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Sleep disruption in caregivers of pediatric stem cell recipients

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Abstract

Parents/caregivers of hospitalized patients are at risk of sleep disruption. We performed a cross-sectional quantitative and qualitative evaluation of sleep in parents/caregivers of children undergoing hematopoietic stem cell transplant (HSCT; n = 17). Additionally, we explored the frequency of room entries for hospitalized patients undergoing HSCT (n = 189 nights). Twelve caregivers (71%) demonstrated significant sleep disturbance, 12 (71%) described sleep quality as poor, 15 (88%) averaged < 6 hours of sleep per night, 14 (82%) awakened at least four times per night. Patient rooms were entered a median of 12 times per night (interquartile range 10–15). Intervention studies to improve caregiver sleep during hospitalization are needed.

Keywords

caregivers; hematopoietic stem cell transplant; pediatrics; sleep

1 INTRODUCTION

Sleep is an essential biological function that is important for physiological rest and emotional well-being.¹ Sleep deprivation exists when sleep is insufficient to support adequate alertness, performance, and health, either because of decreased sleep quantity (reduced total sleep time) or decreased sleep quality (fragmentation of sleep secondary to disruption).^{2,3} Frequent room entries for vital sign measurement, overnight administration of medication, and monitor alarms increase sleep disruption in both patients and parents/caregivers during hospitalization.^{4,5} Sleep disruption in the caregivers of hospitalized

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

patients can lead to increased stress and fatigue, decrease the quality of life, and ultimately affect parents'/caregivers' ability to support their child.⁶⁻⁹ Hematopoietic stem cell transplant (HSCT) recipients spend a minimum of 4–6 consecutive weeks in the inpatient setting, and 50% are readmitted to receive treatment for transplant-related complications.¹⁰ Caregivers of patients undergoing HSCT may be at risk for sleep deprivation, adding additional pressure in a setting already associated with high stress. Caregivers take an active role in caring for the sick child and commonly stay with the patient throughout the prolonged hospitalization. Although there are several studies evaluating sleep in parents/caregivers of pediatric patients with cancer,^{11,12} there are no studies describing sleep experiences of parent/caregivers of children hospitalized for HSCT.

2 MATERIALS AND METHODS

Here we report findings on two related pilot studies. First, we performed a cross-sectional evaluation of sleep in caregivers/parents of children undergoing HSCT. After Institutional Review Board approval was obtained, a member of the study team approached caregivers of patients undergoing HSCT. We included only caregivers with no prior diagnosis of a sleep disorder, who stayed at least 5 days per week with their child in the hospital, and whose children had undergone HSCT and were between days 0 (stem cell infusion) and +30. We used the General Sleep Disturbance Scale (GSDS) to evaluate caregiver sleep disturbance and sleep quality.^{13,14} The survey consists of 21 items asking respondents to rate the frequency of specific sleep problems during the previous week from 0 (not at all) to 7 (every day).^{14,15} The GSDS total score is the sum of its seven subscale scores (i.e., quality of sleep, the quantity of sleep, sleep onset latency, midsleep awakenings, early awakenings, medications for sleep, excessive daytime sleepiness) that can range from 0 (no disturbance) to 147 (extreme sleep disturbance). A GSDS total score of 43 indicates a significant level of sleep disturbance.¹⁴ Complementing the GSDS, caregivers completed an investigator-developed questionnaire to collect demographic information, caregiver's impressions of their sleep before and during the hospitalization, and factors caregivers endorsed from a list which affected their sleep in the hospital setting. Participants could also list additional variables associated with sleep disruption not provided in the questionnaire. Sleep quantity, quality, and sleep interruptions during hospitalization and prehospitalization were compared using Wilcoxon-signed rank test in IBM SPSS Statistics for Windows, Version 24.0.

In a second cohort, we explored the frequency of room entries for hospitalized patients undergoing HSCT. We tracked room entries on the 24 bone marrow transplant unit beds over 7 days using a simple table placed on the door of each patient room. Hospital staff marked the time of room entry on the form each night.

3 RESULTS

Seventeen caregivers of patients undergoing HSCT consented to the first study, the majority being females (88%). The study refusal rate was 15% (n = 3) of individuals approached. Demographics of caregivers and the children undergoing HSCT can be found in Table 1.

The caregiver's median GSDS score was 50 (interquartile range [IQR] 40–57), with 12 (71%) scoring ≥ 43 indicating a significant level of sleep disturbance. The GSDS tool showed high internal reliability ($\alpha = 0.87$). Caregivers spent an average of 6 days each week in the hospital (range 5–7; Table 2). In the investigator-developed questionnaire, 12 caregivers (71%) described sleep quality as poor in the hospital setting compared to one caregiver (6%) reporting poor sleep before hospitalization. During the hospitalization, 15 caregivers (88%) averaged less than 6 hr of sleep per night and the majority (82%) awakened at least four times per night. Sleep quantity, quality, and sleep interruptions were significantly worse during hospitalization than prehospitalization ($P < 0.001$). Cardiac monitor alarms (76%), infusion pump alarms (82%), staff assessments (82%), and door openings (71%) were the most commonly reported causes of sleep disruptions in caregivers.

Thirty-two patients were hospitalized over the 7-day period for a total of 189 overnight room entry observations. Room entries were tracked for a median of 9 hr per night (IQR 8.1–9.6). Patient rooms were entered a median of 12 times per night (IQR 10–15) or 1.4 times per hour (IQR 1.1–1.7).

4 DISCUSSION

This is the first study to evaluate sleep in caregivers of pediatric HSCT recipients during hospitalization. We found a high level of sleep disturbance (GSDS) and frequent reporting of poor sleep quality in caregivers of hospitalized HSCT recipients. Additionally, caregivers reported significantly lower sleep quantity with more frequent night-time interruptions in the hospital setting than at home. Participants also identified variables associated with sleep disruption, several of which may be modifiable (e.g., loud hallway noises).

This study is limited by the small sample size and the inherent limitations of single-center studies. Although our sample was small and findings were largely descriptive, these findings dovetail with those from a recent article on the negative sleep experiences (and their detrimental effects) of the caregivers of children with cancer who sleep on the unit.¹⁶

There are limited data evaluating interventions to improve sleep during hospitalization, however, overnight staff may be able to modify some of the factors contributing to nocturnal awakenings.¹⁷ Interventions may include implementation of mechanisms to reduce noisy alarms, having earplugs and eye masks available for caregivers, and bundling of overnight care.^{5,18–20} Additionally, units should regularly assess and mitigate variables associated with poor sleep. This study represents a key launching point, highlighting the need for intervention and beginning to build the evidence base for developing sleep interventions for patients and caregivers undergoing HSCT.

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Abbreviations

GSDS	General Sleep Disturbance Scale
HSCT	hematopoietic stem cell transplant
IQR	interquartile range

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TABLE 1

Demographics of patients hospitalized for HSCT and caregivers staying in the room (n = 17)

Subjects (n = 17)	
Caregiver median age in years (range)	39.2 (18–59)
Caregiver gender	
Female	15 (88%)
Male	2 (12%)
Caregiver marital status	
Married	13 (76%)
Single	3 (18%)
Divorced	1 (6%)
Caregiver employment status	
Employed	6 (34%)
Homemaker	5 (30%)
Unemployed	5 (30%)
Retired	1 (6%)
Caregiver total number of children (including patient)	
1–2	5 (30%)
3–4	8 (46%)
5–7	3 (18%)
8+	1 (6%)
Patient median age in years (range)	10.0 (1.1–15.2)
Patient gender	
Female	9 (53%)
Male	8 (47%)

TABLE 2

Variables associated with sleep in study subjects (n = 17)

	30 days before admission	During hospitalization	P-value
Rating of sleep quality			<0.001
Very bad	0	3 (18%)	
Fairly bad	1 (6%)	9 (53%)	
Fairly good	8 (47%)	4 (23%)	
Very good	8 (47%)	1 (6%)	
Average amount of time spent sleeping at night			<0.001
2–4 hr	0	5 (30%)	
5–6 hr	2 (12%)	10 (58%)	
7+ hr	15 (88%)	1 (6%)	
Uncertain	0	1 (6%)	
Average number of times awoken at night			<0.001
0–1	11 (65%)	1 (6%)	
2–3	6 (35%)	2 (12%)	
4–5	0	7 (42%)	
6–7	0	4 (23%)	
8+	0	3 (17%)	
Medication use to help sleep			
None	11 (64%)	12 (70%)	
Melatonin	2 (12%)	2 (12%)	
Acetaminophen/ibuprofen with diphenhydramine	2 (12%)	1 (6%)	
Acetaminophen, dextromethorphan and doxylamine	1 (6%)	0	
Tramadol	1 (6%)	1 (6%)	
Alprazolam	0	1 (6%)	
Sleep-related variables during current hospitalization			
Mean number of nights per week spent at hospital (SD)	6.00 (±0.94)		
Current caffeine or stimulant consumption			
None		2 (12%)	
1 cup of coffee or equivalent per day		7 (41%)	
2–3 cups of coffee or equivalent per day		5 (29%)	
4 or more cups of coffee or equivalent per day		3 (18%)	
Variables that keep you awake at night during hospitalization			
Sounds in the hallway		2 (12%)	
Talking in hallway at night		9 (53%)	
Overhead paging		2 (12%)	
Pump alarms		14 (82%)	
Monitor alarms		13 (76%)	

	30 days before admission	During hospitalization	P-value
Lights in room		3 (17%)	
Lights in hallway		1 (6%)	
Staff using Nurse Server		6 (36%)	
Noise from staff's keys		4 (23%)	
Noise from trash pulls		9 (53%)	
Room door open/closing		12 (71%)	
Removal of plastic packaging from supplies		7 (42%)	
Blood pressure cuff inflating		4 (23%)	
Curtain being pulled in room		3 (18%)	
Side rails of crib moving up/down		2 (12%)	
Staff assessments/vital signs		14 (82%)	
Diaper changes		4 (23%)	
Toileting (patient)		6 (36%)	
Pain (patient's)		11 (65%)	
Nausea (patient's)		10 (59%)	

SD, standard deviation.