Charlie Gard and other precious children

The debate over a dying British infant reveals the moral complexities of health care.

From the Editors in the August 30, 2017 issue



A neonatal intensive care unit. Some rights reserved by Kaveri appala.

Every parent could identify with the tenacity of Charlie Gard's parents, who fought mightily to give infant Charlie—suffering from a rare and fatal genetic disease—what they believed was his best chance for a longer and better life. For Chris Gard and Connie Yates, that effort extended to taking a London hospital to court in an effort to get Charlie a never-before-tried experimental treatment.

The dramatic and unusual legal conflict between the parents and the hospital, which ended with Charlie's death on July 28, explains the widespread interest in Charlie's

case and why such diverse figures as Pope Francis and President Trump were moved to voice support for Charlie's parents. It was easy—especially at a remove from the medical details—to view the doctors and hospital as callous toward the parents and indifferent to Charlie.

Left out of many accounts, however, was the complicated reality at the heart of the case: Charlie's doctors also affirmed the preciousness of Charlie's life, and it was because of their commitment to serving Charlie's best interests that they recommended ending treatment. Doctors are called upon to render their best judgment as to when treatment is futile and when further treatment will do more harm than good.

A necessary part of any moral reflection on Charlie's case, therefore, is to remember that doctors are not mere contract workers paid to do whatever the client asks. Doctors and hospitals would violate their own professional ethic of care were they to pursue a treatment simply because the patient's family wanted it or because someone was willing to pay for it.

The issue of money is also a necessary part of any moral reflection on Charlie's case, not because the British hospital didn't want to spend more money on Charlie's treatment (there's no evidence that finances played a role in the decision) but because Charlie's parents raised close to \$2 million in donations to pay for the highly experimental treatment they wanted in the United States.

Of course, Charlie's life is worth the \$2 million. In some abstract moral universe, Charlie's life or any life is priceless. But anyone eager to defend the preciousness of Charlie's life must note how the lives of countless other children just as precious as Charlie could be saved for much less money. A \$2 million investment in, for example, clean water, vaccinations, prenatal care, wellness clinics, or nutrition programs would save a great many children's lives in this country and abroad.

The point here is not to be grudge the Charlie Gards of the world the care they need. The point is to be honest about what affirming the preciousness of life entails not only in hard cases like Charlie's but in the everyday practices of health-care systems that try to marshal limited resources for the good of all.

A version of this article appears in the August 30 print edition under the title "Charlie Gard and other precious lives."