectives. To conduct a qualitative exploration of the lived experience of insomnia disorder and its management amongst a sample of mixed-diagnoses cancer survivors.

Methods. Twenty-seven cancer survivors with persistent insomnia were recruited to this qualitative study following completion of treatment for breast (12), prostate (7), colorectal (7), and gynaecological (1) cancers. Eleven males and 16 females (mean age 62 years), who met DSM-5 criteria for insomnia disorder, contributed to one of four focus group discussions, designed to explore the lived experience of persistent insomnia and its management within cancer care services.

Results. Poor sleep was a persistently troubling complaint for participants, long after the completion of active cancer treatment. The impact of insomnia was significant for all participants, with six key domains emerging as those most affected: temperament, sociability, physical well-being, cognitive functioning, relationships, and psychological well-being. In terms of insomnia management, participants frequently resorted to unfruitful self-management strategies, due to the lack of professional insomnia expertise within cancer care settings. Three main themes emerged in relation to insomnia management: self-management, seeking professional intervention, and a lack of focus on sleep. A lack of clinician understanding of the importance of sleep health and the poor availability of evidence-based insomnia interventions, such as cognitive behavioural therapy for insomnia (CBT-i), were highlighted as important gaps in cancer care.

Conclusions. Insomnia was found to have a detrimental and pervasive impact on cancer survivors' quality of life, which persisted long into survivorship. There is an absence of professional attention to sleep throughout the cancer care trajectory, contributing to its prevalence, persistence, and impact. In order to break this cycle, sleep health should be integrated as a key aspect of cancer treatment and rehabilitation, much like maintaining a healthy diet and appropriate levels of physical activity.

Statement of contribution

What is already known on this subject?

- Insomnia is up to three times as prevalent in cancer survivors than in the general population.

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- Persistent insomnia is a recognized risk factor for the development of physical and mental ill health.
- Cognitive behavioural therapy is the gold standard insomnia treatment, but is rarely available to cancer survivors

What does this study add?

- A comprehensive, qualitative account of the lived experience of insomnia disorder from the patient's perspective. This subjective experience is under-reported in the literature.
- Unfruitful self-management strategies are commonly utilized by cancer survivors who are living with insomnia disorder.
- A life-course perspective on cancer survivorship is vital to ensure that emotional and psychological well-being are prioritized during cancer rehabilitation.

Background

Despite the global increase in cancer rates, recent developments in detection and treatment mean that cancer survival has doubled in the last 40 years (Irwin, 2013; Stanton, Rowland, & Ganz, 2015). Such progress has led to a considerable number of cancer survivors requiring ongoing support for persistent cancer-related physical and psychological side effects, with numbers expected to increase with an ageing population (Peoples *et al.*, 2017; Zhou, Michaud, & Recklitis, 2020). Across various cancer groups, the co-occurrence of symptoms such as sleep disturbance, pain, fatigue, low mood, anxiety, and reduced quality of life (QoL) has been reported (Ho, Rohan, Parent, Tager, & McKinley, 2015; Wu & Harden, 2015). Around one third of cancer survivors report the persistence of such symptoms following the cessation of active cancer treatments (Savard, Ivers, Villa, Caplette-Gingras, & Morin, 2011), placing a significant burden on both cancer survivors and the health care system (Savard *et al.*, 2011).

People with cancer are disproportionately affected by insomnia relative to the general population (Garland *et al.*, 2014). In the general population, prevalence rates of acute sleep disturbance are estimated at around 30–40%, with around a 10% rate of chronic insomnia (Ellis, Gehrman, Espie, Riemann, & Perlis, 2012). Disturbed sleep is estimated to affect 70% of cancer patients, with 18–29% reporting sleep disturbance that meets diagnostic criteria for insomnia disorder (Savard *et al.*, 2011). Insomnia is diagnostically defined by the DSM-5 as difficulty with sleep initiation, maintenance, and/or non-restorative sleep with associated impairment or significant distress (American Psychiatric Association, 2013). Once established, insomnia commonly develops an unremitting and chronic course (Schieber *et al.*, 2019) and has often been described by cancer survivors as being more challenging than cancer diagnosis and subsequent treatment (Palesh *et al.*, 2010).

The development of chronic insomnia is problematic since persistent sleep disturbance may be associated with considerable risk of further morbidity and mortality in cancer patients (Andersen, Goyal, Westbrook, Bishop, & Carson, 2017). Indeed, rather than simply being viewed as a symptom of cancer, insomnia is now widely regarded to be an independent risk factor for the development of physical and mental ill health (Peoples *et al.*, 2019). It has been associated with a twofold increase in the risk of depression (Cha *et al.*, 2017), with emerging evidence suggesting that insomnia may actually have temporal precedence to the onset of depressive disorders (Irwin, Olmstead, Ganz, & Haque, 2013). Furthermore, insomnia may confer risk for poorer cancer outcomes by adversely impacting immunity and influencing tumour growth and progression (Irwin *et al.*, 2013).

The aetiology of insomnia is complex and multifaceted, particularly in relation to cancer (Fleming *et al.*, 2019). Spielman's 3P model (Spielman, Caruso, & Glovinsky,

1987), outlining the development and maintenance of insomnia, posits that pre-disposing, precipitating, and perpetuating factors all contribute to the onset and persistence of insomnia (Spielman *et al.*, 1987). Pre-disposing factors such as age and gender, mainly being older and female, for example, place some individuals at an elevated risk of developing insomnia (Espie *et al.*, 2008). The onset of insomnia is then precipitated by a stressful life event, such as bereavement, relationship breakdown, or diagnosis of a serious illness (Davis & Goforth, 2014). For cancer patients, reduced daytime activity and the side effects of treatment such as increased fatigue can further elevate the risk of developing persistent insomnia (Zhou, Suh, Youn, & Chung, 2017).

For many people, disturbed sleep is a normal psychological response to a life stressor such as a cancer diagnosis, which occurs acutely, often self-resolving following adjustment to their diagnosis, or remission of cancer following treatment (Garland *et al.*, 2014). However, approximately 18–29% of cancer patients develop a persistent sleep problem that fails to self-resolve following completion of active cancer treatment (Savard *et al.*, 2011). This is often as a result of maladaptive coping behaviours being enacted to compensate for sleep loss, which become entrenched and persist after cancer remission (Fleming *et al.*, 2019). Alterations to behaviour such as daytime napping, irregular sleep–wake schedules, spending excessive time in bed, and worrying about the impact of insomnia on overall well-being and recovery from cancer are all commonly reported (Garland *et al.*, 2014). This pattern of behaviour and thinking about sleep tends to increase physiological, cognitive, and emotional reactivity at bedtime, creating a state of conditioned arousal which is counter to the state of relaxation required for sleep initiation and serves to perpetuate insomnia disorder (Perlis, Giles, Mendelson, Bootzin, & Wyatt, 1997).

Despite the prevalence and potential impact of cancer-related insomnia, its management in clinical care remains suboptimal (Zhou, Clark, Recklitis, Obenchain, & Loscalzo, 2018). It is often presumed by both clinicians and cancer patients to be a transient response to cancer diagnosis and treatment that will ultimately self-resolve (Schieber *et al.*, 2019). Consequently, insomnia is not routinely screened for in cancer clinics and is a subject that patients rarely discuss with their oncology team (Coles *et al.*, 2017; Schieber *et al.*, 2019). Evidence suggests that clinicians perceive themselves to be inadequately trained or qualified to assess and treat sleep disturbance in cancer patients, reducing the likelihood that it will be on the agenda during clinic appointments (Johnson *et al.*, 2016; Schieber *et al.*, 2019).

Hypnotic medications, in conjunction with sleep hygiene education, are presently the most frequently utilized approach to treating cancer-related insomnia according to research conducted in US cancer care centres (Zhou *et al.*, 2018). Sleeping medication is only designed for use with acute sleep disturbance and is also associated with negative side effects such as dependence and tolerance, as well as being undesirable to many cancer patients (Garland *et al.*, 2014; Savard & Savard, 2013). An alternative non-pharmacological treatment approach known as cognitive behavioural therapy for insomnia (CBT-i) has accumulated a substantial evidence base as an efficacious and durable therapy for insomnia (Balleisio *et al.*, 2018) and is now widely regarded as the gold standard treatment for persistent insomnia in the general population (Balleisio *et al.*, 2018).

Cognitive behavioural therapy for insomnia is a brief, sleep-focused, multimodal intervention that targets the aspects of insomnia that are most amenable to change, such as maladaptive sleep behaviours and faulty sleep cognitions (Zhou *et al.*, 2017). CBT-i comprises five potential elements, including stimulus control, sleep restriction, sleep

hygiene, cognitive restructuring, and relaxation training. Evidence demonstrates that CBT-i can be successfully administered using a range of delivery methods, including groups (Jansson & Linton, 2005; Verbeek, Konings, & Aldenkamp, 2006), telephone (Bastien, Morin, Ouellet, Blais, & Bouchard, 2004), online (Espie *et al.*, 2013; Vincent & Lewycky, 2009), and self-help manuals (Mimeault & Morin, 1999). Importantly, the effectiveness of CBT-i has been demonstrated for insomnia that occurs alongside medical conditions such as cancer, without the need to modify the core aspects of the intervention (Espie *et al.*, 2008).

The efficacy of CBT-i is well established in cancer survivors (Johnson *et al.*, 2016) and is a treatment that has high patient acceptability (Davidson, Feldman-Stewart, Brennenstuhl, & Ram, 2007). Several randomized controlled trials have demonstrated its efficacy in improving insomnia symptoms in cancer survivors (Espie *et al.*, 2008; Matthews *et al.*, 2014; Savard, Simard, Ivers, & Morin, 2005). A recent systematic review of eight controlled and four uncontrolled trials of CBT-i in cancer survivors demonstrated large effect sizes for self-reported insomnia severity for those who received CBT-i, compared to those who did not (Johnson *et al.*, 2016). Furthermore, CBT-i has also been found to have the potential to have a positive impact beyond simply improving sleep, with secondary benefits in mood (Peoples *et al.*, 2019), fatigue (Fleming, Randell, Harvey, & Espie, 2014; Heckler *et al.*, 2016), and QoL (Fleming *et al.*, 2014; Peoples *et al.*, 2017). Additionally, CBT-i-based interventions that specifically target other cancer-related symptoms, such as hot flushes and night sweats, have shown promise (Mann *et al.*, 2012).

Despite current and emerging evidence to support the use of CBT-i in addressing sleep disturbance in cancer patients and survivors, challenges remain regarding its accessibility in cancer care (Savard & Savard, 2017). A lack of adequately trained clinicians (Zhou *et al.*, 2017), being time-intensive relative to pharmacological treatments (Zhou *et al.*, 2018), and people having to travel long distances to access the intervention (Savard & Savard, 2017) are commonly cited barriers to its wider dissemination. Numerous research studies have investigated methods of overcoming these concerns in cancer care and have demonstrated the efficacy of CBT-i in online digital formats (Zachariae *et al.*, 2018), video format (Savard, Ivers, Savard, & Morin, 2016), brief adapted versions of the standard CBT-i protocol (Casault, Savard, Ivers, & Savard, 2015), and when delivered by non-CBT specialists such as oncology nurses (Dean *et al.*, 2019; Espie *et al.*, 2008). Indeed, the clinical improvement in insomnia symptomatology demonstrated by these different modes and intensities of treatment suggests that CBT-i could be incorporated as part of a standardized and structured stepped care approach to the treatment of cancer-related insomnia (Zhou *et al.*, 2020). CBT-i is presently the recommended treatment for persistent insomnia according to NICE guidelines in the United Kingdom (National Institute for Health & Care Excellence, 2015). However, there is currently a lack of research on how best to deliver sleep interventions within cancer care. There is also a lack of clarity around the optimal timing of sleep interventions in order to achieve maximum therapeutic benefit for individuals suffering from the effects of cancer-related insomnia.

This study qualitatively explores the lived experience of insomnia in a cohort of cancer survivors. The main objectives of this study are (1) to investigate the impact of insomnia on cancer survivors' lives, (2) to provide insight into the strategies used by cancer survivors to self-manage insomnia, (3) to explore the attention given to sleep difficulties throughout the cancer care trajectory, and (4) to consider the availability of support or interventions for sleep that are available to cancer survivors.

Methods

Participants

Criteria for inclusion in this study were (1) a diagnosis of breast, colorectal, prostate, or gynaecological cancer, (2) DSM-5 diagnostically defined chronic insomnia, (3) completion of active cancer treatment by at least 1 month with no further anticancer therapy planned (thus excluding transient sleep effects associated with cancer treatment), and (4) aged 18 years or over. Exclusion criteria were (1) short-term or acute insomnia, <3-month duration and (2) evidence of another sleep disorder (e.g., sleep apnoea). Potentially eligible participants were identified by clinical teams at oncology outpatient clinics at the Beatson West of Scotland Cancer Centre in the United Kingdom over a 6-month period. In total, 54 potential participants were contacted by letter asking if they would like to take part in a focus group discussion to explore (1) the impact of poor sleep on QoL and (2) ways in which insomnia is managed. A consent form and participant information sheet were also enclosed, providing further details about the purpose and nature of the study. A total of 27 individuals responded, providing written consent. Those participants were then contacted by the study researchers and were screened for eligibility by the researchers using standard screening procedures. All participants met DSM-5 criteria for insomnia, with no indication of the presence of other sleep disorders, and were thus deemed eligible for the study. Participant demographic details are provided in Table 1.

Procedure

The use of focus groups was considered as an appropriate approach. Alongside being an efficient means of data collection, focus groups permit participants to identify topics that are important to them and to utilize their own frames of reference for discussion (Koffel, Amundson, Polusny, & Wisdom, 2019). This approach permits direct access to participant experiences and perceptions. Each focus group lasted 90 min on average, which was

Table 1. Participant Demographics (all data are frequency except mean age/time since cancer diagnosis/insomnia duration)

Mean age (years)	62
Gender	
Male	11
Female	16
Civil status	
Partner	21
None	6
Occupational status	
Employed	10
Not employed	17
Cancer diagnosis	
Breast	12
Prostate	7
Colorectal	7
Gynaecological	1
Mean time since cancer diagnosis (months)	34
Mean insomnia duration (months)	17

agreed during consent, and participants were randomly allocated to one of four focus groups. Once the groups were confirmed, participants were offered a range of times and dates, and groups were organized based on times that suited everyone.

The groups consisted of 6, 7, 7, and 7 people, respectively. The focus group discussions were facilitated by a research psychologist and a post-graduate psychology student. The focus group topic schedule was developed using published literature and the research team's previous experience.

Participants were asked to respond to questions on the following topics:

1. the timing of insomnia onset
2. precipitating factors for its development
3. the impact of their sleeping pattern
4. management strategies to compensate for poor sleep.

The following questions were used to stimulate focus group discussion:

1. When did you start to sleep poorly?
2. What do you think caused your insomnia?
3. What impact did insomnia have on your life?
4. When did you become concerned about your sleep?
5. What did you do to try and resolve your insomnia?
6. What professional help or support were you offered to manage your insomnia?

All participants were given the opportunity to respond fully to all questions, and group discussion was encouraged and supported. At the end of each session, the facilitator provided a verbal summary of the main topics and issues highlighted during the discussion and asked the participants to confirm this as an accurate account. Immediately following each of the sessions, the facilitators held a debriefing meeting in order to discuss and record the main topics that emerged during the focus groups. The facilitators then generated summary sheets of the content of the focus groups and these were sent to each of the participants, the purpose of which was to ensure that the summary notes were an accurate reflection of their discussion. These summary notes were checked, agreed, signed, and returned by all participants.

Analysis

Focus groups, data collection, and analyses were concurrent. Once all focus groups had been conducted and initial analyses had been undertaken, it became clear that no new topics were emerging from the data. All focus group sessions were audio-recorded and were transcribed verbatim. Thematic analysis was used to systematically analyse the data produced in accordance with Braun and Clarke's guidelines (Braun & Clarke, 2006). Five key steps were undertaken during data analysis. First, the lead author familiarized themselves with the data by reading and re-reading the transcripts. An inductive approach to analysis was employed. Initial ideas and impressions relating to the research objectives were noted and highlighted, allowing the researcher to develop a thorough understanding of the data. Second, initial codes were constructed comprising brief descriptions of the concepts identified from the data. These coded data were then arranged semantically. Initial potential themes were extracted from the coded data and were reviewed in consultation with the co-author to assess appropriateness of the themes and the relevance of coded data. Differences in opinions were resolved by discussion. Finally, the extracted data were arranged into tables and themes were labelled. During the process of theme

generation, particular attention was paid to both the words used by participants and to the context in which the participants expressed themselves.

Results

The impact of insomnia was significant for all participants. Indeed, many ($n = 18$) reported that the consequences of poor sleep were often more overwhelming than the impact of cancer treatment. Insight was also provided into the means by which participants attempted to manage their insomnia. Overall, nine main themes emerged from the analysis. The first six themes related to the impact of insomnia, whilst the final three themes captured the processes involved in insomnia management. Themes and subthemes related to the impact of insomnia are presented in Table 2.

I don't feel like myself

A significant change in personality and temperament, feelings of guilt, and persistently low motivation were frequently reported following the onset of sleep disturbance. Participants described 'massive guilt about feeling tired all of the time', and in general 'constantly feeling guilty' about the impact poor sleep was having on their daily functioning and ability to relate to others. Indeed, these changes impacted on close personal relationships with people becoming 'irritable', 'snappy', 'grumpier', and

Table 2. Themes and subthemes related to the impact of insomnia

Theme	Subthemes
I don't feel like myself	Irritable Lacking motivation Avoidance Loss of interest Frustration Guilt about tiredness
Planning life around something uncontrollable	Withdrawn/Isolated Not making plans Giving up work
My body hurts	Fatigue Pain Headaches Nausea
My brain is not functioning	Concentration Memory Keeping up with conversation
It's more than just not sharing a bed	Sleeping separately Missing out on conversations Partner irritation Different bedtimes
Worry	Racing mind Pre-occupation with sleep Pressure to get back to normal

'intolerant'. These difficulties were compounded by a perception that significant others did not understand or empathize with such personality changes, and expected them to be the person they were prior to their cancer diagnosis.

Many participants reported that their 'QoL had gone out the window', and they were completely lacking in motivation. 'So many things I remember not doing, things that I wanted to do and things you put off until tomorrow, I can't be bothered to do, I'm too tired'. The pervasive impact of insomnia on all domains of functioning and sense of self was evident throughout cancer survivors' descriptions of their experiences and is well summarized by one survivor who said 'you are not interested in anything really. . . it makes you a bit depressed'.

Planning life around something uncontrollable

As highlighted in the previous theme, insomnia had a profound detrimental impact on the ability to interact with others. This also extended into the domain of social functioning, as poor sleep resulted in participants becoming increasingly withdrawn, avoidant, and isolated. Some described becoming a 'recluse', with one stating that 'I don't mix with people when I've had a bad night's sleep'. There was a tendency to no longer make plans or commit to anything due to the unpredictable nature of sleep and concern that they might be 'bad tempered' with others. One participant described it as being in 'fear of having to do something'. If plans were made for the following day, people would often unsuccessfully attempt to get sufficient sleep by going to bed early. Indeed, one participant described deciding whether they wanted to do something on 'a tired day' or not. Additionally, three participants decided to give up work due to the impact of insomnia on their daily functioning, with one describing it as being forced into retiring 'basically because I was so tired'. This theme effectively captures the feelings of helplessness and perceived loss of control that can result from an inability to sleep well, with so many aspects of cancer survivors' social life being dictated by the quality of their sleep.

My body hurts

Sleep disruption had a considerable impact on physical well-being. Symptoms such as a 'heightened pain level within your body', 'thumping headaches', and feeling 'physically sick' were reported by the majority of participants. They also highlighted how lack of sleep tended to 'exaggerate' the experience of these difficulties. Furthermore, these symptoms would often lead to reduced daytime activity and a tendency to engage in behaviours such as daytime napping and increased caffeine intake to mitigate the effects of insomnia. These physical symptoms and maladaptive coping behaviours only served to compound the aforementioned difficulties with social interaction and overall functioning, leaving participants stuck in the vicious insomnia maintenance cycle of poor night-time sleep and impaired daytime functioning.

My brain is not functioning

Cognitive impairments were also frequently highlighted as a problematic consequence of poor sleep. Forgetfulness, difficulty concentrating, and an impaired ability to follow conversations in social and occupational settings were most common. These impairments only served to exacerbate participants' difficulties in social and interpersonal functioning, in addition to precluding the enjoyment of previously pleasurable activities. The impact of

the cognitive impairments outlined is well conceptualized by the following participant description: ‘I can’t concentrate, I can’t hold a thought, I can’t remember what that person said to me three minutes ago. . .yeah, memory, concentration, conversations, sociability, everything’s affected’.

It’s more than just not sharing a bed

Insomnia had a significant adverse impact on close and intimate relationships, beyond simply being more irritable or less inclined to engage in social activities. A number of participants reported sleeping in a different bedroom from their partner in order to avoid disturbing them during periods of night-time wakefulness. This enforced separation resulted in participants feeling that ‘their relationship had changed’ and that they ‘missed out on conversations and making plans with their partners’ at bedtime or the following morning. There was also a sense that there were ‘many, many more’ adverse influences of insomnia on intimate relationships that were harder to articulate.

Worry

An all-consuming pre-occupation with sleep was reported by many participants. Racing thoughts in bed, a feeling of their ‘imagination going into overdrive’, and catastrophizing about the impact of poor sleep on daytime functioning were very common. Such ruminative worry only serves to heighten psychological and physiological arousal that is known to inhibit sleep onset. The stress associated with an increase in sleep effort in order to feel able to cope with the day ahead is well illustrated by the following participant extract:

It’s the stress of it. . .it’s the fact that you’re worrying about it, it’s how am I going to get up tomorrow morning, and how am I going to get out, and how am I going to get through work.

There was a patent and powerful sense of frustration at the persistence of sleep difficulties, which was intensified by a feeling of pressure to return to ‘pre-cancer’ family and occupational roles from others, who could not understand or empathize with the pervasive impact of chronically disturbed sleep (Table 3).

Table 3. Cancer survivors’ perceptions of insomnia management

Theme	Subthemes
I tried to help myself	Herbal remedies Wind-down routine Daytime napping Sleep hygiene Early bed time
I tried to get help	GP Sleeping tablets Oncology team
Sleep is not on the agenda	Sleep was never mentioned No referral route

I tried to help myself

Unsurprisingly, in the absence of any alternative, attempts to self-manage the impact of insomnia through strategies such as daytime napping and time in bed extension were common. Other methods employed included an evening wind-down routine, sleep hygiene practices such as avoiding caffeine and chocolate later in the day, and using herbal remedies to aid sleep. Although some of these sleep hygiene strategies may have some benefit, many of the self-management strategies reported by participants were unsuccessful, increasing feelings of helplessness, worry, frustration, and anger.

I tried to get help

A significant proportion of participants raised the issue of poor sleep with their GP and were offered a short-term prescription for sleeping medication ($n = 13$), which left many feeling that this was 'all that could be offered to you'. Others reported that they raised the issue of poor sleep during routine cancer clinic appointments, only to be advised that it was 'nothing to do with treatment'. In addition, many survivors also mentioned that they found the lack of treatment options 'very depressing'. This is concerning and poses a significant risk of cancer survivors feeling that disturbed sleep is a result of personal failing, and has the potential to increase the feelings of hopelessness and helplessness that have been discussed throughout. Many cancer survivors felt resigned to a persistent pattern of chronic sleep disturbance being something that would never be resolved. Indeed, this is exemplified by the participant who stated: 'I've spoken to people that can't sleep and I've said, what have you done about it, but what can be done about it?'

Sleep is not on the agenda

It was reported that 'no professional ever said to you, you might have sleep issues', at any point during cancer treatment or routine follow-up appointments. Many participants reported feeling that clinicians were very reluctant to have any discussion around sleep, and if patients did want to discuss something that was not routine, or 'on the agenda', then they were not particularly interested. However, they did caveat this by suggesting that it may be partly due to professionals 'having nowhere to refer you to' and there 'not being anything helpful out there'. They also highlighted that being pre-emptively told that sleep would likely become disturbed may have helped them to better understand and accept their subsequent sleep difficulties. 'If you were told sleep would be disrupted, particularly during treatment then you might have accepted it'. Participants emphasized the need for sleep to be discussed and assessed during cancer treatment and for clinicians to have a referral route for those with sleep difficulties. This demonstrates the importance of sleep health becoming a necessary, routine aspect of a holistic approach to cancer treatment and rehabilitation.

Discussion

Insomnia commonly occurs during times of stress such as a diagnosis of cancer and is amplified by the treatment process (Savard & Savard, 2013). The current study utilized a qualitative approach to directly assess cancer survivors' lived experience of insomnia, its impact on daily functioning, and its management within cancer care. Concordant with previous literature (Casault *et al.*, 2015), cancer survivors experienced insomnia as a '24-

hr disorder', affecting sleep at night and daytime functioning. This had a pervasive and chronic impact on several domains of functioning. The physical and psychological effects of cancer-related insomnia and their detrimental influence on survivors' QoL are evident. The chronicity and persistence of these symptoms highlight the need for the implementation of sleep management protocols within cancer care clinics.

Participants' perceptions of the management of insomnia were also explored. Consistent with previous findings, routine sleep assessment was absent in cancer care, and insomnia, when reported, was primarily treated with hypnotic medications (Coles *et al.*, 2017; Schieber *et al.*, 2019). More alarmingly, all participants highlighted that sleep was never discussed by clinicians and that they were never informed that disrupted sleep was a common occurrence following cancer diagnosis and treatment. Informing cancer patients that sleep disturbance is a normal response to cancer diagnosis and treatment may help to reduce distress (Zhou *et al.*, 2017), and offering sleep management guidance may also help to prevent the development of a persistent sleep problem (Marion, Ivers, & Savard, 2019).

Clinical implications

There is increasing acknowledgement within cancer care services that people diagnosed with cancer will spend more time in survivorship care than in treatment (Garland, Mahon, & Irwin, 2019) and that living longer following a cancer diagnosis does not necessarily imply living well (Peoples *et al.*, 2017). Many cancer survivors will spend months and years recovering from the consequences of a cancer diagnosis and subsequent treatment (Peoples *et al.*, 2017). This has led to a shift in focus to optimizing the health of cancer survivors, rather than simply disease treatment and symptom management (Garland *et al.*, 2019). Such an approach would be commensurate with advocates of lifeworld-led health care, which emphasizes patient choice and involvement in their own care, as well as not viewing health as simply the absence of illness (Dahlberg, Todres, & Galvin, 2009).

In the context of optimizing the long-term health of cancer survivors, the need for the development of standardized assessment and treatment protocols for sleep disturbance following cancer is evident. Indeed, in other areas of medicine, brief sleep medicine training has been demonstrated to improve recognition and treatment of sleep apnoea, for example (Valerio & Heaton, 2014). There is an increasing focus on preventative care with cancer-related insomnia, and there have been some promising findings that such early interventions offering sleep knowledge and education may have the ability to prevent the onset of chronic sleep disturbance and reduce unhelpful beliefs about sleep, when initiated prior to chemotherapy (Marion *et al.*, 2019). Research in this area is still very much in its infancy; however, normalizing sleep disturbance associated with cancer diagnosis and treatment, and educating patients about ways to manage such difficulties and improve sleep health, is certainly an important area for cancer services to further develop (Zhou *et al.*, 2017). It is also important to recognize that even if such preventative measures could be incorporated into cancer care, the stress and side effects of treatment mean that large numbers of cancer patients will still require further input and intervention for sleep disturbance (Savard & Savard, 2017).

There is much debate surrounding whether it is possible to offer intervention for sleep disturbance during active cancer treatment (Savard & Savard, 2017). Understandable concerns have been raised that this may be too onerous a time for cancer patients to engage with any cognitive behavioural sleep programme, especially whilst they are attempting to manage the significant physical and psychological effects of cancer

treatment (Zhou *et al.*, 2017). Indeed, CBT-i is a very active treatment and places considerable responsibility on the individual to elicit change through engaging with its main recommendations, and active treatment may be an ill-advised time to attempt to encourage engagement with such an approach (Savard & Savard, 2017). Furthermore, intervening at the wrong time could increase the likelihood that patients would disengage with CBT-i and be less willing to re-engage further on in their cancer care journey (Zhou *et al.*, 2020).

The post-treatment survivorship phase should be given particular attention and may also be an optimal time to offer therapeutic intervention for those suffering from persistent sleep disturbance following cancer. Following treatment and cancer remission, survivors often have less contact with health care services and diminished social support and also very often feel a pressure to return to 'normal life', whilst still attempting to manage a significant cancer-related psychosocial symptom burden (Wu & Harden, 2015). Furthermore, given that cancer survivors are no longer having to manage acute side effects of anticancer treatments, this is likely to be a less burdensome time to attempt to undertake active treatments such as CBT-I and may increase their efficacy (Savard & Savard, 2017).

Greater attempts must also be made to improve the availability of efficacious non-pharmacological interventions. CBT-i is now available for delivery in a number of different modalities, helping to overcome previously cited concerns surrounding accessibility and resource (Johnson *et al.*, 2016). Indeed, this versatility in methods of delivery makes it compatible with a stepped care approach to cancer-related insomnia care (Zhou *et al.*, 2017). Additionally, such attempts to offer CBT-i in a variety of formats have recognized that help must be given to cancer care centres in accommodating these interventions, when their primary role is to deliver cancer treatment (Zhou *et al.*, 2020). It is clear that sleep is a potentially fruitful therapeutic target to improve both physical and mental health in cancer patients and requires the development of protocols for it to be routinely assessed and treated in cancer care. Indeed, the future development of preventative interventions prior to cancer treatment may well help to reduce the prevalence of chronic insomnia in cancer survivors and thus reduce the potential for further morbidity and mortality associated with persistently disturbed sleep.

Study limitations

Measures such as using summary sign off sheets following focus groups to ensure the topics covered were a fair reflection of participants' accounts, thereby enhancing validity, were employed to strengthen the study's methodology. However, it is important to acknowledge some limitations also. The study sample was not representative of all individuals with cancer and sleep problems, limiting generalizability to the cancer population as a whole. A selection bias in favour of people who feel comfortable discussing their experiences and who are highly motivated to co-operate is assumed. Using focus group methodology may have limited the depth of information it was possible to obtain on the emotional experience of insomnia. Whilst all participants were encouraged to contribute to the focus group discussion, we acknowledge that one-to-one interviews may have allowed participants to discuss their lived experience of insomnia in greater detail. Furthermore, it is also acknowledged that the researchers did not share the experience of cancer-related insomnia with participants, and thus, this could have had an influence on the interpretation of the experiences that were shared.

Future research

Based on current research evidence, CBT-i is presently the only recommended treatment for insomnia related to cancer (Johnson *et al.*, 2016; Matthews, Carter, Page, Dean, & Berger, 2018). Future research should seek to address the unanswered question of the optimal time to intervene in cancer-related insomnia. Research at each stage of the cancer trajectory, that is following diagnosis and prior to treatment, during treatment, and in post-treatment survivorship, is required. Increasing attention must be paid to the potential of preventative interventions prior to treatment initiation and also interventions in the immediate post-treatment phase, in an attempt to reduce the chronicity of cancer-related insomnia. A need for research with a diversity of cancer types and also possibly adapting CBT-i for cancer patients, to include elements of cancer symptom management, similar to Mann *et al.* (2012), where they targeted hot flushes and night sweats, along with sleep disturbance in breast cancer survivors, may also be worthwhile.

A need for improved awareness of sleep disturbance amongst professionals involved in cancer care is also necessary. Qualitative methodologies such as those employed in the present study may help to shed light on the training needs of clinicians, as well as providing insight into their views on the optimal intervention time for cancer-related insomnia. Furthermore, cancer patients' views would also be invaluable regarding both the timing and method of intervention delivery. Patient preferences and expectations are known to influence treatment outcomes, yet these are very rarely captured or reported in clinical research (Mills *et al.*, 2011).

Conflicts of interest

All authors declare no conflict of interest.

Author contributions

Paul Reynolds-Cowie (Writing – original draft); Leanne Fleming (Conceptualization; Formal analysis; Writing – review and editing).

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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