The memory, now decades old, still haunts Susan O’Conner-Von. When she began her career as a pediatric nurse, common wisdom held that children did not feel the pain of medical procedures and, if they did, they soon forgot it. Yet, she found herself restraining young patients during procedures—and feeling their pain.

That experience led O’Conner-Von, PhD, RN, now an associate professor at the School of Nursing, to devote her life’s work to developing practical strategies to help kids cope with the pain of medical procedures and treatments.

Since the days when O’Conner-Von steadied kids for medical procedures, studies have confirmed what she felt: Young patients do feel and remember the pain of treatments. And, in the case of children with cancer, research shows that the trauma of medical procedures is often more feared than pain associated with the disease.

“My involvement in pain management research is my ‘apology’ to all the kids I held during procedures,” she says.

ASKING THE EXPERTS
O’Conner-Von wants to ease the discomfort of teens facing arduous treatment for cancer. She points out that, except for behavioral research, early and mid-adolescents—those between 10 and 16—are under-studied. Cancer patients in this age group are scared but don’t want to admit it. They’re also very concerned about body image and the effect of the treatment on their appearance and relationships with their friends.

With U of M Grant-in-Aid support, O’Conner-Von began her search for potential interventions that would help teens cope with cancer. She turned to the experts: four adolescents who had completed cancer therapy within the year. After gathering data through extensive interviews with them and their parents, O’Conner-Von focused on education about cancer, cancer treatment, pain, and healthy coping skills. She also decided to make these educational materials available online, so that teens and their parents would have access to accurate, current information anytime, anyplace.
Susan O’Conner-Von

- Pediatric pain and palliative care
- Preparation for surgery: pre-operative fears
- Non-pharmacologic interventions for pain management

DEVELOPING THE WEB SITE

Through funding from the School of Nursing’s Center for Health Trajectory Research, established with support from National Institute for Nursing Research, O’Conner-Von took the next step: the design of a Web site with lively graphics, eye-catching colors, fun features, and content presented in easy-to-understand language.

She turned to Red Racer Studio, a Minnesota-based group that provides illustration, toy and game design, creativity consulting, and Web development. Together they created a site that includes a journal with a series of interactive entries based on the experiences of kids who have undergone cancer treatment. The journal provides down-to-earth information such as: “EMLA (medication that numbs the skin) is very good stuff with a port” and “You don’t have to worry that you’ll glow in the dark after radiation treatment.”

The “kid advice” page offers tips like these: “I made sure to rest after each treatment,” “It helped me to take deep breaths during the procedures,” and “I brought along a friend when I had to see the doctor... it was fun to hang out with someone my age.”

The site also includes a “who’s who” which explains the roles of health professionals involved with cancer care, a glossary of “med speak,” and a resource page for parents.

FIELD-TESTING

Once the beta version of the “Coping with Cancer” Web site was constructed, O’Conner-Von asked 20 early-to-mid adolescents in their first year of cancer treatment to critique it. To establish a baseline measurement of their cancer knowledge prior to exposure to the Web site, she developed and validated the Adolescent Cancer Knowledge Questionnaire (ACKQ). The ACKQ includes questions like these: What are vital signs? What’s hemoglobin? What do you call a doctor who cares only for people with cancer? If you have cancer, do you have to drop out of school? Is cancer contagious?

During the field test, study participants were given access to the Web site for one month. Each was asked to log the amount of time he or she spent on the site each day. At the end of the month, participants were again asked to complete the ACKQ. Their answers will enable O’Conner-Von to compare their pre- and post-study knowledge. Additional pre/post measures included situational anxiety and coping skills. She expects to complete data analysis this fall.

PROMOTING LONG-TERM WELL-BEING

We’ve come a long way in reducing the anxiety and pain associated with childhood cancer treatment, O’Conner-Von says. But she believes that more can and should be done to promote long-term well-being—especially since more children are now surviving cancer.

“Longitudinal studies of patients who had cancer as children show that a significant percentage experienced emotional challenges, such as post-traumatic stress symptoms, uncertainty and depression,” she says. “Helping young patients cope with the trauma of illness and treatment today may pay health dividends for years to come.”

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