

Life after a Pediatric Liver Transplant: New study on functional outcomes

VITA LERMAN

By the first year anniversary of their liver transplant, most children are back to school full time. However, these children's academic performance is often lower than expected, and maladaptive behavior and attention deficit hyperactivity disorder (ADHD) are common. How widespread are these effects? Which variables might predict less than optimal development or quality of life in children after a liver transplant? These questions will be examined in a new study on functional outcomes after pediatric liver transplantation, conducted in 20 centers and led by Estella Alonso, MD, medical director of the Liver Transplant Program at Children's Memorial Hospital, in collaboration with neurocognitive psychologist Lisa Sorensen, PhD, also at Children's Memorial. The study is funded by a \$2.3 million 5-year grant from National Institutes of Health and is expected to start in the spring of 2005.

"This is the first large multi-center study on quality of life for pediatric solid organ transplants," says Alonso. "It is also the first multi-center study in solid organ transplants to look at cognitive function. If we can figure out the medical factors that link to learning disabilities or other functional deficits, then we can change the way we care for these children."

Alonso explains that discrepancies between a child's IQ and academic achievement appear to be more prevalent after all types of transplants. These children are still within normal range for their age, but as a group they perform worse than the general population. "Processing abilities appear to be more vulnerable to insults that occur with transplants, in comparison to knowledge that is crystallized, or previously acquired," she says. "Post-transplant children with such isolated cognitive abnormalities generally go undiagnosed, which is a big concern since they do not receive appropriate interventions."

The arm of Alonso's study that will focus on cognitive development will involve 150 children, 5 to 7 years of age, who have had a liver transplant at least 2 years prior. Participants will be comprehensively tested at stages 2 years apart, to determine if function improves with age and increased time after the transplant. Using a battery of age-appropriate tests, researchers will evaluate IQ, academic achievement, language, behavior, school readiness and development. Results will be compared to those of the general population of corresponding ages.



Photo by Russell Ingram

Estella Alonso, MD, medical director, Liver Transplant Program

In addition, teachers will be asked about the child's behavior and performance in class. One of the study's aims is to determine the incidence of maladaptive behaviors, including ADHD, in this population and study the relationship between problematic behavior and academic achievement, intellectual ability, and utilization of special educational support.

The quality of life arm of the study will recruit 800 children, 1 to 18 years of age, who have had a liver transplant at least 1 year ago. Children who are 8 years or older will complete a new well-validated health related quality of life questionnaire (Peds QL 4.0) that asks about school, emotional, and social functioning. Parents will complete another questionnaire about their assessment of the child's quality of life. Researchers will assess the relationship of quality of life with variables, such as demographics, center volume, time since transplantation, number and duration of hospitalizations, primary disease, allograft type and function, nutritional status, and renal function.

Information gained from this study will be critical for early identification of children at risk for cognitive and psychosocial difficulties after a liver transplant, in order to provide anticipatory guidance and targeted interventions. This research will also clarify expectations for outcomes, enabling patients, families, and clinicians to make evidence-based clinical decisions as they weigh medical and functional tradeoffs of liver transplantation. ■