

Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU

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The American College of Critical Care Medicine (ACCM), which honors individuals for their achievements and contributions to multidisciplinary critical care medicine, is the consultative body of the Society of Critical Care Medicine (SCCM) that possesses recognized expertise in the practice of critical care. The College has developed administrative guidelines and

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clinical practice parameters for the critical care practitioner. New guidelines and practice parameters are continually developed, and current ones are systematically reviewed and revised.

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Objective: To provide clinicians with evidence-based strategies to optimize the support of the family of critically ill patients in the ICU.

Methods: We used the Council of Medical Specialty Societies principles for the development of clinical guidelines as the framework for guideline development. We assembled an international multidisciplinary team of 29 members with expertise in guideline development, evidence analysis, and family-centered care to revise the 2007 Clinical Practice Guidelines for support of the family in the patient-centered ICU. We conducted a scoping review of qualitative research that explored family-centered care in the ICU. Thematic analyses were conducted to support Population, Intervention, Comparison, Outcome question development. Patients and families validated the importance of interventions and outcomes. We then conducted a systematic review using the Grading of Recommendations, Assessment, Development and Evaluations methodology to make recommendations for practice. Recommendations were subjected to electronic voting with pre-established voting thresholds. No industry funding was associated with the guideline development.

Results: The scoping review yielded 683 qualitative studies; 228 were used for thematic analysis and Population, Intervention, Comparison, Outcome question development. The systematic review search yielded 4,158 reports after deduplication and 76 additional studies were added from alerts and hand searches; 238 studies met inclusion criteria. We made 23 recommendations from moderate, low, and very low level of evidence on the topics of: communication with family members, family presence, family support, consultations and ICU team members, and operational and environmental issues. We provide recommendations for future research and work-tools to support translation of the recommendations into practice.

Conclusions: These guidelines identify the evidence base for best practices for family-centered care in the ICU. All recommendations were weak, highlighting the relative nascency of this field of research and the importance of future research to identify the most effective interventions to improve this important aspect of ICU care. (*Crit Care Med* 2017; 45:103–128)

Key Words: family; patient-centered care; intensive care; intensive care; neonatal; critical care; critical care nursing

There is increasing evidence of the significant impact that critical illness has on family members of the critically ill. Stressful decision making often falls to family members because most patients in the ICU are too ill to participate in decision making (1). Furthermore, family members bear a significant burden of caregiving to the more than 50% of critical illness survivors who have postdischarge disability (2, 3). Approximately one quarter to one half of family members of critically ill children or

adults experience psychological symptoms, including acute stress, post-traumatic stress, generalized anxiety, and depression both during and after the critical illness of a loved one (4–6). The sum total of family exposure to critical illness may result in what has been termed “Post-Intensive Care Syndrome-Family” (3, 5). There is increasing awareness of the importance of improving outcomes for family caregivers and that support for family caregivers can also improve patient outcomes (6, 7).

Structured interventions and approaches to support family members of critically ill patients are needed both to mitigate the impact of the crisis of critical illness and to prepare family members for decision-making and caregiving demands. Family-centered care recognizes the central importance of the family to a patient's recovery and describes the responsibilities of the healthcare team to provide support for families of seriously ill patients. The objective of these guidelines is to provide clinicians with evidence-based strategies to optimize support of the family of critically ill patients in the ICU.

The original clinical practice guidelines for support of the family in the patient-centered ICU from the American College of Critical Care Medicine were published in 2007 (8). These prior guidelines have been one of the most widely cited documents on family-centered care and stimulated research on the role of families in ICU care. However, the prior guidelines were developed using what is now an outdated evidence analysis. The new guidelines described in this work are not an update of the prior guidelines, but instead are the result of a completely new and more rigorous analysis. These new guidelines represent the current state of international science in family-centered care and family support for family members of critically ill patients across the lifespan. We report here the process for the systematic review of the literature, grading of the evidence, consultation with patients and families, and development of consensus among international experts on the final recommendations herein.

METHODS

In brief, these guidelines were developed using the Council of Medical Specialty Societies Principles for the Development of Specialty Society Clinical Guidelines framework (9). The guideline writing group was composed of international experts in the fields of neonatal, pediatric, and adult critical and intensive care medicine and family-centered care. The goal was to create a document to optimize family-centered care for the global community of ICU clinicians who care for patients and family members of all age groups. Full methods are provided in **Electronic Supplement 1** (Supplemental Digital Content 1, <http://links.lww.com/CCM/C240>).

Incorporation of Patient and Family Perspectives

The perspectives of patients and family members were incorporated in guideline development in two ways: through initial qualitative literature review and through direct consultation. We conducted a scoping review of the qualitative literature relevant to neonatal, pediatric, and adult patient and family perspectives using PubMed, CINAHL, Web of Science, and PsycINFO. The

purpose of this review was to identify issues of importance to patients and families to generate “Patient, Intervention, Comparator, Outcome” (PICO) questions. A citation report showed that the number of publications exceeded 100 per year beginning in 1994 (**Electronic Fig. 1**, Supplemental Digital Content 3, <http://links.lww.com/CCM/C242>). We used this as a basis to determine the year to begin our literature search in 1994 (for qualitative literature search strategy and results, see **Electronic Appendix C**, Supplemental Digital Content 4, <http://links.lww.com/CCM/C243>).

Former ICU patients and family members were recruited from the University of Maryland (UOM) School of Medicine and the University of California San Diego Health System (UCSD), as well as through patient advocacy organizations, including the Acute Respiratory Distress Syndrome Foundation, Survivors of Sepsis, and Project Help. This recruitment was done in parallel with an ongoing research study at the UOM (Institutional Review Board [IRB] HP-0058018) and UCSD (IRB 140458).

Patient and family participants ($n = 27$) were consulted at three time points during the guidelines preparation: 1) development of the definition of family and family-centered care; 2) creation of the domains for development of PICO questions; and 3) ranking of the importance of outcomes. At each time point, interviews were done by telephone or email at the preference of the participant.

Definitions of “Family” and “Family-Centered Care”

The definitions for “family” and “family-centered care” were adapted from prior definitions and unanimously agreed upon by the guideline writing committee and the former ICU patients and family members. Our definitions are as follows:

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.

Family-centered care is an approach to health care that is respectful of and responsive to individual families’ needs and values.

Defining the Relevant Outcomes and Prioritizing the Outcomes

The guidelines writing group developed a list of domains for family-centered care outcomes through a review of the qualitative literature identifying domains important to patients and family members (10–21). We then had group members rate the relative importance of each outcome on a scale of extremely important (10) to not at all important (0). In addition, a sample of survivors and family members also rated the importance of these outcomes on the same scale producing similar results and supporting the rating results. These outcomes and their importance scores are shown in **Electronic Table 2** (Supplemental Digital Content 2, <http://links.lww.com/CCM/C241>).

Search Strategy for Systematic Review

In accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, our

systematic review protocol was registered with the International Prospective Register of Systematic Reviews on June 14, 2015, and was last updated on December 8, 2015 (registration number CRD42015023445). PubMed, CINAHL, and EMBASE databases were searched for quantitative studies in the area of family-centered care in critical care. We narrowed literature to English language studies with a publication date during or after 1994. The PubMed search strategy and results are shown in the electronic supplement.

Eligible studies for this systematic review included randomized trials and observational studies. For interventions lacking experimental or observational studies, qualitative literature that helped to answer the PICO question was accepted but considered to be very low quality of evidence. We excluded studies where outcomes were not focused on the family or that were not conducted in an ICU environment (exception made a priori: family presence at resuscitation in the emergency and prehospital setting).

Our December 2014 searches identified 4,158 reports after deduplication. Seventy-six additional studies were subsequently included from alerts and hand searches, and 236 studies were included in the final analyses. We used the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) tool to assess the level of evidence from included studies. **Electronic Supplement Figure 2** (Supplemental Digital Content 3, <http://links.lww.com/CCM/C242>) describes the PRISMA flow diagram of study identification and inclusion.

GRADE Process for Grading the Evidence

GRADE assigns the strength of a recommendation based on the priority of a problem; balance of benefits and harms; certainty of the evidence of effect; values and preferences; equity; acceptability; and feasibility (22). Two or three investigators examined and summarized the literature relevant to each PICO question. To avoid intellectual conflict, guidelines writing group members who had authored a study of interest did not perform the GRADE analysis of their own scientific work.

The entire guidelines writing group voted on all recommendations. At least 50% of members had to vote in favor of, and no more than 20% against, each recommendation. Strong recommendations use the language “we recommend,” whereas weak recommendations use the language “we suggest” according to GRADE standards. All recommendations were based upon the published evidence and not from consensus statements. For additional details, see Electronic Supplement 1 (Supplemental Digital Content 1, <http://links.lww.com/CCM/C240>).

RESULTS: PICO QUESTIONS AND RECOMMENDATIONS

In the section to follow, the evidence summary and recommendations for each PICO question are presented. GRADE worksheets and voting summaries are archived with the Society of Critical Care Medicine (SCCM). For all of the PICO questions, evidence varied significantly in study design and outcome measures, such that it was difficult to combine results statistically. For this reason, the nature of the individual studies is described in the narrative after each question.

Executive Summary of Recommendations

All recommendations in these guidelines are made from moderate, low, or very low quality evidence and constitute weak recommendations per GRADE methodology (23). When outcomes are listed at the conclusion of a recommendation, it is because these outcomes have been tested (whereas others may not have been). We note the lack of research addressing the use of multiple simultaneous interventions. Although it seems likely that some combination of the interventions may improve outcomes, there are currently no data on the additive or synergistic effects of combined interventions. Clinicians and institutions will need to make a judgment about which intervention or combination of interventions are likely to be most successful in specific circumstances. We also note that adverse effects have not been described for most of the interventions, but are possible. Statements as to adverse effects or risks for each PICO question are not repeated below; unless the intervention's specific adverse effects or risks were described. Recommendations apply to neonatal ICU (NICU), PICU, and adult ICUs unless otherwise specified. When specified, it is because the evidence was available in only one age category.

ICU Family-Centered Care Recommendations

We suggest the following:

1. Family presence in the ICU
 - 1.1. Family members of critically ill patients be offered open or flexible family presence at the bedside that meets their needs while providing support for staff and positive reinforcement for staff to work in partnership with families to improve family satisfaction. (2D)
 - 1.2. Family members of critically ill patients be offered the option of participating in interdisciplinary team rounds to improve satisfaction with communication and increase family engagement. (2C)
 - 1.3. Family members of critically ill patients be offered the option of being present during resuscitation efforts, with a staff member assigned to support the family. (2C)
2. Family support
 - 2.1. Family members of critically ill neonates be offered the option to be taught how to assist with the care of their critically ill neonate to improve parental confidence and competence in their caregiving role and improve parental psychological health during and after the ICU stay. (2B)
 - 2.2. Family education programs be included as part of clinical care as these programs have demonstrated beneficial effects for family members in the ICU by reducing anxiety, depression, post-traumatic stress, and generalized stress while improving family satisfaction with care. (2C)
 - 2.3. Peer-to-peer support be implemented in NICUs to improve family satisfaction, reduce parental stress, and reduce depression. (2D)
 - 2.4. ICUs provide family with leaflets that give information about the ICU setting to reduce family member anxiety and stress. (2B)
- 2.5. ICU diaries be implemented in ICUs to reduce family member anxiety, depression, and post-traumatic stress. (2C)
- 2.6. Validated decision support tools for family members be implemented in the ICU setting when relevant validated tools exist to optimize quality of communication, medical comprehension, and reduce family decisional conflict. (2D)
- 2.7. Among surrogates of ICU patients who are deemed by a clinician to have a poor prognosis, clinicians use a communication approach, such as the "VALUE" mnemonic (Value family statements, Acknowledge emotions, Listen, Understand the patient as a person, Elicit Questions), during family conferences to facilitate clinician-family communication. (2C)
3. Communication with family members
 - 3.1. Routine interdisciplinary family conferences be used in the ICU to improve family satisfaction with communication and trust in clinicians and to reduce conflict between clinicians and family members. (2C)
 - 3.2. Healthcare clinicians in the ICU should use structured approaches to communication, such as that included in the "VALUE" mnemonic, when engaging in communication with family members, specifically including active listening, expressions of empathy, and making supportive statements around nonabandonment and decision making. In addition, we suggest that family members of critically ill patients who are dying be offered a written bereavement brochure to reduce family anxiety, depression, and post-traumatic stress and improve family satisfaction with communication. (2C)
 - 3.3. ICU clinicians receive family-centered communication training as one element of critical care training to improve clinician self-efficacy and family satisfaction. (2D)
4. Use of specific consultations and ICU team members
 - 4.1. Proactive palliative care consultation be provided to decrease ICU and hospital length of stay (LOS) among selected critically ill patients (e.g., advanced dementia, global cerebral ischemia after cardiac arrest, patients with prolonged ICU stay, and patients with subarachnoid hemorrhage [SAH] requiring mechanical ventilation). (2C)
 - 4.2. Ethics consultation be provided to decrease ICU and hospital LOS among critically ill patients for whom there is a value-related conflict between clinicians and family. (2C)
 - 4.3. A psychologist's intervention be provided to specifically incorporate a multimodal cognitive behavioral technique (CBT)-based approach to improve outcomes in mothers of preterm babies admitted to the NICU; furthermore, targeted video and reading materials be provided in the context of psychological support to mothers of preterm babies admitted to the ICU. (2D)

- 4.4. Social workers be included within an interdisciplinary team to participate in family meetings to improve family satisfaction. (2D)
 - 4.5. Family navigators (care coordinator or communication facilitator) be assigned to families throughout the ICU stay to improve family satisfaction with physician communication, decrease psychological symptoms, and reduce costs of care and length of ICU and hospital stay. (2C)
 - 4.6. Spiritual support from a spiritual advisor or chaplain be offered to families of ICU patients to meet their expressed desire for spiritual care and the accreditation standard requirements. (2D)
5. Operational and environmental issues
- 5.1. Protocols be implemented to ensure adequate and standardized use of sedation and analgesia during withdrawal of life support. (2C)
 - 5.2. Nurses be involved in decision-making about goals of care and be trained to provide support for family members as part of an overall program to decrease ICU and hospital LOS and to improve quality of communication in the ICU. (2D)
 - 5.3. Hospitals implement policies to promote family-centered care in the ICU to improve family experience. (2C)
 - 5.4. Given the evidence of harm related to noise, although in the absence of evidence for specific strategies, ICUs implement noise reduction and environmental hygiene practices and use private rooms to improve patient and family satisfaction. (2D)
 - 5.5. Family sleep be considered and families be provided a sleep surface to reduce the effects of sleep deprivation. (2D)

A table of the summary of recommendations for future research can be found in Appendix 1. Note that this list is not exhaustive in nature.

Family Presence With Patients in the ICU. *PICO question 1.1.* In the critical care environment, does open family presence at the bedside (also called “open visiting”) affect family satisfaction?

Evidence Summary: The majority of literature examining the effect of open family presence at the bedside (defined as no or minimal restrictions on presence at the bedside) is observational or descriptive in nature. Many families value the opportunity to be at the bedside (24–28) and sometimes report the need to safeguard the patient or be vigilantly present (29–31). However, open family presence policies can be challenging to ICU staff and may be perceived to increase workload (13, 32) and staff stress (33). Family presence is necessary for family engagement at the bedside, which has been demonstrated, when coupled with an educational program, to improve outcomes (34–36).

There are no randomized trials addressing the effect of open or flexible family presence on family-centered outcomes. Data from existing observational studies addressed family satisfaction with variable ICU accessibility. One study examined open versus restricted family presence and demonstrated no differences

in information or comfort for the families (37). Another study exposed families to open family presence with one group also receiving an information booklet (38). When comparing unrestricted with open family presence, there was a statistically significant increase in nine out of 11 measures of knowledge with open family presence. The sample of families ($n = 50$) who received the informational booklet were more knowledgeable about specific facts. A third study conducted a pre- and postsurvey after implementation of flexible family presence. When minimal restrictions were lifted from family presence (during report times) family satisfaction improved without changing staff satisfaction (39).

The quality of the evidence is very low for family presence with patients because there are no randomized trials and the observational studies are of poor quality. Studies are limited by small sample sizes, inadequate reporting of study results, and methodological issues. It is therefore difficult to understand how open family presence affect families. The literature would at least suggest that open family presence are more beneficial for families and may affect staff workload or perception of workload. In the future, shifting away from the term visiting to family presence and/or engagement would better reflect alignment with the family-centered paradigm.

Recommendation: Given the value family members place on family presence, their dissatisfaction associated with restricted presence, and the benefit of engagement associated with presence, we suggest that family members of critically ill patients be offered open or flexible family presence at the bedside that meets their needs while providing support for staff and positive reinforcement to work in partnership with families. (2D)

Further research is needed to understand the best ways to implement open flexible visitation and fully understand the impact on family member outcomes and conflict in the ICU.

PICO question 1.2. Does family presence during interdisciplinary team rounds improve family psychological symptoms, family trust in clinicians, family satisfaction with and preferences for care or communication, family or clinician conflict, degree of shared decision making (as a direct result of family participation), and family knowledge?

Evidence Summary: The majority of literature examining family presence on rounds is descriptive or observational in nature and focuses on the needs, perceptions and preferences of family members and healthcare providers. Studies have been conducted in the adult ICU (40–42), PICU (43, 44), or neonatal ICU (45, 46). In general, family members are as satisfied or slightly more satisfied when they participate in rounds and tend to be more in favor of family participation than the traditional rounds format that excludes family members. Family members who participate in family-centered rounds report slightly or somewhat greater understanding and involvement in decision making and satisfaction with provider communication than those who do not. There was inconsistency in reports of greater anxiety or stress or privacy concerns related to participation in rounds, with some studies reporting an increase and others reporting no difference. No studies examined family or clinician conflict or alterations in the quality of bedside teaching. There is limited description to distinguish between the presence and active participation by

family members. All studies had significant limitations in the use of nonvalidated measures and single-item questions of different dimensions of family experience.

Randomized trials and observational studies assessing validated family-centered outcomes related to this important topic are lacking. One small single-center randomized crossover trial in the PICU setting compared parent ($n = 27$) and resident ($n = 21$) perspectives after rounds were randomly assigned to occur at the bedside or in the conference room for two consecutive mornings. Parents reported increased satisfaction with bedside rounds on multiple survey items: understanding of what the doctor said, confidentiality and intimacy respected, questions were answered, enough time was spent with them, their child was respected, their problem was taken seriously, and understanding of tests and treatment plans. Parents preferred bedside case presentation, and 81% wished that the next case presentation would take place at their child's bedside.

Data from several small observational studies (47–50) suggest improvement in family preferences (47), satisfaction (48–50), involvement in asking questions and in decision making (47), and support with decision making (50). Anxiety could theoretically increase or decrease with family presence on rounds compared with rounds without family presence (50). One study (51) found that family perceptions change over time: compared with later in the ICU stay, on the day of admission families understood the plan less, felt less comfortable asking questions, did not want bad news during rounds, were more likely to be concerned about privacy, and wanted more information after rounds. However, because all studies reported generally high levels of satisfaction with traditional rounds, most of the described differences were small.

The evidence is of low quality because the single randomized trial is of low quality as are the limited number of observational studies. Studies are limited by small sample sizes, inadequate reporting of study results, and methodological issues (crossover, lack of validated measures). These limited data suggest no immediate harm, and there are no data on long-term psychological outcomes. Family members generally express a preference to have the option to be present. In one study (50), residents had slightly less satisfaction with bedside rounds with parents participating compared with parents present but not participating. There is no evidence to determine the relative risks, feasibility, burden, or cost of family presence and participation during rounds compared with traditional rounds without family presence or participation.

Recommendation: We suggest that family members of critically ill patients be offered the option of participating in interdisciplinary team rounds to improve satisfaction with communication and increase family engagement. (2C)

Further research is needed to fully understand the best method of including family members in medical rounds and the impact of this on family outcomes. Further research is also needed to understand potential benefits and burdens and long-term effects on family outcomes

PICO question 1.3. Does family presence during resuscitation affect family psychological symptoms, caregiver burden,

family trust in clinicians, family satisfaction with care, family satisfaction with communication, family or clinician conflict?

Evidence Summary: Both family members and clinicians have strong opinions about family presence during resuscitation efforts and several national organizations, including the Emergency Nurses Association (52), the American Heart Association (53), the American Association of Critical-Care Nurses (54), the American Academy of Pediatrics (55), the European Federation of Critical Care Nursing Associations (56), the European Society of Pediatric and Neonatal Intensive Care (56), and the European Society of Cardiology Council on Cardiovascular Nursing (56, 57), have made formal statements in support of family presence during resuscitation. There is a large body of descriptive and qualitative literature that explores the attitudes of family members and clinicians about this practice. However, there are few randomized trials or observational studies that assess family-centered outcomes related to family presence during resuscitation.

Numerous studies examining family member attitudes about family presence during resuscitation suggest a supportive attitude for this practice, and many family members express a desire to be present during the resuscitation of a loved one (58–68). In one study of deaths in the emergency department, family members of decedents reported the belief that their presence would have helped the patient and the belief that their presence during the resuscitation would have attenuated their grief (58). An evaluation of resuscitation in a PICU identified similar findings, with family members who were present for resuscitation reporting the belief that their presence brought comfort to their child and that their presence helped them adjust to the loss of their child (62). Themes from the qualitative literature include the idea of being there for the patient, seeing firsthand what was happening during the resuscitation, and protecting and supporting the patient (69, 70).

Support for family presence among clinicians is not consistently positive, and studies suggest that few institutions have adopted policies regarding the presence of family members during resuscitation in the ICU or emergency department (56, 71–73). Survey data suggest that nurses have a more positive outlook about family member presence during resuscitation compared to physicians (60, 67, 74–78). In addition, providers with limited experience with family presence are less supportive of this practice than those who have participated in resuscitation efforts that included family members (67, 79, 80). Concerns about family presence include the possibility of family interference with procedures, impaired staff performance, psychological trauma for family members, and litigation that may arise following a resuscitation attempt (60, 61, 74, 75, 77, 81–97). In a study assessing family-witnessed resuscitation in 162 UK emergency departments, 57 departments reported adverse events associated with family member presence (98). Adverse events included family member distress, interference with resuscitation, distracting the team, and making inappropriate demands on the team. Only one emergency department reported any medicolegal issues related to family presence during resuscitation, and none of the emergency departments that permitted family-witnessed resuscitation had plans to stop this practice based on adverse events (98). Other studies evaluating implementation of

family presence programs have not reported interruptions in care related to family member presence (74, 99).

To date, two randomized trials have addressed family presence during resuscitation in the emergency department (100, 101), but none have addressed this issue in the hospital-based ICU. Both of these studies have significant limitations. The first trial only included 25 patients undergoing resuscitation at a single center (100). The authors assessed eight different family member psychological measures and did not identify any significant differences between witnesses of resuscitation and the control group. The other randomized trial evaluating family presence during resuscitation only provided descriptive data, and no quantitative comparisons were made between family members who witnessed resuscitation and those who did not (101).

Although randomized trials in the emergency department and ICU are lacking, research done in the out-of-hospital setting has offered important insights into family presence. In a cluster-randomized trial, family presence was evaluated during resuscitation of cardiac arrests occurring at home. Emergency medical service units ("mobile ICUs") assigned to the intervention asked family members if they wished to be present at the resuscitation (102). Ninety days after resuscitation, enrolled relatives completed the Impact of Event Scale and the Hospital Anxiety and Depression Scale by telephone. Frequency of posttraumatic stress disorder-related symptoms was significantly higher in the control group than in the intervention group and also higher among family members who did not witness CPR compared with those who did. Family-witnessed resuscitation did not affect resuscitation characteristics, patient survival, or the level of emotional stress in the medical team (102). A study following long-term psychological outcomes in these family members found that at 1 year after the event, psychological distress was higher for those family members not offered the option to witness resuscitation: PTSD-related symptoms, major depressive episode, and complicated grief (103).

Data from existing observational studies (104, 105) do not clarify or answer remaining questions about family presence during resuscitation. One study enrolled 50 family members of patients undergoing trauma resuscitation in a single center. They found no significant differences in family member anxiety, satisfaction, or well-being when comparing family members who were present for the resuscitation to those who were not. Another study collected ratings of satisfaction from parents of children in a PICU and compared ratings of satisfaction between parents present during resuscitation compared with parents not present. Sixty-four parents completed the self-developed survey of parental satisfaction, and no significant differences in satisfaction were found when comparing parents who were present during resuscitation to those who were not.

The role of staff in supporting family members is one important aspect of family presence during resuscitation that has also been left largely unaddressed in randomized trials or observational studies. Many institutions with policies or programs regarding family presence have mandated that when possible a nurse, chaplain, or other trained staff member be available to support family members who choose to witness resuscitation (74, 99, 106–108). The presence of support personnel was

also included in the existing aforementioned randomized trials (100, 101, 103); however, the relationship between family-centered outcomes and the presence of a dedicated support person has not been well described. Because most studies included an individual designated to provide family support, this fact should be considered in implementation of this intervention.

The quality of evidence is low as existing randomized trials are of low quality or completed outside of the ICU setting. Studies are limited by small sample sizes, inadequate reporting of study results, and methodological issues (such as crossover and early termination due to lack of experimental concealment).

Recommendation: We suggest family members of critically ill patients be offered the option of being present during resuscitation efforts, with a staff member assigned to support the family. (2C)

Future research is needed to better understand the influence of family presence for resuscitation on patient and family outcomes and the best approach for supporting family presence.

Family Support. PICO question 2.1. Among families of ICU patients, does teaching family members to participate in patient care affect family satisfaction with care, family self-efficacy, or time to do not resuscitate (DNR) order?

Evidence Summary: We identified two randomized trials that addressed teaching families to participate in care in the NICU (109, 110). Both studies evaluated satisfaction with participation and being provided information. One study, including 55 mothers in both the control and treatment group demonstrated that participation and presence in the NICU increased maternal satisfaction (110). The other study ($n = 133$) demonstrated increased satisfaction with information and pain control information, as well as a sense that nurses showed the parent how to look for signs of pain and perform comfort techniques, but did not reduce maternal stress (109). In addition, there is one randomized trial comparing standard care versus basic developmental care and another comparing basic developmental care versus care based on the Newborn Individualized Developmental Care and Assessment Program including behavioral observations (111). Both had sample sizes over 100. Parents of the infants born less than 32 weeks of gestational age received questionnaires after the first week of admission in the neonatal unit and approximately 2 weeks after the birth of their infant. Results showed no significant difference in parental stress with these interventions.

Data from existing observational studies (112, 113) do not clarify or answer questions about family self-efficacy or time to DNR order. One study evaluated opinions of family members and desire to help with care in the ICU and 84% of families expressed a wish to be engaged in care (112). Another study involving 216 parents aimed to evaluate the impact of a national program designed to promote family-centered care in NICUs and to provide information and comfort to families during the NICU hospitalization of their newborn (113). Results of the study revealed better communication with the national program in place.

The majority of literature examining teaching family members in the ICU to participate in patient care is limited to two randomized trials and several observational studies focusing

mainly on the neonatal setting. Maternal and other family participation in providing patient care in the NICU is strongly correlated with increased maternal satisfaction but does not decrease stress for the mother.

The quality of evidence is moderate for satisfaction. Existing randomized trials show benefit for this outcome. Observational studies are limited in number and in the provided evidence. Family members of NICU patients express the desire to assist with care, and studies show increased satisfaction among mothers of those patients with this intervention.

Recommendation: We suggest that family members of critically ill neonates be offered the option to be taught how to assist with the care of their critically ill neonate to improve parental confidence and competence in their caregiving role and improve parental psychological health during and after the ICU stay. (2B)

Further research concerning the benefits and limitations of family participation for care for children and for adult patients is needed.

PICO question 2.2. Among family members of ICU patients, do training/education programs for family members affect family psychological symptoms, family stress, family satisfaction, family self-efficacy, and hospital LOS and costs?

Evidence Summary: The majority of literature examining the effect of family training/education programs is observational or descriptive in nature. There are three randomized trials addressing family-centered outcomes (34–36). The types of family training/education programs vary widely in type, duration, and purpose and as such are difficult to compare.

There are seven studies addressing family psychological symptoms (primarily depression and anxiety) with family training/education programs. There are three randomized trials; one is of very low quality and found no effect of the training/educational intervention on family psychological outcome (34), whereas two randomized trials, one of high and one of moderate quality, found the Creating Opportunities for Parent Empowerment (COPE) educational program reduced family stress and depression (35, 36). There are also three observational studies (114–116) and a secondary analysis of a randomized trial (117) all of which found reduced anxiety. The observational studies are of very low quality.

Data from four studies address family stress with family training/education programs. There are two randomized trials (34, 35), a secondary analysis of a randomized trial (117), and one observational study (118). The three studies (34, 35, 117) used the COPE program. In secondary analysis of the randomized trial (117), maternal perceived stress was reduced by COPE training and maternal anxiety was directly associated with stress. In one randomized trial, the COPE training resulted in a decrease in several measures of stress (34); another study found that the COPE training decreased stress at 2 months in mothers but not in fathers (36). The observational study using an NICU education program found the program reduced stress in fathers but not in mothers (118). The observational study and secondary analysis are very low quality, whereas the two randomized trials have high and moderate quality evidence. The results of the studies are not definitive with the two high-quality studies

showing reduced stress but one only in mothers and the other study having a small effect size.

Data from existing observational studies address family satisfaction with family training or education programs. There are four observational studies with very low quality evidence. One study assessed a family education program and found that the intervention group had a significant increase in family satisfaction with small effects (119). Another study used a family education program and found higher satisfaction in the experimental group with small effects (115).

Data from one randomized trial and three observational studies address family self-efficacy with family training/education programs. The observational studies (120–122) are of low quality. One study used a program to teach parents how to do exercises with their preterm children and found that the parents performed the exercises on most days (93%) and made few errors (120). A positive parent education program found that the family was able to gain perspective on the situation and learn key concepts and find resources (121). A training program with families of children with tracheostomy found high satisfaction with the training (122).

Data from existing observational studies address cost and LOS with family training or education programs. One observational study reported reduced median hospital LOS by 24 days after the education program (123). A cost analysis of the COPE training found estimated cost savings of \$4864 per preterm born child with reduced hospital LOS by 3.8 days (124). Both studies have very low quality of evidence.

The overall quality of evidence is low as there are predominately observational studies that are of low quality and three randomized trials, of which one trial is of low quality and two are of high quality. Studies are limited by small sample sizes, inadequate reporting of study results, and other methodological issues. The literature suggests that family education programs may reduce family psychological symptoms (depression and anxiety) and family stress. These programs may increase family satisfaction and family self-efficacy and may reduce hospital LOS and costs.

Recommendation: We suggest that family education programs be included as part of clinical care as these programs have demonstrated beneficial effects for family members in the ICU by reducing anxiety, depression, post-traumatic stress, and generalized stress, while improving family satisfaction with care. (2C)

Further research is needed to understand the educational/training programs and their impact on family member outcomes and ICU LOS and costs. In addition, much of the work to date has been done in pediatric populations; this research should be extended to adolescents and adults.

PICO question 2.3. Among family members of ICU patients, does provision of family support such as family peer-to-peer support, “date night,” or family respite affect family psychological symptoms like PTSD and family satisfaction with care?

Evidence Summary: We found no studies of single interventions of date-night or respite support. There are four studies of a single intervention of peer-to-peer support in the NICU. Three (125–127) are descriptive, qualitative studies of small convenience samples in a single site that describe perceptions

of health professionals (126) or mothers (125, 127) receiving a peer-to-peer counseling about breast feeding infants in the NICU. The mothers felt supported and satisfied to work with the peer counselors who had experienced themselves the difficulties of providing milk and breastfeeding in the NICU setting (125) and most ranked the peer support as most important for development of their maternal role in the NICU (127). The fourth descriptive study documented the utilization of peer-to-peer support provided in three formats: in groups, one-to-one at the bedside, and by telephone. Of the 477 parents (301 families) followed up over a 2-year period, 78% consistently used only one type of peer-support (bedside). A minority of families using the multiple types of support used them frequently. Of the 48 parents who completed the survey, 92% felt that the program met their needs and would recommend the program to another NICU family (128).

One small study (129) compared peer support for mothers of NICU infants at one site with a control group of mothers at another similar NICU site. The mothers at the site with peer support reported less stress at 4 weeks and less state anxiety, less depression, and more social support at 16 weeks than the mothers in the control group.

One small retrospective comparison study of peer support as part of a package of interventions to integrate parents into the care of NICU infants found that 92% would recommend the program to others (128). The evidence available for this topic is of very low quality.

These interventions, particularly peer-to-peer support, have low cost and low risk, with the suggestion of possible benefit. Qualitative research suggests that families value peer support in NICU (125–127).

Recommendation: We suggest that peer-to-peer support be implemented in NICUs to improve family satisfaction, reduce parental stress, and reduce depression. (2D)

There is no evidence to evaluate date-night or respite, and therefore no recommendation can be made about those topics at this time.

Further research is needed to evaluate the value of peer-to-peer support in all age groups to improve family-centered outcomes. Further research is also needed to evaluate family support options such as date-night or respite.

PICO question 2.4. Do written materials such as pamphlets, education materials, and bereavement materials targeting ICU family members improve psychological distress or communication compared with usual care?

Evidence Summary: Ample evidence exists describing the many psychological, financial, and social challenges faced by the family members of ICU patients both during and after the period of ICU care (130–132). Two studies show that written materials can improve family member psychological distress. One randomized trial of 126 patients and their family members compared a bereavement brochure plus a proactive family conference to usual care finding that the intervention reduced PTSD, depression, and anxiety symptoms among family members at 90 days after the patient's death (4). In another randomized trial including 175 family members, a family information

leaflet compared with usual care improved family members' comprehension of medical information (133).

The quality of evidence is moderate because the results of these two studies demonstrated large treatment effects. Because studies were relatively small, no dose-response relationship could be tested. In addition, the strongest study (4) included two interventions—a proactive family conference and a bereavement pamphlet—making it impossible to determine the relative effectiveness of each intervention. The benefits seem quite strong and compelling with no associated risk or burden for relatives and can be implemented at relatively low cost.

Recommendation: We suggest that ICUs provide family with leaflets that give information about the ICU setting to reduce family member anxiety and stress. (2B)

Further research is needed to examine the relative benefits of different approaches to providing written materials to family members.

PICO question 2.5. Among family members of ICU patients does an ICU diary program improve/affect psychological symptoms (PTSD, anxiety, or depression)?

Evidence Summary: Ample evidence exists describing that post-ICU burden for relatives, especially in the form of anxiety, depression and PTSD, in the months that follow the patient's discharge or death (130–132). During the patient's stay, families have difficulty in understanding and assimilating information, in maintaining a connection with the critically ill patient, and they may also question the quality of care (134, 135). All this contributes to the development of post-ICU burden after patient's discharge or death. The ICU diary is a diary that is written for the ICU patients during their time of critical illness. It can be written by relatives, nurses, physicians, and others. Two randomized trials show that, in family members, receiving an ICU diary can reduce the risk of post-traumatic stress 3 months (136) and 12 months (137) after the patient's discharge or death. The quality of evidence is low with sample sizes of 36 and 143, respectively. These trials are conducted in single center or included only two sites. Across studies, the procedure involved in providing the patient or family with a diary is very different. In one trial (136), the diary was given to the patient by a research nurse or doctor who discussed its content with the patient. In the other trial (138), the diary was handed to the patient as the patient left the hospital with no discussion. Although both trials assess the impact of the diary on post-traumatic stress symptoms, they do not use the same outcome scales. The limits of both trials suggest the need for more research such as a multicenter randomized trial to further assess the effect of a diary on patients' relatives' well-being. Qualitative studies allow relatives to describe the benefits of ICU diaries (138–140). No harm has been described and relatives mostly describe improved communicative, emotional, and humanizing experiences including improved comprehension of information, connection to the patient, and trust in caregivers. No risks or burdens for relatives have been described (see qualitative literature [138–140]). There is a potential time investment to hospitals and ICUs for development of diary programs. The overall quality of evidence for ICU diaries is low.

Recommendation: We suggest that ICU diaries be implemented in the ICU to reduce family member anxiety, depression, and post-traumatic stress. (2C)

Further research should be developed to assess the effectiveness and cost-effectiveness of a diary on family outcomes.

PICO question 2.6. In the ICU environment, do decision support tools for families or shared decision making itself improve/affect communication, cost or LOS?

Evidence Summary: Surrogate decision makers of ICU patients face significant challenges during hospitalization of their loved ones. Barriers to good-quality decision making include stress, emotion, the complexity of the clinical situation, uncertainty, poor communication quality, and lack of social support. One published article describes a small before and after study of a written shared decision support aid designed for surrogate decision makers of patients with chronic critical illness (141). The study took place in three academic medical centers. The decision support tool was associated with lower clinician-family discordance about prognosis, better quality of communication, and better medical comprehension. Hospital costs were approximately \$68,000 lower in the intervention group. Quality of evidence is very low due to the small size of the study and the before and after design.

Recommendation: We suggest that validated decision support tools for family members be implemented in the ICU setting when relevant validated tools exist to optimize quality of communication, medical comprehension, and reduce family decisional conflict. (2D)

Further research is needed to assess the effect of a decision aid on surrogate decision makers' well-being and the quality of decisions, as well as the important components of decision aids for improving outcomes.

PICO question 2.7. In the ICU environment, do clinician support tools targeting family support or primary palliative care such as checklists, worksheets, and mnemonics improve family satisfaction, communication, or psychological distress compared with usual care?

Evidence Summary: Several studies have examined the impact of clinician support tools targeting families on patient- and family-centered outcomes (69, 142, 143). One observational study examined the impact of implementing a bundle of interventions (ICU Quality Bundle) on family satisfaction. The ICU Quality Bundle was a multifaceted educational intervention targeting improving communication with family members during their loved one's admission to the ICU, and included a family conference by 72 hours, documentation of surrogate decision maker, and documentation of advanced directives, among other aspects. Eighty-six individuals in the intervention period were compared with 26 in the preintervention period. The intervention was associated with nonstatistically significant differences in family satisfaction within 72 hours from admission. Authors propose that nonsignificance was due, in part, to poor protocol compliance initiating conferences when indicated (142). Another multicenter randomized trial allocated families of ICU patients to a combined intervention of a bereavement packet

and family conference, described above, focused on end-of-life care where clinicians employed the VALUE mnemonic. The intervention significantly reduced symptoms of PTSD, depression, and anxiety among family members at 90 days after the patients' death (4).

The evidence is of low quality. The observational study was rated very low due to study design although it could also be very low due to the imprecision of effect (142). The single randomized trial provided the most compelling evidence of benefit of the VALUE mnemonic. In addition to use of VALUE during the family conference, the intervention also included a bereavement packet. It is impossible to determine whether the effect is attributable to the use of the mnemonic or the bereavement packet or both. The study was upgraded because it identified several large and clinically meaningful improvements in family outcomes. Benefits seem quite strong and persuasive without known risk or burden for relatives and likely can be administered at very low costs.

Recommendation: We suggest that among surrogates of ICU patients who are deemed by a clinician to have a poor prognosis, clinicians use a communication approach, such as the mnemonic "VALUE," during family conferences to facilitate clinician-family communication. (2C)

Further research is needed to identify the most effective methods to improve communication with family members of critically ill patients.

Evaluation of Interventions Focused on Improving Communication. **PICO question 3.1.** In the ICU setting, do routine interdisciplinary family conferences improve patient or family outcomes, including increasing family satisfaction with communication and trust in clinicians, and reducing conflict between clinicians and family members?

Evidence Summary: The effect of routine interdisciplinary family conferences on family satisfaction with care was addressed in one observational study (144). In comparing family members of 106 patients from Neurological and Medical ICUs who did not participate in any formal family meetings to those who did participate, those who did not participate were less likely to feel completely satisfied with the concern and caring shown to them as family members by ICU staff. Four different articles conducted analyses from an observational study of 51 ICU family conferences showing that family satisfaction with communication during family meetings was associated with improved communication techniques (two with mixed qualitative-quantitative designs [145, 146] and two with quantitative, observational designs [147, 148]). One study (147) found that an increased proportion of family speech during meetings was significantly associated with increased family satisfaction with physician communication. In another (145), there was a significant association between the number of empathic statements made during family conferences and higher degree of family satisfaction with communication. In the latter study, there was a dose-response gradient such that more empathic statements were associated with greater satisfaction. Furthermore, specific statements were associated with increased family satisfaction, including assurances of

nonabandonment; assurances of comfort and not suffering; and support for family's decision to withdraw or not to withdraw life support (146). The third analysis (148) found that higher levels of shared decision making were associated with greater family satisfaction with communication. Findings from these studies provide indirect evidence that interdisciplinary family conferences, when conducted well, are associated with increased family satisfaction with communication.

Quality of communication was also associated with family conferences using medical interpreters in three different observational studies (149–151) during which interpreters were used for non-English-speaking families. Alterations in interpretation (i.e., additions, omissions, substitutions, and editorializations) were present in 55% of communication exchanges between clinicians and family members (149); three quarters were judged to have potentially significant consequences on conference goals, and 93% were considered negative. In addition, non-English-speaking family members received significantly less information and support than English-speaking family members (151). Another study (150) quantified examples of good quality of communication from qualitative content audiotaped in family conferences with Spanish- and English-speaking families. Overall, quality of communication was found to be poor in both interpreted and noninterpreted ICU family meetings, but worse with Spanish-speaking patients.

Regarding conflict, in a before and after study (152), the use of a proactive interdisciplinary (represented by the various disciplines involved in the patient's care) family conferences decreased the rate of family "nonconsensus" from 1.7 to 0.09 days per patient. In an observational study, an increased proportion of family speech was also associated with decreased family ratings of conflict with clinicians (147).

ICU LOS was addressed as an outcome associated with having family conferences in four studies, three of which were before and after studies (152–154) and one of which was a retrospective chart review (155). In the largest and only multicenter study, there was no significant difference in LOS between usual care (with or without a family meeting) and a system-level intervention that included formal family conferences (153). However, a single-center study of a similar intervention (152) found a significant decrease in LOS for those who received physician-led conferences during the "intensive communication period." In a 4-year follow-up of this same study (154), the difference in LOS between the intervention groups at each time period was not significant. In a retrospective chart review of PICU patients (155), families who had a family conference were more likely to be discharged to a "new environment" (e.g., if the patient had been living at home and was discharged to a long-term care facility) versus families who did not have a family conference although there were likely multiple confounders to this association beyond presence of a family conference. The overall quality of evidence for family conferences is low. There are no data to identify the most effective clinician participants or the most effective timing or frequency of family conferences.

Recommendation: We suggest routine interdisciplinary family conferences be used in the ICU to improve family

satisfaction with communication and trust in clinicians and to reduce conflict between clinicians and family members. (2C)

Further research is needed to identify the most effective and cost-effective ways to implement routine family conferences in the ICU setting.

PICO question 3.2. Among healthcare clinicians in the ICU, do specific communication techniques such as active listening, empathy and empathic statements, provision of supportive comments, language translation, or cultural mediation affect family psychological symptoms, family satisfaction with care, communication or decision making, physician-family conflict, or ICU utilization (LOS)?

Evidence Summary: Numerous observational studies have suggested the need for improved communication with family members (131, 156–161). One multicenter observational study analyzed recordings of 51 family conferences and published results in a series of articles (145–147). As stated in section 2.1, these studies showed that higher family satisfaction was associated with several features of high-quality communication including higher proportion of family speech, increased empathic statements, and with specific statements of support regarding non-abandonment, symptom control, and support in decision making. In addition, higher proportion of family speech was associated with fewer family reports of conflict with physicians.

A before and after study of an intervention to train multidisciplinary teams of ICU clinicians in a standardized approach to communicating serious news using the "SPIKES" approach (Set-up, Perception, Invitation, Knowledge, Emotions, Summarize) (162) showed higher family satisfaction with decision making in the postintervention period (163). The study did not show significant improvement in overall family satisfaction in the postintervention period.

Review of the literature identified only one multicenter prospective randomized trial, which explored the impact of specific communication strategies on family-centered outcomes. This study (4) showed that providing relatives of patients who are dying in the ICU with a brochure on bereavement and using a proactive communication strategy for family conferences ("VALUE") resulted in longer conferences and more time for family members to talk. The authors found that family members in the intervention group reported fewer symptoms of PTSD, depression, and anxiety 3 months after death in the ICU: they demonstrated a 22–27% absolute reduction in family reported symptoms of PTSD, depression, and anxiety (4). However, in this study, family members experienced very high levels of PTSD, depression, and anxiety in the control group.

The quality of evidence is collectively low. Only one randomized trial assessed the outcome of a specific communication strategy on family outcomes. Its quality of evidence was downgraded due to the high level of symptoms in the control group and the relatively small sample size limiting statistical stability.

Recommendation: We suggest healthcare clinicians in the ICU use structured approaches to communication such as that included in the "VALUE" mnemonic when engaging in communication with family members, specifically including

active listening, expressions of empathy, and making supportive statements around non-abandonment and decision making. In addition, we suggest that family members of critically ill patients undergoing withdrawal of life support be offered a written bereavement brochure to reduce family anxiety, depression and post-traumatic stress and improve family satisfaction with communication. (2C)

Further research is needed to identify the most effective ways to improve communication with family members and which components of a communication strategy are most effective.

PICO question 3.3. In the ICU environment, do communication-training programs for clinicians, such as education or simulation, improve family psychological symptoms, family-rating of quality of dying, patient- or family-rated quality of communication, family satisfaction with communication, clinician self-efficacy, or clinician psychological symptoms?

Evidence Summary: Ample evidence exists describing the importance that patients and families place on high-quality communication in the ICU (164–167). Furthermore, additional evidence demonstrates that poor communication can cause patient and family dissatisfaction (156–159) and even harm in the form of anxiety, depression, symptoms of PTSD, and complicated grief (131, 160, 161, 168). Given the importance of high-quality staff-family communication to family-centered outcomes, many investigators have examined communication training programs as an intervention to improve the quality of communication in the ICU setting. The training programs examined in the literature vary widely, with training interventions ranging from purely didactic to simulation based. Additionally, the training program intensity differed from a 1-hour workshop to a 12-month didactic series. All studies that examine the effect of training programs on clinician self-efficacy showed a significant improvement in clinician-reported communication skills and comfort with family communication training (163, 169–178). Despite this consistent self-reporting of improved skills and comfort with communication, only one of two studies examining the effect of communication training on staff anxiety demonstrated improvement in staff-reported anxiety with family communication (176), whereas the other study found no improvement (179). Importantly, although clinicians consistently self-report improvement in communication skills and comfort with communication, studies that employed more objective third-party measurements of the quality of communication showed mixed results, with at best only modest improvements in a limited number of communication elements. Of note, the interventions that demonstrated at least some improvement were of a longer training duration (1–12 mo) (169, 174, 178, 179), in contrast with a 1-hour training (172) and 1-day training (180) that showed no improvement. Additionally, one study found that the improvement in quality of communication seen immediately after the training was lost at a 6-month follow-up (180).

Only two studies examined family-reported outcomes. One of these studies found potential improvements in some aspects of family satisfaction with communication (frequency of nursing

communication, frequency of physician communication, and honesty of communication after a training program intervention). Due to the very low quality of the evidence, it is difficult to draw conclusions based on this single study (163). The other study showed no significant improvement in patient or family satisfaction with communication or with patient- or family-rated quality of end-of-life care with high-quality data (181). In fact, surprisingly, this same study showed an increase in patient-reported depressive symptoms for those patients assigned to the clinician group who had received the communication training intervention. Therefore, educational interventions have been shown to improve clinician-reported self-efficacy in communication skills and comfort with family communication and some improvement in objectively documented communication skills, but these interventions have not been shown to improve patient- or family-reported outcomes.

The quality of evidence is very low for this PICO question for several reasons. First, although “clinician self-efficacy” was consistently shown to improve with the intervention (often with a large magnitude of effect), the quality of evidence from these studies was generally limited due to pre-post designs with lack of nonintervention controls, relatively small study numbers, and use of nonvalidated surveys. Second, studies examining other outcomes of interest showed inconsistent family-reported results with no clear direction of evidence.

Intuitively, patients and families would benefit from clinicians who are well-trained in family-centered communication. It has been established that the risks and burdens of poor communication include patient and family dissatisfaction, anxiety, depression, PTSD, and complicated grief (131, 156–161, 168). Communication training for ICU clinicians is seemingly a low-risk intervention. Costs are unknown and may range from minimal to considerable depending on the nature of the training. At this time, best practices for specific communication training programs are not well established in the literature.

Recommendation: Based on the existing evidence of patient and family burdens associated with poor communication, as well as improved clinician-reported skills and comfort following communication training, we suggest that ICU clinicians receive family-centered communication training as one element of critical care training. However, no recommendation can be made to suggest the use of any of the specific communication training programs that have been evaluated based on the existing evidence. (2D)

Further research is needed to determine whether and how communication-training programs can be implemented to improve patient- and family-centered outcomes. Important components of future research include validation of a quality of communication measurement tool for consistency of reported outcomes; increase in the use of family-reported outcomes as the standard for quality of family communication; inclusion of data on cost of implementing communication training programs; more long-term follow-up studies since skills may dissipate over time; comparison of different communication teaching modalities such as didactic training, role-plays, and simulation, and further investigation of possible risks to patients such as increased depression (181).

Evaluations of the Use of Specific Consultations and Team Members. *PICO question 4.1.* Among family members of ICU patients does a palliative care consultation impact ICU and hospital utilization?

Evidence Summary: There are limited data including five very low- to low-quality studies that suggest that proactive consultation of palliative care decreases ICU and hospital LOS among certain patients, such as patients with advanced dementia, global cerebral ischemia after cardiac arrest, patients with prolonged ICU stay, and patients with SAH requiring mechanical ventilation (182–186). However, one study showed no significant changes in ICU and hospital LOS (185), and another showed a significant decrease in ICU LOS but no change in hospital LOS (184). Quality of the evidence is low as all studies used a nonrandomized, before and after study design, sample sizes were relatively small (under 100 patients in each study arm), and there were some inconsistent results. Although data from different studies varied, studies showed a decrease in ICU and in hospital LOS. The risks involved in this intervention, and the other interventions in these guidelines, are mostly in terms of costs and specifically the opportunity costs for the resources involved in implementation of the intervention. Increasing palliative care consults may incur a cost saving in ICU and hospital LOS (187).

An important randomized trial was published after completion of our systematic review that showed no benefit of one or two palliative care-led family conferences (without palliative care consultation), and the intervention was associated with increased symptoms of PTSD among family members (188). However, this study did not examine the effect of a full palliative care consultation and therefore would not change our recommendation.

Recommendation: We suggest proactive palliative care consultation be provided to decrease ICU and hospital LOS among selected critically ill patients (e.g., advanced dementia, global cerebral ischemia after cardiac arrest, patients with prolonged ICU stay, and patients with SAH requiring mechanical ventilation). (2C)

Further research is needed to better understand the effective and cost-effective components of a palliative care consultation and to identify the patients for whom palliative care consultation is most beneficial.

PICO question 4.2. Among family members of ICU patients does ethics consultation impact family satisfaction or ICU or hospital LOS?

Evidence Summary: There are limited data reporting the effect of ethics consultation on family satisfaction, with only one single-center randomized trial that assessed the impact of ethics consultation on family satisfaction showing no significant change (189). There are two trials in which family satisfaction was examined in the intervention arm but not in the control arm; family satisfaction appeared high in both these studies (190, 191).

There are four studies of diverse methodological quality, each testing slightly different types of ethics consultation in different

populations for effect on LOS (189–192). Three of the four studies reported shorter ICU and hospital LOS among patients receiving ethics consultations. The effect appeared strongest in studies in which the trial involved ethics consultation in response to clinician-family conflict, rather than using ethics consultation preventatively to improve communication. An important limitation is the heterogeneity in the nature of the deployed intervention. The highest quality study, which randomized 551 patients, showed only a relatively small effect of ethics consultation on ICU LOS (191). The studies that showed that the greatest effect had the smallest sample size and had the greatest methodological weaknesses. There are financial and opportunity costs of increasing the size and scale of ethics consultation services in hospitals to meet the demand of the large group of ICU patients who would be eligible and no evidence of harm. Increasing ethics consults may incur a cost saving in ICU and hospital LOS. The overall quality of evidence for ethics consultation is low.

Recommendation: We suggest that ethics consultation be provided to decrease ICU and hospital LOS among critically ill patients for whom there is a value-related conflict between clinicians and family. (2C)

Further research is needed to better understand the effective and cost-effective components of ethics consultations and to identify the patients for whom ethics consultation is most beneficial.

PICO question 4.3. Among family members of ICU patients does a psychologist consult improve/affect family outcomes?

Evidence Summary: Access to psychologists for ICU family members appears limited; psychology consultation service provision range from 4% in the United Kingdom (193) and United States (194) to 29% in Australia (195) for PICU patients. In one study of adult ICUs in Europe, 37% of relatives had access to psychologists (168). Only three publications describing two interventions were considered evidence to assess the effect of psychological consultation. All three studies assess the effect on mothers' symptoms in the context of preterm neonates admitted to NICUs. One randomized trial compared 36 mothers supported by a psychologist during the infant's hospitalization with 23 mothers receiving psychologist support and reading and video material dealing with specific subjects related to prematurity, affective mother-child connection, and care of a premature baby. The group receiving additional materials in this study had more favorable anxiety levels at follow up (State-Trait Anxiety Inventory) (196).

Another randomized trial compared 43 mothers undergoing six general support sessions to 62 mothers whose six sessions included targeted specific psychological interventions, namely, trauma-focused CBT. Targeted therapeutic sessions included psychoeducation about PTSD, cognitive restructuring, narrative, and muscle relaxation. The first publication (197) describes outcomes at 4–5 weeks after the birth of the preterm infant compared with the time of the intervention, and the second (198) describes the maintenance of improved outcomes at 6 months. The targeted session improved all spheres of evaluated outcomes including Davidson Trauma Scale, Beck Anxiety, and Beck Depression Inventory.

One small observational study has been conducted in trauma patients in the adult ICU. Early psychological support was associated with a nonsignificant reduction in depression, significantly reduced PTSD, and increased use of psychiatric medications at 1 year (199).

Quality of the evidence is very low for the study of supplementary informational material; it is a single study, the timing of the intervention is not described, and the effect of intervention is not reported (study design limitation). The study of trauma-focused CBT (198) is low-quality evidence (observational study, single-center, small numbers). The greatest improvement was found in the mothers who were the most distressed (and thus the most likely to not be functional in their parental role).

Uncertain benefit, low cost and low risk were noted in the study describing the provision of additional informational materials.

Recommendation: We suggest a psychologist's intervention be provided to specifically incorporate a multimodal CBT-based approach to improve outcomes in mothers of preterm babies admitted to the NICU. Furthermore, we suggest that targeted video and reading materials be provided in the context of psychological support to mothers of preterm babies admitted to the ICU. (2D)

Further research testing the impact of psychological support in adult and pediatric populations, and larger studies in the preterm neonatal population are needed.

PICO question 4.4. Among family members of ICU patients does a social work consultation impact family satisfaction?

Evidence Summary: One large randomized trial involving 873 (200) assessed the value of a social worker to provide support for family members; one small observational trial addressed the effect social workers have on family satisfaction (201). The trial showed a nonsignificant improvement in overall satisfaction, satisfaction with the amount of information provided, and satisfaction with involvement in decision making. In the observational study, the presence of social workers independently predicted increased family satisfaction. Quality of the evidence is very low as there is only the single randomized trial and a small, very low quality observational study. The cost of utilizing social workers in this way is not known and would depend in part upon whether they are already available in the ICU.

Recommendation: We suggest social workers be included within an interdisciplinary team to participate in family meetings in order to improve family satisfaction. (2D)

Further research is necessary to evaluate outcomes associated with social worker interventions.

PICO question 4.5. Among family members of ICU patients does a navigator (care coordinator or communication facilitator) improve family anxiety, depression, post-traumatic stress, family satisfaction, family, or clinician conflict or resource utilization?

Evidence Summary: One moderate quality study suggests that a navigator may decrease psychological symptoms in family members (202). This randomized trial assessed the effect of communication facilitators, trained to identify and support family members' communication styles and to identify and mediate conflict, who met with family members regularly in the ICU (and 24 hr post discharge) to support communication

between the family and the ICU team. This intervention was associated with a reduction in depression severity among family members at 6 months, albeit with limited follow-up (202). There was no significant reduction in anxiety or PTSD at 3 or 6 months (202). Another study assessed limited (one to two visit) nurse liaison involvement aimed specifically at family anxiety related to ICU-ward transfer; the intervention did not alter state-trait anxiety inventory scores at 3 months (203).

Two publications derived from the same study address physician and nursing communication and satisfaction with that communication by families (204, 205). Families and staff were surveyed before and after integrating a family support coordinator (a nurse with ICU experience and psychological/social work training) assigned to families of patients who were expected to require ICU care for 5 days or were at high risk of death; the coordinator's role included identifying information needs, clarifying medical information, assisting in decision making, organizing meetings with relevant team members, and relaying family needs to the team. Family members rated physician communication, social work communication, and respiratory care communication but not nursing communication more favorably after the involvement of a family support coordinator. Perception of family/physician conflict did not change from "before" to "after" the intervention of a family support coordinator.

The single randomized trial of communication facilitators in the ICU found a reduction in ICU costs among all patients and decedents. The intervention reduced ICU and hospital LOS among decedents (202). In a before and after study, changes of ICU LOS and ICU costs after the introduction of a family support coordinator did not achieve statistical significance. The analysis was not stratified by patient mortality (204).

The quality of the evidence is low for navigator impact on family psychological symptoms; the single randomized trial appears to improve family outcomes in terms of depression at 6 months, but had substantial loss to follow-up. The two studies addressing satisfaction were before/after design and suffer from the imprecision of small numbers. The quality of evidence for evaluating resource utilization is moderate, as the data from a single randomized trial showed substantial reductions in ICU and hospital LOS (among decedents only), and costs of care (among all patients). The second study showed a similar trend but with no statistical difference in costs. Observational data suggest that timely (i.e., earlier) discussion of prognosis is essential to allow family members to prepare emotionally and logistically for the possibility of a patient's death (5). Potential benefits include satisfaction with physician communication, decreased family depression, and decreased LOS, at potentially moderate personnel cost if hiring a family support coordinator is required.

Recommendation: We suggest that family navigators (care coordinator or communication facilitator) be assigned to families throughout the ICU stay to improve family satisfaction with physician communication, decrease psychological symptoms, and reduce costs of care and length of ICU and hospital stay. (2C)

Further research is needed to examine the most effective and cost effective approach to training and implementing

navigators, identify patients and family members most likely to benefit, and describe any potential adverse outcomes associated with navigators interacting with families.

PICO question 4.6. Among families of ICU patients, does routine consultation of a spiritual care provider improve outcomes?

Evidence Summary: Many families express that they value spiritual care (165, 206, 207) and the availability of a spiritual advisor or clergy (208–210). Spiritual care has been identified as a core element of palliative care (16). The Joint Commission requires that patients receive a spiritual assessment (PC.01.02.01.04), that hospitals provide care that accommodates spiritual end-of-life needs (PC.02.02.13.01) and that patients have a right to spiritual and religious services (RI.01.01.09) (211).

Many families interact with spiritual care providers during a patient's ICU stay (212). In one study, patients on telemetry units were visited by chaplains and perceived their interventions as helpful (213). No evidence exists comparing the intervention of a spiritual care provider versus standard care for patient and family outcomes. One observational study describes the types of activities spiritual care providers engage in, and found that, among families who interacted with spiritual care providers, there was increased overall family satisfaction with ICU care when spiritual care providers conducted discussions about the patient's wishes for end-of-life care and when there were a greater number of spiritual care activities performed by spiritual care providers (212). In another observational study in which family members ($n = 356$) were surveyed about spiritual care, family members had greater satisfaction with spiritual care if a spiritual advisor or pastor was involved within 24 hours of the patient's death (214). Provision of spiritual care and satisfaction with the ICU experience were strongly correlated (214). A before-after study described the involvement of a comprehensive support care team, which included a chaplain, and resulted in a decrease in intensity of care, as assessed by the average Therapeutic Intervention Scoring System for patients (215).

Collectively, the evidence is very low quality as no studies provided a control group and interventions did not consist solely of involvement of a spiritual care provider. There is probable benefit with low risk of harm. Additional costs may be incurred in settings where spiritual care providers are not already available.

Recommendation: Given the consistency of expression of family values for availability of spiritual care, the accreditation standard requirements, and the association with increased satisfaction, we suggest that families be offered spiritual support from a spiritual advisor or chaplain. (2D)

Further research testing the impact of a spiritual care provider on patient and family outcomes is needed. The best method for provision of spiritual support has not been studied and warrants further investigation.

Operational and Environmental Issues. PICO question 5.1. In the ICU environment, do protocols for withdrawing life support improve outcomes?

Evidence Summary: Only four articles were found that specifically addressed the use of protocols for withdrawal of

life support (143, 216–218). Of these, three directly addressed withdrawal of life support (143, 216, 217), whereas one (218) addressed the impact of a protocol on sedation and analgesia use. The first three studies addressed only the documentation of protocol use. No measures of family satisfaction were directly obtained although one study showed high levels of clinician satisfaction (218). This study evaluated the use of a protocol for sedation and analgesia in a before and after study design showing increased use of sedation and analgesia without hastening death. High levels of clinician satisfaction were reported with the protocol, supporting the use of a protocol for managing patient symptoms.

The evidence on protocols for withdrawal of life support is of low quality. Only one study, a before-after design (218), examined outcomes demonstrating that protocols led to increased use of sedation and analgesia without affecting time to death or ICU LOS. Quality of dying and death was not significantly improved although power was limited by small sample size. The benefits of a protocol potentially optimizing sedation and analgesia are persuasive. Although family outcomes have not been explicitly examined in existing studies, family burden of poor withdrawal of life supports this recommendation.

Recommendation: We suggest that protocols be implemented to ensure adequate and standardized use of sedation and analgesia during withdrawal of life support. (2C)

Further research is needed to assess the effect of protocols for withdrawing life support on patient- and family-centered outcomes.

PICO question 5.2. Does the inclusion of nurses in ICU communication about decision making about the goals of care improves family-centered outcomes?

Evidence Summary: Although nurses are ubiquitous and integrally involved in all aspects of ICU care, this question examines whether or not specifically including nurses in communication about decision making about the goals of care improves communication or family outcomes. In the ICU, inclusion of nurses in decision making may improve family-centered outcomes such as quality of communication, quality of care, family satisfaction with care, and conflict. The majority of literature examining the inclusion of nurses in ICU decision making is descriptive or qualitative in nature (170, 219–222). These studies were conducted in adult ICUs, PICUs, and NICUs and focused on the quality of communication, quality of care, and family satisfaction with care.

In general, studies of initiatives to include nurses in decision-making situations were pre- and postintervention survey designs or descriptions of existing practice. There are no randomized trials on this topic. No standard intervention was used and therefore no specific training or involvement of nurses can be recommended. Nevertheless, the need for efforts to improve quality of communication is evident.

Two studies provide informative evaluations of interventions to increase nursing involvement in decision making about the goals of ICU care. One single-unit study compared patients exposed to a multiprofessional care communication team including clinical nurse specialists (along with unit-wide

palliative care training) with patients who received standard practice. A statistically significant decrease in ICU LOS and hospital LOS and total costs of care (222) were described with the intervention. A small, single-unit study of 15 patients used a single nurse trained as a family support specialist finding that families and physicians reported improvements in the quality of communication and patient-centeredness (223).

Quality of evidence is very low due to the limitations of the two relevant studies. Although both report empiric evidence, the studies used before and after, rather than randomized designs. Both had a relatively small sample of clinicians (e.g., physicians, nurses, and therapists) and patients and did not attempt to adjust for confounding or other influences. The first study used unit-wide palliative care education and therefore the impact of each intervention alone (nursing involvement vs education) is unknown (222). The second (223) was conducted in a single unit, included only 15 patients, and relied on a single nurse interventionist. Therefore, it is unknown whether this result would be generalizable. No studies currently exist that examine the impact of such an intervention on family-reported outcomes other than family satisfaction with communication. One study suggested decreased ICU and hospital LOS. There are limited data to estimate the relative risks, feasibility, burden, or costs.

Recommendation: We suggest that nurses be involved in decision making about goals of care and trained to provide support for family members of critically ill patients as part of an overall program to decrease ICU and hospital LOS and to improve quality of communication in the ICU. (2D) No recommendation can be made about how to accomplish this goal due to lack of supporting evidence.

Further research is needed to examine the potential benefits of nursing involvement in ICU decision making for family and clinician outcomes.

PICO question 5.3. Does a comprehensive “family-centered care” approach to ICU care improve family-centered outcomes during critical illness?

Evidence Summary: Some ICUs have instituted procedures and policies meant to improve the unit’s entire approach to family-centered critical care. These policies are intended to shift the paradigm of critical care away from paternalistic or hierarchical care and toward an approach that integrates families as care partners in the ICU (224). Limited empiric evidence exists evaluating the effect of the comprehensive programs on outcomes important to families. One study developed and implemented a Family Support System in a single NICU that consisted of three components (1): new policies regarding flexible family presence at the bedside, unit communication, and team rounding promoting family involvement (2), identification and referral of parents at high risk of psychosocial distress to social workers, and (3) a post-ICU stay home care visitation program (225). The authors used hospital resource utilization as the primary outcome and also sought to measure the effects on parental hypervigilance and anxiety. There were 80 patients included in the control (preintervention) arm and 90 patients who received the intervention. Following introduction of the programmatic and policy changes, there was a reduction in hospital

readmission days. A second study created and implemented a hospital-wide program intended to emphasize the importance of family members and to change policies to allow families to participate more fully in care (226). This included education of family members on their role, 24-hour family presence, and encouraging families to participate in bedside care. Family members could elect to participate in the program. The authors measured satisfaction with the program, with over 84% of participants reporting that it made the hospital stay more or much more positive. There was no reported comparison of overall satisfaction with care among those family members who did or did not participate.

The quality of evidence is low due to study design limitations, and the data are limited to quality improvement project assessments. Both studies have limited generalizability as they were conducted within a single center and among a limited population of patients. One study used a pre- and postimplementation design (225) and the other did not compare the participating family members with a control group (226).

There is potential for burden on staff and family members, and the intervention is potentially costly depending on extent of program components, but there are unlikely to be important risks other than the opportunity costs.

Recommendation: We suggest hospitals implement policies to promote family-centered care in the ICU to improve family experience. (2C)

Further research is needed to examine the effect of hospital and ICU policies designed to promote family-centered care. Additionally, future research should identify specific program components that drive improvements in family-centered outcomes.

PICO question 5.4. In the ICU do noise reduction strategies, private rooms, or space for family members (beyond single rooms for patients) affect patient/family satisfaction, staff stress, or noise?

Evidence Summary: Ample evidence exists that noise levels are high in the ICU and negatively affect patient outcomes (26, 227–232). However, a paucity of data exists evaluating the effect of noise reduction on family-centered outcomes. Of the literature reviewed, only one study addressed family satisfaction with care associated with noise reduction (233). This randomized trial of cobedding multiple-gestation infants in the NICU versus bedding infants alone (infants $n = 37$, parents $n = 19$) resulted in a statistically significant increase in parent affirmations of the questionnaire item “attempts were made to create a quiet environment for my baby” that was one component of a Family Satisfaction Score.

Single family rooms are associated with noise reduction, as well as greater family and patient privacy. In a study comparing family attitudes toward single family rooms compared with an open bay ward NICU design, families had increased satisfaction with single rooms in several areas. These improvements were in response to the questions “parent comfortable visiting,” “privacy for bonding,” and “could control light.” Noise levels were 20 decibels higher in the open ward ICU (234).

The majority of literature examining space for family members is descriptive or qualitative in nature and limited to

single-center studies. The focus of this work is the needs and impact on the family members and clinical staff satisfaction. Two descriptive survey studies included evaluation of the psychological symptoms of families using previously validated tools (sleep disturbance, Beck anxiety index, and fatigue scales). Although these described fatigue, lack of sleep, and anxiety among family members, they did not measure the impact of improvements in ICU design or space for family (235, 236).

Five additional studies attempt to provide information on ICU design using pre- and postdesign. One study evaluated three physical design layouts of a NICU using focus groups (237) of parents with surviving infants ($n = 5$) and staff ($n = 11$) of the unit. Designs studied included open space (multiple infants in a single, large room without parent beds), modified room (a curtained space for each infant that included a parent bed) and smaller room designs (a private room with a parent bed for each infant). The focus groups suggested that the smaller room design would promote bonding between parent and infant, lead to better comprehension of illness among parents, and allow healthcare providers to meet healthcare needs.

These findings were supported by other studies comparing an open bay and single family room in a NICU. A pre-post study measured baseline, 6-month, and 12-month family member and staff reaction to change to a single family room from open bay. Families of long-term stay infants in single family rooms were more likely to report privacy for bonding with the infant and control of lighting; surrogate markers for satisfaction. However, over 30 other surrogate outcomes were evaluated with non-significant results. There was also inconsistency in staff results at 1 year. For instance, there was a significant improvement in staff willingness to help each other but the work was reported as more physically demanding. Another study used similar methods, surveying staff members ($n = 67$) and family members ($n = 85$) longitudinally prior to and following a move from an open bay NICU to one with private rooms. Following the move to the single family room, family satisfaction related to design significantly improved, including perception of privacy at 6 months and 1 year and the opportunity to interact with other families (238). Of the clinician outcomes of interest to these guidelines, there was no long-term effect on staff stress.

Another pre-post relocation design study interviewed 103 hospitalized patients and families prior to and after a move to assess satisfaction with the new environment, namely, privacy, space, noise, light, and atmosphere. Additionally, the investigators used Hospital Consumer Assessment of Healthcare Providers and Systems and Press Ganey survey questions specific to environment to explore similar issues. The interviews revealed that the privacy of room, room size, and bathroom were key features that led to improved patient satisfaction. Areas of dissatisfaction included noise, lighting systems, television controls, and chairs. The survey data revealed that there were improvements in satisfaction with every aspect of the environment of care following the relocation (228).

Study design and scope substantially limit the application of findings to other settings. There are no randomized trials of the effect of design changes or space for family members on

family-centered outcomes. All studies are limited to a single center with small sample sizes and a narrow patient population. Most of this work has been described as quality improvement assessment rather than research.

Given the benefits of ICU noise reduction for patient clinical outcomes (e.g., delirium), noise should be addressed in all ICUs. There is a significant cost associated with building private rooms. However, building new ICUs private rooms are advocated by SCCM for a variety of reasons (including infection control), only one of which is family-centered care outcomes (239), so the cost may be justified given the multiple benefits. The data available suggest harm in the form of staff stress that needs to be managed with a change from open bay NICU s to private rooms. There is no evidence to determine the relative risks, feasibility, burden, or justification of cost of additional bedside space for family members. The overall quality of evidence for noise reduction strategies is very low.

Recommendation: Given evidence of harm related to noise, although in the absence of evidence for specific strategies, we suggest ICUs implement noise reduction and environmental hygiene practices and use private rooms to improve patient and family satisfaction. (2D) No recommendation can be made for family space. However, it is noted that the SCCM guidelines for ICU design recommend designing new ICUs with family space based upon consensus statement (239).

Further research is needed evaluating the effect on family-centered outcomes of interventions to reduce noise or improve the ICU environment in the ICU. Further research is also needed regarding the impact on outcomes of private rooms and family space and the effect of private rooms on family-centered outcomes.

PICO question 5.5. Do executive (hospital leadership) walk rounds improve family-centered outcomes in the ICU?

Evidence Summary: Increased presence of hospital leadership in the form of executive walk rounds in the physical space of the ICU has been considered as a method of improving outcomes important to family members (240–243). Two primary investigations specifically measure the effect of such executive walk rounds on clinician burnout. Both of these articles demonstrated no clear evidence that executive walk rounds increases or decreases clinician burnout in small samples, with design limitations preventing clear conclusions (242, 243).

Quality of evidence is very low due to limitations in the design of the two studies. One study used a pre-post design that included a small sample of clinicians and did not attempt to adjust for confounding. The executive walk rounds were merely one component of what the authors describe as a “comprehensive unit-based safety plan.” Similarly, the second study examines surveys of clinicians in a convenience sample of 44 NICUs. Participants reported their exposure to executive walk rounds. Executive walk rounds were not prospectively tested nor could the authors account fully for other cultural or policy variations among ICUs. No studies currently exist that examine the impact of such an intervention on family-reported outcomes.

These limits suggest that there is a need for more research that tests executive walk rounds in a randomized trial, ideally

on a multicenter scale and testing family-reported outcomes. Treatment effects are not reported in the literature. There is a potential for high burden to hospital leadership.

No recommendation can be made due to lack of supporting evidence.

Further research testing executive walk rounds on family-reported outcomes is needed.

PICO question 5.6. Does consistency in staffing improve family-centered outcomes during critical illness?

Evidence Summary: Continuity of care in the ICU is defined as the establishment of a continuous caring relationship between the medical care team and the patient and family members, typically measured by the number of professionals who primarily care for the patient over a given period of time (244, 245). Two studies tested the effect of aspects of this continuity of care on family satisfaction with communication or ICU LOS (244, 246, 247). One study introduced a care model emphasizing consistency of care for long-term pediatric patients in a single ICU in a pre- and postintervention design (246). The authors found that the chronic care nursing model resulted in improvements in the opportunity for parents to participate in the plan of care (28% vs 100%; $p = 0.019$) and in the parents' view of the relationship with the ICU staff (57% vs 100%, $p = 0.008$), based on surveys among 33 parents. An observational study of 292 PICU patients of a single unit, calculated an index of continuity of nursing care based on the ratio of the total number of nurses assigned to the patient over each week. The authors examined the association between this index and ICU LOS, adjusting for patient characteristics such as severity of illness, and finding that patients with the highest quartile of discontinuity had shorter ICU stays when compared with those with the highest quartile of continuity (hazard ratio = 0.12; 95% CI, 0.05–0.31). This finding was unexpected and may be due to confounding by unmeasured patient characteristics (244).

Quality of evidence is low due to study design limitations and inconsistency of results. These two studies all have limited generalizability as they were each conducted within a single ICU. The studies also did not show a consistent trend toward or away from improvements in the selected outcomes with increased continuity. There is likely low risk associated with interventions increasing staffing consistency, but it is difficult to assess the overall cost or burden associated with these interventions.

No recommendation can be made due to lack of supporting evidence.

Further research is needed to examine the effect of nurse and physician staffing consistency on family-centered outcomes.

PICO question 5.7. Among family members of ICU patients, does providing a surface for sleep improve family psychological symptoms, quality of life, satisfaction with care, caregiver burden, family or clinician conflict, satisfaction with communication, self-efficacy, trust in clinicians, conferences, quality of communication, or time to DNR?

Evidence Summary: Multiple studies find striking levels of sleep-deprivation and sleep-associated morbidity among family members in the ICU. These observational studies utilized both qualitative (248–251) and validated, objective

measurements (235, 236, 252–254). The need for access to a location for sleep is a theme expressed by families of the critically ill (249). Indirect evidence informs us that provision of facilities for napping and allowing on-demand naps increases sleep and reduces fatigue among medical staff on call in the hospital (252–255). Napping in a bed reduces driving errors (256) and also relieves pain hypersensitivity resulting from sleep deprivation (257).

Families in the ICU suffer significant sleep deprivation and related morbidity. Napping increases daily sleep duration and reduces fatigue, errors, and pain (in non-family, non-ICU populations). Provision of a surface for napping may reduce morbidity among family members although no studies have been conducted to evaluate the effect of providing a sleep surface on family health. There is a cost to purchasing or building sleep surfaces/space. Given that families desire presence, and there is clear evidence of harm (sleep deprivation) the risk benefit analysis suggests that a sleep surface for families should be provided. The quality of evidence is collectively very low.

Recommendation: We suggest that family sleep be considered and families are provided a sleep surface to reduce the effects of sleep deprivation. (2D)

Further research is indicated to determine outcomes related to provision of a family sleep surface, sleep space, napping, and/or light therapy and sleep in the ICU environment.

WORK TOOLS

Clinicians and healthcare organizations may use these strategies to develop individualized interventions and programs to improve family-centered care in their own ICUs. Tools to enhance translation of the research highlighted in these guidelines into clinical practice are provided on the SCCM website (www.sccm.org) and are also available as **Appendix D** (Supplemental Digital Content 5, <http://links.lww.com/CCM/C244>). Additional work tools are under development and as available will be posted to the sccm.org website. Finally, a gap analysis tool is being developed by SCCM to support translation of recommendations into practice. **Electronic Table 7** (Supplemental Digital Content 2, <http://links.lww.com/CCM/C241>) is also offered as a starting point. Recommendations in Electronic Table 7 (Supplemental Digital Content 2, <http://links.lww.com/CCM/C241>) are summarized in order of ranked importance of outcomes. Organizations and clinicians may prioritize staged implementation based upon the importance of outcomes, perceived barriers and facilitators, and resources at hand.

LIMITATIONS

These guidelines have important limitations that should be acknowledged. First, all 23 recommendations in these guidelines were weak recommendations, reflecting the relatively low quality of evidence regarding interventions to improve family-centered care. The fact that all recommendations were weak highlights the newness of this field of research and the importance of future research to identify the most effective interventions to improve this important aspect of ICU care. Future research is needed that examines

the benefits and risks of family presence and participation in ICU settings for patients, families, staff, and clinicians. Quantifying the benefits of partnership with families and the impact on patient outcomes is also needed. Furthermore, research in this area will require additional work to develop, validate, and disseminate rigorous family-centered outcome measures incorporating diverse domains such as satisfaction with care, quality of communication, and quality of decision-making. Second, although we used the qualitative literature to support the generation of topics important to patients and families, and validated topics and importance of outcomes through survivors and families, our pool of patient and family informants was small. Future guidelines writing teams should consider recruiting patients or family members as co-authors. Furthermore, guidelines writing teams should consider implementing focus groups or key informant interviews serially to validate the progress of the writing team over time. Fourth, although we identify 23 recommendations that we suggest ICUs consider implementing, we found no comparative effectiveness studies that can help identify the most effective interventions and it would be impractical to try to implement all 23 recommendations in a single ICU. Therefore, it will be important that the clinicians and administrators in individual ICUs identify a strategy for staging implementation of selected interventions according to priorities and available resources. Finally, because of the low level of evidence, it is premature to create accreditation or reimbursement standards from these recommendations. However, we offer the suggested recommendations as best known practice given the evidence available today.

SUMMARY

The primary goal of these guidelines is to identify best practices for family-centered care in the ICU based on existing evidence. These guidelines were developed using a rigorous, objective, and transparent assessment of the relevant published evidence with use of the GRADE methodology. After a systematic review of the literature, the recommendations were developed by taking into consideration not only the quality of the evidence but also important clinical outcomes and the values and preferences of diverse ICU stakeholders, including patients and family members. The recommendations provide a summary of best practices as identified by the existing evidence to form internal hospital policies related to supporting families in the ICU. Communication, clinician and family training, family presence, involvement and engagement, provision of consultative resources and environmental and organizational processes are all elements to consider when building an optimal program of family-centered care in the ICU.

APPENDIX 1: RECOMMENDATIONS FOR FUTURE RESEARCH

Family Presence in the ICU (see also Family Communication)

- Measure long-term effects of witnessed resuscitation.
- Measure outcomes in support personnel caring for family members who choose to witness resuscitation.

- Measure outcomes related to date-night or respite.

Family Support

- Measure the value of peer-to-peer support in all age groups to improve family-centered outcomes.
- Measure the relative benefits of different approaches to providing written materials to family members.
- Further assess and measure the effect of a diary on family outcomes.
- Measure the best method of implementing a patient/family diary program.
- Assess outcomes of a decision aid on patients' surrogate decision makers' wellbeing.

Communication With Family Members

- Determine whether and how communication training programs can be implemented to improve family-centered outcomes. Specifically, we recommend the following for future research: 1) validation of a quality of communication measurement tool for consistency of reported outcomes; 2) cautious use of self-assessment tools as these appear to be imprecise measures of true quality of communication; 3) increase the use of family-reported outcomes as the standard for quality of family communication; 4) collect data on cost of implementing communication training programs; 5) more long-term follow-up studies because skills may dissipate over time; 6) comparison of different communication teaching modalities such as didactic training versus role-plays versus simulation; and 7) further investigation of possible risks to patients such as increased depression.
- Determine the best ways to implement open flexible visitation and fully understand the impact on family member outcomes and conflict in the ICU.
- Determine the best method of including family members in medical rounds and the impact of this on family outcomes.
- Measure the benefits and limitations of family participation in care for the adult patient population.
- Measure the impact of educational/training programs on family member outcomes and ICU LOS and costs. In addition, much of the work to date has been done in pediatric populations and research should be extended to adolescents and adults of all ages.

Use of Specific Consultations and ICU Team Members

- Measure the impact of ethics consultation on family satisfaction and other family-reported outcomes.
- Measure the effectiveness and cost-effective components of ethics consultations and identify the patients for whom ethics consultation is most beneficial.
- Measure the impact of psychological support in adult and pediatric populations, with larger studies in the preterm neonatal population needed.

- Measure the effective and cost-effective components of a palliative care consultation and identify the patients for whom palliative care consultation is most beneficial.
- Measure the impact of ethics consultation on family satisfaction and other family-reported outcomes. Further research is needed to better understand the effectiveness and cost-effective components of ethics consultations and to identify the patients for whom ethics consultation is most beneficial.
- Measure outcomes and return on investment from family support coordinators.
- Measure outcomes and return on investment of a patient/family navigator on family psychological symptoms, conflict, and resource utilization. Determine the best navigator model, which families to target, and evaluation of any negative outcomes associated with navigators interacting with families.
- Measure the impact of a spiritual care provider on patient and family outcomes.
- Test the best method for provision of spiritual support.
- Measure outcomes from social worker intervention.

Operational and Environmental Issues

- Identify the important components of decision aids for improving outcomes.
- Measure the effect of protocols for withdrawing life support on patient- and family-centered outcomes.
- Measure the impact of executive walk rounds on family-reported outcomes.
- Measure family outcomes associated with consistency of staffing.
- Measure family outcomes associated with family inclusion in decision making.
- Measure outcomes associated with nursing involvement in ICU decision making and the impact on family outcomes.
- Measure the effect of interventions to reduce noise or improve environmental hygiene in the ICU on outcomes important to families.
- Measure the impact of private rooms on patient and family outcomes.
- Test outcomes associated with architectural design including dedicated family space.
- Test outcomes associated with family sleep, sleep space, and napping in the ICU.

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