Project Director's Perspective*

The Critical Care Family Assistance Program

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Abbreviation: CCFAP = Critical Care Family Assistance Program

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The Critical Care Family Assistance Program (CCFAP) is designed to respond to the unmet needs of families of critically ill patients in hospital ICUs through the provision of educational and family support services. In May 2002, the Joint Commission on the Accreditation of Healthcare Organizations convened an advisory panel to explore the establishment of an "ICU core measures set framework." The panel, composed of experts in critical care representing academic medical centers, medical specialty societies, the federal government, and business consulting groups, seeks to develop a framework for ICU core measures and the identification of potential key measurements within that framework. One of the goals of the CCFAP model is to be capable of meeting those measures, and from a research perspective, to provide data that will contribute to the field of critical care medicine.

CCFAP Model Sites

The sites selected for participation in the CCFAP have been chosen for their geographic, institutional, and patient diversity. CCFAP research studies focus on the similarities and differences within each of the following model types.

Community Teaching Hospital

One of the original pilot sites is an example of this model. Evanston Northwestern Healthcare, located in suburban Chicago, IL, shares faculty with Northwestern University Medical School, has a residency program defining it as a teaching hospital, serves the local community, but also draws patients from across the country due to its excellent tertiary care in certain specialties. In 2003, the CCFAP was expanded to a second hospital within the Evanston Northwestern Healthcare system, Highland Park Hospital in Highland Park, IL.

Governmental Institution for Veterans of US Military Service

The Oklahoma City Veterans Affairs Medical Center, Oklahoma City, OK, the second pilot site selected, reflects this model and serves a statewide and regional population.

Inner-city Hospital

Ben Taub General Hospital in Houston, TX, a replication site selected in 2003, reflects this model, having a large Medicaid and uncompensated care population.

Academic Medical Center

The University of South Alabama Medical Center, located in Mobile, AL, is an example of this model, because it consists of a tertiary care center and research institution that is affiliated with a medical school. This replication site was selected in 2004.

Rural/Small Community Hospital

Pardee Hospital of Hendersonville, NC, is an example of a "feeder" hospital in a geographic area of $< 100{,}000$ persons that may have a small ICU but will typically transfer patients with more complicated cases to a tertiary center. This model was selected during the 2004 replication cycle.

Each of these hospitals replicates the CCFAP model, seeks new ways to respond to the unmet needs of the families of critically ill patients, and demonstrates how the CCFAP program can serve as a model of care for families of critically ill patients in ICUs or wherever critical care is delivered within the hospital setting.

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Background

In section 1 of this supplement, "Origin and Development: The Critical Care Family Assistance Program," numerous studies conducted over the past 2 decades are cited, which investigate the varied reactions of families with loved ones in ICUs. One research study[1] examining these and other studies of families involved with an ICU concludes, "The results of these studies suggest that family members want honest, intelligible, and timely information; liberal visiting policies; and the assurance that their loved one is being cared for by competent and compassionate people." Burck,[2] in a commentary on the ethical responsibilities of those charged with operating an ICU, notes that quality of life claims that are developed without the patient's participation are very susceptible to observer bias and that any ICU that does not include the objective measurement of family satisfaction is not doing its job. He concludes, "Contextual features recognize that the good in health care is not just about the patient. It is about everybody involved with the patient-doctors, nurses, other providers, and family. Usually, the patient counts most, but everybody counts."

The concept that "everybody counts" would serve well as an axiom describing the multiple activities comprising the CCFAP. ICUs are a complex part of an even more complex institution, the hospital. Staffing the ICU in any hospital are men and women who are trained to perform very specialized and critical functions in an environment that has very high morbidity and mortality. Historically, critical care practitioners have their primary focus on the patient. Their orientation is to deliver outstanding care, expedite recovery, and shorten the length of stay in the ICU environment. However, on a daily basis, caregivers deal with patients who are either incommunicative or have limited ability to communicate because of the severity of their illness. This means that, frequently, family members or close friends who are emotionally invested in the patient become the surrogate decision makers. In the past, caregivers, in their efforts to address the patient's needs, might have found themselves in an organizational structure in which, despite their best intentions, they had neither the time nor the opportunity to address the family's needs. As a result, patient care was potentially impacted because caregivers were repeatedly dealing with the family about matters that could have been dealt with more efficiently at an earlier stage through more systematic communication. The CCFAP attempts to address multiple family needs, including communication, in such a way that it enhances trust between caregivers and family, and reduces some of the stress felt by caregivers and family.

Focus on Being Family-Friendly

Much of the research cited both in the first article of this supplement and in this article makes clear that if the critical care unit focuses exclusively on the patient to the exclusion of the family, it fails in its obligations to the family and possibly impairs the recovery of the patient. More recently, research has attempted to define the characteristics of an ICU with a significant orientation toward the family. Harvey,[3] in an editorial, noted that a critical care unit can only be family-friendly and have a firm grip on reality when it is diligent in gathering and utilizing data, rather than relying on subjective opinion, for decisions relative to family care. The subtitle of Harvey's editorial "Why Can't We Just Be Decent?" indicates where the author feels emphasis should be placed. As a result, the hospitals represented in the CCFAP gather data regularly from both family members and staff. The tabulation and analysis of those data through The CHEST Foundation evaluator, Dr. Jane Dowling, President, Wellington Consulting Group, enables the participating CCFAP sites to take that information and apply it in ways that advance their individual commitment to the family. Dodek and others[4] have indicated that an ICU team using a systematic, evidence-based approach to improvement will be far more likely to devise strategies that will effectively change behavior.

Outside of the CCFAP, the concept of a more family-friendly ICU has received significant notice in the popular press. In Flint, MI, the Hurley Medical Center pediatric unit has set about privatizing its 14 intensive care rooms, dedicating space for conscious sedation and for procedures such as inserting IV lines, and developing and enhancing the children's playroom both for play and for meeting with families.[5] The *Indianapolis Star* discussed[6] a program at the Riley Hospital for Children, where parents are encouraged to play a much more active role in the treatment of their child in the pediatric ICU.

Focus on Communication

It is a fundamental research finding that, for families of ICU patients, communication is the critical element. The ICU is an area where communication cannot be left to chance. Families are there to support the healing process. When families are misinformed or do not receive adequate information