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## Specific Quality of Life Measures for Sleep Disorders

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### 1. Introduction

Sleep is one of the most important needs for a healthy life. It is therefore considered to be an important aspect of health, affecting well-being and quality of life (Karadağ & Ursavaş, 2007; Léger & Bayon, 2010). Sleep disorders have been long to be known as a disease symptom. Recently, there has been a rapid increase in the number of studies on sleep disorders, which has come to be considered a problem or a syndrome in its own right. Insomnia is one of the most common sleep disorders and an important public health issue with high prevalence (Karadağ & Ursavaş, 2007; Léger & Bayon, 2010). 30% of the general population and 9-10% of the US population are affected by sleep disorders (Laar, et al., 2010; Roth, 2007). Insomnia is defined as the subjective perception of one's dissatisfaction with the amount and/or quality of sleep. It may manifest as difficulty in initiating or maintaining sleep or too early awakening and inability to return to sleep (Roth, 2007; Smolensky, et al., 2011).

Sleep disorders might cause life-threatening accidents, severe loss in work productivity, and disruptions in psychosocial functioning. Epidemiological studies indicate that sleep-related crashes represent up to 20% of all traffic accidents in industrial societies (Roth, 2007; Smolensky, et al., 2011). The literature suggests that sleeping difficulty doubles the risk of a fatal work-related accident (Scott, et al., 2011). Chronic insomnia has a negative impact on psychological well-being and quality of life. Almost 40% of the adults suffering insomnia were diagnosed with at least one psychiatric disorder, most commonly depression (Botteman, 2009; Laar, et al., 2010; Léger & Bayon, 2010; Roth, 2007).

### 2. Quality of Life (QoL) and Health-Related Quality of Life (HRQoL)

The concept of "quality of life" has a long history in the fields of sociology and medicine. Aristoteles, one of the earliest philosophers, dealt with the nature of happiness and the necessities of a 'good life'. For Aristoteles and most of his successors, the ultimate end of human life is achieving the highest good, that is attaining the best condition that one's life permits. In this way, an individual who achieves this goal has a life of highest quality. In the field of medicine, improving the well-being of patients was part of physicians' education, besides treating and curing their problems, as early as the times of Hippocrates (Müezzinoğlu, 2005).

After the World Health Organization (WHO) defined health positively as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” in 1946, the interest in the concept of “Quality of Life (QoL)” has drastically increased. It is very difficult to make a precise definition of “Quality of Life”, as it is a multifactorial concept covering several domains. The definition of quality of life changes from society to society as well as from individual to individual in a given society. According to general opinion, the following domains should be covered by the concept of Quality of Life: functional competence, complaints about illnesses and treatment, competence in psychological and social functioning. The World Health Organization Quality of Life (WHOQOL) group defines quality of life as: “an individual’s perception of their position in life, in the context of the culture and values in which they live and in relation to their goals, expectations, standards, and concerns”. This definition focuses on the way patients evaluate their quality of life from their own perspective (Kyle, et al., 2010; WHO,1990).

Health-related quality of life (HRQoL) is an integral subcomponent of quality of life. These concepts are thus closely related. Following the general consensus, health-related quality of life could be defined as “the patient's own evaluation of the impacts of illness and treatment on themselves” (Kyle, et al., 2010; Müezzinoğlu, 2005).

The WHO model explains how the incompetencies resulting from various illnesses affect quality of life (Figure 1). Impairment is defined as a loss or abnormality of psychological, physiological or anatomical structure and function. Disability is a restriction or lack of ability to perform an activity in the manner considered normal for a human being. Handicap is defined as a condition resulting from an impairment or a disability that limits the fulfillment of a role that is normal for an individual (given his or her age, gender, social and cultural background). The presence of these three factors eventually leads to disability and thus to a reduced quality of life by making them depend on others. Social well-being is a complex concept consisting of many aspects such as mutual family support, social activities and friendship, financial sufficiency, personal life (protection of privacy and preservation of abilities), individual success, sexual satisfaction and life philosophy (Müezzinoğlu, 2005).

Indeed, a PubMed search reveals that publications with the term ‘Quality of Life’ in the title or abstract has risen more than approximately three-fold in the last ten years (2001–2011: 114.736), relative to the previous decade (1991–2001:42.244) (Kyle, et al., 2010; Müezzinoğlu, 2005). This increase is mainly caused by the important developments realized in the field of medicine, as a result of which most diseases have become curable, life span has increased, and everybody is now in a position to live with chronic diseases for longer periods. Patients' level of knowledge about illnesses and level of participation in the decisions concerning treatment have also increased inasmuch as communication possibilities have multiplied, and internet has become more accessible. Increased interest in the idea of “sanctity of life” in the field of medicine has also boosted the interest in the concept of quality of life.

Today, indicators such as reducing patient complaints and increasing life span are no longer sufficient to evaluate medical treatment. New criteria that take patients' perspective into account should be incorporated into the evaluation process (Müezzinoğlu, 2005; Kyle, et al., 2010). Moreover, HRQoL has become an important variable when deciding upon which treatment method to follow, how to use resources, and what type of service to provide (Kyle, et al., 2010).

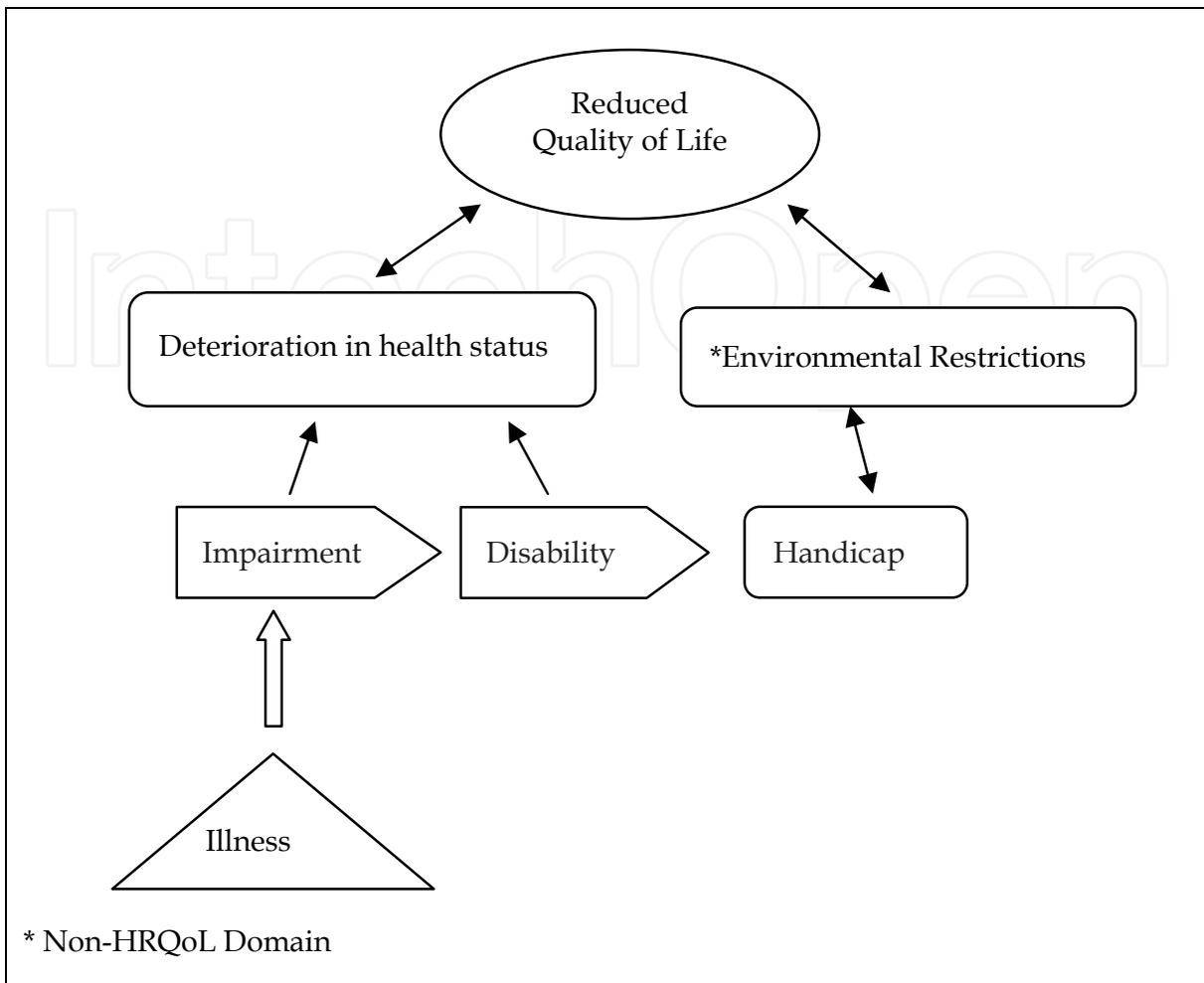


Fig. 1. The WHO model explains the interaction between the illness and the Quality of Life (WHO,1990)

Quality of life is essentially what individuals perceive as their overall sense of well-being based on functional ability, health, and satisfaction with the important dimensions of their lives. It is thus best determined in interaction with the individual. HRQoL measures could be divided into two main groups: generic and specific measures (Table 1) (Müezzinoğlu, 2005; Reimer & Flemons, 2003).

As generic scales comprise a broad spectrum of functional losses and general illnesses concerning HRQoL, they are applicable to all segments of society for all illnesses and are used in various medical practices. Generic scales are also divided into two sub-groups: "Health Profiles" and "Utility Measurement". Health profiles consist of a single scale and analyzes various aspects of health. It can compare different medical interventions. Possible disadvantage of these scales are unresponsiveness to small changes. Among the frequently used examples of generic measures are SF-36, the World Health Organization Quality of Life Scale (WHOQOL), Nottingham Health Profile, Functional Limitations Profile (FLP), Sickness Impact Profile (Table 1) (Müezzinoğlu, 2005; Reimer & Flemons, 2003; Weaver, 2001).

<b>A-General Scales</b>	<b>Domains</b>
A-1.Health Profiles	
SF-36	Physical functioning, Mental health (Psychological distress, Psychological well being), Role functioning, Social functioning, Health perceptions, Pain, vitality.
WHOQOL -BREF	Physical functioning, Mental health, Social functioning, Environment
Nottingham Health Profile	Physical functioning, Mental health (Psychological distress), Social functioning, Pain, vitality,sleep
Sickness Impact Profile	Physical functioning, Mental health (Psychological distress), functioning, Social functioning, Mobility/travel, sleep, Cognitive functioning, Eating, Recreation/hobbies, Communication, Home management
Functional Limitations Profile (FLP)	Physical functioning, Mental health (Psychological distress), functioning, Social functioning, Mobility/travel, sleep, Cognitive functioning, Eating, Recreation/hobbies, Communication, Home management
A.2.Efficacy Measurements	
The self-administered form of the QWB (QWB-SA)	mobility, physical activity, and social activity
EuroQol Instrument / EQ5-D	mobility, self-care, usual activities, pain/discomfort, and anxiety/depression
Health Utility Index-HUI	vision, hearing, speech, ambulation, dexterity, emotion, cognition, pain, self-care, pain, and fertility
B-Specific Scales	
B.1. Specific Quality Of Life Measures for Sleep Disorders	
Ferrans and Powers	Health, function, socioeconomic, psychological/spiritual, and family
Functional Outcomes of Sleep Questionnaire (FOSQ)	activity level, vigilance, intimacy and sexual relationships, general productivity, and social outcome
Sleep Apnoea Quality Of Life Index (SAQLI)	Daily functioning, social interactions, emotional functioning, symptoms, and treatment-related symptoms, which is applicable following the initiation of treatment.
The OSA Patient-Oriented Severity Index (OS APOSI)	sleep problems, awake problems, medical problems, emotional and personal problems, and occupational problems associated with OSA

Table 1. Distribution of Quality of Life Scales across Domains

Having been developed in light of various theories in the field of health economics, utility measurement scales are used for cost utility analyses, and most importantly for calculating

quality-adjusted life year (QALY). HRQoL is reduced to a single score between '0' and '1'. It is very difficult to identify the utility values, and these scales cannot determine different aspects of quality of life. Like health profiles, utility measurement profiles cannot identify small changes either. Among the most frequently used utility measurement scales are the self-administered form of the QWB (QWB-SA), the Europe Quality of Life Instrument (EuroQol Instrument / EQ5-D) and the health utility index (Health Utility Index-HUI) (Table 1) (Müezzinoğlu, 2005; Reimer & Flemons, 2003; Weaver, 2001).

Specific measures, however, are clinically sensitive and can identify small changes. On the other hand, being dependent on the group or intervention to which the measure would be applied is a disadvantage of specific measures. It cannot compare different situations. Measures could be specific to a particular population segment: children, seniors, adults. There is a specific measure for almost all diseases (epilepsy, diabetes, rheumatoid arthritis), conditions (pain), and functions (sexual function, emotional status, and sleep) (Table 1) (Müezzinoğlu, 2005; Reimer & Flemons, 2003; Weaver, 2001).

### **3. Specific Quality Of Life Measures for Sleep Disorders**

Insomnia affects the daily lives of sufferers. Quality of Life is an effective instrument of measurement to calculate the impact of insomnia on daily functions. Sleep disorder specific measures of quality of life among insomniacs are quite few (Léger & Bayon, 2010; Reimer & Flemons, 2003). It is stated that there is a need for more sleep disorder specific quality of life measures. Among the well-known examples of such measures are the Ferrans and Powers Sleep Disorder Specific Quality of Life Index, the Functional Outcomes of Sleep Questionnaire (FOSQ), the Calgary Sleep Apnea Quality of Life Index (SAQLI), and the OSA Patient-Oriented Severity Index (OS-APOSI) (Léger & Bayon, 2010; Reimer & Flemons, 2003).

#### **3.1 The Ferrans and Powers sleep disorder specific Quality of Life Index**

Ferrans and Powers developed one of the first sleep disorder specific quality of life measures for use in narcolepsy. They adapted this specific measure from their own generic quality of life measure. The Ferrans and Powers index has four domains; health and function, socioeconomic, psychological/spiritual, and family. Each domain and the total score have a range of 0 to 30, calculated by averaging all the item scores. However, the sleep disorder specific quality of life measure has not been much adopted (Reimer & Flemons, 2003; Flemons & Reimer, 2002).

#### **3.2 Functional Outcomes of Sleep Questionnaire (FOSQ)**

The Functional Outcomes of Sleep Questionnaire (FOSQ) is a functional instrument of measurement to identify the impacts of intense sleep disorders on social, mental and physical functions required in daily activities (Reimer & Flemons, 2003). The questionnaire aims to identify whether an individual is having difficulties performing daily activities when they feel tired or sleepy. In this questionnaire, "sleepy" and "tired" indicates inability to keep one's eyes open, having a droopy head or feeling an urge to take a nap (Şengül et al., 2011; Reimer & Flemons, 2003). The questionnaire consists of 30 questions and 5 subscales, namely activity level, vigilance, intimacy/sexual relationships, general productivity, and social outcome (Reimer & Flemons, 2003). There are five possible answers for each question: no difficulty, a little, moderate, or extreme. Total score and subscale scores are calculated by

summing up participants' answers. The intimacy/sexual relationships subscale is a unique feature of the FASQ. Despite having important consequences in the long run, this subscale is often confused with sleep disorder, and the significance of this life experience is often underestimated. The weakness of this subscale is that some participants are unwilling to respond to the questions or do not engage in sexual activities. One of the strengths of the subscale is that it excludes all factors except insomnia from analysis. Being used with SF-36, the FASQ is gaining popularity in the field. Successful testing of a Spanish version of the FASQ has been reported (Reimer & Flemons, 2003; Weaver, 2001).

### 3.3 Sleep Apnea Quality Of Life Index (SAQLI)

The Calgary Sleep Apnea Quality of Life Index (SAQLI) was developed as an evaluative instrument to measure within-subject change in response to a therapeutic intervention. The first 35 questions measure four domains: daily functioning, social interactions, emotional functioning, and symptoms (Flemons & Reimer, 2002; Reimer & Flemons, 2003).

The SAQLI use a 7-point Likert scale ranging from 1 (maximal impairment) to 7 (no impairment). Domain scores are averaged by dividing the total score by the number of questions answered, and the total score is averaged over the four domains so that all scores maintain a total range of 1 to 7. The SAQLI includes a fifth domain, to capture some of the adverse consequences of currently available therapies for sleep apnea. This fifth domain, comprising treatment-related symptoms, is used after a therapeutic intervention, and is subtracted from the other four domains in determining the total SAQLI score (Flemons & Reimer, 2002; Reimer & Flemons, 2003). Later, a shorter version of SAQLI form was developed, which could be filled in by the participants themselves. This shorter version of SAQLI was composed in light of the original SAQLI and the results of a clinical study (Reimer & Flemons, 2003; Weaver, 2001). Items were selected on the basis of their responsiveness, repeatability, readability, and representativeness of each of the first three domains. In order to make it easier for the participants to fill in the forms by themselves, "symptoms", which is the fourth domain, was replaced by the most commonly answered questions in the original SAQLI. Following the original SAQLI, a final question was added to the short SAQLI. Preliminary results show that the short SAQLI is as successful as the original SAQLI (Reimer & Flemons, 2003). In a study identifying the measurement characteristics of the Calgary Sleep Apnea Quality of Life Index (Measurement Properties of the Calgary Sleep Apnea Quality of Life Index), Flemons and Reimer (2002) evaluated quality of life using SAQLI, SF-36 and the Ferrans and Powers Index. They found that the SAQLI was closely related to other measures of quality of life and that it makes perfect measurements (Flemons & Reimer, 2002).

In a study comparing two health-related quality of life questionnaires among patients with sleep apnea, namely the Calgary Sleep Apnea Quality of Life Questionnaire (SAQLI) and the Functional Outcomes of Sleep Questionnaire (FOSQ), Kasibowska-Kuźnia et al. (2004) found that both measures had a Cronbach's alpha of 0.94 and verified their reliability. Even though both measures produced similar results, SAQLI was found to be more sensitive than the FOSQ. Their study also proves that the Polish version of the FOSQ is a useful measure for assessing HRQOL among patients with SAS (Kasibowska-Kuźniar, et al., 2004).

### 3.4 The Obstructive Sleep Apnea (OSA) Patient-Oriented Severity Index (OS APOSI)

The OSA Patient-Oriented Severity Index (OS-APOSI) is a 32-item HRQL measure that surveys the sleep problems, awake problems, medical problems, emotional and personal

problems, and occupational problems associated with OSA. The OS-APOSI has established internal consistency, but analyses of concurrent validity and test-retest reliability have not been reported (Weaver, 2001).

#### **4. Insomnia and Quality Of Life**

Sleep quality and quality of life are naturally related. For patients, the impact of the symptoms of sleep disorder on their quality of life is an important input in their decision to go on with the existing treatment or look for a new one. For physicians, the impact of sleep disorder on patients and their partners is an important input when setting up a treatment program. For researchers, quality of life measures are often a primary outcome variable (Reimer & Flemons, 2003).

The findings reported here suggest at least some quality of life domains are almost always affected when patients experience a chronic sleep disturbance (Reimer 2003). In a study conducted by Şahbaz et al. (2008), it was found that patients who had Obstructive Sleep Apnea had a lower quality of life than people who did not (Şahbaz, et al., 2008). Sleep quality and quantity should be routinely assessed in primary care because of its association with quality of life, including symptoms of fatigue, energy levels, daytime sleepiness, mental and physical functioning, family relationships, and even bodily pain (Reimer & Flemons, 2003). In a study examining the impact of Nocturia on the sleep quality and quality of life among male patients, Kim et al. (2011) found that Nocturia had an immense negative effect on health-related quality of life and sleep quality (Kim, et al., 2011). In a study analyzing the relationship between quality of life and sleeping difficulties among patients with chronic obstructive pulmonary disease (COPD), Scharf et al. (2011) found that most patients with COPD suffered sleeping difficulties and that disease-specific quality of life and sleeping difficulty were related (Scharf, et al., 2011).

The general impact of sleep on the quality of life of a healthy individual is underestimated. The quality and quantity of sleep depend on various factors like level of energy. Level of energy could be associated with many types of diseases. At least some of the generic measures should thus be included in the studies evaluating the impact of a disease on one's life. The number of generic measures evaluating positive health is quite low. It is suggested that quality of life scales that include positive health be used on the healthy population under normal daily circumstances (Reimer & Flemons, 2003).

There are very few articles showing the impact of insomnia on quality of life. Most of the articles evaluate the impact of insomnia on quality of life among cancer patients. A considerable number of studies analyze the relationship between quality of life and sleep disorders among patients with diabetes, depression, Parkinson's disease, chronic kidney failure, and Human Immunodeficiency Virus (HIV). Indeed, quality of life should be systematically used to evaluate the pharmacological and non-pharmacological methods of insomnia treatment. In a report on sleep published by the World Health Consensus, it was suggested that more studies be conducted on insomnia and quality of life. SF-36 is one of the most frequently used scales to evaluate quality of life (Parish, 2009; Léger & Bayon, 2010).

#### **5. Quality of Life in the management of insomnia**

Insomnia affects daily lives of millions of people all over the world. In the medical literature, a strong relationship is identified between sleep duration, mortality and morbidity (Bixler,

2009; Crowley, 2011; Léger & Bayon, 2010). Sleep disorders are considered to have a great impact on economy. In the United States, direct and indirect costs associated with insomnia exceed \$100 billion annually (Botteman, 2009). Moreover, the number of evidence showing the relationship between insomnia and other public health issues such as depression, accidents and anxiety is steadily increasing (Léger & Bayon, 2010; Roth, 2007; Crowley, 2011). Approximately 20% of all motor vehicle accidents are associated with driver sleepiness (independent of alcohol) (Scott, et al., 2011). Sleep apnea, restless leg syndrome, shift work sleep disorders, hypersomnia have also been proved to have an important impact from a socio-economic perspective (Léger & Bayon, 2010; Roth, 2007; Crowley, 2011). Patients' family and colleagues could also be negatively affected by insomnia. There are many studies in the medical literature showing that treating sleep disorders increase quality of life (Moyer, et al., 2001; Scott, et al., 2011). Protective measures should be taken in order to underscore the benefits of a good night's sleep and to ensure regular sleep among high-risk individuals. Public authorities should pay more attention to sleep hygiene and education (Bixler, 2009; Léger & Bayon, 2010). In a controlled clinical trial study evaluating the effectiveness of the sleep hygiene education provided to the workers of Information Technology Company, Kakinuma et al. (2010) found that the education program did not affect workers' night's sleep but decreased afternoon sleepiness at work (Kakinuma, et al., 2010).

Insomnia could be prevented by taking simple measures if the factors making one more sleepy or lose one's sleep are carefully considered. Exercise, relaxation techniques, taking a warm shower and behavioral therapy methods should be preferred to medication in the management of insomnia (Morgenthaler, et al., 2006; Akdemir & Birol, 2003; Öztürk, 2004). In a randomized controlled trial study conducted by Reid et al. (2010), it was found that aerobic physical activity accompanied by sleep hygiene education increased the quality of life and sleep quality among insomniac patients (Reid, et al., 2010).

In a pretest-posttest study on patients diagnosed with primary insomnia, Houdenhove et al. (2011) analyzed the impact of cognitive behavioral therapy for insomnia on quality of life using SF-36. It was found that cognitive behavioral therapy increased physical and mental HRQoL. However, absence of a control group was a weakness of this study (Houdenhove, et al., 2011). Şengül et al. (2011) analyzed the impact of exercise on the sleep structure and quality of life among patients with obstructive sleep apnea syndrome (OSA) using the FOSQ and SF-36. In their experimental study, exercise was found to improve the quality of life and sleep structure among patients with mild to moderate sleep apnea (Şengül, et al., 2011).

The first step in the management of insomnia is to check whether there is a notable mental or organic problem underlying insomnia. If so, the problem should get the appropriate medical treatment. Subsequently, the risk factors that could cause insomnia should be identified. Another important responsibility of health professionals is to educate others about sleep hygiene. Moreover, misknowledge and unhealthy practices among patients should be identified and corrected. General principles of sleep hygiene are as follows:

- Do not rush to medication solutions for insomnia,
- Get up in good time and perform activities of daily living as usual regardless of how late you went to bed, and avoid sleeping during day time,
- Avoid alcohol, coke, coffee, tea and cigarette after dinner,
- Do physical exercises a few hours before bedtime but avoid exhausting activities 1-2 hours before sleep,

- Avoid using bed room for activities other than sleeping such as studying, watching TV etc.,
- Avoid heavy meals for dinner,
- Do not force yourself to sleep when you are not sleepy but try to engage in relaxing activities that does not require too much effort instead. Refrain from stimulating TV shows or books (American Sleep Association, 2007; Morgenthaler, et al., 2006; Özgen, 2001; Öztürk, 2004; Timur & Şahin, 2010).

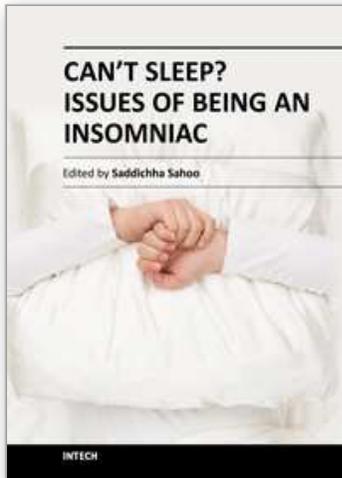
## 6. Conclusion

In conclusion, insomnia is an important health problem with high prevalence rates. It affects daily life negatively and could be a symptom or cause of various diseases. Evaluation of quality of life plays a big role in identifying the level of impact that insomnia has on an individual. Generic as well as disease-specific instruments of measurement are needed to assess quality of life. Sleep disorder specific quality of life measures are insufficient. Health professionals should aim to increase patients' quality of life as well as manage their sleep disorders. However, preventive measures should be considered before medication solutions. Sleep hygiene education is one of the most important preventive measures to increase sleep quality, and therefore quality of life.

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### **Can't Sleep? Issues of Being an Insomniac**

Edited by Dr. Saddichha Sahoo

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The word insomnia originates from the Latin "in" (no) and "somnus" (sleep). It is a disorder characterized by an inability to sleep or a complete lack of sleep. Various studies have noted insomnia to be quite a common condition, with symptoms present in about 33-50% of the adult population. This book provides a comprehensive state of the art review on the diagnosis and management of the current knowledge of insomnia and is divided into several sections, each detailing different issues related to this problem, including epidemiology, diagnosis, management, quality of life and psychopharmacology. In order to present a balanced medical view, this book was edited by a clinical psychiatrist.

#### **How to reference**

In order to correctly reference this scholarly work, feel free to copy and paste the following:

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