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Nursing Strategies to Support Family Members of ICU Patients at High Risk of Dying

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Abstract

Objectives: To explore how family members of ICU patients at high risk of dying respond to nursing communication strategies.

Background: Family members of ICU patients may face difficult decisions. Nurses are in a position to provide support. Evidence of specific strategies that nurses use to support decision-making and how family members respond to these strategies is lacking.

Methods: This is a prospective, qualitative descriptive study involving the family members of ICU patients identified as being at high risk of dying.

Results: Family members described five nursing approaches: Demonstrating concern, building rapport, demonstrating professionalism, providing factual information, and supporting decision-

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making. This study provides evidence that when using these approaches, nurses helped family members to cope; to have hope, confidence, and trust; to prepare for and accept impending death; and to make decisions.

Conclusion: Knowledge lays a foundation for interventions targeting the areas important to family members and most likely to improve their ability to make decisions and their well-being.

Keywords

Palliative Care; Nursing Communication; Family Members; End-of-Life; Critical Care

Introduction

Fifty percent of U.S. hospital deaths occur during or after a stay in an intensive care unit (ICU), [1] and two thirds of ICU deaths involve an active decision to limit treatment. [2-6] Because most ICU patients are not able to make decisions for themselves, [7-10] family members must make these difficult decisions on behalf of their loved ones. When doing so, they may worry that their loved one has suffered or that they have given up too soon, and they frequently harbor lingering feelings of doubt, regret, and guilt. [11,12] During this vulnerable time family members rely on healthcare professionals to guide them through the decision-making process.

ICU nurses are positioned uniquely to provide such support because they have the most contact with both patient and family. Nurses deliver intimate, personal care allowing them to develop trusting relationships with patients and families, assess their needs, [13,14] and observe the responses that family members have to the changing condition of the patient. Some experts have advocated that nurses facilitate end-of-life (EOL) communication in the ICU; [15-18] however, little evidence points to which specific strategies are effective in this setting. [19] Without knowing which approaches family members find helpful or harmful, nurses rely on intuition [20] or personal preferences to guide them, or they avoid such discussions altogether.

Research indicates that physicians can learn to communicate better about difficult topics and that intuition alone is a poor guide. [21] Some communications skills described for physicians treating patients at the end of life may translate to nursing practice; however, the role that nurses play is distinct enough that strategies specific to nurses are likely to be more effective. Thus, empirical evidence about what strategies are perceived as effective by family members is needed so that nurses can guide their practice by knowledge of what works rather than relying on intuition. This study explored, from the perspective of family members of ICU patients at high risk of dying, the specific communication and support strategies that nurses used and how family members responded to these strategies.

Methods

We used a prospective, qualitative descriptive design, identifying patients likely to need complex decision-making and interviewing their family members. We recruited participants from two 16-bed adult ICUs in a tertiary care university hospital system in the Southeastern

United States. Because physicians are better able to discriminate between survivors and non-survivors than scoring systems, [22] to determine eligibility, we asked the attending physician or fellow to identify patients whom they deemed to be at high risk of dying or needing complex decision-making.

We applied a purposive sampling technique using maximum variation, [24,25] varying on attributes shown to explain differences in attitudes about the use of life support, including ethnicity, gender, and socioeconomic status (SES). [26,27] Ethnicity was stratified into 2 main groups, African American and Caucasian; SES was stratified into presence or absence of private insurance (including Medicare with a private supplement). We attempted to recruit at least two cases from each combination of these attributes with the goal of a maximum of 16 cases. Data collection ended when we achieved acceptable variation in attributes and redundancy of themes in analysis.

We followed each case until one of the following occurred: the patient died, the patient was discharged from the ICU, a decision was made to either withdraw life support or perform a tracheostomy for long-term life support. Because a two week time period prompts physicians to discuss EOL decisions, [29] we followed each case for up to two weeks. We interviewed each participating family member up to three times. We began each interview by asking the participant to tell the story of how the patient came to be in the ICU. We then asked directed questions, such as “what things have the nurses said or done that made it easier (or harder) for you,” and “how was the nurse helpful (or unhelpful) in making decisions?” The hospital’s Institutional Review Board approved the study, and all participants signed informed consent.

Between October 2012 and February 2013, one of the authors (JA) spent a minimum of four hours daily for six days per week on the units observing interactions among staff, family members, and patients; engaging in informal discussions with the staff and family; and attending rounds and family meetings. Data collected included patient and family demographics, observations of family meetings, daily flow sheet of patient condition, and narrative style recorded family member interviews. Daily field notes were used to provide context and assist with data interpretation. Interviews were transcribed verbatim, and the accuracy was verified by comparing the transcription to the recorded interview. [30] We used ATLAS.ti qualitative data analysis software system [31] to aid in coding, organizing, and managing the data.

We applied qualitative content analysis to these data. [30] To increase trustworthiness, we kept an audit trail of coding decisions and theme development. [30] In addition, we used reflexive memos to explore assumptions. [32] To identify family member responses to specific strategies that nurses used when supporting family members making EOL decisions, we used provisional coding [33] with a priori codes based on a review of the literature and our own pilot work. [19,34] We also used open coding, [35] identifying nursing actions and family members’ responses to those actions. [33] Once the data were coded using both *a priori* and *a posteriori* codes, we used pattern codes to categorize the data and explore emerging themes. [33] The coded text were arranged into categories and subcategories based on how the codes were related. [32] In order to understand the underlying meaning of the data, categories

were linked to emerging themes, which involved interpretation and explanation. [36,37] This combination of inductive and deductive coding allowed us to go beyond the codes from the literature to develop a greater depth of understanding of how family members perceive nursing strategies.

Results

We identified 17 cases (see Table 1) and completed a total of 42 interviews with 32 family members. We achieved variation in the attributes of the family members with regard to gender (24 female, 8 male) and ethnicity (7 African American, 25 Caucasian). We also had variation in age and relationship of the family member to the patient. The income and education levels indicate a higher SES status than the general population.

Of the 17 patients, 11 died; eight died in the ICU. Nine of the 11 deaths involved decisions to limit or withdraw treatment. These decisions included a “one-way extubation” (removing the endotracheal tube in hope that the patient will survive but with a pre-set plan to not re-intubate if the patient does poorly), an unaggressive approach to infection, a do not attempt resuscitation (DNAR) order, and a decision to withdraw life support.

NURSE COMMUNICATION STRATEGIES

Family members’ descriptions of nurse communication strategies and responses were collapsed into five categories described below and in Tables 2-6. The family members’ responses to these strategies are summarized in Table 7. The categories are equally weighted in importance but presented in an order that shows cumulative logic, where suitable. For example, the fifth category, supporting decision-making, relies on the foundation of the first four categories.

Demonstrating Concern

Nurses exhibited a number of behaviors that demonstrated concern (or lack thereof) for the physical, emotional, psychosocial, and spiritual well being of the family and the patient (Table 2). These included ensuring that the patient and family member were comfortable, encouraging family members to express their emotions, having an optimistic outlook, and supporting spiritual practices. For example, the need for nurses to be flexible and allow liberal visitation was a recurrent theme. The wife of a patient who subsequently died expressed this need:

> I know that there is a rule that there is only 2 visitors in there, but for me and both kids to be able to be in the room at the same time and not have to separate us as a family…means a lot so we can be there together…It helped me be with my kids… for their support…We need to be together as a family right now. (Wife of P11)

When family members perceived that the nurse was caring and compassionate, they were able to trust that the nurse would be “there for them” and their family member, that the nurse “had their back.” Having this trust and confidence allowed them to leave at night and be able to rest and take care of themselves and their other family members.

Some family members described nurses demonstrating lack of concern for them or their loved one. One example was a nurse who told the wife of a dying patient that the patient could not hear her:

> We always just come in and get right down in his ear and say, 'Hey how are you? We're here.' [The nurse] came up and said, 'he can't hear you.' And I'm like, 'well I don't care if he can hear me or not, I'm still going to talk to him.' Oh, it pissed me off…Don't come in here and tell me he can't hear me…That doesn't leave you with a good feeling…I go to bed feeling agitated. (Wife of P11)

She stated that she was anxious about leaving her husband under this nurse's care.

Building Rapport

Family members described strategies that strengthened the therapeutic relationship (Table 3), which included holding family members in high esteem, being approachable, and being affable. Example behaviors included encouraging family members to talk about themselves and the patient, making eye contact, sitting close, using touch, engaging in small talk, and using humor. These strategies helped family members feel personally connected with the nurse, to trust the nurse, and to be more confident in the nursing care.

Although family members reported mostly very positive experiences with nurses engaging with them, in three cases family members described encountering a nurse who did not seem to be engaged with the family. The behaviors they identified included looking at the computer and not making eye contact, turning their back to the family member, and not introducing themselves when the family member entered the room or at shift change. The daughter of a patient described her experience with one such nurse:

> Normally at shift change, you'll get the hug or the care from the one leaving and the invitation that, 'everything's going to be okay' from the one coming on board. And at [one] shift change I got the care and concern from the one leaving, and the one coming on board wouldn't even look me in the eye. And if you don't look a person in the eye…I did not want to leave [my father]; I was like 'dear Lord please I've got to leave this place.'…When I left, there was no eye contact, there was no attempt to shake my hand, not even turn the chair in my way. So he's here with the nurse, I'm leaving …this is not good…[and] no you don't sleep. (Daughter1 of P13)

Family members described experiencing difficulty coping, lack of trust and confidence in care, hesitancy to ask questions, anger, and dissatisfaction in response to nurses whom they perceived as not engaging with them.

Demonstrating Professionalism

Behaviors demonstrating professionalism included showing a professional demeanor, showing respect for the patient and family members, and providing evidence that the nurse was collaborating with other health care providers (Table 4). A calm and confident demeanor helped family members cope by allowing them to know that their loved one was in competent hands. Demonstrating respect for the patient and family also instilled

confidence and helped the family members cope. Some family members described behavior that demonstrated a lack of professional ethics, such as chatting about non-work related issues and not paying attention to the patient's needs, which resulted in difficulty coping and lack of trust.

Perceived collaboration among health care team members instilled confidence in the care of the patient and trust that information received was consistent and truthful. Several family members described nurses working together as a team, helping each other for the greater good of the care of the patient. Family members also described collaboration between nurses and physicians. The daughters of one patient described seeing the nurse interact with the physician on rounds:

> Daughter2: It's good interaction between the doctors coming through and [the nurse], and it just, it makes you feel good.
>
> Daughter1: For me it was like, 'these people have their ducks in a row, and if anything happens to my father, I truly believe that he was at the best place, and he is getting the best care.'
>
> Daughter2: It made me feel that they're not dropping the ball because they're not communicating…At least they're working as a team to try and help our father. (Daughter1 and Daughter2 of P13)

Providing Factual Information

Family members described nurses as an important source of information about the ICU environment, treatments, and the patient's health status (Table 5). Having the nurse explain what was happening inspired confidence and allowed them to cope better. Some expressed feeling more prepared for what might happen next.

Much of the information that family members received was simply factual without interpretation. Nurses told them the vital signs and lab values, often focusing on the positive aspects of this information. Family members described how they came to an understanding of the prognosis by combining what they were seeing with what they were told by the nurses and physicians. At times, the family members' interpretations were overly optimistic, as evidenced by the following quote from the wife of a patient who was doing poorly and for whom the nurses and physicians had expressed no hope of survival. She described to me why she was more hopeful:

> When I asked about the labs. And I noticed that he's not getting any more… blood; so if he's not, my gut is those levels are okay. He's putting out the hundred [cc of urine] an hour, [it] seems [that] he's putting out something—that's better than nothing. He's still not moving any less than he had been. Um…I noticed the tube feeding amount has changed, and they've increased it, and he's tolerating that. Respiratory was just in there, and I asked how his lungs were, and apparently they're better today than they had been. I know these are just little things. (Wife of P5)

Although family members appreciated how busy the nurses were, having one come to the phone when the family member called for an update was crucial to their ability to cope. Being told to call back later was described as excruciating for some as they wondered what was happening to their loved one.

Although most often the family members found the nurses to be informative and forthcoming, in a few instances the family members described strategies that blocked information, such as being unable to answer questions, giving vague answers, guessing at what might be wrong, and giving inaccurate information. This decreased trust and coping ability. One family member described her response to being given inaccurate information:

> Some will say, 'well nothing's changed since last night,' and then I will find out, yes he [had] a seizure, …well that to me is important to know in the overall scheme of things. So, I'm thinking that he didn't have a seizure for two days, when actually he did have one the day before. (Domestic Partner of P8)

Supporting Decision-Making

Family members described that nurses supported decision-making by remaining unbiased in the face of decision-making, including leaving the decision to the family member, avoiding personal opinions, and accepting the decisions that the family member made (Table 6). Few participants described nurses openly discussing prognosis or formally delivering bad news. In many cases, nurses avoided discussing EOL decisions, deferring to the physician and focusing on other approaches, such as demonstrating concern and building rapport. However, some described that nurses interpreted information in more subtle ways, hinting at the prognosis by reminding the family member that the patient was still very ill, pointing out that the patient's condition had worsened or was unchanged from day to day, verbalizing uncertainty about the prognosis, and using body language and facial expressions to indicate a poor prognosis.

The response of family members to this approach varied. Several described that they expected to hear the prognosis from the physician, after which the nurse would discuss it. Several family members expressed an appreciation for the ability of some nurses to indicate a poor prognosis in ways that allowed them to be informed and prepared but also to remain hopeful. Other family members described nurses whom they perceived as pushy, judgmental, or callous. An example was the wife of a patient with liver failure who described two nurses as being pessimistic and judgmental when they tried to discuss the prognosis. When probed further, she explained that what she found difficult was the way they delivered the information; she expressed resentment and mistrust because of their tone of voice and failure to make eye contact. She related that other nurses were able to "tell it like it was" with a good attitude and a positive outlook. She described these nurses as "real people people," saying they could let her know how sick he was but do it with kindness.

Family members described nurses discussing the nature of decisions after the physician had initiated such discussions, including discussions of available options and consequences of those options, goals and values of the patient, and code status. They described nurses as sometimes approaching these discussions indirectly by hinting, for example, that a patient

might have been expressing a desire not to continue life support. Some were more direct, such as the nurse who discussed the patient's quality of life, saying, "oh yeah we can keep him on the ventilator for years, but then you have to look at the quality of life that they are going to have." (Wife of P11)

The daughter of a patient who subsequently died told a story of a nurse who explained that continued aggressive care would cause pain for her mother and who expressed his/her own desire not to inflict unnecessary pain. The daughter said:

> [The nurse] said, 'As long as I'm here taking care of her, I'm going to do everything that I can to make her as comfortable as possible'…I came to a point where I've got to accept it…I felt very comfortable; I even slept better at night knowing that [this nurse] was here with mom; so I felt better. (Daughter of P15)

This nurse's ability to frankly explain what continued aggressive treatment would entail and to reassure that the patient would be comfortable helped this family member to reframe her hope, to cope with situation, and to accept that her mother might die.

Some family members indicated that the nurses did not discuss any decisions with them and avoided bringing up the topic of EOL. One family member expressed dismay that nurses were not talking to her sister-in-law, who was the health care power of attorney, about EOL decisions:

> The main thing they [nurses] are doing is just sitting there…I'm not criticizing them, but they will…say, "everything is about the same."…I don't know who…but it's time…that somebody told her it's time to start dwindling him off. Am I wrong to think that? Do you get how long this has been? (Sister of P5)

Although this participant was not the decision-maker, she indicated that what she perceived as avoidance of EOL discussions was delaying decision-making.

Discussion

We examined 17 cases of patients who were at high risk of dying to explore their family members' responses to nursing communication and support strategies. We identified five categories of strategies: Demonstrating concern, building rapport, demonstrating professionalism, providing factual information, and supporting decision-making. These findings support and extend prior data from the nursing literature indicating that family members rely on nurses as they navigate this difficult transition. [19]

The nursing literature indicates wide variation in how nurses approach discussions of EOL issues and a lack of clarity about their role. [19,38] Our study shows that nurses varied in their approaches with some avoiding EOL discussions and deferring to the physician, some using indirect approaches, and others openly discussing EOL issues. In addition, recent literature demonstrates that nurses often give family members technical information without interpretation. [39] We also saw this tendency in our study; however, some nurses were able to place the factual information in a broader context and help the family member understand the prognosis.

Findings from studies of family members of ICU patients indicate that family members look to physicians for medical decisions and discussion of prognosis. [40,41]

However, one study found that some family members expressed appreciation for nurses who gave them clear prognostic information, affirmed their decisions, and helped them with decisions, such as whether to try to take their loved one home. [41] Our study demonstrated that, although some family members expected the prognosis to come from the physician, others were open to hearing prognostic information from nurses, especially if the topic had been initially addressed by the physician.

Previous studies have reported numerous needs expressed by family members of ICU patients, the most important being the need for information, having questions answered honestly in lay terms, and knowing the prognosis. [40,42,43] Other studies reported that family members also express a strong need to be heard, to feel connected with nurses and physicians, and to have frequent contact with their loved one. [44,45] We found that, although family members were hungry for information, they also highly valued nurses caring and relationship building skills and the ability of nurses to deliver information in a way that supported hope. This study demonstrated that the style of communication and the strength of relationship had a strong influence on how family members responded, regardless of the professional role of the messenger. Nurses who had developed strong connections with family members by demonstrating concern, building rapport, demonstrating professionalism, and providing information, at times were able to support decision-making by discussing the prognosis and goals of care. However, when family members perceived a nurse as uncaring, disconnected, or unprofessional, they voiced mistrust and distress at that nurse's attempts to engage in EOL discussions.

Limitations

Because of the inherent uncertainty in determining a patient's prognosis early in the ICU stay, participation of seven of our enrolled cases did not involve a transition from curative to palliative care; either the patient survived (n=5) or died (n=2) before any EOL decisions were made. Although data from these cases did not contribute to understanding of EOL decision-making, they did contribute to the understanding of strategies nurses use with families to demonstrate concern, build rapport, demonstrate professionalism, and provide information. The study time period of two weeks also limited the findings because several patients were in the ICU for more than two weeks. Three patients died after they had completed the study, and EOL decision-making occurred after they were no longer in the study. Additional limitations included lack of participants representing lower socioeconomic status. Additionally, the presence of the researcher on the unit and the knowledge that the researcher was a nurse might have affected how the family members responded.

Implications for Practice

Approaches to demonstrate concern and build rapport are crucial to the ability of family members to cope. When nurses use strategies such as making eye contact, facing the family, and coming to the phone when a family member calls, they instill trust and confidence, helping family members to cope. In contrast, being curt, telling a family member that their

loved one cannot hear them, avoiding eye contact, and making family members wait unnecessarily for updates on the condition of their loved one are a few examples of behaviors that erode trust and make it more difficult for a family member to cope. Nurses can and should be taught these specific skills.

Implications for Future Research

Given that many of the family member participants were open to hearing prognostic information from nurses, potential research areas emerge, including investigation of how family members respond to nurses who take a leadership role in approaching discussions of goals of care. If family members are accepting of nurses engaging in such discussions, interventions could be developed and tested for their effects on family member outcomes, such as depression, anxiety, post traumatic stress disorder, regret, and guilt.

Conclusion

When interacting with family members of patients who are transitioning from curative to palliative care in the ICU, nurses use strategies that help family members cope; to have realistic hope, confidence, and trust; to prepare for the impending loss; to accept that their loved one is dying; and to make decisions. Nurses also use harmful strategies that negatively affect family members' trust and confidence in the nurses, increase their difficulty coping, and, in some cases, might delay decision-making. Although physicians are typically the first health care professional to deliver bad news of a poor prognosis, these data suggest nurses can employ identifiable strategies that serve as an important source of information and support for family members making EOL decisions in the ICU.

Abbreviations

ALL:	Acute Lymphoblastic Leukemia
AML:	Acute Myelogenous Leukemia
ARDS:	Adult Respiratory Distress Syndrome
CKD:	Chronic Kidney Disease
COPD:	Chronic Obstructive Pulmonary Disease
CPR:	Cardiopulmonary Resuscitation
DNAR:	Do Not Attempt Resuscitation
EOL:	End-Of-Life
HCPOA:	Health Care Power Of Attorney
ICU:	Intensive Care Unit
L:	Limitation Of Treatment
MOSF:	Multisystem Organ Failure
MVA:	Motor Vehicle Accident
OWE:	One Way Extubation

W: Withdrawal Of Life Support

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Table 1

Description of Cases and Demographics

Patient ID	Patient Demographics Age Race Gender Diagnosis	Family Member Demographics Relationship Race Gender	Decision to limit or withdraw	Disposition
P1	72 y/o CM Aspiration pneumonia	Wife CF	No	Discharged from ICU and later to home
P2	49 y/o AAF Altered Mental Status of unknown etiology	Sister-in-law AAF Brother AAM	No	Died in hospital after prolonged stay of several months
P3	55 y/o CM COPD and ARDS	Wife CF 2 Sons CM Daughter CF	No	Died in ICU after 5 days; CPR
P4	58 y/o CF relapsed AML	Husband CM	W	Died in ICU after prolonged ICU stay
P5	65 y/o CM hepatic failure, MOSF	Wife CF Sister CF	L/ DNR	Died in ICU
P6	76 y/o CM pneumonia, CKD	Friend/HCPOA CM Friend CF 2 sons CM	L/OWE	Discharged from ICU; died several days later in skilled nursing facility
P7	71 y/o AA F s/p cardiac arrest	Daughter AAF	No	Discharged from ICU
P8	70 y/o CM s/p cardiac arrest	Daughter CF Partner CF	W	Died in ICU
P9	50 y/o AAM with relapsed ALL	Sister AAF	L/avoid intubation/ DNAR	Discharged from ICU; Died in hospital
P10	23 y/o CM MVA	Mother CF	No	Discharged from ICU
P11	65 y/o CM with Hepatitis C hepatorenal Failure, MOSF	Wife CF	L/OWE	Died in ICU
P12	65 y/o AAM Stage IV lung cancer	Wife AAF Daughter AAF	L/DNAR	Died in ICU
P13	72 y/o CM Neurological disorder, aspiration pneumonia	Wife CF 3 Daughters CF	L/OWE	Discharged from ICU
P14	70 y/o CF Ischemic Bowel	Son CM Daughter-in-law CF Granddaughter CF	W	Died in ICU
P15	59 y/o AAF Pulmonary Hypertension	Daughter AAF	L/DNAR	Died in ICU
P16	33 y/o CM with ARDS	Mother CF	No	Discharged from ICU
P17	46 y/o CM with ALL	Wife CF	No	Discharged from ICU

Note. W = Withdrawal of life support L=Limitation of treatment DNAR=Do not attempt resuscitation OWE=One way extubation C=Caucasian A=African AA=African American F=Female M=Male HCPOA=Health care power of attorney COPD=Chronic obstructive pulmonary disease ARDS=Adult Respiratory Distress syndrome AML=Acute Myelocytic Leukemia MOSF=Multisystem organ failure ALL=Acute Lymphocytic Leukemia CKD=Chronic kidney disease MVC=Motor vehicle accident

Table 2

Demonstrating Concern

Strategies	Exemplar Quotes
Physical: FM described behaviors that supported the physical well-being of the patient and family members	
Assure Patient is Comfortable **Concern for family member needs** **Suggest that patient needs to rest**	Yesterday I mentioned to the day shift nurse that you know 'heck I haven't eaten anything today; I haven't thought about it.' Well the night shift nurse asked me had I eaten anything? That's incredible to me. They care about me. And they're not just here drawing a paycheck…It makes me feel valued; it reassures me…it makes me feel really good to be here and that my mom's here. I know that in a sense that they're taking care of me too because they care about my feelings and what's going on with me. (Son of P14, Single Interview, Day 5)
Negative **Avoid Patient care** **Rough with patient**	Daughter 1: [My dad] was choking, and the nurse was just kind of playing on the computer- 'Well you can do that [suction] if you want to'… And my dad was choking, and I said for me to have to say 'are you going to do something? Like move or I'm going to come and move you,' …and I went straight to [my sister's] house and said 'what did you think about that nurse,' and she said, 'I didn't have a good feeling, Daughter 2: And here he is, he's having extreme trouble breathing, and I was jumping up and down trying to suck it out of the back of his throat. He was sweating profusely, and his temperature had gone up a little bit, and [the nurse] said 'oh you can put a wet rag on him if you'd like.' What the [expletive] are you getting paid to do?…And nurse's turned his/her back talking to the nurse next door. And my anxiety and temper went out the roof. And I'm watching the clock twenty minutes later they're still chit-chatting about transfers, job openings, this that and the other. Like okay there's family here I can take a break. I was livid. …Oh yeah I had to do all that too. I had to keep his mouth…And I knew when I left, they weren't going to get it done. (Daughter1 and Daughter2 of P13, Second Interview, Day 8)
Emotional: FM described behaviors that supported the patient's and FM's emotional well-being	
Acknowledge FM Feelings **Empathy for patient and FM** **Optimistic** **Reassure** **Show emotions** **Stay with FM in a crisis** **Talk to the patient** **Validate FMs love and concern for patient**	He/she listened to me, he/she listened to what I had to say and…seemed to understand when I was about to cry. When I needed that extra pat on the shoulder or…that extra look across the room, he/she seemed to be very in tune with that, and that was just that connection. (Daughter2 and Daughter3 of P13, Third Interview, Day 11) If you ask, 'well it's been a better day,' or even if the first four hours were crap, they let you know but not dwell on it and give you the hope that 'okay since the last four hours have been better,…working towards a positive instead of a negative. (Daughter 2 of P13, Second Interview, Day 11) I like it when they talk to him, when they interact with him, even though he is not interacting a whole lot… And I think that brings the best out in him. It engages him, and that's really important. (Domestic Partner of P8, Single Interview, Day 9) He/she let me know how serious her condition was; didn't sugar coat anything; kept saying 'don't beat yourself over this' and letting me know how good of a daughter I was and how I stood by mama's side. (Daughter of P15, Third Interview, Day 14)
Negative **Blunt** **False Reassurance** **Say that the patient cannot hear** **Tell FM this is all normal**	I called and [the nurse] said…'well he has requiring 16 of PEEP and he's on 60% of FIO2 and he's only Satting 89%, and the next step is the oscillator.' In my mind I'm thinking, 'Oh my God.' But he/she's [said], 'he's not actively crumping.' I'm like, 'but what you just said to me, like as a family member who knows a little too much and is not thinking clearly, that is very scary.' (Daughter of P3, Single Interview, Day 3) I've heard [the nurse], 'Darlene, keep your faith up,' that he/she has a member of his/her family very sick, and they came back…If I had

Strategies	Exemplar Quotes
	not heard that doctor that day, I would have thought, oh that's wonderful but I think he/she was giving her false hope. (Sister of P5, Second Interview, Day 13)
Psychosocial: FM described behaviors that supported their coping and ability to maintain an intact family unit	
Allow FM to Stay During Procedures **Assess social situation** **Bend the rules** **Encourage FM to participate in care** **Encourage FM to care for themselves** **Explain that patient can hear** **Go beyond regular duties** **Use personal story to encourage coping**	When [the nurse] was here, he/she don't really stress me about having to leave out the room. [The nurse] let me stay right there because that's my mama. (Daughter of P15, Third Interview, Day 14) He/she asked a lot of questions that probably weren't on the paper, about our situation at home, 'do you care for him by yourself, is there someone else there that's with you? How do you feel about that? Are you stressed at all? Do you think you might want help when you go home?' It seemed like he/she was truly interested in getting the whole picture. (Wife of P1, Single Interview, Day 2) And he/she even asked me to help him/her move mama and put the pillows behind her to help her position and stuff. (Daughter of P15, Third Interview, Day 14) [The nurse] said [to patient's grandmother], 'yeah, a lot of times they can hear you talking, so say all you need to say to him. Say it in his ear, talk to him.' It helped her instantly. I saw it because she thought, 'my grandson heard me,' and she did not know at the moment whether it would be the only time she would get to say what she needed to say to him. And hopefully he did hear her. But that's important because…if you lose somebody right after that, that's going to help you to say, 'I said what I needed to say and they heard me.' (Mother of P10, Single Interview, Day 2) But [the nurse] told me, 'you've got to go home. You've been here two days, you've got to go home and get you some rest, you've got to take care of yourself,' I knew he/she was very concerned about me…I felt that. (Wife of P11, First Interview, Day 4) I started crying, and [the nurse] said, 'That's going to make you feel better, I know the feeling, I'm a nurse now, but I've been in a situation, and I always felt better when I cried.' It just made me feel like it was a person coming just for our family. And he/she didn't share details but just said something like that, 'go ahead and cry.' (Sister-in-law of P2, single Interview, Day 2)
Negative **Rigid**	[[That nurse] sticks right by the rules; 2 people; doesn't bend the rules any. …We just want to sit with him, but he/she kicks us out. If our time is limited, we want to be with him every minute we can be with him. And he/she knows how critically ill he is. Like right now, I don't have anywhere to go, anything to do for two and a half hours, why can't I sit there quietly on my lap-top? Nothing major's going on with him. I just want to be there. But, I can't. (Wife of P11, Third Interview, Day 12)
Spiritual: FM described behaviors that supported spiritual well-being	
Acknowledge Faith	When Claude came in, we had gotten a prayer cloth that we wanted to put…over him. [The nurse] explained that that was fine but that also his temperature had been going up; that's why the room was so cool; so it may [need to] be removed. But he/she honored her request to put it over him and understood that…Even when the nurse came to tell what my father had done [pulled out his ET tube] he/she also [said] 'continue to pray,' so that lets me know that you too know the powers that God has as well and that prayer can change things… It makes you feel good. (Daughter of P12, First Interview, Day 3)

Table 3

Building Rapport

Strategies	Exemplar Quotes
Demonstrating High Esteem: FM described behaviors demonstrating that the nurse held the patient and FM in high esteem	
Affirm **Encourage to talk about patient**	And [the nurse] asked about Memaw, like 'what does she like to do'. [It was] personal, Memaw wasn't just a patient. It's like [this nurse] wanted to get to know her. I just felt like they care. That made me feel good about him/her taking care of her. It's like if he/she wants to know this about her that he/she cares enough to ask, then I know he/she's going to take good care of her… It's hard to leave, but it makes it easier to leave knowing that they're going to be taking care of her. (Granddaughter of P14, Single Interview, Day 6)
Negative **Ask Why FM Not Visiting More Often** **Condescending**	[That nurse] really talks down. 'Ma'am I told you, this is.' [This nurse] will repeat him/herself like, 'are you not getting what I'm telling you?' And it's just the way he/she talks, and I don't care for that at all. So, I go to bed kind of agitated myself. [The nurse was] very condescending on the phone last night when I called, like I was bothering him/her. Like if [the patient] was agitated, it was going to be a bother to him/her. (Wife of P11, Second Interview, Day 8)
Approachable: The FM described the nurses being open and warm in their interactions.	
Acknowledge FM **Encourage to Ask Questions and Call** **Listen and Hear with Thoughtful Attention** **Make Eye Contact** **Patience** **Willing to Engage** **Willing to Admit Mistakes**	They've been super open…. really personable…I have no problem asking them, or feel like I'm interrupting them or they have taken time away from things they need to do. I get the sense that talking to the family is part of their job; they devote their attention to it. They might be doing other stuff while talking to you, but a lot of them just take time just to sort of, not sit down with you but stand there with you and look you in the eye and talk to you directly, as opposed to sort of while they're doing something else or…(Husband of P4, Second Interview, Day 7) They explain, even if they had to explain it five times to me because I just couldn't hear, I couldn't think. Nobody acted agitated, or irritated, or no bad bedside manner, it was none of that. It's so important because you are so raw right then… You find yourself buzzing, you don't mean to, but…it's because you're sitting there waiting. And you would think that they probably think, 'please quit hitting that buzzer, I told you we can't do that right now.' But, no they never were short, or…important. (Mother of P10, Single Interview, Day 2)
Negative **Avoid Engaging** **Curt or Short** **Dismissive of Concerns** **Impatient**	But I didn't feel like I could ask him/her questions…When I…was back there, visiting Memaw, when he/she kind of sat at the computer, he/she was the only one that didn't really speak when I walked into the room. He/she never came into the room when I was in there. But he/she was the only one that didn't offer any information…I felt the vibe he/she was giving off was that he/she didn't want to be bothered, that kind of thing…he/she didn't really make eye contact, he/she didn't acknowledge that we were coming, that we were back there. He/she didn't say anything to us, so…(Granddaughter of P14, Single Interview, Day 6) I said 'hi' and called this person's name, 'how's my dad doing,' and the response I got was exactly this 'well the same as any other day.' I'm like 'you sorry sack of shit, I want to drive to [name of hospital] right now; my dad is going to get in trouble overnight.' So the fact that he had to be intubated that morning does not surprise me at all. Oh I wanted to get in the car…I knew it was out of my hands and it was in the hands of somebody less than competent, and it made me feel extremely vulnerable and helpless as someone who cares about that patient laying in the bed, vulnerable and helpless…(Daughter1 of P13, Second Interview, Day 8)
Affable: The FM describes the nurse as friendly, open, and engaging	
Personable **Physical Touch/Closeness** **Make Small Talk** **Use Humor**	They are all very friendly when I walk back there. They don't know me, but they all speak as if it matters that I'm coming through. 'Hi, how you doing? And if there is anything we can do for you be sure and let us know.' And that's very important…I feel like I wouldn't

Strategies	Exemplar Quotes
	hesitate if I needed them for something, to ask. (Sister of P5, First Interview, Day 5)
	And you know being an only child and trying to face this all day long most days by myself, I need that, I need those nurses to care. I need those doctors to care, and I need those doctors to care about me because most of the day, I don't have that family support to grab a hold of. And I know that if I need to go back there and cry, somebody's going to hug my neck. (Son of P14, Single Interview, Day 5)
	And the nurses kind of like…you'll hear them chuckle, or they'll say something to him 'did you hear what she said' or something like that… I mean they don't carry it on, but they do lighten the load some. I like that. I don't want everything to be doom and gloom…I never feel stressed, I never feel tight, I never feel anxiety or anything when I'm in there. (Sister of P9, First Interview, Day 3)

Table 4

Demonstrating Professionalism

Strategies	Exemplar Quotes
Demeanor: FM described the nurses demeanor as demonstrating professionalism	
Calm Presence **Confident and Competent** **Morale** **Professional Ethics**	Just seeing how good they are has made me more hopeful…It was just their, it was just their demeanor and their calm demeanor and their grasp of the facts… it wasn't like they had to go ask somebody. They knew, they just explained things clearly and um…right off the top of their head. With just a, just in a very calm reassuring way. (Husband of P4, First Interview, Day 2)
	And that made a difference to me because if you are doing something that you don't want to do, a person can tell, and he/she didn't seem that way. He/she seemed to be glad and happy to do what it was that he/she was doing. It made me feel better…And it makes a difference if you're talking to someone that act like they don't want to talk to you. And he/she didn't sound like that, Yeah it makes a difference. (Daughter of P7, Single Interview, Day 2)
Negative **Unprofessional Behavior**	And she's turned her back talking to the nurse next door. And my anxiety and temper went out the roof. Really, all of the other nurses have kept their eyes on him. And she's got her back, and I'm watching the clock twenty minutes later they're still chit-chatting about transfers, job openings, this that and the other. (Daughter 2 of P13, Second Interview, Day 8)
Collaboration: The FM described evidence that the nurses were collaborating with other professionals	
Express Confidence in Plan **Collaboration with others**	[The nurse assured me] that he is getting good care, and that this is just not something enormously experimental, or that this is not a shot in the dark, this is not a wing and a prayer. That this is the way they handle this situation. [Confidence] in what the doctors are doing. Yeah and maybe give some explanation of…not we do it all the time in a flippant manner, but we are very good at doing this type of treatment or therapy. (Wife of P3, Second Interview, Day 4)
	Daughter 2: It's good interaction between the doctors coming through and [the nurse], and it just, it makes you feel good. Daughter 1: For me it was like, 'these people have their ducks in a row, and if anything happens to my father, I truly believe that he was at the best place, and he is getting the best care.' Daughter 2: It made me feel that they're not dropping the ball because they're not communicating…At least they're working as a team to try and help our father. (Daughter1 and Daughter2 of P13, Second Interview, Day 8)
Negative **Inconsistent Information**	There was a huge debate about whether or not to remove his breathing tube amongst the whole staff…[The nurse] went to speak to them; he/she was like, 'I really think that it might be time…' they'd reverse themselves; they told me they were going to do it, and then when I called at eight, they said, 'no we think he's a little too weak.' (Wife of P17, Second Interview, Day 9)
Respect: FM described nurse demonstrating respect for the patient and Family	
Confidentiality **Respectful** **Respect Patient Dignity**	They've talked to me…like I am a person that…that's important to them…the caring part really helps you when you're in a situation like this…I like for people to talk to me, and it helps me to deal with stuff and that kind of thing so. (Mother of P16, Single Interview, Day 4)

Table 5

Providing Factual Information

Strategies	Exemplar Quotes
Explain Environment: FM described the nurse giving explanations of the equipment and procedures.	
Answer questions **Explain equipment** **Explain the treatment plan** **Use lay terminology**	But [the nurse] said 'I'm going to reposition him; you will see him at different positions, and I'm doing this because I don't want him to lay in one spot too long.' I guess for the circulation and for the…all that. Anyway, he/she explained very, it's one of those things that seem, little small details, but it was so important to me. You know, 'I changed his bandage here because it looked a little bad,' he/she was saying that to me. (Mother of P10, Single Interview, Day 2) I know that [the nurse] will be that bridge to me, the one that's going to bring it down to the kindergarten terms that I need. And I felt confident and comfortable that [Nurse L] was competent in translating that to my terms. [Nurse L] is the communicator bridge; he/she understands the ten-dollar lingo. I don't get it; it's all confusing to me. But when they walked away, I knew that I could pepper Nurse L with questions, and he/she would give everything I needed on my terms. (Daughter1 of P13, Second Interview, Day 8)
Present Findings: FM Described the nurse describing to them physiological findings	
Avoid Rendering a Prognosis **Describe Positive Findings** **Keep Apprised of Patient's Condition**	Well it's a glimmer of hope, but they are not so, 'oh no he's not going to make it,' or 'I've never seen anybody come through this.' Just, if they've got that opinion, they are not saying it, so that I can hold on to that glimmer of hope. (Wife of P11, Second Interview, Day 8) Well any time that they tell me that a number looks better, that's hopeful. His ammonia level was just like 13 points better today. And I went 'oh, well that was a little glimmer of hope. He's not on any sedation, but yet we are getting a little bit of response. That's a little bit of hope.' Just little things like that, that. (Wife of P11, First Interview, Day 4)
Negative **Fail to Keep Apprised of Condition** **Give Inaccurate Information** **Guess at What Might Be Wrong** **Leave FM hanging** **Unable to Answer Questions**	Some will say, 'well nothing's changed since last night,' and then I will find out, yes he [had] a seizure, … well that to me is important to know in the overall scheme of things. So, I'm thinking that he didn't have a seizure for two days, when actually he did have one the day before. (Domestic Partner of P8, Single Interview, Day 9) I called at two o'clock this morning to see how he's doing. And whoever answered the phone said, "I know that it's in the middle of the night, but you're going to have to call back in an hour." And right away I'm thinking, is he/she working on him? is there something [wrong]? So I waited, and I called back and he/she said no change, and that was it…not much of a change, so… For the hour or so just wondering what's going on. (Wife of P5, Second Interview, Day 6)

Table 6

Supporting Decision-Making

Strategies	Exemplar Quotes
Interpretations of Findings: FM described the nurse providing information that included some level of indication of what that information means for the patient's prognosis for survival and/or quality of life.	
Avoid False Hope **Make Comparisons** **Describe the Severity of the Illness** **Hint at the Prognosis** **Honesty** **Say Patient is Likely to Die** **Verbalize Uncertainty**	So I think they wanted us to know what had improved, but they still wanted us to know the reality of the situation. Like they didn't want to give us false impressions that she's doing better…I don't think that's a bad thing; I think that's actually good. I wouldn't want them to lead us to believe that everything's going to be okay… if it wasn't so. Of course I want to hear how she's improving, but I don't want to …I don't want to leave at night thinking 'she's definitely going to be here.' (Granddaughter of P14, Single Interview, Day 6)
	They constantly let me know that she is very sick…They [want] me to know that this disease…is a disease that hits hard…I think what they want me to just keep in mind, that if for some reason the medicines do not work, or if her body is not strong enough to accept the treatments, just to keep me informed that it's the disease, and it's not my fault, and it's not her fault, but it's just what she's up against and what she has to fight against. (Daughter of P15, Second Interview, Day 10)
	It is [very reassuring]…to know beforehand what the possibilities are…because when they do happen, then you're not in shock. You can kind of prepare for things. Well I mean they've been candid enough to tell me that the possibility is always there that she could not make it through this. They've been up front with me. But at the same time, they give me hope in saying she may have enough to do that; we just don't know yet. So like I said, I just couldn't ask for it to have been any better as far as communication and the caring for my mom and me. (Son of P14, Single Interview, Day 5)
Negative **Avoid EOL discussions** **Give False Hope**	The main thing they [nurses] are doing is just sitting there…I'm not criticizing them but they will…say, "everything is about the same." …I don't know who…but it's time, that somebody…told her it's time to start dwindling him off. I think. Am I wrong to think that? Do you get how long this has been? (Sister of P5, Second Interview, Day 13)
Discuss Nature of Decisions: FM described the nurse discussing the decisions, including their consequences and meaning	
Describe What to Expect **Discuss Code Status** **Discuss Options** **Discuss Trade-offs** **Explore Values** **Reframe Hope** **Say Do Not Want to Inflict Pain on Patient**	When that time should come, if it comes, what is the protocol for the patients and the family, are we able to…stay in that room…is he taken to a private area.' They just explain, 'no, you will probably stay in that room'…Pull the curtain, he would not be receiving as much care, like checking his blood pressure every few minutes, and that they would pull the curtain and just allow us to be there with him. It's not something I want to have that conversation about. But, it's a conversation I needed to know. It gives you time to think about what to expect if it gets to this point down the road, and you're not just suddenly there. [It was helpful because] I don't want to just end up there and go,' okay what now?' (Wife of P11, First Interview, Day 4)
	The way they explained it is that what would happen is if we take him off antibiotics, which he's on now, if we take him off platelets, if we take him off the blood pressure medicine and all that, we can keep him comfortable, he just won't have any help in continuing life. And they said, 'is this what you want because if this is what you want, and you tell the doctor then you know…' (Sister of P9, Second Interview, Day 5)
	Yeah the nurse let me know how her condition was and just said 'you don't have to let go of her; you let nature take its course and leave it up to God,' and he/she said, 'as long as I'm here taking care of her, I'm going to do everything that I can to make her as comfortable as possible…It helped a lot…I guess I came to a point where I've got to accept it… I felt very

Strategies	Exemplar Quotes
	very…comfortable; I even slept better at night knowing that he/she was here with mom and stuff, so I felt better. (Daughter of P15, Third Interview, Day 14)
	[The nurse] was just saying how he/she didn't want to inflict any more pain on her; they were saying about changing out those lines and stuff and [the nurses] was like that's going to hurt-it's painful because it's in her neck…so I don't want that, so I was appreciative of them telling me that .. It was hard to hear them say that, but them being honest it helped…Yeah, it did [help with decision] because I was thinking 'please just do whatever you've got to do' I was thinking 'I don't care what you do, do what you've got to do' but when they came in and was like Sharlene, 'we don't want to keep inflicting pain on her; she done been poked so many times, and she gots these lines and stuff in her; we don't want to keep doing that and seeing her hurt and suffer.' And you know they the ones that have to do it, so I understood what they were saying, and it just showed that they cared a little more than a nurse would so. (Daughter of P15, Third Interview, Day 14)
Remain Unbiased: FM described the nurse discussing decisions without bias	
Accept decisions **Avoid Unsolicited Recommendations or Advice** **Leave Decision to Family Member**	It was comforting to know that we had made that decision and that, based on Roger's personality and his degree of agitation, that he would not have wanted that in his throat. [The nurse] didn't say yay or nay; we explained…his degree of agitation when he gets tired of something. And [the nurse] laughed and said, 'I have gathered that' And it was reconfirming that, what [the nurse] saw in Roger and what we explained to him/her that he/she thought that we had made a good decision. (Wife of P13, Second Interview, Day 14)
Negative Lack of Support for Decisions Render a Personal Opinion FM described the nurse avoiding giving recommendations.	Um I guess maybe an opinion about…'well, if it were my family member'…'my mother has power of attorney for me and she knows exactly what I want.' Well, I also discussed this with my husband when we got this… [I thought] Um that's fine for you but, you're not me and, everyone is different. And I don't really care what you want to do with your life and your family. It's like questioning you. (Wife of P5, First Interview, Day 5)

Table 7

Family Member Responses

Response	Definition
Cope	FM indicated that the behaviors made them “feel better” or “deal with” the situation. Includes an expressed ability to be able to rest and sleep or take care of themselves. Also includes ability to provide support to other family members.
Closure	FM indicated that the behaviors led to their being able to feel at peace with the death of their loved one without a sense of unfinished business
Make Decisions	FM indicated that the behaviors helped them to make EOL decisions
Accept	FM indicated that the behaviors helped them to accept that the patient was dying
Afraid to Ask Questions	FM indicated that behaviors led them to feel uncomfortable or afraid to ask questions. FM indicated that they felt like they were a bother
Comfortable Asking Questions	FM indicated that behaviors led to their ability to feel comfortable and to be encouraged to ask questions
Confidence in Nurse	FM indicated that the behaviors contributed to their ability to trust that the nurse would provide skilled and personalized care to the patient
Difficulty Coping	FM indicated that the behaviors caused them to experience distress, anxiety, anger, or other strong emotions
Dissatisfied	FM indicated that the behaviors led to their feeling dissatisfied with the care by that nurse
Feel Judged	FM indicated that the behaviors caused them to feel that the nurse had a negative view of the FM’s decisions or actions.
Hopeful	FM indicated that the behaviors led to their ability to have hope. Hope may include hope that patient would get better, hope that patient would get good care, hope that patient not suffer, or hope that the FM would be cared for with love and concern.
Informed	FM indicated that the behaviors helped them to understand the patient’s condition.
Lack of Trust and Confidence	FM indicated that the behaviors caused them to have a fear that they and/or their loved one would not receive the care that they wanted or needed.
Personal Connection	FM indicated that behavior allowed them feel the sense that the nurse was more than just a person taking care of their loved one’s physical needs.
Prepared	FM indicated that the behaviors helped them to feel emotionally and cognitively prepared to hear the news that their loved one would not survive.
Trust in Nurse	FM indicated that the behaviors gave them a sense that the nurse would be there for them to provide information and support.
Uninformed	FM indicates that behaviors led to their lack of understanding or misunderstanding the condition of the patient
Unprepared	FM indicates that the behaviors led to them feeling unprepared for hearing news that the patient was not going to survive. Might have led to dismay or confusion.
Delay Decision-Making	FM indicates that behaviors led to a delay in the decision to withdraw or withhold life support.

Note. FM = Family Member