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****Health personnel help brothers and sisters of children with chronic illnesses

DALLAS---Most children's medical clinics don't have their own personal photographers. But then they don't have two-year-old Kristen Krage as a patient or her four-year-old brother Jensen, who visits the clinic with her, either.

Kristen, who was diagnosed within the last two months with acute leukemia, sees medical personnel at Children's Medical Center in Dallas on a regular basis. There she is being treated by physicians on the pediatric faculty of The University of Texas Health Science Center at Dallas and other members of the oncology/hematology team.

From the beginning, the little girl coped well with the strangeness and discomfort associated with these visits. Jensen was a different story. Although not a patient himself, the four-year-old found the hospital environment strange, felt the stress the disease brought to the family and noticed that attention had overwhelmingly shifted to his little sister.

"It was obvious when Jensen began having problems because he began to be irritable and difficult," says his mother. "He didn't want us to tell him anything about Kristen or the hospital. When we'd try, he'd put his hands over his ears and come on apprehensive."

Kay Krage and her husband took the problem to hospital child-life specialist Sally Francis. Francis, who directs the child life/child development program at Children's Medical Center (CMC), is assistant professor of clinical pediatrics at the health science center. Francis, who has become increasingly sensitive to the traumas associated with brothers and sisters of chronically ill children, came up with a solution -- making Jensen a chronicler of Kristen's experience. Now, each day the little boy accompanies his sister to the clinic he has an important role to play. With a Polaroid camera, he takes pictures of all the health personnel who see Kristen. He also photographs Kristen receiving treatment and other children in the clinic.

"It's really made a difference," says his mother. "Now Jensen has an important part to play in the visit, and it's not so scary. We're putting the pictures in a scrapbook and labeling them at home so we can look at them. He's still not ready to talk about what's going on, but he'll watch. And there has been a definite improvement in his behavior."

Francis says that while pediatric hospital staffs are very aware of the emotional problems of their small patients and their parents, too often not enough attention is paid to siblings. But things are changing. CMC is moving more and more toward accommodating the needs of the whole family in times of medical crisis, including special attention to brothers and sisters. The hospital has become more liberal with its visiting policies, holds special play-group sessions for brothers and sisters during daytime hours and sponsors family meetings in the evenings. There are also "grief groups" open to families of children who have died.

Working with family groups, and seeing how the illness of a sibling affects other brothers and sisters has led Francis and her co-investigator, Dr. Hilda Glazer-Waldman, to look at the problem on a long-term basis. They began in 1981 with an institutional grant of \$5,000 from the health science center's School of Allied Health Sciences. They are looking at several questions surrounding families that have children with chronic leukemia. These include how much brothers and sisters of different ages know about the disease, feelings about the siblings' illnesses and levels of the brothers' and sisters' self-esteem.

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"We want to know how brothers and sisters cope with illness, so we can help everyone in the family and be more supportive," says Francis. Glazer-Waldman, who is an educational psychologist and an assistant professor in the Department of Allied Health Education, also points out that it's important to make sure the teaching material given to families includes information appropriate to siblings of different ages.

Francis says the increased attention to the needs of CMC patients' siblings has been good for the entire clinical staff. "Everyone has become more aware of their needs because of the research project, and all the personnel are spending more time with the brothers and sisters of the patients. The doctors, in fact, have been especially wonderful."

And, she says, hospital staff members now realize just how important the needs of the siblings are. For some, coping with a chronic illness is just as difficult as dealing with the death of a brother or sister. Indeed, since many children with serious chronic diseases are living longer these days, child life/child development personnel at CMC are putting an even greater emphasis on helping the living.

So far, the two researchers have studied 23 children between 5 and 15 years of age who have brothers and sisters with leukemia. At the same time, they are looking at a group of healthy youngsters, the same age as the controls. Standard tests, interviews and questions about the disease are being used as tools.

While Francis and Glazer-Waldman say that their sample is still too small for conclusive results, they have learned a lot that is helping health personnel in their day-to-day dealings with the patients, their brothers and sisters, and their parents. In addition, preliminary results seem to indicate that the greater the coping skills of the family as a whole, the greater the coping skills of the patients' brothers and sisters.

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