

Sleep Disruption in Parents of Children with Atopic Dermatitis: A Cause of Concern

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Abstract

It is well-established that an individual's physical, mental, and cognitive health depends on proper sleep. However, regular sleep patterns are likely disrupted in persons who care for persons with chronic illnesses. Atopic dermatitis is a common, chronic inflammatory cutaneous disease affecting a proportion of the pediatric population. Most parents experience stress while caring for atopic dermatitis in their children. It is a time-intensive and emotionally demanding situation that adversely affects sleep and leads to exhaustion and worry. Sleep disruption of parents further contributes to difficulty coping with dermatitis management and parenting demands. This brief review aims to identify the extent and nature of sleep disruption in parents of atopic children and interventions to address the same.

Key words: Atopic Dermatitis; Caregivers; Interventions; Parents; Sleep; Sleep Disturbance

Introduction

Atopic dermatitis (AD; atopic eczema) is a common, chronic inflammatory skin disease that affects approximately 15-20% of the pediatric population.^{1,2} Any chronic pediatric condition leads to increased stress and distress among caregivers, especially parents.^{3,4} As routine care of the offspring is a recurring role of the parent, the parent's financial, social, and psychological burden increases in a child suffering from a chronic disease.⁵ Consequently, this increases the parents' responsibility in multiple domains that may adversely affect their physical and psychological well-being.^{6,7} The symptoms of AD, particularly the nocturnal pruritus, are more disturbing at night. Therefore, it increases the probability of qualitative and quantitative sleep disturbances in parents. The present brief account summarizes the sleep disturbances in the parents of children suffering from AD.

Sleep disruption in the parents during routine care of the child

Sleep disturbance can arise from various predisposing, precipitating, and perpetuating factors.⁸ For the parents of an atopic child, sleep disturbance can be directly related to the diseased condition of the child. Predisposing risk factors for disorders in parents' sleep may just be associated with the inherent responsibilities of parenthood.⁸ It has been reported that sleep duration and satisfaction do not fully recover to the pre-pregnancy levels until the child is at least six years of age.⁹ Females tend to have more sleep disruption-associated impairment than males as they are more often in the role of caregiver.¹⁰ It has been reported that 60% of parents experienced sleep interruption more than two times per night to care for their child with AD.¹¹ Ramirez et al., in their population-

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based cohort, found that 5-12% of mothers of atopic children slept less than 6 hours per night.¹² Meltzer and Booster also found that parents of children with AD reported shorter sleep duration than parents of healthy children.¹³ Similarly, another study documented that parents of children with AD lost a median of about 39 minutes of sleep per night.¹⁴ Children with AD also have more frequent sleep interruptions and stay awake significantly longer when they wake up.¹⁵ This observation can be directly extrapolated to the sleep disruptions faced by the parents. Consistent with this, it was reported that parents had to get up 2-4 times per night to attend to the AD child.¹⁴ Therefore, the sleep disruptions in parents are directly related to a child's nighttime awakening.

Sleep disturbances may also be related to certain other factors. The chronic course of childhood AD leads to stress and anxiety in the caregivers and thus contributes further to sleep disruption.¹⁶ Many authors have found that psychological distress and depression rates are higher in parents of children with AD,¹⁷⁻¹⁹ which explains some of their sleep disturbances. Moore et al., reported that anxiety and depression scores correlated with sleep disruptions in parents of AD children.¹⁴ Another survey among families of AD children found that about 55% of caregivers suffered from sleep disturbance.²⁰ However, these studies have not explored the exact nature of sleep disturbance. Research is needed to comprehend the etiopathogenesis of these sleep disruptions better and to characterize their consequences on daytime functioning, well-being, and health outcomes in parents of children with AD.¹²

In their qualitative interview-based study, Angelhoff et al., found that parents significantly changed their routines and behaviors to compensate for sleep loss.²¹ Parents also reported that healthcare professionals often ignored their sleep loss and had a perception that sleep disturbances affected their emotional state, mood, cognition, and well-being.²¹ Chamlin et al., reported that about 30% of parents slept with their AD child. These parents reported frequent awakenings and disturbances in sleep and significant association with the severity of the children's disease.²² Other workers have also objectively reported similar sleep disturbance in parents due to their caregiving responsibility.^{13,23}

Interventions for sleep disturbances of parents of AD children

The long-term health effects of sleep disruptions on parents of AD children have largely been ignored. Interestingly, sleep disturbance for the suffering children has received due acknowledgment, and various interventions have been adopted to improve the sleep quality of children with AD.^{24,25} However, there is a lack of studies on sleep interventions in the parents of children with AD. In a randomized control

trial, 'structured parental education' was found beneficial in this aspect. It significantly decreased sleep disturbance, stress and anxiety levels in the parents of children with AD.²⁶ The authors of the study recommended that such educational interventions be considered for the caregivers of atopic children.²⁶

Therefore, any chronic illness of a child is likely to be the cause of stress for the family members and may result in changing roles and responsibilities of the parents, caregivers, and even siblings.²⁷ This often leads to disruption of the usual routines in the family. The appropriate routine chores in the family are essential for the sense of security and physical and emotional well-being of one and all. Research into the psychological aspects of chronic illness has shown that parents and siblings of children with chronic diseases are at an increased risk of various adverse psychological effects.

Atopic dermatitis is an inflammatory skin condition associated with nocturnal pruritus and sleep disturbances. This is often reported in early infancy when children's sleep patterns have not been established appropriately. Furthermore, itching and scratching of AD interfere with the initiation and maintenance of sleep. The situation is problematic for parents due to co-sleeping with a sick child. Some authors have also reported that parents may lose sleep to prevent their child from scratching at night.²⁸ It leads to sleep disruption in the parents and increases parenting stress.

Therefore, health care providers should be aware of the perspective of the caregiver of the child with atopic dermatitis. It is crucial to enquire the parents and caregivers about their sleep. It must be recognized that the family, as a complex system, is impacted by illnesses in various domains. The atopic child's treating physician is the first informed healthcare provider who can easily access the concerns of the caregivers and effortlessly recognize the red flags of sleep issues.

The literature shows that some interventions have been helpful. Therefore, the 'structured parental education' may be adopted for this.²⁶ The focus should be directed towards honing the coping skills of parents while concentrating on the treatment of the child with AD. Adequate communication among other family members should be encouraged to relieve emotional distress and promote responsibility-sharing by all. Parents should receive informational support to improve their quality of life and address their concerns.²⁹ The treating physician should consider evaluating parents' sleep of atopic children to achieve the appropriate care for the family's well-being. A few sleep questionnaires may be utilized for screening, e.g., the Insomnia Symptom Questionnaire (ISQ), Pittsburgh Sleep Quality Index (PSQI), Functional Outcomes of Sleep Questionnaire (FOSQ), etc. Parents and caregivers with significant sleep disruption should be thoroughly evaluated and managed.

Conclusion

To conclude, poor sleep in parents of atopic children should be recognized and adequately addressed. Appropriate management of sleep disturbance in

parents of atopic children is likely to have positive long-term consequences on the health of the family as a whole.

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