Title: The relationship between sleep quality, fatigue and psychological wellbeing amongst primary carers for those with brain injury

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ABSTRACT

Objectives: The study aimed to investigate possible mediating factors that contribute to poor sleep quality in carers for those with brain injury (BI). More specifically, whether fatigue, anxiety, depression and perceived burden were associated with and/or predicted poor sleep in carers of those with brain injury.

Methods: A cross-sectional correlational design was utilised. The Pittsburgh Sleep Quality Index (PSQI), Hospital Anxiety Depression Scale (HADS) Fatigue Severity Scale (FSS), Zarit Buren Interview Short (ZBI-12) were completed by 237 carers of people with BI to assess sleep quality, psychological wellbeing and fatigue.

Results: Carers demonstrated elevated levels of poor sleep quality, fatigue and poor psychological wellbeing. The results indicated there was a significant relationship between anxiety, depression, perceived burden, fatigue severity and sleep quality. Multiple regression analysis revealed that anxiety, depression, fatigue and burden explained 31.8% of variance in sleep quality. Depression and fatigue were significant predictors of sleep quality with fatigue symptomology being the strongest predictor of poor sleep amongst carers.

Conclusion: Psychological wellbeing, perceived burden and fatigue are associated with sleep disturbances in carers with fatigue and depression predicting poor sleep quality. These results provide insight into an under-researched area and emphasise the necessity for support provisions which aim to improve sleep hygiene practices, improve psychological wellbeing and fatigue symptomology.

CONFLICTS OF INTEREST

The authors report no conflicts of interest.

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INTRODUCTION

Depending on injury severity, many people with brain injury (BI) require long term care and support, which in many cases is provided by family members such as spouses or partners (1). Carers may often have to make significant adjustments to their own lives to meet the needs of their caring role (2) and they often may face difficulties and stress when managing the care-recipients behavioural, cognitive or emotional impairments (3–5).

Heightened levels of perceived burden, poorer family functioning and emotional distress have been found to be adverse negative outcomes for carers for those with BI (3). Significant levels of emotional distress such as anxiety, depression as well as reduced family functioning and reported somatic symptoms, such as tiredness has been found in caregivers for those with BI (6,7).

Studies examining the emotional functioning of carers have found that clinically significant levels of anxiety and depression remain unchanged at both 2 and 5 years post injury (7–9). Such findings indicate that adverse psychological outcomes may remain debilitating and persistent (2,9). Depending on injury severity, the person with BI may require extensive support which can result in carers being at risk for experiencing significant distress and burden(1).

Carers for those with traumatic brain injuries (TBI) have also been found to experience significant burden as a result of their caring role (10). One study highlighted that 56% of carers experience mild to moderate burden (10). One year post severe TBI, 34% of caregivers have been found to report moderate burden (11). Burden can encompass the social, emotional and psychological difficulties associated with providing long-term care (10,12,13). Long term

experiences of burden can have a range of negative outcomes including reduced quality of life, social isolation and poor mental health (7,8,13,14).

Research also indicates that caregivers may experience disrupted sleep quality as a result of their caring role (15,16). If a care-recipient needs assistance or monitoring during the night, the primary carer may sleep in interrupted sessions, varying in duration and quality. Evidence from other caring populations suggests that carers may develop inhibited relaxation during periods of sleep which may be due to increased stress and worry about the care-recipient (17). Even when asleep, carers may be physiologically alert and ready to respond to the recipient's needs (17).

Coupled with caring throughout the day, carers may be at risk for substantially disrupted sleep quality and daytime impairments. Alongside the management of other responsibilities, the degree of physical and emotional care required may directly impact sleep quality (18). Evidence from other caring populations has highlighted that caregiving sleep quality is related to poor physical and psychological outcomes and increased risk for depression (15,16).

Self-reported poor sleep amongst carers of oncology patients has also been associated with reported somatic symptoms such as pain and increased anxiety with sleep fragmentation being a common complaint (19). 95% of oncology carers were found to have poor sleep quality with depression being associated with poor sleep quality, sleep efficiency and daytime impairments (20). Progressive and continuous sleep deprivation amongst carers has also been found to impact perceived ability to care and emotional wellbeing (21). In carers for those with Parkinson's disease, perceived burden and engagement in caring has been related to poor sleep quality and sleep disturbances (22). Role strain has also been found associated with sleep quality in informal caregivers (23).

The majority of research has focused on carer sleep quality in other caring populations (5,19–21,23,24); reports from a recent qualitative study highlighted that caregivers of individuals with traumatic injuries frequently discussed experiencing poor sleep in relation to reduced health-related quality of life (25). This is also supported by research which found that carers report debilitating somatic symptoms such as tiredness, low energy with over half of respondents reporting fatigue related symptoms and difficulties sleeping (26). Earlier research has also reported that carers for those with BI often report somatic complaints such as disrupted sleep quality (4).

Carers may be at risk of experiencing physical fatigue due to the demands associated with their role (27). Somatic complaints such as headaches and tiredness have been reported in studies investigating the quality of life of carers for those with BI (26,28). One study highlighted that primary carers frequently report having low energy and exhaustion (26). Sleep disturbances and poor sleep quality has also been associated with severity of fatigue symptoms (27). Another study highlighted that carers demonstrated moderate levels of fatigue which were associated with subjective reported disturbances in sleep (29). Despite this evidence in other caring populations, a recent meta-analysis indicates that fatigue symptomatology is one of the most under-investigated factors in relation to the health and wellbeing of BI carers (30).

Scottish Intercollegiate Guideline Networks (SIGN, 2013) recommends that carers should have access to continued support after hospital discharge including information provisions, such as signposting to supportive organisations and charities (31). In addition, long-term rehabilitation and outcomes of the person with BI is often related to the caregiver's psychological wellbeing (32,33). An in-depth understanding of sleep quality in carers of people with BI is essential in providing the foundations for developing effective and tailored support provisions for this group. No study to date has investigated sleep quality in carers for those with BI and whether

poor psychological wellbeing and fatigue symptoms are associated with and predict sleep quality.

METHODS

The study was approved by the University of Glasgow School local ethics committee.

Participants

Participants were primary care-givers to someone with acquired or traumatic BI (n=237). The primary carer was defined as the principal person taking responsibility for the care of the individual. Brain injuries were defined as conditions affecting the brain that arise after birth, such as trauma, strokes, anoxia and infectious (34). Inclusion criteria for the study was that participants had to be: a) over 18 years, b) proficient English speakers and c) defined themselves as the principle person responsible for care. Exclusion criteria included suffering from untreated conditions that disturb sleep (such as sleep apnoea).

Measures

Demographics

Caregiver demographics including age, gender, relationship with care-recipient, details of caring role (daily hours spent caring and other caring duties) were recorded; for the care-recipient, type of brain injury sustained was reported.

Sleep

The Pittsburgh Sleep Quality Index (PSQI) was used to measure sleep quality (35). The PSQI is a 19 item self-report measure that provides a global score for sleep quality and assesses

subjective sleep quality, duration, latency, habitual sleep efficiency, sleeping medication use and daytime dysfunctions. Higher scores indicate poorer sleep quality with a score >5 indicating poor sleep. The PSQI has good reliability, with Cronbach's α of .83 and a test-retest correlation of .85 [2] and has been used in other caring populations (18,21).

Mood

The Hospital Anxiety and Depression Scale (HADS) was used to measure anxiety and depression (36). HADS is a 14-item self-report scale with subscales for anxiety (HADS-A) and depression (HADS-D). Higher scores indicate increased levels of anxiety or depression with a score of 8 or above indicates 'caseness' (36). The scale has reported reliability scores ranging from 0.83 for anxiety and 0.82 for depression (37) and has been used previously in research assessing the psychological wellbeing of carers (38).

Fatigue

The Fatigue Severity Scale (FSS) is a 9-item general fatigue scale used to assess fatigue intensity, the behavioural consequences of fatigue and the impact it has on daily functioning (39,40). Scores of over 4 indicate high levels of fatigue. The FSS is sensitive to clinical changes and has good internal consistency (Cronbach's alpha 0.88)

Burden

The Zarit Caregiver Burden Interview Short (ZBI-12) was used to measure personal strain. Higher scores indicate higher perceived burden with a score of >17 suggesting significant caregiver burden (41). Correlations between the short and the full version ranged from 0.92 to 0.97 with a reported internal consistency of $\alpha = 0.85$ (42).

Procedure

Carers of people with BI were recruited through voluntary organisations and online support groups. These organisations support families and those affected by BI, raise awareness for BI and promote research. Following consent, eligible participants completed a survey containing a series of questionnaires assessing sleep quality, wellbeing and fatigue. Participants were invited to take part in the study if they defined themselves as the principle person responsible for caring for someone with BI.

RESULTS

All analyses were carried out using R Statistics (Version 3.4.2) for windows 10. The sample consisted of 237 primary carers. Carer demographics are presented in Table 1. Demographic information (type of brain injury) on care-recipients are presented in Table 2.

[Insert Table 1]

Of the care-recipients, 156 were reported to have had ABI, (65.82%) and 81 TBI (34.17%). Data available on specific types of ABI revealed that 65 (28.57%) had a stroke, 81 care recipients had an infection (36.16%), 13 (5.8%) brain haemorrhage and 6 (2.67%) had anoxic or hypoxic brain injury. Characteristics of the care-recipient are displayed in Table 2.

[Insert Table 2]

In relation to sleep, 94.09% of carers were classed as poor sleepers based on the PSQI cut off of? (35). Using a more conservative PSQI score cut-from greater than >8, 75.10% of carers were classed as having poor sleep quality. This cut off score has been utilised in past carer research to discriminate poor versus good sleepers stringently in oncology outpatient family caregivers (43).

Scores between 8 and 21 on the HADS are indicative of mild to severe anxiety or depression(36). Of those who took part, 79.74% of carers reported levels of anxiety and 59.49% of primary care-givers reported depression scores indicating “caseness” (>8). Using a more strict cut off criteria, 59.49% of carers were classified as having moderate anxiety (> 11) and 24.89% were classified as having moderate depression scores (>11). Stringent scoring criteria (> 11) was utilised according to the HADS scoring manual (36,37). In relation to burden, 84.3% of carers had significant levels of burden with a score of greater than 17. Experiences of fatigue were common, with 74.26% of carers having symptoms indicative of sever fatigue (>4). Table 3 shows the self-reported clinical characteristics of the sample.

[Insert Table 3]

Assumptions of normality were met and Pearson’s product correlation was utilised. The relationship between anxiety and sleep quality was positively significant ($r=.403$, $p < .001$), along with depression ($r=.484$, $p < .001$) and perceived burden ($r=.335$, $p < .001$). Fatigue severity was also significantly associated with sleep quality ($r=.468$, $p < .001$). These results suggest that primary caregivers who report higher levels of burden, poor mental health and heightened fatigue symptoms may experience poorer sleep quality (Table 4).

[Insert Table 4]

Multiple regression analysis (Table 5) was conducted to examine and account for the variance in sleep quality. This resulted in a significant model: $F(4,237) = 11.67$, $p < 0.001$, $R^2 = 31.8$. The model explains 31.8% of variances in sleep quality. Of the variables entered, fatigue severity and depression were significant predictors of sleep quality in primary carers. The strongest predictor of poor sleep quality was fatigue severity $\beta_2 = .760$. This positive

relationship suggests that poor sleep quality is associated with an increase in fatigue severity and depression.

[Insert Table 5]

DISCUSSION

The aim of this study was to explore potential mediating factors in poor sleep quality amongst those caring for people post brain injury. Our findings indicate that carers demonstrated elevated levels of perceived burden, anxiety, depression, fatigue symptoms and poor sleep quality compared to normative populations (44–46). Previous studies have also reported that carers experience burden and their psychological wellbeing is negatively affected by their caring role (1,8,47,48).

Anxiety and depression was significantly associated with poor sleep quality amongst carers. Risk of clinical depression and anxiety has been associated with poor sleep in other carer populations including elderly carers (49) Parkinson disease primary carers (22), Dementia carers (15,50,51) and spousal carers for those with Alzheimer's disease (52). Our results are consistent with one study which found that anxiety and depression were related to poor sleep quality in carers for war veterans with stroke (53). These results are similar with research on sleep and depression in Alzheimer's carers (52)

However, limited research is available which considers the connection between psychological wellbeing and sleep quality in BI carers, with most research papers focusing on other care-giving groups (20,27,29,54).

Perceived burden was significantly associated with poor sleep in the current group. The direct relationship between poor sleep and perceived role strain has not been investigated before in BI carers. These findings relate to research indicating carers express concerns regarding how the demands of their caring role may have direct consequences in terms of their sleep. Phillips

and colleagues found a similar relationship between burden and sleep quality amongst informal caregivers in which those with higher care burden scores had poorer overall sleep quality (23). Role burden was not found to be a significant predictor of poor sleep quality in carers. These findings contrast research on dementia carer sleep quality in which role burden was related to poorer sleep quality (57).

Fatigue severity was also found to be significantly associated with poor sleep. Our findings support research indicating that carers report greater levels of somatic complaints(55). One study which looked at health related quality of life amongst family carers of veterans with traumatic brain injury (TBI) also found that carers reported poor sleep and fatigue symptoms (26). In addition, previous work has also found a relationship between fatigue symptoms and sleep quality in palliative care (56). We found that fatigue severity was a significant predictor of poor sleep quality in carers. Instances of fatigue predicting sleep problems have previously been reported (58). However, the predictive relationship between fatigue symptoms and sleep disturbances is complex. Some studies suggest an opposite relationship in which sleep deficits predict fatigue symptoms (59). The complex relationship between sleep and fatigue stems from the notion that if you are fatigued you may not sleep well and if you do not sleep well you may be fatigued (60). Therefore, classifying fatigue and sleep disturbances in a linear framework may not be appropriate when investigating potential predictors of sleep quality. Despite this, it is important to continue to investigate the association and predictive role fatigue symptoms may have on sleep quality (61).

Limitations

Severity of BI and specific neurological impairments of the care recipient was not recorded during data collection. However, some studies have failed to find a relationship between severity measures such as posttraumatic amnesia and length of coma with carer psychological

wellbeing (3,4,62). Specific functional impairments of the care recipient were also not controlled for when assessing carer sleep quality, fatigue or psychological wellbeing. Care-recipient's functional status and levels of executive function impairments have been associated with fatigue symptomology and carer burden one year post BI (10,56). Time since BI was also not controlled for when assessing fatigue and psychological wellbeing in primary carers. However, longitudinal studies suggest levels of carer psychological distress may remain persistent post injury (4,6,8)

The amount of support carers received such as respite care was unknown. A recent meta-analysis highlighted that social support can mediate carer burden (63). To address these potential limitation, the study was disseminated widely in order to gain a wide and diverse caring experiences.

Future research directions

Examining the day time impacts of poor sleep quality and the utilisation of objective sleep measures, such as actigraphy monitors is a potential avenue for future research. Studies utilising actigraphy assessment measures have found that carers have excessive day time sleepiness and sleep fragmentation (64). Objective measures such as actigraphy have also demonstrated that carers have poor sleep duration (29,65), increased sleep onset latency(27) and utilise coping strategies such as napping (65). At present, no studies have utilised objective measures to examine sleep experiences of carers for those with BI.

Future research should also focus on assessing the feasibility and efficacy of support provisions and sleep interventions such as cognitive behavioural therapy for insomnia (CBT-I) for the management of sleep complaints. Studies in other caring populations have found that such interventions produce improvements in sleep quality and mental wellbeing (15, 54).

Given the interrelationships between poor sleep quality, carer burden and heightened fatigue symptomology it is critical that clinicians perform a systematic assessment of a primary carers sleep quality and support is designed to address the complex relationship fatigue alongside poor psychological wellbeing play in influencing sleep. Research indicates psychological distress impacts not only the primary carer but also the person they are providing caring for(67). Providing supportive services to carers that address sleep and psychological wellbeing may in turn, have potentially beneficial influences on the rehabilitation and wellbeing of those with BI.

Conclusion

This study provides evidence that fatigue and poor psychological wellbeing- primarily anxiety and depression are related to disrupted sleep in carers of those with a brain injury. In addition, depression and fatigue severity were found to predict poor sleep. Overall, carers experience disrupted sleep quality which is possibly related to carers having elevated rates of poor mental health and fatigue symptomology. A deeper understanding of how fatigue symptomology and wellbeing predict and are related to sleep quality may allow for clinicians to formulate tailored systematic assessments of carer needs and provide recommendations. Of critical importance, is assessing the feasibility and acceptability of sleep interventions within this caring population.

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Table 1. Carer Demographics

Carer	M and SD or Frequency
Age (Years)	47.08 (10.72)
Gender	
Male	20 (11.23%)
Female	158 (88.76%)
Employment	
Full time carer	67 (28.27%)
Employed (Full-Time)	58 (24.27)
Employed (Part-Time)	58 (24.7%)
Unemployed	10 (4.21%)
Self-Employed	23 (9.70%)
Retired	16 (6.75%)
Student (Full-Time)	4 (1.68%)
Student (Part-Time)	2 (0.84%)
Prefer not to disclose	7 (2.53%)
Carer Role	
Daily Hours Caring	10.86 hours (6.26)
Additional Carer duties	Yes 139 (58.64%), No 95 (40.08%)
Relationship	
Spouse/ Partner	93 (29.24%)
Parent	111 (46.83%)
Friend	1 (0.42%)
Prefer not to disclose	5 (2.1%)
Other	27 (11.39%)

Table 2. Care-recipient demographics.

Care recipient	Frequency
Type of BI	
Traumatic BI	81 (34.17%)
Acquired	156 (65.82%)
Specific Type of ABI	
Stroke	65 (28.57%)
Infection	81 (36.16%)
Brain Haemorrhage	13 (5.80%)
Anoxic/ Hypoxic Injury	6 (2.67%)
Other	2 (0.89%)

Table 3. Means and standard deviations of measurement variables.

Dependent Variable	M (SD)
Sleep Quality (PSQI)	10.70 (3.36)
Independent Variables	
Anxiety (HADS-A)	12.42 (4.39)
Depression (HADS-D)	9.30 (3.75)
Fatigue Severity (FSS)	4.94 (1.33)
Burden (B-ZBI Short)	26.27 (9.16)

Table 4. Correlation between variables.

Variable	PSQI	FSS	HADS-A	HADS-D	Z-BI (short)
PSQI	-	.468	.403	.484	.335
FSS	.468	-	.408	.449	.426
HADS-A	.403	.408	-	.646	.495
HADS-D	.484	.449	.646	-	.565
Z-BI (Short)	.335	.426	.495	.595	-

Table 5. Multiple regression analysis.

Variable	B	Std. Error B	β^2
Fatigue (FSS)	0.760212	0.159306	0.0003*
Anxiety (HADS-A)	0.072841	0.056	0.194538
Depression (HADS-D)	0.260302	0.069675	0.000235*
Burden (ZBI- Short)	-0.001386	0.025158	0.956118