



# ADVANCING PRACTICE THROUGH INQUIRY

*SON researchers are providing knowledge that can inform interventions that improve the lives of patients.*

## The Family Impact of Chronic Disease

Frances Hill Fox Distinguished Professor Kathleen Knaf, PhD, FAAN, has been advancing the field of family nursing for decades. She is known for her contributions to the development of the Family Management Style Framework (FMSF), an evidence-based conceptualization of the family response to chronic conditions.

The FSMF emerged from an early collaboration between Drs. Knaf and Janet Deatrick, PhD, RN, FAAN, at Shriners' Children's Hospital. Dr. Deatrick, who was director of nursing research at the time, was asked to conduct research that would provide the basis for family-centered care at the hospital. Together, they launched studies of families' needs during a child's hospitalization, family preferences for involvement in the child's care, and family management of the child's condition following hospitalization.

"We focused on how families responded to a child's chronic illness," says Dr. Knaf. "We wanted to identify different patterns or styles of family response and examine the relationship between the family's pattern of response and the child's wellbeing. We thought understanding the relationship between the pattern of family response and child's wellbeing was an important first step in intervention development."

The FMSF led to the Family Management Measure (FaMM), a questionnaire measure that Dr. Knafel and her colleagues used to more precisely study the relationship between family response and the child's health outcomes. In a recent investigation, they examined 575 parents of children with diverse chronic conditions, such as type 1 diabetes or cystic fibrosis. Participants completed the FaMM as well as additional questionnaires to determine family functioning and child adaptation.

Based on the FaMM results, the investigators determined the pattern of family management used to cope with the child's condition. For example, families identified as having a Family Focused management pattern were caring for the child's condition effectively. Their lives did not revolve around condition management. In contrast, for families identified as Condition Focused, a great deal of their everyday life was centered on the child's special needs and the treatment regimen.

Dr. Knafel and her colleagues found a relationship between the management pattern and a family's wellbeing. Family functioning and child adaptation were significantly better for families who were Family Focused or Somewhat Family Focused versus families who were Condition Focused or Somewhat Condition Focused.

Because of the relationship between condition management and family functioning, the FaMM, could be a useful tool in practice settings. Responses to the FaMM would launch discussions with a family's care team about strategies that would lead to a better balance between family functionality and caring for a child with a chronic illness.

Dr. Knafel is continuing her work by examining the intersection between childhood chronic conditions and family life on a larger scale. She recently received a grant from the National Institute of Nursing Research to synthesize the findings of all available empirical research related to family life and childhood chronic conditions. Cary C. Boshamer Distinguished Professor Margarete Sandelowski, PhD, FAAN, is the co-principal investigator for the study.

In addition to her faculty role as a distinguished professor, Dr. Knafel is Associate Dean for nursing research at the SON. She oversees the SON's Office of Research Support and Consultation, which offers researchers technical, scientific, and editorial support for their grant proposals.

"Nursing has increasingly become research-focused, and the sources of support for nursing research have expanded considerably," she says. "With a growing number of well-prepared nurse researchers and a growing emphasis on

research in our educational programs, nursing research has really come of age."

## Self-Care Strategies For Sickle Cell

Assistant professor Coretta Jenerette, PhD, RN, has built a program of research around improving the lives of people with sickle cell disease, a disorder in which a gene mutation results in sickle-shaped red blood cells that can cause significant pain. It is the most common inherited blood disorder in the United States, affecting 70,000-80,000 Americans.

When she was practicing as a staff nurse, Dr. Jenerette noticed that patients with sickle cell disease were treated differently than other patients who had similar pain symptoms. At the peak of a sickle-cell crisis, how a person responds to the pain can range from being severely withdrawn to outwardly suffering. Both states make it difficult for providers to determine the patient's needs. "If patients come in a little earlier, perhaps they'll be able to give a better medical history and be perceived as more credible," says Dr. Jenerette.

Seeing an opportunity to enhance care for individuals living with sickle cell disease, Dr. Jenerette decided to investigate self-care strategies that might improve their health outcomes. In a pilot study aimed at decreasing health-related stigma in young adults (18-35 years old) with sickle cell disease, she focused on two things: 1) getting young adults to the hospital sooner during a crisis and 2) teaching them how to communicate better with their providers.

In the study, Dr. Jenerette taught participants to use a communication technique called SBAR, which stands for situation, background, assessment and recommendation. Health-care providers use this standardized technique to share patient care information with each other. Using SBAR, a person with sickle cell disease can communicate health needs using a strategy with which the provider is familiar.

Dr. Jenerette has seen positive results from the pilot study and is now fine-tuning an intervention to improve health outcomes for young adults with sickle cell. She is conducting a similar study with teenagers living with sickle cell disease and is also exploring the relationship between sleep and pain in young adults with sickle cell disease.

"If the health care system can't currently meet a patient's needs," says Dr. Jenerette. "Then researchers and health professionals need to help develop strategies that will leave patients more satisfied with the health care system and lead to better outcomes. That's what I'm hoping to do with my work on sickle cell disease." ■