

**Public release date: 5-Oct-2005**

Contact: Kelly Perry

[kelly.perry@stjude.org](mailto:kelly.perry@stjude.org)

901-495-3306

[St. Jude Children's Research Hospital](#)

**Children and adolescents with advanced cancer can make complex end-of-life care decisions**

***Groundbreaking St. Jude study finds that young cancer patients understand the consequences of their decisions and show altruistic behaviors toward family and other children with cancer***

Pediatric cancer patients as young as 10 years old who are aware that their disease is incurable have the ability to participate meaningfully in discussions of their own end-of-life care with family members and the health care team, according to investigators at St. Jude Children's Research Hospital and Sydney Children's Hospital (Sydney, Australia).

These children identified their deaths as an outcome of their decisions to end or limit treatment, understood that they were participating in decisions about the end of their own lives, and recognized the consequences of their decisions, the researchers said. A report on this study, which was done as part of the Palliative and End-of-Life Care Program at St. Jude, appears in the Sept. 19 online issue of *Journal of Clinical Oncology*.

The St. Jude study was important because research on end-of-life preferences has typically focused only on parents and clinicians rather than the children, according to Pamela Hinds, Ph.D., R.N., director of nursing research at St. Jude and first author of the report.

In the study, 20 participants 10 to 20 years old being treated at either St. Jude or Sydney Children's Hospital participated in one of three end-of-life decisions: enrollment on a Phase I study of a drug that would not benefit them in their terminal stage (seven patients); adoption of a "do-not-resuscitate [DNR]" order (five patients), or initiation of terminal care, i.e., aggressive treatment of disease symptoms rather than the disease itself (eight patients).

A striking finding was that consideration of others' preferences was the factor most frequently reported to affect decision making by patients, parents and physicians, Hinds said. This indicates that human relationships strongly influence end-of-life decisions in pediatric oncology, she added.

Another key finding was that, among 11 of the 20 patients, a part of the decision-making process included the wish to benefit others, even though they themselves would not benefit. The St. Jude investigators say they did not anticipate this finding since such behavior is not reflected in existing theories of child development, which maintain that children expect personal benefit when they help someone else.

The St. Jude team interviewed pediatric patients within seven days of participating in one of the three end-of-life decisions--enrollment in a Phase I trial, adopting a DNR order or initiating terminal care. The patient, a parent and the primary pediatric oncologist were interviewed separately, and all interviews were taped and transcribed. Fourteen of the patients in the study were female; 17 were white. The diagnoses included solid tumor (12 patients), brain tumor (four patients) or leukemia (four patients).

The investigators reported that the children understood the short-term consequences of their decisions (e.g., getting sick from an experimental drug), the intermediate consequences (e.g., delaying their inevitable death), and the long-term consequence (dying).

"Some patients considered participating in a Phase I study of a new drug because the drug might benefit other children," Hinds said. "But Phase I studies are designed to look at the safety and proper levels of an investigational drug, and not effectiveness," she noted. "So we found it remarkable that young people would knowingly offer to participate in studies to help other children in the future even though they themselves would never benefit from it."

For example, 19 of the 20 patients (95 percent) said their decisions were affected by caring for others (family, hospital staff and future patients), the preferences of others, and the desire to benefit others. One 14-year-old girl noted that, "If I can help someone else, that's wonderful, I think." A 19-year-old female who decided to enter a Phase I trial said, "If I don't take it, my family would support me, but they don't want me to quit."

Grandpa said he would worry himself to death if I don't try it. My boyfriend wants me to take it for him. I don't want to do it but for my family."

Young patients who wanted to end all therapy, even if that therapy might extend their lives (65 percent), came to that decision because of "wanting no more," the researchers report. For example, a 15-year-old girl with acute lymphoblastic leukemia said, "We decided not to go with chemo because I don't want to be sick the rest of my days, and it's not like it is going to cure me, so I just said, 'We'll go home and take it from there.'" Other patients said they were ready to die and go to heaven (50 percent) or that they had seen other patients die on mechanical support and wanted to avoid that course of treatment (50 percent).

Clinicians see this type of research as a priority because they often feel unprepared to offer adequate assistance to parents and patients during this time, according to Wayne Furman, M.D., a member of the Department of Hematology-Oncology and deputy director of the Solid Tumor Clinic.

"Knowing what their child's end-of-life care preferences are would let parents and clinicians honor them where possible," said Furman, the paper's senior author. "This could provide comfort to parents after the loss of their child and reassure clinicians about the quality of care they provide. It might also give patients a sense of control during a time when most decisions are not within their control."

The finding that decisions made by young patients were relationship based also means that pediatric oncology professionals should include this observation in their attempts to facilitate end-of-life care preferences, Furman said.

Parents and physicians were also questioned about their responses to the child's decisions. For example, among parents whose child chose terminal care, the most frequent responses were: "child is happier," and "this is right for us."

"Although this study gave us valuable insights into how best to help patients and parents make end-of-life decisions, our findings are preliminary," Hinds said. "More and larger studies are needed to fully understand this unique and very important time in the life of a child with an incurable disease."

The Palliative Care program at St. Jude relieves the suffering of children and adolescents with catastrophic diseases; reduces their pain, nausea, and other

symptoms; enhances their quality of life during treatment; and attends to the psychosocial needs of these patients and their families. The program cares for children who are cured as well as children for whom treatment ultimately fails.

The program is now developing a research-based "model of excellence" for end-of-life care that will guide not only staff members, but also the patient and family as they make decisions about the care and comfort of the young patient. "The assertion of the Palliative Care program is that the death of a child is a social policy issue, and that how society helps a child to die is how society helps the child's survivors to live with that loss," Hinds said.

Other authors of the paper include Donna Drew (Sydney Children's Hospital; Sydney, Australia); Linda L. Oakes, Maryam Fouladi and Sheri L. Spunt (St. Jude); and Christopher Church (Baptist Memorial College of Health Sciences, Memphis).

###

This work was supported in part by grants from Project on Death in America (the Soros Foundation), the Oncology Nursing Foundation, the National Institutes of Health and ALSAC.

### **St. Jude Children's Research Hospital**

St. Jude Children's Research Hospital is internationally recognized for its pioneering work in finding cures and saving children with cancer and other catastrophic diseases. Founded by late entertainer Danny Thomas and based in Memphis, Tenn., St. Jude freely shares its discoveries with scientific and medical communities around the world. No family ever pays for treatments not covered by insurance, and families without insurance are never asked to pay. St. Jude is financially supported by ALSAC, its fundraising organization. For more information, please visit <http://www.stjude.org/>.

---