



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 ± 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).

Table 1
Socio-demographic characteristics of patients' family members.

| | N | % |
|---|-------|--------------------|
| Gender | | |
| Male | 81 | 36.3 |
| Female | 142 | 63.7 |
| Educational level | | |
| Elementary | 22 | 9.9 |
| Junior High School | 22 | 9.9 |
| High School | 85 | 38.1 |
| University/Technical Institute graduate | 71 | 31.8 |
| Post graduate | 23 | 10.3 |
| Professional status | | |
| Unemployed | 37 | 16.6 |
| Housewife | 30 | 13.5 |
| Freelancers | 40 | 17.9 |
| Employee | 46 | 20.6 |
| Civil servant | 65 | 29.1 |
| Student | 1 | 0.4 |
| Pensioners | 4 | 1.8 |
| Relationship | | |
| Spouse | 36 | 16.1 |
| Offspring | 91 | 40.8 |
| Parent | 11 | 4.9 |
| Sibling | 43 | 19.3 |
| Cousin | 4 | 1.8 |
| Uncle/Aunt | 3 | 1.3 |
| Other relative | 31 | 13.9 |
| Friend | 4 | 1.8 |
| Living with the patient | | |
| Yes | 79 | 35.4 |
| No | 144 | 64.6 |
| | Mean | Standard Deviation |
| Age | 41.53 | 11.90 |

The Greece versions of the OAS and ESS questionnaires have been translated and validated into Greece by members of our research team (Gouva et al., 2016a,b).

Procedure

The approach of the family members for informed consent and participation to the study took place on the third day of the patient's ICU admission. Individuals who agreed to participate in the study were informed about its purpose and were assured of the confidentiality and anonymity of the process. Coded numbers were allocated to each person participating in the study to assure participant confidentiality and anonymity. One researcher carried out the entire process to decrease the likelihood of information leakage and enhance trust between the researchers and participants. An envelope containing the self-assessment questionnaire (socioeconomic characteristics, ESS, OAS) was given to those who participated in the study and they were asked to return it in the next few days, during the afternoon briefing. The researchers were available to answer any questions.

Statistical analysis

Descriptive and inferential statistics was performed. Normal distribution was checked with the Shapiro-Wilk test. The Students' *t*-test and one way analysis of variance (ANOVA) were used for comparisons, along with the Bonferroni correction for post-hoc analysis. Specifically, the independent student *t*-test was adopted to compare men and women scores and the quantitative variables of relatives that cohabited with the patient and those that did not cohabit with the patient. The data from general Greece population derived from Gouva et al. (2016a,b) are cited with our results for clarification and further information. Although these data are not results from this study, they were emerged from our research group. One way ANOVA was used to test the differences between

the subgroups of different types of demographic characteristics on internal and external shame. Given the found correlations between the educational level of the participants we applied the Bonferroni correction for post-hoc analysis. The statistics were performed using the statistical package IBM SPSS Statistics (version 22.0; IBM Inc., New York, USA). A probability of <0.05 (two-tailed) was considered significant in all tests.

Results

We studied 223 family members (81 men and 142 women, mean age 41.5 ± 11.9 years) corresponding to 147 critically ill patients. These patients were admitted to the Intensive Care Unit with coma (acute stroke, brain trauma), acute respiratory failure (pneumonia, aspiration, chronic obstructive pulmonary disease exacerbation), septic shock, multiple trauma injuries and cardiac arrest. Patients' demographics were as follows: 103 (70%) men and 44 (30%) women, mean age 58.3 ± 18.6 years, length of stay 14 ± 8 days with a 19% mortality.

One family member was interviewed for 90 (61.2%) patients, two family members for 42 (28.6%) patients, and three or more for 15 patients (10.2%). Family members' socio-demographics are outlined in Table 1.

ANOVA testing OAS and ESS scores based on educational level of family members of ICU patients did not reveal any difference concerning ESS scores but only for OAS scores (Table 2a). Analysis revealed, the higher the educational grade, the lower the external shame. Elementary and Junior High School graduates had significantly higher total OAS, inferiority and emptiness scores when compared to post graduates ($p < 0.001$) and High School and University graduates ($p < 0.05$) (Post hoc analysis, Bonferroni *t*-test) (Table 2b).

Family members who lived with the patient reported significantly higher external shame, as indicated by a higher total OAS score, compared with those who did not live with the patient (16.38 ± 10.05 vs 13.28 ± 9.96 , $p = 0.028$). The major difference was recognized in the "emptiness" subscale (3.25 ± 3.02 vs 2.36 ± 2.67 , $p = 0.024$), while differences in mistakes perception were marginal ($p = 0.055$). No differences between men and women were detected (Table 3).

Family members who lived with the patient when compared to those who did not live with the patient experienced marginally higher internal shame ESS score ($p = 0.51$), and higher and statistically significant score in Behavioural shame subscale (19.14 ± 6.88 vs 17.41 ± 5.71 , $p = 0.046$). No differences between men and women were detected (Table 4). Comparative presentation of the general populations values of the OAS and ESS scores is presented in Tables 3 and 4 (Gouva et al., 2016a,b).

Discussion

The family members of patients hospitalized in ICUs may experience severe stressors, setting their personal health and family cohesion at risk. Those who lived with the patient experienced the burden and stress of caring and our results reflects their struggle to cope with their stressors. Moreover, ICU patients' family members seem vulnerable to perceived criticism, as suggested by the OAS score being higher among those who lived with the patient, especially when they are of low educational level.

The high levels of external shame of family members observed in our study was considered as a source of intense stress for them. That could be associated with the patient's hospitalization in the ICU and with a self-blame culture where family members blame themselves for their relative's condition. Furthermore, the literature asserts that high levels of external shame seem to have a

Table 2
One Way Analysis of Variance (ANOVA) testing OAS & ESS scores based on educational level of family members of ICU patients and Post Hoc Tests.

| a. | | | | |
|----------------------------|--|--|-----------------------|----------------|
| Variables | F | p ^a | | |
| External Shame (OAS) | | | | |
| Total External Shame (OAS) | 6.994 | 0.000 | | |
| Inferiority | 5.260 | 0.000 | | |
| Emptiness | 6.667 | 0.000 | | |
| Mistakes perception | 3.398 | 0.010 | | |
| Internal Shame (ESS) | | | | |
| Total Internal Shame (ESS) | 1.059 | 0.378 | | |
| Characterological Shame | 2.400 | 0.051 | | |
| Behavioural Shame | 0.481 | 0.750 | | |
| Bodily Shame | 0.708 | 0.587 | | |
| b. | | | | |
| Dependent Variable | Educational Level (mean ± SD) | Educational Level (mean ± SD) | Mean Difference (I–J) | p ^b |
| Total External Shame (OAS) | Elementary graduate (21.27 ± 13.97) | Junior high school graduate (20.64 ± 9.54) | 0.636 | 1.000 |
| | | High school graduate (13.55 ± 9.61) | 7.720 | 0.009 |
| | | University/Technical Institute graduate (12.62 ± 8.21) | 8.653 | 0.003 |
| | Junior high school graduate (20.64 ± 9.54) | Post graduate (10.30 ± 8.29) | 10.968 | 0.002 |
| | | High school graduate (13.55 ± 9.61) | 7.083 | 0.023 |
| | | University/Technical Institute graduate (12.62 ± 8.21) | 8.017 | 0.007 |
| | | Post graduate (10.30 ± 8.29) | 10.332 | 0.004 |

P value: statistical significance < 0.05; OAS Other As Shamer Scale; ESS: Experiences of Shame Scale.

^a represents comparisons of total and subscales of OAS and ESS between groups of family members of different educational levels.

^b represents comparisons of OAS between Elementary and Junior high school graduates and other educational level groups, Post Hoc Tests: (Bonferroni criterion) between Types of Educational Level.

negative association with social stigma, social power and social status (Gilbert, 1998; Kurzban and Leary, 2001). These factors have been found to lead to social rejection (Gilbert, 2003) and shame (Cohen, 2003; Schweder, 2003). The above finding, then, is in agreement with the results of previous publications, which connect the external shame with the image that others have for the individual and their judgment for their flaws (Heller, 2003). The findings of this study highlight the serious issues in terms of socio-psychological and physical health of relatives living with the patient, since shame can prevent them from seeking help (Tangney and Dearing, 2002), while it also seems to lead to the withholding of information and the decrease of satisfaction from medical practice (Lazare, 1987).

High levels of internal shame in the patients' family members who had a symbiotic relationship with them can be interpreted by their stress, that, as it is already stressed, is associated with conditions such as disease (Gilbert, 1998; Kurzban and Leary, 2001). They probably feel internal shame because of obvious or less obvious deficits that others attribute to them with respect to their patient's disease.

Disgust is also an emotion that people fear causing others, as this would render them non-attractive and unwanted (Gilbert, 1998). Without the approval and recognition of others, they may feel worthless, and then, as Gilbert suggests (Gilbert, 2003), the pathologies of shame and stigma appear. Knowing that stigmatized groups exist in society can lead people to fear being placed in them, referred to as "stigma consciousness" (Pinel, 1999). As the "look of the other", i.e. the judgment of the community, is often internalized, even when the person is judged by an outside judge, the "look of the other" and its consequences are present (Heller, 2003). The above finding therefore confirms this position, and it is in agreement with the findings of previous research, that self-assessment and the assessment by others are connected (Goss et al., 1994).

The key finding in the study was shame, especially external shame, was more evident in family members living with the patient and those who had lower educational levels. As inferiority is likely to obstruct effective coping strategies that would otherwise serve as a reframing mechanism (Grodzinsky et al., 2015), its incidence in

patients' relatives may deserve attention. The current study examined the internal and external shame of family members of ICU patients so to understand and explain their attitudes and reactions. Furthermore, from the current study emerges a potential hypothesis that there may be a correlation between socioeconomic inequities and shame-induced inferiority of these family members, whereby the greater the socioeconomic inequities the more these family members experience shame-induced inferiority. While the current study was not designed and cannot claim to focus on the correlation between socioeconomic inequities and shame-induced inferiority, nonetheless it highlights the need to explore any potential correlation as to capture in greater extent the complexity of variables that affect the attitudes and reactions of family members that have loved ones being nursed in ICU and to enable health professions to consider the possible implications for patients and family members in their care

Limitations

Our study is not without limitations; unfortunately we did not measure how feelings of shame in our study population have changed over time and if limited visiting times may have influenced the study results. Although we recognize that ICU visiting time is very short compared to other internationally reported, this happens in the majority of Greece ICUs throughout our country, and relates to the cultural context in which the study was done. Moreover, there is a paucity of studies in medical literature regarding shame feelings and satisfaction of the ICU patient's family members in correlation to visiting time duration.

Conclusion

Intensive Care Unit patients' family members are prone to shame feelings, especially when having low levels of education and living with the patient. These findings should lead the ICU care professionals to redefine their views regarding the needs of ICU patients' family members. Future studies should focus on firstly

Table 3
Comparative presentation of the OAS score between ICU patients' family members and their general population counterparts.

| | ICU family members Mean ± SD | Healthy Greece Population Mean ± SD | ICU men family members Mean ± SD | ICU women family members Mean ± SD | P-value ^a p ^a | Healthy Greece Men Population Mean ± SD | Healthy Greece Women Population Mean ± SD | ICU family members living with the patient Mean ± SD | ICU family members not living with the patient Mean ± SD | P-value ^a p ^b |
|---------------------|---------------------------------|--|-------------------------------------|---------------------------------------|-------------------------------------|--|--|---|---|-------------------------------------|
| Total OAS | 14.38 ± 10.08 | 13.91 ± 10.04 | 15.58 ± 10.86 | 13.70 ± 9.58 | ns | 13.07 ± 10.55 | 14.42 ± 9.72 | 16.38 ± 10.05 | 13.28 ± 9.96 | 0.028 |
| Inferiority | 5.07 ± 4.31 | 4.87 ± 3.97 | 5.69 ± 4.84 | 4.72 ± 3.95 | ns | 4.70 ± 4.21 | 4.97 ± 3.83 | 5.70 ± 4.76 | 4.73 ± 4.02 | ns |
| Emptiness | 2.68 ± 2.82 | 2.40 ± 2.61 | 2.80 ± 3.18 | 2.61 ± 2.61 | ns | 2.06 ± 2.64 | 2.61 ± 2.57 | 3.25 ± 3.02 | 2.36 ± 2.67 | 0.024 |
| Mistakes perception | 5.90 ± 3.88 | 5.96 ± 3.95 | 6.22 ± 4.00 | 5.71 ± 3.82 | ns | 5.65 ± 4.10 | 6.14 ± 3.86 | 6.57 ± 3.76 | 5.53 ± 3.91 | 0.055 |

Notes: SD: Standard Deviation, OAS: Other As Shamer Scale, ICU: Intensive Care Unit, ns: non-statistically significant, ANOVA: One way Analysis of Variance. Values of the OAS score for healthy population are derived from [Gouva et al., 2016a,b](#).

^a p value was derived using T test immediate command in SPSS, p value: statistical significance <0.05.

^a represents comparisons between men and women family members.

^b represents comparisons between family members who were living with the patient and those who did not live with the patient.

Table 4
Comparative presentation of the ESS score between ICU patients' family members and their general population counterparts.

| | ICU family members Mean ± SD | Healthy Greece Population Mean ± SD | ICU men family members Mean ± SD | ICU women family members Mean ± SD | P-value ^a p ^a | Healthy Greece Men Population Mean ± SD | Healthy Greece Women Population Mean ± SD | ICU family members living with the patient Mean ± SD | ICU family members not living with the patient Mean ± SD | P-value ^a p ^b |
|-------------------|---------------------------------|--|-------------------------------------|---------------------------------------|-------------------------------------|--|--|---|---|-------------------------------------|
| Total ESS | 45.43 ± 13.45 | 45.27 ± 13.15 | 46.28 ± 14.50 | 44.94 ± 12.84 | ns | 42.47 ± 13.99 | 46.96 ± 12.34 | 47.53 ± 15.5 | 44.28 ± 12.08 | ns |
| Characterological | 20.57 ± 6.31 | 20.12 ± 6.18 | 21.56 ± 7.07 | 20.01 ± 5.79 | ns | 19.60 ± 6.59 | 20.44 ± 5.91 | 21.44 ± 7.49 | 20.10 ± 5.53 | ns |
| Behavioural shame | 18.02 ± 6.19 | 18.30 ± 5.95 | 18.31 ± 6.40 | 17.86 ± 6.08 | ns | 16.95 ± 6.06 | 19.11 ± 5.75 | 19.14 ± 6.88 | 17.41 ± 5.71 | 0.046 |
| Bodily shame | 6.83 ± 3.05 | 6.93 ± 2.80 | 6.42 ± 3.03 | 7.07 ± 3.04 | ns | 6.13 ± 2.47 | 7.41 ± 2.875 | 6.95 ± 3.19 | 6.77 ± 2.98 | ns |

Notes: SD: Standard Deviation, ESS: Experience of Shame Scale, ICU: Intensive Care Unit, ns: non-statistically significant, ANOVA: One way Analysis of Variance.

Values of the ESS score for healthy population are derived from [Gouva et al., 2016a,b](#).

^a p value was derived using T test immediate command in SPSS, p value: statistical significance <0.05.

^a represents comparisons between men and women family members.

^b represents comparisons between family members who were living with the patient and those who did not live with the patient.

how to better identify at risk family members and secondly what strategies would benefit them while they attempt to manage the stress associated with an ICU admission of their loved one.

Conflict of interest

The authors have no conflict of interest to declare.

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Ethical statement

The study has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki). The Ethics Committee of our Hospital approved the study and informed consent was obtained from the patients' relatives.

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