Family-Centered Care; A Caring Competency

Judy E. Davidson DNP RN FCCM FAAN
AKI CRRT Conference  jdavidson@ucsd.edu
March 8, 2017 Manchester Grand Hyatt, San Diego
Disclosures

• I have no financial disclosures
• I would like to disclose that I enjoy hand quilting and hiking with my dog
• I have quilted on every continent (not with my dog)
Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU

Judy E. Davidson, DNP, RN, FCCM, FAAN¹; Rebecca A. Aslakson, MD, PhD, FAAHPM²,³; Ann C. Long, MD, MS⁴; Kathleen A. Puntillo, PhD, RN, FAAN, FCCM⁵; Erin K. Kross, MD⁴; Joanna Hart, MD, MS⁷; Christopher E. Cox, MD, MPH⁸; Hannah Wunsch, MD, MSc⁹; Mary A. Wickline, MLIS, MEd¹⁰; Mark E. Nunnally, MD, FCCM¹¹,¹²; Giora Netzer, MD, MSCE¹³; Nancy Kentish-Barnes, PhD¹⁴; Charles L. Sprung, MD, MCCM, JD¹⁵; Christiane S. Hartog, MD¹⁶; Maureen Coombs, PhD, RN¹⁷; Rik T. Gerritsen, MD, FCCM¹⁸; Ramona O. Hopkins, PhD¹⁹,²⁰; Linda S. Franck, PhD, RN, FRCPCH, FAAN²¹; Yoanna Skrobik, MD, FRCP(c)²²; Alexander A. Kon, MD, FCCM²³; Elizabeth A. Scruth, PhD, MPH, RN, CCRN, CCNS, FCCM²⁴; Maurene A. Harvey, MPH, MCCM²⁵; Mithya Lewis-Newby, MD, MPH²⁶; Douglas B. White, MD, MAS²⁷; Sandra M. Swoboda, MS, RN, FCCM²⁸; Colin R. Cooke, MD, MS²⁹; Mitchell M. Levy, MD, MCCM, FCCM³⁰; Elie Azoulay, MD, PhD¹³; J. Randall Curtis, MD, MPH⁴
Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005

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Objective: To develop clinical practice guidelines for the support of the patient and family in the adult, pediatric, or neonatal patient-centered ICU.

Participants: A multidisciplinary task force of experts in critical care practice was convened from the membership of the

Conclusions: More than 300 related studies were reviewed. However, the level of evidence in most cases is at Cochrane level 4 or 5, indicating the need for further research. Forty-three recommendations are presented that include, but are not limited to, endorsement of a shared decision making model, early and
Definitions

- *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.
Current Endorsements

- Institute for Patient- and Family-Centered Care
- European Society of Intensive Care Medicine
- American Association of Critical-Care Nurses
- American College of Chest Physicians
- Society of Critical Care Medicine
- British Association of Critical Care Nurses
- The Pediatric Cardiac Intensive Care Society
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Family Presence (not visiting, as the family wishes)

- At the bedside
  - open or flexible

- On rounds

- During resuscitation
  - w/trained staff member
Communication

• Routine family conferences

• Structured approaches
  – Messages of hope, caring, non-abandonment
  – Example: VALUE method of conferencing
    • V  Value family contributions to discussion
    • A  Acknowledge family emotions
    • L  Listen
    • U  Understand the patient as a human
    • E  Elicit questions from the family

• Communication training
  (for clinicians)
Team

• Spiritual support is offered

• Palliative care consultation
  – for selected populations (e.g., advanced dementia, cerebral ischemia after CPR, prolonged ICU stay, SAH requiring mechanical ventilation)
Caring Competency

• Everything you have heard so far has been a recommendation for 10 years

• Time to move these items into competencies

• Accountable to encourage:
  – Family presence: (not visiting)
  – Family communication: rounds, conferences

• Consider simulation check-offs
  – Competency in caring communication during conferences
  – How to include family presence at resusc
  – How to include family in rounds
New Recommendations

- If you are not doing these already:
  - Select high priority and begin action planning
  - Tools available to help you (end of slide deck)
Family Support

- Provide families with informational leaflets
- Provide family education programs
- Implement ICU diaries
Family support

• Use validated decision-support tools

• Use structured communication approaches
  – (“VALUE” or Spikes)
  – particularly for poor prognosis patients
Family support

In neonatal ICU’s

• Parents taught to assist w/care*

• Implement peer-to-peer support*

• *emerging data in adults.....
Other teams to involve

- Ethics consultants
  - value-related conflict

- Psychologists
  - provide CBT for NICU moms

- Social workers
  - family meetings

- Navigators
Operational/environment

- Nurses be involved in decision-making about goals of care
- Clinicians trained in communication
- Implement sedation/analgesia protocols
Operational/environment

- Hospital FCC policies

- Noise
  - Noise reduction protocols
  - Private rooms

- Sleep
  - Provide family sleep surfaces
  - Consider family sleep
• How should your local ICU go about changing your current practices to reflect the guideline?
How do you organize an approach to FCC? Through Facilitated Sensemaking

• Facilitated Sensemaking
  – Model of family engagement
  – Derived from the same lit review as guidelines

• Help families make sense out of
  – New role as caregiver
  – What they are going through

• Taking action in crisis may be brain protective
  • Preserve mental health
  • Decrease Post-Intensive Care Syndrome-Family
Facilitated Sensemaking

Exposure to Critical Illness → Adaptation → Consequences

- Make sense out of what happened
  - Caring Relationships
  - Communication
- Make sense out of new role
  - Presence
  - Decision-Making
SCCM FCC Gap Analysis Tool

• A free tool that evaluates your practice against recommended practice

• Creates a priority list for change

• Assess barriers to change

• Develop an feasible organization-specific bundle to enhance FCC in your ICU
How to find the gap analysis tool

- sccm.org
How to find the gap analysis tool

Guidelines
Guidelines are developed in an effort to help ensure consistent, evidence-based care of critical care patients using the most up-to-date and relevant knowledge available. Access guidelines in a variety of ways.

Guideline Proposal Form
Members of the creative community are encouraged to submit suggested topics for potential future guidelines. Submitted topic proposals will be reviewed by the American College of Critical Care Medicine.
How to find the gap analysis tool

Clinical
Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU
Crit Care Med. 2017;45(1):103-128
Evidence-based strategies to optimize the support of the family of critically ill patients in the ICU.

Gap Analysis Tool - Identification of Your ICU's Practice Differences
Family-Centered Care Guidelines - Gap Analysis Tool Instructional Video
Family-Centered Care Guidelines - Implementation Tools

Download the .zip file and open the Excel spreadsheet inside
Watch this YouTube video to learn how to use the tool
# Step 1: Gap Analysis Questions

<table>
<thead>
<tr>
<th>Item</th>
<th>Recommendation</th>
<th>Outcome Points</th>
<th>Frequency</th>
<th>Item Score</th>
<th>Item Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category 1: Family Presence</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Family members of patients are offered open, flexible presence at the bedside.</td>
<td>3</td>
<td>Nearly Always</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>2</td>
<td>Family members of patients are offered the option of participating in interdisciplinary team rounds.</td>
<td>3</td>
<td>Nearly Never</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>Family members of patients are offered the option of being present during resuscitation efforts, with a staff member assigned to support the family.</td>
<td>5</td>
<td>Sometimes</td>
<td>25</td>
<td>4</td>
</tr>
<tr>
<td><strong>Category 2: Family Support</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Family members of critically ill neonates are offered the option to learn how to assist with the care of their loved ones.</td>
<td>5</td>
<td>N/A</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>5</td>
<td>Family education programs are included as part of clinical care.</td>
<td>5</td>
<td>Nearly Never</td>
<td>50</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>Peer-to-peer support in the neonatal ICU has been implemented.</td>
<td>5</td>
<td>Nearly Always, Usually, Sometimes</td>
<td>25</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>Family members are provided information leaflets about the ICU setting.</td>
<td>5</td>
<td>Nearly Never</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
### Step 2: Prioritization Matrix

<table>
<thead>
<tr>
<th>Item Rank</th>
<th>Item Score</th>
<th>Recommendations that are in potential need for attention, prioritized by Item Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>50</td>
<td>Family education programs are included as part of clinical care.</td>
</tr>
<tr>
<td>2</td>
<td>40</td>
<td>Validated decision support tools for family members are used when relevant validated tools exist.</td>
</tr>
<tr>
<td>3</td>
<td>30</td>
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- **Questions for planning:**
  - How does *your* ICU differ from each recommendation?
  - What are the **barriers to implementing** the guideline recommendation?
  - Re-rank the recommendations in order of *your* priority
Addressing your gaps

• Awareness of resources that already exist is key for efficient implementation

• FCC guidelines appendix has 9-page “work tools” list to help implement ICU change

• Resources for each recommendation in all 5 domains listed with weblinks for easy access
How to find the work tools list

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

• Active weblink in the guideline .pdf (page 120)
• Also available via sccm.org/guidelines
All guideline tools listed as part of ABCDE “F” ICU Liberation bundle
Questions?