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 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 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 (e.g: 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 2.1a 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 2.1b 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% |   |   |
| **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)?**  |
| Quality of Evidence  | Low Quality |   |   |
| Recommendation  | 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. |
| Strength of Recommendation  | Weak Recommendation  |
| Task Force Voting  | Agree  | Disagree  | Abstain  |
| Votes | 25 | 1 | 1 |
| Percentages  | 92% |   |   |
| **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)?**  |
| Quality of Evidence  | Very Low  |   |   |
| Recommendation  | 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. |
| Strength of Recommendation  | Weak Recommendation  |
| Task Force Voting  | Agree  | Disagree  | Abstain  |
| Votes | 27 |   | 1 |
| Percentages  | 100% |   |   |
| **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)?**  |
| 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 1.5b 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 1.5c 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 1.5d 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 5.2b 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) |
| 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% |   |   |

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

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| --- |
| “Family-centered care” |
| **Domain** | **Definitions** |
| Definition by tenets  | “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 |
| “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  |
| Care involving patient preferences and goals | “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 |
| Care involving compassion, empathy, and the whole patient |  “Patient-centered encompasses qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient.” 25 |
| Care respectful of cultural competence | “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 |
| Care that treats the patient and family | “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 |
| “[Family centered care] is an approach to health care in which: providers recognize the importance that families paly in ensuring the health and well-being 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 |
| Care that is a partnership between providers and patients and families | Collaboration between providers and families and patients in the planning, delivery and evaluation of care- family-centered care and patient andfamily-centered care “more explicitly capture the importance of engaging the family and the patient in a developmentally supportive manner as essential members of the health care team.” |

Electronic 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. *Derived from 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. *Derived from 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. *Derived from 23*  |

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  | Inter-personal 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  |

Electronic Table 7: 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 | * 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 Communication7.67 | * 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 Clinicians7.66 | * Routine interdisciplinary family conferences be used in the ICU. (Rec 2.1)
 |
| Family Satisfaction with Care7.33 | * 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 Communication7.33 | * 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-Efficacy6.93 | * 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 Conflict6.70 | * Routine interdisciplinary family conferences be used in the ICU. (Rec 2.1)
* 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 Dying6.30 | * 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 | * 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 | * ICU clinicians receive family-centered communication training as one element of a critical care training program. (Rec 2.3)
 |