Disabled Girl Reportedly Denied Transplant

Kevin Begos & Matt Moore, AP
The parents of a three-year-old New Jersey girl say she's being denied a kidney transplant because of her mental disabilities, but experts caution the situation may be much more complex. The girl's mother, Chrissy Rivera, last week posted a blog entry that described an encounter she claimed happened at The Children's Hospital of Philadelphia. She said she was there to discuss treatment for her daughter, Amelia, who was born with Wolf-Hirschhorn syndrome, a rare genetic defect that can cause physical and mental disabilities.
Rivera wrote that a doctor, whom she did not name, told her and her husband, that Amelia wouldn't be eligible for a transplant because of her quality of life and her mental condition. "I put my hand up. 'Stop talking for a minute. Did you just say that Amelia shouldn't have the transplant done because she is mentally retarded. I am confused. Did you really just say that?'" she wrote. "I begin to shake. My whole body trembles and he begins to tell me how she will never be able to get on the waiting list because she is mentally retarded."

Rivera's story was seen by Sunday Stilwell, the mother of two severely autistic boys, and she began an online petition, demanding that the hospital give a transplant to the girl. By Tuesday night, more than 23,700 people had signed it. "I read Chrissy's original blog post, and I just cried. I couldn't believe it," said Stilwell, whose boys are 6 and 9. "I shared it on Twitter with all my followers and on Facebook."

Children's Hospital said in a statement that it "does not disqualify potential transplant candidates on the basis of intellectual abilities. We have transplanted many children with a wide range of disabilities, including physical and intellectual disabilities," it said, adding that it is deeply committed to providing the best possible medical care for all children, including those with disabilities. The hospital did not comment further, citing patient confidentiality laws.

Stilwell has been in contact with Rivera daily over the events. "There's a lot of camaraderie" between parents of special-needs kids, Stilwell said. "Almost all of us, across the board, have experienced some discrimination. I've certainly had some bad run-ins with some certainly ignorant doctors, but nothing like this. That's part of the reason I did it. I couldn't actually believe this was happening." Messages seeking comment from the Riveras through Facebook and to their home were left Tuesday but were not immediately returned.

The issue the Riveras face is not simple, said Arthur Caplan, director of the University of Pennsylvania Center for Bioethics. For example, the blog notes that Rivera told the hospital that "we plan on donating" the kidney, since they come from a large family. "Most adults can't donate an organ, because it won't fit" a child, Caplan said. "You're starting to say you're going to use another child as a living donor, and that's ethically really trouble." The supply of organs for child transplants

is "extremely limited," Caplan added. "So you have hard choices to make. Dialysis may be a better option."

According to the National Institutes of Health, 87,820 people were awaiting kidney transplants as of last February. The National Kidney Foundation, which seeks to enhance the lives of people affected by kidney disease, said 4,573 patients died in 2008 while waiting for kidney transplants. A 2006 study from Ohio State University on kidney transplants for patients with mental disabilities found that the one-year and three-year survival rates for 34 people were 100 percent and 90 percent, respectively. "The studies reported good compliance with post-transplant medications due to consistent support from family members or caregivers," the paper noted.

The researchers added that previous controversies over mental disabilities and transplants led the Joint Commission on Accreditation of Healthcare Organizations to express concern that many people with disabilities are "denied evaluation and referral for transplantation." Rivera's blog noted that doctors said Amelia won't need a transplant for six months to a year.

Some experts said that if Rivera's claims are accurate, the hospital's actions are very disturbing. "Everyone deserves an equal chance to these organs, regardless of your mental capacity," said Charles Camosy, a professor of Christian Ethics at Fordham University. Camosy said that while it's true that there are shortages of kidneys and other organs, the criteria used to make transplant decisions "should not ever devalue those that are mentally disabled."

Whatever the medical details of Amelia's situation, her mother's blog captured the anger of parents with disabled children who don't want outsiders to decide life and death issues. "Do not talk about her quality of life," Rivera wrote of her exchange with the doctor last week. "You have no idea what she is like. We have crossed many, many road blocks with Amelia and this is just one more. So, you don't agree she should have it done? Fine. But tell me who I talk to next."

Mary Beth Happ, a professor at the University of Pittsburgh Medical Center whose research focuses on communication with non-vocal patients, said that the issue of severe mental disability and kidney transplants has been a source of contention for nearly two decades. "Co-existing health problems such as weakened immune system and/or heart disease, which are prevalent in (Wolf-Hirschhorn syndrome), are an additional risk that transplant centers and parents must consider," Happ wrote in an email.

But Happ and Caplan noted that it's virtually impossible to have a full discussion of Amelia's case because of medical privacy laws. "We're seeing this more and more where very private, difficult medical decisions are debated in the media without the full facts," Happ said, adding that while the general discussion can be good, the risks of one side or another inflating the situation is problematic.

Caplan said he has heard of cases in which other transplant programs considered severe mental disability as a factor in transplants. "With scarcity, social factors do

count, with every transplant," he said.

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