

For thousands of leukemic children across the United States, their life-and-death struggle against the disease may be needlessly complicated by psychological problems, such as low self-concept, according to a study done by a member of the faculty at the University of Alabama School of Nursing at UAB.

"I first became interested in the subject of the low self-concept level of youngsters while working with leukemic children at the Pediatric Research and Transplant Unit at the University of Colorado in Denver in 1975," says Dr. Joanne Scungio, an associate professor, who joined the faculty in January. "I was working on my first master's degree in nursing at the time. It became evident to me that the leukemic children held themselves in low esteem compared to their healthy peers."

Investigation of the literature revealed that very little research had been done on the subject of the self-concept level of children with leukemia as opposed to well children.

"Thirty years ago, the median survival for children with acute lymphocytic leukemia was three to six months," says Dr. Scungio, who received her bachelor's degree in nursing from the University of Rhode Island in 1973. "Currently, 60 percent of children with leukemia survive five years after diagnosis, and increasing numbers of children live for 10, 15 and even 20 years after diagnosis."

The increased life expectancy for leukemic children has resulted in a shift in psycho-social emphasis—that is, from coping with imminent death to helping the child and the family live with cancer as a chronic illness, notes the petite brunette.

It was not until 1980, however, that Dr. Scungio decided to study the subject in depth—choosing it as the topic of her dissertation research at the University of Pittsburgh School of Nursing. That research was to produce "The Relationship Between Self-Concept and Social Activity of School-Age Leukemic and Healthy Children."

In August of 1981 Dr. Scungio returned to her hometown of Providence, R.I., to begin the data collection phase of her dissertation. Under the supervision of Dr. Edward Forman, a pediatric oncologist at Rhode Island Hospital

in Providence, she began interviewing school-age leukemic children as well as healthy children. For one month, she worked 12 hours per day, seven days per week gathering her data.

"It was tough work, but I loved every second of it," she recalls. "After spending 10 to 12 hours at the office provided me at Rhode Island Hospital collecting data, I would return home each night, and spend several hours computing the information."

In order to obtain the information for the dissertation, she compared 20 healthy children with 20 children with acute lymphocytic leukemia. All children were between the ages of 8 and 11.

Children were asked to complete two drawings, a wish expression test, a children's self concept scale, and a children's social activity level evaluation.

"Only the children with leukemia were interviewed to learn more about their feelings about their illness," she says. "Parents of healthy children and children with leukemia were given parent questionnaires to determine the social activities of the children one year prior to the study and one year prior to the children's diagnosis of leukemia."

Dr. Scungio administered the various tests to the leukemic children at the hospital, in a quiet, plain room with a minimum of distractions. She answered questions as simply as possible, leaving interpretations of the tests to the children.

After administering the first three tests, Dr. Scungio had the children complete the Piers-Harris Children's Self-Concept Scale.

"I wanted to know what the children felt about themselves," Dr. Scungio says. "The questions dealt with physical appearance, anxiety, popularity, intellectual and school status, behavior, and happiness and satisfaction. The test was completed with a paper and pencil.

"All leukemic children said their looks bothered them," she adds. "They also expressed displeasure at being made fun of when they went to school. Children would tease them about their loss of hair, skin discoloration, or loss of weight.

"I'm sure their schoolmates did not intend to be cruel, but were just

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Leukemic children are topic of research

naturally curious about the leukemic children."

The findings of the Piers-Harris Scale and the Social Activity Scale showed significantly lower self-concepts, and participation in fewer social activities among the leukemic children.

Several residual findings emerged from Dr. Scungio's study.

"I found that children diagnosed longer than two years had better self concepts and participated in more social activities, than children diagnosed less than two years," she says. "I also found that children who had been told by their parents that they had leukemia had a better self-concept and participated in more social activities than children whose parents hid the fact that they had leukemia."

The ramifications are plain—if parents are truthful to their children in respect to their illness, the children are freer to go on with the normal tasks of growth and development. The children trust their parents and nursing staff more and cope better with the ramifications of the illness.

"When parents try to conceal the seriousness of the illness, the children sense something is wrong," says Dr. Scungio, "Why am I not begin punished for something that two months ago would have gotten me a spanking?" the child asks himself. Parents, too, must cope with learning of the seriousness of the illness."

The experience was a challenging one for Dr. Scungio, with the children often confiding in her—discussing painful experiences that they had not, could not, or would not share with even their parents.

"These children told me their whole lives," she recalls. "Emotionally, I felt their pain. There isn't anything wrong with feeling their pain. If the child were mine, I believe it would be unhealthy for me to try to control these same emotions."

Dr. Scungio receives drawings from the leukemic children regularly and reports having received "about a half dozen letters from parents."

All parents received a short summary of her study.

Some of the more revealing comparisons in the Piers-Harris scale included:

—All 20 leukemic children believed they caused trouble to their families, but no healthy child agreed with the statement.

—Half of the leukemic children responded yes to "I think bad thoughts," but no healthy child agreed with the statement.

—All the children with leukemia believed their families were disappointed in them, but none of the healthy children believed the statement.

—Seventeen of the 20 leukemic children said they were not good looking, but all the healthy children said yes to "I am good looking."

—All leukemic children stated yes to "My looks bother me," whereas only one healthy child agreed with the statement.

—Nineteen of 20 leukemic children reported they worried often,

but no healthy child reported worries.

—Seventeen of 20 leukemic children said they did not have many friends, whereas all healthy children reported having many friends.

—All leukemic children believed they were different than other people, while only four of the 20 healthy children agreed with the statement.

—Seventeen of the leukemic children stated they were unhappy, and none of the healthy children expressed unhappiness.

—All leukemic children said they were unlucky, but no healthy child believed himself/herself to be unlucky.

—Nineteen of the 20 leukemic children said they disliked being the way they were, but no healthy child disliked the way he/she was.

Dr. Scungio plans to begin a similar study here using a younger age group and, also, a one year follow-up study of the leukemic children from Rhode Island.

