CHAPTER 10

FAMILY-CENTERED CARE

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Introduction and Chapter Objectives

This chapter will review definitions of family and family-centered care, post-intensive care syndrome-family (PICS-F), and essential elements of a program of family-centered care (FCC) within the context of biomedical ethics. Two different theoretical models are used to explore the application of family-centered care to practice: Joanne Duffy's Quality Caring Model, and Judy Davidson's Facilitated Sensemaking Theory. A leadership strategy for quality monitoring of a program of FCC will be presented. Where applicable, global variation in practice is highlighted. The chapter will conclude with a first person testimony from one author who served as a family member of a critically ill infant illustrating how applying FCC can work in practice.

Definitions

Family and Family-Centered Care are defined many different ways by various professional organizations. Those adopted by the Society of Critical Care Medicineare presented here, which were vetted through patient and family informants as well as the LGBTQ community.

FamilyFamily 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. (J. E. Davidson et al., 2017)(p105)

(J. E. Davidson et al., 2017)
The common premise is that family is determined by the patient and may include those who are not relatives or spouses. Adhering to principles of biomedical ethics, as healthcare providers we have an obligation to respect the decision of the patient as to who constitutes family and not challenge those that present themselves as 'family' of the patient.

Family-centered Care

Several terms are used to reflect the type of care provided which is inclusive of the patient/family unit: patient centered, patient and family-centered, and family-centered care, published without consistency with and without hyphens between the words. For the purposes of this chapter, because the focus is on family, the term family-centered care (FCC) is used. The SCCM endorses this definition: Family-centered care is an approach to health care that is respectful of and responsive to individual families' needs and values. (J. E. Davidson et al., 2017)(p105)

The key to FCC is that it is a mutually beneficial relationship between healthcare providers, families and the patients. Family-centered care transcends merely including families in care, or allowing their presence and moves towards true collaborative relationships. Family-centered care flattens the bureaucracy of healthcare so that families may, when desired, serve on equal grounds to provide care, participate in decision-making and collaborate on the best approaches to

obtain optimal wellness or dignified death in the best interest of the patient. Family-centered care acknowledges that the social, emotional and in the case of children, developmental support are just as important as the physical care or treatments rendered. Family-centered care hinges on the premise that the integrity of the family unit is protected by preserving dignity and control whenever possible. ("Patient-and Family-Centered Care,"). Core tenets of family-centered care include developing bi-directional relationships built from respect, the sharing of information, presence, participation and collaboration (J. E. Davidson et al., 2017; J.E. Davidson et al., 2007; Neff et al., 2003; "Patient-and Family-Centered Care," ; Shields et al., 2012).

When reviewing the qualitative literature regarding family needs a message also rises to the surface. Families need us to help them either bond and become a family, in the case of newborns, or adapt and cope and maintain family integrity in the case of children or adults experiencing critical illness (Eggenberger & Nelms, 2007; Fenwick, Barclay, & Schmied, 2000; Meyer, Ritholz, Burns, & Truog, 2006).

The provision of FCC nearly dictates the need for relationship building. The family is not an 'extra' part of the care, or something you pay attention to if you have time, or above and beyond the responsibilities of the nurse. The patient and family are an inseparable unit and need each other to optimize health and wellness. The family is part of the nurse's duty of care, not an aside. Relationship building with the family is just as important as gaining the trust of the patient. In critical illness, the family often serves as the surrogate for the patient, and only by engaging in relationship building with the family will the nurse be able to get to know the patient. This is particularly important when the patient is starting to recover. Recovering ICU patients make reference to losing their sense of identity, and perceive family and friends as critically important in helping maintain a sense of self, (Logan & Jenny, 1997) They also perceive that family and friends assist them to make sense of their surroundings and communicate more effectively(Magnus & Turkington, 2006).

How exactly does the nurse provide care while building these relationships within the context of a time-pressured environment?

The nurse's role in provision of FCC will be described as applied through two theoretical frameworks: Joanne Duffy's Quality Caring Model and Davidson's Facilitated Sensemaking Theory which was designed to describe how to provide family care in the ICU. The examples and vignettes used in this chapter are not contrived. They have been generated from actual clinical experiences and/or research interviews or observations. Each section provides examples to help the learner apply and synthesize the contextual knowledge. Questions are posed intentionally to engage the learner in critically thinking through the concepts of study as they progress and build upon one another.

Post Intensive Care Syndrome-Family

Family-centered care is needed to prevent or minimize Post-Intensive Care Syndrome-Family (PICS-F). Post-intensive care syndrome is defined as new or worsening impairments in physical, cognitive, or mental health status arising after critical illness and persisting beyond acute care hospitalization. The term could be applied to a survivor (PICS) or family member (PICS-F) (Needham et al., 2012). The

lay explanation of PICS-F is provided: You or other family members may have new problems that start in the ICU and linger after discharge that may affect the body, thoughts, feelings or mind (J.E. Davidson, Hopkins, Louis, & Iwashyna, 2013). At least one third of family members of critically ill patients will experience anxiety, depression, and symptoms of post-traumatic stress months after discharge or death (Kentish-Barnes, Lemiale, Chaize, Pochard, & Azoulay, 2009; Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008). Others suffer from complicated grief. It is known that how we communicate and the way that we communicate can either help the family through a critical illness or cause harm (Siegel et al., 2008). The family response to critical illness may be partially mediated by our care. Tending to the family while caring for the patient is more than a matter of optimizing satisfaction as a business objective; it is instead a duty to do no harm. The exact mechanisms of how families are injured in the process of exposure to critical illness are not well known. However, models of care to minimize the stress and stress response have been proposed. These models universally include fostering the development of caring relationships, optimizing communication, sharing in decision-making and family engagement in care.

Figure 1 depicts an updated model for PICS-F. Adapted from (Needham et al., 2012)
INSERT FIGURE 1 HERE

       The family is exposed to critical illness and may develop anxiety, depression and symptoms of post-traumatic stress which may last many years following the discharge or death of the patient. Bereaved family members may also experience complicated grief also known as persistent complex bereavement disorder which persists longer than six months following a death. The symptoms may include social isolation, suicidal ideation, maladaptive behaviors or thoughts about the person who died or the death experience (*Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, 2013). Approximately half of discharged patients will need caregiving after discharge (Desai, Law, & Needham, 2011; Herridge et al., 2003; Wunsch et al., 2010). For these families, the responsibilities may result in caregiving burden. Most families are not prepared for the burden of providing care at home ("Family Caregiving," 2011) . Caregiving burden can exacerbate psychological symptoms previously triggered in the ICU setting and result in physical and emotional fatigue. For older adults fatigue and inability to provide care at home are magnified and may result in institutionalizing the discharged patient, fracturing the once stable family unit. Some family members will experience financial strain from missed work, financial collapse of the household due to loss of patient or family income, fractured family dynamics (divorce, estrangement) due to intra-family conflict or strain from dealing with the responsibilities of caregiving. Even though these long-term caregiving outcomes occur post-discharge, ICU caregivers have an obligation to set families up for as successful a transition home as possible while they are still within our care. In the following sections specific examples will be given of how to protect the health and well-being of the families of critically ill patients.

Joanne Duffy's Quality Caring Model

       Joanne Duffy's model of Quality Nursing Caring (Duffy, 2013) presents a modern approach to providing holistic care in a relationship-based model grounded

in the understanding of the demands for our time. The core of the model depicts the importance of strong and healthy relationships first in the community and then within the context of a healthcare experience.

People normally live in communities and have human relationships within those communities. Positive relationships in normal life can promote positive and healthy lifestyles. When people experience uncaring relationships or negativity they are less likely to care for themselves. Illness may result. When they can no longer care for themselves, they have professional encounters with the healthcare system and team. In the most stressful of these, the patient and family experience critical illness. If the encounters with healthcare providers during critical illness are positive the recipient of care feels cared for.

Feeling cared for, in turn, generates feeling empowered, whole, valued, worthy, human, supported, encouraged, appreciated, connected, engaged, and hopeful. Feeling cared for also generates a feeling of being understood, known, safe, secure and protected. These outcomes of feeling cared for help to provide the patient and family with the energy and initiative to move forward through illness towards health. In the context of critical illness, helping the family to feel cared for can generate the energy, strength and motivation to navigate through the experience either towards health or a dignified death.

Understanding the limited strength of those in crisis, the duty to help the family feel cared for could serve as a buffer to maintain the strength necessary for caregiving later. It is known that up to 50% of ICU patients will require caregiving support from their families up to a year following the hospitalization. However, Duffy cautions that these caring experiences do not occur in a vacuum. If one nurse in a unit is kind and caring to family members, and another is not, the net result can produce a negative effect which reaches past the individual nurse/patient/family relationship. Even though each nurse has their own assignment, their work, energy attitudes and behaviors add up into relationships and teamwork. Further, it is not enough for a single nurse to be 'good' to their own patient and their family. If nurses are not kind to each other it can have a negative effect on the environment that spills over into what is experienced by all others within the environment.

We need to have healthy relationships with each other as nurses and with the other members of the healthcare team to be able to provide care to the patients and their families (Figure 2). Think of a situation where the people working together that day do not get along, and the tension is felt throughout the unit during the whole shift. Do these warring nurses easily ask each other for help with turning and lifting or break coverage? Or do they instead avoid each other, at times neglecting the needs of the patient and family in the process? What about a situation where the nurse and physician do not agree on the plan of care? Can the family help but notice and be affected by these tensions? The family is already of fragile psychological health due to the crisis they are enduring. The added tension in the environment may actually cause these at-risk family members harm. Duffy explains the importance of spending the time to create a healthy work environment that will then support caring in a manner that will optimize healing of the patient and family. Creating a healthy work environment is strongly endorsed by the American Association of Critical Care Nurses ("AACN's healthy work environment's initiative,"

2005). Many references are available at www.aacn.org to assist teams improve the healthy nature of the work environment.

According to Duffy, three forms of relationships between, a) nurses, b) nurses and other professionals, and c) professionals and patients and families, are developed contingent upon eight essential factors. These factors include:

- basic human needs
- the healing environment
- appreciation of unique meanings
- encouraging manner
- human respect
- attentive reassurance
- problem-solving
- affiliation needs

So how does this relate to ICU nursing? To follow, each of these 8 factors will be explored with examples relevant to critical care nursing and FCC. With each of these factors we need to consider the triad of relationships: nurse/other professionals/and patients and families.

Basic Human Needs

The Quadruple Aim endorsed by the Institute of Healthcare Improvement dictates that we implement strategies to care for the caregiver.(Berwick, Nolan, & Whittington, 2008; Bodenheimer & Sinsky, 2014; Leape et al., 2009) As nurses we need to tend to our own basic human needs to be able to tend to those of others. Is everyone on shift getting their breaks? How does this relate to FCC? Without breaks would we have the patience to answer the same question from the family that has been asked by fifteen others before? Further, is an issue from home clouding our minds preventing us from authentic caring at the bedside? Tending to our own needs is essential to build the resiliency, focus, clarity, and authenticity to provide for others. In FCC, there is a natural tendency for families to feel the need to safeguard during illness. Once they have watched the nurse give attention to the basic needs of the patient it will help them to develop trust that the best of care is being provided. After trust is formed, the need to safeguard will be less intense. Consider this example experienced during a research interview. When asked, "Is there anything more that I can do for you given what you are going through?" the family responded ''Yes, my mom's tubing says *change Tuesday* and it is Wednesday. Shouldn't it be changed?'' The family member was referring to a tag on the ventilator tubing, and had been ruminating about it all morning. As soon as the respiratory therapist was called to change out the circuitry, she visibly calmed down. In another situation after the same question about further needs was asked, the family remarked about a bloody bandage that was on her mom's chest. After investigating, the researcher found that it was a clear bandage with betadine soaked gauze underneath. The family members, in this crisis, look at our care critically, not to blame, but instead because of their human instinctive need to safeguard (Burr, 1998; J. E. Davidson, Daly, Agan, Brady, & Higgins, 2010b). With limited knowledge of critical care, they often make false assumptions or place false importance on small tasks. However, instead of battling over what is important and what isn't, it is most

productive to take care of what families are focused on so that they can develop trust and feel safe.

The Healing Environment

The environment should be managed to be as calm, caring and supportive as possible. This may be seen in unusual ways. Consider the active intention to optimize alarms to reduce noise. For instance, is the heart rate alarm for the patient whose heart rate is controlled on beta blockers to a rate of 48 set below the normal resting rate? In most ICUs this would have to be an intentional act because the default low heart rate alarm is set between 50 and 60. On the surface it is not obvious that attending to these details are acts of kindness or caring. The impact of not adjusting the alarms is to unnecessarily startle the family every time that they ring. Think about how many times you've been approached by family members because an alarm was ringing, only to say something to the effect of 'that one's not important'. If it is not important, should it be adjusted? Being thoughtful in our approach to individualizing the care to each unique situation is indeed an act of human caring. When we care enough to tend to the details through acts like these we create the optimal healing environment.

Providing care in a transparent way by talking through actions out loud helps family members follow your thoughts and learn how you are prioritizing care. Think of this relationship building as akin to precepting. When training a new nurse it helps if the preceptor thinks out loud. The orientee then learns how decisions are made through the thought process of the preceptor. This method of learning is just as effective for the family, many of whom are new to critical illness. It cannot be assumed that they will understand why you are doing what you are doing simply because they are watching. "I am clipping this tubing to your gown and straightening it out so that it doesn't kink. This will make it more comfortable for you. Looks like your kidneys are working better now. We're getting more than 30cc/hr of urine. That's an improvement. How about a pillow under your calves so that your heels don't touch the bed?." Listening to you explain your thoughtful actions puts caring into the air, soothing the environment and making it feel safe to the family who wouldn't otherwise know what was happening.

Appreciation of Unique Meanings

Appreciating unique meanings refers to understanding the patient's cultural and religious needs, their values and preferences. To understand and appreciate the dynamic of difference, it is important to know the same things about yourself and those on your team. By understanding our own values it will be easier to detect when the patient or family's values differ. Our natural default is to provide the care to others that we would want for ourselves. After years of caring for patients at the end of life, I thought it would obviously put the family at ease if I explained that I would be giving morphine to make sure the patient wasn't having any pain. I was taken aback by the response. The son said, 'No, you can't. Don't give him that. He wouldn't want it now.' I had at first thought the son wanted his father in pain. After further investigation it became clear that the family was Muslim and in their faith the father was supposed to say the Call to Prayer as he left this life on earth. Sedated on morphine, the son feared we would take away his only chance to meet that spiritual obligation. When a family interaction triggers the thought, 'Why did he

respond that way' or 'I wouldn't have felt that way', this should in turn trigger an evaluation of what values, preferences, cultural, or spiritual needs are different in this person or family from your own.

Understanding and accepting the needs of unique family units is also part of providing FCC. Nurses will encounter families where the family structure is already tense, such as in divorce or separation. The patient who is the husband may be visited by the wife and his girlfriend. People may present themselves as 'cousins' or 'children' who have no biological relationship. Often they do this to ensure that they will be allowed in as visitors. With the global recognition of an open definition of family, our nursing duty then is to accept that these people have chosen each other as family and tend to them equally and without judgment. If they have the ties to call each other family, then they will also have the same emotional needs as those who are biologically related or related by traditional marriage.

Attending the unique cultural needs of family members is as simple as asking what the needs are. Questions such as "If you were in your home country, what would you be doing now that we are not doing here? Is there a tradition that we can help you with?" Spiritual needs are similar. The question to ask might be, "Is there a spiritual advisor that I can contact for you to help you through this situation? Would you like me to contact our chaplaincy service for you? Did you know that we have a chapel on the first floor? If you need a quiet place to reflect, it is open all day and night." Through research at a faith-based hospital it was found that even though there was a 15 foot statue of Jesus in the lobby right in front of the chapel, family members in crisis would walk past it every day without thinking that it might be in front of a chapel. They didn't know that they could ask for a chaplain. The obvious escapes families in crisis, and as part of FCC, we can help them to see the resources around them to help them meet their needs. Nurses often question whether it is appropriate to pray with family members. Prayer is a deeply personal experience. If a family member wants to pray and makes that known, it is within the realm of nursing to minister to that need. In the 2007 Society of Critical Care Medicine guideline for FCC, prayer is recognized as an inter-professional intervention when requested by the patient or family and not conflicting with the professional's own values. The nurses' role in addressing spiritual needs is not addressed in the 2017 version of the guidelines; the 2007 recommendation still stands. If the nurse is requested to pray and this conflicts with his or her own values the next action would be to find a health professional, spiritual guide, or chaplain who would fulfill this need for the family. Often when families request a nurse to engage in prayer, the family member will actually start the prayer and say their thoughts out loud hoping for the nurse to engage with them quietly listening in solidarity or by holding hands.

Encouraging Manner, Human Respect, Attentive Reassurance

Duffy reminds us that it is important to demonstrate respect for, encourage, and reassure each other during our work relationships. This in turn will allow us to do the same for the patients and their families. Respect, encouragement and reassurance in professional relationships can take the form of debriefing together after critical incidents. Recently a body of knowledge has formed surrounding the concept of second victim syndrome. Second victim syndrome is defined as feeling victimized by experiences in the work environment. This may include feeling like

you've failed the patient, decreased self-efficacy, and self-doubts about career choice (Scott et al., 2009; Scott et al., 2010; Seys et al., 2013). To minimize the impact of second victim syndrome providers are encouraged, as Duffy advocates, to help each other take a time out after a negative outcome or adverse event has occurred. Find solace through talking through the situation with others that you trust. Help the person going through the situation take a break before entering back into providing care. Feeling like a victim at work can also occur because of being exposed to situations that remind us too much of something a friend or family member might have gone through. For this reason it would be appropriate to allow a nurse to decline an assignment of a patient who has the same terminal cancer her husband was recently diagnosed with.

Once these acts of encouragement, respect and reassurance are routine within and between healthcare clinicians , we are better suited to do the same for the families within our care. Recovering from critical illness is not a linear event. Families will need constant reassurance during times when it seems as though progress is one step forward and two steps back. Respect may take the form of ensuring that the patient is properly covered. Consider the husband who says of his wife after watching the nurse adjust the gown around the neckline, and the covers in bed, 'My wife is a lady, she wouldn't have wanted her shoulder showing that way, Thank you for covering her back up.' During a research interview, a Muslim gentleman explains, 'To pray we need to have our knees covered, but here the gowns all stop short of the knees. How am I going to pray?'

Respect and dignity also involve recognizing the human as an individual. This has been done with *All about Me* posters. Large flip chart sized post-its or printed sheets of oversized papers that affix to the wall can be used for families to describe the patient and family, attach pictures, and describe favorite pastimes. In this manner the person who is being cared for is honored not as 'sepsis in bed 13' but instead 'George Jones, grandfather of three, whose loving wife quilts in her spare time while they vacation in their motor home around the country.' *All about Me* posters provide an invitation for staff and physicians to engage in the life of the patient and family to form a true caring relationship instead of providing surface tasks at the outer edge of a relationship. Authentic discussions with patients and families about their lives promote a caring connection. Discussions can easily begin with "Tell me about your Dad...."

Problem Solving

Families may be given opportunities to engage in problem solving through presence during rounds and during family care conferences. Use of technical jargon may preclude family engagement in problem solving. Despite training in communication, teams may lapse into technical discussions that are not understood by families. When this happens, the nurse's role is to translate the problem-solving process so that families can understand. With routine nurse advocacy teams will be more likely to develop family-centered communication skills that meet the information needs of the families. This is best achieved during rounds or conferences. The reality is that physicians are often pressured for time during rounds. A less desired alternative is to explain how the decisions were made and why following rounds.

When the nurse is problem-solving changes in the patient's condition at the bedside, one strategy to keep families involved in problem solving is to talk through the problem solving out loud. For instance, "I see your Dad's urine output has dropped, and these measurements [pointing to the monitor] are a little lower than usual. I believe this suggests that he might be a little dehydrated. I am going to talk to the doctor to see if he agrees and discuss whether your Dad's treatment should change." Discussions like these build trust with the family and also help them to understand the purpose of all of the monitoring.

When present during rounds it has been documented that families often have information about baseline medical history that helps inform rounds and contributes to the differential diagnosis, altering the treatment plan (Jacobowski, Girard, Mulder, & Ely, 2010; Knoderer, 2009; Rotman-Pikielny et al., 2007). When this happens, it is important to thank the family for the information and comment to them that the information was helpful. Maintaining eye contact with the family during rounds and asking whether or not they have anything to add opens up the discussion. Many families will at first be intimidated, but when invited into the discussion will be more likely to contribute key information. The invitation to participate demonstrates respect, diminishes hierarchical structure, and makes families feel as if they are a part of the team. This engagement may decrease stress and build trust.

Family presence on rounds may be more common in the United States than in other countries. For instance, in many ICUs in the United Kingdom, families are asked to leave during medical rounds because of the environment. The layout of many intensive care units makes it difficult for discussions about patients held at the bed space to be kept confidential from visitors at adjacent bed spaces. Therefore, families are prevented from contributing to discussions, and gaining information and building a sense of trust as suggested above. Units need to explore ways of maintaining a patient's confidentiality while including families in decision-making as part of the team. Strategies have been proposed to overcome this environmental barrier and include asking families of the person in the next bed to leave while the family of the patient being rounded on is present. A values analysis could also be conducted to see if privacy is a concern for the families involved. When asked, families often report that being allowed to be present is more important than someone overhearing information about their family member (J. E. Davidson, 2013).

The role of surrogate decision-maker

When patients cannot speak for themselves, families need to be taught the role of surrogate decision-maker. The patient surrogate is the person who is responsible for helping the physician make decisions in the patient's best interest given what is known about the patient's wishes. The surrogate needs to be instructed early and often regarding the standard of substituted judgment: that when asked opinions regarding decisions, the response should be framed within the context of "What would the patient have wanted?" Emphasizing the patient's own preferences accomplishes two goals: 1) maintaining respect for the patient as an individual with personal values and 2) relieving the family of the burden of making decisions based upon their own values.

Families have different levels of desired participation. It is recommended that each family is assessed for their own individual preference for participating in decision-making. It is further recommended that a shared decision-making model be implemented as a default, because it has been shown that most families prefer to be involved after being presented facts and options. However, the team needs to be flexible in approach if the family does not want to participate in decision-making, preferring a more paternalistic approach, (Cox et al., 2012; J. E. Davidson et al., 2017; Kon, Davidson, Morrison, Danis, & White, 2016) One fear of clinicians when offering family involvement in decision-making is that families will request inappropriate treatment. It is the role of the physician to only offer medically appropriate treatments. If the family suggests inappropriate treatment, and the physician declines the request, it is the role of the nurse to support the families in understanding why the request was declined. Whenever a dispute about the treatment plan cannot be resolved by increased communication, explanation or family care conference, an ethics consult is indicated. More detail about dealing with intractable cases has been published in two key documents published by the Society of Critical Care Medicine. (Bosslet et al., 2015; Kon, Shepard, et al., 2016)

Each family will have their own method of determining who will participate in decision-making, or who will serve as surrogates for incapable patients, which may be culturally mediated. In some cultures the oldest son is the decision-maker. In others it is the oldest child. In still others it is a tribal elder, or religious leader, who is consulted for important decisions. Depending upon the country and region there may be guidelines for who should participate in decision-making. In the United States there is a standard consent lineage that physicians are free to modify when indicated by the best interests of the patient. The surrogate decision-maker is considered in this order: designated durable power of medical attorney, spouse, child, adult sibling. Others may be considered according to patient preference, culture, and best interest of the patient. For instance, if the patient does not have a durable power of medical attorney (DPOMA) designated or a spouse, but has been living with a domestic partner for several years, and this person knows the patient best, the physician may use this person to inform decision-making over a child or adult sibling who has been estranged or not connected to the patient. However, this can give rise to conflict, where functional and legal families disagree, and there have been a small number of such cases reported in healthcare journals. (Gonzales, Dever, & Singleton, 1999; Hyde, Kautz, & Jordan, 2013).

In parts of the UK, the Mental Capacity Act was introduced to address decision-making in relation to financial, healthcare, and other day-to-day issues ("Mental Capacity Act Code of Practice," 2013). It applies to all people 16 years and over, resident or present in England and Wales. Where a patient is deemed not to have the mental capacity to make decisions related to their own care, the Act requires healthcare workers to ensure that decisions made on behalf of an individual are always made in the best interests of that individual. The Act provides a checklist of factors that decision-makers must work through in deciding what is in a person's best interests. A patient's mental capacity should be tested using recognized tools. They cannot be deemed incapable just because they make decisions that others consider unwise. If an adult is not able to give valid consent, no person may give valid consent to treatment on behalf of an adult patient lacking capacity. Therefore, where an individual such as a carer (including a friend or relative), an attorney appointed under a Lasting Power of Attorney (LPA), or a deputy appointed by court, is approached with regard to treatment approval, this is recorded as 'assent', not 'consent', and healthcare organizations use separate documentation to acknowledge this difference. The Act also recognizes the consent given in advance by an individual in the form of an 'advance directive'. Where an LPA has been appointed by an individual to act as their proxy, this will have been lodged with the Office of the Public Guardian. The LPA does not authorize an attorney to refuse life-sustaining treatment unless there is express provision to this effect in the formal document (Johnston & Liddle, 2007).

Recently, researchers have been paying more attention to conflicts in ICU, including those that arise between the healthcare team and the family. In 2007, the European Society of Intensive Care Medicine's (ESICM) ethics committee felt the need to define conflicts in ICU, to aid with monitoring their sources and consequences (Fulbrook et al., 2007). Conflicts have a negative impact on patient safety, patient/family-centered care, team welfare, and cohesion. Conflicts generate staff burnout and increase healthcare costs. Prevention strategies need to be developed, to include guidelines on how to improve the understanding of family experience, preferences and values, as well as evidence-based communication (Fassier & Azoulay, 2010).

Communication

Critical illness is an unfamiliar experience for most families. Everything that is done needs to be explained iteratively and repeatedly throughout the stay. Due to the crisis nature of critical illness, it cannot be expected that families will remember what was said earlier in the day or the day before. Most families have an unquenchable thirst for information. The more they understand about what is happening in the room, the more confidence they can have that everything is being done. Lack of communication or delayed information is one of the most frequently reported family dissatisfiers. Physicians are encouraged to update families daily and with significant changes in condition. When this is not happening, the nurse's role is to facilitate a discussion between the family and physician. Designating a spokesperson to communicate with the physician streamlines communication and decreases the time the physician will spend in communicating with families. However, the entire family will need information to minimize stress response to

their exposure to critical illness. The nurse's role also includes teaching the spokesperson methods of keeping the family unit informed. This may include strategies like starting a family webpage or other social media.

Often nurses are uncomfortable with what information they can share with families. It is customarily accepted that the physicians should inform families of new diagnoses, comorbidities, or likelihood of death. Once any of these items has been shared with the family it is acceptable for the nurse to explain the condition in terms the family understands or provide supportive educational materials about the condition or prognosis. Many items for families can be found free of charge at http://www.myicucare.org/Pages/default.aspx. The UK patient organization *ICU Steps* has produced a guide for patients and relatives. It is available to download for free in 14 languages from www.icusteps.org along with other patient education tools. Nurse leaders should maintain a ready reference library of brochures, videos or written information that can supplement verbal discussion with family. It is known that pamphlets coupled with verbal communication and/or video are more effective at reducing stress than either method of education alone (Lautrette et al., 2007; Melnyk et al., 2004; Melnyk & Feinstein, 2009; Melnyk et al., 2006).

Family care conferences

Due to the complexity of critical illness there are often multiple providers involved in the care of each patient. Each provider contributes to the treatment plan. Family care conferences provide the opportunity to weave together all of the input from the variety of people on the team into one consolidated description of what is happening and what could happen next. Family care conferences are advocated especially in cases where there is concern that the patient may not survive the hospitalization.(J. E. Davidson et al., 2017) The best timing and frequency of conferences has not been established. However, methods of care conferencing have been studied in greater detail.

There are many methods of care conferencing. All of them have these commonalities: Obtain information from consults prior to the conference to gain a full understanding of the current situation. Attempt to hold the conference at a time of the day that will encourage family presence, acknowledging the work responsibilities of some families. Invite key participants in the patient's care. Provide introductions so that each person in the room understands the role of each person present. Prepare a comfortable environment for the discussion. Allow families to vent their concerns, frustrations and questions first by asking probing questions. Families will not truly hear or absorb any new information until their communication needs are first met. Come to understand the patient as a person through the eyes of the family. Gain an understanding for the values of the patient. Explain the surrogate role. Explain the current situation. Explain the choices for appropriate next steps. Collaborate with the family to formulate goals and plans. Thank the family for their time and valuable contributions to the discussion. Record the major points in the medical record and provide updates during hand-off between providers and shifts (Baile et al., 2000; Curtis & White, 2008; Lautrette et al., 2007; D. J. Shaw, Davidson, Smilde, Sondoozi, & Agan, 2013). Using a structured approach to conduct care conferences is recommended because a structured approach has been shown to improve outcomes.(J. E. Davidson et al., 2017)

The nurse's role in this process varies from organization to organization and may include: stimulating the conference after identifying the need, coordinating the conference, documenting conference outcomes, clarifying physician input to family in lay terms, facilitating discussion so that family members have a voice, gathering input from consultants who cannot attend the conference to present to the family and/or providing a summary of the progress of the patient to date. The nurse clarifies role expectations prior to the start of the conference.

Affiliation Needs

It is a basic human need to need each other. Isolation is not a normal existence. A sense of belonging is essential. This factor of affiliation takes into account the family member's need to be engaged in the critical care experience and included in decision-making. Facilitating family presence at rounds, resuscitation and procedures (when desired), and promoting flexible open family presence at the bedside are all ways that we help families to meet their affiliation needs during critical illness. Without presence it is difficult for them to have the knowledge to engage in surrogate decision-making.

*Family Presence*The term family presence is preferred over the outdated term of visiting. Family presence should be open and flexible to meet the needs of the family. (J. E. Davidson et al., 2017) Traditionally 'visiting' hours have been set to meet the needs of staff and physicians. There are several issues with posting rigid visiting times: the times may not meet family needs, the family may feel obligated to stay despite restrictions, and the cultural or religious obligations of the family require presence despite limitations imposed by the healthcare clinicians.

Family obligations may preclude family members from being present when it is convenient for staff. One common example is the family member who works 8 hour days, then travels an hour to the hospital. This would invariably result in a visit landing on or just before a change of shift. If the staff is rigid with rules and times, the family member would be asked to leave for the peri-shift routine which could last two hours. By then exhausted, they would be allowed to come back in before going home to bed. Often family members are asked to go home at night to rest. When researching this topic in the literature, no evidence was found to support sending home family members at night. During the period of critical illness where family members feel the need to safeguard, sending them home may actually cause harm. One autobiographical case study confirms possible harm by sending families home when they feel the need to stay (Judy. E Davidson, Harvey, Schuller, & Black, 2013). In this case the patient was a young adult trauma victim. Physicians rounding throughout the day had alerted the mother that she might die at any time. She was not expected to survive. At night the mother couldn't bear the thought of her daughter lying alone helpless in the bed and possibly dying without her there. The staff, however, enforced a no nighttime visitation policy and told her that they would call her in with changes. The mother rented a motor home so that she could sleep in the parking lot closer to her daughter. One night she even hid under the bed because she couldn't bring herself to leave. During the night the daughter asked for her mother's presence because she feared death. The nurses told her that they had called her, but she never came. The patient, though sedated and critically ill, realized that the nurse had not been truthful and her mother was never called. She

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miraculously recovered from the event, but five years later the mother and daughter were both receiving psychotherapy to overcome the post-traumatic stress: stress that they describe was caused not by the critical illness, and not by the trauma, but instead by the forced separation during this near-death event.

There is no evidence to support the notion that family presence increases infection. To the converse, there is evidence to support that healthcare workers transmit infection. There is no evidence to support the notion that families increase stress or cause patient harm. There is partial truth to the statement that families may cause staff stress(J. E. Davidson et al., 2014). For this reason, it is important to include methods of dealing with family members and how respond to family needs as a part of critical care training.

The British Association of Critical Care Nurses (BACCN) commissioned a Position Statement on Visiting policies for UK Adult Intensive Care Units as it had received so many requests for guidance on best practice(Gibson et al., 2012) . Easily available at:

http://www.efccna.org/images/stories/publication/BACCN_visiting.pdf

The position statement sets out a list of standards that should be expected by both patients and relatives:

Patients should expect:
- To have their privacy, dignity and cultural beliefs recognized
- Confidentiality
- The choice of whether or not to have visitors
- The choice to decide who they want to visit including children and other loved ones
- The choice of care assisted by their relatives
- A critical care team who recognize the importance and value of visiting

Relatives should have:
- A comfortable and accessible waiting room with bathroom facilities nearby
- Access to overnight accommodation in the vicinity of the ICU
- Easy access to food and drink
- A telephone nearby
- Access to relevant information regarding critical illness, the critical care environment and aftercare and support. This should be reinforced with written materials
- A separate area for private discussions with healthcare professionals
- Involvement in patient care as the patient would wish
- Written information regarding the unit procedures e.g. hand washing, times of ward rounds
- Information concerning patient progress on at least a daily basis
- Information when there are any significant changes to the patient's condition
- Not have to wait for long periods of time in the waiting room without regular updates
- Access to interpretation facilities if needed

A particular issue for critical care units in Europe related to the provision of facilities for visitors, as most patients are not nursed in single rooms. Relatives can

spend a significant part of any visit in a waiting area, away from the patient's bedside. These waiting areas can be some distance from the clinical area, and require the negotiation of a number of barriers to gain access to their loved one. When constructing new ICUs it is now recommended as best practice to provide dedicated family space at each bed space (Rashid, 2006, 2014). Waiting areas can be improved through attention to décor, seating, and the provision of a receptionist or volunteer that could act as an intermediary in facilitating communication between ICU staff and patient families(Deitrick et al., 2005). One waiting room was described as 'a place to go, not a place to stay'(Kutash & Northrop, 2007).

Pet visitation remains controversial, yet there is no evidence that pet visitation can cause harm (J.E. Davidson et al., 2007). There is evidence that pet visitation improves recovery. In some situations the relationship that humans have with their pets is just as strong as those that they have with other humans. Receiving unconditional love from a pet during difficult times has been known to help heal (Cole, Gawlinski, Steers, & Kotlerman, 2007). Animal presence has been shown to decrease anxiety, cortisol levels, pain, fear, blood pressure while increasing satisfaction with care(Abraha et al., 2017; Gilmer, Baudino, Tielsch Goddard, Vickers, & Akard, 2016; Krause-Parello, Levy, Holman, & Kolassa, 2018; McCullough et al., 2017; Stevens, Kepros, & Mosher, 2017) Animals may be present in three forms. In some countries (e.g: United States and Canada) people may have registered service animals that, by law, must be permitted to stay with the patient. Many hospitals globally have volunteer programs of animal-assisted therapy dogs and sometimes cats that are trained to visit patients. Lastly, patients own pets, though rarely stated in a policy, are permitted to visit with a human escort. These visits are normally coordinated by the nurse assuring that no one involved in the care of the patient is allergic to the animal, the animal is healthy, and the animal has a temperament suitable for presence in the hospital. Upon an informal survey of the international co-authors of the SCCM FCC guidelines, it was identified that there is wide variation in these practices globally, but no formal evaluation has been conducted to date.

Rounds /Resuscitation and Procedures

There is ample evidence that family presence on rounds supports family communication without significantly lengthening rounds, detracting from teaching or causing harm to families (Cypress, 2012; J. E. Davidson, 2013; J. E. Davidson et al., 2017). Families often provide new knowledge to the team to help refine the treatment plan and prevent unnecessary testing. It has been found that between 85 and 100% of families, when asked, want to be present on rounds and value the opportunity for obtaining information during rounds (J. E. Davidson, 2013).

Admittedly, there is controversy amongst clinicians regarding the benefit vs. risk of including families in rounds. Most opposition comes from clinicians who have not experienced family presence on rounds and worry about time, teaching or risk of litigation. However, when tested, the benefit outweighs the burden and may include greater faith that the clinicians attempted everything possible, earlier recognition that efforts should be stopped, and greater trust in the healthcare team. Although the fear of litigation has clearly been reported, it has not been substantiated. Clinicians universally agree that if families are provided the

opportunity to be present during resuscitation that a family liaison is needed on the resuscitation team to attend to their needs. (J. E. Davidson, 2013) Staff and physicians also need training on how to deal with family presence at these events and debriefings to process the exposure to raw grief when patients do not survive (J. E. Davidson et al., 2017; J. E. Davidson, Buenavista, Hobbs, & Kracht, 2011; J. E. Davidson, K. Powers, K. M. Hedayat, M. Tieszen, A. A. Kon, E. Shepard, V. Spuhler, I. D. Todres, M. Levy, J. Barr, R. Ghandi, G. Hirsch, & D. Armstrong, 2007).

On a similar note, it has been recommended that families be allowed presence at procedures, including brain death evaluation (Davidson 2007, Tawill, 2014). If the family expresses a wish to be present, it may help the family process what is happening while calming the patient.

Because research has shown that family presence at resuscitation may improve family outcomes and does not cause harm, family presence at resuscitation is endorsed by the American Association of Critical Care Nurses and Society of Critical Care Medicine (J. E. Davidson et al., 2017; J.E. Davidson et al., 2007; Gould, Umscheid, Agarwal, Kuntz, & Pegues, 2010).

In 2007, the European Federation of Critical Care Nurses (EfCCNa) coordinated the development of a position statement also endorsing the presence of family members during cardiopulmonary resuscitation (Fulbrook et al, 2007). The following statements were made (direct quotes):

- All patients have the right to have family members present during resuscitation (where this is in the best interests of the patient)
- The patient's family members should be offered the opportunity to be present during resuscitation of a relative
- Support should be provided by an appropriately qualified health care professional whose responsibility is to care for family members witnessing cardiopulmonary resuscitation
- Professional counseling should be offered to family members who have witnessed a resuscitation event
- All members of the resuscitation team who were involved in a resuscitation attempt when family members were present should participate in team debriefing
- All intensive and critical care units should have multi-disciplinary written guidelines on the presence of family members during cardiopulmonary resuscitation

A systematic review of the evidence supports the practice of family presence at resuscitation despite staff and physician reluctance to adopt the practice (Salmond, Paplanus, & Avadhani, 2014). There is worldwide debate by staff and physicians regarding family presence at resuscitation and geographic variation in acceptance and adoption of this practice (Leventakou, 2011; Salmond et al., 2014). Presence at resuscitation appears to be a component of FCC that may be mediated by cultural values. For instance, perspectives of staff and physicians in Turkey (Badir & Sepit, 2007; Demir, 2008; Gunes & Zaybak, 2009), Greece (Vavarouta, Xanthos, Papadimitriou, Kouskouni, & Iacovidou, 2011) and Israel (Ganz & Yoffe, 2012), demonstrate a consistently negative response to the idea of FP at

resuscitation by nurses and physicians. Globally, despite positive benefit noted in experimental trials and published reports of family desire to be present, policies are either not present or not endorsed. Obstacles to staff and physician adherence to policies related to family presence at resuscitation include the fact that clinicians do not feel prepared or do not want to be watched during these stressful events (J. E. Davidson, 2006; J. E. Davidson et al., 2011). Most opposition comes from staff or physicians who have not experienced FP at resuscitation (J. E. Davidson, 2006). Because the positive benefit of family presence has been documented, organizations are encouraged to proactively work on reducing the barriers to presence by preparing clinicians to work during crisis in the presence of family. Most, but not all families want to be present (Salmond et al., 2014). Because of cultural and personal variation in the desire to be present, the resuscitation team should take family's beliefs, values and rituals into account and offer, but not mandate family presence. Weighing the pros and cons to this controversial issue, the SCCM continues to endorse family presence at resuscitation because of the known benefits to family. However, a liaison is needed to help staff field family emotions during the situation and clinicians need training/practice on how to include families at the bedside.(J. E. Davidson et al., 2017)

Summary of the Quality Caring Model

In summary, each of the eight factors influencing quality caring has been reviewed with commentary as to how they could be applied to practice in the critical care environment. It is obvious that the focus of the Quality Caring Model is to develop relationships that will enhance a healthy work environment that will be conducive to providing authentic caring and healing. Next, Facilitated Sensemaking, developed and tested for feasibility by this author (J. E. Davidson, 2010; J. E. Davidson et al., 2010b), will be explored as an adjunctive prescriptive strategy to further address the needs of family members of critically ill patients. The two models are complementary and at times overlap, but do not conflict or compete with each other.

Facilitated Sensemaking

The Facilitated Sensemaking mid-range theory of nursing is presented as a way to engage the family in care. This theory specific to ICU nursing complements Joanne Duffy's Quality Nursing Caring model while being prescriptive regarding nursing interventions. The model has been tested for feasibility and well-received by families. When tested, these activities added approximately 17 minutes of care per day. The amount of time it took to care for the family in this manner increased when previous needs were unmet (J. E. Davidson, 2010; J. E. Davidson et al., 2010b) . Facilitated Sensemaking has been recommended as one method within which to deploy an organized approach to FCC (Hwang, 2017). Each of the interventions has been demonstrated in the literature to improve outcomes, as they were derived from the same data-driven literature used to construct both FCC guidelines (J. E. Davidson, K. Powers, K. M. Hedayat, M. Tieszen, A. A. Kon, E. Shepard, V. Spuhler, I. D. Todres, M. Levy, J. Barr, R. Ghandi, G. Hirsch, D. Armstrong, et al., 2007). The theoretical model as a whole has been shown to decrease family anxiety (Skoog, Milner, Gatti-Petito, & Dintyala, 2016). The assumptions and propositional statements are presented in table 2.

Table 2: Facilitated Sensemaking Assumptions and Propositions
Assumptions:
- Critical illness is a family crisis.
- Families desire proximity and information.
- Each family is unique and may require different approaches to family-centered care.

Propositions:
- Families need and benefit from a purpose in crisis.
- Families need our support to interpret what is happening during an ICU stay.
- Families require care from ICU staff and caring for families is within the realm of ICU nursing.
- How we deal with families of ICU patients may have a long-term impact on both patients and families.
- Minimizing fear, horror and helplessness through structured ICU care of families may decrease PICS-F.
- Supporting families during critical illness may have a positive downstream effect on patients in terms of:
    - Treatment adherence
    - Mobility and Physical Function
    - Cognitive function
    - Attaining treatment goals

INSERT FIGURE 3 HERE: Facilitated Sensemaking

Families experience a crisis when exposed to critical illness. They need to understand what has happened, and then reframe their lives to understand what their new role is as family member of an ICU patient. Sensemaking includes discrete structured activities that a nurse deploys to support families in understanding what has happened and how to adjust to their new role. These sensemaking activities can be clustered into four themes: developing caring relationships, communication, presence and decision-making. It is theorized that if the nurse tends to these sensemaking activities that family outcomes will improve. Families are experiencing an acute crisis. We are there in the moment of their crisis. They are being exposed to a life threatening situation that may cause feelings of fear, horror or helplessness. These are the antecedents to post-traumatic stress syndrome. If we take action to decrease fear though making sense of the situation and environment, allow them to engage in meaningful activities to prevent helplessness and put the situation in context to decrease horror, it is possible that we could modulate the limbic system response to stress and minimize the stress response and resultant outcomes. The healthier, better adjusted family member will be in a better position to provide caregiving and support to the patient which should in turn improve patient outcomes.

Developing caring relationships

Developing caring relationships is important to establish the trust needed to allow families to cope. In qualitative studies on clinician/family dynamics families

report that the relationship between the nurse and family can either help them cope or cause stress. According to the biomedical ethical principle of nonmaleficence, to do no harm, we are duty-bound to authentically care for families in a way that does not stimulate stress. Families also report that stress is increased when the relationship is strained by perceived power-based relationships. When the clinicians tell families what they can and cannot do instead of treating them as equal partners in care it causes stress (Fenwick et al., 2000). Respect is shown when the nurse authentically demonstrates interest about the life of the patient and family, their values and goals. It is not enough for families to be allowed to be present, but instead welcoming their input and active participation is encouraged. Create an atmosphere open to hearing their fears and concerns. Allow them to speak about the risk of death or permanent impairment. Ask a question such as, "Is there anything I can do for you today that would make this any easier given what you are going through?" This simple question has been shown to reveal specific family needs otherwise unknown to the healthcare team (J. E. Davidson, Daly, Agan, Brady, & Higgins, 2010a).

Family presence should be encouraged in the environment. It is known that nurses do not adhere to visiting policies or standards even if they exist. Families report that the inconsistency between providers causes undue stress. Families of infants report wondering, 'Whose baby is this anyway?' 'Why do I have to ask to be allowed to be present?' Think about the nurse's station and how in many hospitals this is 'off limits' to families. The clear demarcation between 'our space' and 'their space' creates tension and detracts from the family-centered approach. Presence at rounds and resuscitation has already been discussed. In order to avoid doing harm to families, we need to be consistent about our approach to family presence. Presence should be dictated by the needs and values of the families.

New ICU nurses may be challenged with learning how to care in front of families and dealing with their own stress of being watched in the workplace. These simple techniques may help adjust to family presence. First read all of the patient education materials in your department specific to the types of patients who are commonly admitted. Also read the patient/family education brochures at http://www.myicucare.org/Pages/default.aspx . Reading patient education materials provides nurses with useful phrases and descriptions of common ICU occurrences to become better informed to speak to families in a way that they can understand. Often new nurses report that they are uncomfortable being watched while working and describe it as if they are an actor on stage. The feeling of being watched causes discomfort especially when developing new skills. An approach to get past these feelings is to talk through your actions in a calm voice aloud converting the situation from 'actor' to 'teacher'. "I am now measuring how much urine came out over the last hour. I always hope it is more than 30 milliliters and yes, it is. We're doing fine here. Now I'm taking down all the numbers from the monitor. The most important one to me is the blue one. That measures the amount of oxygen in the blood. As long as that one stays about 90 we are O.K." Keep the sentences calm and confident as your preceptor might have done when teaching you. Even if things start going badly, the fact that you've picked up on it and are doing something about it can be reassuring to the family.

Communication Sensemaking Activities

Truth-telling

Families have an insatiable thirst for information, though limited capacity to process it during crisis. For this reason it is always better to over-communicate and not assume that they already understand what is going on. Family members will fill in any blank in their knowledge with distortions and myths that can be harmful to the psyche. It is generally accepted that for most people the factual truth is less painful to endure than not knowing what is happening. However, nurses need to be prepared for cultural variations regarding the need to be informed of negative prognoses.

Western values hold disclosing factual information to patients and/or their families as a basic moral rule. This relates to the ethical principle of autonomy, where withholding information would be considered denying autonomy to a patient and/or their family. In addition, clinicians can feel obliged to tell the truth because of legislation and professional codes of ethics. In the West, autonomy has been called the 'first amongst equals' in relation to the other principles of nonmaleficence, beneficence, and justice. However, in other cultures such as in Japan, or Iran, nonmaleficence (do no harm) is seen as superior, and should be considered in relation to information giving, in particular where this relates to the concept of hope. When taking away hope is seen as harmful to the patient, and/or their family; withholding the truth may be seen as an admirable act.

Various studies have suggested that in countries where non-disclosure is the norm, a high majority of people want to be informed. Yet, in other countries where truth telling is the norm there are patients who are reluctant to be informed (Shahidi, 2010). Some patients or their family may appear to be avoiding information, because they only make indirect requests. If clinicians do not recognize this, it can lead to information seekers experiencing frustration and uncertainty about their illness and outcomes. Older, less educated patients may appear to be avoiding information because of the use of passive communication styles. Further, where interpreters have been used to convey information, the information communicated may be altered, or the interpreter may refuse to translate certain facts, as the interpreter conforms to cultural norms. Alternatively, where interpreters have conveyed information accurately, this may result in negative evaluations of healthcare services by the patient on the receiving end (Brashers, Goldsmith, & Hsieh, 2002).

The important message to take away from this is that it is crucial that clinicians avoid premature assumptions based on their own values regarding information giving. (Pergert & Lutzen, 2011). The first action is to spend time understanding the patient's preference for information and act in the patient's best interests. (Brashers et al., 2002; Pergert & Lutzen, 2011; Shahidi, 2010). The ACCM/SCCM has recognized the right to refusal of information and endorses honoring patient wishes to defer information (J.E. Davidson et al., 2007).

De-Coding the Environment

The nurse de-codes the environment by explaining the purpose of the machines, alarms, readings, lines and tubes. This may need to be done repeatedly

and frequently for the family to absorb during crisis. It is also helpful to give them some guidance about the alarms. Explain how they have a different tone and sound.

"Some of them are not critical, like when the alarm that tells you your clothes are dry in the dryer. If you don't get the clothes right away it is O.K. Other alarms are like the one on the oven telling you the cake is done. That alarm is more important but still, the cake will be OK if you wait a few minutes to attend to it. Other alarms need immediate attention, like the smoke alarm in your house. Nurses know all the alarms and which ones need attention right away. If no one is in the room, the alarms are also displayed at the desk, so there is always someone else that can help."

In addition to talking through your actions, nurses provide interpretation of communication provided to the family by others. Attend every discussion that the physicians have with family members. This is challenging, but it is reasonable to ask the charge nurse to watch your patients so that you can be with the physician during informational meetings. After the physician leaves, the nurse is better prepared to answer family questions, redirect false understandings, and identify when family members may have received mixed messages from multiple providers.

Apply principles of reflective learning to family communication. Before the end of every visit ask questions like, "What was the most important thing that happened with your husband today?" and "What will you tell the rest of your family about what happened today?" Ask, instead of tell, to see if the facts have been embedded properly. Sort them out and untangle any myths before the family leaves so that they don't become permanent distortions in the perception of what has happened.

A diary has been shown to improve family and patient outcomes (Garrouste-Orgeas et al., 2012; Griffiths & Jones, 2009; Jones et al., 2010; Jones, Backman, & Griffiths, 2012) and are recommended for use in the ICU (J. E. Davidson et al., 2017). Generally these diaries are maintained by staff and physicians, writing notes of encouragement and daily progress. Pictures of the equipment and an explanation about them can be included. A debriefing session is advocated before giving the diary to the family member at the end of stay or at a discharge follow up visit. Then family members can help patients reconstruct their ICU stay using the diary when they are ready to hear about it. Filling in the gaps in the memory can be an important step towards recovery following discharge. For bereaved spouses, the diary may serve as a reminder of the caring relationships they had developed with staff and physicians which may bring them comfort in their grief. Instructions for how to set up a diary program for your ICU can be found at www.icudiary.org.

Participation in Care

Family participation in care should be offered as a standard element of FCC. Family members vary in their desire to participate at the bedside. Family preference for caregiving may be assessed using standardized tools such as the Family Preference Index that can be found at consultgerirn.org/uploads/File/trythis/try_this_22.pdf. (Boltz, 2012) For many, engaging in the care helps to decrease the sensation of helplessness that is a precursor to anxiety and stress disorders. Having a purpose during crisis helps humans to navigate crisis. We define ourselves by the actions we take during crisis. To adjust to

the new role of 'family member of a critically ill patient' the family needs to learn what actions they can take to support the healing or dying process. This will need to be encouraged and taught by the nurse. Understanding how to participate in care decreases the fear and horror of the unknown. Participation may be as simple as applying lip balm, or as complex as helping with personal hygiene or bathing.

Because over 50% of ICU patients require caregiving after being discharged to home, the more the family learns about caregiving in the hospital, the better they will be prepared for caregiving at home (Desai et al., 2011; "Family Caregiving," 2011). When the Facilitated Sensemaking model was tested a kit was given to family members with these items:

- Nail file and fragrance free lotion
- Dominoes
- Word Searches
- Playing cards
- Lip Balm
- Blank Journal
- Non-denominational prayer and common list of family needs
- Standard lead pencil (not mechanical) with occupational therapy foam grip attached

All families reported that the items were helpful and recommended keeping all items in the kit. The list of family needs could be reviewed together as an assessment tool to see if the family had any unmet needs. This was often helpful and produced a different answer than when asked, 'Do you need anything?' For instance, one family reviewed the list and said that yes, they could use a visit from the chaplain and didn't know one was available. The rest of the contents in the kit could be used in a modified manner based upon the level of illness/injury of the patient. Cards or dominoes could be set out on the bedside table and the patient could be asked to point to the one with the most points. Or 'point to the 2'. With word searches, enlarged in a very large font, the patient could be asked to point to the letters of his name or point to the J. These activities were referred to as 'brain strengthening activities' which gave the family the connotation that they were helping with something of importance (J. E. Davidson et al., 2010b).

For those patients not yet able to bear weight or get out of bed, families were taught passive flexion of the ankle to prevent blood clots. The instruction was to flex the ankle and hold for 10 seconds, repeat 10 times on each foot. It was described that the flexion mimicked the activity of putting pressure on the bottom of the foot while walking. Preventing blood clots from immobility also conveyed to the family that they were being trusted with an important aspect of care. It is true that this is not necessary if the patient is on anticoagulants and pulsatile venous compression, but it is not false that it does add support to the regime of deep vein thrombosis prevention. Passive range of motion activities were also taught. Families were encouraged to rotate, flex and extend every joint (not affected by trauma) 10 times every hour (J. E. Davidson et al., 2010b).

If the patient was not conscious or able to participate, the family was told they could use the items in the kit to busy themselves while visiting. It was not

possible to predict which items different family members would use. For instance, a man was found to giving his brother a pedicure, something that one might think of as a 'female' activity. The most commonly used item in the kit was the lip balm, which families used instinctively without interfering with the endotracheal tube.

Families were encouraged to speak in conversation to the patient as if they were awake, even if not conscious or able to respond. They were taught how to use the pencil with occupational therapy grip foam attached to communicate with awake intubated patients. Families were also encouraged to play music that the patient liked or read the newspaper or novels while visiting to engage the brain. Explaining that keeping the brain active and engaged helps to keep the brain strong emphasized why the participation could be helpful. The point of all of these activities is that even in the worst of outcomes, if the family had important activities to engage in, they could look back and confirm to themselves that they had done everything possible to help their family member prior to death (J. E. Davidson et al., 2010b).

Whereas nurses of children and adult patients help to maintain family integrity, by providing activities that the families can do while visiting, families of babies need help to become a family. Participation in care is an important aspect of bonding as parents, grandparents and siblings. All activities between family members and critically ill infants need to be encouraged and taught to include skin-to-skin care, feeding, reading and conversation to promote brain stimulation and provision of touch. These activities are standard components of developmental care to prevent long-term developmental delay (Caskey, Stephens, Tucker, & Vohr, 2014; Westrup, 2014).

Nurses Improving Care for Healthsystem Elders (NICHE) is a program built to support healthcare organizations in optimizing care of older adults. Their website includes a free open source section for caregiving information which can be found at http://www.nicheprogram.org/patient_and_family_resources.

Participation in Decision-Making

As stated above in the section on Problem Solving, families have an opportunity to participate in decision-making during daily rounds, family care conferences and while visiting. According to the Facilitated Sensemaking theory, it is the nurse's responsibility to keep the family informed well enough to participate in the decision-making process and encourage the family to provide input during discussions about the treatment plan. By listening to the decision-making activities of all members of the healthcare team, the family learns to make sense of the situation which decreases fear and horror of the unknown, known precursors to stress disorders.

When the family provides useful information, it is important to thank them for the information to call attention to the fact that their input has been helpful. Family members of patients with chronic pain often have useful insight into the non-verbal expressions of pain that the patient exhibits at home. Inquiring about these is one easy place to start a dialogue of respect and involvement in the treatment plan. Inviting the family to alert the nurse when the patient exhibits these non-verbal cues of pain also invites involvement and further helps the family to define their role in the ICU.

Leadership Responsibilities: Creating a Family-centered Care Sustainability Plan

Setting up a sustainability plan to promote FCC is a leadership responsibility generally shared between nursing and medicine. The program of FCC will be more successful if quality monitoring is set up to ensure that policies, procedures or guidelines related to FCC are adopted into practice. A quality monitoring program conveys to staff and physicians that the principles of FCC are not optional and are instead essential elements of care.

The first step is to come to consensus on the essential elements of this organization's FCC. Which aspects of FCC will become practice standards? What is the current state vs. future state of FCC? Once consensus is achieved on this, transform what was once a visiting policy into a FCC policy. Create interdisciplinary practice standards that will be monitored and adhered to. To start, conduct a gap analysis to evaluate what is currently done in your environment vs. missing. Read the latest FCC practice guideline published on www.guideline.gov. Discuss whether any of the recommendations should be adopted into practice at an interprofessional critical care committee. A gap analysis tool is available free of charge to help quantify opportunities for improvement complete with an instructional video on how to perform the assessment. (http://www.iculiberation.org/Bundles/Pages/Family-Engagement.aspx)

Once minimal standards have been set, and communicated to the team, performance improvement monitoring should include both process measures of success and outcome measures of success. Process measures will include whether or not the targeted services are in place (e.g., family presence on rounds) and staff and physicians are adhering to these practices. For instance, if an ICU chooses to include family presence and engagement on rounds, a weekly spot check of the number of families present on rounds could be tallied on one shift to measure compliance with the protocol. Another method of gathering this data is to walk through the ICU one day a week and ask families if they were invited to rounds. If the ICU had already included family presence on rounds, but now wants to advance to family engagement in rounds (actively included : encouraged to participate by informing the team of patient baseline, history or asking questions), this could also be counted on one day's rounds per week to calculate protocol compliance. The number of families during one day's rounds that are invited to speak during the rounding process can be calculated as a percent.

Outcome measures include measuring whether the program of FCC results in family satisfaction with ICU services. Routine patient satisfaction surveys rarely adequately assess patient and family satisfaction with services performed in the critical care environment. One commonly used validated tool that can be used instead for this purpose is the FS-ICU (FS =family satisfaction) developed by the Society of Critical Care Medicine and may be found open-source at http://www.thecarenet.ca/resource-center/family-satisfaction-survey The survey includes two subscales: family satisfaction with care and family satisfaction with communication. The survey does not include questions related to timeliness of information, appropriateness of communication and comportment (professional vs. rude communication which have been found to be important to families and affect

satisfaction with care. (David J. Shaw, Davidson, Smilde, Sondoozi, & Agan, 2014). The FS-ICU tool may be used to conduct a baseline assessment prior to taking action to improve FCC, and then tailor action items based upon the results.

Action plans are based upon recommendations to provide family with structured communication, presence, tactics for engagement at the bedside, and support to help families bond (in the NICU) or maintain family integrity (in pediatrics and adults).

The following case study that illustrates how using the strategies discussed for a program of FCC can assist families to come to terms with critical illness quickly and effectively. This enables the family to live through, and make sense of the crisis in a way that avoids the development of PICS-Family.

Case Study: Putting it All Together: Making Sense of Critical Illness: One Family's Experience

The benefits of FCC are clear to my own family in view of our experience with our first child, born several years ago with a severe congenital heart defect. Throughout the crisis of his birth, sudden illness, rescue, treatment, and eventual recovery, we faced emergencies and uncertainties we'd never dreamed of. We confronted options and decisions we never wanted to think about, much less live through. Our situation demanded immediate response, ongoing accommodations, and radical readjustment of hopes, and expectations. Our baby was born fighting for his life. We found ourselves fighting along with him, and for him, in the terrible and wonderful NICU, with doctors and nurses and technicians, our new friends and allies. In the end, after two years of treatment, three open-heart surgeries, multiple visits to the catheterization laboratory, and some difficult complications, he won. We won. They saved him, and as they did so, they brought us along, my wife and me, in such a way that we could somehow manage and keep ourselves together as a family, ready to care for a sick little baby and able to care for ourselves.

In this section, I'll share some of our experience as a family making sense of our son's critical illness. I'll highlight typical family needs and professional interventions that drive effective family-centered critical care. These needs are many: Family members need humane interpersonal support as they react to the emotional and psychological impact of the crisis. They need continual communication from the care team, and they need to see that team members communicate effectively with each other. They need medical education as they struggle to understand and gain insight into their loved one's condition, and what it means for the future. They need orientation to the often new and intimidating environment of the ICU, with its monitors, machinery, and bustle of nurses and doctors. They need guidance to understand their role as surrogate decision-makers, where this applies, and explanation of relevant bioethical concepts and principles of substituted judgment and best interest of the patient. They need practice, coaching and technical training, mostly from nurses, to prepare them for home caregiving. They need personalized, culturally competent emotional and spiritual care as they manage their own fears, uncertainties, and grief in the face of illness and mortality. Fundamentally, they need to feel *trust*: that they can trust the professional team to

provide excellent care for their loved one, come what may. They need continuing assurance of the team's professionalism and interprofessionalism, working together for the good of their patient. And they need to feel included and cared for themselves--which they are brought into the "inside" of their loved one's care and they have a welcome role to play in it. When these needs are addressed, families fare better through the immediate crisis of illness and treatment, and are better prepared for phases to come, whether these include at-home caregiving, bereavement, or both. Family-centered care minimizes harms to the family and thereby fosters conditions more favorable to the patient's best recovery, during and after intensive care.

Making Sense of Critical Illness: Communication in Crisis

Critical illness can be expected and inevitable, or sudden and traumatic. Either way, it forces families to contend with novel questions. As they put the pieces together and try to make sense of things, they need continuing communication and support from various members of the care team, and nurses in particular. In early stages of intensive care, families need basic medical information in order to come to terms (quite literally) with their patient's condition, often in the context of their participation in shared decision-making processes. They need personalized, culturally competent emotional, psychological, and spiritual care, as they contend with the impact of the crisis on themselves. Families are desperate for information and reassurance, and utterly reliant on relationships with care providers, as sources of information and support. Effective communication and relationship building are fundamental to effective FCC.

In my family's own case, our son's illness was wholly unexpected and emotionally devastating. Minutes after he was born, he went into apparent respiratory distress, and his rescue began. He was hustled quickly from the delivery room for treatment. Starting there, in those first few minutes, our own need for information, counsel, and human support was absolute. I'm grateful to say that our doctors and nurses met this need, to the best of their ability. We were updated as the indications became clear and even as they grew more dire. Postpartum "fluid in the lungs" became "pneumonia." Pneumonia gave way to a "heart murmur." Suctioning of the airway led to placement of an oxygen hood, soon followed by a mechanical ventilator. As we waited, moment by moment, finding by finding, we were at least kept in touch with things, alarming as they were. Our son (I'll call him John) was born with an undetected case of hypoplastic left heart syndrome (HLHS), a cluster of problems that includes, typically, an underdeveloped and too-small left ventricle, a dysfunctionally narrow aorta, an atrial septal defect (patent foramen ovale), leaky or narrow mitral and aortic valves, and (in our baby's case) a leaky tricuspid valve.

Presentation of John's illness could not have been more dramatic. He was born full term, nine pounds, rosy and pink. For his first few minutes, as his mom held him, and we cut the umbilicus and cleaned him up, he was fine, thanks to a small but critical thing: The ductus arteriosus stayed open. The patent ductus, normal to fetal anatomy, provides a passage between the aorta and the pulmonary artery, shunting circulation away from the fetal lungs. Typically, it closes soon after birth---minutes or days. In John's case, however, the ductus, located just below the

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disastrous pathological narrowing of his aorta, was the only open route for any arterial circulation whatsoever. A dozen minutes after he was born, the ductus closed. I imagine it, surely inaccurately, as a doorway snapping shut---as it normally should---but in this case it shut down that only open route, backing up the entire system: decompensation, respiratory distress, desaturation, cyanosis, and all that follows. As soon as he was born, and his heart switched over to its normal course, he was in trouble. He stopped crying, started up with a little coughing sound, and before we knew it, the nurse had him out the door, the first one that day to save his life, after the OB brought him forth. Not a word was spoken, but the look in her eyes said it all.

Over the next two hours, we watched that door and clung to every word from each succeeding visit from doctor or nurse. John was rescued, stabilized, diagnosed with a heart murmur, and eventually transported to a children's hospital with a level three neonatal intensive care unit (NICU). "Would you like to hold the baby before he goes?" "Yes, we would," and we did, IV's, endotracheal tube, and all. There, downtown, HLHS was confirmed in the ghostly flicker of echocardiogram. A friend drove me there to meet with the doctors, on my own, my wife left behind, in pain, exhausted and horrified in the care of nurses and friends. The doctors advised a plan: John's condition, on the spectrum of HLHS, was not so severe--he had just enough left ventricle to work with. And the leaky valves could be sealed and the aorta ballooned up and stented, all in the catheterization laboratory, for circulation to begin. No need for open-heart procedures, a bit of grace. Treatment will proceed the next day, if you agree. I called my wife, and yes, we said yes.

Within hours, the doctors revised their assessment: John's condition was too severe, so the cardiac catheter treatments wouldn't do. Instead, a stronger response was advised: the Norwood procedure, a staged reconstruction of the system over three open-heart surgeries: one the next day, if we agreed a second in five or six months, and the third at 18 to 24 months of age. We were to go to the hospital the next morning, to talk to the doctors and decide how to proceed, whether to proceed, and what was best for the baby.

My wife was in labor for 21 hours, pushing for nearly three, before John was born. She held him at birth, those few minutes, and in minutes he was gone, off to the NICU. All we knew was what they told us. That morning, that day, we had only minutes or seconds to process things as they happened, and make some quick decisions about transport and treatment. We relied absolutely on John's care team for information, advice, and reassurance, and our need to make sense of things was an emergency in its own right. No one is prepared for such a thing, and we had no time at all to wrap our heads around it, but circumstances demanded our comprehension and decision-making.

Here is how the teams at both hospitals took care of us that first impossible day: They kept us informed, each step of the way, as much as possible. They acknowledged our own suffering and let us know they cared---that we counted, too. They showed that they understood, how much we needed information, and they promised to share what they found, as soon as they found it. Doctors and nurses provided information, explanations, and emotional support, all at once, in direct words and sympathetic gestures. Chaplains and social workers stopped in to check

on other needs and offer spiritual care, additional support, and further resources (a breast pump and access to a medical library were high on our list). What helped us most, in those first hours, was not being left out, and knowing that we would hear from people, to help us bare with things.

Making Sense of Critical Illness: Building Trust in the Care Team

Two days old, John went through a six-hour surgery, Norwood stage one, and did well. He recovered steadily, but spent nearly three weeks in the NICU. We couldn't have coped without the information and support we received from the doctors, nurses, and other hospital staff. Our fears and anxieties were balanced against our growing sense of trust in the care team: Our baby was in bad shape, but he was in good hands. In the NICU, frightful as it was, we took confidence from the professionalism and commitment of John's providers; doctors, nurses, and technicians alike. I could relax, just a bit, and reconcile myself to my own uselessness and helplessness in this situation, knowing that very useful people were providing very expert help. It's out of my hands, but it's okay. Better hands were at work.

John's providers inspired confidence and trust in various ways. They helped to take the mystery out of things---not just John's condition, but the ICU as a whole. From our first visit to the NICU, we were made to feel welcome. We were told straight up that our presence and engagement in John's care were important to his success. We received a thorough orientation---a tour of the facilities and explanation of protocols, for hand-washing, visitation, entrance to the unit, and so forth---giving the impression that our presence and participation there were taken for granted, totally the norm. At bedside, a superb nurse explained the various tubes, wires, machines, monitors, alarms, and routines. She explained her own work as she drew medications, cleaned lines, monitored fluids, and so on. She fielded our 10,001 questions, and she kept it light. We managed a laugh now and again. Talking us through it all, she conveyed the indirect message of her own professionalism, expertise, and technical control, in the midst of ongoing crisis. This, it struck me, is her "every day." She is comfortable here---it's *possible* to be comfortable here---and I drew comfort from this.

We were encouraged, leaned-upon even, to make ourselves known to the baby---to touch him, talk to him, sing to him---so that, despite the crisis and tubes and machinery, we could begin the serious business of loving our child. They made it possible for us to hold him, before and as soon as possible after his surgery, and invited us to feed him, bathe him, and change his little diapers, as he recovered and progressed. We were made to know by the nurses that this was our child, ours to love and protect, and no one else could take our place, particularly in this time. And my early sense of uselessness and helplessness began to fade. I learned how to be a father in such a place. Our nurses knew the importance of our presence there before we did, and helped us see it, too.

Our nurses helped us know what to do, and how to help---when, where, how, and why. We learned enough about the NICU, all we needed to know, and settled into some routines. We were welcome at bedside practically any time besides shift change, and were sometimes present during rounds, just to listen in. Our nurses encouraged us to go home at night, to take care of ourselves and get some rest, for

the sake of the long haul ahead. They told us to call in at any time to check on the baby and say good night, and we did, every night, and the nurse was there with a good word, every time. Days went by, and nurses rotated in and out, caring for John, and it struck me: That nurse was great! And this one is just as good! And they work so well together---to manage the hand-off---and with the doctors too! We learned how healthcare is a team endeavor, an interprofessional domain. The night that John was recovering from his first surgery, we were brought in for a first post-operative visit. I marveled at the ballet before me, the team's movements together, as they monitored the baby, adjusted meds, switched out lines, and completed the perioperative transition. Our surgeon stood stock still at the foot of the bed, watching and offering occasional directions, soft-spoken, as nurses and techs dispatched various duties, following protocols and checklists all their own, all together. That image, of all that concerted activity, is emblematic for me, representing at its best the interprofessional nature of healthcare. That night, with so much at stake, my wife and I took certain refuge in this demonstration. Highly focused professionals working seamlessly together in cooperation and respect. Indirect message: *It's all about the baby. We're on it. Everyone works for the best outcome: For the baby.* Okay. I trust you.

Making Sense of Critical Illness: Medical Decision-Making

Imagine how we felt, my wife and I, first-time parents facing this decision, practically the first we ever made as parents: Thinking about what is best for the baby, did we want to pursue risky and complicated treatment, which *could* allow him to live? Or did we want to keep him comfortable and let him go, sick as he was and hard as his treatments would be, *on him,* over three open-heart surgeries? I remember thinking: *It's not supposed to be like this. How can this be happening? How can I make this choice?*

Family members, faced with surrogate decision-making responsibility, often need support, guidance and basic explanation of their role. Concepts and standards of decision-making, like substituted judgment and best interest, must be explained in clear terms, and surrogates should be provided sufficient counsel and support as they work toward a decision. From a certain angle, every other communication about the patient's condition, all the information sharing and emotional support, and all the relationship- and confidence-building endeavors, are merely preparations for the process and goal of sound decision-making. When the family is well informed about their patient's condition, when they understand its meaning for the patient's quality of life, and when they have the emotional resilience and support to consider things clearly, decision-making will proceed with less difficulty, even if the decision itself is a difficult one, among difficult options.

The morning after his birthday, we visited John in the NICU at the children's hospital, stabilized with a drug (prostaglandin E series) that reopens the ductus. Then we sat with two doctors and a social worker to discuss the decision before us. The surgeon and cardiologist reviewed the long list of things wrong with John's heart, and they explained the surgeries that were indicated. John, if we agreed, would undergo three reconstructive surgeries: In the end, venous blood would bypass his heart altogether and feed directly into his lungs. Oxygenated blood would enter the heart (as normal) through the left atrium; there, however, it would

mostly pass over to the right atrium, through the existing atrial septal defect, widened up and made virtuous. Oxygenated blood would flow down into the right ventricle, and the right ventricle (the wrong ventricle!) would pump blood to the body. How? Through the ascending pulmonary artery, now grafted onto a reconstructed and widened aortic arch's we saw it, eventually, and over-simply, our son would end up with a two-chambered, vaguely amphibian, perhaps reptilian heart: the Amazing Frog Boy! And we owned it: We found baby socks with little froggies on them and brought them to the NICU, and in years to come we dressed him in pajamas decorated with frogs and lizards and turtles, and gave him Kermit the Frog stuffies, and so on.

We consented to treatment, but only after a long discussion. The doctors told us that, given the baby's critical condition, the long road ahead, the burdens and risks of three surgeries, and the uncertain outcome, we had the option of saying no, selecting only comfort care. "Parents in your position sometimes choose comfort care only," they said, neutrally, opening doors without giving directions. Still, that implicit permission sank in hard: Our little boy really *was* that sick.

So we worked through the decision: We reviewed the chances for basic physiological success of treatment (pretty good, at least for the first surgery, given the baby's maturity, healthy birth weight, and relatively simple HLHS presentation). Then we discussed other sorts of risks---neurological outcomes were especially important to us. The doctors talked of how John should not have suffered any anoxic injury as yet, and how such risks are minimized in surgery. They told us about "slow flow" and "no flow" techniques, to slow or even stop the heartbeat for a window of time to work on the tissues, and how they take measures to protect the brain from hypoxia---how for example the body is cooled below normal body temperature, affecting metabolism. I recall that story I heard back in Ohio, the typical story of a kid who fell through thin ice on a frozen pond, lost for half an hour, rescued, revived, to walk away uninjured. And chances are the heart needn't be stopped altogether, anyhow.

We talked about the future, and the sort of life he'd have as a kid and adolescent. Mostly good news: a fairly normal life, most likely. He'll see his share of doctors. He'll have a couple/three trips to the catheterization laboratory as he grows. He won't be a track star. And he won't play contact sports. Not a problem for us, in any case. I thought. He'll have every hope of a decent life. We soon realize: On the children's hospital spectrum, in that frame of reference, we're *lucky*. It's a wonderfully good prognosis: three-year-old boy on a tricycle in the driveway. As for the remote future? No one really knows. At the time, back in 2002, the oldest Norwood kids were barely in their twenties, so it remained to be seen how well these hearts would age. In sum, though, John was judged to be a good candidate for surgery, and should it succeed, he would have a good life.

My wife and I were left alone to talk. We considered all the unforeseen and unpredictable bad things that could happen---all the complications, over three operations, but we stared them down. They were nebulous, where John was crystal clear. Our discussion with the doctors had led us through the right questions, and we considered the necessary things: what it meant for John, how it affected him, and what we risked to get him better. In as many words, under the doctors'

guidance, we considered the basic bioethical concepts: John's best interest, the proportionality of benefits and burdens of treatment, and the impact on quality of life. We signed the consent forms, left the conference room, and everybody went to work.

Making Sense of Critical Illness: Preparing for the Future

With information, advice, and support from our nurses and doctors, we made it through the first hours and days. We came to terms with our son's condition, considered the possibilities, and found our way to a treatment decision that felt right to us. Our focus turned to John's recovery and eventual homecoming. We spent nearly three weeks in the NICU, at bedside every day. Here I learned about nurses, and nursing, and what nurses do. At the time I had no real idea. I had been dumb-luck healthy all my life: a couple of nights in the hospital, total, in forty years. I remember riding down to the hospital that first morning, as my friend drove me, wondering what was to come. I knew the doctors would spring into action and do amazing things to save my son: I knew this from TV! But I had no idea about nurses. And yes, over the course of those two years the doctors intervened a half-dozen times and performed seeming miracles to save our baby's life, and I cannot express sufficient thanks for that. What I soon saw was that those calm courageous NICU nurses intervened a half-dozen times *an hour* and performed routine tasks and saved our baby's life time and again, countless times, just by keeping him cozy and warm and well-fed, dosed and diapered and comforted and mothered, all the time and in so many ways we could not. And I saw my future in what they did. I saw the day we would take John home, and I was terrified.

I knew nothing about babies. I was the baby of my family. I had never been near a baby, the day I drove my pregnant wife-in-labor to the hospital. Who was I to take home a baby, much less a baby on seven different meds with a zipper scar and a nasogastric (NG) tube and sat levels of 78 on a good day? But now, here were these NICU nurses, these absolute experts, teaching *me* how to feed, bathe, diaper, medicate, hold, and comfort a baby. They put my wife and me through baby boot camp, basic training, getting us ready to take him home. Here's how to bottle-feed an aerobically deficient little man, too tired to suckle, each sip a victory, and here's how to send the rest of the feeding down the nasogastric tube, to baby's little belly. Here's how to crush an aspirin to dust, and mix it with some breast milk, and suck it into a syringe, and squirt it into baby's mouth. Here's how to get the poo out of all those wrinkles, fat little baby fats. Here's how to draw the meds without getting bubbles in the oral syringe. Here's how to wrap the baby in a blanket so he feels happy and safe and looks like a baby-filled burrito. Here's how to replace that NG tube *again*, weeks later, the third time he's pulled it out and we're down at the hospital again. Babies don't like NG tubes, and they have ways of getting that little pinky finger under that tape to pull it out. This time, teach me how to put it back in. (And they did.)

Thus: Almost three weeks later, the day came, and we took our baby home. I half-believed that we could do this, my wife and I, as we took over his care. In fact, our nurses had trained us well: We managed. John was on seven medications on an every-three-hour dosing schedule, 24 hours a day, lined up with his feeding schedule, 30 ml of EBM every three hours. My wife pumped as I fed the baby and

administered medications, around the clock. With his makeshift circulation, after stage one; his saturation levels were at 72-75%. Breastfeeding was beyond him, too much work, so my wife pumped milk (for six months!) and I prepared the bottle, and John drank about half of his feeding before passing out, and the rest went down the nose hose. And we measured out the doses and kept up his meds and managed his feedings and he made it. And we did too. We took over for the nurses and nursed our child together, in every meaning of the word. Five months went by, and it was time for the next surgery.

And again we made it, and again, through stages two and three, and today our son is a normal adolescent, scowling and angry and bored---the way it should be. Years later, now I see how clever they were, those nurses: They welcomed us into the NICU so that we could get to know our son, get to know them, and get to know how to get along without them, eventually. All along they were coaching us, training us, and modeling good care. They taught us not just how to change a diaper, draw meds, or feed a baby through a tube: They taught us how to be tough-minded and caring at once, and believe in our baby's recovery. They taught us that we could do all this, mostly by doing it themselves, as we watched and listened and learned. Thanks to their care, we could take over. Now it made sense. We were ready, and we made it.

Conclusion

This case study exemplifies the key role that nurses play in promoting FCC. While support for family-centered care with the promotion of open visitation, family participation on rounds, and family presence during invasive procedures or resuscitation varies internationally, there is an increasing focus globally in promoting FCC.

FCC is important to help families through the crisis of critical illness. The nurse's role in encouraging family presence and engagement, assuring information needs are met, developing caring relationships, promoting family bonding and preserving family integrity may minimize or prevent PICS-F and optimize caregiving required after discharge from the ICU. A structured approach to FCC set out in a policy, standards of care or organizational guideline is advocated. A monitoring program to assure compliance with FCC standards is advised. The FS-ICU may be used to gather direct feedback on unit performance from ICU families. Both the Quality Caring Model and Facilitated Sensemaking mid-range theory of nursing can help nurses understand how to apply the principles of FCC in practice. As the family plays an essential role in promoting recovery from critical illness, advancing the involvement of families and advocating for FCC in the ICU is a priority area for nurses worldwide.

Figure 1: Post-Intensive Care Syndrome-Family (PICS-F)
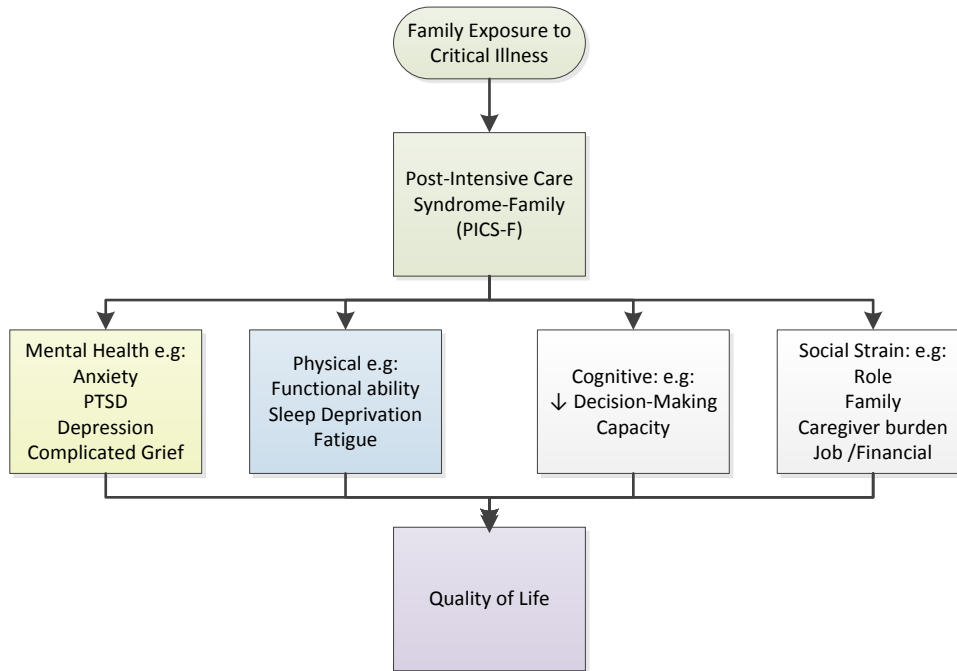
Legend: PTSD= Post Traumatic Stress Disorder

Figure 2: Caring Relationships: The Core of Quality Nursing Caring. Adapted with permission from (Duffy, 2013).
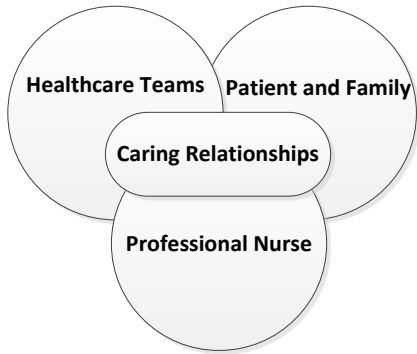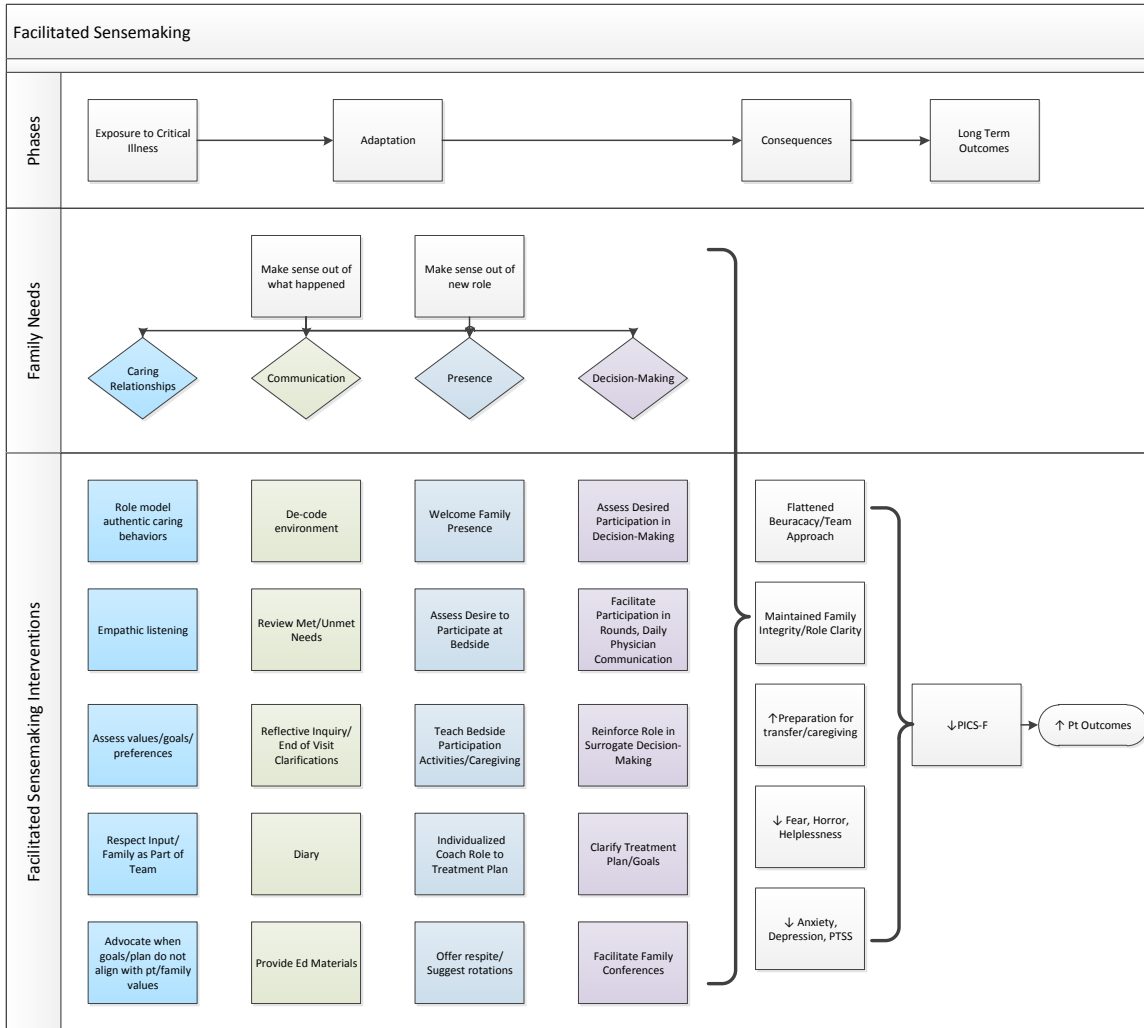
Figure 3: Facilitated Sensemaking Conceptual Model

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