Concern for the family members of patients who are at high risk of dying in intensive care units is both a necessary and integral part of providing holistic nursing care. When patients are at high risk of dying, their families experience burdens such as decision making and treatment choices that can cause the families psychological and physical symptoms, most commonly stress, anxiety, and depression. These symptoms in turn can affect family members’ general well-being. Since the late 1990s, several quantitative and qualitative studies have been done to assess symptoms in such family members. In this review of the literature, the current state of the science on symptoms experienced by family members of patients in the intensive care unit is reviewed and critiqued. Risk factors associated with an increase in symptoms experienced are discussed. Overall, surveys that use self-report measures were the most common study design. Limitations of the studies include convenience sampling, small sample sizes, and a lack of description of patients’ characteristics, all of which make comparison and use of findings difficult. Recommendations to address gaps in the literature are highlighted, and future research goals are discussed. (American Journal of Critical Care. 2009;18:200-210)
Every year in the United States, approximately 20% of all deaths occur in an intensive care unit (ICU), and more than half of those occur after life-sustaining measures are withdrawn or withheld. Many of these patients are unable to communicate their wishes because they are sedated, receiving mechanical ventilation, confused, or comatose. The noncommunicative state of such patients places much of the burden of decision making and treatment choices on the patients’ family members. This type of experience may adversely affect family members by increasing their stress levels and increasing their risk for psychological and physical symptoms.

Concern for the family members of ICU patients who are at high risk of dying is both a necessity and an integral aspect of providing holistic care in the ICU. Since 2003, clinical practice guidelines and a consensus document that support and encourage family-centered care in the ICU have been published. Recent recommendations for incorporating family-centered care include assessing psychological symptoms such as stress and anxiety levels of patients’ family members. Potential benefits of this care philosophy include improved satisfaction with care and reduced occurrence of symptoms for patients’ family members. Yet, before this recommendation can be incorporated into practice, more research is needed on what types of symptoms patients’ family members experience, the effects of these symptoms, and what types of interventions are most effective in reducing the symptoms and improving outcomes for both patients and their families.

Most research on family members in the ICU has been focused mainly on family members’ needs and satisfaction with care. Considerably less has been published on family members’ symptoms and even less on symptoms experienced by family members of ICU patients at high risk of dying. To provide appropriate care to both ICU patients and the patients’ family members, clinicians must first gain knowledge of family members’ symptoms. In this article, we critically review the current literature on what is known about symptoms experienced by family members in the ICU and factors that may influence those experiences. We highlight gaps in the literature, provide implications for practice, and suggest areas for future research.

**Integrated Literature Review**

The current relevant literature was searched by using the electronic databases PUBMED, PsycInfo, and CINAHL. Key words and combinations of key words searched included family, signs and symptoms, stress, anxiety, depression, critical care, intensive care, end-of-life, terminal care, palliative care, coping, and experiences. No limitations were placed on the dates of the search because of the relatively new emphasis on this topic in the literature. Abstracts were reviewed for relevancy and content. The limitations applied to the search were publications in English only and topics involving adult ICU patients only. Review articles, abstracts, conference proceedings, editorials, case studies, anecdotal commentaries, and studies that focused primarily on pediatric and neonatal ICU populations were excluded. Studies of adults that also included children and infants were retained for analysis. The final search strategy used was to review the obtained articles’ reference lists for any further pertinent articles. The results yielded a total of 18 studies that met the criteria. (The studies are summarized in an appendix available online at www.ajcconline.org.)

**History of Symptom Research**

Research on family members’ symptoms in critical care had its origins in the mid-1970s. Most of the research was qualitative and descriptive and had small to moderate sample sizes, from 20 to 166 family members. The majority of these studies were completed in single centers and included mostly patients from coronary care units. Most of the family members in the ICU could potentially suffer from clinically diagnosable psychological conditions.
could be detrimental to the family members’ physical and mental health.

Several investigators have built on previous work by examining family members’ symptoms and associated risk factors. Most confirmed that family members have psychological symptoms such as anxiety, depression, and stress or symptoms of acute stress disorder (ASD), posttraumatic stress disorder (PTSD), and posttraumatic stress reaction (PTSR). This research is summarized in the following section.

Survey Research on Stress, Depression, and Anxiety

Stress

Most of the research measuring stress in family members has been descriptive. A total of 1 cross-sectional study and 6 longitudinal and descriptive studies had sample sizes from 32 to 284 family members. The studies included mostly families of patients from medical, surgical, cardiac, and trauma ICUs. Only 1 study included family members of patients in pediatric and neonatal ICUs. Most of these studies were completed in single centers. A variety of instruments were used to measure stress. Range, 0 to 75 Higher scores indicate more traumatic stress Two common cutoff points used in research (not for diagnosis): scores >19 indicate possibility of PTSD and scores >30 indicate high probability of PTSD

Traumatic stress scores are higher in families without advance directives compared to those with directives. Overall stress response scores, traumatic stress scores are higher in families without advance directives compared to those with directives.

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Factors associated with higher stress response scores and symptoms related to ASD, PTSD, and PTSR in patients’ family members have been reported. Azoulay et al., using a multivariate linear model, found that mean PTSR scores were significantly higher in females, children, and persons who thought the information regarding the patient’s condition was incomplete. Chui and Chan reported that females had significantly higher traumatic stress scores than did males ($t = -4.60, P < .001$). They also reported that family members had significantly higher traumatic stress scores if the family members had lower education levels ($P = 3.0, P = .05$) and the patient’s ICU admission was unplanned ($t = -2.2, P = .03$). Several investigators reported that stress response scores and ASD scores were higher for patients’ family members when the patient was admitted to the ICU, but tended to decrease by the time the patient was discharged. Other investigators, however, found that a longer stay for a patient was significantly associated with higher traumatic stress levels in the patient’s family members ($r = 0.5, P < .001$). Because length of stay was not clearly reported in 2 of the studies and because length of stay varied from a mean of 3 days to 26 days in the other studies, how much length of stay influences stress levels in patients’ family members is still unclear.

The effect of a patient’s death on family members’ traumatic stress and PTSR scores was assessed in only 2 of the 7 descriptive studies. Tilden et al. studied traumatic stress levels in 74 family members of patients 2 months after the family members had to make end-of-life decisions in the ICU. The traumatic stress scores were significantly higher in family members of patients who did not have any form of advance directives than in family members of patients who had either verbal or written advance directives. Azoulay et al. assessed PTSR scores in 234 family members of patients discharged from the ICU and compared the scores with those of 50 family members of patients who died in the ICU. The prevalence of PTSR was greater in family members of patients who had died in the ICU, particularly if the family member was involved with end-of-life decision making (81.3%).

Depression

A total of 1 longitudinal study and 4 descriptive studies on depression in family members were reviewed. Sample sizes were from 32 to 836 family members. Most of the studies included family members of patients in medical, surgical, and cardiac ICUs; only 1 study included pediatric ICU patients. The studies were mostly prospective and descriptive and were completed in multiple hospitals. Most of the investigators used the same instrument to assess depression, the Hospital Anxiety and Depression Scale; one group used the Center for Epidemiologic Studies Depression Scale (Table 2). The time frames for measuring depression varied, from 3 to 5 days after admission, to 3 months after discharge, to the time of the patient’s death or discharge from the ICU.

In general, the findings indicated that depression affected about 15% to 35% of patients’ family members. When investigators assessed factors associated with depression, they found that being a spouse (odds ratio [OR] = 2.1, $P < .001$) and being female (OR = 2.0, $P < .001$) significantly increased the risk for symptoms of depression. In addition, inconsistent information given to family members about the patient’s condition was associated with significantly higher risk of symptoms of depression (OR = 1.67, $P = .04$).

Pochard and colleagues assessed the impact of a patient’s severity of illness and death on family members’ symptoms of depression. In a study completed in 2001, the investigators found no significant correlation between the patient’s severity of illness or death and family members’ depression scores. However, in another study completed in 2005, the odds of family members of patients who died in the ICU having symptoms of depression were twice as high as those of family members of a patient who survived (OR = 2.09, $P = .01$). The patient’s severity-of-illness score also influenced depression in family members, but the influence was negligible. The discrepancy between these studies could be explained by the differences in the patients in the 2 studies. Although no information was provided about patients’ diagnoses, the severity-of-illness scores were lower (median Simplified Acute Physiology Score II, 38 vs 42) and the length of stay....

Medical ICU families have more negative feelings than do those in other types of ICUs.
injuries ($t = 2.04, P = .05$) had significantly more anxiety than did other family members. Having no regular meetings with a physician or nurse also was significantly associated with an increased risk of anxiety in family members (OR = 1.36, $P = .02$), as was the patient having an absence of chronic disease (OR = 1.52, $P = .02$). Reider also reported that coping strategies may affect anxiety levels in family members, whereas Delva et al. found that family needs may affect anxiety in family members. In only 1 of the 7 descriptive studies was the prevalence of anxiety in family members of patients who died in the ICU (n = 91) compared with that in family members of ICU survivors (n = 435). Even though both groups had high prevalence rates of anxiety, the difference in the prevalence between the 2 groups was not significant.

### Qualitative Research on Family Symptoms

#### Anxiety

Several investigators examined anxiety in family members of ICU patients. Most of these studies were descriptive, and the sample sizes varied from 32 to 836 family members. The majority of the studies were conducted at a single center and were focused mainly on patients from medical, surgical, and cardiac ICUs. One study also included pediatric patients. Time frames used to measure anxiety varied, from 48 to 72 hours after a patient’s admission, to 3 months after discharge, to the patient’s death or discharge from the ICU. The main instruments used in these studies were the Spielberger State Trait Anxiety Inventory, the Hospital Anxiety and Depression Scale, and the Brief Symptom Inventory (Table 2).

The prevalence rate of anxiety in family members in several of the studies was from 35% to 73%. In other investigations, intensity levels of anxiety in family members ranged from moderate to high. Risk factors associated with an increase in symptoms of anxiety in patients’ family members included being a spouse of a patient, being a female family member, the patient’s having had an unplanned ICU admission, and having a lower educational status. Reider reported that family members of patients with neurological illness ($t = 2.55, P = .01$) and traumatic injuries ($t = 2.04, P = .05$) had significantly more anxiety than did other family members. Having no regular meetings with a physician or nurse also was significantly associated with an increased risk of anxiety in family members (OR = 1.36, $P = .02$), as was the patient having an absence of chronic disease (OR = 1.52, $P = .02$). Reider also reported that coping strategies may affect anxiety levels in family members, whereas Delva et al. found that family needs may affect anxiety in family members.

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### Table 2: Instruments used to measure anxiety and depression

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Measures</th>
<th>Score range</th>
<th>Psychometric properties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Anxiety and Depression Scale</td>
<td>Two subscales: anxiety (7 items) and depression (7 items)</td>
<td>Range, 0-21</td>
<td>Cronbach α = 0.93 for anxiety and 0.90 for depression subscales</td>
</tr>
<tr>
<td>Spielberger State-Trait Anxiety Inventory</td>
<td>6-item subscale with a 5-point Likert scale used to measure psychological anxiety at current point in time</td>
<td>Range, 0-24</td>
<td>Stability ranges from .16 to .62</td>
</tr>
<tr>
<td>Brief Symptom Inventory</td>
<td>6-item subscale with a 5-point Likert scale used to measure psychological anxiety at current point in time</td>
<td>Range, 0-60</td>
<td>Cronbach α ranges from 0.83 to 0.88</td>
</tr>
</tbody>
</table>

Family members have high anxiety levels and moderate depression levels.
family members of patients in the medical ICU had more negative feelings than did family members of patients in other types of ICUs.13

Titler et al10 used a phenomenological approach to assess the effect of critical care hospitalization on patients’ family members from multiple perspectives. The researchers interviewed and audiotaped 23 family members, 9 patients, and 12 ICU nurses. Both patients and family members had feelings of guilt, fear, and uncertainty. In addition, family members had potential stressors, such as marked changes in family relationships, multiple conflicts about the roles of the family members, and lack of communication within the family, that could cause symptoms. Nurses and family members differed in their perceptions of the impact of critical care on the families. Nurses perceived the impact as less severe than family members did.12

Experimental Research on Family Symptoms

Two studies5,11 on family members of ICU patients provided interventions to reduce PTSD-related symptoms, anxiety, and depression levels in family members. Two other studies5,10,11 focused on reducing just anxiety levels in family members.

Lautrette et al25 used a randomized controlled trial design in 22 ICUs in France to test the effectiveness of a proactive communication intervention on reducing PTSD-related symptoms and symptoms of anxiety and depression in family members of ICU patients at the end of life. The intervention involved an end-of-life conference based on the mnemonic VALUE.53,54 This mnemonic includes specified guidelines where clinicians value what the family wishes, listen, ask questions in order to understand who the patient was as a person, and elicit questions from the family members. Lautrette et al25 found that the prevalence of PTSD-related symptoms was lower in the intervention group than in the control group (45% vs 69%, P = .01). They reported that the prevalence rates of anxiety and depression also were lower in the intervention group than in the control group (anxiety, 45% vs 67%; P = .02; depression 29% vs 56%; P = .03).

In another study, Chien et al13 used a quasi-experimental pretest-posttest design to determine the effectiveness of a needs-based education program on reducing anxiety levels in family members of patients in a medical ICU in Hong Kong. The intervention involved a one-hour-long educational session focusing on specific family members’ needs on both days 2 and 3 of the ICU stay. Compared with the group receiving standard care, the treatment group had significantly reduced anxiety levels (t = 2.37, P = .006).13

Jones et al16 tested the effectiveness of a self-help educational module on reducing family members’ PTSD-related symptoms, depression, and anxiety and found that the intervention did not significantly reduce PTSD-related symptoms, anxiety, or depression in the treatment group. Halm30 used a quasi-experimental design to measure the effects of a support group intervention on anxiety in family members of patients in a surgical ICU. Halm also found no significant difference in reduction of anxiety levels between the treatment group (n = 25) and the control group (n = 30).

Researchers reported significant decreases in psychological symptoms in family members in 2 of the 4 intervention studies, whereas no significant results were reported in the other 2 studies. These findings may best be explained by the specificity of the interventions. Possibly, general interventions (eg, informational booklets and support groups) are not as effective as more individualized interventions (eg, targeting family members’ specific needs and using a specific proactive communication technique) for reducing the symptoms experienced by patients’ family members.

Summary Critique of the Literature

In this review of the literature, 18 studies have been presented. A total of 89% were quantitative and 11% were qualitative. Of the quantitative studies, 78% were descriptive and 22% were experimental. Most often only 1 symptom was assessed, but in several studies, multiple symptoms such as PTSD, PTSD-related symptoms, anxiety, and depression were measured together. The main findings from all of the quantitative studies suggest that family members of ICU patients have high levels of stress, including PTSD, PTSD-related symptoms, and ASD. These findings also suggest that family members have high anxiety levels and moderate depression levels. Certain variables are associated with higher levels of psychological symptoms in family members (Table 3). The main findings from the qualitative studies indicate that patients’ family members have negative emotions and multiple stressors that could affect family relationships, roles, and communication.
Overall, self-report measures and surveys were the predominant methods used. Of the 4 experimental studies, only 2 yielded any statistically significant results. Therefore, despite promising data from these studies, assessments of family members' symptoms and interventions are still at the early phase of development. Although these studies help build a knowledge base of symptoms experienced by patients' family members, several limitations are apparent.

Convenience samples, small sample size, and a lack of description of characteristics of patients in the sample make it difficult to compare and generalize findings across settings and populations of patients. Some of the researchers did not describe the content of the survey items or the reliability of the tools, although several others provided more detail regarding the instruments used and the established reliability and validity of the tools. No consistent time frames were used to measure the symptoms (range was 48 hours after ICU admission to 3-6 months after ICU discharge or death), so it is difficult to know the best time to gather data on the symptom experience. Symptoms appeared to have occurred at all time frames, however, indicating that family members may have symptoms throughout the ICU experience and long afterward.

Another limitation of the research on symptoms experienced by family members is that most of the studies were completed in countries other than the United States, countries where the health care system and ICU cultures are vastly different from those in the United States. Finally, most studies were not focused on family members of ICU patients at high risk of dying, but on family members of patients who were discharged from the ICU. It therefore remains unclear whether family members of high-risk patients may have a different symptom experience.

**Implications for Practice**

Even though research on symptoms experienced by family members of ICU patients who are at high risk of dying is in its infancy, the findings from current studies can shed some light on how to reduce family members’ symptoms. Investigators have documented risk factors associated with an increase in symptoms in patients’ family members (Table 3).

These risk factors can be identified during a family assessment. Once the factors are identified, ICU clinicians can offer spiritual and emotional support to the family and intervene as appropriate with referrals to chaplain services or another service according to hospital policy.

ICU clinicians can also be proactive in their approach with family care conferences. Incorporating a structured care conference that improves communication, such as the one discussed earlier by Lautrette et al, significantly reduces symptoms of PTSD, anxiety, and depression in family members who are making end-of-life decisions. In addition, ICU clinicians can have regular meetings with patients’ family members and provide honest and consistent information about the patient. This process may reduce anxiety and depression in patients’ family members.

Finally, ICU clinicians can develop supportive relationships with family members by assessing the members’ needs and by showing compassion and respect for the members and the members’ decisions. This supportive relationship has been linked to an increase in satisfaction of patients’ families and could possibly reduce family members’ symptoms.

**Directions for Future Research**

This review of the literature revealed several gaps in knowledge. The most noticeable gap is the lack of information on the symptoms experienced by family members of ICU patients at high risk of dying. Only 2 of the 18 articles focused specifically on this population. Although the findings from other studies could cautiously be generalized to all families in the ICU, more research is needed on the risk factors for family members of high-risk patients.

Another area that requires further investigation is patient-related factors such as length of stay, severity of illness, and mortality rates found in previous studies. Because of the conflicting results, more descriptive research on these factors is required to see if the factors are associated with an increase in symptoms...
in family members’ psychological symptoms. Knowledge of these factors will help clinicians identify those family members at greatest risk of symptoms and intervene as appropriate.

Prior research included samples consisting mostly of white, female, and educated family members. Therefore, our knowledge of the symptoms experienced in males and people of diverse cultural and educational backgrounds is limited. More descriptive research is needed on diverse samples of family members to assess if variables such as a family member’s cultural and educational background affect the family member’s symptoms. Future research should also focus on the role of spiritual care to assess the effect that such care may have on reducing family members’ symptoms. Research is also needed on other factors, such as the family’s coping skills, needs, and family functioning. These factors are associated with an increase in psychological symptoms in family members and in other critical care populations such as neonates in ICUs.

Most researchers have focused mainly on psychological symptoms of patients’ family members such as stress, anxiety, and depression. Knowledge about other types of symptoms that family members may have, such as sleep and fatigue problems, appetite problems, or pain, have not been addressed. Physical symptoms must be assessed because these symptoms could affect overall well-being.

Most of the research on family symptoms has been cross-sectional and descriptive. Additional research should include mixed-methods research designs and longitudinal and interventional studies. Mixed-methods designs are more comprehensive and may be useful in identifying variables unique to patients’ family members by using both qualitative and quantitative strategies. Longitudinal studies would allow researchers to assess long-term consequences of symptoms, such as complicated grief or PTSD reactions, in family members. Interventional studies would allow researchers to test strategies to reduce symptoms in family members that may prevent long-term consequences of these symptoms.

Organizationally, studies are needed to assess hospital or ICU factors that may affect symptoms in patients’ family members. Studies are needed to assess ICU clinicians’ perceptions of the severity of family members’ symptoms and to determine whether those perceptions are similar to or different from the families’ reports of their symptoms. Any discrepancies could affect the amount of support and interventions offered to the family members. Studies are also needed to compare hospitals that have end-of-life protocols or palliative care programs with hospitals that lack such policies and programs. The results of these studies can help researchers determine if hospital policies on end-of-life care, such as end-of-life care conferences, affect the level of support for patients’ families and help reduce symptoms in family members.

Although research on end-of-life care in the ICU has raised potential ethical issues for investigators, these concerns are not unique to this field of study. Yet researchers in this field need to ask appropriate research questions, use appropriate methods, and provide valid findings that are generalizable. Investigators should ensure that the consent process remains thoughtful and that the study design ensures maximum benefits while minimizing risks to participants.

Conclusion

Family members of dying patients play an integral role in the patients’ care in the ICU. Patients’ families are expected to make unprecedented decisions and deal with many difficult situations. In turn, they may have psychological symptoms such as stress, PTSD-related symptoms, anxiety, and depression, which can affect their general well-being. Researchers have developed a knowledge base on variables associated with an increase in family members’ symptoms. However, additional research is critical to expand our knowledge of symptoms experienced by family members of patients in the ICU, especially at the patients’ end-of-life. Further research will help clinicians develop supportive measures to assist patients’ family members during this difficult time.

FINANCIAL DISCLOSURES

None reported.

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For more about helping the families of patients in the intensive care unit, visit the Critical Care Nurse Web site, www.ccnonline.org, and read the article by Carter and Clark, “Assessing and Treating Sleep Problems in Family Caregivers of Intensive Care Unit Patients” (February 2005).

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1. What is the purpose of the article?
   a. Question family members about their experiences
   b. Develop a research study to further understand family experiences
   c. Critically review literature regarding family member experiences
   d. Develop care plan to help families and patients during ICU stay

2. Why is concern for family members of patients in the ICU important?
   a. It is an integral part of holistic care.
   b. It lessens the burden in decision making.
   c. It assists with treatment choices.
   d. It is part of clinical guidelines since the 1970s.

3. What research design was mostly used for family member studies starting in the 1970s?
   a. Quantitative and descriptive
   b. Qualitative and descriptive
   c. Quantitative and experimental
   d. Qualitative and experimental

4. What was the setting and participant type for the majority of the studies from the mid-1970s?
   a. Coronary care unit and wives
   b. Medical intensive care unit and parents
   c. Surgical intensive care unit and wives
   d. Coronary care unit and husbands

5. When did investigators understand family members in the ICU could potentially suffer from clinically diagnosable psychological problems?
   a. Mid-1970s
   b. Early 1980s
   c. Late 1980s
   d. Early 1990s

6. What symptoms were reported among the family members studied by Perez et al?
   a. Mania
   b. Suicidal depression
   c. Schizophrenia
   d. High energy depression

7. What is ASD?
   a. Acute suicidal depression
   b. Acute symptomatic depression
   c. Asymptomatic stress disorder
   d. Acute stress disorder

8. Which of the following were factors associated with high stress scores of family members?
   a. Incomplete information about a loved one
   b. Higher education levels
   c. Planned ICU visit
   d. Early discharge from the ICU

9. Which of the following statements is true?
   a. Length of stay was clearly a stressful factor.
   b. Clear advance directives helped to lessen stress in family members.
   c. There was no prevalence of posttraumatic stress reaction in families making end-of-life scores.
   d. High education helped increase stress scores.

10. What 2 factors increased the risk of depression?
    a. Spouse of patient and female
    b. Inconsistent information and male
    c. Severity of illness and child
    d. Prolonged ICU stay and male

11. Which family members had more negative feelings?
    a. Family members in a surgical intensive care unit
    b. Family members in a coronary intensive care unit
    c. Family members in a neonatal intensive care unit
    d. Family members in a medical intensive care unit

12. What intervention significantly decreases symptoms of posttraumatic stress disorder, anxiety, and depression in family members making end-of-life decisions, according to Lautrette and colleagues?
    a. Structured care conferences
    b. Chaplain services
    c. Informal family meetings
    d. Supportive relations

The American Association of Critical-Care Nurses is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center’s Commission on Accreditation.
Symptoms Experienced by Family Members of Patients in Intensive Care Units
Jennifer L. McAdam and Kathleen Puntillo

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