



## CLINICAL REVIEW

## Qualitative studies of insomnia: Current state of knowledge in the field



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## SUMMARY

Despite its high prevalence and burden, insomnia is often trivialized, under-diagnosed, and under-treated in practice. Little information is available on the subjective experience and perceived consequences of insomnia, help-seeking behaviors, and treatment preferences. The use of qualitative approaches (e.g., ethnography, phenomenology, grounded theory) may help gain a better understanding of this sleep disorder. The present paper summarizes the evidence derived from insomnia studies using a qualitative research methodology (e.g., focus group, semi-structured interviews). A systematic review of the literature was conducted using PsycINFO and Medline databases. The review yielded 22 studies and the quality of the methodology of each of them was evaluated systematically using the critical appraisal skills programme (CASP) appraisal tool. Selected articles possess at least a very good methodological rigor and they were categorized according to their main focus: "Experience of insomnia", "Management of insomnia" and "Medicalization of insomnia". The main findings indicate that: 1) insomnia is often experienced as a 24-h problem and is perceived to affect several domains of life, 2) a sense of frustration and misunderstanding is very common among insomnia patients, which is possibly due to a mismatch between patients' and health care professionals' perspectives on insomnia and its treatment, 3) health care professionals pay more attention to sleep hygiene education and medication therapies and less to the patient's subjective experience of insomnia, and 4) health care professionals are often unaware of non-pharmacological interventions other than sleep hygiene education. An important implication of these findings is the need to develop new clinical measures with a broader scope on insomnia and more targeted treatments that take into account the patient's experience of insomnia. Greater use of qualitative approaches in future research may produce novel and more contextualized information leading to a more comprehensive understanding of insomnia.

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## Introduction

Insomnia is a widespread and debilitating condition that can affect anyone, including children [1], adults, and the elderly [2]. It is characterized by difficulties initiating and/or maintaining sleep, and is associated with significant distress or daytime impairments,

despite adequate sleep opportunity. Clinical diagnosis is based on the presence of these subjective symptoms during at least three nights per week, for at least three months [3]. About one-third of adults in the general population report occasional sleep problems and 6%–10% report symptoms that meet diagnostic criteria for insomnia disorder [4,5]. Insomnia is more prevalent among women, middle-aged and older adults, and individuals with poor self-rated physical or psychological mental health [2]. In primary care settings, approximately 10%–20% of individuals complain of significant insomnia symptoms with greater functional impairments and reduction in productivity, as well as increased health care utilization [6–8].

*Abbreviations:* CASP, critical appraisal skills programme; CBT-I, cognitive behavioral therapy for insomnia.

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The burden of insomnia is high, producing significant adverse effects on the individual and on society [6,9,10]. Its consequences lie predominantly in the negative impact it has on daytime functioning with significant distress and/or impairments in the personal (e.g., fatigue), social (e.g., isolation), occupational (e.g., reduced attention), economic (e.g., absenteeism) and health (e.g., co-morbidity, depression, anxiety) domains [11], as well as on the quality of life [6,8].

Despite its high prevalence, negative impact, and substantial direct and indirect costs [6,9,10], insomnia remains an under-recognized, under-diagnosed, and under-treated condition [12]. Differing perceptions of insomnia and its treatments between patients and clinicians may contribute to this paradox. Indeed, patients typically describe their insomnia in terms of its daytime impairments in everyday life, extending the experience beyond nighttime sleep difficulties. They usually perceive available insomnia treatments as ineffective or unattractive, they are prone to self-medicate, and tend to believe that insomnia will resolve spontaneously [4,13–15]. Conversely, clinicians have a tendency to focus on standard diagnostic criteria rather than on the patient's subjective experience of insomnia [16,17] and usually perceive this problem as less of a priority and less urgent than other medical symptoms seen in their practice. They often report a lack of adequate knowledge and training in sleep interventions, and as a result, they manage insomnia mainly through basic sleep hygiene recommendations and hypnotic medication [16,18].

The discrepancy between patients' and clinicians' perspectives concerning the significance and the emphasis given to the experience, assessment, and treatment of insomnia could be explained partially by the fact that several studies in this domain focus on the quantitative features of insomnia. Generally, the quantitative descriptors of the sleep disorder (e.g., severity and duration of insomnia) are favored while the qualitative descriptions of the nature or experience of insomnia and its interventions, as well as of the meaning of the patient–clinician relationship, are frequently put aside. Indeed, epidemiological, cross-sectional, and meta-analytic studies traditionally rely on diagnostic assessment of insomnia based on clinical interviews, validated surveys, or more objective measures, such as polysomnography [19]. Conversely, qualitative studies take into account the context and the experiences of the patient and the clinician, as well as the patient–clinician relationship and its variations over time from a more nuanced perspective.

To date, the majority of existing meta-analyses or literature reviews of insomnia have adopted a quantitative approach and have traditionally focused on randomized clinical trials of pharmacological or non-pharmacological interventions for insomnia [e.g., 20–22] and observational studies of clinical symptoms [e.g., 23] and impairments in daily life [e.g., 11]. To the best of our knowledge, there is only one narrative review that has focused on the insomnia patient's perspective [18], yet 70% of the studies included in that review used a quantitative methodology.

Insufficient attention has been paid to the subjective experience of insomnia, and this accounts for a significant gap between patients' and clinicians' definitions, expectations, and beliefs about this sleep disorder. There is much less research exploring how patients experience insomnia in their daily lives and how clinicians manage insomnia in their clinical practice. There is even less research exploring how the multiple contexts related to insomnia (e.g., economic, physical, spiritual, emotional, social) contribute to shape patients' and clinicians' subjective experiences and their interactions. A more thorough understanding of the subjective experience of insomnia is therefore needed to narrow the gap between patients and clinicians.

Qualitative approaches may play a significant role in moving the field forward, as these approaches offer a more detailed and nuanced perspective on human experience, and particularly on insomnia and its complexities, by generating novel, individualized, and more in-depth data. Qualitative research comprises different approaches (see Table 1) and has gained increasing recognition in various disciplines (e.g., anthropology, sociology, education, marketing, psychology, clinical medicine, and health services) since the early 1900s with a burgeoning of interest since the early 2000s [24–27].

Qualitative research is a form of scientific inquiry that, in contrast to quantitative research, focuses primarily on generating hypotheses. It is concerned with meaning rather than generalized statements. Open-ended discussions and observations (e.g., words, ideas, images) are used to explore individuals' experiences and perspectives on complex phenomena or processes [26]. Data collection involves semi-structured interviews (i.e., in-depth discussion between researcher and participant, driven by participant), focus groups (i.e., guided discussions within a group of people who share a common characteristic or interest), audio-diaries (i.e., recording of personal perceptions of a given phenomenon in participants' environments), participation (i.e., learning through exposure to or involvement in the day-to-day or routine activities of participants in natural settings), or observation (i.e., examination of people in natural settings) [24,26]. The sample size varies according to the complexity of the phenomenon and is generally small, specific, and studied intensively in natural settings. Most of the time, adequacy of sample sizes in qualitative research is determined by achieving saturation, a point at which no new or relevant information or concepts can emerge from the data collection [28]. Qualitative researchers are immersed in the study and use an inductive process to create patterns, categories, taxonomies, themes and theories to reduce and analyze detailed data [25]. Researchers' biases and personal stances are identified (e.g., reflexive) and participants' meanings of the phenomena are explicitly mentioned in the presentation of the results (e.g., verbatim) [27].

Qualitative research has contributed to the advancement of knowledge in different fields and topics by producing new types of data (e.g., verbatim recordings collected from social interactions), extracting detailed descriptions of individual perceptions and experiences, generating hypotheses concerning potential causal mechanisms, developing sound quantitative measurement processes or instruments, and improving methods for recruitment, retention and measurement of underrepresented populations in research [25]. Within the sleep research community, there is also increasing interest in and recognition of the capacity of qualitative approaches to improve our understanding of sleep disorders such as insomnia [18,29]. However, to date, little is known about the experiences and perceptions of insomnia and its impact on daytime functioning, help-seeking behaviors, and treatment preferences. Synthesizing the evidence derived from qualitative studies on insomnia may further our knowledge by helping to identify gaps and by generating new hypotheses grounded in the patients' and clinicians' subjective experiences. Therefore, the first aim of the present paper was to conduct a systematic review and synthesis of qualitative studies of insomnia, exploring and contrasting clinicians' and patients' perspectives. A secondary aim was to critically assess the utilization of qualitative approaches in insomnia research, and to make recommendations for future studies.

## Method

### *Search and identification of eligible articles*

A systematic literature search was conducted by the first author (TA) between December 2013 and November 2015. Articles were

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