Review Article

Sleep and Sleep-Wake Disturbances in Care Recipient-Caregiver Dyads in the Context of a Chronic Illness: A Critical Review of the Literature

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Abstract

Context. Alterations in sleep-wake patterns of care recipients and their informal caregivers are common in the context of a chronic illness. Given the current notion that sleep may be regulated within and affected by close human relationships, concurrent and interrelated sleep problems may be present in care recipient-caregiver dyads.

Objectives. To critically analyze evidence regarding concurrent sleep patterns or changes in care recipient-caregiver dyads in the context of a chronic illness and address methodological and research gaps.

Methods. Using a wide range of key terms and synonyms, three electronic databases (Medline, CINAHL, and Embase) were systematically searched for the period between January 1990 and July 2011.

Results. Ten studies met prespecified selection criteria and were included for analysis. Study quality was fair to good on average. Seven studies were conducted in the context of dementia or Parkinson's disease, two in the context of cancer, and one study included a group of community elders with mixed related comorbidities and their informal caregivers. Bidirectional associations in the sleep of care recipient-caregiver dyads seem to exist. Concurrent and comparable nocturnal sleep disruptions also may be evident. Yet, inconsistencies in the methods implemented, and the samples included, as well as uncertainty regarding factors coaffecting sleep, still preclude safe conclusions to be drawn on.

Conclusion. The dyadic investigation of sleep is a promising approach to the development of truly effective interventions to improve sleep quality of care recipients and their caregivers. Nevertheless, more systematic, longitudinal dyadic research is warranted to augment our understanding of co-occurrence and over time changes of sleep problems in care recipient-caregiver dyads, as

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well as to clarify covariates/factors that appear to contribute to these problems within the dyad and across time and context of illness. J Pain Symptom Manage 2013;45:579–594.

Key Words
Sleep, sleep-wake disturbances, patient-caregiver dyad, informal caregiving, dyadic approach, chronic illness, critical review

Introduction

The notion that the patient-caregiver relationship is made up of two people, both of whom influence and are influenced by the other, has been stressed as particularly relevant to health care.[1,2] Now more than ever, chronic illness is considered a shared experience that impacts individuals on a level that transcends mere individualistic limits and cannot be understood solely within person-centered models of care[3–5] but in the context of complex networks of relationships.[5] According to social contextual models, health outcomes are likely to covary in close relationships, as in the patient-caregiver relationship.[2,6–17] For instance, any change in the functioning of one individual can affect the functioning of their significant ones.[18] Similarly, although external factors, such as disease severity and social support, may affect patients' and caregiver's physical and psychosocial well-being directly and unidirectionally, interdependence can contribute to a bidirectional situation in which the well-being of each individual in the dyad also affects the well-being of the other.[19] There is general consensus that when patients and caregivers are treated simultaneously, important synergies can be achieved contributing to the well-being of each person.[20,21] Conversely, when these interrelated and often concurrent needs are neglected, patient-caregiver dyads are denied the opportunity to obtain optimal care. Therefore, it has been argued that to provide optimal comprehensive health care, the care plan must focus on these patient-caregiver units.[22]

Sleep is considered a vulnerable state that, in part, occurs, or otherwise is optimized, in the presence of adequate levels of physical comfort and emotional safety, as well as in the relative absence of psychological distress and psychophysiologic arousal.[23–25] An adequate social environment may be particularly important for such feelings to emerge.[26] Hence, for humans, the social projections of sleep are being recognized,[23] as sleep may be regulated within and affected by close human relationships,[23,27] such as the patient-caregiver relationship. Sleep-wake disruptions have been frequently reported in care recipients[28–31] and their informal caregivers[29,32–34] in the context of a chronic illness. However, the fact that the science of sleep has tended to view sleep as an entirely individual phenomenon can be described as a rather confined approach, impeding assessment and management of sleep disorders that might manifest themselves especially during periods of adjustment to illness. Given that interdependence is a defining feature of human relationships, it also might be a defining feature for sleep as seen in the context of a close patient-caregiver relationship.[35]

According to the attachment hypothesis, persons in close relationships may develop expectations from one another that are thought to mediate affect and arousal, particularly in times of real or perceived threat.[23,26,36,37] This theory could, to a certain extent, justify the value of concurrent assessment of sleep patterns of patients and their primary informal caregivers, either in a family[26] or in a wider support context. As care recipients and caregivers go through the experience of illness together, their emotional reactions, distress, and coping strategies also might coaffect their sleep. In a situation involving the copresence of persons, cooperation from each other to achieve their own "sleep ritual" can be of particular importance.[38] This might involve the choice of common bedtimes and complementary sleep conditions.[38] In the context of a chronic illness, however, this "cooperation" can become blurred, given that patient symptom experience, caregiver burden,