

Electronic Appendix D: Work Tools

SCCM Family-Centered Care Guidelines Supplement: Work 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 in the ICU

- Family members of critically ill patients be offered open or flexible family presence at the bedside that meets their needs while providing support for staff and positive reinforcement for staff to work in partnership with families to improve family satisfaction.

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 increase 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 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. [Additional apps to facilitate communication with mechanically ventilated adults are provided below.]

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
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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

- 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.

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 framework for a clinical nurse specialist 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 in NICUs to improve family satisfaction, reduce parental stress, and reduce depression. [It is not known how effective peer-to-peer support is in the adult population, but additional relevant 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/
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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

- ICUs provide family with leaflets that give information about the ICU setting to reduce family member anxiety and stress.

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 to reduce family member anxiety, depression, and post-traumatic stress.

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/

- 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.

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

- 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, during family conferences to facilitate clinician-family communication.

“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/
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Category 3: Communication with Family Members

- Routine interdisciplinary family conferences be used in the ICU to improve family satisfaction with communication and trust in clinicians and to reduce conflict between clinicians and family members.

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

- Healthcare clinicians in the ICU should use structured approaches to communication, such as that included in the “VALUE” mnemonic, when engaging in communication with family members, specifically including active listening, expressions of empathy, and making supportive statements around nonabandonment and decision making. In addition, we suggest that family members of critically ill patients who are dying be offered a written bereavement brochure to reduce family anxiety, depression, and post-traumatic stress and improve family satisfaction with communication.

<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>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

- ICU clinicians receive family-centered communication training as one element of critical care training to improve clinician self-efficacy and family satisfaction.

<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
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: Use of Specific Consultations and ICU Team Members

- 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).

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 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.

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 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.

Behavioral Interventions for Mothers of Pre-Term Babies	A manualized 6-session treatment based on trauma-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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- Social workers be included within an interdisciplinary team to participate in family meetings in order to improve family satisfaction.
- 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.

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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- 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.

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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- 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.

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
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- 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

- 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.

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

- Family sleep be considered and families are provided a sleep surface to reduce the effects of sleep deprivation.

