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Critical Care Nurse Manager's Perspective*

The Critical Care Family Assistance Program

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Key words: critical care nursing; family-centered care; family satisfaction; intensive care unit; palliative care

Abbreviation: CCFAP = Critical Care Family Assistance Program

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The Critical Care Family Assistance Program (CCFAP) emerged as a collaboration between the CHEST Foundation, which is the philanthropic arm of the American College of Chest Physicians, and the Eli Lilly and Company Foundation. The goal of the CCFAP is to respond to the unmet needs of families of critically ill patients in hospital ICUs through the provision of educational and family support resources.

The CCFAP was introduced as a pilot program into two hospitals in January 2002 (Evanston Northwestern Healthcare, Evanston, IL; and the Oklahoma City Veterans Affairs Medical Center, Oklahoma City, OK). These hospitals were known not only for high-quality care, but also were institutionally diverse. In 2003, the program was expanded to Highland Park Hospital as part of the Evanston Northwestern Healthcare system and was introduced at Ben Taub General Hospital in Houston, TX, to add an urban model to the program. By the fall of 2004, the CCFAP was being replicated in a total of six hospital sites across institutionally and geographically diverse care settings, with the addition of Pardee Hospital in Henderson County, NC, and University of South Alabama Medical Center in Mobile, AL. This article presents observations about the CCFAP and its effectiveness from the perspectives of the critical care nurse managers from the three pilot hospitals utilizing the CCFAP.

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Review of Research

For those seeking the attitude of critical care nursing toward the introduction of family-friendly practices, one need only carefully examine the literature on this subject. Nurses, both scholars and practitioners, have assumed a leadership position in exploring the benefits accruing both to the family and to the hospital when practices that recognize the needs of family are implemented in the ICU. As these practices are being put into place today, critical care nurses occupy strategic positions. The authors of this article are all critical care nurses who are involved in a variety of leadership positions at hospitals participating in the CCFAP.

The following citations taken from articles written by nurses foreshadow the type of intellectual and practical leadership to be assumed by critical care nurses within the CCFAP. Collopy,[1] investigating complex cases, demonstrated that "when patients' characteristics are joined with nurses' competencies, optimal outcomes for patients can be achieved." Henneman and Cardin[2] asserted, "Family-centered care moves beyond a theoretical recognition of patient's family members in healthcare. . . and views a patient's family as a unit to be cared for and organizes care delivery around the patient's family, as opposed to the more traditional patient-centered model." Lopez-Fagin[3] used the critical care family needs inventory of Molter[4] to demonstrate the validity of the "beliefs of nurses that critically ill patients are linked to their families, environment, and society psychologically, socially and spiritually. This holistic view focuses not only on critically ill patients, but also on families and their needs as human beings for the humanistic touch of the critical care nurse."

Bournes and Mitchell[5] endeavored to provide a basis for future research. They took the experience of waiting and using the phenomenological method of Parse that asked the question, "What is it like to wait while a friend or loved one is in critical care?" Their synthesis of the waiting experience demonstrated the "importance of equitable care, dignity, respect, assurance, support and comfort for family." Appleyard and colleagues[6] conducted further re-

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search into the needs of the families of critically ill patients. Based on their findings, they developed and examined a program to use hospital volunteers to help meet the needs of patients' families. Their conclusion was that "nurses are key to finding strategies in the critical care environment that can address the needs of patients' families." A more specific examination of families in intensive care was presented in a study by Engstrom and Soderberg,[7] which focused exclusively on the experiences of spouses when their partner was taken into an ICU. Their study found the following three key themes:

1. It was important to be present; nothing else mattered.
2. Showing respect for the critically ill spouse was essential.
3. Receiving support from family and friends was critical.

Further investigation into the needs of family members was done by Bond and colleagues,[8] who limited themselves to the family members of patients with traumatic brain injury. Their findings were in line with previous discoveries, placing high reliance on a holistic approach to care. They found the following four specific needs that rated high: need to know; need for consistent information; need for involvement; and need to make sense of the experience.

Lam and Beaulieu[9] studied families in which some member of the family was a patient in the neurologic ICU. Their findings support the "bedside phenomenon," which offers insight into the desire of a family to be at the bedside. The phenomenon observes that a family is motivated by the following two goals: (1) the family wants to ensure that their loved one is receiving the best care possible; and (2) the family wants to maintain an active connection with the patient.

Miller and colleagues[10] explored the cultural values influencing end-of-life decisions, as well as the limited involvement of nurses in such planning, and offered recommendations for changing nursing practice. After reviewing several studies, the authors advocated preparing nurses to be part of the process whereby end-of-life decisions are made indicating that the absence of nursing from that process deprives families of the holistic, caring perspective that a nurse can bring. Leske[11] examined a variety of ways that nurses can function to help reduce family anxiety during this critical period. She concludes that "the focus of nursing interventions is to maintain the present level of family functioning, prevent further psychological or physical deterioration, and educate families so that normal adaptation to the health crisis can be fostered."

Assumptions

On the basis of this research, all of which was conducted by nurses, certain assumptions can be drawn about the characteristics of an ICU seeking to fulfill the CCFAP goal, "to respond to the unmet needs of families of critically ill patients in hospital ICUs through the provision of educational and family support resources" (the CHEST Foundation; unpublished data; December 2002). All of these assumptions have been examined by at least one of the research findings cited above. While these assumptions can be reviewed in a variety of ways, they will be presented here from the perspective of critical care nurses who have the opportunity of observing, at close range, the application of these assumptions. Critical care nurses posses certain characteristics that are vital to an ICU and have played an essential part in the development of the CCFAP. Critical care nurses take very seriously their clinical responsibilities and will typically demonstrate loyalty to the hospital, to the ICU, and to one another. However, this loyalty is not given uncritically; critical care nurses look for participatory decision making, and seek systematic communication between clinical nurses and leadership.[12]

First Assumption

Health-care organizations have a responsibility to foster an environment that protects the physical and emotional health of severely stressed family members who assemble in their facilities to participate in the treatment of a relative.

While no one has suggested that the hospitals have deliberately developed an atmosphere that is harmful to family members, the intense focus of all staff on the critically ill patient has, over time, placed the family in a distinct secondary position. An entirely plausible attitude is that the greatest benefit the ICU can render a family is to give full attention to the patient. Twenty years ago, entry into the field of critical care nursing meant mastering new technologies that were making dramatic contributions to the capability of the ICU to save lives. Oftentimes, if it meant that this happened at the expense of discussion with and updates for the family, the tradeoff appeared justified on medical grounds. Nothing, however, kept family members from continually approaching nurses and seeking the desired information or demanding their attention. Nurses were forced to deal with this reality, but there was frustration on the part of both nurses and family members. This period has been described by a number of nurses as a time when nurses were dealing with families, not caring for families. The introduction of the CCFAP awakened, in many nurses, a realization

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that family members not only had a right to be present, but that they could have a positive impact on the patient. The program has heightened the awareness of nurses of the balance that needs to be maintained between technical expertise and interpersonal skills.

The development of the CCFAP has reinforced an understanding that the physical and emotional well-being of family members is important. The improvement of the waiting room, the access to places of rest, the opportunity for buying food, the supply of cell phones and beepers that promote instant communication, and all of the other things that are done to make the wait easier for families all convey a message: the staff has organized itself to care for them and to help them deal with anxiety and stress.

In most ICUs, there have been families that stay at the ICU anywhere from a few days to a year. To be in an uncomfortable place for any length of time can cause considerable strain. The nurses not only look after the patients, but also try to observe what is going on with the family. For example, if a nurse goes to the waiting room and a patient's spouse is not looking well, the nurse might discover that the spouse has not taken a needed medication in 3 days. With the aid of the CCFAP, the nurses can give the spouse a voucher for a cab to go home and bring back the needed medications. Compared to the great advances in medical technology, these are small things, but they affect the health of the family. This type of approach has changed significantly the atmosphere of the waiting room in a way that is not easily observable. Casual observers may see the patients and see the families as they come in. They do not always see what is happening with these families.

Critical care nurses have long observed that families, when stressed, can hinder a situation much more than they can help it. Family members do not know what to do; they want to be there, and they want to be helpful. Stress can cause them to hinder that process without their realizing it. The CCFAP offers them opportunities to reengage, to take time off away from their loved one, but still be close. It permits them to divert their energies for a short time, to refocus on themselves. Nurses tell families when they first come into the ICU and get an orientation to the CCFAP that their loved one is getting the best care possible. The nursing staff ratio is very low. These units have close to a 1:1 or 1:3 nurse/patient ratio. The message for family members is that the unit needs them to take care of themselves at this time: "Rest up, get something to eat, and come back later." At a later time, the family will need the support of the staff, and the staff may need family members' help with decisions. The CCFAP allows family members to give themselves permission to leave the bedside for a little time and refocus their energies. Once refreshed, they can again be a helpful part of the care team.

Second Assumption

Any family-friendly or patient-friendly program must ultimately justify its presence in a hospital by demonstrating, over time, that it can have a positive impact on key issues, such as the health of the patient, their length of stay in the hospital, the satisfaction of family members, and cost-effectiveness.

In commenting on studies dealing with patient and family satisfaction within an ICU, Burck[13] states that the results of any program should be measured by the "goals of medicine and fiduciary responsibility: nursing skill and competence, compassion and respect given to the patient, pain management and coordination of care, and frequency of physician communication." From the beginning, the CCFAP has committed to a program evaluation that aims at fully examining the impact of its many components. Another article in this supplement presents a quantitative analysis of program effectiveness through the initial years of the program. The description presented in this section reflects the program effectiveness from a qualitative perspective as perceived by critical care nurse involvement in the piloting of the CCFAP.

To one group of nurse managers, the average length of stay has actually decreased since the introduction of the CCFAP. They confirmed this by reviewing patient records. They also presented the following anecdotal record of one cardiology patient who they did not think at all atypical:

> A cardiology patient is admitted who is having a heart attack. His anxiety is not solely due to his chest pain but also his concern for his 80-year-old wife who will have difficulty driving around a city she does not know. She has only the clothes she is wearing, has had nothing to eat, has left her medicine behind at home, and does not know how to contact her son who is away on a business trip. The patient's anxiety level increases, the chest pain level increases, $\dot{V}O_2$ increases, and the possibility of more heart damage increases. Within the CCFAP, the process to take care of the family has already started. The patient is told that one of the staff took his wife to the cafeteria for a meal, has found her a room in a local motel, and through the son's place of employment, has located him. The son is going to drive to the hospital, picking up the wife's clothes and medicine on the way. The wife has been given a taxi voucher so she does not have to worry about driving, and all of the services have been provided at no cost. Suddenly, there is a sigh of relief that says it all. The chest pain subsides. The patient has his procedure; it is successful, and the couple goes home.

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This is how the program can impact the lives of both the patient and family members.

Hospitals have always had a great regard for delivering quality care. It would be erroneous to say that the care has improved because of the CCFAP, but the program has enabled the transfer of quality patient care to be extended further to family members. The hospitality components of the CCFAP (*ie*, meals, hotel rooms, and more comfortable waiting rooms) might be dismissed as peripheral to the responsibilities of a high-quality hospital. The nurses, physicians, and staff members at the CCFAP pilot sites would differ on that assessment; they consider the reduction of stress, the clarity of communication, and the attention to details of personal care to be goals worthy of attention.

Staff members pay close attention to both the qualitative and quantitative aspects of a CCFAP evaluation. CCFAP team leaders receive quarterly reports both from the hospital, as part of its regular evaluation, and from the CHEST Foundation, as part of its consistent review of the CCFAP. That information is shared with all members of the ICU staff and with all of the multidisciplinary units within the hospital that support the CCFAP. The multidisciplinary committee that meets regularly to discuss progress in programs and priorities reviews these results to enhance performance where possible and to apply remedies to whatever deficiencies are discovered.

As a result of these quarterly evaluations, a number of changes have taken place. Some of these changes brought about through the evaluation process have included a review of visiting hour policies, the addition of a children's play corner in a waiting room, the recruitment of several hospital volunteers to help with staffing the waiting room, and the addition of an evening social worker to assist family members who must work during the day.

Third Assumption

Nothing is as effective in meeting needs and promoting satisfaction, not only with the families, but also with the hospital staff, as improved and consistent communication. All members of the staff must be able to depend on every other team member to be faithful to their communication responsibilities.

The CCFAP has placed a high priority on improved communication. An essential element of the CCFAP model is that in establishing a plan of action, nothing is left to chance; for all activities, there is a process recognized by all staff, and responsibility for handling specific tasks is assigned. In one hospital, a common problem was communication with the family after surgery. Some basics were covered by the physician, but getting answers to other family concerns depended on the assertiveness of the family in asking questions. The staff assumed the responsibility for alleviating communication problems after surgery. A pamphlet was prepared in which the generic guidelines for surgery were explained, the recovery process was discussed in detail, and the family was prepared for the appearance of the family member after surgery. As this kind of communication has become more common, anxiety and stress within the family has decreased.

Each ICU in the CCFAP has observed that stress in families appears to decrease in inverse ratio to the percentage that communication increases. Over the years, anxiety and concern on the part of the family was one of the major barriers affecting communication between staff and family. In drawing up the action plan for the CCFAP, nurses frequently noted that when family members were tired, when they had not eaten all day, and when they had been sitting in a drab waiting room for many hours hoping for news of their loved one, the probability of their hearing and understanding any news, particularly unwelcome news, was very minimal. Unless a proper atmosphere for communication is created, the family will not be receptive. One of the goals of the CCFAP pilot sites in providing a sleep room with basic amenities within a friendly and open atmosphere was to foster mutual dialogue.

Since good communication involves both the delivery and reception of information, the CCFAP sites have employed a variety of strategies to encourage and support communication. Every effort is made to heighten the importance of discussion and dialogue with families. The fundamental basis of this strategy is to make sure that family members see and feel the presence of hospital staff.

While physicians, social workers, chaplains, and all staff are called on to support communication, nursing plays a special role. Critical care nurses are present in the ICU for their entire shift; in completing their tasks, they have the closest contact with the patient and have the greatest opportunity to observe the patient's condition. When nurses are in contact with the family, they have the opportunity of reinforcing what the attending physicians have already communicated. At times, families are too anxious and upset to really hear and understand what the physician stated. This role sometimes becomes more critical when the prognosis worsens. Family members then have the natural tendency to hold on to selective components of the physician's report and to disregard the negative components. Again, critical care nurses have an opportunity to help the family understand the medical report; consequently, they

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are able to explain again the condition of the patient and how it is related to the prognosis given by the physician.

CCFAP sites also have put pager programs in place to enhance communication. Pagers allow family members to leave the hospital for food, sleep, or just a change in environment. The pager is activated if, at any point, a family member's presence is required in the ICU. Additionally, the pager frees family members from the necessity of waiting in the lounge until the doctor makes his rounds. If family members wish to ask specific questions of the doctor, they can be paged when the doctor arrives.

Fourth Assumption

The implementation of a program such as the CCFAP requires a staff that is able to think and act in nontraditional ways. This ability to work constructively "outside the box" becomes a hallmark of a family-friendly program.

The entire development of the CCFAP has been an exercise in creative thinking. ICUs that had been designed and staffed to take care of seriously ill patients needed to add new priorities without impacting negatively on any ongoing priorities. While staff and family surveys pointed out the needs of the families, it was left to the creativity of staff to determine how these needs were to be met. The results of these efforts can be seen in refurbished waiting rooms; computer kiosk information centers; family conference rooms; provisions for hospitality with hotels, restaurants, and taxis; pagers and cell phones, and many other items contributing to the creation of a family-friendly atmosphere.

This atmosphere of creativity encouraged individual initiative on behalf of the ICU team. A critical care nurse approached a local retailer and received DVD and CD players for the patients' rooms as donations. One CCFAP site has set up a massage center where a licensed masseuse gives massages to family members to help relieve stress. A music therapist is also available at one CCFAP site and performs live music as a means of relieving pain and stress both for the patient and the family. The periodic visit of a pet therapy dog to one waiting room allows family members to relax and release their emotions in a playful manner. A variety of other innovations are being considered that a few years ago would have been dismissed as medically unnecessary.

In all of the participating CCFAP hospitals, family members have always expected clinical excellence. Now, these hospitals are seeking to emphasize customer satisfaction by becoming customer-friendly. This new approach to patient care helps in providing some closure to the ICU experience, as well. In the end, the ICU care team may not be able to change the patient's condition. However, the family will remember the care and attention given to them by the nursing staff during difficult times.

Fifth Assumption

While the ICU is the contact point of family members, the unit itself only exists as a part of the larger whole, the hospital. The CCFAP can only succeed when the goals and objectives of the program are in harmony with the priorities of the hospital. The changes made in the ICU must be integrated into the goals and objectives of the hospital.

Staff comments have been generally favorable and support the premise that the CCFAP can reduce family stress levels and promote positive outcomes. On an organizational level, the harmony existing between the goals and objectives of the CCFAP and the goals and objectives of the hospital promotes a mutually supportive environment. A number of examples of this synergy can be cited as follows:

1. Critical care is delivered by a multidisciplinary team of specialists who work together to provide the type of care necessary for critically ill patients. The CCFAP encourages a high degree of coordination of professional staff services, which distributes work responsibilities more rationally, lessens the burden on critical care nurses, and prepares hospitals for the shortages of members of the critical care team forecast for the next decade.
2. Critical care units must be concerned with customer satisfaction. Here, as elsewhere in the hospital, customer satisfaction is one way of measuring the quality of care. Clearly, family members are customers and participate in decisions regarding the treatment of a family member. On the basis of experience within the ICU, decisions are made about the quality of care in the total hospital.
3. Since the CCFAP requires close coordination between various hospital units, it has fostered with staff, in general, and even with those who do not have direct patient care, a more proactive attitude in dealing with needs of family members. The CCFAP has become a total hospital program, not merely a project for the ICU.
4. The coordinated involvement of multiple departments has resulted in the creation of additional family support services (*eg*, the program developed by the chaplain's office and social

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services to orient family members to the ICU, music therapy, massage therapy, and pet therapy).

5. With greater communication between various units of the hospital, the CCFAP has facilitated the discussion of certain topics that previously had been passed over, including palliative and end-of-life care, and do-not-resuscitate status.

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