

Implementing Family-Centered Care Through Facilitated Sensemaking

Judy E. Davidson, RN, DNP
Sidney Zisook, MD

ABSTRACT

The Society of Critical Care Medicine has released updated recommendations for care of the family in neonatal, pediatric, and adult intensive care units. Translation of the recommendations into practice may benefit from a supporting theoretical framework. Facilitated sensemaking is a mid-range theory built from the same literature that formed the basis for recommendations within the guidelines. The process of facilitated sensemaking may be used to help

nurses adopt the SCCM recommendations into practice through the development of caring relationships, promoting family presence, teaching family engagement strategies, and supporting families with communication, information gathering, and participation in decision-making.

Keywords: Post-intensive care syndrome, family, intensive care, family-centered care theory

Theoretical frameworks are often used to guide a process for project development.¹ When new guidelines are released, an analysis of current state versus desired state is conducted, and an action plan is developed to make the indicated changes.^{2,3} *Facilitated sensemaking* is a mid-range theory for nursing that provides prescriptive advice on how to care for the families of intensive care unit (ICU) patients during the ICU stay.^{4,5} Facilitated sensemaking previously has been tested for feasibility⁵ and shown to decrease state anxiety in a cohort of family members of hospitalized cardiac surgery patients.⁶ The purpose of this article is to inform readers about how the process of facilitated sensemaking can be used to guide translation of the guideline recommendations for family-centered care (FCC) into practice.

The Society of Critical Care Medicine (SCCM) released FCC guidelines in 2007,⁷ and these original guidelines recently have been updated by an interdisciplinary and international panel of content experts and published.⁸ The guidelines were developed using the qualitative and quantitative

literature dating back to 1994, with the goal of serving ICU patients' family members of all ages. They guidelines are structured around answering questions constructed in the PICO format: population, intervention, comparison, outcome.⁹ The questions seek to determine if "x versus y improves z," where x is an intervention specific to family-centered care, y is current practice, and z is an important measurable outcome. Evidence is gathered from studies that tested the intervention and measured the predetermined important outcomes within the PICO framework. During the FCC guidelines development, both family members and the guidelines writing team selected

Judy E. Davidson is Evidence-based Practice/Research Nurse Liaison, University of California, San Diego Health, 200 W Arbor Drive, San Diego, California 92103 (j davidson@ucsd.edu).

Sidney Zisook is Distinguished Professor, Department of Psychiatry, University of California, San Diego, and San Diego Veteran's Administration Health Care System, San Diego, California.

DOI: <https://doi.org/10.4037/aacnacc2017XXX>



Figure 1: Derived from Roy's adaptation model.¹²

post-intensive care syndrome-family as the most important outcome to be addressed in FCC. *Post-intensive care syndrome* (PICS) is defined as a cluster of symptoms that generate from exposure to critical illness and last after the hospital stay.⁸ When these symptoms affect family members, the term *Post-intensive care syndrome-family* (PICS-F) is used.¹⁰ PICS-F includes mental health, physical, cognitive, and societal outcomes (eg, anxiety, depression, posttraumatic stress, decreased physical function); caregiver burden; decreased decision-making capacity role; marital and financial strain; and decreased quality of life.¹¹

The interventions advocated in facilitated sensemaking were formed from the same literature as the guidelines; they are congruent in message and philosophy. The desired outcomes from facilitated sensemaking include reduction in PICS and PICS-F. Given that these outcomes are also the highest-ranked outcomes listed within the SCCM guidelines,⁸ facilitated sensemaking is an appropriate theoretical framework to guide clinical or research efforts targeted to optimize FCC.

Origins of Facilitated Sensemaking

Facilitated sensemaking was derived deductively from both Sister Callista Roy's Adaptation Model, which represents a grand theory in nursing,¹² and Karl Weick's business theory on organizational sensemaking.¹³ The focus of Roy's adaptation model is related to how people respond to health issues. During illness, people need to adapt to the situation using coping mechanisms that result in either adaptive or maladaptive coping. Adaptive or maladaptive coping results further in positive or negative outcomes and consequences (Figure 1).

Weick instructs us that, as humans, we define ourselves by the actions we take in crisis. To optimally adapt to crisis, at least 2 critical tasks are required to (1) make sense of the situation and (2) make sense of our new role.¹³ Facilitated sensemaking proposes that we combine those 2 tasks. When families are exposed to the crisis of critical illness, they

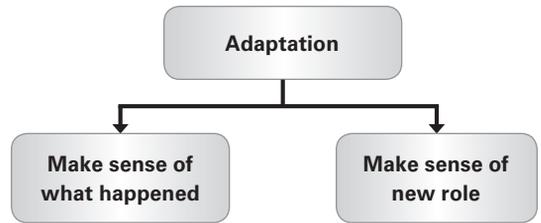


Figure 2: Derived from Weick's organizational sensemaking.¹³

need to adapt to the situation by making sense of what has happened as well as making sense of what to do in their new role as caregiver of a critically ill patient (Figure 2). It is assumed that being exposed to critical illness is a crisis not only for patients but also for their families. Further, families want to be nearby during the crisis and may feel the need to serve or safeguard their loved one. Finally, families are different from one another and will need individually tailored approaches to help them through the crisis.^{4,5} It is within the role of clinicians to care for the family and support them through their adaptation process with the goal of minimizing adverse family outcomes. By serving the family, clinicians may be in a better position to support the patient with caregiving needs in the ICU as well as across the continuum of care. Family support and engagement may result in improved patient outcomes.^{7,8}

ICU Family Stress and Mental Health Implications

Like other severe stressors, ICU family stress can trigger a broad spectrum of stress-related conditions, including but not limited to anxiety and mood disturbances, sleep problems, aggression, substance abuse, and many other physical and psychological symptoms.¹⁴ When the stressor is actual or threatened death or serious injury to oneself or a loved one, as is often the case in ICU patients and families, posttraumatic stress disorder (PTSD) may result.¹⁵ Historically, risk of PTSD among ICU patients and their families has been underappreciated, but a recent review found that clinically important posttraumatic stress disorder symptoms occurred in one-fifth of critical illness survivors at 1-year follow-up,¹⁶ and family members of ICU patients also are at risk for mental health morbidity, including PTSD, both during and after the ICU stay.^{17,18}

PTSD is a serious, devastating psychiatric illness that develops in the aftermath of exposure to a traumatic event, usually involving intense fear, horror, and helplessness. Once present, PTSD tends to be persistent and chronic, and is associated with a markedly diminished quality of life as well as devastating emotional suffering in patients and their families. PTSD is not simply a psychological reaction to trauma, but rather it is associated with a host of biological perturbations. These include a multitude of disturbances in the way the brain customarily adapts to stress: (1) disturbances of the endocrine system, including dysregulation of the hypothalamic-pituitary-adrenal and hypothalamic-pituitary-thyroid axes; (2) the neurochemical system, including increases in dopamine, epinephrine, glutamate, and β -endorphins, as well as decreases in serotonin, plasma neuropeptide Y, and GABA activity; and (3) dysregulation in the circuitry of the hippocampus-amygdala-prefrontal cortex network, brain regions known to regulate fear behavior.^{19,20}

Whereas much research is needed to develop effective strategies to decrease vulnerability to PTSD and other stress-related disorders,²¹ interventions aimed at attenuating the immediate fear, horror, and helplessness experienced by people witnessing life-threatening events would have salutatory effects.²² As the following paragraphs demonstrate, facilitated sensemaking is aimed at reducing these risks of stress disorders for ICU family members.

Facilitated Sensemaking Interventions

Practice guidelines review the literature and inform us which interventions are recommended for a health condition. Mid-range theories specifically instruct nurses on how to provide this care. The interventions for facilitated sensemaking fall into 4 categories: (1) developing caring relationships, (2) communication, (3) presence and engagement, and (4) decision-making. A crosswalk of the facilitated sensemaking interventions against the SCCM guideline recommendations is presented in the Table.

Developing Caring Relationships

Caring relationships between the family and the clinician are necessary for trust to

form and to help the clinician understand the family's unique personal situation. By entering into the family's suffering through authentic presence and seeking to understand their experience, clinicians gain insight into the family's needs. Demonstrating caring while providing care is essential for trust and relationship building. Adding an element of caring touch, using a caring voice, and asking about the patient as a person are all behaviors that role model caring. Families will know it is acceptable to touch the patient when they witness the clinician or nurse touching the patient first.⁶ They will come to know that speaking to a semi-conscious or unconscious patient as if the patient were listening to every word is acceptable when they witness the clinician or nurse addressing the patient respectfully while providing care. When a clinician asks about the patient's likes and dislikes so they can carry on a meaningful conversation, it shows the family that the clinician truly cares and is not just providing obligatory care.

Caring relationships are also built with empathic listening. Allowing families to talk while authentically listening will build trust. As trust builds, the families may bring up areas of concern and unmet needs that can be addressed proactively. Through this discussion, values, preferences, and goals may be assessed. In this manner, nurses might gain the information needed to advocate when patient or family goals do not align with the current treatment plan. During this phase of relationship building, it is especially important to respect the family's input and to acknowledge them when they provide feedback that is helpful for providing optimal care. By providing verbal affirmation of the importance of the family's contributions, nurses facilitate the transition from family as visitors to family as members of the patient's care team.

Families naturally focus on the hemodynamic and electrocardiogram numbers on the monitor. It is important to inform them that it is normal and that it is actually good for the numbers to fluctuate. Consider the following simplistic messaging when working with the family at the bedside or teaching new nurses family-centered care:

You will notice that the numbers change constantly. The reason the numbers on the monitor change is because the different parts of the body are responding to changes in the other.

Table: Crosswalk Between Facilitated Sensemaking Interventions and the SCCM's FCC Recommendations

SCCM FCC Guideline Recommendation Topics

	Presence	Family Support	Family Communication	Consults	Organizational/Environment
	Open flexible visiting rounds and resuscitation	Families taught to assist in care Peer-to-peer for parents of infants Diaries Decision support tools Information leaflets Structured conferences	Clinician communication training Routine conferences Families of dying patients receive conferences and information booklet	Palliative care Ethics Psychologist Social worker Family navigator Spiritual	Protocols for withdrawal of life support Nurses involved in decision-making Nurses trained to support families FCC policies and programs Noise reduction, environmental hygiene, private rooms Family sleep considered, sleep space provided
Facilitated sensemaking interventions				X	
Relationships	Role model authentic caring behaviors Empathic listening Assess values, goals, preferences Advocate for consultations, advocate when goals/plans do not align with patient/family values Respect family's input				
Communication	Decode environment Review met/unmet needs Reflective inquiry/end of visit clarifications Diaries Provide educational materials	X	X		
Presence	Welcome family presence Assess desire to participate Teach bedside participation Individualize coach role to treatment plan Offer respite/suggest rotations				
Decision-making	Assess desired participation in decision-making Facilitate participation in rounds Facilitate daily communication with physician Reinforce role in surrogate decision-making Clarify treatment plan/goals Facilitate family conferences		X		X

Abbreviations: SCCM, Society of Critical Care Medicine; FCC, family-centered care.

These changes are signals of compensation. If the numbers never changed, in most cases we would worry because it would mean that the body systems are not speaking to each other.

The messaging to the family would be tailored to different situations, such as the respiratory rate being controlled by a ventilator or the heart rate being controlled by a pacemaker. Further, while performing routine patient care, the nurse can explain the most important number on the monitor today. For instance, imagine that the most important number is the oxygen saturation. The nurse could inform the family of the patient's saturation goal and what will happen if the goal is met or not met (eg, changes in mechanical ventilation settings).

Providing context and direction can give family members purpose in crisis and a sense of what they can do in their new role as caregivers of an ICU patient. Just as physicians, nurses, and nursing assistants each have their own scope of practice, the nurse can teach family-appropriate role expectations. For example, if oxygen saturation is low, the nurse can teach the family to do things that normally would calm the patient. The family can be taught that anxiety increases the workload of the body and consumes precious oxygen, and they can be encouraged to try approaches that the patient would find calming. Examples include playing soothing music, reading a book aloud, massaging the patient's hands, or reciting prayers. In addition, because anxiety can be transmitted between humans,^{23,24} if a family member feels anxious, the patient and family member both might benefit from the family member taking a break.

All of these nuances about how and why to help need to be verbalized. Because the family is under stress, and because different family members may rotate in, the instruction may need to be repeated. With experience, nurses become comfortable providing care while teaching care, and the process requires little or no extra time.^{4,5}

Communication

Decode Environment. Communication and information sharing opportunities exist in many ways beyond the initial relationship building. First, nurses are responsible for helping the families with cue-sorting in the

environment. Weick explains that organizational leaders provide employees with an analysis of which cues are important in the environment and what they mean relative to the status of the company and the organization-employee relationship.¹³ In facilitated sensemaking, this same leadership strategy is translated into the intensive care environment by clinicians helping families to understand the meaning of environmental cues. The nurse may start cue-sorting by explaining each piece of equipment, the values on the monitor, and the relative importance of the alarms. Just as new ICU nurses need to learn about prioritization of alarms, family members need to be made aware of the same priorities so that if the nurse does not respond immediately to an alarm, the lack of action does not generate fear. In normal circumstances, a needs assessment would be performed to determine appropriate elements of family education. In the ICU, nearly all families will be distressed by the sound of alarms if the concern is not proactively addressed. In the feasibility testing of the facilitated sensemaking model, the following analogy was found to be helpful when it was provided for direct use with families or when teaching novice nurses about performing family-centered care:

Think about the alarm on the clothes dryer, the alarm on the stove when a casserole is done, and the smoke alarm. If you don't come right away at the sound of the clothes dryer alarm, the clothes may get a little wrinkled, but they can definitely wait. The casserole will be perfectly edible 1 to 2 minutes on either side of the stove's alarm. However, the smoke alarm needs to be tended to immediately. The nurses know the difference between all of these alarms and come to tend to them based on the relative urgency of the situation. The alarms are visible at the nursing station, so even if no one is in the room, a nurse will respond.

With this analogy, family members visibly relaxed, their clenched fists opened, and their jaws and shoulders softened.^{5,6}

Review Unmet Needs. For nearly 30 years, family needs have been studied through the use of Molter and Leske's CCFNI (Critical Care Family Needs Inventory).²⁵⁻²⁹ In the feasibility testing of facilitated sensemaking, this list of common family needs was shown to families who were then asked, "Is there

anything on this list that would help you?" This simple intervention was useful in finding unmet needs that otherwise would not have come to light. Families do not realize without guidance what resources are available. For instance, in a faith-based organization where there was a very large statue of Jesus in the lobby, a family member didn't realize that there was a chapel in the building (even though visitors had to pass it to get to the ICU) or chaplains available for spiritual counseling.⁵ Since the early 1990s, it has been recognized that physicians and nurses do not reliably predict the needs of families.³⁰⁻³³ Therefore, bidirectional communication is necessary to optimize the likelihood of meeting the unique needs of each family. The conversation with clinicians and families about their needs also produces the necessary information to advocate for referrals to other disciplines as needed.

Reflective Inquiry. Left to their own devices families may construct a false narrative of events in the ICU. As Weick has described in business, organizational leaders need to explain to employees what is happening in the business through strategic corporate messaging.¹³ Likewise, nurses can prevent and correct "mythical realities" that families might create when they do not understand the business of health care.

One way to stay abreast of these false assumptions or misconceptions is for nurses to engage in reflective inquiry with the family at the end of a visit or the end of the nurse's shift. The following question was found to be helpful in this regard: "If you were going to tell the rest of your family the most important thing that happened in your [husband's, brother's, mother's, daughter's] care today, what would it be?"⁵ An open-ended question will often bring to light distortions and mistruths that the nurse would not otherwise know existed. When this exchange happens on a daily basis, the falsehood does not have time to embed itself in the brain as fact, preventing unnecessary fear or horror as well as the stress disorders that might result from fear or horror.³⁴

Additionally, at the end of a visit or at the end of the nurse's shift, the nurse should take a moment to thank family members for their contribution to care. Simple messages such as, "I'm sure your presence helped to calm your husband today" or "It was good

that you were here for rounds to inform the doctor of how your dad responded to pain medicine the last time he had to take it" make family members feel they are part of the team and that they have a meaningful role in this family crisis.

Diaries. Diaries were added to the options for facilitating sensemaking interventions in the revision of the theoretical model.¹¹ Although diaries have been common in the Netherlands for more than 20 years,³⁵⁻⁴⁰ are well-received by families, found helpful for decreasing stress-related conditions and depression in both patients and families,³⁹⁻⁴¹ they have had poor uptake in the United States. Families and clinicians can make entries into the diaries, which are used to convey caring and should not be a duplicate of the medical record. The diary also supports the family in constructing a factual narrative of the ICU that can later be used to debrief patients who may have lapses in memory due to sedation or disease condition.³⁵ Use of diaries is specifically recommended in the updated SCCM guidelines for FCC as a helpful form of caring communication.⁸

Patient/Family Education Materials. Educational materials help support the sensemaking process by providing concrete audio or visual supplements to verbal explanations. Leaflets, flyers, brochures, videos, or web materials can be reviewed at the patient's convenience and shared with the rest of the family. In studies on providing educational materials to families in the ICU, interventions with the greatest benefit combine written materials with verbal instructions.⁴²⁻⁴⁵ It is more helpful to review and discuss a brochure with family members than to passively hand the brochure to them.

Family Presence and Engagement

Welcome Family Presence. For sensemaking to occur, and for families to develop a sense of their new roles, they need to be present. Nurses set the stage for welcoming family presence in the ICU. Nurse leaders are accountable for changing rule-based policies to "presence philosophies." Though safety needs to be considered, locks on the ICU doors should be removed, as they physically communicate that the ICU is a closed, controlled space. Forbidden spaces restricted to health-care personnel need to be readdressed and eliminated whenever possible base on

regulations or accreditation standards while maintaining staff safety. Only when the environment conveys a message of shared space will family members feel they belong. Environments are often challenged by outdated or cramped space. Even newly built environments can thwart FCC efforts. For example, if family members were told they have open, flexible visiting rights but there are no sleep accommodations, would they really feel welcome? If the sleep surface is not comfortable, do family members feel that hospital staff want them there? Flexible family visitation has been advocated by the American Academy of Pediatrics,^{46,47} supported by the American Association of Critical-Care Nurses (AACN),⁴⁸ and explicitly recommended since the first FCC SCCM guideline.^{7,46} Even if the policy has been written to reflect this philosophy, nurses do not always adhere to the standard. When family members call the ICU to ask about visiting hours, they should receive an answer consistent with the recommendations: that presence is encouraged. Naturally, with open, flexible presence, things like noise, multiple people visiting at one time, and rest periods will need to be proactively managed. Whereas there is no evidence in the literature that flexible visiting causes harm, there is also no evidence in the literature about how best to manage noise or an excessive number of visitors. Nursing judgment is needed until best practices are identified.

Assess Desire to Participate. During family presence, it is important to assess the family's desire to participate in care. Family members may have different levels of desire to engage in care. There is no one assessment tool advocated for this purpose; however, the Family Preferences Index Tool may be helpful.⁴⁹ This short assessment is not intended to cover every aspect of possible engagement but can open a dialogue between the nurse and the family so families understand the possibilities. Preference for engagement in care may shift over time as families become more comfortable in the ICU environment. When considering which activities a family member might participate in, as is common with surrogate decision-making, ask the family if they think the patient would want a specific family member to help with a specific activity. If the patient's wishes are not known and the patient cannot be interviewed, consider

whether this family member should be the one to assist with this activity after discharge. For privacy concerns, one strategy might be to restrict care activity that would physically expose the patient to only those who will serve as direct care providers following discharge.

Teach Bedside Care Activities. Family participation in care can include simple activities such as applying lip balm to an intubated patient or performing passive or active range of motion activities after instruction. For conscious patients, cognitive activities such as card games, word searches, or dominoes are recommended. These activities can start with just searching for a letter instead of a word, pointing to the domino with the highest points, or singling out a card displayed on the bedside table if the patient is not alert or strong enough to play an actual game. Nurses are advised to explain to families that activities such as these may help the patient maintain or regain brain strength after sedation, coma, or delirium.^{4,50} When these activities are described as cognitive or brain-strengthening, the family receives the message that they are actively involved in an important aspect of the treatment plan. Including families in care when they wish to be included not only helps give purpose in crisis but also helps for transition out of the ICU.

As many as half of ICU survivors will require care after hospital discharge.²² Much of this care is provided by family members who report that they are not prepared for this role. Even if the nurse does not include the family member in turning or lifting, family member can be encouraged to be present to witness these procedures while the nurse explains how they are performed. At discharge, families often asked to perform such duties as making an occupied bed, lifting the weakened patient up in bed, or transferring the patient from bed to chair without having been instructed how to do so properly.

Individualize Coach Role. Family members are in a unique position to serve as coaches to the patient for more complex activities such as participating in mobility goals, weaning trials, or incentive spirometry exercises following extubation. Once the goals for the day are determined, the family can provide encouragement and support to help the patient achieve these goals. At this

point, the nurse may actually say, “While you are here, it would help us if you could serve as your husband’s coach. Our goals are to ———. Together, we will try to reach these goals today.”

Offer Respite and Encourage Rotations. Whereas presence in the ICU is encouraged, families also need rest. Just as employees need to take breaks during the day and have time off from work, families need to refuel to maintain resiliency and strength. However, some families will feel the need to safeguard the patient and sit vigil. Although no studies support how best to deal with the safeguard instinct, anecdotal evidence suggests forcibly separating families from patients whom they feel they need to safeguard can cause harm.^{51,52} Through facilitated sensemaking, trusting relationships may develop more quickly, perhaps making the instinct to safeguard pass more quickly. Once the family’s perceived need to protect the patient from the health care environment dissipates, the family will feel more comfortable taking a respite because they have faith that competent and compassionate care will continue in their absence. Another option is to create family rotations so that one family member is present while others rest.

Participation in Decision-Making

The SCCM and American Thoracic Society produced a joint document encouraging the use of shared decision-making with families of ICU patients. Most but not all family members desire shared decision-making; therefore, desire to participate in shared decision-making should be assessed.^{53,54} Though this assessment is primarily a provider responsibility, the details of the conversations that nurses have with families may help with this assessment. Nurses advocate on behalf of families when they recognize that the family’s preferred level of involvement has not been met.

Family Role in Surrogate Decision-Making. Nurses also play a part in reinforcing the appropriate role of the surrogate decision-maker. Such support is important from a mental health perspective. The burden of making decisions on the patient’s behalf cannot be overstated. Nurses can reinforce that the surrogate’s role is to inform the physician of the decision the patient would have made if he or she were able to speak, not

the decision that the family member is making for the patient. This distinction may help to decrease decision regret, rumination, and subsequent stress disorders.⁵³⁻⁵⁵

Participation in Rounds. Ninety-five percent of families, when asked, would appreciate being present at rounds; families value patient privacy less than the need for information.⁵⁷ Family presence at rounds is generally the role of the surrogate decision-maker. According to HIPAA (Health Insurance Portability and Accountability Act), family presence is permissible for anyone who can help contribute information in the best interest of the patient.⁵⁷ Further, family presence offers another opportunity for families to have purpose in crisis. They can be encouraged to report untoward response to proposed treatments or offer information about the patient’s medical history that the team is not aware of. Families can be encouraged to create a written list of questions in advance. The nurse can review these prior to rounds and address those that are within scope of practice and leaving the patient’s prognosis, new diagnoses, or new laboratory results for the physician to explain.

When families are present at rounds, the nurse can first model inclusion by inviting the family member to stand next to the nurse. The nurse may mediate the active inclusion of the family in rounds by advocating for the family member to ask any questions prior to the conclusion of rounds. A typical nurse advocacy behavior in cases in which the family member has not had the opportunity to speak would be to ask with direct eye contact, “Do you have any questions or comments for the team before they leave?” Even a question such as, “Does this plan sound OK to you?” can be affirming and demonstrate respect. Clinicians fear that allowing family members to speak will increase time spent in rounds, but rounds increase by only 1 to 3 minutes per case, and allowing family members to speak in rounds may decrease clinicians’ time spent answering questions by phone or in off-hours later in the day.⁵⁶ Giving the family a voice helps them transition from passive observer to active participant in care. Encouraging presence and encouraging family members to use their voice demonstrates respect, building trust and further deepening family members’ ability to make

sense of their role as caregiver of a critically ill patient.

Clarify Treatment Plan and Goals. At the end of rounds or when meeting with the family, clinicians should clarify treatment plans and goals. Due to the likelihood that stress may prevent comprehensive understanding, iterative discussions are necessary even if the physician has already had a detailed discussion with the family. Nurses should be present during all physician-family communication to avoid confusion and to ensure that congruent messages can be reinforced.

Facilitate Family Conferences. In cases in which the patient has any chance of death, the patient or family goals are in conflict with the current treatment plan, there is conflict between providers, or a prolonged length of stay is necessary, a family conference is warranted.⁷ Nurses are in a unique position to advocate for and organize a family conference with key stakeholders. Conferences that strategically include messages of hope, compassion, and caring are recommended because they are more likely to preserve the mental health of family members.⁸ When the nurse attends a conference, and the family's voice has not been heard or the key elements of caring, compassion, and hope have not entered the conversation, it is within the scope of nursing practice to add a statement of caring, compassion, or hope that is appropriate to the situation (eg, hope for a day without pain).

Outcomes

When facilitated sensemaking occurs, the family benefits from a flattened bureaucracy, maintenance of family integrity, improved role clarity, and preparation for transfer across the continuum of care. Exposure to critical illness can be positive when it results in improved coping skills and resiliency. Psychologically, through decreased fear, horror, and helplessness, families may benefit from decreased adverse outcomes such as anxiety, depression, and posttraumatic stress. The net benefit to society could be significant if families remain intact with the capacity to handle the burden of caregiving after ICU discharge. Family members' grief for decedents could be lessened by the knowledge that they did everything possible to help during the intensive care stay despite the negative outcome. Further research is needed to confirm benefits,

but the evidence-based process of facilitated sensemaking can be used as a framework to translate the SCCM recommendations for FCC into practice to reduce PICS-F.

REFERENCES

- Chinn PL, Kramer MK. *Knowledge development in nursing: Theory and process*. St Louis, MO: Mosby/Elsevier; 2014.
- Davidson JE, Harvey MA, Bemis-Dougherty A, Smith JM, Hopkins RO. Implementation of the pain, agitation, and delirium clinical practice guidelines and promoting patient mobility to prevent post-intensive care syndrome. *Crit Care Med*. 2013;41(9 Suppl 1):136-145.
- Davidson JE, Winkelman C, Gelinas C, Dermenchyan A. Pain, agitation, and delirium guidelines: nurses' involvement in development and implementation. *Crit Care Nurse*. 2015;35(3):17-31.
- Davidson JE. Facilitated sensemaking: a strategy and new middle-range theory to support families of intensive care unit patients. *Crit Care Nurse*. 2010;30(6):28-39.
- Davidson JE, Daly BJ, Agan D, Brady NR, Higgins PA. Facilitated sensemaking: a feasibility study for the provision of a family support program in the intensive care unit. *Crit Care Nurs Q*. 2010;33(2):177-189.
- Skoog M, Milner KA, Gatti-Petito J, Dintyala K. The impact of family engagement on anxiety levels in a cardiothoracic intensive care unit. *Crit Care Nurse*. 2016;36(2):84-89.
- Davidson JE, Powers K, Hedayat KM, et al. 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. *Crit Care Med*. 2007;35(2):605-622.
- Davidson JE, Aslakson R, Long AC, et al. Guidelines for family centered care in the neonatal, pediatric and adult ICU. *Crit Care Med*. 2017;45(1):103-128.
- Davidson JE, Tung A, Kishman CP Jr, Barr J. Reflecting on use of the GRADE process for development of the 2013 PAD guidelines. *Semin Respir Crit Care Med*. 2013;34(2):262-272.
- Needham DM, Davidson J, Cohen H, et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. *Crit Care Med*. 2012;40(2):502-509.
- Davidson JE, McDuffie M, Campbell K. Family centered care. In: Kleinpell R, ed. *Global Best Practices in Critical Care*. New York, NY: Springer. In press.
- Roy C, Andrews HA. *The Roy Adaptation Model*. Upper Saddle River, NJ: Prentice Hall; 1999.
- Weick KE. *Sensemaking in Organizations*. Thousand Oaks, CA: Sage; 1995.
- Dohrenwend BP. *Adversity, Stress, and Psychopathology*. Oxford, England: Oxford University Press; 1998.
- Association AP. *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Arlington, VA: American Psychiatric Association; 2013.
- Parker AM, Srichraoenchai T, Raparla S, Schneck KW, Bienvenu OJ, Needham DM. Posttraumatic stress disorder in critical illness survivors: a metaanalysis. *Crit Care Med*. 2015;43(5):1121-1129.
- Anderson WG, Arnold RM, Angus DC, Bryce CL. Post-traumatic stress and complicated grief in family members of patients in the intensive care unit. *J Gen Intern Med*. 2008;23(11):1871-1876.
- McAdam JL, Puntillo K. Symptoms experienced by family members of patients in intensive care units. *Am J Crit Care*. 2009;18(3):200-209.
- Sherin JE, Nemeroff CB. Post-traumatic stress disorder: the neurobiological impact of psychological trauma. *Dialogues Clin Neurosci*. 2011;13(3):263-278.
- Mahan AL, Ressler KJ. Fear conditioning, synaptic plasticity and the amygdala: implications for posttraumatic stress disorder. *Trends Neurosci*. 2012;35(1):24-35.

21. Forneris CA, Gartlehner G, Jonas DE, Lohr KN. *Preventing and Treating PTSD and Related Conditions in Adults: A Research Agenda*. Research Triangle Park, NC: RTI Press. doi: 10.3768/rtipress.2013.rb.0005.1309.
22. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: Post-intensive care syndrome-family. *Crit Care Med*. 2012;40(2):618-624.
23. Eley TC, McAdams TA, Rijdsdijk FV, et al. The intergenerational transmission of anxiety: a children-of-twins study. *Am J Psychiatry*. 2015;172(7):630-637.
24. Larson RW, Almeida DM. Emotional transmission in the daily lives of families: a new paradigm for studying family process. *J Marriage Fam*. 1999;61(1):5-20.
25. Al-Mutair A, Plummer V, O'Brien A, Clerehan R. Family needs and involvement in the intensive care unit: a literature review. *J Clin Nurs*. 2013;22(13-14):1805-1817.
26. Kynoch K, Chang A, Coyer F. Interventions to meet family needs of critically ill patients in an adult intensive care unit: a systematic review. *Aust Crit Care*. 2012; 25(2):134-135.
27. Macey BA, Bouman CC. An evaluation of validity, reliability, and readability of the Critical Care Family Needs Inventory. *Heart Lung*. 1991;20(4):398-403.
28. Padilla Fortunatti CF. Most important needs of family members of critical patients in light of the Critical Care Family Needs Inventory. *Invest Educ Enferm*. 2014; 32(2):306-316.
29. Hickey ML, Leske JS. Needs of families of critically ill patients: state of the science and future directions. *Crit Care Nurs Clin North Am*. 1992;4(4):645-649.
30. Takman C, Severinsson E. Comparing Norwegian nurses' and physicians' perceptions of the needs of significant others in intensive care units. *J Clin Nurs*. 2005;14(5): 621-631.
31. Kleinpell RM, Powers MJ. Needs of family members of intensive care unit patients. *Appl Nurs Res*. 1992;5(1):2-8.
32. Mi-kuen T, French P, Kai-kwong L. The needs of the family of critically ill neurosurgical patients: a comparison of nurses' and family members' perceptions. *J Neurosci Nurs*. 1999;31(6):348-356.
33. Higgins I, Cadd A. The needs of relatives of the hospitalised elderly and nurses' perceptions of those needs. *Geriatrics*. 1999;17(2):18-22.
34. Kessler RC. Posttraumatic stress disorder: the burden to the individual and to society. *J Clin Psychiatry*. 2000;61(suppl 5):4-12.
35. Egerod I, Christensen D, Schwartz-Nielsen KH, Ågård AS. Constructing the illness narrative: a grounded theory exploring patients' and relatives' use of intensive care diaries. *Crit Care Med*. 2011;39(8):1922-1928.
36. Egerod I, Schwartz-Nielsen KH, Hansen GM, Laerkner E. The extent and application of patient diaries in Danish ICUs in 2006. *Nurs Crit Care*. 2007;12(3):159-167.
37. Ewens B, Chapman R, Tulloch A, Hendricks JM. ICU survivors' utilisation of diaries post discharge: a qualitative descriptive study. *Aust Crit Care*. 2014;27(1):28-35.
38. Gjengedal E, Storli SL, Holme AN, Eskerud RS. An act of caring - patient diaries in Norwegian intensive care units. *Nurs Crit Care*. 2010;15(4):176-184.
39. Jones C, Bäckman C, Griffiths RD. Intensive care diaries reduce PTSD-related symptom levels in relatives following critical illness: a pilot study. *Am J Crit Care*. 2012; 21(3):172-176.
40. Jones C, Bäckman C, Capuzzo M, et al. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised, controlled trial. *Crit Care*. 2010;14(5):R168.
41. Garroute-Orgeas M, Coquet I, Perier A, et al. Impact of an intensive care unit diary on psychological distress in patients and relatives. *Crit Care Med*. 2012; 40(7):2033-2040.
42. Melnyk BM, Alpert-Gillis L, Feinstein NF, et al. Creating opportunities for parent empowerment: program effects on the mental health/coping outcomes of critically ill young children and their mothers. *Pediatrics*. 2004; 113(6):e597-607.
43. Melnyk BM, Bullock T, McGrath J, Jacobson D, Kelly S, Baba L. Translating the evidence-based NICU COPE program for parents of premature infants into clinical practice: impact on nurses' evidence-based practice and lessons learned. *J Perinat Neonatal Nurs*. 2010; 24(1):74-80.
44. Melnyk BM, Feinstein NF. Reducing hospital expenditures with the COPE (Creating Opportunities for Parent Empowerment) program for parents and premature infants: an analysis of direct healthcare neonatal intensive care unit costs and savings. *Nurs Adm Q*. 2009; 33(1):32-37.
45. Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. *New Engl J Med*. 2007;356(5):469-478.
46. Committee on Hospital Care. American Academy of Pediatrics. Family-centered care and the pediatrician's role. *Pediatrics*. 2003;112(3 Pt 1):691-697.
47. Shields L, Zhou H, Pratt J, Taylor M, Hunter J, Pascoe E. Family-centered care for hospitalised children aged 0-12 years. *Cochrane Database Syst Rev*. 2012;10: CD004811.
48. AACN issues four new evidence-based practice alerts. *AACN Bold Voices*. 2012;4(1):12.
49. Boltz M. Assessing family preferences for participation in care in hospitalized older adults. Best practices in nursing care to older adults 2012. <https://consultgeri.org/try-this/general-assessment/issue-22>. Accessed April 3, 2017.
50. Jackson JC, Ely EW, Morey MC, et al. Cognitive and physical rehabilitation of intensive care unit survivors: results of the RETURN randomized controlled pilot investigation. *Crit Care Med*. 2012;40(4):1088-1097.
51. Davidson JE, Harvey M, Schuller J, Black G. Post-intensive care syndrome: what it is and how to help prevent it. *Am Nurse Today*. 2013;8(5):32-37.
52. Burr G. Contextualizing critical care family needs through triangulation: an Australian study. *Intensive Crit Care Nurs*. 1998;14(4):161-169.
53. Kon AA, Davidson JE, Morrison W, Danis M, White DB. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society Policy Statement. *Crit Care Med*. 2016;44(1):188-201.
54. Kon AA, Davidson JE, Morrison W, Danis M, White DB. Shared decision-making in intensive care units. Executive summary of the American College of Critical Care Medicine and American Thoracic Society Policy Statement. *Am J Respir Crit Care Med*. 2016;193(12):1334-1336.
55. Allen KA. Parental decision-making for medically complex infants and children: an integrated literature review. *Int J Nurs Stud*. 2014;51(9):1289-1304.
56. Davidson JE. Family presence on rounds in neonatal, pediatric, and adult intensive care units. *Ann Am Thorac Soc*. 2013;10(2):152-156.
57. Summary of the HIPAA Privacy Rule. <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html>. Accessed April 3, 2017.