Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005

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Objective: To develop clinical practice guidelines for the support of the patient and family in the adult, pediatric, or neonatal patient-centered ICU.

Participants: A multidisciplinary task force of experts in critical care practice was convened from the membership of the American College of Critical Care Medicine (ACCM) and the Society of Critical Care Medicine (SCCM) to include representation from adult, pediatric, and neonatal intensive care units.

Evidence: The task force members reviewed the published literature. The Cochrane library, Cinahl, and MedLine were queried for articles published between 1980 and 2003. Studies were scored according to Cochrane methodology. Where evidence did not exist or was of a low level, consensus was derived from expert opinion.

Consensus Process: The topic was divided into subheadings: decision making, family coping, staff stress related to family interactions, cultural support, spiritual/religious support, family visitation, family presence on rounds, family presence at resuscitation, family environment of care, and palliative care. Each section was led by one task force member. Each section draft was reviewed by the group and debated until consensus was achieved. The draft document was reviewed by a committee of the Board of Regents of the ACCM. After steering committee approval, the draft was approved by the SCCM Council and was again subjected to peer review by this journal.

Conclusions: More than 300 related studies were reviewed. However, the level of evidence in most cases is at Cochrane level 4 or 5, indicating the need for further research. Forty-three recommendations are presented that include, but are not limited to, endorsement of a shared decision-making model, early and repeated care conferencing to reduce family stress and improve consistency in communication, honoring culturally appropriate requests for truth-telling and informed refusal, spiritual support, staff education and debriefing to minimize the impact of family interactions on staff health, family presence at both rounds and resuscitation, open flexible visitation, way-finding and family-friendly signage, and family support before, during, and after a death. (Crit Care Med 2007; 35:605–622)

KEY WORDS: family; family support; family presence; resuscitation; rounds; patient centered care; communication; intensive care unit; coping; stress; post traumatic stress disorder; palliative care; cultural; spiritual; religious; decision making; nursing; visiting; family needs; adult; pediatric; neonatal; environment; professional-family relations; multidisciplinary care teams; terminally ill patients; terminal care; critical care nursing; right to die; family-centered care; attitude to death; patient care team; bereavement; family relations; intensive care nursing; pastoral care; patient education; holistic care; grief

I n 2001, the Institute of Medicine strongly recommended that healthcare delivery systems become patient-centered rather than clinician- or disease-centered, with treatment recommendations and decision making tailored to patients' preferences and beliefs (1). In the Institute of Medicine's patient-centered model, a) patients and families are kept informed and actively involved in medical decision-making and self-management; b) patient care is coordinated and integrated across groups of healthcare providers; c) healthcare delivery systems provide for the

physical comfort and emotional support of patients and family members; d) healthcare providers have a clear understanding of patients' concepts of illness and their cultural beliefs; and e) healthcare providers understand and apply principles of disease prevention and behavioral change appropriate for diverse populations.

Several studies have demonstrated that patient-centered care is associated with better clinical outcomes (2–5). Nowhere is the need for patient-centered care greater than in the intensive care unit (ICU), where patient and family involvement can profoundly influence clinical decision making and patient outcomes. Because critically ill patients are often unable to communicate with healthcare providers or participate in care decisions, responsibility often falls to others to function as surrogate decision makers. Surrogates may be immediate family members (as defined by the patient or by legal precedent) or others named in Durable Power of Attorney for Health Care documents.

Patients and families are expressing a desire for a larger role in healthcare decision making and are asking providers to do a better job of responding to patient and family needs (6–8). Despite these concerns, families and other surrogates often feel uninformed and disenfranchised from clinical decision making and day-to-day care of loved ones in the ICU (9, 10). For the patient-centered care model to be realized fully in the ICU, family members and surrogate decision makers must become active partners in multiprofessional decision making and care. These individuals often have firsthand insight into patients' preferences and can make important contributions to care decisions, particularly when patients are unable to advocate for themselves.

To date, there are no published guidelines defining standards for incorporating families into decision making and care for ICU patients. The following guidelines, developed in response to the request of the American College of Critical Care Medicine (ACCM) of the Society of Critical Care Medicine (SCCM), attempt to define evidence-based best practices for support of families in the delivery of patient-centered care in the ICU. The guidelines are organized under the following subheadings:

Decision Making
Family Coping
Staff Stress Related to Family Interactions
Cultural Support of the Family
Spiritual/Religious Support
Family Visitation
Family Environment of Care
Family Presence on Rounds
Family Presence at Resuscitation
Palliative Care

Methodology

These guidelines were developed following an extensive literature review. The search was conducted through the Cochrane library, Cinahl, and MedLine for articles published between 1980 and 2003 related to the entirety of the topic of family-centered care. Additional searches were conducted using keywords associated with the previously listed subheadings. For the topics of family visitation, family environment of care, family presence on rounds, and family witnessed resuscitation, the search years were narrowed due to a clear shift in focus and philosophy in the late 1990s. Articles published in 2004 and 2005 were added after the initial search. The review encompassed adult, pediatric, and neonatal literature.

Search results were loaded by subheading to a task force e-room of the Society of Critical Care Medicine. Authors were assigned a subheading and instructed to retain for further analysis any articles containing metrics (including survey research) or notable publications of consensus.

Cochrane methodology was used to evaluate each article's level of evidence and to grade the recommendations (Table 1). Most of the research reviewed was Cochrane level 4 or 5 (case series, expert opinion, or survey research). Each section of the guidelines concludes with recommendations. Unless otherwise noted, recommendations apply equally to care in adult, pediatric, and neonatal environments.

For the section on palliative care, the task force reviewed the *Clinical Practice Guidelines for Quality Care*, released in 2004 by the National Consensus Project for Quality Palliative Care (11). Although the National Consensus Project guidelines pertain to both patient and family care, they are also applicable to family support. The SCCM endorses the recommendations of the National Consensus Project in their entirety.

For the purposes of this document, the definition of family published by the National Consensus Project for Quality Palliative Care is adopted: "Family is defined by the patient or in the case of minors or those without decision making capacity by their surrogates. In this context the family may be related or unrelated to the patient. They are individuals who provide support and with whom the patient has a significant relationship" (11).

Decision Making

In the past, two primary models of medical decision making have existed: the patient autonomy model and the paternalistic model (12, 13). In the first, responsibility for medical decisions rests with the patient or an appropriate surrogate. In the second, physicians have authority for medical decision making.

During times of crisis, the autonomy model may place an undue burden on families and can be viewed as a form of abandonment (14). In the interests of patient autonomy, physicians may ask family members, who are in a heightened emotional state, to understand complex medical conditions, accept prognostic uncertainty, weigh various complex treatment options, and then take sole responsibility for end-of-life decision making and withdrawal of life support, often with limited information and coping tools.

The literature indicates that patients and their surrogates need more decision-making help from the ICU team than the patient autonomy model allows (15). A new model, known as shared decision making, has been introduced over the past several years (16, 17). In shared decision making, a genuine partnership is formed among the ICU team, patients, and their loved ones. Through this partnership, patients' preferences can be identified, the anxiety of families can be lessened, and physicians can have appropriate input into decisions. A recent multiple-society-sponsored international consensus conference on end-of-life care concluded that shared decision making should be viewed as the primary model for making medical decisions in the ICU (18).

Recent data suggest that families in both North America and Europe favor the shared decision-making model (18–23). Cultural attitudes of the patient and family need to be addressed and respected

Table 1. Cochrane methodology: Levels of evidence and grades of recommendations, November 23, 1999

Grade of Recommendation	Level of Evidence	Therapy/Prevention, Etiology/Harm	Prognosis	Diagnosis
A	1a	SR (with homogeneity[a]) of RCTs	SR (with homogeneity) of inception cohort studies, or a CPG validated on a test set	SR (with homogeneity) of level 1 diagnostic studies, or a CPG validated on a test set
	1b	Individual RCT (with narrow confidence interval)	Individual inception cohort study with ≥80% follow-up	Independent blind comparison of an appropriate spectrum of consecutive patients, all of whom have undergone both the diagnostic test and the reference standard
	1c	All or none[c]	All or none case series[d]	Absolute SpPins and SnNouts
B	2a	SR (with homogeneity) of cohort studies	SR (with homogeneity) of either retrospective cohort studies or untreated control groups in RCTs	SR (with homogeneity) of level ≥2 diagnostic studies
	2b	Individual cohort study (including low-quality RCTs; e.g., <80% follow-up)	Retrospective cohort study or follow-up of untreated control patients in an RCT, or CPG not validated in a test set	Any of the following: 1. Independent blind or objective comparison 2. Study performed in a set of nonconsecutive patients, or confined to a narrow spectrum of study individuals (or both) all of whom have undergone both the diagnostic test and the reference standard 3. A diagnostic CPG not validated in a test set
	2c	"Outcomes" research	"Outcomes" research	
	3a	SR (with homogeneity) of case-control studies		
	3b	Individual case-control study		Independent blind comparison of an appropriate spectrum, but the reference standard was not applied to all study patients
C	4	Case-series (and poor-quality cohort and case-control studies[e])	Case-series (and poor-quality prognostic cohort studies[f])	Any of the following: • Reference standard was unobjective, unblinded, or not • Independent • Positive and negative tests were verified using separate reference standards • Study was performed in an inappropriate spectrum of patients
D	5	Expert opinion without explicit critical appraisal, or based on physiology, bench research, or "first principles"	Expert opinion without explicit critical appraisal, or based on physiology, bench research, or "first principles"	Expert opinion without explicit critical appraisal, or based on physiology, bench research, or "first principles"

SR, systematic review; RCT, randomized controlled trial; CPG, Clinical Prediction Guide; SpPins, diagnostic finding whose *specificity* is so high that a *p*ositive result rules *in* the diagnosis; SnNout, diagnostic finding whose *sensitivity* is so high that a *n*egative result rules *out* the diagnosis.

[a]By homogeneity we mean a systematic review that is free of worrisome variations (heterogeneity) in the directions and degrees of results between individual studies. Not all systematic reviews with statistically significant heterogeneity need be worrisome, and not all worrisome heterogeneity need be statistically significant. Studies displaying a worrisome heterogeneity should be tagged with a "-" at the end of their designated level. [c]Met when all patients died before the prescription became available, but some now survive it, or when some patients died before the prescription became available, but none now die on its. [d]Met when there are no reports of anyone with this condition ever avoiding (all) or suffering from (none) a particular outcome (such as death). [e]By poor-quality cohort study we mean one that failed to clearly define comparison groups and/or failed to measure exposures and outcomes in the same (preferably blinded), objective way in both exposed and nonexposed individuals and/or failed to identify or appropriately control known confounders and/or failed to carry out a sufficiently long and complete follow-up of patients. By poor-quality case-control study we mean one that failed to clearly define comparison groups and/or failed to measure exposures and outcomes in the same blinded, objective way in both cases and controls and/or failed to identify or appropriately control known confounders. [f]By poor-quality prognostic cohort study we mean one in which sampling was biased in favor of patients who already had the target outcome, or the measurement of outcomes was accomplished in <80% of study patients, or outcomes were determined in an unblinded, nonobjective way, or there was no correction for confounding factors.

when using the model (see Cultural Support of the Family).

Shared decision making requires regular meetings between ICU team members as well as meetings between the ICU team and family (19). The authors of this document concur that good communication skills, conflict management skills, and meeting facilitation skills are needed for the shared decision-making model to be effective; training in these skills should become a standard component of medical education and should be widely available for all ICU caregivers. One intervention study in a neonatal intensive

care unit (NICU) found that meetings between healthcare professionals and parents using the shared decision-making model produced fewer decision-making conflicts, created fewer unrealistic parental expectations, and improved collaboration between providers and family members. The model also helped parents gain a more accurate understanding of their child's medical condition (24).

Health information privacy regulations regarding the choice and number of family members involved in discussions are considered while acting in the best interest of the patient. During a family meeting, once all stakeholders are present, family members should be asked open-ended questions about what they understand about their loved one's condition, how they are coping, and what they fear (25). Once family members have spoken, care providers should repeat what they have heard. Reflective iteration allows family members to correct any misunderstandings; it also fosters trust in the healthcare team and the decision-making process.

After all family members have spoken and verified that practitioners have heard them correctly, practitioners should provide clear and honest information regarding prognosis (20, 26–38) and then allow ample opportunity for questions. The goal is to enable families to clarify the decisions they face and practitioners to understand the values and experiences of family members.

In the case of an incompetent patient who was previously competent, it may be helpful to ask, "If your loved one were able to speak for herself, what do you think she would want us to do for her?" Such a question helps family members frame the question from the patient's perspective (25).

When decisions must be made, it is best to strive for consensus. Respect and acknowledge what each decision maker brings to the table. Together, all present should determine the best course of action (25). When all stakeholders have expressed their opinions and feel that they have been heard, they are generally willing to support the group decision, even when it runs counter to their own views.

Recommendation 1: Decision making in the ICU is based on a partnership between the patient, his or her appointed surrogate, and the multiprofessional team. Grade of Recommendation: B

Recommendation 2: Practitioners fully disclose the patient's current status and prognosis to designated surrogates and clearly explain all reasonable management options. Grade of Recommendation: B (see recommendations 3 and 4 in the Cultural Support of the Family section)

Recommendation 3: ICU caregivers strive to understand the level of life-sustaining therapies desired by patients, either directly from those patients or via their surrogates. Grade of Recommendation: D

Recommendation 4: Family meetings with the multiprofessional team begin within 24–48 hrs after ICU admission and are repeated as dictated by the condition of the patient with input from all pertinent members of the multiprofessional team. Grade of Recommendation: B (see also Staff Stress Related to Family Interactions section)

Recommendation 5: ICU caregivers receive training in communication, conflict management, and meeting facilitation skills. Grade of Recommendation: C

Family Coping

Having a loved one in an ICU is stressful for family members. The literature identifies a variety of stress factors, as well as factors that do *not* correlate with family stress or anxiety. For example, surveys that looked at cultural differences in stress levels found none (39–43).

The use of mechanical ventilation was not found to be predictive of stress or anxiety for family members; objective acuity scores remained constant whether or not the patient was on a ventilator (44–47). Stress levels do not seem to lessen with longer ICU stays (48).

Families of ICU patients have a variety of needs: Stress levels rise when these are not met. High on the list is the need to maintain hope; to have questions answered honestly, in terms families can understand; to be notified promptly of any changes in the patient's status; and to be allowed to visit the patient anytime. Families also require assurance that their loved one is receiving quality care (49–63). The definition of hope may extend past the absence of death and include hope for a pain-free and dignified death or hope for more time or quality time together. Environmental amenities were found to be low on the list of family needs

(60, 64). The transfer from the ICU to the floor induces stress on the patient and family. Written information provided to families may ease the transition out of the ICU (65). Computerized education services such as access to the SCCM-endorsed www.icu-usa.com may help meet some family needs for information (66).

Families find it frustrating and confusing to deal with a host of healthcare providers in the ICU. Family dissatisfaction increases if more than two ICU physicians care for the patient or if the patient has a different nurse from one day to the next (67, 68). Nurses need more training in assessing stress levels and anticipating family needs. In studies to determine whether family needs were being met, nurses were generally only about 50% accurate in predicting family needs (49, 50, 52, 69–71).

Factors associated with the highest stress for parents of neonatal and pediatric patients include disruption of normal interactions with the child, changes in the child's behavior or emotions, parents' inability to comfort the child, having a child undergo painful procedures, and changes in the child's appearance (72–76). Parents experience stress long after their children are discharged. Two pediatric studies found that parents' stress-related symptoms persist as long as 6 months postdischarge. A neonatal study showed that mothers of high-risk, very low birth weight infants experienced psychological distress even when the child reached 2 years of age (77–79).

Children of ICU patients also experience anxiety. One study showed that children of ICU patients fear their parent's death and that these fears lessen when children were allowed to visit (80).

High levels of anxiety and depression in family members may affect their ability to make end-of-life decisions (81). The use of problem-focused coping strategies and social supports lowers stress for family members (82, 83), although formal support groups seem to be more effective for parents of children in intensive care than for families of adult patients.

Two interventional studies evaluating families of adult patients showed no statistical difference in stress reduction in family members who attended a support group (84, 85). A third study showed a 50% reduction in state anxiety (anxiety caused by an experience) for family members who attended a support group (compared with a control group) (86). Another

small pediatric study showed that parental anxiety was reduced if parents were allowed to observe and be with their child while undergoing procedures (87).

Parent education can be very helpful in minimizing the stress of a pediatric intensive care unit (PICU) or NICU admission. In a randomized interventional pilot study, parents received written and audiotaped information about infant and child behavior while in the ICU, parent-child interactions, and therapy. Compared with the control group, study parents had less stress, fewer depressive symptoms, and better bonding and interactions with their child (88, 89). Other forms of parent support have also been shown to reduce stress and improve parent-infant interactions, including individualized and formalized family-based interventions, training in coping strategies and stress management techniques, pairing of parents of current NICU or PICU patients with parents of former patients, and journal writing (90–95).

It is now known that families of critically ill patients of all ages may develop anxiety, depression, and posttraumatic stress syndrome (96–105). One intervention study has shown that prospective diaries with review and follow-up may improve communication and goal setting and provide comfort (96). In a study of parents of children in the PICU, no relationship was found between incidence of posttraumatic stress disorder in the parent and severity of illness (100). Although none of the literature reviewed spoke to the issue of family involvement in care, the authors agree by consensus that liberal inclusion into care for those who desire it should be allowed. (See also Family Presence on Rounds and Family Environment of Care and Family Visitation.)

Recommendation 1: ICU staff receive training in how to assess family needs and family members' stress and anxiety levels. Grade of Recommendation: C
Recommendation 2: Nursing and physician staff assigned to each patient are as consistent as possible. Family members receive regular updates in language they can understand, but the number of health professionals who provide information is kept to a minimum. Grade of Recommendation: C
Recommendation 3: Families are encouraged to provide as much care as the patient's condition will allow and they are comfortable providing. Grade of Recommendation: D
Recommendation 4: Family members are provided with ample information in a variety of formats on emotional needs in the ICU and methods appropriate to comfort and assist in care. Grade of Recommendation: C
Recommendation 5: Family support is provided by the multiprofessional team, including social workers, clergy, nursing, medicine, and parent support groups. Grade of Recommendation: C

Staff Stress Related to Family Interactions

The literature reviewed for these guidelines included articles representing the perspectives of physicians, nurses, support staff, and families. Survey results, qualitative grounded theory, and opinion pieces described how particular institutions handled staff stress (106–153).

Poor communication is a major source of stress for staff. One study showed that nursing stress increases when nurses do not have enough information about a case to answer questions from the family and also when communication is poor between the physician and the family (152).

In a patient-centered environment, multiprofessional care is the norm. With many people involved in and concerned about the patient's care, it is important to establish clear lines of communication, both among various members of the healthcare team and between the team and the family.

Educating families on how the ICU works with respect to visiting hours, when rounds occur, and when and how the physician can be reached can also reduce friction. It is useful to identify a family spokesperson and the family member who will be making decisions on the patient's behalf as soon as a patient is admitted to the ICU.

Routine communication from the ICU physician, both with family representatives and with the healthcare team, is indicated to clarify treatment goals and duties of various team members. Family representatives should be introduced to the care team, and the roles played by each team member should be clearly explained.

The healthcare team includes the ICU physician, consulting physicians (including the primary care physician, if available), nurses, social worker, chaplain, and appropriate additional ancillary staff. For example, a respiratory therapist should be included in discussions with the family regarding ventilated patients. Involvement of clergy can help the staff understand different cultures and belief systems and thus prevent or relieve stress. A broadly inclusive multiprofessional team allows healthcare providers to take an organized approach to achieving common goals, which may also prevent or eliminate stress (152).

Well-planned routine care conferences are important to provide objective information, to share opinions, and to reach consensus on common goals. These conferences may be held for the purpose of providing status reports or for making a treatment decision. All team members should be invited to discuss the case from their perspective, which educates each member of the team. Collaborative care planning may resolve or defuse conflicts between the family and the team or within the team, thereby reducing staff stress (121, 126, 127, 148).

In addition to care conferences, ICU staff members need the opportunity to decompress and confront feelings about patients and their outcomes. An unexpected adverse event or medical error may trigger the need for a staff debriefing, and the resuscitation team may require routine debriefings. A survey of pediatric nurses found that stress increases when the decision to continue treatment is against the nurse's own values or when a nurse feels powerless to effect a change (150). Nurses in such a position need an opportunity to work through these conflicts. The American Association of Critical-Care Nurses has published a white paper on moral distress that describes how to handle these situations (153).

One study demonstrated that stress increases when staff expectations for a good death are not met. Factors associated with perceptions of a good death include good rapport and support among team members, good communication, timely anticipation of symptoms and adequate time to prepare for the patient's death, and good relationships with the patient and family (148). Training in grief counseling may be useful for nursing staff; lack of counseling skills has been identified as a stress factor for nurses (152). Even when death is perceived as a good death, the death of a patient may be extremely unsettling. The routine use of

support groups has not been seen as effective in reducing staff stress (151). However, timely debriefing after a critical incident may be helpful, and the services of trained personnel such as psychologists, medical social workers, palliative care clinicians, or hospice grief counselors may be very beneficial. (See also Family Presence at Resuscitation.)

Recommendation 1: The multiprofessional team is kept informed of treatment goals so that the messages given to the family are consistent, thereby reducing friction between team members and between the team and family. Grade of Recommendation: C

Recommendation 2: A mechanism is created whereby all staff members may request a debriefing to voice concerns with the treatment plan, decompress, vent feelings, or grieve. Grade of Recommendation: C

Cultural Support of the Family

Culture is a pattern of learned beliefs, shared values, and behavior; it includes language, styles of communication, practices, customs, and views on roles and relationships. The concept goes beyond race, ethnic background, and country of origin (154). Over the past 2 decades, >600 citations have documented disparities in access to care and health status between members of the dominant culture and members of racial and ethnic minority groups in the United States (155–157).

Among the factors that may affect disparities are lack of trust in the healthcare system and patients' spiritual and cultural beliefs (158). For example, in a study of a Chinese community in Toronto, respondents rejected advance directives because they believed that negative outcomes can result from negative thoughts (159). A recent study showed important differences between African Americans and Caucasians regarding advance care planning and end-of-life decision making. Caucasians were more likely to discuss withdrawal of life support and other treatment options from the perspective of a desire not to prolong the dying process. In contrast, treatment decisions for African Americans were more likely to be based on the desire to prolong life (160). Differences in healthcare proxy completion rates across Caucasian, African American, and Hispanic

elderly populations appear related to reversible barriers such as lack of knowledge and perceived irrelevance of advance directives (161).

An effective relationship between healthcare providers and their patients and families has five key components: personal self-awareness, knowledge of the patient's and family's cultural beliefs, cultural assessment, dynamics of difference, and effective communication (162).

Studies have demonstrated that communication between healthcare provider and patient may be affected by race. Although patients are more likely to be satisfied by a visit to a healthcare provider of the same race (163), race concordance may not always be achievable. Knowing this, providers can be trained in interpersonal interpretation: that is, to look beneath the surface when communicating with someone from another culture, to listen actively, and to seek out the real meaning underlying a patient's statements (164).

Interpreter choice is important when dealing with patients who speak a different language. Children and family members should not be placed in the difficult and sometimes embarrassing situation of interpreting, as this may compromise the patient's confidentiality. The complex medical issues that arise in the ICU environment require a trained interpreter to communicate effectively. Availability of professional interpretive services is regulated by the Joint Commission on Accreditation of Healthcare Organizations and many state agencies (165). It has been found that it may be helpful to have a preliminary meeting with the medical interpreter, who is viewed as a member of the multiprofessional team (166).

Ethical principles applied to end-of-life care, such as autonomy, nonmaleficence, beneficence, and truth telling, should accommodate varying cultural perspectives. North American ICU medicine was founded on the basis of Western biomedical values and assumptions about the beginning and end of life, including the acceptance of brain death as death. These are not universally accepted criteria (167).

Similarly, American bioethics are based on Western philosophical principles that place a high value on individual autonomy (168). Patient autonomy is meaningful only if one has access to timely information about one's clinical condition and prognosis. Yet some families consider it detrimental to tell the

patient the truth (169). Many cultures, including Asian, Mexican, Middle Eastern, and African American (170), view the individual not as an autonomous entity but as part of a network of family and social relationships. In some cultures, family members are expected to bear the bad news of terminal illness; the patient's receipt of such news is believed to hasten death. Being frank with people from these cultures can create mistrust or hostility that may not be ameliorated for the duration of care (170). Respecting the request of the patient to direct information to an adult child or spouse, informed refusal, is advocated.

This professional society has emphasized family-centered, culturally sensitive, and relevant ICU care (171). Difficulty arises when the values of the care provider are in conflict with those of the family. For example, this may occur when a family member requests that pain medication not be given (172).

Although it is important for both the ICU staff and the patient to feel that their moral principles are not violated, balancing conflicting principles can be challenging. Kagawa-Singer and Blackhall (170) suggested a three-fold method to determine the patient's desire for disclosure and how much clinical information to disclose:

Indirect discussion: "Some patients in your situation would rather have the doctor discuss details of their care with their family. What do you prefer?"

Discussing a hypothetical case: "Some people who have your condition have found it helpful to consider several options for their care including . . ."

Watching for nonverbal cues such as facial expressions and body position to assess the impact of the discussion on the patient.

This method may be used to discern cultural differences in recommended age of assent, consent lineage, and requests for informed refusal of information. Whenever allowable by law, cultural preferences are honored. When the difference in cultural values causes moral distress, an ethics consult is advised.

Recommendation 1: On request or when conflict arises due to cultural differences in values, when there is a choice of providers, the provider's culture is matched to the patient's. Grade of Recommendation: C

Recommendation 2: Healthcare professionals receive education to provide culturally competent care. Grade of Recommendation: C

Recommendation 3: The patient's desire to be told the truth about his or her clinical situation is determined by a routine assessment. Grade of Recommendation: D

Recommendation 4: For patients who are actively engaged in decision making about their care, their desire for truth takes precedence over that of their family when there is a conflict. Grade of Recommendation: D

Recommendation 5: When requesting assent for procedures, cultural norms are considered and respected whenever possible. Grade of Recommendation: D

Recommendation 6: If a patient makes an "informed refusal" of information, the request is respected. Subsequent information about the patient's illness and its prognosis is delivered in a culturally relevant and appropriate manner as indicated by the patient. The outcome of such discussions is documented in the patient's medical record. Grade of Recommendation: D

Spiritual and Religious Support

Opinion pieces, historical reviews, and instrument design and validation studies were reviewed but excluded as references. Four broad categories of articles informed these guidelines: healthcare provider surveys, patient surveys, outcome studies, and meta-analyses of the impact of spirituality and religion on health. These studies primarily involved patients outside intensive care units and indicate the need for ICU-specific studies. The following discussion first reviews findings related to practitioners and then reviews findings on patients' needs and preferences for spiritual and religious support.

Practitioner Attitudes and Practices. Most studies surveyed family practice and internal medicine physicians; some included nurses, social workers, and physical therapists. Researchers asked practitioners to rank their level of religiosity, how actively they examine matters of faith in their patient histories, and whether they would pray with patients if requested. Although studies from the 1960s and 1970s indicate a level of agnosticism or atheism among physicians higher than that of the general public, recent studies indicate a level of religiosity closer to that of the general public.

Most physicians do not conduct spiritual histories, nor do they feel comfortable praying with their patients unless requested to do so; even then, a substantial number feel uncomfortable with such a proposal. The more religious the physician, the greater the probability that he or she would pray for or with a hospitalized or dying patient (173). Even physicians with a relatively high self-reported level of spiritual awareness tend to refer patients to a chaplain rather than address spiritual concerns themselves (174). Even though religiosity among physicians is increasing, the discomfort of physicians with addressing matters of faith may stem from the fact that physicians tend to have a lower degree of spirituality than their patients (175–177).

Academic pediatric attending physicians and residents surveyed in a single-site urban setting appeared to be more willing to inquire into family spiritual and religious dynamics than physicians caring for adults. Residents felt it was more appropriate to pray with patients than did their attending physicians. The degree of self-ranked religiosity or spirituality correlated with the belief that faith plays a role in healing and enhances the clinical relationship. Regardless of their own views, >90% of pediatricians felt it appropriate to discuss religion or spirituality during severe illness and crises (178).

In one study it was found that nurses held a positive view of religion's impact on health. More than 90% felt that belief in religion is an effective therapy, and the majority were willing to consider praying with their patients. Barriers to teaching about religion, health, and complementary practices included lack of evidence of efficacy and inadequate teaching skills (179).

Physical therapists acknowledge the importance of religion and spirituality in the lives of their patients but also report they lack the skills to address these issues (180).

A national survey indicated that, among all healthcare practitioners, social workers were the most comfortable approaching patients about religion, spirituality, and end-of-life issues and also had the skills to do so (181), even though social workers and mental healthcare workers self-report as less religious or spiritual than their patients (177). Impediments to patient interaction were related to incompatible personal beliefs, cross-cultural issues, lack of familiarity with non-Judeo-Christian traditions, and conflicting values on controversial issues such as assisted suicide and euthanasia.

Patient Attitudes and Needs Related to Spirituality and Religion. The impact of religious and spiritual beliefs on patients' healthcare decisions has not been examined extensively in the medical literature. Studies reviewed for this discussion, although limited in number, were heterogeneous, including AIDS patients, cancer patients, inpatients, and outpatients. Studies indicate that the older the patient and the more infirm with a chronic illness, the greater the level of self-perceived religiosity or spirituality. In clinic-based studies, approximately 50% of patients tend to consider themselves religious or spiritual (181, 182). In contrast, among mental health outpatients and residents of nursing homes, ≥90% consider themselves to be religious or spiritual (183, 184).

Age and declining health have an inverse relationship on the use of religious or spiritual resources to cope and maintain a positive outlook (185–187). This also held true for families of sick children in a single-center site (188). Numerous studies confirmed that the sicker the patient, the greater the likelihood that he or she would want the physician to inquire into the impact of spiritual beliefs on healthcare issues and, in some instances (in particular as death approaches), to pray for or with the patient.

A survey by MacKenzie et al. (184) suggested that in this highly religious and spiritual population, patients believed in prayer and divine intervention to promote health, while also accepting medicine and physicians' care. In a survey of outpatients with stable health issues, only 45% said that spirituality or religion influences healthcare decision making. Most, regardless of self-ranked spirituality or religiosity, would welcome physician inquiry about matters of faith if worded in a way patients did not regard as intrusive (189).

Religion or spirituality had a positive impact on AIDS patients' perspective on life and death and was correlated with greater willingness to discuss resuscitation status (188). Two barriers to discussing resuscitation status were fear of death and guilt associated with the illness.

Whereas a majority of patients wanted physicians to be aware of their religious views, patients' desire for healthcare workers to pray for or with them varied. The sicker the patient, and the less intru-

sive the inquiry, the more patients wanted their physician to inquire about their religious views or pray with them (182). This held true in a study of hospice patients as well: patients wanted physicians to be aware of the role of spirituality in their lives but did not want their physicians to be preachy or judgmental (190). An inpatient study suggested that a uniform majority of patients wanted nurses to inquire respectfully into patient spirituality and pray with them (191). A parish-based model of nursing visits, which incorporated a holistic view of patient concerns, including religion and spirituality, was well received by patients in a rural region of the southeastern United States (192).

These authors concur that all members of the interdisciplinary team need to recognize the impact of spirituality on the patient/family ICU experience, especially with regard to matters of faith at the end of life. Failure to have appropriately trained personnel explore these issues may create barriers to a meaningful discussion of resuscitation status or the possibility of hospice care. The chaplaincy service carries the lead position in providing spiritual assessment and care, but all team members have a role in incorporating spiritually appropriate care to those patients and families who have disclosed preferences.

Training ICU clinicians to incorporate spiritual care of the patient and family into clinical practice is an important step in addressing the goal of caring for the whole person (193). Training may include how to assess spirituality, how to use findings from the spiritual assessment in the plan of care, and participating in prayer with the patient on request. Training is provided either in the clinical setting or as part of formalized academic course work. Regional concentrations of various cultural and religious groups should be considered when designing and providing training.

Recommendation 1: Spiritual needs of the patient are assessed by the healthcare team, and findings that affect health and healing incorporated into the plan of care. Grade of Recommendation: C

Recommendation 2: Physicians will review reports of ancillary team members such as chaplains, social workers, and nurses to integrate their perspectives into patient care. Chaplains and social workers are trained to explore spiritual issues and can provide intensivists with valuable insights into the patient's condition. Grade of Recommendation: D

Recommendation 3: Nurses and doctors receive training in awareness of spiritual and religious issues so that they may properly assess patients and make use of findings in the plan of care written by social workers and chaplains. Grade of Recommendation: C

Recommendation 4: If a patient requests that a healthcare provider pray with him or her, and the healthcare worker agrees to and feels comfortable with it, the request is honored and considered to be part of the spectrum of holistic intensive care. Grade of Recommendation: D

Family Visitation

With healthcare consumers more knowledgeable about their health, available care, and their healthcare rights, demand for access to hospitalized loved ones is increasing. As the healthcare industry strives for a more "family friendly" environment of care, great efforts have been made to evaluate the needs of patients and families as well as attitudes and behaviors of nurses and other members of the healthcare team (194–209).

Flexible (open) visitation policies and regular reports on patient status answer some of the significant needs of families with loved ones in the critical care unit. Nurses' attitudes toward visitation are inconsistent (195, 199, 202, 204, 210, 211). Some nurses allow more liberal family visitation privileges than the unit policy (210) dictates, whereas others reduce family visiting time based on patient anxiety. Still others base family visiting on the nursing schedule, restricting visits when the unit is busy (199). Many nurses expressed a belief that patients need visitors; others felt the room was simply too small to allow for visitation and patient care at the same time (195, 211). In a study completed in Scotland (202), pediatric RNs perceived themselves as family friendly but were very resistant to allowing parents in the unit.

Nurses' attitudes notwithstanding, the preponderance of the literature supports greater flexibility in ICU visitation policies. Descriptive studies of the physiologic effects of visiting on mental status, intracranial pressure, heart rate, and ectopy (212–216) demonstrated no physio-logic rationale for restricting visiting. In fact, in seven of 24 patients with neurologic injuries, family visits produced a significant positive effect, measured by decrease in intracranial pressure. One ethnographic study has demonstrated that family visiting may help the nurse to "get to know" the patient and that family may be helpful in contributing to the care of the patient (217).

Several interventional studies used satisfaction data to document the effects of changes in visitation policies. Three studies examined an increase in time allowed for visitation (215, 218, 219), and two focused on patient-controlled visitation (219, 220). In four studies both visitors and nursing staff reported increased satisfaction, although families expressed a need for greater flexibility and more access to their loved ones (218, 219, 221, 222). Increasing patient control over visiting correlated with greater patient satisfaction but also with requests by the family for increased access (220, 223).

Several studies were based in pediatric or neonatal environments. Two assessed the behavior of siblings of newborns (224, 225). One study compared two ICUs, one allowing sibling visitation and one prohibiting it (224). The data suggest that sibling visitation is not likely to be harmful and might be beneficial to the patient and the family. The other study found that children who were allowed to visit showed less negative behavior and more knowledge about their critically ill sibling than children who were not allowed to visit (225). Two studies supported the value of participating in a sibling education program before visitation (221, 226). References showed no increase in neonatal infection rates due to sibling visits (227, 228).

Many people have strong attachments to their pets. There is no evidence that pets that are clean and properly immunized should be restricted from the ICU environment (229–232). Animal-assisted therapy is a goal-directed intervention in which an animal is incorporated as an integral part of clinical treatment. Animal-assisted therapy is delivered or directed by a healthcare professional who demonstrates expertise in the clinical applications of human-animal interactions (233). Animal-assisted activities are delivered by a professional, paraprofessional, or volunteer and provide motivational and recreational benefits (233).

Recommendation 1: Open visitation in the adult intensive care environment allows flexibility for patients and families and is determined on a case-by-case basis. Grade of Recommendation: B

Recommendation 2: The patient, family, and nurse determine the visitation schedule collectively; the schedule takes into account the best interest of the patient. Grade of Recommendation: C

Recommendation 3: Visitation in the PICU and NICU is open to parents and guardians 24 hrs a day. Grade of Recommendation: C

Recommendation 4: After participation in a previsit education process, visitation by siblings in the PICU and NICU is allowed with parental approval. Grade of Recommendation: C

Recommendation 5: Caution is taken with sibling visits to immunocompromised infants; with physician approval, sibling visits should be considered. Grade of Recommendation: D

Recommendation 6: Pets that are clean and properly immunized are not restricted from visiting the ICU. Guidelines are created to provide animal-assisted therapy and animal-assisted activities for patients. Grade of Recommendation: B

Family Environment of Care

The articles reviewed for these guidelines included a summary by Roger Ulrich et al. (234) of 600 peer-reviewed studies conducted since 1968. The bulk of the studies reviewed to produce that document pertained to research performed on patient (not family) outcomes. In addition, the architectural literature describes, color, lighting, ventilation systems, and floor coverings as having the potential to affect patient outcomes (235–251). As visitation policies become more flexible in the patient-centered ICU, the environment of care has a growing impact on families. Further studies are indicated to validate that the research findings related to impact of color, lighting, noise, music, laughter, arrangement of furniture, view, and artwork are generalizable to family (vs. patient) biopsychosocial well-being.

Ulrich et al. identified >120 studies linking infection rates to the built environment. Transmission of infection to patients generally occurs through two routes: airborne and direct contact. The design of the physical environment affects both transmission routes. The Joint Commission on Accreditation of Healthcare Organizations, the American Institute of Architects, and the American Society of Heating, Refrigerating and Air-conditioning Engineers (252–254) all provide guidelines for ventilation systems and facilities design approaches to reducing infection as well as for enhancing patient and family privacy and comfort (252–257).

The Health Insurance Portability and Accountability Act created new incentives for redesigning patient care areas to enhance privacy. With increased family access to the critical care environment through open visiting, privacy becomes a family issue as well. Several articles examine the Health Insurance Portability and Accountability Act's impact on the structure of new facilities (236, 240, 241, 258, 259). A study by Barlas et al. (260) suggested that lack of privacy can affect patient safety. The study found that walls separating patient rooms, rather than curtains, provide more privacy and encourage patient to speak more directly about important personal information. Private rooms are also more conducive to family involvement in patient care. Private rooms decrease patient visibility. Measures to maintain patient safety while enhancing privacy are indicated (261).

Patient, family, and caregiver safety is the focus of several articles encouraging the use of "green," ergonomically efficient furniture to reduce back stress, fatigue, and other injuries in the hospital environment (262–266). Evidence indicates that social interactions increase when lounges, day rooms, and waiting rooms are provided with furniture arranged in small flexible groupings (267–269). Facilities design can reduce noise, which Johnson (270, 271) in 2001 demonstrated has a negative impact on patient outcomes. Noise decreases oxygen saturation and respiratory rates, interferes with sleep, and also elevates blood pressure and heart rate (272–279). World Health Organization guidelines for acceptable background noise levels are 35 dB, not to exceed 40 dB. Background noise levels in hospitals are typically 45–68 dB, with peaks frequently exceeding 85–90 dB (234). Hospital noise comes from two primary sources: equipment and environmental surfaces. Hospital floors, ceilings, and walls are typically hard surfaces that reflect sound and thus contribute greatly to unacceptable levels of background noise (234).

Since the days of Florence Nightingale, who strongly believed in natural light as adjunct to the hygienic environment, light has been known to have an impact on patient outcomes. In 1996 Beauchemin and Hays (280) found that patients hospitalized for severe depression reduced their stays by an average of 3.67 days if assigned to a sunny rather than a dark room. A randomized prospective study by Walch et al. (281) in 2004 found that patients exposed to increased sunlight reported less stress and pain; they also required 22% less analgesic medication per hour, reducing pain medication costs by 20%.

Several articles provide the business case for incorporating environment of care guidelines and recommendations into the design of new facilities and the redesign of older facilities (244, 257, 262, 282–286). For example, as hospital facilities become more complex, poor way-finding systems can be extremely costly, in terms of both patient and family satisfaction and hard dollars. A 1990 study by Zimring (287) at a major regional 604-bed tertiary-care hospital reported that an ineffective way-finding system cost the main hospital about $220,000 per year, or $448 per bed; about 4,500 annual staff hours were required just to provide directions. Nelson-Schulman (288) in 1983–1984 found that patients who had the benefit of a well-designed information system on reaching the admitting area, such as a welcome sign, hospital information booklet, patient letter, and orientation aids, were more self-reliant, made fewer demands on staff, and reported higher rates of satisfaction with the hospital.

As more is learned about the effects of the environment of care on patients and families, efforts will increase to include families in the design process for new hospital facilities. New facilities not only will be more comforting to patients and families but also will be more energy efficient and more ergonomic and will provide for greater patient/family control of the environment.

Recommendation 1: Improve patient confidentiality, privacy, and social support by building ICUs with single-bed rooms that include space for family. Grade of Recommendation: B

Recommendation 2: Develop signs and way-finding systems to reduce

stress on patients, families, and visitors. Grade of Recommendation: B
Recommendation 3: Replicate patient research regarding the effect of furniture arrangement, natural lighting, access to nature, positive distractions (music, laughter, art), and reduced noise levels on the biopsychosocial health of family members visiting in the ICU. Grade of Recommendation: D

Family Presence on Rounds

One randomized study demonstrated that parents prefer to be present on daily pediatric oncology rounds, on the grounds that inclusion affords them a better opportunity to obtain information. Although parents felt that rounds were generally upsetting to children, the children themselves did not support this belief (289). Another randomized study showed a trend toward increased patient satisfaction and improved physician-patient communication when patients on a medical ward were included in rounds, although the trend was not statistically significant (290).

One cohort study demonstrated that 94% of patients on a medical ward viewed their participation in rounds as a positive experience and felt that it should continue. The majority (66%) stated that participation in rounds improved communication with healthcare providers (291). Another cohort study demonstrated that 85% of patients on a medical ward preferred to be present on rounds (292).

One opinion publication reported both pro and con opinions on parental presence on rounds in a NICU (293). Pros included improving respectful information to parents, family sharing of patient condition/likes/dislikes with the healthcare team, efficiency of time spent with parents, and decreased parental anxiety. Cons included perception of not having enough time to answer parental questions during rounds, confidentiality, and crowding. Three letters to the editor argued in favor of including patients on medical ward rounds (294–296), one argued against inclusion of patients (297), and one discussed both the pros and cons of patient inclusion (298).

Recognizing that the topic of family presence in rounds is the least studied of any section within this document, these authors concur that family participation in rounds is beneficial. In our collective experience the burden imposed by the challenges related to privacy and teaching of the resident teams is outweighed by the greater benefit of improving bidirectional communication between families and the healthcare team.

Recommendation 1: Parents or guardians of children in the ICU are given the opportunity to participate in rounds. Grade of Recommendation: B (randomized controlled trial was done on general medical patients and not ICU patients)
Recommendation 2: Whenever possible, adult patients or surrogate decision makers are given the opportunity to participate in rounds. Grade of Recommendation: B
Recommendation 3: Pediatric patients in the ICU are given the opportunity to participate in rounds with parental permission. Grade of Recommendation: D
Recommendation 4: Patients and family members who participate in rounds are given the opportunity to ask questions to clarify information discussed on rounds. Grade of Recommendation: D

Family Presence at Resuscitation

In family presence at resuscitation (FPR), a limited number of family members, usually one, are present in the resuscitation room during CPR or other resuscitation procedures. The literature reviewed for these guidelines included one systematic review (299), one randomized controlled trial dealing with family stress (300), research-based studies (301, 302), family and staff surveys (303–315), and a variety of review articles, descriptive reports, and expert opinions.

Most of the literature deals with sudden death and trauma resuscitation in the emergency department and focuses on adult patients, although the literature indicates that FPR is common in the pediatric arena. Because almost all of the data regarding FPR come from the emergency department, further ICU-specific research is needed (300).

Families today are exercising their right to be present during resuscitation the same way they once did to have fathers present in the delivery room (302). Seventy-five percent or more of families surveyed wanted the option of being present in the resuscitation room. A similar percentage of patients, asked if they wanted their family present, answered yes (315). Of families who experienced FPR, ≥75% felt that the experience was positive and helped in their grieving process and said they would repeat the experience (306, 310, 313, 316–318); ≥60% felt that their presence helped their dying relative (306, 310, 319).

A randomized trial of emergency department resuscitations reported by Robinson et al. (300) offered FPR in 13 cases and did not offer it in 12 cases. In the group receiving the offer, two families declined. Ten deaths occurred in this group, and eight families participated in follow-up psychological testing 3 and 9 months after the deaths. In the control group, three families asked to witness the resuscitation and were allowed to do so despite the study design. There were 12 deaths in the control group, and ten families participated in follow-up testing at 3 and 9 months. The witnesses in the experimental group scored better in five of the eight psychological tests performed ($p = .73$). The authors concluded that the witnesses experienced no more stress than the control group and showed a trend to better adjustment to their loss than the control group. The study was terminated early because staff was convinced FPR was significantly beneficial and should not be withheld.

Several organizations have made formal statements in support of FPR, including the Emergency Nurses Association (320) and the American Heart Association, whose 2005 guidelines for cardiopulmonary resuscitation advocate FPR (321); the American Association of Critical-Care Nurses (322); and the American Academy of Pediatrics (323).

Survey data indicate that healthcare professionals vary in their opinions of FPR; nurses tend to support it and physicians to oppose it. McClenathan et al. (303) found that approximately 60% of nurses support FPR, compared with 30% of physicians. These findings were consistent with other surveys. Other pertinent findings in these surveys were that experienced physicians and nurses were more likely to support FPR than inexperienced staff. Staff, especially physicians, were more likely to support FPR if families were not present during invasive procedures (303, 304–309, 311–319, 323, 324). Bassler et al. (302) used a pre- and post-test design to show that nurses' acceptance of FPR could be increased with an

educational intervention. In a survey of emergency department pediatric practitioners, residents were less likely to support FPR than nurses or attending staff (323). In a study of hospital nurses and Emergency Nurses Association members, nurses with higher education and specialty certification were more likely to promote FPR (325).

A number of objections to FPR have been raised. One is that family presence subjects the resuscitation team and subjects staff to extra stress that may adversely affect performance (305–306, 312, 316, 326, 327). Staff stress does occur during resuscitation efforts; Boyd and White (301) showed that 22% of staff study participants (25 of 114 questionnaires) showed symptoms that could be classified as an acute stress reaction. Nonetheless, staff felt that FPR was a positive experience, that the presence of family members increased professionalism, that more attention was given to the patient's dignity and need for pain management, and that the presence of family reduced the black humor common in resuscitation situations (306). The literature, including Foote Hospital's report of 9 years of experience with FPR (317), does not report any interference with resuscitation by family members (306), nor does it indicate that resuscitation procedures are prolonged by family presence.

Some opponents of FPR fear that FPR increases stress on families during an already difficult time. Families, however, are not concerned about stress levels (300, 306, 310, 313, 317, 319, 328).

Families involved in FPR report that their fears of resuscitation were much worse than the procedure they actually witnessed (300). Still, opponents of FPR worry about an increase in lawsuits if families misunderstand resuscitation procedures or interpret them as abuse. A survey of the American Association for the Surgery of Trauma showed that for many trauma surgeons, fear of lawsuits is reason enough to exclude family members (305). Experts in medical malpractice feel that FPR, by strengthening the bond between staff and family, actually decreases the likelihood of legal action (329). To date there have been no medical malpractice suits involving families who either were allowed to witness resuscitation or were excluded from presence at resuscitation.

Any institutional FPR program will have to address physician objections to be successful. A well-designed, carefully structured protocol is advocated. The patient's confidentiality must be ensured, and the patient's wishes, if known, should be followed regarding FPR. The protocol should designate a specially trained staff member to offer the family the option of entering the resuscitation room with permission of the staff. This liaison should explain beforehand what the family may see, stay with the family in the resuscitation room, escort the family out of the room when requested by the family or when an invasive procedure is needed, and support the family after the resuscitation is over, whatever the outcome (319). A study of 984 ICU and emergency department nurses reported that few hospitals have policies in place for FPR, but most hospitals have allowed families to be present and have had families request to be present (330).

> Recommendation 1: Institutions develop a structured process to allow the presence of family members during cardiopulmonary resuscitation of their loved one that includes a staff debriefing. Grade of Recommendation: C
>
> Recommendation 2: The resuscitation team includes a member designated and trained to support the family during family witnessed resuscitation. Grade of Recommendation: D
>
> Recommendation 3: Resuscitation team and ICU training includes information regarding the process and rationale for FPR. Grade of Recommendation: D

Palliative Care

Articles selected for review covered palliative care delivery in the hospital setting, palliative care education, and family perceptions of critical care delivery. Articles on palliative care for cancer and hospice patients were not included. Articles reviewed consisted mostly of case reports, surveys, and expert opinion. As family support represents only one aspect of palliative care, there were no controlled trials of interventions related specifically to family support.

The *Clinical Practice Guidelines for Quality Care*, released in 2004 by the National Consensus Project for Quality Palliative Care, were also reviewed, and the project's recommendations are endorsed in their entirety. Although the National Consensus Project guidelines focus primarily on the patient, they are also applicable to family support. Several of the project's recommendations are abstracted with permission.

Palliative care is medical care focused on the relief of suffering and support for the best possible quality of life for patients and families facing life-threatening illness. Palliative care is delivered by a multiprofessional team including physicians, nurses, social workers, chaplains, nursing assistants, and other health professionals (331). Palliative care services can be led either by the primary medical team or by a dedicated palliative care service. Key aspects of palliative care include symptom control, psychosocial and spiritual care, a personalized management plan that maximizes patient-determined quality of life, and family-oriented care that extends throughout the hospitalization through discharge or bereavement

Families often perceive that their loved ones suffer during the management of critical illness (332–337). Consequently, the delivery of palliative care to patients in the ICU is an important component of family support. Under today's paradigm, palliative care coexists with aggressive critical care and should begin with the diagnosis of serious illness (330).

Families experience a wide range of unmet needs that are standard components of palliative care (336). Several surveys highlight family perceptions of inadequate relief of loved ones' pain and suffering and communication problems with the healthcare team. According to a survey of bereaved family members, 52% of families felt that the patient did not receive emotional support, 20% felt that the patient was not treated with respect, 38% felt a lack of emotional support for the family, and 50% received insufficient information about what to expect while the patient was dying (337).

There is a striking lack of content on end-of-life and palliative care in medical specialty texts. A review of 50 textbooks in internal medicine, neurology, oncology, infectious diseases/AIDS, and surgery revealed end-of-life content to be absent in 50–72% of the texts (338). A survey of 3,227 oncologists revealed that only 10% had received palliative care courses in medical school and only 33% during residency or fellowship. Ninety percent responded that they learned by trial and error to provide care to terminally ill patients (339). Given the paucity of ICU specific data on this topic, the

following recommendations are made as consensus statements by these authors.

Recommendation 1: Assessments are made of the family's understanding of the illness and its consequences, symptoms, side effects, functional impairment, and treatments and of the family's ability to cope with the illness and its consequences. Family education should be based on the assessment findings. Grade of Recommendation: D

Recommendation 2: The family is educated about the signs and symptoms of approaching death in a developmentally and culturally appropriate manner. Grade of Recommendation: D

Recommendation 3: As appropriate, the family is informed about and offered referral to hospice palliative care and other community-based healthcare resources. Grade of Recommendation: D

Recommendation 4: Bereavement services and follow-up care are made available to the family after the death of a patient. Grade of Recommendation: D

Recommendation 5: Training in the elements of palliative care is a formal component of critical care education. Grade of Recommendation: C

CONCLUSION

Throughout history, families have played a crucial role in the care of injured or critically ill members. The technology and training required to care for critically ill patients have had the unfortunate consequence of limiting family participation in healthcare decision making and the care of their loved ones. The psychosocial needs of critically ill patients who often cannot communicate effectively are often overlooked. This in turn compromises the delivery of patient-centered care in the ICU.

To correct this problem we must acknowledge the important role that family members and other healthcare surrogates play in patient care and embrace their participation. As advocated in the Institute of Medicine patient-centered care model, this guideline includes recommendations related to informing families, maintaining active involvement in decision making, coordinating care across disciplines, providing the physical comfort and emotional support of families, and providing culturally sensitive care in accordance with the patient's goals (1). These guidelines are an initial attempt to make practical recommendations to healthcare providers based on current literature.

Historically, unilateral decision-making models, based on either patient autonomy or physician paternalism, have been preferred in the ICU. Care that is truly patient-centered requires a new paradigm: shared decision making. Since family members and other health care surrogates often serve as the spokespeople for their loved ones in the ICU, they must be included in decision making. Frequent communication through periodic multiprofessional care conferences is indicated. Communication needs to be culturally sensitive, using terms that the family can understand. Shared decision making may decrease family stress and help families to cope. Improved communication may also increase the utilization of advanced directives. Better trained ICU staff, open visitation policies, and accurate and timely multiple-professional communication among ICU healthcare providers can decrease stress and anxiety for both staff and families.

Family involvement and support are facilitated by an ICU environment that includes waiting rooms that are close to patient rooms and that include family-friendly amenities, such as a means to communicate readily with both healthcare providers and the outside world.

Allowing families to be present during cardiopulmonary resuscitation may help families to cope with the death of a loved one in the ICU. Prayer and adherence to cultural traditions also help many patients and families to cope with illness, death, and dying and should be encouraged and respected in the ICU. In addition to formal spiritual counseling by a chaplaincy service, educated members of the ICU staff may help to accommodate the spiritual traditions and cultural needs of patients and families. Symptom management and family involvement in palliative care processes are also advocated to improve care in the ICU.

Including and embracing the family as an integral part of the multiple-professional ICU team are essential for the timely restoration of health or optimization of the dying process for critically ill patients. Support for the psychological and spiritual health of the family is an essential component of patient-centered care for the critically ill.

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