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Facilitated Sensemaking

A Feasibility Study for the Provision of a Family Support Program in the Intensive Care Unit

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Family members of intensive care unit patients may develop anxiety, depression, and/or posttraumatic stress syndrome. Approaches to prevention are not well defined. Before testing preventive measures, it is important to evaluate which interventions the family will accept, use, and value. The purpose of this study was to evaluate the feasibility of an intervention for support for families of mechanically ventilated adults, grounded in a new midrange nursing theory titled "Facilitated Sensemaking." Families were provided a kit of supplies and the primary investigator coached families on how to obtain information, interpret surroundings, and participate in care. Participants were asked to complete an adapted Critical Care Family Needs Inventory and Family Support Program evaluation. Family members of 30 patients consented to participate; 22 participants completed the surveys. Internal consistency reliability of the adapted Critical Care Family Needs Inventory was high ($\alpha = .96$). Results validated the importance of informational needs and provided a score indicating the family member's perception of how well each need was met, weighted by importance, which identified performance improvement opportunities for use by clinical managers. The program evaluation confirmed that families will use this format of support and find it helpful. Personal care supplies (eg, lotion, lip balm) were universally well received. Forty-two referrals to ancillary service were made. Operational issues to improve services were identified. As proposed in the Facilitated Sensemaking model, family members welcomed interventions targeted to help make sense of the new situation and make sense of their new role as caregiver. Planned supportive interventions were perceived as helpful. **Key words:** *adaptation-psychological*, *Critical Care Family Needs Inventory*, *critical care nursing*, *family-centered care*, *family-psychosocial factors*, *intensive care units*, *nurse-patient relations*, *professional-family relations*, *support-psychosocial*

FAMILY-CENTERED CARE is advocated by The Joint Commission on the Accreditation of Healthcare Organizations,[1] nursing practice standards,[2] and professional organizations such as the Society of Critical Care Medicine.[3] The Advisory Board reports that meeting family needs affects satisfaction with care, return business and staff morale.[4] Several authors have shown that family members of intensive care unit (ICU) patients develop anxiety,[5-12] depression,[8,9,12,13] and/or symptoms suggestive of risk for posttraumatic stress.[12-14] Comprehensive discussions of family support and the effect of critical illness on family health have been previously described.[3,15-17] Yet, there have been few reports of successful interventions to

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meet family needs[18,19] or decrease the adverse psychological effect of critical illness on the family.[12–14] Studies to date have each used a different strategy and measured different outcomes, yielding promising results of limited generalizability. However, studies with significant results all used a multimodal approach that included a structured, personalized, verbal intervention in addition to written materials.

Given the frequent contact that nurses have with family members, nurses are in an ideal position to influence the approaches used to meet family needs and minimize development of adverse psychological sequelae. A new midrange theory, titled "Facilitated Sensemaking," provides a basis for the design of family-centered care interventions in the ICU and served as the theoretical framework for this study.[20] The Facilitated Sensemaking model is derived from a combination of the Roy Adaptation model[21] and Weick's business leadership Organizational Sensemaking model.[22,23] From Roy,[21] facilitated sensemaking adopts the principle that family members experience a disruption in their lives when a loved one is admitted to the ICU. To adjust to the disruption, the family undergoes a compensatory process that can be partial or complete, negative or positive. During the compensatory process, family members struggle to sort out what has happened and how to deal with the event.

In further development of the model, business leadership attributes, described by Weick,[22,23] were applied to nursing. Weick stated that business leaders shape the collective perception of how the business is performing by explaining outcomes and outputs to staff. Organizational leaders also shape employee's perception of their roles within the organization through continued feedback on performance and role expectations. Weick further explained that, during a company crisis, the leader's ability to help employees make sense out of the situation was especially critical because actions taken during crisis form the perception of the event. Weick emphasized that reflection, looking back, and evaluating the past were essential components to the sensemaking process. This process needs to be iterative in nature, repeating the process and building upon itself as situations change. In the clinical arena, the nurse can assume a role similar to the executive and assist the family in making sense out of the crisis, both in terms of the family member's new role of caregiver and what has happened during the critical illness event.

Synthesizing these 2 conceptual frameworks, the Facilitated Sensemaking theory proposes that nurses facilitate the sensemaking process with family members through a series of interventions. Two inseparable goals of nursing interventions in this model are to help the family make sense of the situation and of the new role as caregiver. The interventions consist of identifying and meeting the information needs of the family, coaching them how to visit and meet their own needs, providing them support, and providing meaningful activities to perform at the bedside. Family members may not be able to identify their own needs during crisis and nurses and physicians may not accurately predict family needs.[24–27] Therefore, a collaborative proactive process of needs assessment and reflective inquiry is advocated (Fig 1). As depicted in the model, family members of ICU patients evolve through the stages of disruption in normal life events, a compensatory process, and adaptation to the event. The compensatory process results in intermediate outcomes that may include ability to understand what has happened and participate as a caregiver at the bedside. This compensatory process is affected by nursing interventions geared at improving the family member's ability to make sense out of the situation and the new role as caregiver. The interventions center on providing information and teaching the family member how to participate at the bedside. Because the patient's condition changes hour to hour and day to day, the process is iterative as new information needs develop. In the end, adaptation to the critical illness may result in complete coping or incomplete/maladaptive coping as evidenced by, but are not limited to,

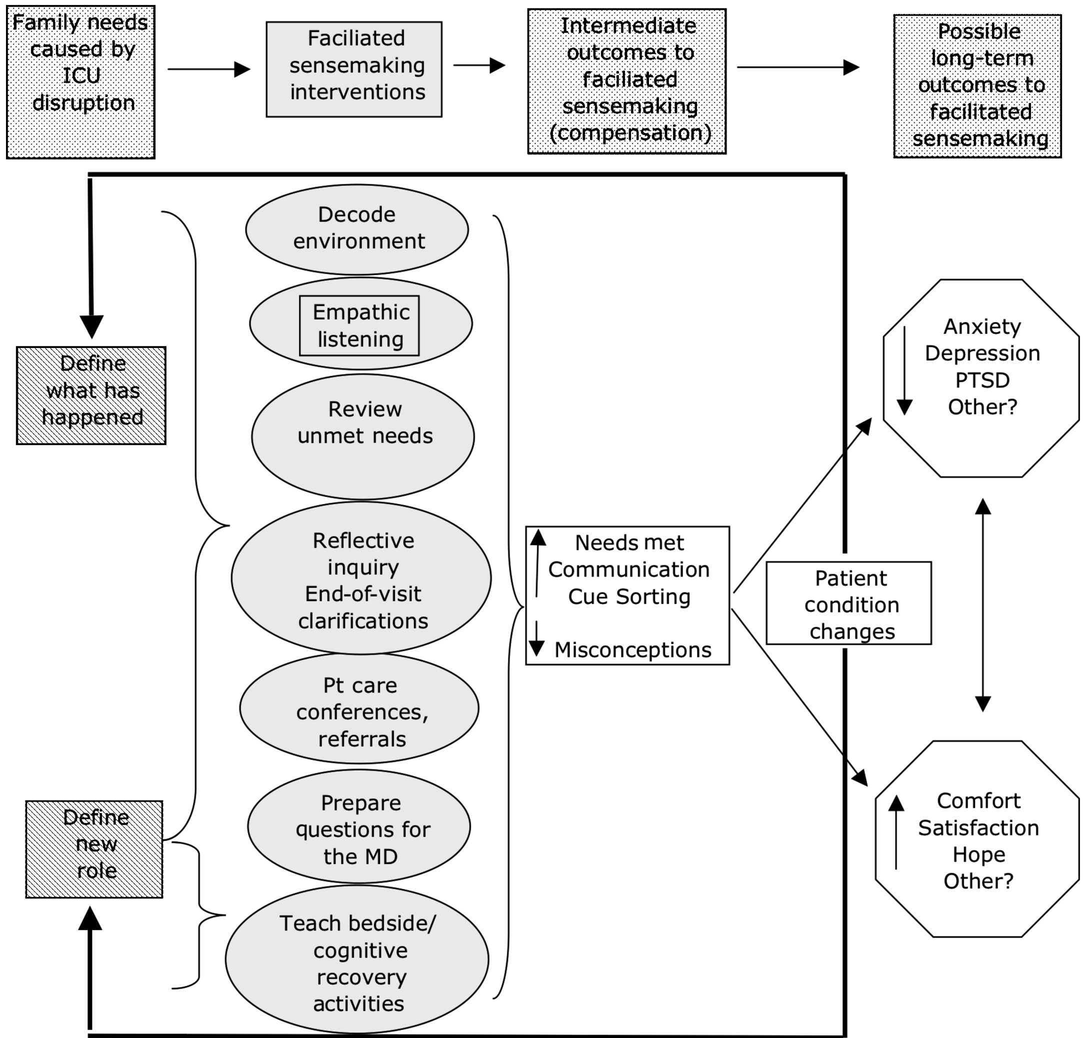

Figure 1. Facilitated sensemaking concept map. Planned nursing interventions to assist the family in making sense out of their new role and what has happened. Process is iterative as condition changes. ICU indicates intensive care unit; MD, physician; Pt, patient; PTSD, posttraumatic stress disorder. ▧ adapted from Weick.[22,23] ▨ adapted from Roy.[21] □ = nursing interventions in the Facilitated Sensemaking model. Modified from reference 20.

adverse, psychological outcomes (eg, anxiety, stress, depression, posttraumatic stress).

PURPOSE

The intervention set in the Facilitated Sensemaking theory was developed using evidence from the literature[3,8,9,12,14,19,28–33] and experience as a critical care nurse. Before designing a controlled trial of the intervention, it was necessary to gather preliminary evidence that the proposed interventions in the model could be implemented, that they would be found useful and helpful to ICU family members, the population of interest, and that families would be willing to take part in the study of effectiveness. Thus, this project was both an evaluation of the feasibility of the intervention and a pilot of research procedures.

METHODS

Design

To evaluate the feasibility of the intervention, we offered the program to a consecutive number of families, documented acceptance and use of the intervention, and asked them for their perceptions of the usefulness of the intervention. We also tracked the time required to provide the intervention. In piloting the research procedures, we administered a family needs questionnaire to the convenience sample and assessed psychometric properties of the instrument (range of scores, scoring method, and internal reliability).

Sample/setting

A convenience sample of 30 family members were recruited from a 32-bed, mixed-use ICU of a southwestern, 400-bed trauma center. Participants were family members of adult mechanically ventilated ICU patients. The family members were at least 18 years of age, English speaking, and literate. The operational definition of family was adopted from the definition published by the National Consensus Project for Quality Palliative Care:

> Family is defined by the patient, or in the case of minors or those without decision-making capacity, by their surrogates. In this context, the family may be related or unrelated to the patient. They are individuals who provide support and with whom the patient has a significant relationship.[34(p611)]

An attempt was made to involve the family spokesperson, defined as the person who either had healthcare durable power of attorney or had volunteered to disseminate information to the rest of the family. However, in light of cultural variation, we did not require that the spokesperson be the closest in western lineage (eg, spouse, adult child, sibling).

Procedure

Following the institutional review board approval and explanation of the project to the nursing staff in staff meetings, family members of patients were screened for eligibility and approached for consent. Consent was not required from patients because the focus of the intervention was the family member's experience in the ICU setting rather than the patient's course of treatment.

Intervention

One investigator, a clinical nurse specialist, performed all of the interventions with each family. Participants who consented agreed to meet with the investigator, a clinical nurse specialist (author), for at least 2 days following the introduction, answer a Family Support Program evaluation, and complete an adapted Critical Care Family Needs Inventory (aCCFNI).[35] Each family met a minimum of 3 times with the investigator and more often if desired. The length of the intervention varied depending on family needs, ability, and willingness to engage in discussion and activities. The interactions often occurred with the patient's nurse in the room. Time allotted to interact with the participant/family member was flexible, based entirely upon needs and expressed interest. The investigator kept the patient's nurse informed of all activities and responses, strategies used for family involvement and family preferences.

The intervention consisted of 2 main components: personalized instruction and provision of family visiting kits. The personalized instructions included an introduction and explanation of the project, *decoding* of the environment at the bedside, instructions on helpful visiting activities (eg, use of the items in the visiting kit, passive range of motion, cognitive recovery activities), coaching on how to ask questions of the doctor and identify unmet needs, review of available of hospital services, and debriefing using reflective inquiry. Decoding was the nurse's explanation of the surroundings, noises, processes, and events occurring within the patient's environment. Reflective inquiry was the process of looking backward to assemble a perception of what had happened using probing questions or statements. The questions, posed by the investigator, were intended to guide the family member in becoming more aware of

Table 1. Family visiting kit contents[a]

Family visiting kit contents
Family workbook
Introduction/instructions
Nondenominational prayer for family strength and patient healing/comfort
Instructions on how to perform cognitive recovery activities
Description of activities to perform at the bedside as desired
List of family needs abstracted from Critical Care Family Needs Inventory
Space for daily summary of events
Space for listing questions for the physician
Cognitive recovery tools
Book of word searches[b]
Pencil[b]
Clipboard
Pad of paper[c]
Dominoes
Playing cards
Pencil grip[c]
Personal care items
Nail file
Hand lotion (approved through infection control)
Lip balm
Information
Library services/medical information Web sites[c]

[a]All items were optional and used on the basis of family preference. Total cost of kit was approximately $10.00 retail. Detailed instructions for how to perform cognitive recovery activities have been describedpreviously.[20]
[b]Altered with family feedback.
[c]Added following family suggestion.

their perceptions, feelings, and concerns and to identify persistent misunderstandings, obtain further information, and reinforce understanding.

All participants were given *family visiting kits* in zip-locked plastic bags labeled with their name, which included a workbook of all the points previously discussed and the items listed in Table 1. The investigator explained the components of the family workbook and demonstrated activities that could be performed at the bedside (eg, passive foot flexion and pumping to prevent venothromboembolism, passive range of motion, hand massage). The investigator also instructed families how to perform personal care activities (eg, applying lip balm around an endotracheal tube, manicuring the nails to promote touch). The use of passive range of motion and the level of complexity of cognitive recovery activity was tailored to the patient's condition and needs as well as the family's receptiveness. An explanation of how to individualize activities (eg, playing cards, dominoes, word searches) was given both verbally and in writing to the participating family member. A nondenominational prayer was offered in writing for families who found comfort in prayer.

On the basis of these interactions with the family, referrals to ancillary services were made and patient care conferences coordinated. The investigator asked the family member to describe the patient's situation in the presence of the patient's nurse. The description was then reviewed with the nurse to clarify misconceptions or distortions and to support focusing on key issues. The family was encouraged to summarize the day in writing, in a provided handbook, if this would be helpful. Families were strongly encouraged to summarize, at least verbally, the daily events with the patient's nurse at the end of each visit. The nurse was instructed that the purpose of this reflective activity was to clarify any misconceptions or distortions and to make sure that the family focused on key issues while maintaining hope.

A list of potential family needs was included in the workbook and reviewed with each family member verbally. The needs listed in the workbook were abstracted from the CCFNI[35] and subsequent needs reported by Burr[36] (ie, to support and protect the patient). The CCFNI is a valid and reliable tool[17] listing 45 different needs statements, and an option for "other." The needs statements were grouped into the following subheadings as originally designed by Molter and Leske[35]: assurance, proximity, support, information, and comfort. These 45 needs were printed within the family workbook and the family was encouraged to review them periodically and disclose to the patient's nurse whether any needs that

were important to them, or any other needs, were unmet. The intent was to ensure that family members knew it was acceptable to disclose unmet needs so that they could be addressed, realizing that many family members in crisis might not be able to identify those needs proactively. For instance, if the family had not been able to speak to the physician for an update, the physician was contacted or a meeting time set up by the nurse. Referrals to chaplaincy, social service, palliative care, and/or patient care conferences were coordinated as indicated.

The cognitive recovery tools provided in the visiting kit were designed to be used with patients recovering from coma, sedation, or brain injury. Family members were encouraged to perform at least 2 cognitive activities per day (eg, working with words, letters, phrases, numbers using dominoes, word search puzzles, large print playing cards). The complexity of the activity was dependent upon the patient's condition. In the early phases of recovery, the family was encouraged to have the patient identify a letter or number. When fine motor movement was possible, the family was to encourage the patient to hold up the number of fingers that correlate with the number of a domino piece or playing card. As cognitive recovery progressed, actual use of the materials as intended was encouraged. Family members of comatose patients also were told that they could use the activities themselves to occupy their time while visiting and that it was acceptable to use the word searches or playing cards as diversionary activities.

At the end of each encounter, the following question was asked, "Is there anything I can do for you right now to make this experience better, given what you have been through?" The question was found to be a helpful prompt for disclosure of unpredictable family issues in previous research (J. E. Davidson, DNP, RN, D. Agan, EdD, J. Murphy, RN, P. Gutierrez, MSN, RN, unpublished data, 2007). The family also was encouraged to think of that question, also printed in the handbook, at the end of each visit. If the investigator was not present, they were instructed to proactively discuss any concerns or unmet needs with the patient's nurse. The investigator-provided feedback was supplied to the patient's nurse and physician as indicated.

Instruments and evaluation

To pilot the measurement approach and feasibility of the intervention, 3 data collection tools were used: the aCCNFI, the Family Support Program evaluation, and an investigator log.

Adapted Critical Care Family Needs Inventory

Permission to use the CCFNI as adapted was provided by its author (J. Leske, personal E-mail communication, June 19, 2007. The original tool contained 45 validated items representing family needs (eg, understandable information, proximity to the patient, assurance, hope) rated on a 4-point Likert scale, from *not important* (1) to *very important* (4). Psychometrics of the original tool have been previously reported.[17] Content validity of the original CCFNI was originally established using group consensus of graduate students, and then by combining the results from multiple studies, using the tool over time with family members. The repeated testing found that all items on the survey were important to some family members.[17] Since then, many authors have used the CCFNI and found these need statements important to family members.[5-7,19,24-26,36,37-40]

The CCFNI was adapted over time by adding a second a 4-point Likert score, this one for how well the 45-item needs were met (ie, needs-met): *never met* (1), *sometimes met* (2), *usually met* (3), and *always met* (4). This adaptation has been used in the past with both the full version of the CCFNI[41-43] and the abridged version[44] without reported psychometrics. The aCCFNI, used in this study, also included a brief family member demographic section and a space for comments. One qualitative question was added to the

survey: "Is there anything else that we should know?" The survey was administered after the third interaction between investigator and family.

Family Support Program evaluation

The evaluation consisted of 11 questions. Participants were asked if they used each intervention (eg, playing cards, dominoes, workbook, lip balm) and answered with a yes/no response. If yes, they were also asked to rank order of the helpfulness of the activity by circling the response on a 4-point descriptor scale: not helpful, somewhat helpful, helpful, very helpful.

Investigator log

The investigator collected field notes of observations, including unsolicited comments from staff and family, obstacles, barriers, and significant occurrences during the study intervention. These field notes were analyzed for themes. In addition, each interaction was noted, with the time required from start to finish.

Data analysis

Data were analyzed using SPSS.[45] Responses to each item on the aCCFNI were tallied and ranked in order of importance. To calculate an overall score, missing data on the aCCFNI were replaced using mean item substitution. Because each need was rated from 2 perspectives, the importance of the need and how well that need was met, an overall (weighted) satisfaction score was calculated by taking the mean score of the needs-met and dividing it by the mean of the importance of each of the 45 items on the tool. For example, if *to feel there is hope* was rated as a *very important* (4), but *sometimes met* (2) on the needs-met scale, that question would have an overall satisfaction of 0.50 (2 out of 4). Lower satisfaction values reflected those items that were important to family members and not being met.

Responses to the Family Support Program evaluation were similarly summarized using SPSS and descriptive statistics.

Table 2. Demographics[a]

	n	% of total
Family demographics		
Female	18	82
Age, y		
18–40	3	14
41–60	14	64
>60	5	23
Relationship		
Spouse	9	41
Child	6	27
Parent	2	9
Sibling	3	14
Other	2	9
Spokesperson—"Yes"	20	91
Experience visiting an ICU—"Yes"	12	55
Patient demographics		
Age, mean	55 y	19–83 y
Female	8	22
Mortality	3	14
Patient type		
Medical	11	50
Surgical	4	15
Trauma	7	22
LOS, average days	24 d	7–68 d
ICU LOS	17 d	2–53 d
APR-DRG severity of illness—extreme	20	90
APR-DRG risk or mortality—extreme	15	67

Abbreviations: LOS, length of stay; ICU, intensive care unit; APR-DRG, all patient-refined diagnostic-related groups.

[a]Severity of illness and risk of mortality obtained from coded records. Extreme reflects worst category on 4-point scale for both measures. One patient in-house at time of analysis and not included in mortality or risk calculations. LOS for that patient declared at 68 days. Total sample size was 30 family members of 30 patients, 22 family completed surveys including demographic data.

RESULTS

Thirty family members of 30 patients (Table 2) consented to participate in the Family Support Program, with 22 surveys returned. Quantitative analysis of the aCCFNI results yielded descriptive statistics of each

Table 3. Top 10 needs of family members

Item
To know how the patient is being treated medically
To be assured that the best care possible is being given to the patient
To feel there is hope
To know specific facts about the patient's progress
To see the patient frequently
To be called at home about changes in the patient's condition
To feel that the hospital personnel care about the patient
To have explanations given that are understandable
To know exactly what is being done for the patient
To receive information about the patient at least once a day

of the 45 items on the tool and a summative score. This was done separately for the *importance* scale and the *needs-met* scale. As reported in other studies, internal consistency reliability of the aCCFNI importance of needs score was high (study $\alpha = .94$, published $\alpha = .92$).[17] Internal reliability of the needs-met scores ($\alpha = .94$) and combined needs-met/importance ($\alpha = .96$) of the aCCFNI were also high, thereby helping validate this tool as a measurement of family needs.

All 45 needs were found to be of some importance, as has been found by others.[17] The importance scale was used to rank items in order of importance, yielding a top 10 list of needs, which further validated the family's need for information (Table 3), as found by others.[26,46–49] A weighted analysis of needs-met to importance was performed to identify unit-specific performance improvement opportunities. These specific findings are not generalizable outside of this study site, but this strategy may be used by others.

From the analysis of the Family Support Program evaluation, all items offered within the intervention were found useful to some family members. The portion of the Family Support Program that best suited their needs varied with the patient condition and personal preference. Each of the proposed interventions (ie, cognitive recovery activities, suggestions for bedside activities) was used and found helpful (Table 4). The journal was least useful and personal care supplies given to the family for use at the bedside were most helpful.

Observations of family members found they were most engaged when receiving information about how to participate at the bedside and how to decode/interpret what they were seeing in the environment (eg, explanations given about the meaning of the numbers on the bedside monitor). Family members showed visible relief when they understood that the alarms could be seen at the nursing station and were being evaluated even when the nurse was not in the room (Table 5).

Forty-two referrals were made for the 30 family members because of investigator interaction for patient care conferences (5), physician updates (18), music ministry (3), chaplaincy services (4), medical social worker (2), discharge planner (6), and palliative care services (4). The average initial investigator consult time ($M = 17$ minutes, mode = 15 minutes, range 5–40 minutes) was shorter if the family was unable to concentrate or needs were being met, and longer if they had questions and/or a need to express frustrations when the needs were not being met. Subsequent meetings ($M = 17$ minutes, mode = 15 minutes, range 5–60 minutes) were also longer if family needs were not being met or included a patient/family care conference scheduled to address unmet informational needs. The time spent was reasonable for inclusion into the practice of the patient's nurse and indicates that when needs are not met proactively, the time spent in supportive measures increases.

Unexpected findings

Additional needs, not listed on the aCCFNI or accounted for initially through the Facilitated Sensemaking model, were reported by families and included needs related

Table 4. Top 10 opportunities[a]

Item	Importance of need, *M* (SD)	Needs-met, *M* (SD)	Weighted satisfaction
To talk to the same nurse everyday	3.30 (0.82)	2.60 (0.95)	0.79
To talk to the doctor everyday	3.73 (0.55)	2.95 (0.84)	0.79
To be called at home about changes in the patient's condition	3.94 (0.21)	3.31 (0.74)	0.84
To talk about the possibility of the patient's death	3.42 (0.78)	2.89 (0.87)	0.85
To have explanations given that are understandable	3.88 (0.29)	3.28 (0.68)	0.85
To have a pastor visit	3.38 (0.84)	2.90 (1.0)	0.86
To know which staff members could give what type of information	3.62 (0.65)	3.1 (0.92)	0.86
To feel accepted by the hospital staff	3.75 (0.42)	3.24 (0.68)	0.86
To receive information about the patient at least once a day	3.84 (.35)	3.32 (.69)	0.86
To feel that the hospital personnel care about the patient	3.89 (.29)	3.37 (.63)	0.87

[a]Opportunities are identified by applying the formula: mean of needs-met score/mean of importance ranking = weighted satisfaction. Both the importance and needs-met scores were ranked on a 4-point Likert scale. The lowest weighted satisfaction values suggest the largest opportunities for improvement in meeting family perceived needs. This list is better suited to identify targeted items to create unit-specific changes than the rank ordering of most important needs (Table 3).

to patient communication strategies and parking. Multiple complaints were received regarding the distance between the parking lot and the ICU, lack of parking, financial strain imposed by parking fees, and inaccessibility of handicap spaces. Families stated that parking caused undue stress during a crisis situation. As the attendant left every evening at 10:00 PM, many described how they would stay late in the hospital to save money. They commented that parking problems consumed energy that could otherwise be spent dealing with how to cope. These parking concerns were referred to hospital administrative staff.

Table 5. Reported helpfulness of facilitated sensemaking interventions in descending rank order[a]

Personal supplies, lip balm, lotion, nail file
Patient/family care conference
Space to write questions for physician
End-of-day clarification
Word search activity
List of bedside activities
Debriefings
Needs list in workbook
Dominoes
Playing cards
Introduction and instructions

[a]Several participants commented that it was too early in the course of care for dominoes, playing cards, and word searches to be helpful. All items were reported as helpful.

One family member identified another unanticipated need. The patient was awake and mechanically ventilated, frustrated at not being able to write. In his first day of consciousness, the family member suggested getting him "grip" material for the pencil, similar to what stroke patients use. After obtaining the grip from occupational therapy, the patient was able to write well enough to communicate. His face lit up and he smiled brightly. The grip was trialed with other subsequent patients with success, each of whom could not write before using the grip (the ICU now stocks grips as a standard supply item). One nursing assistant added that the grip could be

used for eating utensils as well, and made a flyer for the staff with a picture illustrating its use.

The Family Support Program utilizing the Facilitated Sensemaking model was designed with a list of proposed activities for family members to perform at the bedside. In 2 cases, family members startled staff by taking pictures to chronicle the ICU experience. The investigator was asked to intervene and obtain the approval of the risk manager. While staff are not permitted to photograph patients, a patient proxy may take pictures of the patient. In one family, the husband and wife were in town on vacation. He had been vibrant and active before admission with a preexisting diagnosis of cancer now metastasized. His family could not travel, and the wife suggested that they take a picture of the 2 of them together, the husband in a coma on the ventilator and wife with her arms wrapped around him in a loving embrace. The picture was sent electronically to family, which helped them initiate the grieving process. Once they saw the picture, they could better understand the gravity of the situation.

In the second case, the brother took pictures to create a scrapbook with the intent of convincing the patient and his friends to wear a helmet in the future. Although some may not agree with his methods, the act of creating the scrapbook gave the brother purpose during crisis. Both examples demonstrated the unexpected use of photography to assist with coping.

DISCUSSION

Limitations

Several family members provided consent, verbal feedback, and active participation in the study, but chose not to complete the surveys ($n = 8$, 27%). This limitation diminishes generalizability and replication with a larger sample is warranted. However, the attrition rate is understandable and suggests that the early critical care period may be too stressful to concentrate on writing. This idea is further validated in the observed use of supportive interventions. Although families reported the workbook components as helpful, only 2 family members were observed taking notes, writing daily summaries, or writing lists of questions for the physician after the initial introductory meeting. The lack of acceptance of a family journal or diary early in the ICU stay has been described previously[10]; however, the workbook did serve as a vehicle to provide initial instruction.

This study was designed primarily to test the feasibility and acceptance of a set of interventions. That goal was obtainable through observations and descriptive statistics from the Family Support Program evaluations; however, the sample size was a limitation. Family support nurse researchers have reported similar problems because of small sample size in the past,[10,13,42,43] suggesting the need for research collaboratives promoting well-powered studies to achieve statistical significance. Generalizability is also limited to English-speaking adults of mechanically ventilated patients.

Family visiting kits

The family visiting kits (Table 1) were refined with family feedback during the study. Mechanical pencils were changed to traditional wooden pencils with sturdier lead. The word search booklets were enlarged for visibility. A pad of paper was added for the clipboard to enhance patient communication.

Originally, the kit contents were to be trimmed into only those items that were most useful and would then be suggested for future use. However, family members unpredictably reported the usefulness of each item. For example, one large, young, male, a self-proclaimed street-fighter by trade, was the family member of a comatose trauma victim. He was given the kit and standard explanations. At the second meeting with the investigator, he was found filing the toenails of his younger brother. He stated, "While the doctors are taking care of that [pointing to the intracranial bolt], I'll take care of this [pointing

to his feet]. He's gonna be a lady-killer when he gets out of here." On the other hand, wives who expressed concern about the condition of their comatose husbands' feet and nails did not use the nail file at all.

One nursing assistant, after watching the Family Support Program in operation for several days, suggested that it might be helpful to build a family supply cart that could be wheeled around the unit to offer supplies to family members, allowing them to take anything that they found useful. The timing of the study precluded use of certain items (eg, dominoes, playing cards). Family members verbally acknowledged that the items and instructions on how to assist with brain recovery would be helpful in the future, but it was too early in the course of recovery for them to be helpful at the time of the surveys.

Operational issues

During the study, many unit-specific issues arose regarding current practice and were forwarded to the leadership team for action. For example, while screening patients for inclusion into the study, the investigator discovered that many patients did not have family members or visitors. A visiting ministry to meet the social needs of those patients has been suggested.

Nurses and families alike were unaware of the hospital's family room in the medical library equipped with an Internet-connected computer and handy hot-linked Web sites as well as novels. Because of study referrals, the librarian reported an increased use in the family room (M. Robinson, personal oral communication, September 30, 2007). An informational sheet of family-friendly medical information sites was prepared for inclusion in the visiting kit and later use. A note card explaining library services was developed, printed, and stocked in the waiting areas.

As found in studies by Lautrette et al,[31] Melnyk et al,[14] Jones et al,[13] and Kloos and Daly,[33] family members appreciate supportive interventions that are multimodal in nature, both verbal and written. In this study, families also self-reported and it was observed that tactile interventions using common household items for hands-on bedside activities were a welcome addition to the family support services.

CONCLUSION

The Family Support Program based on the model of facilitated sensemaking is not only feasible but also helpful to family members of mechanically vented, adult ICU patients. The demonstrated reliability of the aCCFNI supports its continued use in identifying important needs and evaluating whether those needs are met for families of ICU patients. An overall score weighting importance and needs-met for each item aided in ranking opportunities for improvement. Future research is warranted to continue evaluation of the Facilitated Sensemaking theory and measure effect of these interventions on outcomes (eg, anxiety, depression, symptoms suggestive of risk for posttraumatic stress). Inclusion of this nursing intervention is warranted to assist family members in communicating with the patient as part of the list of bedside activities. Future study design should be expanded to other cultures or patient groups. Educational programs targeted to provide instruction for nurses on how to include family members into daily practice are also warranted. The time the lead investigator spent per family in supportive interactions appeared reasonable for inclusion into the bedside nurse's practice.

Feasibility was further supported in that family members accepted and used the interventions that were based on concepts of the Facilitated Sensemaking model. Information to assist with decoding by explaining equipment, alarms, and surroundings was notably accepted. Instructions for interacting with or assisting ICU patients were appreciated. The provision of personal care supplies was found to be most helpful and useful. Verbal instructions and hands-on activities were preferred over journaling activities.

Each family member welcomed different aspects of the Family Support Program. Family-centered care may best involve a range of supportive interventions while encouraging family members to proactively review whether their own needs are being met. Reflective inquiry was found to be a successful method identifying unmet needs and indications for referrals to individualize the family's plan of care.

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