



Clinical research article

## Shame feeling in the Intensive Care Unit patient's family members



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### ABSTRACT

**Objective:** To investigate the levels of internal and external shame among family members of critically ill patients.

**Research methodology/ design:** This prospective study was conducted in 2012/2013 on family members of Intensive Care Unit patients using the Others As Shamer Scale and the Experiential Shame Scale questionnaires.

**Setting:** Greek university hospital.

**Results:** Two hundred and twenty-three family members mean-aged ( $41.5 \pm 11.9$ ) were studied, corresponding to 147 ICU patients. Out of these 223, 81 (36.3%) were men and 142 (63.7%) were women, while 79 (35.4%) lived with the patient. Family members who lived with the patient experienced higher internal and external shame compared to those who did not live with the patient ( $p = 0.046$  and  $p = 0.028$  respectively). Elementary and Junior High School graduates scored significantly higher than the other grades graduates in total Others As Shamer Scale, inferiority and emptiness scale ( $p < 0.001$ ).

**Conclusion:** Intensive Care Unit patients' family members are prone to shame feelings, especially when being of low educational level. Health professionals have to take into consideration the possible implications for the patients and their care.

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### Implications for clinical practice

- The study provides a better insight into feelings of shame among caregivers-relatives of critically ill patients.
- Patient's relatives who lived with the patient and relatives with low educational level experienced higher internal and external shame.
- Health professionals during patient's care should take into consideration the shame feelings of patient's relatives.

### Introduction

Life-threatening diseases often demand hospitalization in the Intensive Care Unit (ICU). In many cases, this is devastating for the families and can lead to emotional stress, anxiety and fear (Bandari

et al., 2014). Research indicates that more than two thirds of family members, who visit the ICU, experience anxiety or depression during the early days of hospitalization (Chui and Chan, 2007; Hickman and Douglas, 2010; Pochard et al., 2005).

McAdam et al. (2010) investigated the symptoms of 74 family members of patients at high risk of mortality in the ICU to evaluate the risk factors associated with the highest burden of these symptoms. The results of their study showed high rates of burden, with more than half of the family members having moderate to severe levels of traumatic stress, 80% having borderline anxiety symptoms and 70% borderline depression. More than 80% of the family mem-

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bers had other physical and emotional symptoms as well, such as fatigue, sadness and fear.

The environment of the ICU is inhospitable and frightening for the patients and their family and there is a high risk of depression, anxiety and stress in family members of ICU patients (Davidson et al., 2012). In relatives of patients in critical condition, the cluster of negative psychological reactions such as anxiety, acute stress disorder, post-traumatic stress disorder, depression and complicated grief, is called post-intensive care syndrome-family (PICS-F). These complications can affect the ability of relatives to act as caregivers and may also hinder their daily activities (Davidson et al., 2012; Jezierska et al., 2014; Schmidt and Azoulay, 2012).

Shame and guilt may also moderate stress coping mechanisms. It has been hypothesized that individuals with Post-Traumatic Stress Disorder (PTSD) who report higher levels of shame would be more prone to engage in self-critical thinking and less prone to engage in self-reassuring thinking than individuals with PTSD who report lower levels of shame (Harman and Lee, 2010; Leskela et al., 2002). Shame is the deeply felt and highly motivating experience of the fear of being judged defective. It is the anxious experience of either the real or anticipated loss of status, affection or self-regard that results from knowing that one is vulnerable to the disapproving gaze or negative judgment of others (Shweder, 2003). Shame comprises of “internal shame”, which originates inside the self, involves self-generated criticism and negative self-evaluation and “external shame” which originates outside the self and involves a distressing awareness that others view the self negatively (Gilbert, 1998). Guilt has been linked to prosocial and reparative behaviors, whereas shame has been linked to hiding and social withdrawal (Tangney and Dearing, 2002). The feelings of shame involve a painful focus on the self – the sense that “I am a bad person” – whereas feelings of guilt involve a focus on a specific behavior – the sense that “I did a bad thing.” (Tangney et al., 2014). The consequent feelings of inferiority and the lack of self-esteem could result in emotional disorders, which in turn may seriously affect the quality of life of the caregiver and the quality of care (Ho et al., 2009).

There is a paucity of studies regarding shame in informal caregivers of critically ill patients and its study could provide valuable information for future interventions (Saraiya and Lopez-Castro, 2016).

The purpose of this study was to describe ICU patients' family members' experiences of internal and external shame.

## Methods

### *Characteristics of the participating ICU*

This study was conducted in the period from March 2012 to July 2013, in the ICU of the University Hospital of Ioannina, located in North-Western Greece. This unit has operated for the last 22 years and it cares for critically ill patients with medical and surgical conditions, who come from throughout North-Western Greece and the Ionian islands (approximately 450–500 patients/year). It is a closed unit with 14 beds and a full time intensive care physician (intensivist), who determines admission and discharge from the unit. The staff consists of 12 intensivists, 35 nurses and two physiotherapists. The protocol of the unit for informing family members includes a morning briefing with family members by the Professor/Director of the ICU and an evening briefing by the doctor on duty. The family members' visiting time is every afternoon for half an hour. However, many of them stay throughout the day and night in the waiting room of the unit, something that is a cultural tradition almost all around Greece.

The Ethics Committee of University Hospital of Ioannina approved the study and informed consent was obtained from the patients' family members.

### *Characteristics of the patients and family members*

For each patient, the following information was recorded: age, sex, date of birth, marital status, citizenship, reasons for ICU admission, and clinical status. Length of ICU stay and vital status at ICU discharge were also recorded. Family members were defined as all relatives and friends over 18 years old who stayed in the waiting room of the unit during the hospitalization, with sufficient knowledge of the Greece language so as to understand the psychometric tools being used in the study.

### *Measurements*

All participants' family members completed a questionnaire of socioeconomic characteristics (age, gender, date of birth, region, educational qualification, employment, marital status, relationship to the patient) and declared if they lived in the same house with the patient. The Experience of Shame Scale (ESS) and The Other As Shamer Scale (OAS) were used.

### *Experience of shame scale*

The ESS is a self-report questionnaire (Andrews et al., 2002), which assesses participants about whether they have felt ashamed of specific personal characteristics as well as their behavior and is based on a previous shame interview measure by Andrews and Hunter (Andrews and Hunter, 1997). It is a 25-item scale that measures the internal shame and assesses the frequency of shame experiences related to one's character (“Have you ever felt ashamed of the sort of person you are?”), behavior (“Have you tried to cover up or conceal things you felt ashamed of having done?”), and body (“Have you avoided looking at yourself in the mirror?”). Using a 4-point Likert Scale from “not at all” to “very much”, participants rated the frequency of their shame experiences, yielding total scores in the range 25–100. Research has shown the ESS to have good discriminant and construct validity, as well as high test-retest reliability. In clinical settings, the ESS has been used in order to investigate the link between domains of shame and depression (Andrews et al., 2002), eating disorders (Kelly and Carter, 2013), self-harm (Gilbert et al., 2010) and different diagnostic and body shaming groups (Rockenberger and Brauchle, 2011).

### *Other as shamer scale*

This statement-based scale measures the external shame (Allan et al., 1994; Goss et al., 1994) and is a modification of a subset of the items from the Internalized Shame Scale (Cook, 1993). The original statements were rewritten to reflect a person's perception of what others feel about him or her, e.g. ‘I think that other people look down on me’. The total scale consists of 18 items: Inferiority (being seen as inferior, 7 items), emptiness (being seen as empty, 4 items), mistake (how others behave when they see me make mistakes, 6 items), while an item included in the total scale is not an item on any of the subscales. Respondents are asked to indicate the frequency on a 5-point scale (0 = Never to 4 = Almost Always) of their feelings and experiences. The total score, calculated by summing up item scores, ranges from 0 to 72, with the higher scores indicating greater external shame. OAS has a high internal consistency (Cronbach's alpha = 0.92) and has been correlated to depressive symptoms and other clinically significant difficulties (Allan et al., 1994).

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