

**CADTH RAPID RESPONSE REPORT:
PEER REVIEWED SUMMARY WITH CRITICAL APPRAISAL**

Treatments for Insomnia: A Review of Patients' and Caregivers' Experiences and Perspectives

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Context and Policy Issues

Poor sleep quality may have a negative effect on the overall quality of life in terms of daytime physical, psychological and social well-being.¹ Of the different sleep disorders that exist, insomnia is known to be the most prevalent¹ with a reported rate of 10% to 25% of the adults in the general population in most countries.² Insomnia disorder entails a subjective dissatisfaction with sleep quality or quantity characterized by difficulty falling asleep, staying asleep, or falling back asleep after early morning waking which causes clinically significant distress or impairment in daily functioning.³ Additionally, according to DSM-5 Diagnostic Criteria, this disturbance cannot be attributed to another sleep disorder or the physiological effects of a substance and should continue several times a week for at least three months despite having adequate opportunities to sleep.³

Treatments for insomnia can be divided into two groups: pharmacotherapy (e.g. benzodiazepines, z-drugs) and non-pharmacological therapies. Non-pharmacological therapies include psychological and behavioural options like cognitive behavioural therapy for insomnia (CBT-I) as well as complementary and alternative medicine (CAM) therapies such as dietary changes or herbal remedies.^{1,4} Pharmacotherapy is a common clinical approach for managing insomnia due to its appeal as providing relatively rapid relief.⁴ On the other hand, sleep habits and psychological problems can also be a factor when it comes to the onset and persistence of insomnia.⁴ According to Spielman's 3P Model for Insomnia,⁵ factors associated with insomnia fall within three primary categories: predisposing, precipitating and perpetuating. While several studies focus on precipitating factors (e.g. onset of medical and psychiatric illnesses) or perpetuating factors (e.g. dysfunctional beliefs about insomnia), some also allude to predisposing factors such as the tendency toward excessive worrying or biological predispositions.⁶ In all cases, management strategies aimed at addressing psychological, cognitive, and behavioural factors barring re-establishment of normal sleep patterns have been identified as crucial.⁴ For example, CBT-I has been demonstrated in some studies to produce clinical benefits and sleep improvements that are well sustained over time.^{1,2,4}

The connection between treatment preference and treatment outcome is founded on the basis that patients who view treatments as providing benefit will participate and adhere to treatment, thereby increasing the therapeutic potential of a given intervention.¹ Understanding patients' perspectives on treatment options can help support patients in adhering to the treatments for insomnia.¹ This understanding allows clinicians to better work with patients while navigating potential treatments most suitable to their expectations and desired outcomes.¹ For instance, a mixed methods study aiming to explore patients' perceptions toward pharmacotherapy and the psychological or behavioural management of insomnia, reported that patients who found treatment as "annoying" or "boring" tended to have poorer treatment outcomes compared to patients who found the therapy relaxing.¹

The objective of this Rapid Response report is to identify, appraise and describe the current literature on patients' and their family caregivers' experiences with and perspectives on the treatment and management of insomnia to help inform decision-making in this area.

Research Question

What are patient, caregiver, or family member experiences with and perspectives of treatment and management of insomnia?

Key Findings

Only patient perceptions were available for review, there were no relevant data on caregiver or family member experiences. Patients' perceptions of and engagements with pharmacotherapy tend to vary in relation to nightly levels of fatigue, daytime responsibilities and social normalization of medical sleeping aids. While the duration and intensity of insomnia also plays a role, this review was unable to identify any consistent timeframes or severity levels that could serve as indicators. Rather, the use of pharmacotherapy tends to be informed by a certain level of pragmatism balancing need with desired outcomes. For instance, while several individuals perceived pharmacotherapy as the better choice due to its rapid relief, others were concerned with daytime side-effects and issues of long-term dependence or addiction.

Some people living with insomnia also report trying alternatives to pharmacotherapy including cognitive behavioural therapy, mindfulness, exercise, relaxation, herbal remedies, or other complementary therapies. For many of these people, non-pharmacological treatment is viewed as a long-term solution that can address the underlying cause of insomnia and ultimately overcome the disorder. They appreciate that the personalized nature of these treatments helps them to adhere and obtain longer-term outcomes.

Many patients appear to struggle when deciding on which treatment option to consider, and in their decision consider what is more important to them: a long-term outcome that addresses underlying factors in their insomnia or a quick short-term relief. By allowing themselves the time to sit with and listen to the patient's lived experience of suffering, perhaps clinicians could help this decision become clearer.

Methods

Literature Search Methods

A limited literature search with main concepts appearing in title or major subject heading was conducted on key resources including PubMed, Embase, Medline, PsychINFO, The Cochrane Library, University of York Centre for Reviews and Dissemination (CRD) databases, Canadian and major international health technology agencies, as well as a focused Internet search. Methodological filters were applied to limit retrieval to qualitative studies. Where possible, retrieval was limited to the human population. The search was also limited to English language documents published between January 1 2007 and February 28 2017.

Selection Criteria and Methods

Two reviewers independently screened citations and selected studies according to pre-defined eligibility criteria, and two others independently verified the selections.

Discrepancies between reviewers were resolved by deferring to one reviewer. In the first level of screening, titles and abstracts were reviewed and the full-text of potentially relevant articles were retrieved and assessed for inclusion. The final selection of full-text articles was based on the selection criteria presented in Table 1.

Table 1: Selection Criteria

Population	Adults with insomnia or their family members or non-professional caregivers
Intervention	Any pharmacotherapy or psychological or behavioural intervention, ^a or treatment for insomnia
Comparator	No comparator necessary
Outcomes	Any outcome of importance to patients or their family caregivers that might emerge from the literature, including but not limited to: <ul style="list-style-type: none"> • experiences of benefits and harms; (including long-term) • expectations versus actual experiences; • outcomes of importance to patients, family members, and caregivers; • value of outcomes from the perspective of patients, family members, and caregivers; • values and beliefs of patients and caregivers regarding decision making between treatment options, in particular access to and availability of non-drug options; • experiences and perspectives of patients regarding paying out-of-pocket; and • factors of importance to patients and caregivers that may influence decisions not to pay or to pay for these expenses.
Study Designs	Qualitative studies, systematic reviews of qualitative studies, and the qualitative portion of mixed methods studies

^aWhile CAM therapy options were not specifically listed in the inclusion criteria for this review, if CAM therapies were discussed in studies primarily focusing on pharmacological, psychological or behavioural therapies, they were included for this review.

Exclusion Criteria

Articles were excluded if they did not meet the selection criteria outlined in Table 1, they were duplicate publications, or were published prior to 2007. Studies describing perspectives on CAM therapies alone, or in isolation from pharmacological, psychological or behavioural therapies, were excluded. This review focusses on the last ten years to reflect current practices as well as recent patients' and caregivers' experiences and perspectives. To be eligible, studies must have explored or assessed the perspectives of patients or their family caregivers directly and not indirectly; for example, through another person. Studies that assessed only clinician perspectives were excluded. The following types of publications were also excluded: theses and dissertations, data presented in abstract form only, book chapters, editorials, and letters to the editor. Studies were excluded if they are not published in English.

Critical Appraisal of Individual Studies

The included qualitative studies and systematic reviews were critically appraised by one reviewer using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist and the CASP Systematic Review Checklist⁷ respectively as guides. Summary scores were not calculated for the included studies; rather, a review of the strengths and limitations of each included study were described narratively.

Summary of Evidence

Quantity of Research Available

A total of 378 citations were identified in the literature search. Following screening of titles and abstracts, 278 citations were excluded and 100 potentially relevant reports from the electronic search were retrieved for full-text review. Forty-four potentially relevant publications were retrieved from the grey literature search. Of these potentially relevant articles, 121 publications were excluded for various reasons, while 23 publications met the inclusion criteria and were included in this report. Appendix 1 describes the PRISMA flowchart of the study selection.

Summary of Study Characteristics

Characteristics of the included studies are summarized below and details are available in Appendix 2, Table 2.

Twenty-three studies were included as relevant for patients' experiences and perspectives of interventions for insomnia. No studies were identified that described family caregivers' experiences or perspectives.

Six used a qualitative descriptive design,^{1,8-12} seven were phenomenologies,^{1,2,4,13-16} four used a grounded theory design,^{6,17-19} one was a systematic review,²⁰ five used mixed methods.^{11,21-24} Five of the studies were conducted in the United Kingdom,^{9,10,13,16,25} seven in the United States of America,^{8,11,14,17,19,21,23} five in Australia,^{1,4,12,15,24} one in Canada,²⁰ one in China,¹⁸ one in Sweden,⁶ one in the Netherlands,²² one in New Zealand,²⁶ and one in Iran.² Two studies were published in 2017,^{17,24} eight in 2016,^{1,2,6,8,15,16,18,20} four in 2015,^{4,11,22,26} three in 2014,^{12,14,21} three in 2013,^{9,19,23} one in 2011,²⁵ one in 2010,¹³ and one in 2008.¹⁰ The sample size ranged from 10 participants in one phenomenological study¹⁶ to 51 in another phenomenological study.¹ The systematic review²⁰ included 22 studies which used semi-structured interviews or focus groups as their primary data collection methods.

All studies included adults with insomnia accompanied by daytime dysfunction^{1,2,6,9,10,12-14,16-22,24-26} some with comorbidities such as schizophrania,^{4,15} post-acute traumatic brain injury,⁸ heart failure,²³ and obstructive sleep apnea.¹¹

Ten of the studies reported patients' views, experiences and preferences with various treatments for insomnia,^{1,6,9,11,14,21,22,24-26} one included specifically a range of different types of evidence-based therapies for insomnia including standard pharmacological, melatonin-based, and psychological and behavioral-type (talking) therapies,⁴ and another compared a clinic group (those participants who had or were attending specialist sleep or psychology clinics) with a community group (those participants who were not attending specialist groups).¹ Ten studies explored the lived experience and management of sleep problems.^{2,8,10,12,14-16,18,19,23} Four studies explored various aspects of the relationships between patients and health care practitioners and how these relations influence the uptake of insomnia treatments.^{9,11,13,17} The systematic review summarized evidence from a variety of qualitative studies on the experience and perceived consequences of insomnia.²⁰

Summary of Critical Appraisal

Overall, studies included in this report are of moderate to high quality. There are, however, a few exceptions described below. The studies were well conducted and demonstrated congruence with respect to their chosen methodologies and the research objectives. A

summary of the strengths and limitations is included below and details are available in Appendix 3 (Tables 3 and 4).

Each of the twenty-three included studies provided a clear statement of the research objectives or purpose and all study objectives fit well for qualitative inquiry. A range of qualitative study designs were used, and in each case the research design was appropriately aligned with the research objective. The qualitative descriptive study and the systematic review were minimally informed by theories or an analytic framework, which is quite appropriate given the descriptive, versus theoretical nature of the studies.^{8,20} Those studies that used other designs had stronger theoretical orientations, which appropriately guided data collection, analysis and interpretation.

Primary Included Studies

All twenty-two included primary studies described a recruitment strategy however 15 studies did not identify using a purposive sampling strategy.^{1,6,10-18,21,24-26} Six studies did identify using a purposive sampling strategy,^{2,8,9,19,22,23} while one study identified using a snow-ball sampling strategy.⁴ Given the lack of overall reporting on purposive sampling strategies, it is possible that the studies did not include rich samples suitable to develop comprehensive descriptions of patients' perspectives. This concern is compounded, given four of the 22 primary studies mentioned sampling until data or thematic saturation was achieved,^{1,2,14,15} while the remaining 18 did not.

A range of data collection methods were used, which were congruent with the research objectives in the 22 primary studies. Thirteen studies described using semi-structured interviews, which allowed for a consistent set of topics to be raised with each participant.^{1,4,6,8,9,11,12,16,17,19,22,24,25} Eleven studies used focus groups and mentioned having interview options available for those who felt uncomfortable discussing in a group, which is appropriate considering the discomfort that many patients describe from feeling "not normal" and which may lead them to be hesitant to share their true experiences.^{4,9,10,13-15,18,21-23,26} Three studies reported conducting both interviews and focus groups.^{4,9,22} One study used unstructured interviews to capture experiences over time and to explore emergent issues in depth.² The studies using a thematic analysis described that the interviews were conducted by a researcher,^{4,8,9,11,14,15,22,25,26} however, none of the included primary studies discussed how rapport was built with the participants and thus making it unclear whether a rapport was built at all.

Nine studies identified using a thematic analysis approach to analyzing their data,^{4,8,9,11,14,15,22,25,26} while a further five studies described a more generalized iterative data collection and analysis process to develop and cluster emergent themes.^{6,16-19} Two studies reported using a Framework Analysis technique for analysis^{1,12} and another study reported using the Colaizzi method for analysis.² A further study reported using a comparative analysis,²⁵ but failed to elucidate what this might mean or how this form of analysis was useful. The analytic strategies used in each study generally appeared appropriate for qualitative data, although one study utilized "directed content analysis"²¹ which tends to limit a researcher's field of sight when reviewing qualitative data. A range of strategies were described to enhance rigor that focused on reliability in coding, most often coding by more than one researcher.^{1,2,4,8,11,14-17}

None of the included studies provided an overview or detailed descriptions of the researcher's background and efforts to put aside personal beliefs during data collection and

analysis. All studies likewise excluded a discussion of the relationship between the researcher and the participants, and the researcher and the topic.

Systematic Review

One study used systematic review methods to identify and synthesize the findings of qualitative studies on the experiences of patients with insomnia.²⁰ The authors reported searching PsycINFO and Medline, as well as reviewing the reference lists of included studies, although there is no mention of whether unpublished or grey literature was sought. Little information was provided regarding data analysis strategies and corresponding strategies to enhance rigor.²⁰ The authors summarized results from 22 primary studies, which covered the experience of insomnia, management of insomnia as well as the medicalization of insomnia across a diversity of patients' experiences. Critical appraisal of included studies was conducted independently by two reviewers using the Critical Appraisal Skills Programme tool as a guide. Due to limited reporting of methodological details within the primary included studies, a comprehensive appraisal was not possible and therefore it is possible that results of the primary studies lack credibility and dependability, which would have been carried forward into this synthesis.

Summary of Findings

Patients' Experiences of Insomnia

While the individual experience of insomnia varies along a number of heterogeneous pathways, how life with insomnia is understood and described by individuals tends to take course outside of nighttime frustration with sleeplessness.²⁰ One common complaint in the studies analyzed for this review localized around concerns of disruption to daytime activities. Whether these activities were working, studying, engaging in social relationships or contributing to their communities,^{1,2,8,13,15,16,19,20,25} individuals tended to express a desire to get a good night's sleep as a way of reducing the physical, psychological and social health changes keeping them from doing what they cared about.^{1,2,8,15,20} This is not say that sleeplessness itself was not discussed, it was,^{2,9,10,16,23} just that the overall concern tended to return to hampered daytime activities.

For many, this inability to engage with the world in the same ways as before would lead to feelings of frustration, self-pity and isolation.^{2,8,10,18,23} Green et al. draw on one participant who mused: "Why am I the only person awake in the world when everybody else is sleeping soundly?"¹⁰ Of course, this may be an over exaggerated expression of aloneness in the world, but that this patient felt it needed to be spoken is indicative of the powerful disconnect insomnia can bring.

In some cases, individuals spoke to the act of normalizing insomnia wherein it could be attributed to a natural process of aging,^{6,12} cultural beliefs,¹⁸ or form of spiritual punishment.² This internal normalization either prevented the individual from pursuing treatment advice or from adhering to prescribed treatments.^{1,20} One participant waited fifteen years to seek help as she felt her inability to move past insomnia was one of not being tough enough.¹⁹ This use of defeated, demoralized language was not uncommon.^{2,8,10,13,18} Or, as Moloney highlights in her uptake of the conceptual term "virtuous non-user," one study participant pursued medical attention only to refuse adhering to the prescribed pharmaceutical regimen.¹⁷ Citing the abnormality of medical interventions, this particular individual believed they should be able to handle insomnia on their own.¹⁷

While these feelings of isolation and self-deprecation were common lived experiences and barriers reported in the literature, they were not the sole barriers. For some individuals, the procedural requirements for diagnoses were perceived as time consuming and expensive due to the need to travel to another city or location to visit a specialist.^{2,12} And for others, when external validation for their suffering was finally sought (whether by friends, family or health care practitioners), they ran into further feelings of loneliness and social isolation as a result of not being understood, or of being misunderstood.^{12,13,18-20,23} For example, Yung et al. report that friends and family members often waived off patient concerns by commenting on how well they look or how a nap could easily resolve their tiredness.¹⁸ Though patients had learned to live with these misunderstandings, the resulting isolation was often associated with feelings of “torture and suffering” (p. 424).

In other studies, individuals negatively perceived repeated minimizing or normalizing of the adverse influence of insomnia by some clinicians.^{8-10,13,23,26} Intended or not, by restricting space for the life altering effects of insomnia to be spoken of as outside the natural progression of life or as a symptom of some other comorbidity, individuals began to navigate deep seated, and competing, concerns of “therapeutic nihilism” and desperation. Andrews et al.²³ noted the failure of care providers to spend time asking about sleep quality led to further resignation and an internalized mantra of “docs don’t ask, we don’t tell” (p. 9). Though these individuals may be ready to begin seeking treatment (in this case, non-pharmacological), the perceived disconnect between clinician concern and legitimacy of their complaint bars them from potential relief.

Another key theme that emerged from this review was the issue of comorbidities. Comorbidities ranged from co-occurring sleep difficulties¹⁵ to traumatic brain injuries⁸ or heart failure.²³ Participants in some studies reported that the symptoms of their comorbidity exacerbated their symptoms of insomnia. For instance, people living with chronic obstructive pulmonary disorder (COPD) reported the fear of death due to not being able to breathe during their sleep as playing a role in keeping them awake.¹⁴ In connection with this is the role of healthcare professionals in helping to understand symptoms. Some patients perceived their healthcare professionals as giving more priority to other symptoms and less priority to insomnia symptoms, which caused them further frustration.^{1,20}

In some studies, participants also highlighted the importance of the healthcare professional when it came to selecting a treatment option. In many cases, people reported feeling that their healthcare professionals were not well-informed of the various treatment options.^{1,20} Some patients felt that healthcare professionals tended to have a singular focus on sleep hygiene which often felt dismissive of the gravity of their complaints and delayed or prevented their referral to sleep clinics.^{1,20}

Pharmacotherapy

Whether a complete rejection, reluctant engagement, or piecemeal utilization, participants’ experiences with and perspectives of pharmacological therapies for insomnia tended to inform a number of pragmatic entanglements. Intensity and length of lived experience with insomnia certainly play a role in these varied entanglements, but no singular cut off points could be pinned down and arranged as a determinant of perspective. Similarly, studies tended to cut across the breadth of these perspectives rather than focusing specifically on one.

Individuals rejecting pharmacotherapy altogether did so for a number of reasons. In a couple of cases, medications taken for comorbidities such as schizophrenia⁴ and COPD¹⁴

were perceived to interfere with the effectiveness of those taken for insomnia. Another pointed to potential cultural barriers¹⁸ in which there was both a lack of trust and familiarity with western medicine. And while this singular study out of China cannot be directly linked to how some immigrant groups or Indigenous Peoples living in Canada may encounter pharmacological treatments for insomnia, this disconnect observed between cultural ways of knowing is worth noting. Wholesale rejection of pharmacotherapy could also stem from perceptions of what it means to sleep naturally.^{1,8,12,17}

Another entanglement with pharmacotherapy came in the form of what Maloney calls “reluctant medicalization.”¹⁷ For these individuals, pharmacotherapy had become a “harsh necessity”²⁶ that would quickly be discarded in favor of any non-pharmaceutical strategy perceived as working.⁴ Those engaged in this form of pragmatic entanglement often attempted to cut their reliance on pharmaceuticals by modifying prescriptions or mixing and matching over the counter drugs.^{8,9,23,26} Caught between the desire to sleep and the fear of dependency, Andrews et al.²³ report participants nibbling at their pills or exchanging their higher dose with a family member’s lower dose. Matthews et al.⁸ note that the veterans with traumatic brain injuries interviewed for their study enacted a process of trial and error with differing degrees of reliance on prescriptions and provider instructions where decisions to engage or not engage were based on nightly levels of fatigue. And Henry et al.¹⁹ point to the way in which simply knowing their medications are available nearby adds a level of nighttime comfort for some participants.

Even for those individuals committed to the use of pharmacotherapy treatments, a certain amount of pragmatism seemed to inform their engagement. Of course this was not always the case; some individuals simply accepted the “ordinariness” of pharmacotherapy within social groups or clinical practice at face value.¹⁷ But for other individuals, this pragmatism took the form of stockpiling prescriptions in the event that their own was cancelled.¹³ Or, in another case, this meant building an “arsenal”¹⁹ of medications to be consumed circumstantially based on nightly considerations of fatigue and the next day’s needs.

Though arguably no more than a minor resistance, these decisions to align medical advice with their own perceptions could be indicative of a patient’s overall desire to maintain some form of control over how their insomnia affects both daytime and nighttime suffering. For many individuals, the delicate balancing act between dose, sleep requirements and negative side effects is presented as needing daily fine tuning rather than long-term repetition. On a similar note, this partial adherence could also indicate a pushback against individuals’ concerns of being misunderstood or having their suffering minimized by clinicians as noted in the previous section. If the perception is that these pharmacotherapies are prescribed as an attempt to brush off suffering and move on to the next patient, there is a space for uncertainty or distrust of the prescription. Or, perhaps this reluctant engagement points to overall sentiments of a desire to improve or develop more interchangeable treatment regimens. Many of the individuals who modify prescriptions also speak to the desire to engage with other forms of treatment if they can find ones that work.¹

Psychological, Behavioural, and CAM Therapies

Similar to the pragmatic interactions individuals carried out with pharmacotherapies, those choosing (or being prescribed) to follow non-pharmacological treatment options tended to navigate and experience them from a variety of perspectives. Nonetheless, while non-pharmacological options range anywhere from behavioural and psychological methods like CBT-I to CAM therapies like mindfulness training, dietary changes or herbal remedies,^{1,14,16,18,19,21,24,25} several individuals note their interest in these forms of treatment

as stemming from a desire to treat the underlying causes of insomnia holistically rather than attempting a band aid fix.^{1,18,20} Some patients also stressed that managing sleep by incorporating personalized strategies embedded in their daily routines made it easier to adhere to those strategies and thus obtain long-term outcomes.^{14,18,20,21}

As an increasingly standard behavioural therapy for insomnia,²⁵ CBT-I played a featured role in many of the included studies. Whether having experience with computerized (CCBT-I), internet based (ICBT-I) or face-to-face versions, participants typically perceived this option to be a valuable long-term strategy for addressing the root causes of their insomnia.^{1,6,11,24,25} However, as CBT-I requires behavioural change, several individuals found this a challenging therapy for extended adherence. In some cases, the acute severity of their insomnia decreased their ability to see outside of their immediate need for a quick fix. In this case, participants talked about the need for a pharmacological “band aid” fix that could be followed by a more in-depth and intensive psychological or behavioural therapy.^{1,4} By following this process, participants hoped to gain more control over their insomnia and eventually become active rather than passive participants in their healing. In other cases, individuals perceived the stages involved in various forms of CBT-I (e.g. sleep restriction therapy) to be overwhelming and not conducive to adherence.^{18,24,25} This difficulty was further exacerbated for individuals, like those in Chan et al.²⁴ and Blom et al.,⁶ who explored the web-based delivery of CBT-I (defined as ICBT-I in their study) in which there was a lack of contact between clinical practitioner and participant. While participants found ICBT-I useful, they also perceived it would have been more beneficial to have some sort of interaction with a therapist – even if this was simply over the phone – something to let them know they were moving along and someone was watching their progress. In one case, difficulty adhering to CBT-I arose due to the concurrent uptake of positive airway pressure (PAP) machines for their obstructive sleep apnea.¹¹ Trying to navigate the newness of both sleep aides was overwhelming and limited the perceived effectiveness of CBT-I.

Outside of specific treatment options, the importance of holistic care as a way of approaching insomnia played a primary role in individual experience. Whether engaging CBT-I,⁶ mindfulness techniques,²¹ lifestyle changes or cultural medicines,¹⁸ several participants commented on the importance of their accepting of insomnia as an illness in their lives before being able to truly address its causes.

In addition, some patients highlighted other aspects of psychological, behavioural, or CAM therapies as beneficial. For example, some patients highlighted the importance of group sharing and support, and indicated that it was nice to be able to speak to someone who has been in their footsteps and can offer first-hand advice and support through the treatment process.^{20,21} Therapeutic alliance, or therapeutic relationship, was also highlighted as an important factor present in psychological or behavioural treatments.¹⁶ Some patients indicated that the active listening by the therapist or group lead as crucial to understanding their symptoms and to work with them to create a treatment plan.¹⁶

Some of the reported barriers to psychological or behavioural therapies included the cost to see a therapist and the length of time it could take to obtain positive results.^{1,20} Some patients also stated not being aware of psychological or behavioural treatment options however they indicated a willingness to try them and discussed the educational needs for patients regarding the various forms of treatments available for insomnia.⁸

Patients' Preferences: Pharmacotherapy Versus Psychological, Behavioural, or CAM Treatment Options

One theme that emerged in this review was the dilemma that most patients face when considering which treatment options to pursue. This included considering what was important to them: wanting a long-term outcome that addressed underlying factors in their insomnia or a quick short-term relief.^{1,20}

When it comes to whether patients prefer pharmacotherapy or psychological, behavioural, or CAM therapies, there were several factors that people highlighted as guiding their decision. The first was their perception of control of sleep. Some patients viewed sleep as a natural process of the body and something that should be controlled by them and not by drugs.^{1,4,15,17} Many people that reported this perception also reported preferring psychological or behavioural treatments, which they felt empowered them and helped them to regain control over their sleep.^{1,4,15}

Another factor that emerged was consideration of potential for side effects with treatment.^{1,15} One of the major side effects that most patients considered was that of addiction.²⁰ When told about the possibility of becoming addicted to a drug, some individuals perceived this to mean that they could lose control over their sleep forever and were thus more inclined to choose a psychological or behavioural treatment.²⁰ Many people also compared treatments for similarities and differences to previous treatments they have used, considering the duration of the course of the treatment, and any foreseeable challenges to taking up treatment when considering their options.^{1,20} The use of anecdotal evidence from friends and family as well as advice from their healthcare practitioner was also commonly reported when considering treatment options for insomnia.^{1,4,20}

The studies also highlighted a discrepancy in terms of what patients' perceived their treatment goals to be and what healthcare professionals perceived their treatment goals to be.²⁰ It is possible that healthcare professionals believe patients are more interested in obtaining pharmacotherapy for immediate relief, when at least some patients prefer CBTs and other non-pharmacological treatments.²⁰

In some studies, participants provided recommendations on how they felt the treatment process should be carried out for those suffering from insomnia. Many patients emphasized that what works for one patient does not always work for other patients.⁸ Thus the importance of tailoring the approaches to patients' preferences was reported as crucial.^{1,16,20} This bespoke approach could draw on both pharmacotherapy and psychological or behavioural treatments addressing a range of acute to prolonged experiences with insomnia.^{1,4,16,26} Cheung et al. note some patients as suggesting this personalization still follow some form of hierarchical system to triage the patient to different treatment options based on treatment response and symptom severity would be beneficial.¹

Limitations

Several of the studies included for this review indicated that a fair concentration of their participants suffered from comorbidities. Whether these studies focused primarily on the interaction between participant comorbidities and their insomnia,^{4,8,11,15,23} or merely mentioned the presence of more minor comorbidities, transferability of these results to individuals with other conditions, or no comorbidities (however uncommon), could be tenuous. For instance, whether the experience and perceptions of treatment of patients who experience insomnia as a result of a significant life event would have differed is something

that should be considered. Another limitation is that of the 22 primary studies included in this review, seven^{10,12,13,18,19,21,27} were also included in the Araujo et al. systematic review.²⁰ This overlap in studies could have potentially led to a redundancy in the results. Further, the reality that none of the 22 primary studies (excluding the systematic review) were Canadian or Indigenous also serves as a limitation for decision making within the Canadian context. Varied cultural understandings, attitudes, health care delivery models and availability outside of Canada can impact the treatment of insomnia. The studies included in this review also tended to dichotomize insomnia treatments between pharmacologic therapies or behavioural therapies. While some^{1,4,26} alluded to either patients' or health care practitioners' concerns with this dichotomization, analysis of these concerns was largely absent and prevented our review from pursuing the idea further. Finally, none of the included studies presented an analysis of experiences with insomnia as they relate to a person's age, sex or prior experience with treatment. It is likely that individuals of younger or older age, or with more or less experience with a range of pharmacological or behavioural therapies would think differently of their current treatment experience, although our review was unable to explore this issue.

Additional areas not represented by the literature identified in this review, but that could provide insight into this topic include an understanding of patients' expectations of their healthcare professional to manage their sleep disorder, and an understanding as to whether treatment expectations differ for patients not presenting with comorbidity. These questions could help us understand what issues are important to a variety of patients when considering insomnia treatment options.

Conclusions and Implications for Decision or Policy Making

This report provides a summary of 22 primary studies and one systematic review published in the last 10 years that describe patients' experiences and perceptions of treatment for insomnia.

Many patients indicated feeling not being understood or being misunderstood in terms of their insomnia symptoms by their peers and healthcare professionals, which led to frustrations and a feeling of not being normal. The effect on the daytime activities of patients is the major complaint of insomnia and one of the reasons that led most patients to seek medical treatment. Even though many patients state pharmacotherapy provides a faster relief of insomnia symptoms, some patients preferred to undergo psychological or behavioural treatment options in order to address long-term factors in their insomnia, avoid possible side effects and gain control over their sleep. Some patients indicated that they turned to advice from their healthcare professional and anecdotal evidence from their friends and family members when deciding on a treatment option. Comorbidity was highlighted as an important factor when treating insomnia with many patients expressing the importance of treating both morbidities to avoid exacerbation of one (most often insomnia as they felt healthcare professionals tended to dismiss their complaints about insomnia). Most patients felt that healthcare professionals should be more aware of the different treatment options that are available so that they can work with their patients to create a treatment plan which is tailored to the patients' specific needs as not all plans fit everyone. A hierarchical system to triage patients to different insomnia treatment options based on a trial-and-error process was recommended by some patients.

In sum, the primary implication of this review is the need to increase clinical and public understandings of and concerns with the holistic experience of insomnia. Whether

demonstrated in individuals' pragmatic entanglements with pharmacotherapies or the express desire to address root causes of insomnia for those engaging in non-pharmacological options, individuals repeatedly alluded to a desire to be heard holistically. While this certainly can take the form of allowing clinical interactions to be framed by a patient's preference for pharmacotherapy or psychological or behavioural therapy treatment, it could also be informed by an improved willingness to listen to and sit with the individuals suffering in these clinical encounters.

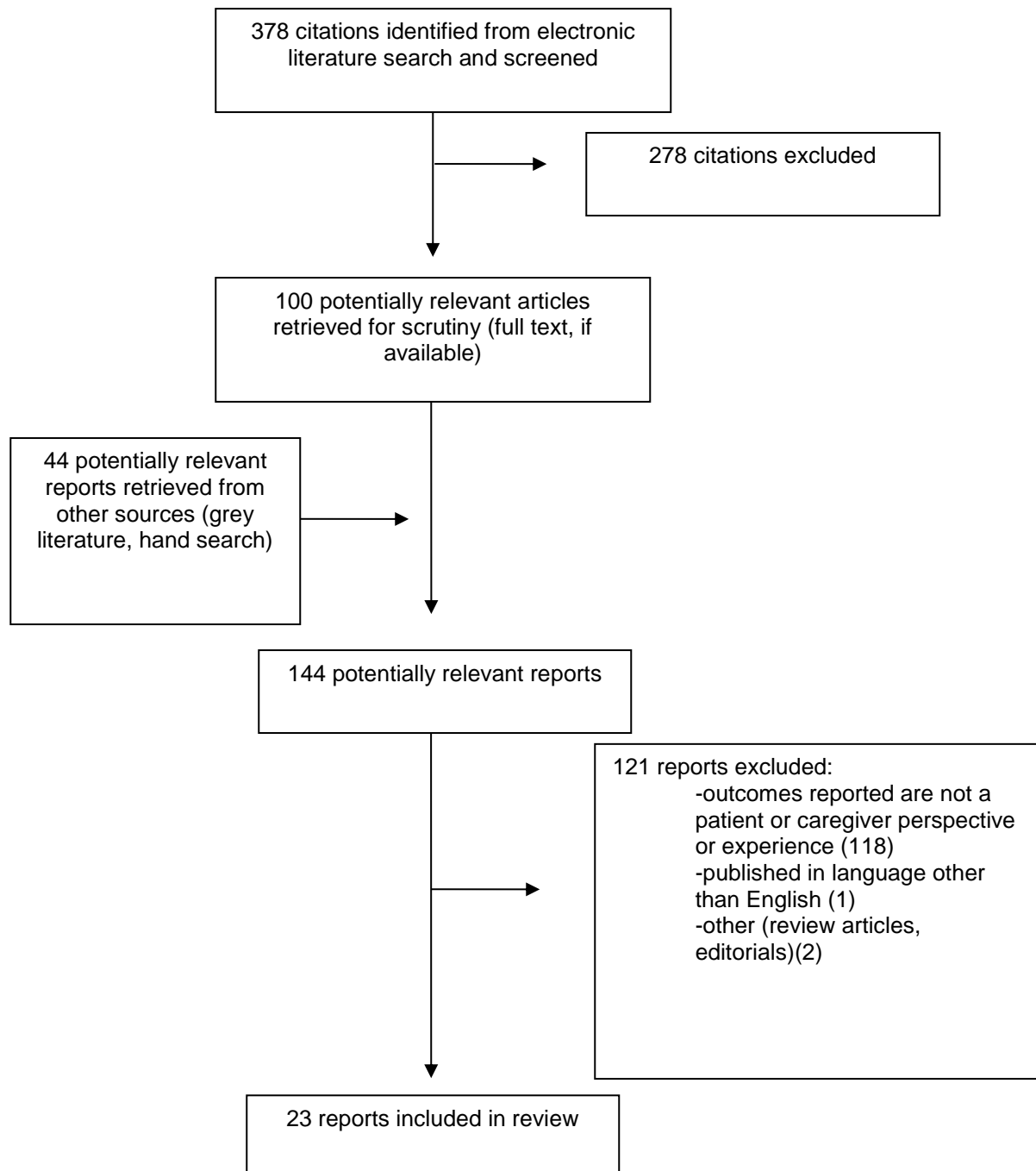
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Appendix 1: Selection of Included Studies



Appendix 2: Characteristics of Included Publications

Table 2: Characteristics of Included Publications

First Author, Publication Year, Country	Data Collection Method	Study Objectives	Sample Size	Inclusion Criteria
Araújo, 2016, Canada²⁰	Systematic Review	To summarize the evidence derived from insomnia studies using a qualitative research methodology.	22 studies	Articles published in either English or French that had the main focus as insomnia in adults and that used any qualitative data collection and analysis strategy.
Chan, 2017, Australia²⁴	Mixed methods; Semi-structured Interviews	To explore barriers and facilitators to use of an adjunctive CCBT-I program among depressed patients in a psychiatric clinic.	N=10	Males aged ≥50 years with a diagnosis of depression and “clinically significant insomnia symptoms reported on the Insomnia Severity Index.”
Moloney, 2017, USA¹⁷	Semi-structured interviews	To provide perspectives on the office visit interaction from both sleepless patients and the physicians who treat them.	Patients: N=27 Physicians: N=8	People who had been prescribed a sedative hypnotic for sleeplessness within the 6 months prior to this study.
Blom, 2016, Sweden⁶	Semi-structured Interviews	To identify facilitating and hindering factors for patients in ICBT-i and ICBT-d and formulate hypotheses for future research.	N=35	Adults diagnosed with comorbid insomnia and depression.
Cheung, 2016, Australia¹	Questionnaire and in-depth semi-structured interviews	To explore patient perceptions toward pharmacotherapy and the non-pharmacological management of insomnia.	N=51	Participants, male and female, to be over the age of 18 years, diagnosed with insomnia, and referred to the study by their clinician: or have self-reported symptoms of insomnia that are consistent with the International Classification of Sleep Disorders, Second Edition.
Chiu, 2016, Australia¹⁵	Focus groups	To explore the lived experience of sleep problems in people with schizophrenia-spectrum disorders.	N=14	Individuals with diagnosis of schizophrenia spectrum disorder aged ≥18, and previous or current experiences with sleeping problems.
Matthews, 2016, USA⁸	Semi-structured interviews	To examine SWD characteristics, factors, consequences, and management strategies from the perspective of veterans with chronic stage, moderate/severe TBI.	N=19	Male veterans with post-acute TBI and SWD.
Rezaie, 2016,	In-depth	To describe and illuminate the	N=15	Patients with chronic insomnia who had been

First Author, Publication Year, Country	Data Collection Method	Study Objectives	Sample Size	Inclusion Criteria
Iran ²	unstructured interviews	experience of living with chronic insomnia.		referred to the sleep disorders research center at Kermanshah University of Medical Sciences in Iran in 2014.
Waite, 2016, UK ¹⁶	Semi-structured interviews	To gain patient perspective on the nature of sleep problems in psychosis and experience of treatment.	N=10	Patients with recent delusions and hallucinations, who had experienced sleep problems and received psychological treatment during a clinical trial (the Better Sleep Trial).
Yung, 2016, China ¹⁸	Focus groups and sleep diaries	Explore subjective experience of chronic insomnia in Hong Kong Chinese adults	N=43	Individuals of Hong Kong ethnicity, fluent in Cantonese, aged ≥ 18 years with primary insomnia according DSM-IV-TR criteria experiencing sleep difficulties 3 or more nights a week for at least six months. Scoring a 10 or above in the Insomnia Severity Index.
Horsch, 2015, Netherlands ²²	Semi-structured interviews and Focus Groups	Gain insight into adherence to technology-mediated insomnia treatment as a solid base for improving rates by applying adherence-enhancing strategies	N=15	Individuals registered at the Sleepcare project website that had used technology mediated sleep products.
MacDonald, 2015, New Zealand ²⁶	Focus Groups	Explore the attitudes and motivations of service users and psychiatrists that influence the long-term use of hypnotic medication and the barriers to widespread adoption of nonmedication therapies for insomnia	Patients = 6	Adults aged 18-65 years with a history of mental illness and either a current or previous history of sleep problems not currently receiving treatment from a participating psychiatrist.
Ong, 2015, USA ¹¹	Semi-structured interviews (as focus group or individually)	To examine the process of care from the patient perspective and to identify important issues related to the assessment and delivery of treatment within an interdisciplinary sleep clinic for patients with obstructive sleep apnea and comorbid insomnia.	N=34	People identified as having symptoms of sleepiness during routine clinic visits.
Waters, 2015, Australia ⁴	Semi-structured focus groups and individual interviews.	To report on the views and preferences of a sample of individuals with a diagnosis of schizophrenia and schizoaffective disorders regarding three different types of evidence-based therapies for insomnia: standard pharmacological, melatonin-based, and psychological and	N=14	Participants diagnosed with schizophrenia or schizoaffective disorder who had substantial past or current sleep problems accompanied with daytime dysfunction.

First Author, Publication Year, Country	Data Collection Method	Study Objectives	Sample Size	Inclusion Criteria
		behavioral-type (talking) therapies.		
Cheung, 2014, Australia ¹²	Semi-structured interviews	To capture help-seeking experiences and behavioral patterns of patients with insomnia who are seeking or receiving specialist care	N=26	Individuals aged ≥18 years seeking or receiving help for insomnia at either the Woolcock Institute of Medical Research, the Brain and Mind Research Institute or the Royal Prince Alfred Hospital in Sydney.
Hubbling, 2014, USA ²¹	Focus groups	To understand how mindfulness training influenced sleep and other aspects of patients' lives.	N=18	Adults diagnosed with primary chronic insomnia who completed 8-week mindfulness-based stress reduction program.
Kauffman, 2014, USA ¹⁴	Focus groups	To describe the subjective sleep complaints of individuals with COPD along with their attributions as to the cause of these symptoms, and their treatment preferences for insomnia.	N=18	Participants with self-reported poor sleep quality, living within 30 minutes of the University campus.
Andrews, 2013, USA ²³	Mixed Methods: Focus Groups and Questionnaire	To evaluate Heart Failure patients' perceptions about insomnia and its consequences; predisposing, precipitating, and perpetuating factors for insomnia; self-management strategies and treatments for insomnia; and preferences for insomnia treatment.	N=11	New York Heart Association classification II-IV Heart Failure; aged 21 years and older; ability to speak and read English; and at least mild insomnia, as determined by an Insomnia Severity Index of 8 or higher.
Davy, 2013, UK ⁹	Focus groups and semi-structured interviews	To understand the current experiences and views of patients and the wider primary care health team, including general practitioners pharmacists and community mental health teams, on the treatment for insomnia	Patients =28	Adults with perceived or diagnosed insomnia
Henry, 2013, USA ¹⁹	Semi-structured interviews	Explore patients' beliefs and behaviors related to the self-diagnosis, management, help-seeking and self-treatment of insomnia.	N=24	Individuals diagnosed with insomnia receiving treatment at one of two sleep clinics in Oregon and Texas.
Kyle, 2011, UK ²⁵	Audio diaries and semi-structured interviews	Explore patient experience of Sleep Restriction Therapy for insomnia, with a particular focus on possible side-effects, challenges to adherence and implementation and perceptions of benefit/impact.	N=18	Individuals aged ≥18 years meeting research diagnostic criteria for primary insomnia and reporting at least one daytime impairment attributed to sleep disturbed sleep.

First Author, Publication Year, Country	Data Collection Method	Study Objectives	Sample Size	Inclusion Criteria
Dyas, 2010, UK¹³	Semi-structured Focus Groups	To explore patients' and primary care practitioners' expectations, experiences, and outcomes of consultations for sleep difficulties as a basis for improving the treatment of insomnia in primary care.	Patients =30	Adults who had consulted with insomnia during the previous 6 months at one of eight general practices taking part in a quality improvement collaborative
Green, 2008, UK¹⁰	Focus groups	Explore patients' experiences with insomnia and investigate informational needs about insomnia and its management.	N=6	Adult patients with insomnia who had attended specialist clinics

CCBT-I = computerized cognitive behavioural therapy for insomnia; DSM-IV-TR = Diagnostic and Statistical Manual for Mental Disorders, fourth edition; ICBT-d = internet based cognitive behavioural therapy for depression; ICBT-i = internet based cognitive behavioural therapy for insomnia; SWD = sleep-wake disturbance; TBI = traumatic brain injury.

Appendix 3: Critical Appraisal of Included Publications

Table 3: Strengths and Limitations of Systematic Reviews using Critical Appraisal Skills Programme Systematic Review Checklist

Strengths	Limitations
Araújo, 2016 ²⁰	
<ul style="list-style-type: none"> • The systematic review was clearly focused around the subjective experience and perceived consequences of insomnia, help-seeking behaviors and treatment preferences. • The authors included only studies using qualitative methodology in the review which is appropriate considering the research question was aimed at understanding the subjective experience and perceived consequences. • The authors searched PsycINFO and Medline databases which are appropriate for the topic under investigation. They also reviewed the reference lists of the relevant papers to identify any additional qualitative studies. • The authors assessed the quality/rigour of the studies they have identified using the critical appraisal skills programme appraisal tool. • The information from the studies was summarized and conceptually organized by themes based on a thematic analysis. This method of analysis is appropriate considering this is a review of qualitative studies. The results were critically synthesized and interpreted which allowed for an overview of the diversity of experiences from the patients’ and clinicians’ perspectives. • The review covered the experience of insomnia, management of insomnia, and the medicalization of insomnia. 	<ul style="list-style-type: none"> • The authors did not include mixed-methods studies – the qualitative component of these studies may have highlighted some important findings. • There is no mention of whether the authors searched for unpublished and/or grey literature. • The authors report that some of the studies included in the review lacked information about the specific steps involved in the methodological analysis and procedures around theoretical saturation – thus questioning the rigour and the validity of the findings of those studies included. • The fact that some of the studies included in this review failed to report sociodemographic information means that the authors are unable to provide an accurate description of the entire sample of this review and thus questions the transferability of the results.

Table 4: Strengths and Limitations of Qualitative Studies using Critical Appraisal Skills Programme Qualitative Research Checklist

Strengths	Limitations
Chan, 2017 ²⁴	
<ul style="list-style-type: none"> Objective to explore barriers and facilitators to use of an adjunctive CCBT-I program among depressed patients in a psychiatric clinic clearly stated. Conducting interviews with participants already enrolled in clinical trial of a CCBT-I program appropriate methodology and sampling strategy to address study objective. Allowed the initial interview guide to evolve over the course of the study to reflect new questions arising throughout patient interviews. The study findings are generally well presented and offer advice on how to improve the patient experience of this particular intervention. Strong use of patient voice throughout the study. Ethics approval was obtained from the Sydney Human Research Ethics Committee and written consent forms were obtained from study participants. 	<p>No evidence of reflexive practice for this study.</p>
Moloney, 2017 ¹⁷	
<ul style="list-style-type: none"> The aim of the research was clearly stated as: to provide perspectives on the office visit interaction from both sleepless patients and the physicians who treat them. A qualitative methodology is the most appropriate considering the nature of the research question. Grounded theory methodology was used. The author described having the clinic head send an institutional review board-approved invitation email/project description to the 24 staff physicians. Possible reasons for non-participation of the patients were discussed. The data was collected by way of semi-structured interviews. The researcher provides a nice justification for why this is the best method of inquiry. The author describes audiotaping the interviews and transcribing it later for analysis. The author described using multiple coding iterations to identify emergent ideas, issues, and themes. NVivo was used for coding and analyses. The researcher discussed several limitations which occurred during the interviews including recall bias and the opportunity for 	<ul style="list-style-type: none"> The researcher does not describe how having the clinic head send out the invitation for recruitment may have forced physicians to participate since the email was coming from their higher authority. The inclusion/exclusion criteria were not clearly stated and there was no discussion of why their participants were the most appropriate for this study. There is no indication whether the researcher used a research guide or not during the interviews. The researcher did not discuss the saturation of the data. The relationship between the researcher and the participants was not discussed. There is no indication of how informed consent was obtained.

Strengths	Limitations
<p>disparate recollections.</p> <ul style="list-style-type: none"> The findings were explicitly stated and organized by theme and subthemes with appropriate quotes to support the findings. The author argues that reluctant medicalization may be useful to understand and is an additional to ambivalent medicalization. 	
Blom, 2016 ⁶	
<ul style="list-style-type: none"> Clearly states the use of grounded theory to identify facilitating and hindering factors for patients in ICBT-i and ICBT-d and formulate hypotheses for future research. Use of telephone interviews is an appropriate qualitative methodology to answer research question. As participants in a larger RCT comparing ICBT-i and ICBT-d, the patients recruited for this study were most appropriate sample. Interview guide with open ended questions allowed participants space to address experience with treatments. Strong use of patient voice throughout which supported analysis presented by researchers. Findings are well presented as hypotheses for improving future interventions for insomnia. 	<ul style="list-style-type: none"> While researcher credentials and involvement in larger RCT are expressed, there is no indication of reflexive practice. While ethics approval can be assumed for RCT, there is no direct mention.
Cheung, 2016 ¹	
<ul style="list-style-type: none"> The purpose the study was clearly stated as to explore the patient perceptions toward pharmacotherapy and the nonpharmacological management of insomnia. This study employed a qualitative approach using semi-structured interviews. This was appropriate considering the nature of the study was to obtain patient preferences. Patients were recruited from specialist sleep and psychology clinics and general community settings which is appropriate to capture the diversity of patients treatment experiences. Inclusion and exclusion criteria were clearly stated. The methods were explicitly stated with the researchers using a schedule of questions to guide the interviews. The interviews were audio recorded and transcribed verbatim and analyzed using the Framework Analysis technique with help from NVivo. Thematic saturation was mentioned but not discussed in detail. The study was approved by the University of Sydney Human Research Ethics Committee. Researchers indicate obtaining informed consent from the participants. 	<ul style="list-style-type: none"> The study design was not clearly stated or justified. How the patients were selected (i.e. voluntary or were they identified by healthcare professionals) was not discussed or made clear in the paper. There was also no discussion around whether participants declined to participate and why. The role of the researcher and potential bias was not discussed. The researchers go into detail explaining the five key stages of the Framework Analysis technique however do not discuss it with relevance to the methods they undertook for analysis of the data.

Strengths	Limitations
<ul style="list-style-type: none"> The findings were presented according to three key themes: Patient Beliefs, Self-Imposed Treatment Boundaries, and Treatment Uptake. The authors discuss the study's limitations including the fact that the results may not be generalizable due to an array of factors during the study (e.g. participant recall bias, description of treatment options, etc.). 	
Chiu, 2016 ¹⁵	
<ul style="list-style-type: none"> The aim of the research was clearly stated as to explore the lived experience of sleep problems in people with schizophrenia-spectrum disorders. As this study's purpose is to explore the lived experience of patients, the use of qualitative methodology is appropriate. The authors indicate recruiting participants from a psychiatric inpatient facility and community drop-in centres. They also indicated advertisements and referral by clinic staff was how the participants were selected. The inclusion/exclusion criteria were made explicit. The data was collected via focus groups. The authors explained that those participants not wanting to participate in the focus groups engaged in one-on-one interviews instead. A semi-structured interview outline was used during the focus groups and interviews and they were audiotaped and transcribed for analysis. The researchers mentioned saturation of data as continuing data collection until the same themes kept re-emerging. Ethical approval for the study was granted by the University of Western Australia and North Metropolitan Health Service – Mental Health Human Research Ethics Committees. Thematic analysis was used to analyze the findings. This is appropriate considering the research methods used for this study. The authors describe coding of the data being done by one researcher and then verified by other co-authors for interrater reliability. They also describe consensus meetings to come to conclusion on the themes and how they can be organized. The findings were explicitly stated and organized under various headings, which were relevant to answering the research question. 	<ul style="list-style-type: none"> The research design used was not made explicit. The role of the researcher was not critically examined for potential influence during the research process.
Matthews, 2016 ⁸	
<ul style="list-style-type: none"> The statement of the aim of the research was explicitly stated as 	<ul style="list-style-type: none"> The researchers do not discuss participant recall bias which is

Strengths	Limitations
<p>to examine sleep-wake disturbance characteristics, factors, consequences, and management strategies from the perspective of veterans with chronic stage, moderate/severe traumatic brain injury.</p> <ul style="list-style-type: none"> • As this study is focused on the perspective of veterans, the use of qualitative methodology is appropriate. • The authors indicate using a qualitative descriptive research design. • The researchers indicate purposely recruiting veterans through flyers and letters of invitation using a voluntary research database for local TBI studies. • The inclusion/exclusion criteria were made explicit. • In-person semi-structured interviews were used to collect the data. This method is appropriate as it allows for the perspectives of the veterans to be collected openly. • Interviews were recorded and transcribed verbatim. • Each team member independently documented biases regarding expected findings – this helped to strengthen the trustworthiness of the inquiry and dependability and confirmability of the analytic process. • The researchers provide an in-depth description of the analysis process and how the themes were derived from the data including multiple researchers and consensus meetings. They highlight the role of documentation to preserve how decisions were made during data analysis. • The results were presented as themes with exemplar quotes to support them. This is appropriate as it helps to understand the experience and the importance of the theme. • The study limitations were discussed by the authors including the fact that the sample was all male and thus not generalizable to other groups. • The authors also discuss implications for practice and research. 	<p>possible as they are dealing with veterans with moderate/severe traumatic brain injury.</p>
<p>Rezaie, 2016²</p>	
<ul style="list-style-type: none"> • The aim of this study was clearly stated as to describe and illuminate the experience of living with chronic insomnia. • As the aim of this study is to explore experience, the use of a qualitative methodology is appropriate. • The authors used a descriptive phenomenology approach and go into detail in the paper about why this is the appropriate research design to answer the research question. • The authors used purposeful sampling to select information-rich cases. 	<ul style="list-style-type: none"> • The authors do not discuss their relationship with the participants. • They do not discuss the potential for participant and researcher bias.

Strengths	Limitations
<ul style="list-style-type: none"> • The inclusion/exclusion criteria are stated explicitly in the paper. • The reason for sampling from the particular sleep centre was also discussed. • The data was collected using in-depth unstructured interviews. This method of data collection is appropriate considering it allows the participants to speak freely of their experiences without any restrictions. • The authors stated that interviews were conducted until data saturation was reached. To determine the level of saturation, the researchers carried out a process parallel with data collection, and they reached consensus about it. • The interviews were audio taped and transcribed for analysis. • The authors used the Colaizzi method for analysis the data. This method involves seven steps of data analysis and the authors go into detail of how they carried out the seven steps in their data analysis. • The authors used several strategies to ensure trustworthiness of the data: bracketing, member check, and an expert panel to discuss trustworthiness. • The findings were clearly stated and a discussion of the contribution of the study to the current body of research was included. 	
Waite, 2016 ¹⁶	
<ul style="list-style-type: none"> • The aim of the research was clearly stated as to gain a patients perspective on the nature of sleep problems in psychosis and experience of treatment. • As the aim of the research is to examine the patient perspective, the use of qualitative methodology is appropriate. • The authors used interpretative phenomenological analysis as their research design. • The authors state recruiting patients from the active arm of a RCT testing CBT for insomnia for patients with delusions and/or hallucinations. • The data was collected using semi-structured interviews. The authors used a semi-structured interview guide which included open-ended questions on three main areas: nature of sleep problems, changes following therapy, and the experience of taking part in therapy. • Ethical approval was obtained from an NHS research ethics committee. • The authors had two researchers complete independent analysis on each transcript before discussions to consider the credibility 	<ul style="list-style-type: none"> • The method for patient selection was not made explicit. • There was not much discussion on the recruitment. • The relationship between the researcher and the participants was not adequately considered. • How informed consent was obtained was not made explicit.

Strengths	Limitations
<p>of the coding.</p> <ul style="list-style-type: none"> An iterative process was used to cluster the emergent themes into subordinate themes. The Yardley criteria for enhancing quality in qualitative research were used. The findings were clearly presented according to the themes and subthemes that emerged. 	
Yung, 2016 ¹⁸	
<ul style="list-style-type: none"> Objective to explore the subjective experience of Chinese adults with chronic primary insomnia clearly stated. Methodological use of focus groups and sleep experience diaries well suited for exploring qualitative research objective. Participant recruitment strategy and eligibility criteria (exclusion/inclusion) clearly indicated. Choice of grounded theory as analytical approach clearly explained and supported. Participant voice visible throughout and well placed to support analytical themes and findings. Authors juxtapose findings of this Chinese study against other Western studies and argue for improvements in cultural knowledge when treating insomnia and other sleep problems. 	<ul style="list-style-type: none"> No indication of obtaining ethics approval, but ethical behavior toward participants noticeable throughout. No reflexive practice indicated
Horsch, 2015 ²²	
<ul style="list-style-type: none"> Objective to gain insight into adherence to technology-mediated insomnia treatment as a solid base for improving adherence rates clearly stated. Though mixed-methods research, the qualitative portions utilized interviews and focus groups, appropriate methodology Clear indication of purposive selection of participants their and minimal threshold on the Pittsburgh Sleep Quality Index. Ethics approval received by the Human Research Ethics Committee of Delft University of Technology. Use of thematic analysis delimited and reasonably visible throughout the paper. Could have benefited from weaving participant voice into actual analysis sections. Though cordoned off from analysis, participant voice is well presented. Findings are clearly demarcated throughout Discussion and Conclusion. Findings used to suggest future room for improvement relevant to sleep disturbance and insomnia treatment adherence. 	<ul style="list-style-type: none"> Participants in study not actually diagnosed with insomnia or poor sleep quality. No reflexive practice indicated.

Strengths	Limitations
MacDonald, 2015 ²⁶	
<ul style="list-style-type: none"> • Research objective to explore the attitudes and motivations of service users and psychiatrists that influence the long term use of hypnotic medication, and the barriers to the widespread adoption of nonmedication therapies for insomnia clearly stated. Well suited for a qualitative inquiry. • A service user was invited to play a role in both the research design and implementation processes. This service user collaborated with a “senior psychiatric trainee” to conduct the focus groups. • A series of separate focus groups with “service users” and psychiatrists was used and is appropriate qualitative methodology. A final focus group of mixed service users and psychiatrists offered an interesting dynamic. • Thematic analysis used and appropriate for qualitative research. Themes well supported by service user voice throughout. • Ethics approval obtained from the University of Otago Human Ethics Committee. • Value of the research noted in the conclusion by calling for further investigation into guidelines for hypnotic medications and barriers to nonpharmacological treatments for insomnia. 	<ul style="list-style-type: none"> • No reflexive practice indicated.
Ong, 2015 ¹¹	
<ul style="list-style-type: none"> • The aim of the research was stated as to examine the process of care from the patient perspective and to identify important issues related to the assessment and delivery of treatment within an interdisciplinary sleep clinic for patients with OSA and comorbid insomnia. • Because this study’s aim is to analyze the patient perspective, a qualitative methodology is appropriate. • The authors state prospectively identifying research candidates based upon symptoms reported during routine clinic visits. • The inclusion/exclusion criteria were explicitly stated. • The methods of data collection included questionnaires and semi-structured interviews conducted as focus groups or individual interviews. The qualitative methods used are appropriate to analyze the patient perspective and has been justified by the researchers. • The interviews were audio recorded and later transcribed for analysis. • Thematic analysis was used to analyze the interview data. The authors described two researchers used an inductive approach 	<ul style="list-style-type: none"> • The research design was not made explicit in the paper. • There was no discussion about why the participants they chose were appropriate for the research. • The researchers did not discuss the relationship between the researcher and the participants.

Strengths	Limitations
<p>to code the interviews and then worked together to create overarching semantic themes. This ensured interrater reliability.</p> <ul style="list-style-type: none"> The local institutional review board approved the study and written informed consent was obtained during the in-person screening interview. The authors explicitly stated and described the limitations faced during the study including the absence of baseline data and a control group for comparison between treatment options. The authors nicely presented the results of the questionnaire and the interviews together – complementing each other in the different theme groups. 	
Waters, 2015 ⁴	
<ul style="list-style-type: none"> A clear statement of the aims of the research was provided: To report on the views and preferences of a sample of individuals with a diagnosis of schizophrenia and schizoaffective disorders regarding three different types of evidence-based therapies for insomnia: standard pharmacological, melatonin-based, and psychological and behavioral-type (talking) therapies. Because this study focuses on the preferences of patients, the use of qualitative methodology is therefore appropriate for addressing the research goal. The use of focus groups and individual interviews, when needed, is appropriate for the purpose of the study. The authors identify recruitment using advertising and a snow-ball technique. The authors used a semi-structured interview schedule developed by themselves during the focus groups. Data collected during focus groups were recorded by way of audiotapes. Thematic analysis was performed on the data, which is appropriate for this methodology. The authors discussed methods employed to ensure interrater reliability, which was coding by two different researchers and then discussing the themes as a group to come to consensus. Findings were explicitly stated according to major themes. The authors discussed the relevant study limitations including the sample size and voluntary recruitment of patients bringing on participant bias. 	<ul style="list-style-type: none"> The study design used in the study was not clearly stated. The inclusion/exclusion criteria were not clearly stated. There was indication of conducting individual interviews with those who did not want to participate in the focus groups however the reason why they did not want to participate in the focus group was not discussed. There is no indication of how participants provided informed consent to participate. Saturation of the data was not discussed. The relationship between the researcher and the participants were not discussed. There is limited discussion on the contributions of the study to the existing research or how the findings can be generalizable.
Cheung, 2014 ¹²	
<ul style="list-style-type: none"> Research objective to capture the help-seeking experiences and behavioral patterns of patients with insomnia seeking specialist 	<ul style="list-style-type: none"> No mention of reflexive practice throughout the study.

Strengths	Limitations
<p>care is clearly indicated.</p> <ul style="list-style-type: none"> • By conducting in-depth, semi-structured interviews with a purposive sample of insomnia patients taken from specialist sleep and mental health clinics, appropriate qualitative methodologies and sampling strategies were used to address objective. • There is a clear explanation for the reasons behind choosing framework analysis as analytical tool of choice. • Findings are clearly stated and helpful in that they indicate the limited awareness and other barriers surround uptake of CBT-I. • Ethics approval obtained from the University of Sydney Human Research Ethics Committee. Consent from was also obtain from participants. 	
Hubbling, 2014 ²¹	
<ul style="list-style-type: none"> • Research objective to understand mindfulness training as experienced by patients with chronic insomnia and to suggest procedures that may be useful in optimizing sleep benefits clearly stated. • Use of focus groups with participants diagnosed with primary insomnia who had just completed an 8-week RCT evaluating MBSR as treatment for chronic insomnia offers methodological rigor appropriate for this study. • Clear explanation why methods and analytical techniques chosen. 	<ul style="list-style-type: none"> • Directed content analysis used as a way of providing context for quantitative results of RCT. While not necessarily inappropriate, deductive analysis limits the researchers' field of sight when reviewing qualitative data. Well analyzed, but seems more geared to proving a point than exploring experience. • Some of the questions chosen for focus group, though open ended, were leading and inappropriate for evaluating patient experience (e.g. "If you had one minute to promote the class what would you say?"). • Researchers' duties delimited and were noted as experienced, but not reflexive practice indicated. • No mention of obtaining ethics approval for the project, but ethical considerations seemed appropriately addressed. • Lack of gender/racial diversity in focus groups
Kauffman, 2014 ¹⁴	
<ul style="list-style-type: none"> • The aims of the research were clearly stated: to describe the subjective sleep complaints of individuals with COPD along with their attributions as to the cause of these symptoms, and their treatment preferences for insomnia. • Considering this study's aim was to describe the subjective experiences of the research participants, the use of qualitative methodology is appropriate. • The authors described recruiting patients who met their inclusion criteria by phone to participate in focus groups about sleep problems in COPD participants. • Data was collected via focus groups. • The authors stated using a structured set of three questions with 	<ul style="list-style-type: none"> • The research design of the study is not clearly stated. • How the participants were selected was not made explicit and there was no discussion as to why these participants were the most appropriate. • How the categories/themes were derived was not discussed by the authors. • Discussion of any researcher or participant bias was not included. • The credibility of the findings have not been discussed in detail.

Strengths	Limitations
<p>probes to identify sleep problems, causes of those problems, and preferences for treatment of the sleep problems.</p> <ul style="list-style-type: none"> The authors indicate that saturation was reached by the third focus group in that nothing new was reported or described by the focus group participants. Each focus group was audiotaped, transcribed, and entered into NVivo 10 to manage data and create an audit trail. The authors indicate that the data were categorized according to the three questions, then coded, compared, and contrasted until themes emerged. Authors state rigour was maintained through close consultation between the coders and the focus groups' moderator. This assisted with assuring adherence to the intent of the study and consensus with the findings. Approval was obtained from the Institutional Review Board of the University of Maryland School of Medicine. The findings were explicitly stated. The authors explain how their findings most likely cannot be transferred to other populations. 	
<p>Andrews, 2013²³</p>	
<ul style="list-style-type: none"> Clearly states the use of content analysis to evaluate Heart Failure patients' perceptions about insomnia and its consequences; predisposing, precipitating, and perpetuating factors for insomnia; self-management strategies and treatments for insomnia; and preferences for insomnia treatment. Purposive sample of participants recruited from an outpatient Heart Failure program. Focus groups with semi-structured interview guide and probing follow-up questions used to elicit patient perspectives. Institutional review board approval was obtained. Data presentation of themes consistent with content analysis. Findings well summarized and clearly stated in conclusion. 	<ul style="list-style-type: none"> Though we are told who conducted focus groups and analysis, there is no mention of reflexive practices.
<p>Davy, 2013⁹</p>	
<ul style="list-style-type: none"> Research goal to explore health professionals' and patients' experiences and perceptions of the management of insomnia in primary care clearly stated. Well suited for qualitative study. Purposive sample of patients recruited for focus groups and interviews with researchers. Use of thematic analysis appropriate for qualitative study. Ethics approval obtained from Leicestershire, Northamptonshire and Rutland Research Ethics Committee. 	<ul style="list-style-type: none"> Though told patients represent a purposive sample, we are not told information about level of insomnia, diagnosis, etc. No indication of reflexive practice. Unsure of how the participants were recruited. Stronger presence of GP voice throughout analysis than patient voice. Analysis was thorough, but under representative of patients.

Strengths	Limitations
<ul style="list-style-type: none"> Well-developed statement of findings and where this research fits within the greater literature. 	
Henry, 2013 ¹⁹	
<ul style="list-style-type: none"> Research objective to gain better insight into patient responses to insomnia (e.g. patient beliefs and behaviours, particularly those related to self-diagnosis, management, help-seeking and self-treatment) clearly stated. Well suited to qualitative methodology. Use of in-depth interviews with patients diagnosed with insomnia an appropriate methodology and purposive sample to address the research objective. Grounded theory utilized to allow analytical themes to be derived inductively. Analytical themes well supported by patient voice. Findings are clearly demarcated and their contribution to the greater field of literature on insomnia is well noted. Institutional review board approval was obtained and patients treated in ethical manner. Moderate level of reflective practice indicated. 	<ul style="list-style-type: none"> Participants had been recruited by their sleep physicians and could thus have felt the need to respond in a certain way to the interview questions.
Kyle, 2011 ²⁵	
<ul style="list-style-type: none"> Research objective of investigating patient experience with sleep restriction therapy clearly noted. The use of audio diaries, semi-structured interviews and follow up phone interviews offers methodological rigor appropriate for this study. By recruiting patients with Primary Insomnia and involved in sleep restriction therapy experiment to offer their perspectives, this study uses appropriate research design and recruitment strategy and data collection. Use of thematic analysis consistent with qualitative research. While this is a mixed-methods study, qualitative data is well presented with clear analysis. Could have been made stronger by weaving patient voice throughout analysis instead of blocking it off in tables. Ethics approval obtained from the Greater Glasgow and Clyde NHS local ethics committee. 	<ul style="list-style-type: none"> Researcher's involvement in the study is noted, but no indication of reflexive practice.
Dyas, 2010 ¹³	
<ul style="list-style-type: none"> Research objective to explore patients' and primary care practitioners' expectations, experiences, and outcomes of consultations for sleep difficulties as a basis for improving the 	<ul style="list-style-type: none"> Though "comparative analysis" stated as analytical approach, it is unclear what is meant by this. This systematic review's author's understanding of comparative analysis is that it is less of

Strengths	Limitations
<p>treatment of insomnia in primary care clearly stated.</p> <ul style="list-style-type: none"> • While this study includes primary care practitioners' perspectives as well as "service users", focus groups were conducted separately and resulting analysis of groups is clearly separated. • Individuals ("service users") who had consulted for insomnia during the previous three months were recruited to attend focus groups via newspaper ads, postal invitations, and waiting room posters. • A phenomenological approach to receiving patient experience said to have been used. • Stated themes derived from analysis are well supported by "service user" voice. • Written consent obtained from participants and extra support was offered to patients in the event of becoming distressed due to interviews. Ethical approval was obtained from the NHS Research Ethics Service. • Authors consistently demonstrate where their research fits within the greater scheme of research on insomnia care. 	<p>an analytical approach in and of itself, but a tool for the implementation of grounded theory. This could have been clarified in the study.</p> <ul style="list-style-type: none"> • Little more than a descriptive analysis seems to have been conducted. • No reflexive practice indicated.
<p>Green, 2008¹⁰</p>	
<ul style="list-style-type: none"> • The study objective to explore the lived experience of insomnia and investigate what information patients want from health professionals is relatively clearly stated. • The choice to use focus groups with a selected group of patients with chronic insomnia is clearly explained and appropriate for a qualitative study. • Notes a lack of gender diversity. • Ethics approval was obtained by the Local Research Ethics Committee. Notes that there was some ethical tension between participants and researchers and discusses this. • Some reflexive practice is indicated. • The study findings are clearly stated and where they fit within the current literature/practice is well noted. 	<ul style="list-style-type: none"> • The sample size was quite limited and failed to include male participants. This could skew interpretation of findings.