**Methods**

These guidelines were developed using the Council of Medical Specialty Societies (CMSS) Principles for the Development of Specialty Society Clinical Guidelines framework (1). 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 Society of Critical Care Medicine (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 Table 3** [Voting Results], Supplemental Digital Content 2, http://links.lww.com/CCM/C241). 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 Fig. 1**, Supplemental Digital Content 3, http://links.lww.com/CCM/C242]. We used this as a basis to determine the year to begin our literature search (1994- ). Qualitative filtering of English language texts was adapted from McMaster’s University Health Information Research Unit filters to identify non-experimental research (2, 3). We performed a PubMed MEDLINE search using this logic statement (see **Electronic Appendix C** [Complete search strategies], Supplemental Digital Content 4, http://links.lww.com/CCM/C243):

("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])

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 Table 1**, Supplemental Digital Content 2, http://links.lww.com/CCM/C241).

Former ICU patients and family members were recruited from the University of Maryland (UMD) 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 UMD (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 (J.D.) and validated for clarity by at least two guidelines writing group members. A committee member (G.N. or P.G.) 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 **Electronic Appendix A** (Supplemental Digital Content 4, http://links.lww.com/CCM/C243). 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 (4-15). We then had group members rate the relative importance of each outcome on a scale of extremely important (10) to not at all important (0). In addition, a sample of survivors and family members also rated the importance of these outcomes on the same scale producing similar results and supporting the rating results. These outcomes and their importance scores are shown in **Electronic Table 2** (Supplemental Digital Content 2, http://links.lww.com/CCM/C241).

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:

((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]))

See Electronic Appendix C (Supplemental Digital Content 4, http://links.lww.com/CCM/C243) 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 (4, 6, 7, 9, 10, 13-16). 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. TheCochraneCentral 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 Figure 2** (Supplemental Digital Content 3, http://links.lww.com/CCM/C242) describes the PRISMA Flow Diagram of study identification and inclusion.

*GRADE Process for Grading the Evidence*

GRADE assigns the strength of a recommendation based on the priority of a problem; balance of benefits and harms; certainty of the evidence of effect; values and preferences; equity; acceptability; and feasibility (17). 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 (**Electronic Appendix B**, Supplemental Digital Content 4, http://links.lww.com/CCM/C243). As with previous guidelines (18, 19), a GRADE grid was used to help reach decisions on recommendations when consensus was not achieved or conflict arose (20). 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 Table 3 (Supplemental Digital Content 2, http://links.lww.com/CCM/C241). 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.

References

1. Council of Medical Specialty Societies: Principles for the development of specialty society clinical guidelines. Chicago, CMSS, 2012

2. McMaster University: Health information research unit (HIRU) search filters for MEDLINE. <http://hiru.mcmaster.ca/hiru/HIRU_Hedges_MEDLINE_Strategies.aspx#Qualitative> Edition. 2003

3. Wilczynski NL, Marks S, Haynes RB: Search strategies for identifying qualitative studies in CINAHL. *Qual Health Res* 2007;17:705-710

4. McAlvin SS, Carew-Lyons A: Family presence during resuscitation and invasive procedures in pediatric critical care: A systematic review. *Am J Crit Care* 2014;23:477-485

5. Staniszewska S, Brett J, Redshaw M, et al: The POPPY study: Developing a model of family‐centred care for neonatal units. *Worldviews on Evidence-Based Nursing* 2012;9:243-255

6. Visser M, Deliens L, Houttekier D: Physician-related barriers to communication and patient and family-centred decision making towards the end of life in intensive care: A systematic review. *Crit Care* 2014;18:604

7. Ciufo D, Hader R, Holly C: A comprehensive systematic review of visitation models in adult critical care units within the context of patient- and family-centred care. *Int J Evid Based Healthc* 2011;9:362-387

8. Boudreaux ED, Francis JL, Loyacano T: Family presence during invasive procedures and resuscitations in the emergency department: A critical review and suggestions for future research. *Ann Emerg Med* 2002;40:193-205

9. Power N, Franck L: Parent participation in the care of hospitalized children: A systematic review. *J Adv Nurs* 2008;62:622-641

10. Clarke E, Curtis J, Luce J, et al: Quality indicators for end-of-life care in the intensive care unit. *Crit Care Med* 2003;31:2255-2262

11. Cleveland LM: Parenting in the neonatal intensive care unit. *J Obstet Gynecol Neonatal Nurs* 2008;37:666-691

12. Halm MA: Family presence during resuscitation: A critical review of the literature. *Am J Crit Care* 2005;14:494-511

13. Shields L, Zhou H, Pratt J, et al: Family-centred care for hospitalised children aged 0-12 years. *Cochrane Database of Systematic Reviews* 2012;DOI: 10.1002/14651858.CD004811.pub3.

14. Cypress BS: Family presence on rounds: A systematic review of literature. *Dimens Crit Care Nurs* 2012;31:53-64

15. Fawole OA, Dy SM, Wilson RF, et al: A systematic review of communication quality improvement interventions for patients with advanced and serious illness. *J Gen Intern Med* 2013;28:570-577

16. Aslakson R, Cheng J, Vollenweider D, et al: Evidence-based palliative care in the intensive care unit: A systematic review of interventions. *Journal of Palliative Medicine* 2014;17:219-235

17. Guyatt GH, Oxman AD, Kunz R, et al: Going from evidence to recommendations. *BMJ* 2008;336:1049-1051

18. Al-Mutair A, Plummer V, Clerehan R, et al: Needs and experiences of intensive care patients' families: A saudi qualitative study. *Nurs Crit Care* 2014;19:135-144

19. Boyles C, Langley R: The transfer of parents from picu to the ward. *Pediatric Critical Care Medicine* 2011;1):A64-A65

20. Jaeschke R, Guyatt GH, Dellinger P, et al: Use of GRADE grid to reach decisions on clinical practice guidelines when consensus is elusive. *BMJ* 2008;337:a744