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Clinical Practice Guidelines for Support of the Family in the Patient-Centered ICU
American College of Critical Care Task Force 2004-2005

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These guidelines were developed by a task force assembled by the American College of Critical Care Medicine (ACCM) of the Society of Critical Care Medicine (SCCM) and have been reviewed by the Society's Council. These guidelines reflect the official opinion of the SCCM and should not be construed to reflect the views of the specialty boards or any other professional medical organization.

The case for the family in patient-centered care

In 2001, the Institute of Medicine (IOM) strongly recommended that health care 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 IOM's patient-centered model: 1) patients and families are kept informed and actively involved in medical decision-making and self-management; 2) patient care is coordinated and integrated across groups of health care providers; 3) health care delivery systems provide for the physical comfort and emotional support of patients and family members; 4) health care providers have a clear understanding of patients' concepts of illness and their cultural beliefs; and 5) health care 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 health care 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 health care decision-making and asking providers to do a better job of responding to patient and family needs (6-8). Yet 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 multidisciplinary 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, put forth by the American College of Critical Care Medicine of the Society of Critical Care Medicine, 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

The methodology for these guidelines was a literature review. Endnote software was used to search 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 subheadings above. 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 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 (see 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).. While the National Consensus Project guidelines pertains to both patient and family care, they are also

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applicable to family support. The Society of Critical Care Medicine (SCCM) endorses the recommendations of the National Consensus Project in their entirety; for this document we have abstracted recommendations specific to Family Centered Care.

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 (sometimes referred to as parental) 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. The patient autonomy model predominates in North America, and the paternalistic model in Europe.

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, to 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 multi-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 when using the model (see Cultural Support of the Family).

Shared decision-making requires regular meetings between ICU team members as well as a secondary level of meetings between the ICU team and family. Because good communication skills, conflict management skills, and meeting facilitation skills are needed for this 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 NICU found that meetings between health care professionals and parents using the shared decision-making model produced fewer decision-making conflicts, fewer unrealistic parental concerns, and improved collaboration. The model also helped parents gain a more accurate understanding of their child's medical condition (24).

During family conversations, the care provider acts as medical expert, as a source of support for the family, as a guide for surrogate decision-makers, and frequently as a family therapist. The following suggestions may be of value in conducting such conversations.

A quiet, private room away from the loved one's bedside greatly facilitates discussions. Whenever possible, discussions should be scheduled in advance so that all stakeholders may attend, including any support staff the family desires, such as social workers, clergy, psychologists, or family therapists. When the primary language of the family is different from the primary language of the ICU staff, families should be offered an interpreter trained to communicate complex medical concepts.

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 health care 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), 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).

In the case of an incompetent patient who was never competent, family members should be asked to consider their own values and the patient's best interests. Judging the patient's best interests

near the end of life is often difficult; such discussions are facilitated by open-ended questions, honesty, and clarity.

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.

Recommendations:

❖ Recommendation 1: Decision-making in the ICU is based on a partnership among patients, surrogates and ICU caregivers. Grade of Recommendation B

❖ Recommendation 2: Practitioners fully disclose the patient's current status and prognosis 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 patients or through surrogates. Grade of Recommendation D

❖ Recommendation 4: Family meetings with the ICU team begin shortly after ICU admission and are repeated as dictated by the condition of the patient with input from all pertinent members of the multidisciplinary 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

Most of the literature on family coping involves the use of surveys, followed by descriptive studies and interventional research studies. Articles reviewed for these guidelines were fairly evenly divided among studies of NICU, PICU and adult ICU patients and families.

Having a loved one in an intensive care unit 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; to be allowed to visit the patient anytime. Families also require assurance that their loved one is receiving quality care (49-63). 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).

Families find it frustrating and confusing to deal with a host of health care 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 (66,67). Nurses need more training in assessing stress levels and anticipating family needs. In studies to determine if family needs were being met, nurses were generally only about 50 percent accurate in predicting family needs (49,50,52,68-70).

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 (71-75). Parents experience stress long after their children are discharged. Two pediatric studies found that parents' stress-related symptoms persist as long as six months post-discharge. A neonatal study showed that mothers of high-risk, very low birth weight infants experienced psychological distress even when the child reached two years of age (76-78).

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 (79).

 High levels of anxiety and depression in family members may affect their ability to make end-of-life decisions (80). The use of problem-focused coping strategies and social supports lowers stress for family members (81,82), although support groups seem to be more effective for parents of children in intensive care than for families of adult patients.

Two intervention studies with families of adult patients showed no statistical difference in stress reduction in family members who attended a support group (83,84). A third study showed a 50 percent reduction in state anxiety (compared to a control group) for family members who attended a support group, but also a 50 percent decline in the number of families attending the support group (85).   Another small pediatric study showed that parental anxiety was reduced if parents were allowed to observe and be with their child while the youngster was undergoing procedures (86).

Parent education can be very helpful in minimizing the stress of a PICU or NICU admission. In a pilot randomized intervention study, parents received written and audiotaped information about infant and child behavior while in the ICU, parent-child interactions, and therapy. Compared to the control group, study parents had less stress, fewer depressive symptoms and better bonding and interactions with their child (87,88). 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 (89-94). It is now known that families of critically ill patients may develop anxiety, depression and post-traumatic stress syndrome (95-97). One intervention study has shown that prospective diaries with review and follow up may improve communication and goal setting, and provide comfort (95). 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)

Recommendations:

❖ 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. Grade of Recommendation D

❖ Recommendation 4 – Family members are also 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 in several forms, including social workers, clergy, and parent support groups. Grade of Recommendation C

Staff Stress Related to Family Interactions

The literature reviewed for these guidelines included 48 articles representing the perspectives of medical, nursing and support staff as well as families. Survey results, qualitative grounded theory, and opinion pieces described how particular institutions handled staff stress (98-145).

Poor communication is a major source of stress for staff. One study showed, not surprisingly, 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 (145).

In a patient-centered environment, multidisciplinary 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 also 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 reduce friction. It is useful to identify a family spokesperson as soon as a patient is admitted to the ICU, and the family member who will be making decisions on the patient's behalf.

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.

 If possible, the healthcare team should include the ICU physician; consulting physicians (including the primary care physician, if available); bedside nurses; ICU nurse manager or clinical coordinator; 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 multidisciplinary team allows healthcare providers to take an organized approach to achieving common goals, which may also prevent or eliminate stress (145).

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 for the purpose of providing status reports or for making a treatment decision. All team members should be welcome 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 (114,119,120,141).

In addition to care conferences, ICU staff members need the opportunity to decompress or vent feelings about patients and their outcomes, either in the ICU or away from the facility. An unexpected adverse event or medical error may trigger the need for a staff debriefing, and the code 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 (143). Nurses in such a position need an opportunity to work through these conflicts.

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 (141). Training in grief counseling may be useful for nursing staff; lack of counseling skills has been identified as a stress factor for nurses (145). Even when a 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 (144). However, timely debriefing after a critical incident may be helpful, using trained personnel such as psychologists, medical social workers, palliative care clinicians, or hospice grief counselors. (See also Family Witnessed Resuscitation).

Recommendations:

- ❖ Recommendation 1: The multidisciplinary 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

Because the population in any given country has become increasingly diverse. It is therefore more urgent than ever for healthcare providers to understand the culture and unique concerns of minority groups. Culture shapes the way we approach our world and affects interactions between patients and clinicians. 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 (146).

Over the past two decades, more than 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 U.S. (147-149). Reasons for these disparities should be explored and respected and will help to focus the encounter between the clinician and patients and their families.

Among the factors that may affect disparities are lack of trust in the healthcare system and patients' spiritual and cultural beliefs (150). 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 (151). 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 (152). Differences in health care 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 (153).

An effective relationship between healthcare providers and their patients and families has five key components (154).

1. *Personal self-awareness:* Healthcare providers need to examine their own beliefs and biases. Self-reflection should include recognition of the power relationship between doctor and patient.

2. *Knowledge of the patient's and family's cultural beliefs* and the roots of these beliefs is important in understanding the significance of the patient's symptoms. This helps to develop the trust so crucial to an optimal healthcare worker/patient family relationship.

3. *Cultural assessment* is necessary in caring for the patient and his or her family. Recognizing diversity not only in patient populations but also within specific groups is important: for example, a Mexican-American of Mayan descent may have quite different views from an Argentinean, though both may be classified as Hispanics. Cultural assessment should be integrated into the social history of the patient.

4. *Dynamics of difference* must be appreciated. The perspective that all patients should be treated alike, regardless of race or culture, disregards patients' personal beliefs and values.

5. *Effective communication* is essential for a respectful and fulfilling relationship. Critical illness leads to a profound sense of loss of dignity. Physicians and nurses need to recognize this and avoid interactions that may be construed as disrespectful or demeaning, taking special care to greet each patient appropriately. Touching the patient in greeting may not be an acceptable custom for some cultures. Touching the opposite sex should be avoided with orthodox Jews and

devout Muslims. Healthcare providers should be sensitive about addressing certain patients by their first name rather than surname.

Studies have demonstrated that communication between healthcare provider and patient may be affected by race. While patients are more likely to be satisfied by a visit to a healthcare provider of the same race (155) 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 (156).

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.

Ethical principles applied to end-of-life care, such as autonomy, non-maleficence, 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 (157).

Similarly, American bioethics is based on Western philosophical principles that place a high value on individual autonomy (158). 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 (159). Many cultures, including Asian, Mexican, Middle Eastern and African American (160), view the individual not as an autonomous entity, but as part of a network of family and social relationships. In such 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 (160).

This professional society has emphasized family-centered, culturally sensitive and relevant ICU care (161). Yet practitioners should be equally wary of *over*-tolerance as of *in*-tolerance of other cultures. Over-tolerance may be quite harmful—for example, acceding to a family member's request that pain medication not be given (162). Providing inadequate prognostic information may impair estate preparation or preclude significant end of life rituals. Withholding the truth could even endanger public health—for example, withholding information about HIV status.

While 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 suggest a three-fold method to determine the patient's desire for disclosure and how much clinical information to disclose (160).

- *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 non-verbal cues* such as facial expressions and body position to assess the impact of the discussion on the patient.

Recommendations:

- ❖ Recommendation 1: 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 should be educated 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, using the method suggested by Kagawa-Singer and Blackhall described above (160). 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 that place the age of social responsibility lower than the standard 18 years are considered and respected whenever possible. Grade of Recommendation D

- ❖ Recommendation 6: If a patient makes an "informed refusal" of information, the intensivist respects this decision. Subsequent information about the patient's illness and its prognosis should be delivered in a culturally relevant and appropriate manner as indicated by the patient and family. The outcome of such discussions is documented in the patient's medical record. Grade of Recommendation D

❖ Recommendation 7: Patients are made aware that they may reverse their decision about the degree of truth-telling they desire at any time during the course of their care. 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. While these studies primarily involved patients outside intensive care units, most of the data may have relevance to the experience of the critically ill. The following discussion first reviews findings related to practitioners, 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. While 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 (163). 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 (164). 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 (165-167).

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, more than 90 percent of pediatricians felt it appropriate to discuss religion or spirituality during severe illness and crises (168).

Nurses in an academic setting tend to have a positive view of religion's impact on health. More than 90 percent feel that religion is an effective therapy, and the majority is willing to consider praying with their patients. Barriers to teaching about religion, health and complementary practices include lack of evidence of efficacy and inadequate teaching skills (169).

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 (170).

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 (171), even though social workers and mental healthcare workers self-report as less religious or spiritual than their patients (167). 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, though 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 percent of patients tend to consider themselves religious or spiritual (171,172). In contrast, among mental health outpatients and residents of nursing homes, 90 percent or more consider themselves to be religious or spiritual (173, 174).

The older and sicker the patient, the greater the use of religious or spiritual resources to cope and maintain a positive outlook (175-177). This also held true for families of sick children in a single center site (178). 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 of nursing home residents 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 (174). In a survey of outpatients with stable health issues, only 45 percent 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 (179).

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 (178). 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 intrusive the inquiry, the more patients wanted their physician to inquire about their religious views or pray with them (172). 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 (180). An inpatient study suggested that a uniform majority of patients wanted nurses to inquire respectfully into patient spirituality and pray with them (181). 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 (182).

Most studies that examined patients' religious beliefs followed patients of family practitioners or internists, often in academic settings. Such relationships could be expected to be longer term and deeper than relationships with an intensivist. Many ICU patients are compromised in their ability to interact by underlying illness, sedation, mechanical ventilation or other factors. Outpatient studies therefore may not be strictly applicable to the critical care setting.

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 in 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 role in providing spiritual assessment and care, but all team members have a role in incorporating spirituality 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 (183). The training can 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 upon request. This should be 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 this training.

Recommendations:

- ❖ 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 that they make use of findings in the plan of care written by social workers and chaplains. Recommendation C

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

Family Visitation

Sixty-five articles were reviewed for the guidelines, including descriptive studies, surveys and interviews, interventional studies, opinion pieces and literature synopses. About half the articles focused on the adult ICU and the rest on PICU and NICU environments.

With health care consumers more knowledgeable about their health, available care, and their health care rights, demand for access to hospitalized loved ones is increasing. As the health care 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 health care team (184-199).

Flexible visitation policies and regular reports on patient status are significant needs of families with loved ones in the critical care unit. Nurses' attitudes toward visitation are inconsistent (185,189,192,194,200,201). Some nurses allow more liberal family visitation privileges than the unit policy

(200) dictates, while 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 (189). 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 (185,201). In a study completed in Scotland (192), 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, intra-cranial pressure (ICP), heart rate, and ectopy (202-206) demonstrated no physiologic rationale for restricting visiting. In fact, in 7 of 24 patients with neurological injuries, family visits produced a significant positive effect, measured by decrease in ICP. 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 (207).

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 (205,208,209), and two focused on patient-controlled visitation (209,210). In four studies both visitors and RN staff reported increased satisfaction, although families expressed a need for greater flexibility and more access to their loved ones (208,209,212,213). Increasing patient control over visiting correlated with greater patient satisfaction, but also with requests by the family for increased access (210,211).

Several studies were based in pediatric or neonatal environments. Two assessed the behavior of siblings of newborns (214,215). One study compared two ICUs, one allowing sibling visitation and one prohibiting it (214). The data suggests 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 (215). Two studies supported the value of participating in a sibling education program prior to visitation (212,216).   References showed no increase in neonatal infection rates due to sibling visits (217,218).

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 (219-222).   Animal Assisted therapy (AAT) is a goal-directed intervention in which an animal is incorporated as an integral part of clinical treatment. AAT is delivered or directed by a healthcare professional who demonstrates expertise in the clinical applications of human-animal interactions (223). Animal Assisted Activities (AAA) is

delivered by a professional, para-professional, or volunteer and provide motivational, and recreational benefits (223).

Recommendations:

 ❖ Recommendation 1: Visitation in the adult intensive care environment allows flexibility for patients and families, and be determined on a case-by-case basis. Grade of Recommendation B

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

 ❖ Recommendation 3: Families are educated about the ICU environment, instructed to wash hands before and after patient contact, and educated about self-care, including the need for adequate rest and nourishment. Grade of Recommendation D

 ❖ Recommendation 4: Visitation in the PICU and NICU is open to parents and guardians 24 hours a day. Grade of Recommendation C

 ❖ Recommendation 5:   Visitation by siblings in the PICU and NICU is allowed with parental approval. Grade of Recommendation C

 ❖ Recommendation 6: Caution is taken with sibling visits to immuno-compromised infants; with physician approval, sibling visits should be considered.   Grade of Recommendation D

 ❖ Recommendation 7: 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

Forty-eight articles were reviewed for these guidelines, including a summary by Roger Ulrich, et al, of 600 peer-reviewed studies conducted since 1968 (224). The literature supports the link between the hospital's physical environment and patient outcomes. For example, color, lighting, ventilation systems and floor coverings have all been found to have an impact on patient outcomes (225-241). With visitation policies becoming more flexible in the patient-centered ICU, the environment of care has a growing impact on families as well.

Ulrich, et al, identified more than 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 (JCAHO), the American Institute of Architects, and the American Society of Heating, Refrigerating and Air-conditioning Engineers (242-244) all provide guidelines for ventilation systems and facilities design approaches to reducing infection, as well as for enhancing patient and family privacy and comfort (242-247).

The Health Insurance Portability and Accountability Act (HIPAA) has created new incentives for redesigning patient care areas to enhance privacy. Several articles examine HIPAA's impact on the structure of new facilities (226,230,231,248,249). A study by Barlas et al suggests that lack of privacy can affect patient safety (224). The study found that spaces set apart by curtains rather than walls encourage patients to withhold important information and even refuse permission for parts of the physical examination. A 2003 analysis by Press Ganey of patient satisfaction data indicates patients in single-bed rooms have a much higher satisfaction rate than patients in multi-bed spaces (224). Of course, private rooms are also more conducive to family involvement in patient care.

Patient, family and caregiver safety are the focus of several articles encouraging the use of "green," ergonomically efficient furniture for the hospital environment (250-254). Poor ergonomic design of patient beds and nurses' stations leads to back stress, fatigue, and other injuries to family and staff caregivers (224). The impact of social supports on patient outcomes has been well established, and evidence indicates that social interactions increase when lounges, day rooms and waiting rooms are provided with furniture arranged in small flexible groupings (224). Facilities design can reduce noise, which Johnson in 2001 demonstrated has a negative impact on patient outcomes (224). Noise depresses oxygen saturation and respiratory rates; interferes with sleep; and also elevates blood pressure and heart rate (224). World Health Organization guidelines for acceptable background noise levels are 35dB, not to exceed 40dB. Background noise levels in hospitals are typically 45dB- 68dB, with peaks frequently exceeding 85-90dB (224). Hospital noise comes from two primary sources: equipment and environmental surfaces. Operating room noises from drills, saws, and other equipment are in the range of 100dB to 110dB, presenting significant potential for noise-induced hearing loss (224). Hospital floors, ceilings and walls are typically hard surfaces that reflect sound and thus contribute greatly to unacceptable levels of background noise. Studies of noise reduction measures suggest that environmental interventions (for

example, sound-absorbing ceiling tiles and the elimination of loud-speaker paging systems) are far more effective than organizational interventions such as quiet time (224).

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 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 (224). A randomized prospective study by Walch, et al, in 2004 found that patients exposed to increased sunlight reported less stress and pain; they also required 22 percent less analgesic medication per hour, reducing pain medication costs by 20 percent (224).

Positive distractions—environmental features or conditions that have been found by research to reduce stress effectively on patients and families—can   include music and laughter-inducing entertainment, companion animals, certain art, and especially nature (224). Diette, et al, in 2003 conducted a randomized prospective study that found adult patients undergoing a painful bronchoscopy procedure reported less pain if they looked at a ceiling-mounted nature scene rather than a blank ceiling (224).

 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 (234,247,250,255-259). For example, as hospital facilities become more complex, poor way-finding systems can be extremely costly, both in terms of patient and family satisfaction and in hard dollars. A 1990 study by Zimring 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 (224). Nelson-Shulman in 1983-4 found that patients who had the benefit of a well-designed information system upon 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 (224).

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 will not only be more comforting to patients and families but will also be more energy efficient, more ergonomic and provide for greater patient control of the environment.

Recommendations:

❖ 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 signage and way-finding systems to reduce stress on patients, families and visitors. Grade of Recommendation B

❖ Recommendation 3:   Provide rooms with natural lighting, access to nature and positive distractions. Grade of Recommendation A

❖ Recommendation 4: Provide lounges, day rooms, and waiting rooms with comfortable movable furniture arranged in small flexible groupings to increase social interactions and promote social support among families. Grade of Recommendation B

❖ Recommendation 5:   Reduce stress-producing noise levels in hospitals by installing high-performance sound-absorbing ceilings and eliminating noise sources such as overhead paging systems. Grade of recommendation A

Family Presence on Rounds

Ten articles were reviewed for these guidelines, including two randomized controlled trials, two cohort studies and six opinion pieces. Two of the publications dealt with pediatric cases. All studies involved surveys of patients or family members. Publications on psychiatric rounds were eliminated.

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 (260). 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 (261).

One cohort study demonstrated that 94 percent of patients on a medical ward viewed their participation in rounds as a positive experience and felt that it should continue. The majority (66 percent) stated that participation in rounds improved communication with healthcare providers (262). Another cohort study demonstrated that 85 percent of patients on a medical ward preferred to be present on rounds (263).

One opinion publication reported both pro and con opinions on parental presence on rounds in a NICU (264).   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

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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 (265-267), one argued against inclusion of patients (268), and one discussed both the pros and cons on patient inclusion (269).

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.

Recommendations:

❖ Recommendation 1: Parents or guardians of children in the ICU are given the opportunity to participate in rounds. Grade of Recommendation B (RCT 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, is present in the resuscitation room during CPR or other resuscitation procedures. The literature reviewed for these guidelines included a systemic review (270), one randomized control trial dealing with family stress (271), research based studies (272,273), family and staff surveys (274-284), 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 (ED) 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 comes from the Emergency

Department, where death is sudden and usually unexpected, the literature may have limited applicability to the intensive care setting (271).

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 (273). 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 (285). Of families who experienced FPR, 75 percent or more felt the experience was positive, helped in their grieving process, and said they would repeat the experience (277,281,284,286,287,288); 60 percent or more felt their presence helped their dying relative (277,281,289).

A randomized trial of ED resuscitations reported by Robinson et al offered FPR in 13 cases and did not offer it in 12 cases (271). In the group receiving the offer, two families declined. Ten deaths occurred in this group, and eight families participated in follow-up psychological testing three and nine 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 10 families participated in follow-up testing at three and nine months. The witnesses scored better in 5 of the 8 psychological tests performed (p=0.73). 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 that FPR was sufficiently beneficial to make it unsupportable to withhold the offer of FPR to future randomly selected control families.

Several organizations have made formal statements in support of FPR, including the Emergency Nurses Association (ENA) (290), and the American Heart Association, whose 2005 guidelines for CPR advocate FWR (291), the American Association of Critical Care Nurses (292) and the American Academy of Pediatrics (AAP) (293).

Survey data indicate that health care professionals vary in their opinions of FPR; nurses tend to support it and physicians to oppose it. McClenathan found that approximately 60 percent of nurses support FPR, compared to 30 percent of physicians (274). These findings were consistent with other surveys. Other pertinent findings in these surveys were experienced physicians and nurses were more likely to support FPR than inexperienced staff. Staff, especially physicians, was more likely to support FPR if families were not present during invasive procedures (273, 275-278,282-289,293-294). Bassler used a pre- and posttest design to show that nurses' acceptance of FPR could be increased with an educational intervention (273). In a survey of emergency department pediatric practitioners, residents

were less likely to support FPR than nurses or attending staff (293). In a study of hospital nurses and ENA members, nurses with higher education and specialty certification were more likely to promote FPR (295).

Physicians have raised a number of objections to FPR. One is that family presence distracts the resuscitation team and subjects staff to extra stress that may adversely affect performance (276,277,283,286,296,297). Staff stress does seem to increase; Boyd and White showed that 22 percent of staff study participants (25 of 114 questionnaires) showed symptoms that could be classified as an acute stress reaction (272). Several other surveys confirm these findings. 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 (277). The literature, including Foote Hospital's report of nine years of experience with FPR (287, does not report any interference with resuscitation by family members (277), 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 (271,277,281,284,287,289,298).

Some physicians point to patient confidentiality concerns as a reason to exclude family members and have advocated that patients' wishes regarding FPR be included in living wills and Durable Power of Attorney for Health Care documents. Pediatric cases may be different from adult cases, in that parents have a different degree of legal responsibility for health-care decisions on behalf of the child (299).

Families involved in FPR report that their fears of resuscitation were much worse than the procedure they actually witnessed (271). 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 (AAST) showed that, for many trauma surgeons, fear of lawsuits is reason enough to exclude family members (276). Experts in medical malpractice feel FPR, by strengthening the bond between staff and family, actually decreases the likelihood of legal action (300). To date there have been no medical malpractice suits involving families who were either allowed to witness resuscitation or excluded from 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 (289). 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 (300).

Recommendations:

- ❖ Recommendation 1: Institutions develop a structured process to allow the presence of family members during cardiopulmonary resuscitation (CPR) of their loved one. Grade of Recommendation C
- ❖ Recommendation 2: The code (or emergency) response team includes a member designated and trained to support the family during family witnessed resuscitation.   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. While 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 an interdisciplinary team including physicians, nurses, social workers, chaplains, nursing assistants and other health professionals (301). 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 (302-307). Consequently, the delivery of palliative care to patients in the Intensive Care Unit 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 (301).

Families experience a wide range of unmet needs while receiving very costly care (307). Several surveys highlight family perceptions of inadequate relief of loved ones' pain and suffering, and communication problems with the health care team. According to a mortality follow-back survey of family members published in JAMA in 2004, 52 percent of families felt the patient did not receive emotional support, 20 percent felt the patient was not treated with respect, 38 percent felt a lack of emotional support for the family, and 50 percent received insufficient information about what to expect while the patient was dying (308).

This is not surprising, given the 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 percent of the texts (309). A survey of 3,227 oncologists revealed that only 10 percent had any palliative care courses in medical school, and only 33 percent during residency or fellowship. Ninety percent responded that they learned by trial and error to provide care to terminally ill patients (310).

Recommendations:

❖ 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 capacity 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, age, and culturally appropriate manner. Grade of Recommendation D

❖ Recommendation 3: As appropriate, the family is informed about and offered referral to hospice 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 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 has had the unintended consequence of limiting family participation in health care decision-making and the care of their loved ones. The needs of critically ill patients who often can't 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 health care surrogates play in patient care and embrace their participation. As advocated in the IOM 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 health care 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 multidisciplinary 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 multidisciplinary communication among ICU health care 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 health care 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 enable 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.

In conclusion, including and embracing the family as an integral part of the multidisciplinary ICU team is 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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TABLE 1 – Cochrane Methodology

Levels of Evidence and Grades of Recommendations- 23 November 1999.

Grade of Recommendation	Level of Evidence	Therapy/Prevention, Aetiology/Harm	Prognosis	Diagnosis
A	1a	SR (with homogeneity[i]) of RCTs	SR (with homogeneity*) of inception cohort studies; or a CPG[ii] 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[iii])	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[iv]	All or none case-series[v]	Absolute SpPins and SnNouts[vi]
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 RCT; 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: 1. Independent blind or objective comparison; 2. Study performed in a set of non-consecutive 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[vii])	Case-series (and poor quality prognostic cohort studies[viii])	Any of: • 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"

[i] 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. As noted above, studies displaying worrisome heterogeneity should be tagged with a "-" at the end of their designated level.

[ii] Clinical Prediction Guide

[iii] See note #2 for advice on how to understand, rate and use trials or other studies with wide confidence intervals.

[iv] Met when all patients died before the Rx became available, but some now survive on it; or when some patients died before the Rx became available, but none now die on it.

[v] Met when there are no reports of anyone with this condition ever avoiding (all) or suffering from (none) a particular outcome (such as death).

[vi] An "Absolute SpPin" is a diagnostic finding whose Specificity is so high that a Positive result rules-in the diagnosis. An "Absolute SnNout" is a diagnostic finding whose Sensitivity is so high that a Negative result rules-out the diagnosis.

[vii] By poor quality cohort study we mean one that failed to clearly defined comparison groups and/or failed to measure exposures and outcomes in the same (preferably blinded), objective way in both exposed and non-exposed 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 cofounders.

[viii] By poor quality prognostic cohort study we mean one in which sampling was biased in favour 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, non-objective way, or there was no correction for confounding factors.