PSYCHOLOGICAL SYMPTOMS OF FAMILY MEMBERS OF HIGH-RISK INTENSIVE CARE UNIT PATIENTS

By Jennifer L. McAdam, RN, PhD, Dorrie K. Fontaine, RN, PhD, Douglas B. White, MD, MAS, Kathleen A. Dracup, RN, DNSc, and Kathleen A. Puntillo, RN, DNSc

Background Family members of patients in intensive care are at increased risk for psychological symptoms.

Objectives To compare levels of posttraumatic stress disorder, anxiety, and depression during and 3 months after the intensive care experience in family members of patients at high risk for dying and to determine if differences were related to the patient’s final disposition.

Methods Longitudinal descriptive study of 41 family members in 3 tertiary care intensive care units.

Results By repeated-measures analysis of variance, family members’ levels of posttraumatic stress disorder were significantly lower ($P = .01$) at 3 months after (mean score, 1.27; SD, 0.86) than during (mean, 1.61; SD, 0.81) the experience. Mean anxiety and depression scores were significantly lower ($P < .001$) after (anxiety: 7.35; SD, 3.91; depression: 5.63; SD, 4.58) than during (anxiety: 11.5; SD, 4.88; depression: 9.51; SD, 4.31) the experience. Scores for posttraumatic stress disorder, anxiety, and depression did not differ significantly between family members of patients who died and family members of patients who survived. Yet, all 13 family members of deceased patients and 42% of the total sample of 41 had traumatic stress scores of 1.5 or greater. Among the total sample, 44% had significant anxiety, and 27% were depressed.

Conclusion Family members’ symptoms of posttraumatic stress disorder, anxiety, and depression significantly decreased 3 months after the intensive care experience and did not differ according to the patients’ final disposition. However, many family members still had significant risk for posttraumatic stress disorder and borderline anxiety and depression at 3 months.

Because patients’ family members are at increased risk for psychological symptoms during the ICU experience, more needs to be known about how the experience may affect family members’ symptoms after the ICU experience. Recently, a few studies have addressed this issue. One group of investigators found significantly more symptoms of posttraumatic stress disorder (PTSD) in family members 3 months after the ICU experience when the members either lost a loved one or were involved in end-of-life decision making. Gries et al reported symptoms of PTSD and depression (prevalence, 14% and 18%, respectively) in family members 6 months after a loved one’s death in the ICU. Other researchers found that even up to 12 months after the ICU experience, one-third of family members who lost a loved one in the ICU were still experiencing complicated grief, major depression, or anxiety disorder.

Patients’ family members are an integral part of care in the ICU, and incorporating a family-centered approach to care has been strongly encouraged by critical care organizations. However, patients’ family members are at an increased risk for symptoms during and even after the ICU experience. In addition, family members may be at an even higher risk for symptoms if their loved one dies in the ICU. Therefore, more needs to be known about how the ICU experience affects the symptoms of patients’ family members. In a previous study, we noted a high prevalence of symptoms of traumatic stress, anxiety, and depression in family members 3 to 5 days after a patient’s admission to the ICU. In this follow-up study, our primary aim was to compare those findings with the symptoms of PTSD, anxiety, and depression in the family members approximately 3 months after ICU death or discharge of the patient. The secondary aim was to determine if those differences depended on whether the patient died or survived in the ICU.

Methods
Setting and Sample
This longitudinal descriptive study was conducted at a large university-based tertiary-care center on the West Coast and was part of a larger study on the symptoms of patients’ family members. The ICUs in the study consisted of a 24-bed medical-surgical ICU, a 16-bed cardiovascular ICU, and a 16-bed neurovascular ICU. All of the ICUs had liberal visiting practices; patients’ family members were allowed to spend large amounts of time at the bedside, with some restrictions on visitation at change of shift.

Members of a patient’s family were eligible for the study if they were adult family members of an adult ICU patient (>18 years old), visited the patient at least once while the patient was in the ICU, identified themselves as the family member most likely to be involved with the patient’s care, read and spoke English, and were family members of a patient at risk for dying. Patients were considered at risk if they were in an ICU for at least 72 hours, received mechanical ventilation, and had a score of 20 or greater on the Acute Physiology and Chronic Health Evaluation II in the first 24 hours.

Symptoms of posttraumatic stress disorder have been found in intensive care unit patients’ family members 3, 6, and up to 12 months after the intensive care unit experience.
A patient’s family was defined as the person who would be most involved in the patient’s treatment and care decisions. The person who was defined as patient’s treatment and care decisions involved in the AMERICAN JOURNAL OF CRITICAL CARE, November 2012, Volume 21, No. 6 www.ajcconline.org

Instruments
The Impact of Event Scale-Revised (IES-R), a 22-item questionnaire with established reliability and validity, was used to measure traumatic stress. The instrument contains subscale items on intrusion (8 items), avoidance (8 items), and hyperarousal (6 items). A Likert-scale format is used to indicate how distressing each item was for the family member during the past week (score range, 0-4). An IES-R mean score of 1.5 or greater indicates a significant risk for PTSD symptoms. The Hospital Anxiety and Depression Scale (HADS) is a screening questionnaire used to measure anxiety (7 items) and depression (7 items). The HADS has a 4-point (0-3) scale for each item (range, 0-21). Scores between 8 and 10 indicate a possible clinical disorder, whereas scores of 11 or greater indicate a probable clinical disorder. This questionnaire also has established reliability and validity. Instruments

Procedures
Initially, a chart review of each patient was completed to determine a patient’s and family’s eligibility for the study. Family members who met the inclusion criteria were approached by the principal investigator (J. M.) approximately 3 to 5 days after the patient’s ICU admission. If the family member agreed to the study, he or she completed the questionnaires and provided sociodemographic information (see the original study for more detailed information on the questionnaires and variables collected). Approximately 3 months after the patient’s discharge from or death in the ICU, the principal investigator made 1 telephone call to the appropriate family member to remind the member that 2 questionnaires, the HADS and IES-R, would be sent to him or her by mail for completion. If the questionnaires were not returned after approximately 2 weeks, another telephone call was placed to the family member as a reminder to complete the questionnaires. In order to ensure optimal quality of the data, recruitment, enrollment, and follow-up were completed by 1 researcher (J. M.) with a doctoral degree and extensive experience working with ICU patients and patients’ family members. The study was approved by the appropriate institutional review board.

Data Analysis
SPSS, version 13, was used to analyze the data (SPSS, Inc.). All continuous variables were described by using means and standard deviations. Categorical variables were reported as proportions and frequencies. Symptoms of PTSD, anxiety, and depression in family members of patients while in the ICU were compared with the members’ symptoms of PTSD, anxiety, and depression approximately 3 months after discharge from the ICU or death of the patient by using a matched paired t test. A repeated-measures analysis of variance was used to determine if differences in symptoms depended on whether the patient died or survived in the ICU. A post hoc power analysis to test repeated-measures analysis of variance with an α of 0.05 and a power of 80% to detect a medium effect size (0.50), revealed that a total of 55 participants would have been needed per group.

Results

Family Members’ Characteristics
Initially, 181 consecutive patients and their family members were screened, and 95 met the study criteria. The initial consent rate was 78% (n = 74). Follow-up data were available for 41 family members (55%). A more detailed description of the demographics of both patients and their family members during the ICU experience has been published previously. Characteristics of the participants at follow-up are presented in Table 1. Most of the family members were spouses (46%) and female (58%); the mean age was 53.6 years (SD, 11.8). The sample was racially and ethnically diverse, but the majority of family members were white (63%). Most family members had previous ICU experience (61%), lived with the patient (58%), and were educated at a college level or higher (76%).

Patients’ Characteristics
The mean age of the 41 patients at follow-up was 57.9 years (SD, 14.2). The mean first 24-hour score on the Acute Physiologic and Chronic Health Evaluation II was 31.3 (SD, 6.2). Most of the patients were female (61%), white (61%), were documented as requesting full resuscitation in the ICU (83%), and had no documentation of an advance directive in their medical chart (88%). A total of 69% survived the ICU; the remaining 31% died either in the ICU or during their hospital stay. We found no statistically or clinically significant differences in either the family members’ or the patients’ sociodemographic

A patient’s family was defined as the person who would be most involved in the patient’s treatment and care decisions.
variables between the family members who completed the study at follow-up (n = 41) and those who did not (n = 33).

### Difference in Symptoms of PTSD Over Time According to Whether the Patient Died or Survived in the ICU

Mean scores for family members’ symptoms of PTSD at 3-month follow-up (1.27; SD, 0.86) were significantly lower (t = 2.60, P = .01) than their scores during the ICU experience (1.61; SD, 0.81; Table 2) PTSD scores of the 13 family members who lost a loved one in the ICU or hospital did not differ significantly from the scores of the 28 who did not (F = 2.70; P = .11; Table 3) However, 32% of the 13 family members who lost a loved one in the ICU and 42% of the 41 members in the total sample had IES-R scores of 1.5 or greater (Table 4), indicating a significant risk for PTSD symptoms 3 months after the ICU experience. A total of 42% of family members scored high on the intrusion subscale, and 29% scored 1.5 or greater on the avoidance and hyperarousal subscales.

### Difference in Symptoms of Anxiety and Depression Over Time According to Whether the Patient Died or Survived the ICU

Family members’ mean anxiety and depression scores (Table 2) at the 3-month follow-up (anxiety: 7.35; SD, 3.91; depression: 5.63; SD, 4.58) were significantly lower (anxiety: t = 5.99; P < .001; depression: t = 5.41; P < .001) than their scores during the ICU experience (anxiety: 11.5; SD, 4.88; depression: 9.51, SD, 4.31). Table 5 presents the number and percentage of family members who scored higher than the borderline and clinical cutoff scores for symptoms indicating risk for anxiety and depression at the 3-month follow-up. Anxiety scores of the 13 family members who lost a loved one in the ICU did not differ significantly from the scores of 28 members who did not (F = 1.04; P = .32). Differences between the 2 groups in depression scores were also not significant (F = 0.10; P = .75) Yet, 44% (n = 18) of family members were still at risk for borderline symptoms of anxiety, and 27% (n = 11) were at risk for borderline symptoms of depression. In addition, 24% (n = 10) of family members were at risk for clinical symptoms of anxiety, and 12% (n = 5) were at risk for clinical symptoms of depression.

### Discussion

Our results suggest that family members’ symptoms of PTSD, anxiety, and depression significantly decreased during a 3-month time frame. These findings are consistent with the results of other researchers. In general, psychological symptoms tend to be high initially but should decrease in most family members over time.

However, a finding of concern in our study was that even though symptoms decreased over time, many of the family members scored at or higher than the cutoff levels on the IES-R and the HADS instruments, indicating that the members were still at high risk for PTSD, anxiety, and depression. This finding supports those of other investigators although most ICU family members eventually...
family members of patients who survived the ICU is that the family members were the patients’ primary caregivers. Family members of these patients, patients who could be classified as chronically critically ill (mechanical ventilation >3 days and an extended ICU length of stay),24,25 have experienced a marked decline in their own health,26,27 an increased sense of burden,26,27 and symptoms consistent with severe depression,26-29 PTSD,29 and generalized anxiety disorder.29 Although we did not study the health care burden borne by caregivers, and, because of our small sample size, we are cautious in our interpretation of the data, assessment of the burdens, stressors, and mental and physical health of family members of patients discharged from the ICU might be beneficial. Critical care nurses could assist family members by providing coping and emotional support through referrals, discussions, and reassurance. In addition, critical care nurses could collaborate with case management or social services to provide individualized home care needs for patients and patients’ families. This type of emotional and instrumental support can be beneficial to family caregivers.27,30 In one study,27 such support helped keep some family caregivers with mild depression from advancing to severe depression.

The family members of patients who died in the ICU were also at high risk for symptoms of PTSD, anxiety, and depression symptoms. One possible explanation of the continuing risk for PTSD, anxiety, and depression symptoms in family members of patients who survived the ICU is that the family members were the patients’ primary caregivers. Family members of these patients, patients who could be classified as chronically critically ill (mechanical ventilation >3 days and an extended ICU length of stay),24,25 have experienced a marked decline in their own health,26,27 an increased sense of burden,26,27 and symptoms consistent with severe depression,26-29 PTSD,29 and generalized anxiety disorder.29 Although we did not study the health care burden borne by caregivers, and, because of our small sample size, we are cautious in our interpretation of the data, assessment of the burdens, stressors, and mental and physical health of family members of patients discharged from the ICU might be beneficial. Critical care nurses could assist family members by providing coping and emotional support through referrals, discussions, and reassurance. In addition, critical care nurses could collaborate with case management or social services to provide individualized home care needs for patients and patients’ families. This type of emotional and instrumental support can be beneficial to family caregivers.27,30 In one study,27 such support helped keep some family caregivers with mild depression from advancing to severe depression.

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PTSD, anxiety, and depression. One reason for this finding could be that many of these family members were involved in end-of-life decision making. Although we did not address this topic in our study, other researchers have reported higher levels of PTSD when family members participated in end-of-life decision making or when family members’ preferences for decision making did not match the families’ actual decision-making roles. However, Anderson et al found that levels of anxiety and depression were higher if the family member chose a more passive decision-making role.

We acknowledge our small sample size and lack of power. Yet, because family members of ICU patients may be at risk for psychological symptoms, we think that critical care nurses can be influential and can act as family advocates by assessing the symptom status of patients’ family members. For example, critical care nurses should be present during end-of-life care conferences to ensure that the patient’s family member understands what is occurring and that the member’s preferences are being respected. Nurses can determine if a patient’s family members are ready for the conference or if they need more time; having family conferences too early in the ICU stay has been associated with more PTSD symptoms. In addition, ensuring that these meetings are run without conflict, unprofessional behavior, or poor communication among the ICU staff, behaviors associated with psychological symptoms in family members, may help lessen family members’ symptoms. Future research with a larger sample is warranted to determine the long-term effects of end-of-life conferences and preferences for a role as decision maker on family members’ psychological symptoms.

A surprising finding in our study was that both family members of ICU survivors and family members of patients who died in the ICU continued to be at high risk for symptoms of PTSD, anxiety, and depression. One explanation may be that the ICU itself can be traumatizing to families regardless of a patient’s outcome. We found that slightly fewer than half of the family members in our study continued to have intrusive symptoms (ie, unwelcome thoughts and memories of the ICU), and approximately one-third of them had hyperarousal symptoms (ie, heightened startle response and nightmares) 3 months after the ICU experience. Others have reported that just experiencing death in the ICU rather than at home with hospice increased the odds for PTSD symptoms in family members of cancer patients. A greater risk for a major depressive disorder has also noted in bereaved family members when care of their loved involved more aggressive medical care.

Sinuff et al reported that ongoing mechanical ventilation was traumatizing for family members. Finally, family members might see their loved ones, especially if the patients are dying, undergoing distressing conditions such as pain and dyspnea, and this experience may lead to the members’ own distress. Regardless of the cause, psychological symptoms are a concern because they could lead to other long-term problems for family members, such as sleep disturbances, major depressive and anxiety disorders, and complicated grief.

Critical care nurses are key in helping ameliorate psychological symptoms. The nurses can prepare a patient’s family members for what the members may see, hear, or experience while visiting in the ICU; this level of preparedness has been associated with improvement in outcomes in caregivers of chronically and terminally ill patients. In addition, critical care nurses can be proactive in establishing referral policies for family members (eg, counseling or spiritual care services) to discuss feelings such as anxiety, depression, stress, sadness, anger, and guilt. At an organizational level, ICUs can initiate palliative care services early in a patient’s ICU stay. This practice can lessen a patient’s symptoms, improve communication between clinicians and the patient’s family members, and increase the family’s satisfaction with care, all of which may help lessen family members’ symptoms.

Finally, we think that critical care nurses should monitor patients’ family members in the ICU for symptoms of PTSD, anxiety, and depression. Critical care nurses work with patients’ families on a daily basis. This frequent interaction allows nurses to build rapport and trust with family members and

### Table 5: Hospital Anxiety and Depression Scale: family members’ scores at 3-month follow-up

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Score, mean (SD)</th>
<th>No. (%) of family members at a borderline cutoff (score ≥8)</th>
<th>No. (%) of family members at a clinical cutoff (score ≥11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>7.3 (3.9)</td>
<td>18 (43.9)</td>
<td>10 (24.4)</td>
</tr>
<tr>
<td>Depression</td>
<td>5.6 (4.6)</td>
<td>11 (26.8)</td>
<td>5 (12.2)</td>
</tr>
</tbody>
</table>

*a Measure of anxiety and depression. Subscale total scores range from 0 to 21. Subscale cutoff scores of 8 or greater indicate borderline risk for symptoms of anxiety and depression; subscale cutoff scores of 11 or greater indicate risk for clinical symptoms of anxiety and depression.*

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**Family members of survivors and of patients who died in the intensive care unit were at risk for post-traumatic stress disorder, anxiety, and depression.**
Interventions may help limit the psychological symptoms of intensive care unit patients’ family members.

Although most family members of intensive care patients eventually cope, a marked minority remain at risk for psychological symptoms. As critical care nurses, we are in the prime position to be the ones to help support patients’ families during this challenging time and to guide the direction of future research in this area.

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FINANCIAL DISCLOSURES
None reported.

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1. Which of the following results on the Hospital Anxiety and Depression Scale indicate a probable clinical disorder?
   a. Eleven or greater
   b. Between 6 and 10
   c. Greater than 25
   d. Less than 7

2. Which of the following is true regarding the posttraumatic stress disorder (PTSD) scores of family members who lost a loved one in the ICU?
   a. They had much higher PTSD scores than those who did not.
   b. They experienced less anxiety than those who did not.
   c. They reported less depression but more anxiety than those who did not.
   d. They did not differ significantly from those who did not.

3. The authors' results suggest that during the 3-month timeframe caregivers' symptoms of PTSD, anxiety, and depression:
   a. Decreased significantly
   b. Increased significantly
   c. Stayed the same.
   d. Increased slightly

4. At 3 months, caregivers' scores on the Impact of Event Scale-Revised and Hospital Anxiety and Depression Scale indicated which of the following?
   a. They were at high risk for PTSD, depression, and anxiety.
   b. They were still at high risk for PTSD, depression, and anxiety.
   c. Those with other involved family members were less at risk for PTSD, depression, and anxiety.
   d. They were frequently experiencing "flashbacks."

5. One possible explanation for caregivers' continued risk for anxiety, depression, and PTSD would be which of the following:
   a. Their own chronic illnesses
   b. Unwillingness to seek assistance with their own symptoms
   c. Concerns over hospital bills
   d. Their continued role as caregivers of chronically, critically ill family members

6. Caregivers whose loved one died in the ICU were at high risk for symptoms of PTSD, anxiety, and depression. The authors postulate that possible reasons for this might include:
   a. Actual roles in decision making did not match their preferences for this might include:
   b. Conflict among family members
   c. Too much information given by physicians
   d. Financial burden of hospitalization

7. One example of the critical care nurse's role at end-of-life care conferences would be which of the following?
   a. Convince caregivers to withdraw support
   b. Suggest ways that caregivers can better cope with the stress of having a family member die
   c. Make sure that caregivers' preferences are being respected
   d. Resolve conflicts among family members

8. At 3 months, caregivers of both ICU survivors and those who died in the ICU continued to have which of the following?
   a. Intrusive symptoms
   b. Poor memory of their time in the ICU
   c. Normal symptoms of grief
   d. Severe fatigue

9. Experiencing a family member's death in the ICU rather than at home with hospice:
   a. Increased the risk of PTSD in family members of cancer patients
   b. Was reported as much easier by family members of all patients
   c. Resulted in the same risk for PTSD
   d. Resulted in increased risk for depression but not PTSD

10. Which of the following is one key role of critical care nurses in helping caregivers cope more effectively?
    a. Explaining the function of all equipment as completely as possible
    b. Preparing family members for what they may see, hear, or experience in the ICU
    c. Reminding physicians to repeat explanations of the patient's disease process if family members do not appear to understand.
    d. Assessing family members for preexisting psychiatric issues before they visit their loved one

11. Preparedness of caregivers prior to visiting in the ICU has been associated with which of the following?
    a. Increased overtime in nursing budgets
    b. Improved patient satisfaction scores
    c. Poorer outcomes for patients
    d. Improved outcomes for patients and caregivers

12. Which of the following is a limitation of the study?
    a. It was conducted in a single center with a small sample.
    b. The sample was too large to be able to control for preexisting conditions in caregivers.
    c. PTSD, anxiety, and depression have never been previously studied in ICU patients or caregivers making it difficult to quantify stress related behaviors in caregivers.
    d. Resulted in increased risk for depression but not PTSD

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