



Psychosocial resiliency is associated with lower emotional distress among dyads of patients and their informal caregivers in the neuroscience intensive care unit ☆☆☆★



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ABSTRACT

Purpose: The purpose of the study is to examine the associations of patients' and their informal caregivers' psychosocial resiliency factors with their own and their partners' emotion domains (distress, anxiety, depression, and anger) after admission to the neuroscience intensive care unit (Neuro-ICU).

Materials and methods: Eighty-three dyads of patients (total n = 87) and their informal caregivers (total n = 99) participated in this observational, cross-sectional study by self-reporting demographics and measures of resiliency factors (mindfulness [Cognitive and Affective Mindfulness Scale Revised], coping [Measure of Coping Status-A], intimate bond [Intimate Bond Measure], self-efficacy [patients: General Self-Efficacy Scale; caregivers: Revised Caregiver Self-Efficacy Scale]) and emotion domains (Emotion Thermometers) within 2 weeks of Neuro-ICU admission.

Results: There were no differences between patients' and caregivers' levels of psychosocial resiliency, distress, or anxiety. Patients reported greater depression and anger relative to their caregivers. Overall, roughly half of patients (50.6%) and caregivers (42.4%) reported clinically significant emotional distress. Patients' and caregivers' own psychosocial resiliency factors were associated with their own, but not their partner's, emotion domains.

Conclusions: Findings of high distress among both patients and caregivers at admission emphasize the importance of attending to the mental health of both patients and caregivers in the Neuro-ICU. As modifiable psychosocial resiliency factors were associated with emotion domains for both patients and caregivers, interventions to enhance these factors may ameliorate emotional distress among these vulnerable populations.

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1. Introduction

Admission to the neuroscience intensive care unit (Neuro-ICU) is traumatic for patients and their family members and friends who provide assistance critical to their recovery (ie, informal caregivers). Estimates suggest between one quarter and one half of patients admitted to an intensive care unit (ICU) and their informal caregivers have clinically significant psychiatric symptoms such as anxiety and depression [1–4], with these symptoms tending to persist from hospital admission through months or years later [5,6]. After acute neurologic injury

(ANI), high emotional distress (eg, greater distress, anxiety, depression, or anger) is related to patients' poor medical adherence [7], slower functional recovery [5,7,8], and higher all-cause mortality [5,9]. Moreover, patients with high emotional distress require more caregiving assistance [2], which may negatively impact caregivers' mental health [8,10]. Caregivers' mental health is important because their own greater emotional distress increases both the risk for their own morbidity [11,12] and mortality [13] and interferes with their ability to provide high-quality care to the patients [4,14].

Resiliency or the ability to adapt effectively under significant adversity [15] provides a framework for understanding why some patients and caregivers experience significant emotional distress and others do not after similar medical traumas. Although resiliency is a multidisciplinary construct with environmental, genetic, epigenetic, and neural mechanisms that evolve through an individual's lifetime [15], research has identified several modifiable psychosocial factors that promote successful adaptation to stress. Resiliency factors associated with psychological well-being after trauma for both patients and caregivers

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include the following: mindfulness, the ability to stay present and defer judgment in the face of adversity [16]; coping, the arsenal and application of one's behavioral, cognitive, and emotional strategies to manage stress [17]; social support, empathetic interpersonal interactions that meet one's emotional and functional needs [18]; and self-efficacy, one's perceived resourcefulness to adapt under adversity [19]. Caregivers' perceived ability to manage caregiving responsibilities for their loved one or caregiving self-efficacy has been associated with their positive mental and physical health outcomes [20].

Prior literature has primarily assessed patient and caregiver factors after hospitalization, with most studies conducted several months after discharge. Moreover, few studies have examined patients and their caregivers together simultaneously (eg, dyads), which is important as literature from other medical illnesses clearly shows that both psychological resilience and distress after illness are significantly inter-related within dyads [21,22]. Hence, this study aims to fill this gap in the literature and provide a more comprehensive picture of patients' and their informal caregivers' psychosocial resiliency and emotion domains (distress, anxiety, depression, and anger) immediately after admission to the Neuro-ICU.

The purpose of this cross-sectional study is 3-fold. First, we characterize the psychosocial resiliency (ie, mindfulness, coping, intimate bond, and self-efficacy) and emotion domains (ie, distress, anxiety, depression, and anger) in dyads of patients recently (within 2 weeks) admitted to the Neuro-ICU and their primary informal caregivers. Second, we compare psychosocial resiliency and emotion domains between patients and their caregivers. Last, we examine the associations of patients' and caregivers' psychosocial resiliency factors with their own and their partners' emotion domains. We hypothesize that, early in the Neuro-ICU admission, greater patient and caregiver psychosocial resiliency will be associated with lower overall emotional distress among dyads.

2. Materials and methods

2.1. Design and setting

These cross-sectional, observational data come from an ongoing prospective natural history study of dyads of patients admitted to the Neuro-ICU within the past 1 to 2 weeks and their informal caregivers, at a major medical hospital in Boston, Massachusetts, from between June 2015 and February 2016. Detailed information on recruitment and procedures has been published elsewhere [23] and is briefly reviewed below. The study was approved by the hospital's institutional review board and was therefore performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All participants provided informed consent before any study-related procedures.

2.2. Participants

To enroll, patients had to be 18 years or older, fluent in English, admitted to the Neuro-ICU within the past 2 weeks, and medically cleared for participation by the medical team. Patients who, based on the clinical judgment of the medical team, were not able to participate, were excluded (eg, those anticipated to die within the ICU, on comfort measures only, with aphasia, or who lacked decision-making capacity as determined by the clinical team). Informal caregivers had to be 18 years or older, fluent in English, and identified as a patient's primary caregiver (ie, family member or close friend providing the majority of unpaid emotional or instrumental care for the patient). Only the patient's single primary informal caregiver was eligible to enroll. Although there was a 2-week enrollment window, most participants (85%) were recruited and completed questionnaires within 2 days of admission.

2.3. Procedures

A research assistant identified dyads of patients and their caregivers, determined eligibility with the patient's medical team, and then approached eligible and medically cleared patients and their caregiver to discuss the study. Enrollment, inclusionary criteria review, and questionnaire completion occurred at the bedside in the single-patient Neuro-ICU rooms. Both the patient and caregiver were approached together in the patient's room. In some cases ($n = 6$), the patient was never able to complete the questionnaire, so only the caregiver provided data. We collected demographic and psychological data directly from patients and caregivers using the HIPAA-compliant REDCap data system [24] and clinical data from patients' electronic medical records. Participants were educated as part of the informed consent process that their data were deidentified and were encouraged to complete questionnaires individually, to minimize reporting bias.

2.4. Measures

2.4.1. Psychosocial resiliency factors

The Cognitive and Affective Mindfulness Scale Revised (CAMS-R) [25] was used to assess the degree to which participants experience their thoughts and feelings in the present moment. The 12 items are scored using a 4-point Likert scale with responses ranging from 1 ("rarely/not at all") to 4 ("almost always"). The total mindfulness score is the sum of all items and ranges from 12 to 48, with higher scores reflecting greater mindfulness. This instrument was developed using 2 samples of healthy subjects where higher mindfulness scores were significantly correlated with lower distress scores, suggesting good validity [25].

The Measure of Coping Status-A (MOCS-A) [26] was used to assess participants' perceived coping ability using skills such as relaxation, awareness of stress, assertiveness, and disputing maladaptive thoughts. The 13 items are scored using a 5-point Likert scale with responses ranging from 0 ("I cannot do this at all") to 4 ("I can do this extremely well"). The total coping skill score is the sum of all items and ranges from 0 to 52, with higher scores indicating higher perceived ability to cope effectively with stress. This instrument has been validated among other medically ill populations [27].

The Intimate Bond Measure (IBM) [28] was used to assess participants' perceptions about the quality of their interactions with the caregiver or patient, respectively. The 24 items assessed the dimensions of perceived care and control by one's partner on a 4-point Likert scale with responses ranging from 0 ("not at all true") to 3 ("very true"). Perceived control by partner items are reverse scored and then summed with all care items, with the total intimate bond score ranging from 0 to 36. Higher scores indicate higher perceived care and lower partner controlling. This instrument has been validated among other populations of persons with medical conditions and their partners [29].

Only patients completed the General Self-Efficacy Scale (GSES) [30] to assess their perception of own resourcefulness to manage challenging situations. The 10 items are scored on a 4-point Likert scale with responses ranging from 1 ("not at all true") to 4 ("exactly true"). The total self-efficacy score is the sum of all items and ranges from 10 to 40, with higher scores indicating higher perceived resourcefulness. This instrument has been widely validated among healthy persons [31] and persons with medical illness [32].

Only caregivers completed the Revised Caregiver Self-Efficacy Scale (CSES-R) [33] to assess their perception of own ability to ask for functional support from family and friends, respond to patient's needs, and manage own upsetting thoughts about the caregiving process. The 15 items are scored on a 100-point scale with responses ranging from 0 ("cannot do at all") to 100 ("certain can do"). The total caregiving self-efficacy score is the average of all items and ranges 0 to 100, with higher scores indicating greater perceived ability to provide assistance effectively. This instrument has been validated among caregivers of frail elders [34].

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