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The Relationship between Home Nursing Coverage, Sleep and Daytime Functioning in Parents of Ventilator-Assisted Children

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Abstract

This descriptive study examined the relationship between home care nursing support, sleep and daytime functioning in familial caregivers of ventilator-assisted children. Thirty-six primary caregivers (27 mothers, seven fathers, one foster mother, and one grandmother) of ventilator-assisted children completed measures of home nursing support, sleep, depression, fatigue, and daytime sleepiness. Daytime nursing coverage was not related to caregiver sleep or daytime functioning, but caregivers with less nighttime nursing coverage had significantly shorter sleep onset latency than caregivers with some night nursing (16–48 hours/week). Caregivers with regular night nursing (>48 hours/week) had a total sleep time of almost one hour more than caregivers without regular night nursing (≤ 48 hours/week). Caregivers with clinically significant symptoms of depression and sleepiness received significantly fewer hours of night nursing/week than caregivers without significant symptoms of depression or sleepiness. Home nursing support, in particular night nursing, is important for the health and well-being of familial caregivers of ventilator-assisted children.

Keywords

Home care nursing; caregivers; ventilator-dependent; sleep; functioning

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Advances in medical technology have resulted in a significant increase in the number of technology-dependent children being discharged from the hospital and cared for in the home (Feudtner et al., 2005). One of the most complex and high risk examples of technology-dependent home care is the child requiring long-term mechanical ventilation because of respiratory failure. Prevalence rates of children who require mechanical ventilation range from 0.5/100,000 in the UK (Jardine, O'Toole, Paton, & Wallis, 1999) to 6/100,000 in the US (Gowans, Keenan, & Bratton, 2007). Although the financial cost of having a ventilator-assisted child cared for at home may be less expensive compared to long-term hospitalization (Downes & Parra, 2001; Noyes, Godfrey, & Beecham, 2006), studies from around the world have shown the financial, physical and emotional costs for parents can be significant (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Kuster, Badr, Chang, Wuerker, & Benjamin, 2004; Ottonello et al., 2007; Wang & Barnard, 2004). Most families require the assistance of additional caregivers (e.g. nurses) when caring for a ventilator-assisted child at home. However, the cost and shortage of trained individuals, especially at night, has resulted in a decline of this important support service for families (Chaguturu & Vallabhaneni, 2005; Heaton, Noyes, Sloper, & Shah, 2005). The purpose of this exploratory study was to examine whether there is a relationship between home care nursing coverage and caregiver functioning, in particular sleep, mood, and daytime functioning.

Background

In the past decade, the impact of caring for a ventilator-assisted child on parents has received increased recognition in the literature, with parents/caregivers often reporting declines in their physical and mental health due to the extraordinary amount of care required for a ventilator-assisted child in the home. One study reported fewer health promoting behaviors in female caregivers, including limited physical exercise, poor nutrition, and shortened sleep (Kuster et al., 2004). Other studies have found lower mental health status, including symptoms of depression, and elevated caregiver burden in parents of technology-dependent children (Hartnick, Bissell, & Parsons, 2003; Thomlinson, 2002; Thyen, Kuhlthau, & Perrin, 1999). Caregivers have also reported disrupted social functioning, with increased isolation due to caregiving responsibilities (Carnevale et al., 2006; Montagnino & Mauricio, 2004; Wang & Barnard, 2004).

Only a few research studies have focused on sleep in parental caregivers of technology-dependent children, reporting regular sleep disturbances. Sixty-two percent of mothers who had technology-dependent infants reported regular sleep disruptions due to false monitor alarms (Andrews & Nielson, 1988). Kuster and colleagues (2004) reported that 61% of mothers of ventilator-assisted children reported never or only occasionally getting adequate sleep. Heaton and colleagues (2005) found that 22 out of 36 caregivers of technology-dependent children (61%) reported regular sleep disruptions (at least two nights per week), waking on average 3–4 times per night. Yet a clear relationship between sleep deprivation and impaired daytime functioning, including mood, decision making, and overall health has been shown in healthy adults (Dinges, Rogers, & Baynard, 2005) and in caregivers of adult patients with cancer or Alzheimer’s disease (Brummett et al., 2006; Carter, 2003; Happe & Berger, 2002; McCurry & Teri, 1995; McKibbin et al., 2005).

(Author citation) reported that mothers of ventilator-dependent children had significantly earlier morning wake times, more night wakings, and more symptoms of depression and daytime fatigue compared to mothers of children with cystic fibrosis or healthy children. Furthermore, mothers of ventilator-assisted children slept on average one hour less than

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mothers of children with cystic fibrosis or children without a chronic illness. This additional hour of sleep loss is significant, as most mothers of ventilator-assisted children were obtaining less than 6 hours of sleep, and 6 hours has been shown to be the minimum amount of sleep needed for adequate cognitive functioning during the day (Dinges et al., 2005). In addition, chronic insufficient sleep, as may be experienced by these mothers, has been associated with negative mood, in particular depression (Dinges et al., 2005; Van Dongen, Maislin, Mullington, & Dinges, 2003). One potential factor related to parental sleep disruptions, but not explored in the (Author citation) study, is the role of home nursing support.

Home nursing support and respite care, particularly at night, is important for families with ventilator-assisted children living at home. However, in the UK, Jardine and colleagues (1999) found that only 17% of ventilator-assisted families had formal respite care arrangements. Similarly, Heaton, Noyes, Sloper and Shah (2006) found that only 11% of families with technology-dependent children had consistent overnight support, with 56% receiving no overnight support in the past year. In the US, families have reported receiving nursing coverage between 9 and 13 hours per day, with up to 17% of families receiving no nursing coverage at all (Aday & Wegener, 1988; Quint, Chesterman, Crain, Winkleby, & Boyce, 1990). A recent study in Utah found 6% of families of ventilator-assisted children received no home nursing (Gowans et al., 2007). Further, 83% of the families in the study received only 8–12 hours of nursing support in a 24 hour period, although the authors did not clarify if this was during the day or at night.

No studies have directly examined the relationship between nursing support and parent sleep. Yet if one considers that parents of ventilator-assisted children report both sleep disruptions due to their own caregiving responsibilities and a lack of sufficient nursing coverage, this relationship is a reasonable expectation. One qualitative study reported that the greatest benefit of nighttime support for parents of technology-dependent children was the ability to get a good night of sleep (Heaton et al., 2006). In terms of daytime functioning, one study found that caregivers who received less than 32 hours of nursing care per week reported more feelings of overburden and social isolation (Aday & Wegener, 1988).

Although families desire and appreciate the nursing support they receive, particularly at night, families may face other challenges and stressors. For example, some caregivers report increased stress due to the constant threat of losing what nursing coverage they have (Kirk, 1998). Another study reported that mothers were surprised that some nurses did not have as much knowledge about the care of their ventilator-assisted child as they did (Reeves, Timmons, & Dampier, 2006). In addition, even with night nursing coverage, parental sleep disruptions may be caused by multiple factors. For example, regardless of nursing support, parents may wake if they hear an alarm or due to their own hypervigilance; night nurses may be required to wake parents to inquire about or ask for assistance with the child's medical care; and parent sleep may be disrupted by noises from the night nurse in the home not related to the child's medical care (e.g., watching television, making popcorn) (Andrews & Nielson, 1988; Heaton et al., 2006). Thus most families desire night nursing coverage, and most likely benefit from this support. Yet it is possible that at night parental sleep may be disrupted due to having this additional support in the home. This study was undertaken to address the current shortcomings of the current literature by examining the relationship between home nursing coverage and caregiver sleep and daytime functioning.

Research Objectives

The specific aims of this study were to: (1) describe the home care nursing services (amount, perceived adequacy of coverage, and satisfaction) for a sample of families with ventilator-assisted children; and (2) examine the relationship between nursing coverage and caregiver sleep patterns (bedtime, wake time, sleep onset latency, and total sleep time) and daytime

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functioning (depressive symptoms, fatigue, and sleepiness). It was hypothesized that caregivers who received more nursing coverage at night would report greater total sleep time, as well as fewer depressive symptoms, less daytime fatigue, and less daytime sleepiness.

Methods

A cross-sectional descriptive design was used to explore the relationship between home nursing support and sleep, mood, and daytime functioning in caregivers.

Participants

Families with ventilator-assisted children were identified by a home-care program that provides case management, advocacy, education, counseling, and respite nursing care funding for over 225 families in a large geographic region in the eastern United States. Inclusion criteria were (a) primary caregiver (e.g., mother, father, grandparent, legal guardian) of a child aged 3–14 years who required mechanical ventilation support; (b) sufficient English language skills to respond to questions during phone interviews; (c) telephone access for data collection purposes. Participants were excluded if they had a diagnosed sleep disorder that would contribute to sleep disruptions (i.e., obstructive sleep apnea, narcolepsy, restless legs syndrome). This study was approved by the Institutional Review Board at the tertiary care children’s hospital associated with the home-care program.

Forty families were identified as eligible and were invited to participate in this study. Nine families declined to participate stating they were either “too busy” (n=5) or “not interested” (n=4), and the interview with one family was never completed due to conflicts with the caregiver’s schedule. Although it was expected that mothers (as they are typically the primary caregiver) would complete the interview, six families stated that both parents equally shared the caregiving responsibilities, and in one family the father was the primary caregiver, thus both mothers and fathers were included in the study.

Primary caregivers included primarily biological mothers (n=27), with seven fathers, one foster mother, and one grandmother. For simplicity, these familial caregivers will be referred to as “caregivers” from this point forward. Participants were primarily Caucasian (89%) and ranged in age from 27 to 48 years (M=38.2, SD=6.2). The majority (75%) had completed some post-secondary education, and 86% were married. Forty-seven percent of the caregivers worked outside the home full-time, and 22% worked outside the home part-time. The ventilator-assisted children included an almost even number of males (n=16) and females (n=14), with an average age of 7.0 years (SD=3.1). Sixty-nine percent of the families had additional children in the home (ages 1 to 21 years). There were no differences between male and female caregivers on any of the outcome variables.

Measures

All measures were completed in a single telephone interview, with the exception of the 24-Hour Sleep Patterns Interviews, which occurred over the two week period following the primary interview.

Ventilation Needs and Home Nursing Support—A series of questions related to the extent of the child’s ventilatory support and home nursing support were created in collaboration with the medical, nursing, and social work staff of the home-care program for families of ventilator-assisted children. These questions were: “How many years has your child required ventilator support?”; “How many years have you been caring for your child at home on ventilator support?”; “How many hours is your child on the ventilator (in a 24 hour day)?”; “How many hours at night is your child on the ventilator?”; “How many total hours of nursing

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care are you approved for (in a 24 hour day?" (responses provided for weekday, weekend, and night); "How many total hours of nursing care do you actually get?" (responses provided for weekday, weekend, and night); "During a typical week, how many times does the night nurse call out or no show?"; "How many times a week does the night nurse wake you for routine or emergency care of your child?"'; "During a typical week, how many times is your sleep interrupted due to extraneous noise from the nurse in your home?"; "How stressful are these wakings for you?" (1=not at all stressful to 5=very stressful); "How adequate do you feel your nursing coverage has been over the past month? (1=not at all adequate to 5=completely adequate); "In general, how comfortable have you felt with the skills of the nurses in your home over the past month?" (1=not at all comfortable to 5=completely comfortable); "How many emergency room visits, unscheduled hospital admissions, or unscheduled emergent care visits have you had in the past six months?".

24-Hour Sleep Patterns Inventory (24-Hour SPI)—The 24-Hour SPI is a series of 4 brief telephone interviews that occur in a 2-week period (Meltzer, Mindell, & Levandoski, 2007). Subjects are asked 12 questions about their sleep patterns over the past 24-hours, including bedtime, sleep onset latency, night wakings (frequency and duration), morning wake time, and overall sleep quality. Two weekday interviews and two weekend interviews are completed for each participant. These interviews last less than 5 minutes each. A pilot study has found this measure to be valid and feasible for adults, with significant correlations found for sleep patterns variables (bedtime, wake time, sleep onset latency, and total sleep time) between the 24-Hour SPI and a sleep diary (r = .61–.89, all $p \leq .001$), as well as the 24-Hour SPI and actigraphy (r = .60–.96, all $p \leq .004$), an activity monitor that provides an objective measure of sleep patterns. In addition, the 24-Hour SPI reliably distinguishes between weekday and weekend sleep.

Center for Epidemiological Studies – Depression Scale (CES-D)—The CES-D is a 20-item measure that asks participants to rate items on a 4-point Likert scale with responses ranging from 1 (never) to 4 (most of the time) (Radloff, 1977). CES-D responses are summed, with higher scores indicating more depressive symptoms. The CES-D has consistently shown adequate internal reliability (coefficient alpha > 0.86) in studies of caregivers (Carter & Chang, 2000; McCurry & Teri, 1995; Schulz, O'Brien, Bookwala, & Fleissner, 1995). A score of ≥ 16 has been identified as a clinical cutoff for those at risk for depression (Radloff), and is commonly used in community based samples.

Iowa Fatigue Scale (Iowa)—This 11-item measure was developed as a screener for daytime fatigue and functioning over the past month in primary care patients (Hartz, Bentler, & Watson, 2003). The Iowa assesses fatigue in multiple domains, including cognitive, energy, and productivity, providing a total score, with a higher score indicating greater fatigue. This measure has good internal consistency (coefficient alpha = 0.90), and is correlated with other measures of daytime fatigue ($r > 0.90$). A score of ≥ 30 distinguished between over 800 patients with illnesses that would likely cause fatigue (e.g., cancer, lupus, heart disease) and primary care patients without these conditions (Hartz et al.).

Stanford Sleepiness Scale (SSS)—This scale assesses subjective perceptions of daytime sleepiness (Hoddes, Zarcone, Smythe, Phillips, & Dement, 1973). It consists of a seven-point Guttman scaled item ranging from 1 (feeling active and vital, alert, wide awake) to 7 (lost struggle to remain awake). Respondents are asked to choose the one option that best describes how sleepy they felt on most days for the past week. This widely used measure is considered one of the best validated measures of daytime sleepiness (Roehrs, Carskadon, Dement, & Roth, 2005).

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Procedure

Recruitment—Families received a letter from the home-care program inviting primary caregivers to participate in a study examining sleep and daytime functioning in caregivers of ventilator-assisted children. This was followed by a telephone call to provide additional information about the study. Primary caregivers interested in participating were then screened for eligibility, verbal consent was obtained, and a time for the primary telephone interview was scheduled.

Data Collection—With the exception of the 24-Hour Sleep Patterns Interviews, the questionnaires included in this report (Ventilation Needs and Home Nursing Support questions, the CES-D, Iowa, and SSS) were completed during the primary telephone interview, and together took approximately 30 minutes to administer. The primary interview was conducted by the first author, a licensed clinical psychologist.

During the two weeks after the primary telephone interview, participants also completed the series of four 24-Hour Sleep Patterns Interviews (24-Hour SPI). Each of the 24-Hour SPI interviews took less than 5 minutes to administer. These interviews were conducted by two undergraduate research assistants who were trained and supervised by the first author.

Data Analyses—Descriptive statistics (means, frequency, percent) were used to describe the child's ventilation needs and the families' nursing coverage. A Pearson correlation analysis was used to examine the relationship between nursing coverage and demographic variables. The difference in sleep patterns for those with and without regular nursing coverage was examined using t-tests and one-way ANOVA. The CES-D, Iowa, and SSS were converted to two group categorical variables (above and below the clinical cutoff for the CES-D and Iowa, and median split for the SSS), and t-tests were used to compare the total nursing hours and the number of night nursing hours for each of these groupings.

Results

Home Nursing

Table 1 provides descriptive information about the child's mechanical ventilation needs and nursing coverage. As families with two parents were reporting on the same number of nursing hours, the results in this section are reported for family units (n=30). Ninety-three percent (n=28) of the children required invasive ventilation. Children's diagnoses fell into three groups: neuromuscular/nervous system (n=11), chronic lung disease (n=8), and congenital anomaly (n=11). No significant differences between diagnosis groups were found for any demographic, medical, sleep or daytime functioning variables.

Families reported that they were approved for an average of 96 nursing hours per week, with an average of 43 home nursing hours approved for night. However, families reported receiving only 76 hours of nursing on average, including 35 hours of night nursing. Eight families (27%) received no night nursing. On average, families received 79% of their approved nursing hours (total hours received / total hours approved).

Sixty-three percent of families felt their nursing coverage was "mostly" or "completely" adequate over the previous month, with only 7% reporting their coverage was "not at all adequate." Although 84% of families reported feeling "mostly" or "completely" comfortable with the skills of their home nurses over the previous month, 17% of families also stated that this question was difficult to answer, as they often felt "completely" comfortable with their day nurse, but less so with their night nurse. Of the 22 families who received night nursing, 23% reported that their night nurse cancelled or failed to show at least once a week. Eighteen

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percent of families reported that their night nurse woke them at least once a week to assist with medical care of the child. In addition, 50% of families reported that they were awakened at least once a week due to noise made by the night nurse that was not related to the child's medical care.

No significant relationships were found between either total nursing hours or night nursing hours received and the child's age (r = .02 and r = 0.22); number of years the child required mechanical ventilation (r = .05 and r = −.01); the number of years the family has been caring for the child with mechanical ventilation at home (r = .06 and r = .01); or the number of hours per day the child required mechanical ventilation (r = −.14 and r = −.04). However, children who received more total nursing hours had fewer urgent care visits in the previous 6 months (r = −.41, p = .02).

Nursing Coverage and Sleep Patterns

For total nursing coverage, caregivers were divided into two groups, those who received 80 hours or less of total nursing coverage per week (n=20), and caregivers who received more than 80 hours per week (n=16). Eighty hours represents 16 hours of nursing per day, five days per week. Three groups were used to examine night nursing, taking into consideration that 25% of the caregivers received no night nursing coverage [3 groups: no coverage (n=9), 16–48 hours/week (n=13), >48 hours/week (n=14)]. More than 48 hours per week suggests approximately 8 hours per night, 6 nights per week. There were no significant demographic or medical differences between either the two groups of total nursing coverage or the three groups of night nursing coverage.

As seen in Table 2, no significant differences were found on any of the sleep patterns variables for caregivers with and without regular daytime nursing coverage. However, significant differences were found for caregivers with and without regular night nursing coverage for sleep onset latency, accounting for 22% of the variance. Post-hoc analyses (Tukey's HSD) found that caregivers who received no night nursing had a sleep onset delay of greater than 20 minutes compared to caregivers who received 16– 48 hours/week. Although not statistically significant, it was clinically notable that caregivers who received more than 48 hours of night nursing per week slept on average almost one hour more than the other two groups. Thus a post-hoc comparison of caregivers receiving ≤ 48 hours night nursing and caregivers receiving >48 hours of night nursing was done, with a significant difference found (5.98 vs. 6.86 hours respectively, $F(1,34)=4.40$, $p=.04$, Cohen's d = .72).

Nursing Coverage and Daytime Functioning

No significant difference in total nursing hours was found between caregivers who fell above and below the clinical cutoff for depressive symptoms (CES-D ≥ 16, Table 3). However, a significant difference was found for the number of night nursing hours, with caregivers above the CES-D cutoff receiving approximately 16 fewer hours of night nursing coverage per week.

No significant differences in either total nursing coverage or night nursing coverage were found for caregivers above and below the cutoff for fatigue on the Iowa (≥30), as seen in Table 3. However, caregivers above the cutoff received 13 fewer hours of night nursing coverage. Finally, a median split on the SSS was used to divide the sample into caregivers who selected "feeling active, vital, alert or wide awake" or "functioning at high levels, but not at peak; able to concentrate" from caregivers with greater daytime sleepiness. T-tests found no differences in the number of total nursing coverage hours for these two groups but caregivers with greater sleepiness had significantly fewer night nursing hours (18 hours).

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Discussion

This exploratory study provides descriptive information about the home nursing coverage for a small group of families with ventilator-assisted children, and the relationship between nursing coverage and caregiver sleep and daytime functioning. Although all families reported receiving at least some home nursing coverage, there was a large range in the number of hours each family received. Almost 40% of the caregivers in this study reported that they felt they had not received adequate nursing coverage in the previous month. Notably, an inverse relationship was found between the total number of nursing hours and the number of urgent care visits for children. Although almost all caregivers reported a high level of comfort with the skills of their home nurses, there were reservations about the skills of some nurses covering the night shifts. In addition, one-fourth of caregivers reported that night nurses regularly cancelled or failed to show in the previous week, with half of the caregivers reporting that they were regularly awakened during the night by noises from the night nurse not related to the child’s care. When examined together, these results reveal the paradoxical nature of home care support; families desire and require more home nursing coverage, which may reduce urgent care visits as well as facilitate parent sleep, yet many caregivers have reservations about nurses skills, and at times experienced additional sleep disruptions due to having nursing support in the home. Future qualitative research studies should explore reasons why caregivers may have felt uncomfortable with the skills of the nurses in their home.

Although insurance and lack of available nurses are the primary culprits for why families are not receiving sufficient home nursing support (Goodin, 2003), it also is possible that families selectively choose not to utilize this service at night. The extent of home nursing coverage in the United States is variable, and depends in part on how the care is being funded (e.g., private insurance, Medicaid). Thus the type of health insurance and/or the insurance company may limit the number of hours available for families (e.g., 12–16 hours per day, 5 days per week). For some families, night nursing may not be available due to the overall nursing shortage, suggesting a service delivery issue that needs to be addressed with additional training and support for home nurses. For other families, when nursing coverage is limited, families may choose to utilize daytime nursing shifts over nighttime shifts out of necessity, allowing the parents to work (a financial need) and the child to attend school (a practical need). Thus, parents by default become nighttime caregivers, resulting in regular sleep disruptions that may consequently have a negative impact on daytime functioning. Further research is needed to clearly identify the reasons why families are not receiving the number of prescribed nursing hours.

As expected, less night nursing support was associated with shorter sleep and more negative mood in caregivers, although the same was not true for daytime nursing coverage. Caregivers with regular night nursing (>48 hours/week) had a similar total sleep time (approximately 7 hours) to caregivers of children with cystic fibrosis or caregivers of healthy children (Author citation), whereas caregivers with limited or no night nursing coverage were not only sleeping about one hour less than caregivers with night nursing, they were averaging six or less hours of sleep per night, the critical limit for daytime performance (Dinges et al., 2005). After 18 hours of cumulative wakefulness, significant performance declines and impairment of executive functioning abilities (e.g., decision making, flexible thinking) have been found (Van Dongen et al., 2003). For caregivers who have been up all day, the ability to make timely and accurate decisions about their child’s health care during the night may be diminished by a lack of sleep; whereas regular sleep disruptions and chronic sleep loss could also result in declines in daytime functioning, including mood, work performance, energy, and general stress.

There are a number of limitations that must be noted. First, all measures were subjective in nature and completed by a single reporter. Future studies should include an objective measure

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of sleep such as actigraphy, a wrist-watch sized device that measures activity patterns and distinguishes sleep and wake patterns for up to 60 days. In addition, the inclusion of nursing logs would provide additional information about nursing coverage. Second, the richness of the data may be limited by the cross-sectional design (collection of data at only one time). The use of multiple evaluations over time, or ongoing assessment of nursing coverage, parent sleep, and daytime functioning would help determine the contribution of nursing coverage to sleep and daytime functioning in parents. Third, although some of the results were clinically meaningful (e.g., difference in total sleep time), the relatively small sample size resulted in insufficient power to detect differences for some of the variables. Further, along with this small sample, caregivers were drawn from a convenience sample of families receiving home support. Thus the generalizability of these results remains to be determined. Fourth, more information should be obtained regarding nursing education (e.g., LPN, RN) as well as specialized training in caring for children who require ventilator-assistance as these factors may play a role in parents' comfort with the nurses in their home. Finally, all family members are affected when there is a ventilator-assisted child being cared for in the home. This study did include a small number of fathers, but future studies should include both parents (when present), as well as siblings when assessing the relationship between nursing coverage, sleep and daytime functioning in families of ventilator-assisted children.

Conclusions/Future Considerations

This descriptive study is one of the first to examine the relationship between nursing coverage and both sleep and daytime functioning in parents of ventilator-assisted children. These data provide preliminary support for the hypothesis that increased home nursing support, in particular night nursing support, may improve the sleep and daytime functioning of caregivers. These preliminary data suggest that without adequate support, parents may experience chronic sleep loss that can then contribute to increased symptoms of depression, fatigue, and daytime sleepiness.

More research is needed in the area of caregiver burden and home nursing support. Future studies should consider reasons why families were not receiving nursing care, how caregiver employment and support outside the home (e.g., family, friends) may alleviate caregiver burden, and how families who are not part of a home care program may differ from the current sample. Interventions are also needed that provide support to parental caregivers, as well as the nurses who provide valuable caregiving assistance to families. With the increasing number of ventilator-assisted children cared for in the home, it is important to explore ways to improve the health and well-being of caregivers.

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Table 1

Descriptive Data for Children’s Mechanical Ventilation Requirements and Nursing Support

Variable	Mean	Median	SD	Range
Years child required ventilator (vent.)	5.5	6.0	2.9	1 – 11
Years caring for child at home on vent.	5.3	5.5	2.8	1 – 10
Total hours per day child on vent.	13.5	11.0	7.7	4 – 24
Total hours per night child on vent.	7.7	9.0	4.8	7 – 16
Nursing hours (total) approved per week	95.6	104.0	26.2	32 – 133
Nursing hours (total) received per week	76.0	75.5	28.2	0 – 124
Nursing hours (night) approved per week	42.7	56.0	23.2	0 – 70
Nursing hours (night) received per week	35.3	44.0	24.3	0 – 70

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Table 2

Differences in Sleep Patterns for Caregivers With and Without Regular Nursing Coverage

Daytime Nursing Received	**<80 Hours/Week (n=20)**		**> 80 Hours/Week (n=16)**			
	M	**SD**	**M**	**SD**	***t*(1,34)**	**ES**[a]
Bedtime	22:39	68	23:16	79	−1.61	.51
Wake Time	06:29	37	06:07	43	1.62	.55
Sleep Onset Latency (min)	21.85	18.00	24.98	17.13	−.53	.18
Total Sleep Time (hrs)	6.64	1.23	5.92	1.29	1.71	.57

Nighttime Nursing Received	None (n=9)		16–48 Hours/Week (n=13)		>48 Hours/Week (n=14)			
	M	SD	M	SD	M	SD	*F*(2,33)	ES[b]
Bedtime	23:15	58	23:05	73	22:35	73	1.05	.06
Wake Time	06:31	44	06:02	41	06:27	35	1.77	.10
Sleep Onset Latency (min)	36.34[c]	18.28	15.85[c]	10.47	21.68	18.32	4.52*	.22
Total Sleep Time (hrs)	5.94	1.26	6.01	1.59	6.86	.81	2.14	.12

<u>Note</u>. Bedtime and Wake Time reported on 24-hour clock, with SD in minutes.

* $p<0.05$

[a] Effect size based on Cohen’s d

[b] Effect size based on partial-eta squared

[c] Significantly different by post-hoc analysis

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Table 3

Differences in Hours of Nursing Received for Caregivers With and Without Negative Daytime Functioning

	Total Nursing Hours				Nighttime Nursing Hours			
Variable	**M**	**SD**	***F*(1,34)**	**ES[a]**	**M**	**SD**	***F*(1,34)**	**ES[a]**
Depression (CES-D)			.00	.00			4.13*	.67
Below cutoff (n=21)	75.05	30.43			42.48	21.03		
Above cutoff (n=15)	74.93	23.99			26.80	25.16		
Fatigue (Iowa)			.06	.08			2.63	.56
Below cutoff (n=10)	76.46	27.93			44.31	22.06		
Above cutoff (n=19)	74.17	27.93			31.22	23.93		
Sleepiness			.002	.02			6.50*	.85
Not sleepy (n=19)	75.21	30.53			44.84	16.90		
Sleepy (n=17)	74.76	24.74			26.00	26.85		

Note. Clinical cutoff for depression ≥16 and fatigue ≥30.

[a] Effect size based on Cohen's d

* $p \leq 0.05$