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Sleep in Family Caregivers of ICU Survivors for 2 months post-ICU discharge

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Abstract

Objective—To describe changes in sleep quality in family caregivers of ICU survivors from the patients' ICU admission until 2 months post-ICU discharge.

Design—Descriptive repeated measure design

Setting—Academic hospital medical ICU

Main outcome measures—Subjective sleep quality (Pittsburgh Sleep Quality Index [PSQI]) and objective sleep/wake variables (SenseWear Armband™) were measured in family caregivers at patients' ICU admission, within 2 weeks post-ICU discharge, and 2 months post-ICU discharge.

Results—In 28 family caregivers of ICU survivors, most caregivers reported poor sleep quality (i.e., PSQI > 5) across the three time points (64.3 % during patients' ICU admission, 53.6 % at each post-ICU time point). Worse trends in sleep quality and objective sleep/wake pattern were observed in caregivers who were employed, and a non-spouse. There were trends of worsening sleep quality in caregivers of patients unable to return home within 2 months post-ICU discharge compared to patients able to return home.

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Conclusions—Poor sleep quality was highly prevalent and persisted in family caregivers of ICU survivors for 2 months post-ICU discharge. Our data support the need for a larger longitudinal study to examine risk factors associated with sleep quality in family caregivers of ICU survivors to develop targeted interventions.

Keywords

Intensive care unit; intensive care unit survivors; family caregivers; sleep; post intensive care outcomes

Introduction

Promoting physical and mental health of family caregivers is an important component of family-centered critical care nursing. Psychological symptoms commonly experienced by family members of intensive care unit (ICU) survivors include depression, post-traumatic stress and complicated grief, a constellation of symptoms referred to as Post-ICU Syndrome-Family (PICS-F) (Davidson et al. 2012). Poor sleep quality and impaired sleep/wake patterns may be major contributing factors leading to PICS-F.

Inadequate rest is a highly prevalent health risk in family members of critically ill patients admitted to an ICU (Choi *et al.* 2013). During the patient's ICU stay, family caregivers report poor sleep quality and its association with decreased daytime functioning (Vergeles *et al.* 2014). The nature of recovery after critical illness is complex and unpredictable (Unroe *et al.* 2010), with many caregivers assuming responsibility for patients' physical and psychological needs (Choi 2009, Van Pelt *et al.* 2007). In addition, patients may experience several transitions between care settings during recovery, providing additional stress (Unroe *et al.* 2010). Stress from these increased responsibilities and the unpredictable nature of the recovery may cause persistent problems with sleep quality. Few studies have explored sleep quality or objective sleep/wake patterns in family caregivers during the post-ICU discharge period, an important phenomenon to explore when designing interventions to address PICS-F.

The aim of this report was to describe the trajectory of sleep quality and objective sleep/wake patterns in family caregivers of ICU survivors from the patients' ICU hospitalization to 2 months post-ICU discharge. We also described sleep quality and objective sleep/wake patterns by caregiver characteristics and patient home discharge status. We hypothesized that poor sleep quality and disrupted sleep/wake patterns would be present across the phases of patients' illness and recovery and vary depending on characteristics of patients' recovery (e.g., timing of home discharge after ICU discharge).

Methods

Design and setting

This descriptive analysis was part of a longitudinal study that explored biobehavioral stress responses in family caregivers of critically ill adults who required mechanical ventilation (4 days) in a medical ICU in a tertiary academic hospital (Choi 2009). Potentially eligible family caregivers and patients were identified by ICU staff and asked to give permission to

be approached by a research team member. If permission was granted, a member of the research team verified eligibility and explained the study's purpose, risks and benefits. Baseline data collection occurred during the patients' ICU hospitalization. Follow up data collection occurred at various locations at each time point, depending on patients' placement after hospital discharge.

Data collection

Medical records were reviewed to obtain patient characteristics. Two instruments were used to assess caregiver sleep. The Pittsburgh Sleep Quality Index (PSQI) measured subjective sleep quality (Buysse *et al.* 1989). The potential PSQI score ranges from 0 to 21; scores over 5 indicate poor sleep quality. Higher scores indicate worse sleep quality. Reliability and validity have been well established (Backhaus *et al.* 2002, Buysse *et al.* 1989, Carpenter & Andrykowski 1998, Fichtenberg *et al.* 2002). The Cronbach's α reported for the Global PSQI score was 0.83 (Buysse *et al.* 1989). The Cronbach's α in a population of ICU family caregivers has not yet been established. The Cronbach's α for our caregiver sample across three time points was 0.76 – 0.82. The SenseWear Armband™ (SWA; Body Media Inc., Pittsburgh, PA) measured objective sleep/wake patterns. The SWA is an accelerometer with two-axis microelectronic mechanical and heat sensors that allows assessment of activity and sleep. The SWA calculates the sleep/wake variables of total sleep time (TST), sleep efficiency (SE) and wake after sleep onset (WASO). Validity of the SWA in estimating TST, SE and WASO was confirmed in studies that found no significant differences in evaluation these sleep/wake variables between the SWA with either polysomnography or Actiwatch actigraphy (Alsaadi *et al.* 2014, Sharif & Bahammam 2013).

Both PSQI and SWA were measured at the following three time points: (1) enrollment which occurred during patients' ICU admission after the patient was on mechanical ventilation for 4 days or longer; (2) within 2 weeks post-ICU discharge, a period requiring initial adjustment following ICU discharge; and (3) 2 months post-ICU discharge, a time point when a majority of patients were discharged to home and challenges to caregivers tend to diversify by patients' care situations (e.g., home or institution, level of physical care needs).

The PSQI was administered face-to-face or via telephone, depending on caregiver preference. Administering the PSQI via telephone interview has been validated in previous studies (Lequerica *et al.* 2014, Monk *et al.* 2013, Tomfohr *et al.* 2013). If a caregiver preferred telephone-administration of the PSQI, a copy of the response options in each item was provided for reference during the phone call. Caregivers wore the SWA for 72 hours (except when bathing or swimming). Data recorded by SWA were downloaded and analyzed using manufacturer software.

Caregivers' depressive symptoms and caregiving burden

Shortened version of Center for Epidemiology Study Depression subscale with 10 items (CESD-10) was used to measure depressive symptoms in caregivers (Radloff 1977). The CESD-10 used a 4-point Likert-type summative scale (range 0 – 30). Higher scores indicated more depressive symptoms. Scores of ≥ 8 have been used as a cutoff to indicate clinically significant depressive symptoms (Schulz *et al.* 2001). Validity has been established

in caregivers and healthy adults (Andresen *et al.* 1994, Logsdon & Teri 1995). The Cronbach's α reported for the CESD-10 was 0.85 – 0.92 (Choi *et al.* 2012, Irwin *et al.* 1999). The Cronbach's α in our sample was 0.86 – 0.87.

Brief Zarit Burden Interview 12-item (Zarit-12) was used to measure caregiver burden (Bedard *et al.* 2001). Items in the Zarit-12 described feelings due to caregiving (e.g., feeling strained) using a 5-point Likert-type scale (range 0–48). Higher scores indicated greater burden. Validity in prediction of depressive symptoms was reported in caregivers of community dwelling elderly (O'Rourke & Tuokko 2003). The Cronbach's reported for the Zarit-12 was 0.88 had been reported (Bedard *et al.* 2001). The Cronbach's α in our sample was 0.76 – 0.92.

Ethics and formal requirements

The study protocol was reviewed and approved by the institutional review board. All family caregivers and patients (or their proxy) provided informed consent.

Data Analyses

IBM-SPSS v. 19.0 (SPSS, Inc.; Chicago, IL) was used. The Friedman test was used to explore changes in sleep data. When significant changes were found, follow-up pairwise comparisons were performed using a Wilcoxon test. The Least Significant Difference (LSD) procedure was used for pairwise comparisons. Mann-Whitney U test was used to compare sleep quality and objective sleep variables by caregiver characteristics. Spearman's ρ was used to examine correlation between subjective sleep quality, objective sleep/wake patterns and caregivers' depressive symptoms and caregiving burden at each time point. Statistical significance was set at $p < 0.05$ (two-tailed). In addition, trends were examined for differences in sleep quality and objective sleep/wake patterns by caregiver characteristics and patients' recovery.

Results

Of the 47 dyads enrolled, 28 caregivers (96% Caucasian; 79% females; age 49.7 ± 12.8 years) completed measures at all three time points. Nineteen dyads were unable to complete measures due to the patients' death during the study period ($n=11$), caregiver withdrawal or lost to contact ($n=6$) or data not provided for one or more time points ($n=2$). Participant characteristics, objective and subjective sleep data in caregivers and patients' home discharge status over 2 months post-ICU discharge are summarized in Table 1. Caregivers were mostly spouses who were employed and working at enrollment. Those who completed all measures were younger ($M \pm SD = 51.3 \pm 16.6$ years vs. 61.5 ± 15.3 years, $p = 0.04$). Except for age, there were no significant differences between dyads who completed all measures and those who did not.

Caregivers' Sleep from ICU Admission to 2 Months Post-ICU Discharge

Mean PSQI scores were highest during patient ICU admission. While mean PSQI scores tended to decrease following patient ICU discharge, over half of caregivers continued to report a PSQI score above 5. Regarding objective sleep/wake patterns measured by SWA,

average TST ranged from 5 hours 28 minutes to 6 hours 7 minutes. Caregivers were awake almost an hour during the night (e.g., mean WASO ranged 54.2 – 66 minutes). The sleep/wake data displayed no statistically significant difference across the time points.

Caregivers' Sleep by Caregiver Characteristics

PSQI scores and objective sleep/wake data were compared at each time point by caregiver characteristics (e.g., employment, relationship to patient, gender, previous history of emotional problem and age). Descriptive results from this comparison are summarized in Table 3. Caregivers who were employed had significantly lower mean TST at 2 months post-ICU discharge compared to those who were unemployed. Non-spouse caregivers had significantly lower SE than spouse caregivers at 2 weeks post-ICU discharge and 2 months post-ICU discharge. Caregivers who reported a history of being seen by a clinician for an emotional problem had a trend of worse PSQI, WASO, and SE at all time points. However, these trends were not statistically significant except PSQI score at 2 weeks and WASO during ICU admission. In our sample, worse PSQI scores were significantly correlated with worse depressive symptoms and worse caregiving burden at all time points (Table 4). However, no significant correlations were observed between variables indicating objective sleep/wake pattern (e.g., TST, WASO, SE) and caregivers' depressive symptoms and caregiving burden (Table 4).

Caregiver Sleep by Timing of Patient Home Discharge for 2 Months Post-ICU Discharge

At 2 months post-ICU discharge, 9 patients (32.1%) had not returned home; 5 patients (17.9 %) were discharged home within 2 weeks and 14 patients (50.0%) were discharged home at 2 months. For caregivers of patients who were not discharged home, all sleep/wake pattern variables showed worsening trends (Figure 1). When discharge home occurred within 2 weeks, mean WASO tended to increase once the patients returned home and then decreased by 2 months post-ICU discharge; and SE improved by 2 months post-ICU discharge.

To determine if there was a difference in caregivers' sleep related to timing of home discharge, we compared sleep variables between caregivers of the patients who were home within 2 weeks post-ICU discharge (n=5) and caregivers of patients who were home by 2 months post-ICU discharge (n=14) at the point when patients were home (2 weeks and 2 months, respectively). In caregivers whose patients did not return home by 2 months post-ICU discharge, we observed worsening trends in both subjective and objective sleep variables. However, these trends were not statistically significant.

Discussion

Whereas previous studies have reported the negative impact of impaired sleep quality and excessive daytime sleepiness on daytime function among family caregivers *during* patient ICU hospitalization (Day *et al.* 2013, Verceles *et al.* 2014), the present study examined impaired sleep quality and disrupted sleep/wake patterns over a 2-month period following patients' ICU discharge. Our findings, although preliminary due to the small sample size, provide preliminary evidence in support of our hypothesis that poor sleep quality among

family caregivers continues after patients' discharge from the ICU and varies depending on caregiver characteristics and discharge disposition.

In the present study, both TST and WASO reflected impaired sleep quality. Average TST was less than the average (7–8 hours) reported for the general population (Carskadon & Dement 2011). Mean WASO was greater than the DSM-5 criteria (WASO > 20 – 30 minutes), indicating difficulty maintaining sleep during the night (American Psychiatric Association 2013). In our comparison of caregivers' sleep quality by caregivers' characteristics, caregivers who were not a spouse of the patient (e.g., adult children, parents) and worked full- or part-time tended to have worse sleep post-ICU discharge. Moreover, caregivers' subjective sleep quality was significantly correlated with depressive symptoms and caregiving burden consistently across the time points while the report from the SWA did not show any meaningful correlations.

Although our small sample size limits depicting causal relationship among these characteristics and caregivers' sleep, our data provides a longitudinal snapshot suggesting (1) working, non-spouse caregivers maybe at high risk for poor sleep quality because of competing demands between caregiver role and their personal and professional lives, and (2) psychological stress and caregiving burden are highly associated with poor subjective sleep quality. We also observed trends of worse sleep quality in caregivers who had history of emotional problems. These results are consistent with reports from multiple studies that support there is a bi-directional relationship between impaired sleep and depressed mood (Buysse 2004, 2014).

Our data also displayed trends in caregiver sleep by patient home discharge status for 2 months post-ICU discharge. Both subjective and objective sleep variables show worsening trends in caregivers of patients who did not return home by 2 months post-ICU discharge. Conversely, among caregivers of patients being discharged to home within 2 weeks post-ICU discharge, both objective and subjective sleep variables were worse than those of caregivers of patients who returned home by 2 months. We speculate that, for caregivers of ICU survivors, prolonged care in a long-term care institution creates psychological stress, predisposing to sleep disturbance. Early home discharge may also create stress by overwhelming caregivers with heightened care demands. If home discharge is the only option due to insufficient insurance, care demands may be further escalated. In our sample, caregivers of patients who were discharged to home within 2 weeks showed trends of worse sleep quality at home discharge than those who had to deal with home discharge at 2 months.

Our data are consistent with prior studies that suggest continued care in an institutional setting may be as stressful as providing care at home (Choi *et al.* 2011, Im *et al.* 2004). While caregiving demands may be less on a day-to-day basis, inability to return home signals recovery will be lengthy or not occur. Given the lack of statistical significance, our results are limited in answering whether caregivers' sleep quality may vary depending on time of home discharge or caregivers' experience in the post-ICU settings. These are important questions to be answered in future studies in order to identify targets of interventions to support caregivers who may be most vulnerable.

The results of this report are limited by our small sample of mostly Caucasian, female, middle aged family caregivers. Therefore, our results need cautious interpretation considering the imbalance in ethnic, gender and age diversity in our sample. We did not retrospectively assess caregivers' overall sleep quality prior to patients' ICU admission or pre-existing sleep disorders (e.g., obstructive sleep apnea and insomnia). Although a previous study reported no significant association between current or past sleep disorders and sleep quality among family caregivers during patient ICU hospitalization (Vergeles *et al.* 2014), it remains unclear whether or not the same results continue during the post-ICU discharge period.

Conclusions

Poor sleep quality was highly prevalent and persisted in caregivers of ICU survivors 2 months post-ICU discharge. In our analysis, subjective sleep quality and report of objective sleep/wake variables (TST, WASO, and SE) were worse when (1) caregivers were required to balance demands of caregiving and work and (2) patients remained in a facility or were discharged home soon after ICU discharge.

Future studies are necessary in a larger diverse sample to further verify risk factors associated with sleep quality in caregivers in conjunction with varied post-ICU transitions by ICU survivors. Targeted interventions based upon caregivers' risks and needs unique in major post-ICU transition patterns will help improving caregivers' sleep quality and ultimately benefit patients' and family recovery.

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Figure 1.

Trends of sleep quality and objective sleep/wake patterns in caregivers of ICU survivors by patients' home discharge status: (1) home ≤ 2 weeks post-ICU discharge, $n=5$ (17.9 %); (2) home at 2 months post-ICU discharge, $n=14$ (50.0%); and (3) never returned home, $n=9$ (32.1 %). The middle circle represents the mean and error bar refers to standard deviations from the mean.

TST, total sleep time; WASO, wake after sleep onset; PSQI, Pittsburgh Sleep Quality Index

Table 1

Characteristics of family caregivers (n=28)

Variables	Mean $\pm$ SD or n (%)
Age, years	49.7 $\pm$ 12.8
Gender, female	22 (79)
Ethnicity, Caucasian	27 (96)
Relationship to patient	
Spouse or significant other	16 (57.1)
Adult child	6 (21.4)
Parent or sibling	6 (21.4)
Education, years	13.9 $\pm$ 2.7 (9 – 21)
Working full or part time	17 (60.7)
Number of chronic health problems	1.5 $\pm$ 1.5 (0 – 6)
History of emotional problem, yes	12 (43)
Caregiver sleep quality	
PSQI score; PSQI $\leq$ 5 poor sleep quality.	
ICU admission	6.9 $\pm$ 4.1; 18 (64.3)
2 weeks post-ICU discharge	6.8 $\pm$ 4.6; 15 (53.6)
2 months post-ICU discharge	6.2 $\pm$ 3.6; 15 (53.6)
Caregiver objective sleep/wake pattern ^{*a}	
TST, minutes	
ICU admission	328 $\pm$ 71
2 weeks post-ICU discharge	368 $\pm$ 115
2 months post-ICU discharge	351 $\pm$ 105
Sleep efficiency, %	
ICU admission	81 $\pm$ 11
2 weeks post-ICU discharge	79 $\pm$ 11
2 months post-ICU discharge	80 $\pm$ 12
WASO, minutes	
ICU admission	54 $\pm$ 36
2 weeks post-ICU discharge	67 $\pm$ 45
2 months post-ICU discharge	66 $\pm$ 60

PSQI, Pittsburgh Sleep Quality Index; ICU, intensive care unit; TST, Total Sleep Time; WASO, Wake After Sleep Onset

Caregivers were asked to answer the item “Have you seen a doctor for emotional, nervous or psychiatric problems?”^{*} Objective sleep/wake pattern measured by SenseWear-Armband™; Sleep quality measured by PSQI^a Missing data exist at ICU admission (n=3), 2 weeks post-ICU discharge (n=4) and 2 months post-ICU discharge (n=5).

Table 2

Characteristics of ICU survivors (n=28)

Variables	Mean $\pm$ SD or n (%)
Age, years	51.3 $\pm$ 16.6
Gender, male	20 (71.4)
Ethnicity, Caucasian	27 (96.4)
Primary diagnosis	
Respiratory	17 (60.7)
Sepsis, Multisystem failure	3 (10.9)
Gastrointestinal, Hepatic	5 (17.9)
Others	3 (10.8)
Charlson Comorbidity Score	3.4 $\pm$ 3.6
APACHE II score	22.1 $\pm$ 8.6
Length of stay in Intensive Care, days	24.9 $\pm$ 12.4
Days on mechanical ventilation, days	22.1 $\pm$ 12.0
Home discharge status	
Home 2 weeks post-ICU discharge	5 (17.9)
Home 2 months post-ICU discharge ^a	14 (50.0)
Never returned home ^b	9 (32.1)

APACHE, Acute Physiology and Chronic Health Evaluation

^aPrior to home discharge, disposition for these patients included a Long-Term Acute Care Hospital (n=6), hospital step down unit (n=7) and a skilled nursing facility (n=1).

^bAt 2 months post-ICU discharge, disposition for these patients included a Long-Term Acute Care Hospital (n=4), hospital step down unit (n=1) and a skilled nursing facility (n=4).

Comparison of family caregivers' sleep at each time point by caregivers' characteristics

Table 3

Caregiver characteristics		PSQI			
		ICU admission	p	2 weeks	p
Gender	Female	7.23 ± 4.02	0.23	7.18 ± 4.38	0.24
	Male	5.67 ± 4.76		5.33 ± 5.50	
Working full or part time	Yes	6.35 ± 3.77	0.48	6.94 ± 4.31	0.70
	No	7.73 ± 4.73		6.55 ± 5.22	
Relationship to patient	Spouse	6.76 ± 4.05	0.92	6.53 ± 4.19	0.91
	Non-spouse	7.09 ± 4.48		7.18 ± 5.36	
History of emotional problem	Yes	8.08 ± 3.72	0.28	8.50 ± 3.63	0.04 *
	No	6.00 ± 3.72		5.50 ± 4.92	

Caregiver characteristics		TST (minutes) ^a			
		ICU admission	p	2 weeks	p
Gender	Female	344 ± 67	0.02 *	386 ± 121	0.07
	Male	263 ± 52		300 ± 50	
Working full or part time	Yes	321 ± 75	0.65	336 ± 100	0.67
	No	341 ± 65		431 ± 123	
Relationship to patient	Spouse	339 ± 76	0.41	394 ± 118	0.33
	Non-spouse	312 ± 64		324 ± 100	
History of emotional problem	Yes	335 ± 70	0.66	344 ± 110	0.40
	No	322 ± 74		388 ± 119	

Caregiver characteristics		SE (%) ^a			
		ICU admission	p	2 weeks	p
Gender	Female	82 ± 11	0.20	81 ± 11	0.15
	Male	75 ± 9		74 ± 10	
Working full or part time	Yes	78 ± 10	0.17	77 ± 10	0.18
	No	84 ± 11		83 ± 13	

Caregiver characteristics		SE (%) ^a			
		ICU admission	p	2 weeks	p
Relationship to patient	Spouse	84 ± 9	0.18	83 ± 10	0.01 *
	Non-spouse	76 ± 12		73 ± 9	
History of emotional problem	Yes	78 ± 12	0.62	78 ± 11	0.66
	No	82 ± 9		80 ± 12	

Caregiver characteristics		WASO (minutes) ^a			
		ICU admission	p	2 weeks	p
Gender	Female	58 ± 38	0.54	70 ± 47	0.37
	Male	40 ± 28		56 ± 43	
Working full or part time	Yes	54 ± 40	0.87	68 ± 47	0.76
	No	55 ± 32		64 ± 44	
Relationship to patient	Spouse	49 ± 33	0.44	63 ± 45	0.53
	Non-spouse	63 ± 41		72 ± 48	
History of emotional problem	Yes	75 ± 42	0.01 *	67 ± 56	0.88
	No	38 ± 21		67 ± 37	

2 weeks, 2 weeks post-ICU discharge; 2 months, 2 months post-ICU discharge; PSQI, Pittsburgh Sleep Quality Index; ICU, intensive care unit; TST, Total Sleep Time; WASO, Wake After Sleep Onset

* Mann-Whitney U test, $p < 0.05$

^a Missing data exist at ICU admission (n=3), 2 weeks post-ICU discharge (n=4) and 2 months post-ICU discharge (n=5).

Table 4
Correlations between family caregivers' sleep, depressive symptoms and caregiving burden at each time point.

	PSQI					
	ICU admission		2 weeks		2 months	
	r	p	r	p	r	p
CESD-10	0.38	0.04 *	0.62	<0.001 *	0.44	0.02 *
Zarit-12	0.45	0.02 *	0.54	0.003 *	0.59	0.001 *

	TST (minutes) ^a					
	ICU admission		2 weeks		2 months	
	r	p	r	p	r	p
CESD-10	0.07	0.73	-0.15	0.48	0.19	0.43
Zarit-12	0.30	0.15	-0.06	0.80	-0.03	0.92

	SE (%) ^a					
	ICU admission		2 weeks		2 months	
	r	p	r	p	r	p
CESD-10	0.12	0.56	-0.29	0.17	0.27	0.25
Zarit-12	-0.02	0.92	-0.19	0.38	-0.02	0.95

	WASO (minutes) ^a					
	ICU admission		2 weeks		2 months	
	r	p	r	p	r	p
CESD-10	0.19	0.39	0.22	0.30	-0.21	0.37
Zarit-12	0.05	0.82	0.32	0.13	0.32	0.17

2 weeks, 2 weeks post-ICU discharge; 2 months, 2 months post-ICU discharge; PSQI, Pittsburgh Sleep Quality Index; ICU, intensive care unit; TST, Total Sleep Time; WASO, Wake After Sleep Onset; CESD-10, Shortened version of Center for Epidemiology Study Depression subscale with 10 items; Zarit-12, Brief Zarit Burden Interview 12-item

* Spearman's rho test, $p < 0.05$

^a Missing data exist at ICU admission (n=3), 2 weeks post-ICU discharge (n=4) and 2 months post-ICU discharge (n=5).