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Caregiver strain following critical care discharge: An exploratory evaluation[☆,☆☆]

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ABSTRACT

Objective: The objective of this exploratory evaluation was to understand the impact of critical care survivorship on caregivers.
Design: Family members who attended a quality improvement initiative within our critical care unit were asked to complete 4 questionnaires.
Setting: The setting for this study was a 20-bedded mixed critical care unit in a large teaching hospital in Scotland. Data were collected as a part of an evaluation of a quality improvement initiative.
Participants: Thirty-six carers completed the questionnaire set.
Measurements and main results: A total of 53% of caregivers suffered significant strain. Poor quality of life in the patient was significantly associated with higher caregiver strain ($P = .006$). Anxiety was present in 69% of caregivers. Depression was present in 56% of caregivers, with a significant association between carer strain and depression ($P < .001$).
Those caregivers who were defined as being strained also had significantly higher Insomnia Severity Index scores than those without carers strain ($P = .007$).
Conclusion: This evaluation has demonstrated that there is a significant burden for caregivers of critical care survivors. Furthermore, they reported high levels of posttraumatic stress disorder, anxiety, depression, and insomnia. Future work on rehabilitation from critical care should focus on the inclusion of caregivers.

1. Introduction

Until relatively recently, the effects of surviving intensive care unit (ICU) were unclear. Seminal work by Herridge et al [1] and Cuthbertson et al [2] has shown that the detrimental effects are still apparent 5 years later. These persistent physical, psychological, cognitive, and social problems [3–7] are now commonly referred to as *Post Intensive Care Syndrome* (PICS). Although PICS can have a significant burden on the individual, there is now more evidence that their carer also suffer, and this has been termed *post intensive care–family* (PICS-F) [8].

Although a relatively new concept, PICS is garnering interest with initiatives such as THRIVE by the Society of Critical Care Medicine. PICS-F is at an even earlier stage in its development, and the longevity of the effects of ICU on caregivers is unclear. In a recent systematic review analyzing psychosocial outcomes in informal caregivers, Haines et al [9] demonstrated that the most commonly investigated and reported outcome across 14 studies was depression, with the incidence reported between 22.8% and 31.9%. Social problems for caregivers which have been described in the literature include social isolation, job loss, disputes over disability, and insurance claims [1]. Griffiths et al (2013) also reported that family members provided 80% of the care needed at 6 months postdischarge for critical care survivors [10].

Despite this, there is limited information of carer strain or posttraumatic stress disorder (PTSD) in caregivers available in the literature, with only 1 study appearing to report on PTSD [11]. Furthermore, there is minimal information of the prevalence of insomnia and anxiety in this group [9].

Evidence demonstrates that these psychological symptoms often co-occur, with fatigue, sleep disturbance, anxiety, and depression

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presenting as a "symptom cluster" [12–17]. Portenoy et al [18] demonstrated that this cluster is highly prevalent (40%-80%) in cancer patients, and work by Liu et al [19] found that the presence of pretreatment symptom clusters in breast cancer patients was associated with poorer sleep, increased fatigue, and lower mood during active treatment. This suggests that each symptom contributes to the maintenance and exacerbation of the others, resulting in further impairment to quality of life (QOL). However, although these interrelationships have been studied in both the general population and oncology groups, little is known about their epidemiology in those surviving critical illness and intensive care and their caregivers. The nature of these associations requires further study to maximize postdischarge QOL.

This evaluation sought to understand these holistic issues in caregivers of critical care survivors.

2. Materials and methods

Data collected were part of an evaluation of a quality improvement initiative. Following local research ethics committee review, it was decided that ethics approval was not required. Data were collected between September 2014 and July 2015.

The quality improvement initiative was a 5-week rehabilitation course for ICU patients and their caregivers. Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE) is a multidisciplinary, peer-supported rehabilitation service. It takes place in the adult critical care unit in Glasgow Royal Infirmary (GRI), a university teaching hospital within NHS Greater Glasgow and Clyde, Scotland. GRI is situated in an area of high socioeconomic deprivation, with 42% of the most deprived geographical areas in Scotland residing in this catchment area of the hospital [20]. In addition, GRI is a tertiary referral center for pancreatic care, burn care, esophageal surgery, and some orthopedic interventions.

Each week, patients take part in 1 hour of physiotherapy and exercise as a group. In addition, patients and their caregivers have individual sessions with a nurse and member of medical staff, a physiotherapist, and the critical care pharmacist. Two psychology sessions are also provided where the patients and carers are divided into 2 groups. One session focuses on sleep and on other common psychological reactions post critical care and development of coping skills. These sessions were led by trained clinical psychologists; however, patients and caregivers were encouraged to contribute to create discussions and shared experiences. Finally, the participants also receive a "social prescription week" where financial advice is offered as well as information on community resources which may be useful.

Participants of working age (16-64 years) are invited to take part in InS:PIRE between 4 and 20 weeks after hospital discharge. However, there are some participants who had been discharged for longer (up to 3 years) who requested to take part in the program. Patients are eligible for the InS:PIRE program if they received mechanical ventilation for greater than 72 hours. Patients were encouraged to attend with their loved ones and caregivers. However, approximately 25% of patients came to the program alone.

A *caregiver* was defined as the individual who provided the majority of the financial, emotional, and physical support for the patient or the individual primarily responsible for caring for the patient on an unpaid basis [21]. At the start of the program, the patient and 1 caregiver were asked to complete a booklet of questionnaires. The questionnaires were completed at home before the first InS:PIRE appointment. If the individual required assistance with completing the questionnaires, a staff member at InS:PIRE supported the completion of the booklet of questionnaires at a clinic appointment.

Four validated questionnaires were included in the family member booklet: the Impact of Events Scale-Revised (IES-R) [22], the Hospital Anxiety and Depression Scale (HADS) [23], the Carer Strain Index (CSI) [24], and the Insomnia Severity Index (ISI) [25].

The IES-R is a 22-point questionnaire which assesses the frequency of a reaction linked to a specific event in the prior 7 days. It assesses 2 key components of a posttraumatic stress reaction: intrusive thoughts and avoidant behavior. It also measure hyperarousal. Patients are asked to rate symptoms on a scale of 1 to 4. A score of 33 or more from a theoretical maximum of 88 signifies the likely presence of PTSD [22,26].

The HADS questionnaire contains 14 statements relating to mood, with 7 questions relating to depression and 7 to anxiety [23]. Table 1 shows the cutoff points commonly used to define anxiety and depression with the HADS questionnaire. Although not specifically designed for carers, the HADS scale has been used previously with caregivers in other populations [27].

This evaluation used the CSI which measures strain related to care provision from the caregivers' perspective [24]. There are elements related to emotional adjustment, social issues, and physical and financial strain. Each question is given 1 point. A score of 7 or greater is the generally accepted cutoff point for a high level of stress [24].

The ISI is a 7-question tool which has been validated as a screening tool for clinical insomnia [25]. Participants are asked to rank the severity of their sleep problems on a scale of 0 to 4 and answer 4 other questions regarding satisfaction with their sleeping patterns. The end result is a score of between 0 and 28. Guidelines for the interpretation of the ISI suggest that a score between 0 and 7 represents no clinically significant insomnia, 8 and 14 subclinical insomnia, 15 and 21 moderate clinical insomnia, and 22 and 28 severe clinical insomnia [25].

Patients' QOL was measured using the widely validated EQ 5D QOL tool (EuroQuality of Life Group). This tool comprises 2 sections: a 5-question descriptive component which explores various health domains and a visual analogue scale about the QOL on the day the questionnaire was completed. Each of the 5 questions has 3 possible answers, numbered 1 to 3. These answers equate to a 5-digit sequence which is then used to determine a health utility score. The derivation of these scores is country dependent; for our population, this derivation was based on responses from 2997 UK citizens who were selected from their postcode [28]. In the EQ 5D evaluations, a health utility score of 1 equates to the best health state possible, a score of 0 equates to death, and a negative utility score equates to a state worse than death. In the literature, the median EQ 5D score a year after ICU has been reported as 0.66, which is below population norms [2].

We chose to categorize the scores rather than use the individual numbers to make it clinically more relevant and meaningful. These categories have previously been validated [23].

2.1. Statistical analysis

The data were transferred to the statistical package RStudio (version 0.98.493) for statistical analysis [29].

Continuous variables were expressed as medians and interquartile ranges and analyzed using the Mann-Whitney *U* test. Categorical variables were compared using χ^2 tests. All tests were 2-sided, and a *P* value of less than .05 was considered significant. Nonintercept models (regression through the origin models) were used for each of the presented correlational analyses. Using nonintercept models ensured that the regression line in each of the models passed through the origin (ie, the point where both variables equaled zero). This approach was taken because all scoring tools involved started at zero.

Table 1
Interpretation of HADS [23]

Score interpretation	Interpretation
0-7	Normal
8-10	Mild
11-14	Moderate
15-21	Severe