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

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"Patient-Centered Care"[Mesh]

"Intensive Care"[Mesh]

"Intensive Care, Neonatal"[Mesh]

"Critical Care"[Mesh]

"Critical Care Nursing"[Mesh]

Family-centered care

Family Nursing

Abstract

Objective: To provide clinicians with evidence-based strategies to optimize 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 Intensive Care Unit. 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 (PICO) 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 (GRADE) methodology to make recommendations for practice. Recommendations were subjected to electronic voting with pre-established voting thresholds. No industry funding was associated with guideline development.

Results: The scoping review yielded 683 qualitative studies; 228 were used for thematic analysis and PICO question development. The systematic review search yielded 4158 reports after de-duplication 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.

Introduction

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 intensive care unit (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 post-discharge disability (2, 3). Approximately one-quarter to 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” (PICS-F) (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

These guidelines were developed using the Council of Medical Specialty Societies (CMSS) 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.

A strict conflict of interest process was followed according to SCCM procedures. A conflict of interest form was completed at the start of the process and yearly. Members were asked to report new conflicts at each meeting. Of the writing members, 19 out of 21 were chosen for their expertise on the topic of family-centered care. This was considered essential to product development and not considered a conflict. Authors did not review their own papers during evidence analysis and Grading of Recommendations, Assessment, Development and Evaluations (GRADE) scoring or write summaries of their own work. Authors with conflicts were asked to abstain from voting. By group consensus, authors were permitted to vote on the recommendations made partially as a result of their scientific contributions. In no circumstance

did these votes make a difference in whether or not the recommendation was accepted (Electronic Supplement Table 3: Voting Results). No authors had influence over the acceptance of the document. None reported the potential for financial gain that could cause bias. There was no industry involvement in the development of these Guidelines.”

A scoping review was undertaken of all qualitative research that explored family-centered care in the ICU from the perspective of patients, families and clinicians. Thematic analyses of results were then used to develop clinical questions regarding best methods of providing family-centered care. In evidence-based practice the Population, Intervention, Comparator, Outcome (PICO) format of constructing a clinical question was used to focus the search. These questions were then used to locate results from quantitative studies testing interventions in specific areas of family-centered care in the ICU to improve outcomes of interest. These studies were reviewed and analyzed using the GRADE methodology to make recommendations for clinical practice.

Search Methodology

The perspectives of patients and family members were incorporated in guideline development in two ways: through literature review and 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 PICO questions. We conducted a broad general search of Web of Science on the topic “family-centered” OR “family-centred” to determine when family-centered care began to be commonly addressed in ICU studies. A citation report showed that the number of publications exceeded 100 per year beginning in 1994 [Electronic supplement Figure 1]. We used this as a basis to determine the year to begin our literature search (1994-). Qualitative filtering of English language texts was adapted from McMaster’s University Health Information Research Unit filters to identify non-experimental research (10, 11). We performed a PubMed MEDLINE search using this logic statement [see appendix 1: Complete search strategies]:

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("Intensive Care Units"[Mesh] OR "Critical Care"[Mesh] OR "Critical Care Nursing"[Mesh] OR "intensive care" OR "critical care")  
AND  
("family centered" OR "family centred")  
AND  
(interview*[Title/Abstract] OR interviews[MeSH:noexp] OR experience*[Text Word] OR qualitative[Title/Abstract])
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Separate searches focused on family versus clinician perspectives and retrieved a total of 683 studies. Duplicates, single case studies, narrative reviews of the literature, and off-topic abstracts were eliminated, resulting in 228 final studies for the scoping review. These abstracts were then sorted into RefWorks® groups based on primary perspectives: studies describing patient/family perspectives (n=133), or studies describing clinician perspectives (n=118). Some studies overlapped both categories and evaluated family-centered care from multiple perspectives of clinicians, patients and family members (n=23). Systematic, Cochrane, and narrative reviews were included (n=12).

The guidelines writing group reviewed the abstracts for relevant findings. A master spreadsheet of study results was constructed to perform a thematic analysis from the results of each abstract. The themes were then clustered further into patient/family and clinician domains, which were then used to develop PICO questions (Electronic Supplement Table 1).

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 ARDS Foundation, Survivors of Sepsis, and Project Help. Participants were also recruited by word of mouth by writing group members. 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 3 time points during the guidelines preparation: 1) development of the definition of family and family-centered care; 2) creation of the domains to be considered for development of PICO questions; and 3) ranking of the importance of outcomes within the PICO questions. At each time point, interviews were scheduled by telephone or email at the preference of the participant. The scripts were developed by one committee member (JD) and validated for clarity by at least two guidelines writing group members. A committee member (GN or PG) sent the script over email and read the script and associated questions during phone interviews.

Definitions of “family” and “family-centered care”

To ensure consensus and consistency in use of key concepts used in guidelines development, we identified previous published definitions of “family” and “family-centered care” from guidelines and key documents on family-centered care, and then conducted an online survey of the entire guidelines writing group to select definitions of family and family-centered. Full details of this process are described in Online Appendix A. We intentionally did not search patient or person-centered care because the focus of these Guidelines is on support of the family. However, we support the concept of person and patient-centered care. The proposed definitions were then reviewed and approved by a group of seven former ICU patients and family members. These final definitions for “family” and “family-centered care” were unanimously deemed appropriate and acceptable by the participating 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 (12-23). 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 Supplement Table 2.

Following the rating of potential outcomes to be used in the PICO questions, patients and family members were again surveyed. The 24 outcomes were rated using a 0-10 numeric rating scale and then ranked according to their mean rating. Nine patients and family members participated. In general, patients and family members scored all outcomes higher than the writing group, with less discrimination between most and least important. No new outcomes were identified in the open comments section. Of interest, patients and family members scored clinician outcomes (e.g. clinician retention and clinical teaching time) higher than the guidelines

writing group. The exercise provides some validation that the outcomes of interest to clinicians were also important to patients and families.

Search Strategy for Systematic Review

This review was in support of clinical practice guidelines for the SCCM which had no role in the review of evidence selected. 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 (PROSPERO) on June 14, 2015 and was last updated 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 was:

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((family-centered[Text Word] OR family-centred[Text Word] OR
"Family/psychology"[Mesh:noexp] OR Professional-Family[TW] OR ("Patient-
Centered Care"[Mesh] AND ("Family"[Mesh] OR Family [TW] OR spouse[TW] OR
significant-other [TW] OR parent[TW] OR child[TW] OR children [TW] OR
sibling [TW] OR friend[TW]))) AND ("Intensive Care"[Mesh] OR "Intensive Care,
Neonatal"[Mesh] OR "Intensive Care Units"[Mesh] OR "Critical Care
Nursing"[Mesh] OR "Critical Care"[Mesh] OR critical care [TW] OR intensive
Care [TW] OR Burn Unit[TW] OR Coronary Care[TW] OR Respiratory Care[TW] OR
"ICU"[TW] OR "PICU"[TW] OR "NICU"[TW] NOT "Recovery Room"[Mesh]))
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See Appendix C for search strategies in all databases. The searches were performed in December 2014. After searches in all databases, records were de-duplicated using “near match” in RefWorks®. Investigators examined reference lists from previous systematic reviews for studies on family-centered care interventions (12, 14, 15, 17, 18, 21-24). Investigators searched the RefWorks® account for intervention terms using “All References” and the “Anywhere” field and sorted records into folders for each PICO question. Alerts were created and monitored by the librarian, and records uploaded when applicable until June 8, 2015. The Cochrane Central Register of Controlled Trials (CENTRAL) was searched for relevant registered trials; 154 records of trials were retrieved, of which 11 were in an ICU setting. An analysis of the predominant source titles was performed by the librarian using Web of Science for a date range of January 1994 through June 2015. We contacted known experts to inquire about unpublished studies that should be noted. We also searched Open Grey <<http://www.opengrey.eu/>> and the New York Academy of Medicine’s GreyLit.org for grey literature.

Eligible studies for this systematic review included randomized trials, and observational studies of family-centered care in an ICU setting that addressed the domains of interest. 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 pre-hospital setting). Proceedings that were not on topic or not original research or systematic reviews of original research were excluded.

Our December 2014 searches identified 4158 reports after de-duplication. Seventy-six additional studies were subsequently included from alerts and hand searches, and 236 studies were included in the final analyses. We used the GRADE tool to assess the level of evidence

from included studies. Electronic Supplement Figure 2 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 (25). The strength of the recommendation should summarize the evidence in a way that can be interpreted by individual clinicians dealing with specific problems under local conditions. Embedded in this summary is the understanding that the variables leading to the decision may vary under these same local conditions. For these reasons, a weak recommendation implies that clinicians consider the recommended action, but allows them leeway to make a decision based on the specific conditions they face. Strong recommendations imply greater applicability of the action across a spectrum of clinical situations.

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. Standard GRADE methodology was used (see Appendix C). As with previous guidelines,(26, 27) a GRADE grid was used to help reach decisions on recommendations when consensus was not achieved or conflict arose (28). Each reviewing team was asked to consider whether publication bias might affect the findings. In addition, we searched for studies with federal funding for which there were no publications. Although publication bias can be difficult to assess, we did not find evidence for it.

The proposed recommendations were then put to a vote of the entire guidelines writing group. At least 50% of members had to vote in favor of, and no more than 20% against, each recommendation. In addition, a strong recommendation required at least 70% of those voting to vote in favor of the recommendation. Otherwise the recommendation qualified as weak. 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. Voting results are posted in electronic supplement Table 3. A GRADE methodologist served as co-author on this project, attended all meetings, and provided oversight to the GRADE process to assure that recommendations were based upon appropriate evidence.

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 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 (29). 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 and seem unlikely, 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, pediatric 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 flexible family presence at the bedside that meets their needs while providing support for staff and positive reinforcement 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 neonatal ICUs 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, 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 non-abandonment 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 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 requiring mechanical ventilation). (2C)
- 4.2. Ethics consultation be provided to decrease ICU and hospital length of stay 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 pre-term babies admitted to the NICU; furthermore, targeted video and reading materials be provided in the context of psychological support to mothers of pre-term babies admitted to the ICU. (2D)
- 4.4. Social workers be included within an interdisciplinary team to participate in family meetings in order 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 length of stay 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)

5.7. Family sleep be considered and families are 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 on Appendix D. Note that this list is not exhaustive in nature.

I. 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 is observational or descriptive in nature. Many families value the opportunity to be at the bedside (30-34) and sometimes report the need to safeguard the patient or be vigilantly present (35-37). However, open family presence policies can be challenging to staff and may be perceived to increase workload (15, 38) and staff stress (39). Family presence is necessary for family engagement at the bedside, which has been demonstrated, when coupled with an educational program, to improve outcomes (40-42).

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 (43). Another study exposed families to open family presence with one group also receiving an information booklet (44). When comparing unrestricted vs. open family presence, there was a statistically significant increase in 9 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 post survey after implementation of flexible family presence. When minimal restrictions were lifted from family presence (during report times) family satisfaction improved without changing staff satisfaction (45).

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 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 (46-48), pediatric (49, 50) or neonatal (51, 52) ICUs. 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 support 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 presence and active participation by family members. All studies had significant limitations in the use of non-validated 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: increased understanding of what the doctor said, increased confidentiality and intimacy respected, more questions were answered, enough time was spent with them, their child was more respected, their problem was taken seriously, and increased 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 (53-56) suggest that preferences (53), satisfaction(54),(55)(56), involvement in asking questions and in decision making(53), support with decision making(56) are improved. Anxiety could theoretically increase or decrease with family presence on rounds compared with rounds without family presence (56). One study (57) found that family perceptions change over time: compared to 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, since 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 (56), 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 to 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 (58), the American Heart Association (59), the American Association of Critical-Care Nurses (60), the American Academy of Pediatrics (61), the European Federation of Critical Care Nursing Associations,(62) the European Society of Pediatric and Neonatal Intensive Care (62), and the European Society of Cardiology Council on Cardiovascular Nursing (62, 63), 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 (64-74). In one study of deaths in the emergency department, family members of decedents reported the belief that their presence would have helped the patient as well as the belief that their presence during the resuscitation would have attenuated their grief (64). An evaluation of resuscitation in a pediatric intensive care unit 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 (68). 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 (75, 76).

Support for family presence among clinicians is not consistently positive, and studies suggest few institutions have adopted policies regarding the presence of family members during resuscitation in the intensive care unit or emergency department (62, 77-79). Survey data suggest that nurses have a more positive outlook about family member presence during resuscitation compared to physicians (66, 73, 80-84). 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 (73, 85, 86). 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 (66, 67, 80, 81, 83, 87-103). In a study assessing family-witnessed resuscitation in 162 UK emergency departments, 57 departments reported adverse events associated with family member presence (104). 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 medico-legal 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 (104). Other studies evaluating implementation of family presence programs have not reported interruptions in care related to family member presence (80, 105).

To date, two randomized trials have addressed family presence during resuscitation in the emergency department (106, 107), 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 (106). The authors assessed 8 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 (107).

Although randomized trials in the emergency department and intensive care unit are lacking, research done in the out-of-hospital setting has offered some 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 (108). Ninety days after resuscitation, enrolled relatives completed the Impact of Event Scale (IES) and the Hospital Anxiety and Depression Scale (HADS) by telephone. Frequency of PTSD-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 to those who did. Family-witnessed resuscitation did not affect resuscitation characteristics, patient survival, or the level of emotional stress in the medical team (108). 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 (109).

Data from existing observational studies (110, 111) 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 pediatric ICU and compared ratings of satisfaction between parents present during resuscitation compared to 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 (80, 105, 112-114). The presence of support personnel was also included in the existing aforementioned randomized trials (106, 107, 109); however, the relationship between family-centered outcomes and the presence of a dedicated support person has not been well-described. Since 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 (crossover, 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.

II. 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 (115, 116). 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 (116). The other study, (n=133), demonstrated increased satisfaction with information, written pain control information, pain control information satisfaction, a sense that nurses showed the parent how to look for signs of pain and perform comfort techniques, but did not reduce maternal stress (115). 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 (NIDCAP) including behavioral observations (117). Both had sample sizes over 100. Parents of the infants born < 32 weeks 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 (118, 119) does 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 (118). 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 (119). 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 only 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

Amongst 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 length of stay 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 (40-42). The types of family training/education programs vary widely in type, duration, and purpose and as such are difficult to compare.

There are 7 studies addressing family psychological symptoms (primarily depression and anxiety) with family training/education programs. There are 3 randomized trials, one is of very low quality and found no effect of the training/educational intervention on family psychological outcome (40), while two randomized trials, one of high and one of moderate quality, found the COPE (Creating Opportunities for Parent Empowerment) educational program reduced family stress and depression (41, 42). There are also 3 observational studies (120, 121), (122), and a secondary analysis of a randomized trial (123) all of which found reduced anxiety. The observational studies are of very low quality.

Data from 4 studies address family stress with family training/education programs. There are two randomized trials (40, 41), a secondary analysis of a randomized trial (123), and one observational study (124). The three studies (40, 41, 123) used the COPE program. In secondary analysis of the randomized trial (123), 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 (40); another study found the COPE training decreased stress at 2 months in but not in fathers (42). The observational study using an NICU education program found it reduced stress in fathers but not in mothers (124). The observational study and secondary analysis are very low quality, whereas the 2 randomized trials have high and moderate quality evidence. The results of the studies are conflicting with the 2 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, finding the intervention group had a significant increase in family satisfaction with small effects (125). Another study used a family education program and found higher satisfaction in the experimental group with small effects (121).

Data from one randomized trial and 3 observational studies address family self-efficacy with family training/education programs. The observational studies (126-128) are of low quality. One study used a program to teach parents how to do exercises with their pre-term children and found the parents performed the exercises on most days (93%) and made few errors (126). A positive parent education program found the family was able to gain perspective on the situation and learn key concepts and find resources (127). A training program with families of children with tracheostomy found high satisfaction with the training (128).

Data from existing observational studies address cost and length of stay with family training or education programs. One observational study reported reduced median hospital length of stay by 24 days after the education program (129). A cost analysis of the COPE training found estimated cost savings of \$4864 per preterm born child with reduced hospital length of stay by 3.8 days (130). Both studies have very low quality of evidence.

The overall quality of evidence is low as there are predominately observational studies which are of low quality and 3 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 may increase family satisfaction and family self-efficacy and may reduce hospital length of stay 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 length of stay 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

Amongst 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 neonatal ICU. Three (131-133) are descriptive, qualitative studies of small convenience samples in a single site that describe perceptions of health professionals (132) or mothers (131, 133) receiving a peer-to-peer counseling about breast feeding infants in the neonatal ICU. 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 neonatal ICU setting (131) and most ranked the peer support as most important for development of their maternal role in the neonatal ICU (133). The fourth descriptive study documented the utilization of peer-to-peer support provided in three formats: in groups, 1-to-1 at the bedside, and by telephone. Of the 477 parents (301 families) followed 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 neonatal ICU family (134)

One small study (135) compared peer support for mothers of neonatal ICU infants at one site with a control group of mothers at another similar neonatal ICU site. The mothers at the site with peer support reported less stress at 4, 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 neonatal ICU infants found that 92% would recommend the program to others (134). 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 neonatal ICU (131-133).

Recommendation:

We suggest that peer-to-peer support be implemented in neonatal ICUs 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 to 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 (136-138). 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 at 90 days after the patient's death (4). In another randomized trial including 175 family members, a family information leaflet compared to usual care improved family members' comprehension of medical information (139).

The quality of evidence is moderate because the results of these two studies demonstrated large treatment effects. Since 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 (136-138). 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 (140, 141). 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 (142) and 12 months (143) 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 2 sites. Across studies, the procedure involved in providing the patient or family with a diary is very different. In one trial (142), the diary was given to the patient by a research nurse or doctor who discussed its content with the patient. In the other trial (144), 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' wellbeing. Qualitative studies show that relatives describe the benefits of ICU diaries (144-146). 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: (144-146)). 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 length of stay?

Evidence Summary:

Surrogate decision makers of ICU patients face significant challenges during hospitalization of their loved ones. Stress, emotion, the complexity of the clinical situation, uncertainty, poor communication quality, and lack of social support all present barriers to good quality decision-making. One published paper describes a small before-after study of a written shared decision support aid designed for surrogate decision makers of patients with chronic

critical illness (147). 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, 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-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' wellbeing 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 to usual care?

Evidence Summary:

Several studies have examined the impact of clinician support tools targeting families on patient-centered outcomes (75, 148, 149). One observational study examined the impact of implementing a bundle of interventions (ICU Quality Bundle) on family satisfaction. The ICU Quality Bundle was a multi-faceted educational intervention targeting improving communication with family members during their loved one's admission to the ICU, and included a family conference at 72 hours, documentation of surrogate decision maker, and documentation of advanced directives, among other aspects. Eighty-six individuals in the intervention period were compared to 26 in the pre-intervention period. The intervention was associated with non-statistically significant differences in family satisfaction within 72 hours from admission. Authors propose that non-significance was due in part to poor protocol compliance initiating conferences when indicated (148). 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 be very low due to the imprecision of effect (148). The single randomized trial provided the most compelling evidence of benefit of the mnemonic VALUE. In addition to use of VALUE during the family conference, the intervention also included a bereavement packet. It is impossible to determine if 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.

III. 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 (150). 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 papers 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 (2 with mixed qualitative-quantitative designs (151, 152) and 2 with quantitative, observational designs (153, 154)). One study (153) found that an increased proportion of family speech during meetings was significantly associated with increased family satisfaction with physician communication. In another (151), 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 non-abandonment; assurances of comfort and not suffering; and support for family’s decision to withdraw or not to withdraw life support (152). A third analysis (154) 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 (155-157) 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 (155); 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 (157). Another study (156) 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 non-interpreted ICU family meetings, but worse with Spanish-speaking patients.

Regarding conflict, in a before-after study (158), use of a proactive interdisciplinary (represented by the various disciplines involved in the patient’s care) family conferences

decreased the rate of family “non-consensus” 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 (153).

ICU length of stay was addressed as an outcome associated with having family conferences in 4 studies, 3 of which were before-after studies (158-160) and 1 of which was a retrospective chart review (161). In the largest and only multi-center 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 (159). However, a single-center study of a similar intervention (158) 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 (160), the difference in LOS between the intervention groups at each time period was not significant. In a retrospective chart review of PICU patients, (161) 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 didn’t have a family conference though 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, 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: Amongst 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 (length of stay)?

Evidence Summary:

Numerous observational studies have suggested the need for improved communication with family members (137, 162-167). One multicenter observational study analyzed recordings of 51 family conferences and published results in a series of articles (151-153). 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-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)(168) showed higher family satisfaction with decision-making in the post-intervention period(169). The study did not show significant improvement in overall family satisfaction in the post-intervention 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” --Value, Acknowledge, Listen, Understand and Elicit) 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 single 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 to “low quality” 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 are 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 (26, 27, 170, 171). Furthermore, additional evidence demonstrates that *poor* communication can cause patient and family dissatisfaction (162-165) and even harm in the form of anxiety, depression, symptoms of PTSD and complicated grief (137, 166, 167, 172). 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 programs 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 (169, 173-182). 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 (180), while the other study found no

improvement (183). Importantly, while 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 studies that demonstrated at least some improvement were of a longer training duration (1 to 12-months) (173, 178, 182, 183), in contrast with a 1-hour (176) and 1-day (184) training 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 (184).

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 (169). 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 (185). 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 as well as 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 non-intervention controls, relatively small study numbers, and use of non-validated 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 (137, 162-167, 172). 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 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 existing evidence. (2D)

Further research is needed to determine if 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 (185).

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IV. 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 length-of-stay among certain patients, such as patients with advanced dementia, global cerebral ischemia after cardiac arrest, patients with prolonged ICU stay, and patients with subarachnoid hemorrhage (SAH) requiring mechanical ventilation (186-190). However, one study showed no significant changes in ICU and hospital length of stay (189) and another showed a significant decrease in ICU length-of-stay but no change in hospital length-of-stay (188). Quality of the evidence is low as all studies used a non-randomized, before-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 length of stay. 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 length of stay (191).

Recommendation:

We suggest proactive palliative care consultation be provided to decrease ICU and hospital length of stay 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 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 length of stay?

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 (192). There are two trials in which family satisfaction was examined in the intervention arm but not the control arm; family satisfaction appeared high in both these studies (193, 194).

There are 4 studies of diverse methodological quality, each testing slightly different types of ethics consultation in different populations for effect on length of stay (192-195). Three of the four studies reported shorter ICU and/or hospital length of stay 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 length of stay (194). The studies that showed 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 that would be eligible and no evidence of harm. Increasing ethics consults may incur a cost saving in ICU and hospital length of stay. The overall quality of evidence for ethics consultation is low.

Recommendation:

We suggest that ethics consultation be provided to decrease ICU and hospital length of stay 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 (196) and United States (197) to 29% in Australia (198) for pediatric ICU patients. In one study of adult ICUs in Europe, 37% of relatives had access to psychologists (172). 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 pre-term neonates admitted to neonatal ICUs. One randomized trial compared 36 mothers supported by a psychologist during the infant's hospitalization to 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) (199).

Another randomized trial compared 43 mothers undergoing 6 support sessions to 62 mothers whose 6 sessions included targeted specific psychological interventions, namely trauma-focused cognitive behavioral therapy (CBT). Targeted therapeutic sessions included: psychoeducation about PTSD, cognitive restructuring, narrative and muscle relaxation. The first publication (200) describes outcomes at 4-5 weeks after the birth of the pre-term infant compared to the time of the intervention, and the second (201) 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, and depression, significantly reduced PTSD and increased use of psychiatric medications at one year (202).

Quality of the evidence is very low for the study of supplementary informational material; it is a single study (little evidence), the timing of the intervention is not described and effect of intervention is not reported (study design limitation). The study of trauma-focused CBT (201) is low quality evidence (observational study, single center, small numbers). The greatest improvement was found in the mothers that 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 cognitive behavioral technique (CBT)-based approach to improve outcomes in mothers of pre-term 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 pre-term babies admitted to the ICU. (2D)

Further research testing the impact of psychological support in adult and pediatric populations, and larger studies in the pre-term 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 (203) 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 (204). The trial showed a non-significant improvement in satisfaction with, satisfaction with the amount of information provided, or 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 a navigator may decrease psychological symptoms in family members (205). 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 hours 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(205). There was no significant reduction in anxiety or PTSD at 3 or 6 months (205). Another study assessed limited (1-2 visit) nurse liaison involvement aimed specifically family anxiety related to ICU-ward transfer; the intervention did not alter state-trait anxiety inventory scores at 3 months (206).

Two publications derived from the same study address physician and nursing communication and satisfaction with that communication by families (207, 208). 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 length of stay among. (205). In another before and after study, changes of ICU length of stay and ICU costs after the introduction of a family support coordinator did not achieve statistical significance. The analysis was not stratified by patient mortality (207).

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 length of stay (among decedents only), and costs of care. 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 length of stay, 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 (26, 209, 210) and the availability of a spiritual advisor or clergy (211-213). Spiritual care has been identified as a core element of palliative care (18). 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) (214).

Many families interact with spiritual care providers during a patient's ICU stay (215). In one study, patients on telemetry units were visited by chaplains, and perceived their interventions as helpful (216). 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, for families that interacted with spiritual care providers, increased overall family satisfaction with ICU care was associated with discussions about the patient's wishes for end-of-life care and a greater number of spiritual care activities performed (215). 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 (217). Provision of spiritual care and satisfaction with the ICU experience were strongly correlated (217). 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 (TISS) for patients (218).

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.

V. 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 (149, 219-221) Of these, three directly addressed withdrawal of life

support (149, 219, 220) while one (221) 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(221) This study evaluated the use of a protocol for sedation and analgesia in a before-after study design showing increased use of sedation and analgesia without hastening. 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 (221), 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. 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 support caused us to include 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:

While nurses are ubiquitous and integrally involved in all aspects of ICU care, this question searches whether or not specifically including nurses in communication about decision-making about the goals of care improves communication will improve 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 (174, 222-225). These studies were conducted in adult, pediatric, and neonatal ICUs 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 post-intervention 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 multi-professional 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 length of stay and hospital length of stay and total costs of care (225) 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 (226).

Quality of evidence is very low due to the limitations of the two relevant studies. While both report empiric evidence, the studies used before-after rather than randomized designs. Both had a relatively small sample of clinicians (e.g. physicians, nurses, 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 versus education) is unknown (225). The second (226) 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 length of stay. 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 length of stay and to improve quality of communication in the ICU. (2D) **No recommendation** can be made regarding decision-making due to lack of supporting evidence.

Further research is needed to examine the potential benefits of nursing involvement in ICU decision-making for family as well as 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 (227). 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 neonatal ICU 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 (228). The authors sought to measure the effects on parental hypervigilance and anxiety, using hospital resource utilization as the primary outcome. There were 80 patients included in the control (pre-intervention) 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 (229). 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 very low due to study design limitations and the data is 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 post-implementation design (228) and the other did not compare the participating family members with a control group (229).

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 (32, 230-235). 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 (236). This randomized trial of co-bedding multiple-gestation infants in the neonatal ICU versus bedding single 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 towards single family rooms compared to an open bay ward neonatal ICU design, families had increased satisfaction in several areas. These 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 (237).

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). While 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 (238, 239).

Five additional studies attempt to provide information on ICU design using pre- and post-design. One study evaluated three physical design layouts of a neonatal ICU using focus groups (240) 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 promoted bonding between parent and infant, led to better comprehension of illness among parents, and allowed healthcare providers to meet healthcare needs.

These findings were supported by other studies comparing an open bay and single family room in a neonatal ICU. A pre-post study measured baseline, 6 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 one 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 neonatal ICU 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 (241). 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 (HCAHPS) 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 (231).

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 ACCM/SCCM for a variety of reasons (including infection control), only one of which is family-centered care outcomes (242), 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 neonatal ICUs 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/ACCM Guidelines for ICU design recommend designing new ICUs with family space based upon consensus statement (242).

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 (243-246). 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 (245, 246).

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 neonatal ICUs. 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 multi-center 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 (247, 248). Two studies tested the effect of aspects of this continuity of care on family satisfaction with communication or ICU length of stay (247, 249, 250). One study introduced a care model emphasizing consistency of care for long-term pediatric patients in a single ICU in a pre- and post-intervention design (249). 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% v. 100%, $p=0.019$) and in the parents’ view of the relationship with the ICU staff (57% v. 100%, $p=0.008$), based on surveys among 33 parents. An observational study of 292 pediatric ICU 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 length of stay, adjusting for patient characteristics such as severity of illness, and finding that patients with the highest quartile of discontinuity had shorter ICU stays as compared to 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 (247).

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 towards or away from improvements in the selected outcomes with increased continuity. There is likely low risk associated with interventions increasing staffing, 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 (251-254) and validated, objective measurements (238, 239, 255-257). The need for access to a location for sleep is a theme expressed by families of the critically ill (252). 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 (255-258, 258). Napping in a bed reduces driving errors (259) and also relieves pain hypersensitivity resulting from sleep deprivation (260).

Families in the ICU suffer significant sleep deprivation and related morbidity. Napping increases daily sleep duration, reduces fatigue, reduces errors, and reduces pain (in non-family, non-ICU populations). Provision of a surface for napping may reduce morbidity among family members, though 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 also provided on the Society of Critical Care Medicine (SCCM) website (www.sccm.org) and as an electronic supplement. Work tools supporting these guidelines are also available as electronic supplement Appendix E. Additional work tools are under construction 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 supplement table 6 is also offered as a starting point. Recommendations in Electronic supplement table 6 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 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 key patient 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 according to priorities and available resources. Finally, because of the low level of evidence, it is premature to create accreditation or reimbursement standards from the 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 existing evidence to form internal policy 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.

Electronic Table 1: Themes from Qualitative Literature

Patient Family Themes	Clinician Themes
Communication	Communication
Presence	Presence
Relationship based care	Relationship based care
Adaptation/Sensemaking	Adaptation/Sensemaking
Operational/Organizational	Operational/Organizational
End of life care	End of life care
Environment	Environment
Individualized care	Individualized care
Maintaining Family Integrity	Staff Consequences

Electronic Supplement Table 2: Outcomes of interest and importance. 7-10 high, 4-6 moderate, 0-3 low.

OUTCOME	AVERAGE CLINICIAN RATING (0-10) (Highest rating most important) (n=28)	AVERAGE FAMILY RATING (0-10) (n=7) (Highest rating most important) (n=7)
Family Psychological Symptoms (Depression, Anxiety, PTSD, Prolonged/complicated grief, Fatigue, PICS)	9.6	9.3
Family Quality of Life	8.2	9.1
Family Quality of Dying/Ratings of Dying	8.2	8.4
Caregiver (family) Burden	8.0	8.7
Family Decisional Regret	7.9	8.4
Quality of Communication or Family Conference	7.7	9.3
Family Trust in Clinicians	7.7	9.3
Family Conferences (#/% receiving conferences, Time to family conferences)	7.6	9.0
Family Impact - integrity (Divorce rates, Bonding)	7.4	7.1
Family Satisfaction with Care	7.3	9.4
Family Satisfaction with Communication	7.3	9.1
Family Self-Efficacy	6.9	8.7
Family or Clinician Conflict	6.70	8.0
Clinician Quality of Dying/Rating of Dying	6.3	7.9
ICU and Hospital Utilization (ICU LOS, ICU costs, Hospital LOS, Hospital costs, Intensity of care, TISS)	6.2	7.7
Clinician Self-Efficacy	5.6	9.0
Clinician Psychological Symptoms (Depression, Anxiety, PTSD, Burnout, Compassion Fatigue, Moral Distress)	5.5	9.0
Time to DNR Order	5.2	6.6
Clinician Job Satisfaction	5.0	8.7
Quality of Teaching	5.0	9.1
Clinician Retention or Intent to Leave Job	4.6	7.6

Clinician Time	4.3	7.7
Adherence to Policy/Protocols	4.1	8.7
Clinician fear of litigation	2.8	7.1

Electronic Supplement Table 3: Voting Results

Family Centered-Care Guideline Voting Summary			
Family Presence			
Question 1.1 In the critical care environment, does open flexible visiting hours affect family satisfaction?			
Quality of Evidence	Very Low		
Recommendation	We suggest that, given the value family members place on presence, dissatisfaction associated with restricted presence and benefit of engagement associated with presence, We suggest that family members of critically ill patients be offered open flexible visiting that meets their needs while supporting staff through the stress imposed by family presence		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	24	1	2
Percentages	88%		
Question 1.2 In the critical care or emergency department environment, does family presence during interdisciplinary team rounds affect: Family psychological symptoms, Family trust in clinician, Family satisfaction with and preferences for care, Family satisfaction with and preferences for communication, Family or clinician conflict, Quality of teaching, Family participation in rounds, Degree of shared decision-making (as a direct result of family participation), Family knowledge?			
Quality of Evidence	Low Quality		
Recommendation	We suggest that family members of critically ill patients be offered the option of participating in interdisciplinary team rounds, but that further research is needed to understand potential benefits and burdens and long-term effects on family outcomes.		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	26		1
Percentages	96%		
Question 1.3 In the critical care or emergency department environment, does family presence during resuscitation affect: Family psychological symptoms, caregiver burden, family trust in clinician, family satisfaction with care, family satisfaction with communication, family or clinician conflict?			
Quality of Evidence	Low Quality		
Recommendation	We suggest that family members of critically ill patients be offered the option of being present during resuscitation efforts.		
Strength of Recommendation	Weak Recommendation		

Task Force Voting	Agree	Disagree	Abstain
Votes	26	1	
Percentages	96%		
Family Support			
Question 2.1 Amongst families of ICU patients, does teaching family members to participate in patient care affect: Family satisfaction with care, Family self-efficacy, Time to DNR order?			
Quality of Evidence	Moderate		
Recommendation	We suggest that family members of critically ill patients be offered the option to be taught how to assist with the care of their loved ones.		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	27		
Percentages	100%		
Question 2.2 Amongst family members of ICU patients do training/education programs for family members affect: Family psychological symptoms; Family stress; Family satisfaction; reduce health care costs; Family self-efficacy; and reduce hospital length of stay and costs?			
Quality of Evidence	Low		
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.		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	24	2	2
Percentages	88%		
Question 2.3 Amongst family members of ICU patients, does provision of family support such as “Date night” or family respite or family peer-to-peer support affect: family psychological symptoms like PTSD, family satisfaction with care?			
Quality of Evidence	Very Low		
Recommendation	We suggest peer-to-peer support be implemented to improve family satisfaction, parental stress and depression. It is not known whether peer-to-peer support would be effective in the adult population		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain

Votes	27		1
Percentages	100%		
Question 2.4 Do written materials such as pamphlets, education materials, and bereavement materials targeting ICU family members improve outcomes compared to usual care?			
Quality of Evidence	Low Quality		
Recommendation	We suggest that ICUs provide family with information leaflets that give information about the ICU setting		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	25		2
Percentages	92%		
Question 2.5 Among family members of ICU patients does an ICU diary program improve/affect psychological symptoms (PTSD, Anxiety, Depression)?			
Quality of Evidence	Low Quality		
Recommendation	We suggest that ICU diaries be implemented in ICUs		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	25	2	
Percentages	92%		
Question 2.6 In the ICU environment, do decision support tools for families or shared decision making itself improve/affect communication, cost or length of stay ?			
Quality of Evidence	Very Low		
Recommendation	We suggest that validated decision support tools for family members be implemented in the ICU setting when relevant validated tools exist.		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	23	3	1
Percentages	85%		
Question 2.6 In the ICU environment, do clinician support tools targeting family support or primary palliative care such as checklists, worksheets, mnemonics improve psychological distress or communication compared to usual care?			
Quality of Evidence	Low Quality		
Recommendation	We suggest that, among surrogates of ICU patients who are deemed by a clinician to have a poor prognosis, clinicians use clinician support tools, such as the use of the mnemonic VALUE during family conferences, to facilitate clinician-family communication		

Strength of Recommendation	Weak Recommendation			
Task Force Voting	Agree	Disagree	Abstain	
Votes	25	1	1	
Percentages	92%			
Task Force Voting	Agree	Disagree	Abstain	
Votes	23	3	1	
Percentages	85%			
Communication				
Question 2.1.a In the ICU setting, do routine family conferences improve/affect patient ICU length of stay (LOS)?				
Quality of Evidence	Low Quality			
Recommendation	We suggest that routine interdisciplinary family conferences should be used in ICU to reduce length of stay for patients who die in the ICU.			
Strength of Recommendation	Weak Recommendation			
Task Force Voting	Agree	Disagree	Abstain	Comments
Votes	20	2	5	
Percentages	74%			
Question 2.1.b. In the ICU setting, do routine family conferences improve/affect family satisfaction with communication or care or quality of communication?				
Quality of Evidence	Low quality			
Recommendation	We suggest that certain, specific communication patterns (e.g. more family and less clinician speech, use of empathic statements and assurance/support statements with families) can be used in communication with family members to improve family satisfaction			
Strength of Recommendation	Weak Recommendation			
Task Force Voting	Agree	Disagree	Abstain	
Votes	25	2		
Percentages	92%			
Question 2.1c In the ICU setting, do routine family conferences improve family trust in clinicians, decrease family/clinician conflict; or affect intensity of , or time devoted to, care?				
Quality of Evidence	Low Quality			
Recommendation	We suggest that routine interdisciplinary family conferences should be used in ICU to improve family trust and reduce conflict between clinicians and family members.			

Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	26		1
Percentages	96%		
<p>Question 2.2. Amongst healthcare clinicians in the ICU, do specific communication techniques such as active listening, empathy and empathic statements, provision of hope, bedside caring behaviors including touch, 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 (length of stay)?</p>			
Quality of Evidence	Low Quality		
Recommendation	<p>We suggest that health care clinicians in the ICU utilize strategies included in the VALUE mnemonic when engaging in communication with family members, specifically active listening, expressions of empathy, making supportive statements around non-abandonment and decision-making. In addition, we suggest that family members of critically ill patients be offered a written brochure.</p>		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	25	1	1
Percentages	92%		
<p>Question 2.3a In the ICU environment, do communication training programs for clinicians such as education or simulation improve/affect: Family Psychological Symptoms (1 study) Family Quality of Dying (1 study) Quality of Communication (5 studies) Family Satisfaction with Communication (2 studies) Clinician Self-Efficacy (10 studies)• Clinician Psychological Symptoms (2 studies)?</p>			
Quality of Evidence	Very Low		
Recommendation	<p>Based on existing evidence of patient and family burden 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 an overall well-rounded critical care training curriculum and ongoing education.</p>		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	27		1
Percentages	100%		
<p>Question 2.3b In the ICU environment, do communication training programs for clinicians such as education or simulation improve/affect: Family Psychological Symptoms (1 study) Family Quality of Dying (1 study) Quality of Communication (5 studies) Family Satisfaction with Communication (2 studies) Clinician Self-Efficacy (10 studies) Clinician Psychological Symptoms (2 studies)?</p>			

Quality of Evidence	Very Low		
Recommendation	No Recommendation can be made to suggest the use of any of the specific communication training programs that have been evaluated based on existing evidence.		
Strength of Recommendation	No Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	25	2	1
Percentages	92%		
Consultations			
Question 1.1 Among family members of ICU patients does a palliative care consultation impact ICU and hospital utilization?			
Quality of Evidence	Low Quality		
Recommendation	We suggest that proactive palliative care consultation be considered to decrease ICU and hospital length among selected critically ill patients		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	26	1	
Percentages	96%		
Question 1.2a Among family members of ICU patients does ethics consultation impact family satisfaction, ICU or hospital length of stay?			
Quality of Evidence	Low Quality		
Recommendation	We suggest that ethics consultation, particularly in reaction to a conflict about goals of care for an ICU patient, may decrease ICU and hospital length of stay among selected critically ill patients		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	24	2	2
Percentages	88%		
Question 1.2b Among family members of ICU patients does ethics consultation impact family satisfaction, ICU or hospital length of stay?			
Quality of Evidence	Low Quality		
Recommendation	No recommendation can be made about using ethics consultation with the goal of increasing family satisfaction		
Strength of Recommendation	No Recommendation		
Task Force Voting	Agree	Disagree	Abstain

Votes	26	1	1
Percentages	96%		
Question 1.3 Among family members of ICU patients does a psychologist improve/affect family outcomes?			
Quality of Evidence	Low Quality		
Recommendation	We suggest a psychologist's intervention to specifically incorporate a multimodal CBT-based approach to improve outcomes in mothers of pre-term babies admitted to the NICU based on a single center study		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	26		1
Percentages	96%		
Quality of Evidence	Low Quality		
Question 1.3b Among family members of ICU patients does a psychologist improve/ affect family outcomes?			
Quality of Evidence	Low Quality		
Recommendation	We suggest that targeted video and reading materials be considered in the context of psychological support provided to mothers of pre-term babies admitted to the ICU, based on a single study		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	25	1	2
Percentages	92%		
Question 1.4 Among family members of ICU patients does a social work consultation impact family satisfaction?			
Quality of Evidence	Very Low		
Recommendation	We suggest social workers be included within an interdisciplinary team to participate in family meetings and improve family satisfaction		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	26	1	
Percentages	96%		
Question 1.5a Among family members of ICU patients does a patient navigator improve/affect family psychological symptoms, family satisfaction, family or clinician conflict or resource utilization?			

Quality of Evidence	Very Low			
Recommendation	We suggest that patient/family navigators be assigned to families throughout the ICU stay to improve family satisfaction with communication, family psychological symptoms, and reduce length of ICU stay and costs of care.			
Strength of Recommendation	Weak Recommendation			
Task Force Voting	Agree	Disagree	Abstain	
Votes	25	1	1	
Percentages	92%			
Question 1.5.b Among family members of ICU patients does a patient navigator improve/affect family satisfaction?				
Quality of Evidence	Low Quality			
Recommendation	We suggest that patient/family navigators be considered in the ICU to improve family satisfaction with physician communication			
Strength of Recommendation	Weak Recommendation			
Task Force Voting	Agree	Disagree	Abstain	Comments
Votes	22	2	3	
Percentages	81%			
Question 1.5.c Among family members of ICU patients does a patient/family navigator improve/affect Family or Clinician Conflict?				
Quality of Evidence	Very Low			
Recommendation	No recommendation can be made due to lack of sufficient evidence			
Strength of Recommendation	No Recommendation			
Task Force Voting	Agree	Disagree	Abstain	Comments
Votes	26		1	
Percentages	96%			
Question 1.5.d Among family members of ICU patients does a patient/family navigator improve/affect resource utilization?				
Quality of Evidence	Very Low			
Recommendation	No recommendation can be made due to lack of sufficient evidence			

Strength of Recommendation	No Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	25	1	1
Percentages	92%		
Question 1.6 Among families of ICU patients, does routine consultation of a spiritual care provider, as compared to usual care, improve outcomes?			
Quality of Evidence	Very Low		
Recommendation	Given the consistency of expression of family values for availability of spiritual care, the accreditation standards, and the results of the observation study we propose that families be offered spiritual support with a spiritual advisor or pastor. The best method for provision of spiritual support has not been studied and warrants further investigation		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	24	3	
Percentages	88%		
Organization/Environment			
Question 5.1+74:80 In the ICU environment, do protocols for withdrawing life support improve outcomes?			
Quality of Evidence	Low Quality		
Recommendation	We suggest that protocols be implemented to ensure adequate and standardized use of sedation and analgesia during withdrawal of life support		
Strength of Recommendation	Weak Recommendation		
Deleted Question Do executive (hospital leadership) walk rounds improve family-centered outcomes in the ICU?			
Quality of Evidence	Very Low		
Recommendation	No recommendation can be made due to lack of supporting evidence		
Strength of Recommendation	No Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	27		1
Percentages	100%		

Question 5.2a Does the inclusion of nurses in ICU communication improve family-centered outcomes?			
Quality of Evidence	Very Low		
Recommendation	We suggest that specialized nurses be used as part of an overall program to potentially decrease ICU and hospital length of stay and to improve patient/family perception of the quality of communication in the ICU		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	25	1	2
Percentages	92%		
Question 5.2.b Does the inclusion of nurses in ICU decision making improve family-centered outcomes?			
Quality of Evidence	Very Low		
Recommendation	No recommendation can be made regarding decision-making due to lack of supporting evidence		
Strength of Recommendation	No Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	26		2
Percentages	96%		
Deleted Question: Does consistency in staffing improve family-centered outcomes during critical illness?			
Quality of Evidence	Low		
Recommendation	No recommendation can be made due to lack of supporting evidence		
Strength of Recommendation	No Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	26	1	1
Percentages	96%		
Question 5.3 Does a comprehensive “family-centered care” approach to ICU care improve family-centered outcomes during critical illness?			
Quality of Evidence	Very Low		
Recommendation	We suggest that hospitals consider implementing policies to promote family-centered care in the ICU to improve family experience		

Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	27		1
Percentages	100%		
Question 5.4 In the critical care environment do noise reduction strategies for family members (beyond single rooms for patients) affect patient/family satisfaction, staff stress or noise?			
Quality of Evidence	Very Low		
Recommendation	In the absence of evidence to support specific strategies other than private rooms for noise reduction, yet given the evidence of harm from noise, we suggest that ICUs implement noise reduction and environmental hygiene practices.		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	27		1
Percentages	100%		
Question 5.4 In the critical care environment do private rooms or space for family members (beyond single rooms for patients) affect patient/family satisfaction, staff stress or noise?			
Quality of Evidence	Very Low		
Recommendation	We suggest the use of private rooms to improve patient/family satisfaction and noise reduction while managing staff stress imposed with the change from open-bay to private rooms in the NICU.		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	25	2	1
Percentages	92%		
Question 5.4 In the critical care environment do noise reduction strategies, private rooms or space for family members (beyond single rooms for patients) affect patient/family satisfaction, staff stress or noise?			
Quality of Evidence	Very Low		
Recommendation	No Recommendation can be made for family space. However, it is noted that the SCCM/ACCM Guidelines for ICU design recommend designing new ICUs with family space based upon consensus statement (Thompson-4843)		
Strength of Recommendation	No Recommendation		

Task Force Voting	Agree	Disagree	Abstain
Votes	25	1	2
Percentages	92%		
Question 5.5 Among family members of ICU patients, does providing a surface or space 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?			
Recommendation	We suggest that family members of critically ill patients be provided a sleep surface or space in close proximity to the patient in order to improve family outcomes		
Quality of Evidence	Very Low		
Strength of Recommendation	Weak Recommendation		
Task Force Voting	Agree	Disagree	Abstain
Votes	25	2	
Percentages	92%		

Appendix A: Developing Definitions of “family” and “family-centered care”

We identified previous published definitions of “family” and “family-centered care” from published guidelines and key documents on family-centered care. A search strategy and hand-search yielded 24 articles, books, and pamphlets offering definitions of “family”, “patient-centered care”, and/or “family-centered care”; (8, 13, 21, 61, 261-278) these definitions were abstracted by a sub-group composed of five panel members. Definitions were summarized in a single document (Electronic supplement tables 4 and 5), circulated to the five sub-group members along with a panel leader (JRC), and discussed. Through an iterative process, proposed definitions were summarized, discussed, eliminated, and modified. The group decided to exclude “patient-centered care” as beyond the scope of the intended review and guidelines. Two potential definitions of “family” and three potential definitions of “family-centered care” were developed and, along with summaries of the discussion surrounding each proposed definition, presented to the entire advisory panel for further development and discussion (Electronic supplement table 6).

Through an online survey, the entire guidelines writing group panel indicated their preferences for the proposed definitions and were given the opportunity to provide alternative definitions. The proposed definitions were also provided to a group of 7 former ICU patients and family members, including three adult survivors of critical illness and four family members of critically ill adults.

Incorporating alternative definitions and refining wording of the proposed definitions, the final definitions were selected and determined to be acceptable by greater than 70% of the expert panel. These final selected definitions for “family” and “family-centered care” were unanimously deemed appropriate and acceptable by the participating former ICU patients and family members. We define family as:

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.

We define family-centered care as:

Family-centered care is an approach to health care that is respectful of and responsive to individual family's needs and values.

Electronic Supplement Table 4: Abstracted definitions of terms “family” organized by domain

“Family”	
Domain	Definitions (examples)
Family is defined by the patient and family.	“Two or more persons who are related in any way—biologically, legally, or emotionally. Patients and families define their families.” ²⁴
	“For the purposes of this document, the definition of family published by the National Consensus Project for Quality Palliative Care is adopted: “Family is defined by the patient or in the case of minors or those without decision making capacity by their surrogates. In this context the family may be related or unrelated to the patient. They are individuals who provide support and with whom the patient has a significant relationship” ⁶
Family is a social unit.	“The family is a basic social unit having as its nucleus two or more persons, irrespective of age, in which each of the following conditions are present: 1. the members are related by blood, or marriage, or adoption, or by a contract which is either explicit or implied; 2. the members communicate with each other in terms of defined social roles such as mother, father, wife, husband, daughter, son, brother, sister, grandfather, grandmother, uncle, aunt; and 3. they adopt or create and maintain common customs and traditions.” ¹⁹
Family defies definition	“We all come from families. Families are big, small, extended, nuclear, multigenerational, with one parent, two parents and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence one another. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations.” ²

Electronic Supplement Table 5: Abstracted definitions of terms “family-centered care” organized by domain

“Family-centered care”	
Domain	Definitions
Definition by tenets	<p>“There are a number of key principles to family-centered care: (1) including parents and families being treated with dignity and respect; (2) parents having a right to know about their infant’s care and condition and updated information should be available to them, health care providers prioritizing open communication and sharing information with parents and families in ways that are affirming and useful; (3) information-giving being tailored according to parents’ individual preferences for detail and their changing needs; (4) parents and families being encouraged to participate in their infant’s care with the aim of them developing a sense of confidence, control and growing independence; and (5) practical and emotional support being provided continuously, through the care pathway”²</p>
	<p>“In the Institute of Medicine’s patient-centered model, a) patients and families are kept informed and actively involved in medical decisionmaking and self-management; b) patient care is coordinated and integrated across groups of healthcare providers; c) healthcare delivery systems provide for the physical comfort and emotional support of patients and family members; d) healthcare providers have a clear understanding of patients’ concepts of illness and their cultural beliefs; and e) healthcare providers understand and apply principles of disease prevention and behavioral change appropriate for diverse populations.”⁶</p>
Care involving patient preferences and goals	<p>“Family centered-care, which sees patients as embedded within a social structure and web of relationships, is emerging as a comprehensive ideal for end-of-life care in the ICU.” “Family centered care is based on the values, goals, and needs of the patient and family, including their understanding of the illness, prognosis, and treatment options and their expectations and preferences for treatment and decision making.”²³</p>
Care involving compassion, empathy, and the whole patient	<p>“Patient-centered encompasses qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient.”²⁵</p>
Care respectful of cultural competence	<p>“Patient-centered care responds precisely to each patient’s wants, needs, and preferences. It gives patients abundant opportunities to be informed and involved in medical decision making, and guides and supports those providing care in attending to their patients’ physical and emotional needs, and maintaining or improving their quality of life to the extent possible. Patient-centered care is highly customized and incorporates cultural competence.”²⁵</p>
Care that treats the patient and family	<p>“A way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognised as care recipients”¹⁹</p>
	<p>“[Family centered care] is an approach to [health care in which: providers recognize the importance that families play in ensuring the health and well-being</p>

	<p>of their children; providers support families in their care-giving and decision making roles; providers have an awareness of the importance of meeting the psychosocial and developmental needs of children and the role of families in promoting the health and well-being of their children; ‘the philosophies, principles and practices that put the family at the heart or center of services;’”¹</p>
<p>Care that is a partnership between providers and patients and families</p>	<p>Collaboration between providers and families and patients in the planning, delivery and evaluation of care- family-centered care and patient and family-centered care “more explicitly capture the importance of engaging the family and the patient in a developmentally supportive manner <u>as essential members of the health care team.</u>”</p>

Electronic Supplement Table 6: Definitions of terms “family” and “family-centered care” presented to entire group

Term	Definitions
Family	“Two or more persons who are related in any way—biologically, legally, or emotionally. Patients and families define their families.” ²⁴
	“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” ⁶
Family-centered care	Family-centered care is an approach to health care that is respectful of and responsive to individual family's needs and values. <i>Derived from</i> ²⁵
	Family-centered care recognizes that patients are embedded within a social structure and web of relationships. It is an approach to health care that is respectful of and responsive to individual family's needs and values. <i>Derived from</i> ²³
	Family-centered care recognizes that patients are embedded within a social structure and web of relationships. It is an approach to health care that is planned around the individual patient as the primary focus, but also views the patient as part of a family whose members are recognized as care recipients. <i>Derived from</i> ²³

Appendix B: Standard GRADE methodology used

The Refworks® account of the master literature review was searched and citations relevant to each PICO question were loaded into a folder from which to conduct the evidence analysis. The evidence analysis worksheet was completed by each member of the dyad independently as a quality control measure. Using a structured PICO summary template, dyads compared their findings and produced a consensus assessment for each question and its relevant outcomes, an aggregate scoring of the strength of the evidence for that question and recommendations based upon the available evidence. Multiple outcomes could inform a recommendation, but their relative contribution to the GRADE assigned was weighed by their ranking in importance. Members were encouraged to be as explicit about judgments as possible.

Appendix C. Search Strategies for systematic review

All searches were narrowed to English language and from 1994 –

In **PubMed** on December 8, 2014:

((family-centered[Text Word] OR family-centred[Text Word] OR "Family/psychology"[Mesh:noexp] OR Professional-Family[TW] OR ("Patient-Centered Care"[Mesh] AND ("Family"[Mesh] OR Family[TW] OR spouse[TW] OR significant-other[TW] OR parent[TW] OR child[TW] OR children[TW] OR sibling[TW] OR friend[TW]))) AND ("Intensive Care"[Mesh] OR "Intensive Care, Neonatal"[Mesh] OR "Intensive Care Units"[Mesh] OR "Critical Care Nursing"[Mesh] OR "Critical Care"[Mesh] OR critical care[TW] OR intensive care[TW] OR Burn Unit[TW] OR Coronary Care[TW] OR Respiratory Care[TW] OR "ICU"[TW] OR "PICU"[TW] OR "NICU"[TW] NOT "Recovery Room"[Mesh])) AND English[lang]

In **CINAHL** on December 16, 2014

(MH "Critical Care Family Needs Inventory" OR IN "Critical Care Family Needs Inventory") OR (family-centered OR family-centred OR developmental care OR "family presence" OR (Family AND Communication) OR MH "Visitors to Patients" OR MH "Family/PF" OR MH "Professional-Family Relations" OR MH "Family Attitudes") AND ("intensive care" OR "critical care")) NOT PT Editorial

In **EMBASE** on December 18, 2014

See next 2 pages with history printout

EMBASE search

1	family centered care/	954
2	family attitude/	1903
3	exp family attitude/	7888
4	family coping	600
5	Health visitor.mp. or health visitor/	2010
6	social worker.mp. or social worker/	7102
7	Decision Support system.mp. or decision support system/	14614
8	exp family/	339299
9	satisfaction/	29918
10	Presence.mp.	1394139
11	Decision making.mp. or decision making/	269888
12	interpersonal communication.mp. or interpersonal communication/	119807
13	Medical decision making.mp. or medical decision making/	70263
14	Patient care.mp. or patient care/	252668
15	Nurse attitude.mp. or nurse attitude/	33623
16	Physician attitude.mp. or physician attitude/	42352
17	Consultation.mp. or consultation/	93158
18	Noise.mp.	109246
19	resuscitation/ or resuscitation.mp.	91232
20	Developmental care.mp.	347
21	Family-cent?red.mp.	3489
22	critical care family needs inventory.mp. or Critical Care Family Needs Inventory/	78
23	1 or 3 or 4 or 5 or 6 or 7 or 22	32888
24	9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18	2231469

25	8 AND 24	54583
26	23 or 25	85714
27	intensive care.mp.	218161
28	Pediatric advanced life support.mp. or pediatric advanced life support/	580
29	critical care.mp.	32442
30	Resuscitation/ or resuscitation.mp.	91232
31	(NICU or PICU or ICU).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	71081
32	27 or 28 or 29 or 30 or 31	318081
33	26 and 32	
34	1 or 3 or 4 or 5 or 6 or 7 or 20 or 21 or 22	35621
35	25 or 34	87804
36	32 and 35	5282
37	(32 and 35) not Editorial.pt.	5053
38	(32 and 35) not Editorial.pt.	5053
39	limit 38 to (english language and yr=*1994 – 2015*)	4313

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 if 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 since skills may dissipate over time; 6) comparison of different communication teaching modalities such as didactic training vs role-plays vs 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 pre-term 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.

Appendix E: Worktools

ACCM Family-Centered Care Guidelines Supplement: Work Tools for Guideline Implementation
All links last accessed on 07.15.2016

The following collaborators participated in this guidelines update, specifically with regards to creating this electronic supplement containing tools for guideline implementation.

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<i>Work Tool Name</i>	<i>Description</i>	<i>Cost</i>	<i>Internet Link / Reference</i>
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Category 1: Family Presence

- Given the value family members place on presence, dissatisfaction associated with restricted presence and benefit of engagement associated with presence, that family members of critically ill patients be offered open flexible visiting hours that meets their needs while providing staff support and positive reinforcement to work in partnership with families.

American Association of Critical Care Nurses (AACN) Practice Alert	Delineates expected practice of appropriate policies to facilitate family visitation, supporting evidence for open visitation in the ICU, and literature available outside of AACN supporting open visitation and family presence.	Free	http://www.aacn.org/wd/practice/content/practicealerts/family-visitation-icu-practice-alert.pcms?menu=practice
Better Together: Partnering with Families	This North American campaign, launched by the Institute for Patient-and-Family-Centered Care and supported by a coalition of Canadian organizations, encourages hospitals to adopt family presence policies. Website includes “change package” of free resources to facilitate 24/7 family presence.	Free	http://www.cfhi-fcass.ca/WhatWeDo/better-together/resources

- Family members of critically ill patients be offered the option of participating in interdisciplinary team rounds to improve satisfaction with communication and family engagement.
- 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.

American Association of Critical Care Nurses Practice Alert and Tools	Provides review of current evidence supporting family presence during resuscitation. Provides basic framework for nursing staff to initiate action plan aimed at including families in resuscitative efforts.	Free	http://www.aacn.org/wd/practice/content/family-presence-practice-alert.pcms?menu=practice
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Category 2: Family Support

- Family members of critically ill patients be offered the option to be taught how to assist with the care of their loved ones.

<i>Apps for Communication with Mechanically Ventilated Patients</i>			
SCCM Patient Communicator App for iPad	Contains a scale that allows patients to identify where on the body they feel sensations of pain and itching to express the intensity of these sensations. More than 30 phrases in 19 languages that allow patients to express various needs related to their care and wellbeing.	\$12.99	http://www.sccm.org/Education-Center/Clinical-Resources/Pages/Patient-and-Family.aspx

SmallTalk Intensive Care for iPhone and iPad; Lingraphicare, Inc	Provides a picture-based vocabulary of phrases that patients can use to communicate their needs and feelings, such as “I have chest pain” and “I want a doctor.” Designed for anyone who has difficulty speaking or is unable to speak, due to having a language impairment, not being a native speaker, being intubated, or having a tracheotomy tube.	Free	Available on iTunes
YoDoc for iPhone and iPad; Docapps LLC	English and Spanish language app for people on ventilators and/or people with speech impairment due to critical medical condition. Patients can write phrases to be spoken out, draw with their finger to show pain areas and speak out pain level and intensity.	Free	Available on iTunes
<i>Instructional Booklet on Infant Comfort</i>			
Comforting Your Baby in Intensive Care	Booklet written for parents to help them learn about infant pain and the role parents can play to keep their child comfortable in the NICU, in partnership with the health care team.	Free	http://familynursing.ucsf.edu/resources-parents

- Family education programs be included as part of clinical care as these programs have demonstrated beneficial effects for family members in the ICU.

COPE for Hope	Organization that provides on-site training for neonatal ICU staff on how to provide support for NICU parents. Teaches parents how to interact with their preterm infant both in the NICU and after discharge in ways that enhances infant growth and development. Helps parents understand the workings of the NICU unit and encourages their active engagement with the NICU staff.	Cost available upon request	http://www.copeforhope.com/index.php
Facilitated Sensemaking	Article that describes a theoretical framework for providing one-on-one personalized instruction to families of patients regarding the ICU environment, interactions with staff, hospital services, participation in patient care, and self-reflection. A list of suggested items for a “family visiting kit” to supplement the instruction is provided as well.	Free with journal access	http://www.ncbi.nlm.nih.gov/pubmed/20234207

- Peer-to-peer support be implemented to improve family satisfaction, parental stress, and depression in neonatal ICUs. It is not known whether peer-to-peer support would be effective in the adult population, but work tools are provided below.

Share Your Story, March of Dimes	An online community for parents to share their experiences with prematurity, birth defects, or perinatal loss	Free	http://share.marchofdimes.org/
SCCM THRIVE	Contains resources to improve patient and family support after critical illness, including connecting with other ICU survivors and/or family members of ICU patients, finding in-person support groups, and providing information on what to expect after discharge.	Free	http://www.mycucare.org/thrive/Pages/default.aspx

Intensive Care Unit Support Teams for Ex-Patients (ICUsteps)	UK resource to improve the care and support available to patients recovering from critical illness and their families, including support groups.	Free	http://icusteps.org
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- ICUs provide family with information leaflets that give information about the ICU setting.

SCCM Patient and Family Support Page	SCCM support page for ICU patients and families. Provides education on a variety of ICU topics along with additional outside resource recommendations. Brochures available for .pdf download.	Free	http://www.mycucare.org
Neurocritical Care Society Family and Patient Resources	Resource guide that provides overview of neurocritical care unit to families, including members of the team, description of common diseases, and links to patient and family resources.	Free for printing; \$40 for 25 brochures	https://www.pathlms.com/ncs-ondemand/categories/413/courses
AHRQ Guide to Patient and Family Engagement in Hospital Quality and Safety	Provides written material to improve communication between patients, families, and clinicians. Downloadable brochures and handouts for patients and families, as well as informational poster to put in ICU.	Free	http://www.ahrq.gov
UCSF Critical Care Innovations Group	Extensive website designed specifically to provide information for families of ICU patients, including details about ICU arrival, the ICU care team, and what to expect after ICU discharge.	Free	http://ccig.ucsf.edu

- ICU diaries be implemented in ICUs.

ICU Diary Network	Network for healthcare providers interested in ICU diaries. Resources include diary overview, literature, implementation assistance, and methods for connecting with institutions who utilize an ICU diary.	Free	www.icu-diary.org
Josie King Foundation Care Journal and App	Journal and downloadable iPhone app to help patients and families manage healthcare information. Prompts user on information to remember and questions to ask healthcare team.	App is free; fee for journal bulk order	http://www.josieking.org
Graham's Foundation MyPremie App	Downloadable iPhone, iPad, iPod, and Android application for families of premature babies. Includes definitions, education, suggested questions, growth charts, diary, and task list.	Free	http://grahamsfoundation.org/resources/the-mypreemie-app/

- 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 and that validated decision support tools for family members be implemented in the ICU setting when relevant validated tools exist.

<i>“VALUE” Mnemonic</i>			
“VALUE” Pocket Card	Pocket card available for download that lists “VALUE” mnemonic for ICU communication with families: value family statements, acknowledge family emotions, listen to family, understand the patient as a person, elicit family questions.	Free	http://depts.washington.edu/eolcare/products/communication-tools/
<i>Decision Support Tools</i>			
Prolonged Mechanical Ventilation	Appendix for this article contains a pilot-tested decision aid for families of patients who have been mechanically ventilated for longer than 10 days and who are re-evaluating patient goals-of-care. Associated with improved communication, decreased cost, and positive physician reviews. Currently being developed in web format.	Free with journal access	http://www.ncbi.nlm.nih.gov/pubmed/22635048
Ottawa Patient Decision Aid Research Group Life Support Decision Aid	Field-tested paper-based decision aid for families of ICU patients who are making decisions regarding life support versus comfort care.	Free	https://decisionaid.ohri.ca/docs/das/Critically_Ill_Decision_Support.pdf
CARENET Code Status Decision Aid	Paper-based decision aid for deciding on code status, developed by the Canadian Researchers at the End of Life Network.	Free	http://thecarenet.ca/docs/CPR%20Decision%20Aid%20revised%20to%20PDF%20brochure%20Nov%203%202009.pdf

Category 3: Family Communication

- 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 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 be offered a written brochure.

<i>Healthcare Clinicians’ Specific Communication Techniques</i>			
“VALUE”	ICU communication with families: value family statements, acknowledge family emotions, listen to family, understand the patient as a person, elicit family questions. Pocket card available at listed website.	Free	http://depts.washington.edu/eolcare/products/communication-tools/
“SPIKES”	Breaking bad news: setup, patient’s perception, invitation to share information, knowledge transmission, explore emotions, summarize & strategize	\$26 for book	Buckman, R. <u>How to Break Bad News: A Guide for Health Care Professionals</u> . John Hopkins, 1992.
“NURSE”	Verbal empathy: naming, understanding, respecting, supporting, exploring	\$40 for book	Fortin, AH; Dwamena, FC; Frankel, RM; Smith, RC. <u>Smith’s Patient-Centered Interviewing: An Evidence-Based Method</u> . McGraw-Hill, 2012.
“AIDET”	Five fundamentals of service: acknowledge, introduce, duration, explanation, thank you	Free	www.studergroup.com

<i>Structured Approaches to Family Communication Improvement</i>			
Rhode Island ICU Collaborative Communication Process Measures	Description of “day 1” and “day 3” goals for family communication that a statewide coalition of ICUs targeted for a coordinated ICU communication quality improvement project.	Free with journal access	http://www.ncbi.nlm.nih.gov/pubmed/24060769
Robert Wood Johnson Foundation Palliative Care Quality Measures	Describes a proposed set of quality measures for ICUs to target with respect to palliative care, divided by domains; the majority of the domains relate to communication with and support of the family, with structured goals that should be achieved during an ICU admission.	Free with journal access	http://www.ncbi.nlm.nih.gov/pubmed/17057606 http://www.ncbi.nlm.nih.gov/pubmed/14501954
VHA Care and Communication “Bundle”	Describes “bundle of care” that includes identification of surrogate decision makers and patient preferences, communication timelines, social work, and spiritual support; with performance measurement and feedback.	Free with journal access	http://www.ncbi.nlm.nih.gov/pubmed/16885251
University of Maryland Family Meeting Algorithm	Description of algorithm (e.g., introduction of clinical team, identification of surrogate decision makers and advance directives, palliative care involvement) designed to improve ICU communication, including time-based checklist (i.e., benchmarks at 24, 72, and 96 hours), as well as triggers to escalate the family communication algorithm.	Free with journal access	http://www.ncbi.nlm.nih.gov/pubmed/24085828
<i>Bereavement Brochure</i>			
Bereavement Support Leaflet, Saint-Louis Teaching Hospital (France)	This appendix to a randomized trial examining the positive effects of a proactive end-of-life conference strategy on long-term adverse psychological outcomes among families contains an extensive brochure that was used in the study to counsel families on bereavement.	Free with journal access	http://www.ncbi.nlm.nih.gov/pubmed/17267907

- Based on 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 an overall well-rounded critical care training curriculum and ongoing education.

<i>Communication Training Programs for Clinicians</i>			
AHRQ Communication Training Slides	Provides definitions of patient and family engagement and overview of communication skills; includes practice exercises in the form of patient/provider scenarios.	Free	http://www.ahrq.gov
Breaking Bad News Foundation	Communication skills training program developed by a neonatologist where physicians and healthcare workers participate in improvisational role-playing sessions with professional actors. Sessions are video-taped and watched remotely by certified instructors. Foundation will work with institutions to fit their local needs.	Costs available upon request	http://www.bbnfoundation.org/

Center to Advance Palliative Care (CAPC)	Formal membership to CAPC includes access to numerous CME/CEU courses.	Range from \$600 for critical access to \$7500 for institution	https://www.capc.org/capc-central/courses/
DocCom	Comprehensive online program with > 400 video modules demonstrating communication skills. Includes evidence-based recommendations, skills checklists, and assessment questions.	\$95/yr for individual; \$40+ per person group pricing; \$25+ per person library pricing	http://www.aachonline.org/dnn/DocCom.aspx
IMPACT-ICU	Quality improvement program at the University of California system designed to integrate palliative care into the ICU by training and supporting bedside nurses. Internet link is to training manual outlining the implementation of communication skills training workshops for nurses.	Free	https://ucsf.box.com/ImpactICUProjectGuide
Institute for Healthcare Communication	Offers variety of workshops on communication, including disclosing unanticipated medical outcomes, end-of-life conversations, and challenging clinician-patient relationships.	Costs available upon request	http://healthcarecomm.org/training/
Vital Talk	Online communication skills courses available for clinicians who work with patients with serious illness and end-of-life care, focused on balancing honesty with empathy.	Costs available upon request	www.vitaltalk.org

Category 4: Consultations

- Proactive palliative care consultation be provided to decrease ICU and hospital length of stay among selected critically ill patients.

Center to Advance Palliative Care – Improving Palliative Care in the ICU Project (CAPC / IPAL)	Free resource available on website regarding the implementation of screening criteria for palliative care in ICUs.	Free	https://media.capc.org/filer_public/80/be/80be3587-6ca1-4eb8-93f0-7fa0e30cd153/76_66_ipal-icu-implementing-icu-screening-criteria-for-unmet-palliative-care-needs.pdf
National Consensus Project for Quality Palliative Care Clinical Practice Guidelines	Guidelines providing a “blueprint” upon which to build optimal palliative care. The document comments on the issue of primary vs. consultative palliative care.	Free	http://www.nationalconsensusproject.org/guideline.pdf

- Ethics consultation, particularly in reaction to a conflict about goals of care for an ICU patient, be provided to decrease ICU and hospital length of stay among selected critically ill patients.

Joint Professional Societies Statement on Responding to Requests for Potentially Inappropriate Treatments in ICUs	Provides a protocol for early consultation with experts in communication and conflict negotiation, namely ethics or palliative care. It is recommended that these practitioners become involved early when conflict is arising, and that they facilitate frequent, effective communication between healthcare providers and the patients and/or their surrogates.	Free with journal access	http://www.ncbi.nlm.nih.gov/pubmed/25978438
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- A psychologist’s intervention be provided to specifically incorporate a multimodal CBT-based approach to improve outcomes in mothers of pre-term babies admitted to the NICU.

Behavioral Interventions for Mothers of Pre-Term Babies	A manualized 6-session treatment based on traum-focused cognitive-behavioral therapy that includes: (1) psychoeducation to educate mothers about PTSD and common feelings and thoughts of NICU parents; (2) cognitive restructuring to help mothers recognize and challenge erroneous and maladaptive cognitions; (3) progressive muscle relaxation to reduce anxiety; and (4) development and processing of the mother’s trauma narrative. The intervention has been shown in a single center study to be effective in reducing symptoms of parental trauma, anxiety, and depression in the NICU and at 6-month follow-up.	Free with journal access	http://www.ncbi.nlm.nih.gov/pubmed/23909669
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- Targeted video and reading materials be provided in the context of psychological support provided to mothers of pre-term babies admitted to the ICU.
- Social workers be included within an interdisciplinary team to participate in family meetings and improve family satisfaction.

- Family navigators assigned to families throughout ICU stay be considered in the ICU to improve family satisfaction with physician communication, psychological symptoms, and reduce length of ICU or hospital stay and costs of care.

Published Training Protocol for ICU “Facilitators”	Describes a protocol for a trained nurse or social worker “communication facilitator” designed to improve psychological distress among family members of critically ill patients, patient length of stay in the intensive care unit and hospital, and costs associated with care and the intervention.	Free with journal access	http://www.ncbi.nlm.nih.gov/pubmed/22772089
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- Given the consistency of expression of family values for availability of spiritual care, the accreditation standard requirements, and the results of the observation study families should be offered spiritual support with a spiritual advisor or chaplain.

Category 5: Operational and Environmental Issues

- Protocols be implemented to ensure adequate and standardized use of sedation and analgesia during withdrawal of life support.

University of Washington Withdrawal of Life Support Orders for Adults	Provides guidance for use of analgesics and sedatives in addition to discontinuation of other therapies not required when <u>adult</u> patients are transitioned to a goal of comfort care. Also describes a set of principles to assist transitioning goals-of-care to promote comfort instead of focusing on disease processes.	Free	http://depts.washington.edu/eolcare/pubs/wp-content/uploads/2011/08/wls-orders2.pdf
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- Specialized nurse be used as part of an overall program to potentially decrease ICU and hospital length of stay and to possibly improve quality of communication in the ICU. Hospitals implement policies to promote family-centered care in the ICU to improve family experience.

Institute for Patient- and Family-Centered Care (work tools for hospital-wide leaders)	Contains links to multiple well-established tools for executives; including “How to Get Started,” which details a step-wise plan for hospitals to build partnerships with patients and families; and ‘Strategies for Leadership,’ which includes a video, resource guides, and a hospital self-assessment inventory.	Free	http://www.ipfcc.org/tools/downloads-tools.html
Institute for Patient- and Family-Centered Care (work tools for ICU leaders)	Assessment tools that provide teams with a structure for assessing their unit and hospital for the four principles of patient and family-centered care in ten areas.	\$10 each	http://www.ipfcc.org/resources/other/index.html

- In the absence of evidence for specific strategies but evidence of harm related to noise, we suggest that ICUs implement noise reduction and environmental hygiene practices and the use of private rooms to improve patient/family satisfaction and noise reduction while managing staff stress imposed with the change from open-bay to private rooms in the neonatal ICU.

ACCM Guidelines for Intensive Care Unit Design	Expert opinion on optimal ICU design, including extensive recommendations for designing a “family support zone.”	Free	http://www.ncbi.nlm.nih.gov/pubmed/22511137
Recommended Standards for Newborn ICU Design	Expert opinion on optimal neonatal ICU design, including extensive recommendations for family support space.	Free	https://www3.nd.edu/~nicudes/RecommendedNICUStandardsFinal8Aug15.pdf

Electronic Supplement Table 6: Recommendations rank ordered by importance of outcome

OUTCOME AND AVERAGE CLINICIAN RATING (10 = highest rating)	ICU FAMILY-CENTERED CARE RECOMMENDATIONS
Family Psychological Symptoms 9.62	<ul style="list-style-type: none"> • A psychologist-delivered trauma-focused multimodal cognitive behavioral therapy (CBT) or targeted video and reading materials providing psychological support be provided to mothers of pre-term babies admitted to the Neonatal Intensive Care Unit (NICU). (Rec 1.3) • Family navigators be assigned to families throughout the ICU stay. (Rec 1.5) • Healthcare clinicians in the ICU use structured approaches to communication with family members, and family members of critically ill patients undergoing withdrawal of life support be offered a written bereavement brochure. (Rec 2.2) • 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. (Rec 3.3) • Family members of critically ill children be offered the option to be taught how to assist with the care of their critically ill child. (Rec 4.1) • Family education programs be included as part of clinical care. (Rec 4.2) • Peer-to-peer support be implemented in pediatric ICUs. (Rec 4.3) • ICUs provide family with leaflets that give information about the ICU setting. (Rec 4.4) • ICU diaries be implemented in ICUs. (Rec 4.5)
Quality of Communication 7.67	<ul style="list-style-type: none"> • ICU clinicians receive family-centered communication training as one element of a critical care training program. (Rec 2.3) • Validated decision support tools for family members be implemented in the ICU setting when relevant validated tools exist. (Rec 4.6) • Among surrogates of ICU patients who are deemed by a clinician to have a poor prognosis, clinicians use a communication approach during family conferences and validated decision support tools for family members be implemented in the ICU setting. (Rec 4.7) • Nurses be trained to provide support for family members. (Rec 5.2)

Family Trust in Clinicians 7.66	<ul style="list-style-type: none"> • Routine interdisciplinary family conferences be used in the ICU. (Rec 2.1)
Family Satisfaction with Care 7.33	<ul style="list-style-type: none"> • Medical social workers be included within an interdisciplinary team to participate in family meetings. (Rec 1.4) • Family members of critically ill patients be offered open flexible visiting that meets their needs while providing support for staff and positive reinforcement to work in partnership with families. (Rec 3.1) • Family education programs be included as part of clinical care. (Rec 4.2) • Peer-to-peer support be implemented in pediatric ICUs. (Rec 4.3) • Hospitals implement policies to promote family-centered care in the ICU. (Rec 5.3) • ICUs implement noise reduction and environmental hygiene practices and use private rooms. (Rec 5.4) • Family sleep be considered and families are provided a sleep surface to reduce the effects of sleep deprivation. (Rec 5.7)
Family Satisfaction with Communication 7.33	<ul style="list-style-type: none"> • Spiritual support from a spiritual advisor or chaplain be offered to families of ICU patients to meet their expressed desire for spiritual care. (Rec 1.1) • Family navigators be assigned to families throughout the ICU stay. (Rec 1.5) • Routine interdisciplinary family conferences be used in the ICU. (Rec 2.1) • Healthcare clinicians in the ICU use structured approaches to communication with family members, and family members of critically ill patients undergoing withdrawal of life support be offered a written bereavement brochure. (Rec 2.2) • ICU clinicians receive family-centered communication training as one element of a critical care training program. (Rec 2.3) • Family members of critically ill patients be offered the option of participating in interdisciplinary team rounds. (Rec 3.2) • Validated decision support tools for family members be implemented in the ICU setting when relevant validated tools exist. (Rec 4.6)
Family Self-Efficacy 6.93	<ul style="list-style-type: none"> • Family members of critically ill children be offered the option to be taught how to assist with the care of their critically ill child. (Rec 4.1)
Family or Clinician Conflict	<ul style="list-style-type: none"> • Routine interdisciplinary family conferences be used in the ICU. (Rec 2.1)

6.70	<ul style="list-style-type: none">Validated decision support tools for family members be implemented in the ICU setting when relevant validated tools exist. (Rec 4.6)
Clinician Rated Quality of Dying 6.30	<ul style="list-style-type: none">Protocols be implemented to ensure adequate and standardized use of sedation and analgesia during withdrawal of life support. (Rec 5.1)
ICU and Hospital Utilization 6.22	<ul style="list-style-type: none">Proactive palliative care consultation be provided among selected critically ill patients. (Rec 1.1)Ethics consultation be provided among critically ill patients for whom there is a conflict about goals of care. (Rec 1.2)Family navigators be assigned to families throughout the ICU stay. (Rec 1.5)Routine interdisciplinary family conferences be used in the ICU. (Rec 2.1)Nurses be trained to provide support for family members. (Rec 5.2)
Clinician Self-Efficacy 5.59	<ul style="list-style-type: none">ICU clinicians receive family-centered communication training as one element of a critical care training program. (Rec 2.3)

Figure 1. Citation analysis of family-centered care publication from Thomson Web of Science

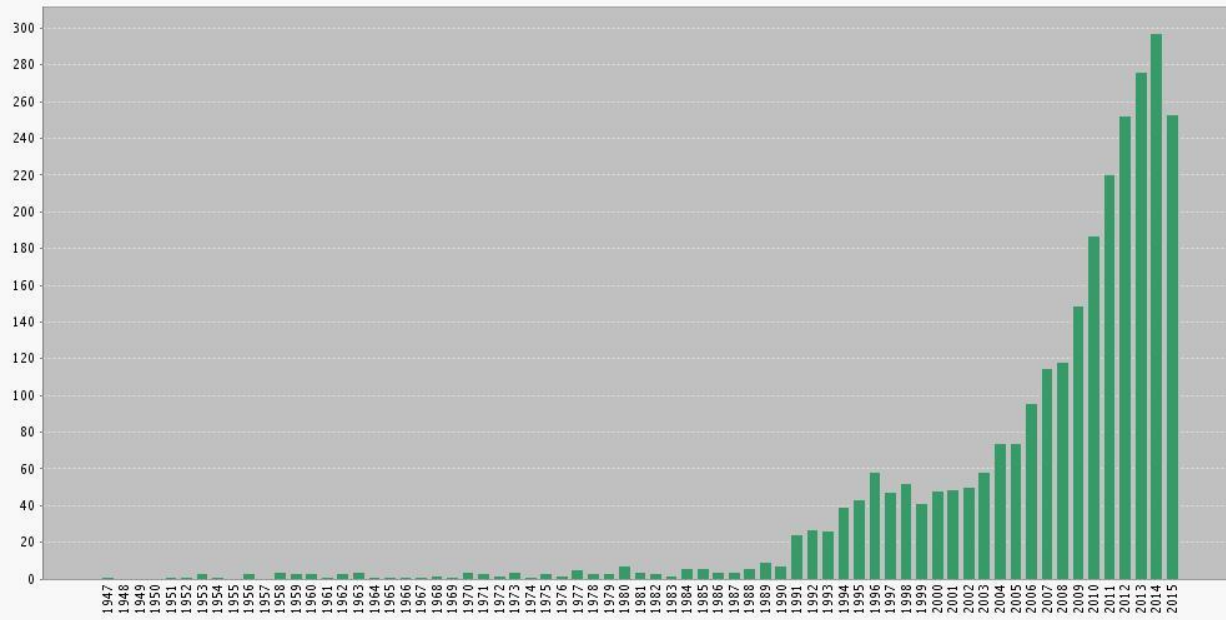
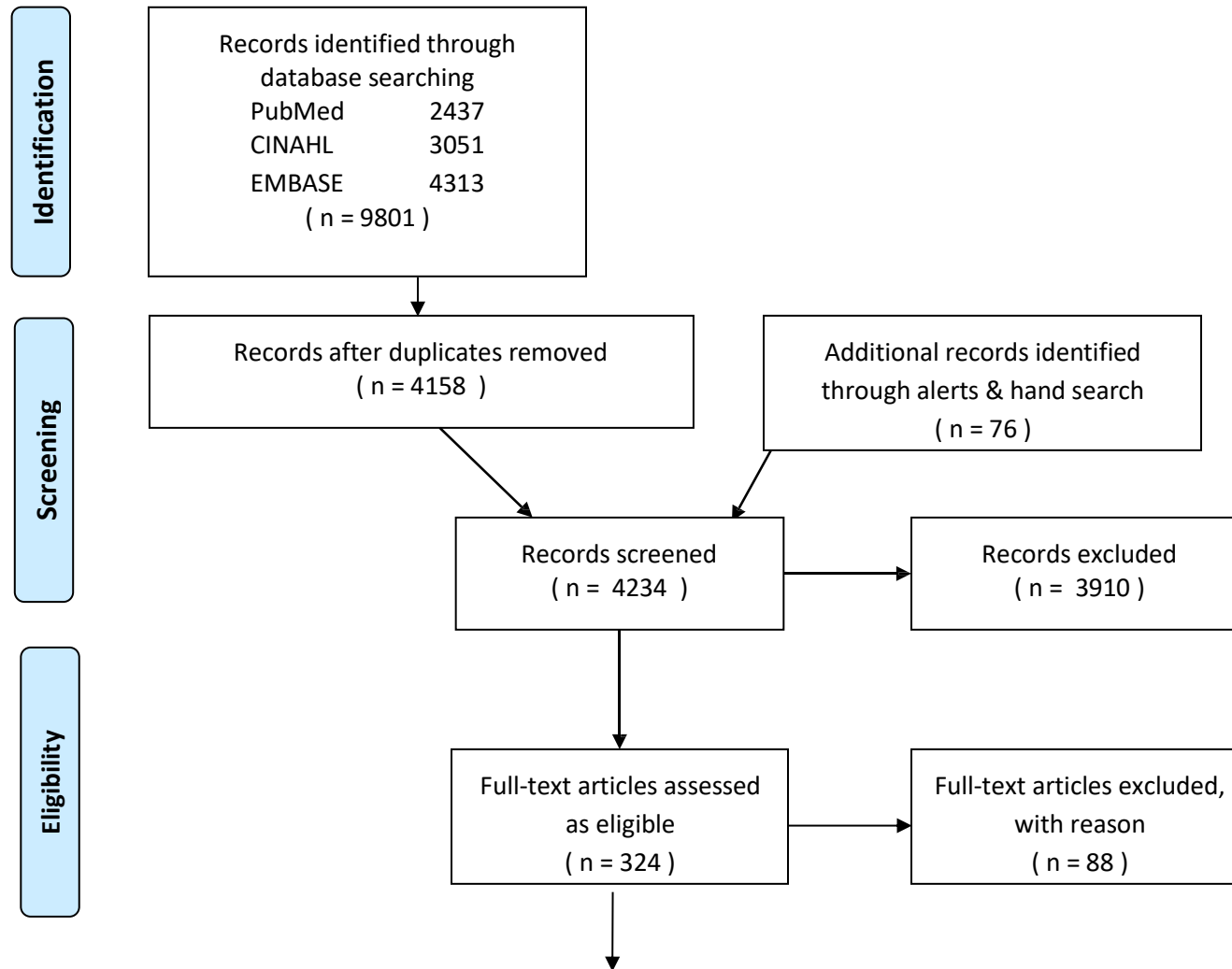
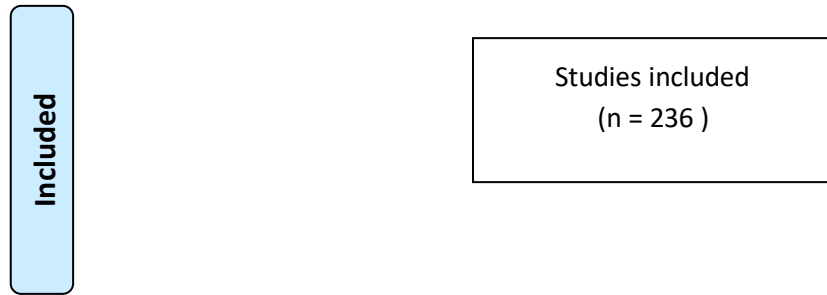


Figure 2: Prisma Flow Diagram for Systematic Review





Adapted from: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta- Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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