

The Catholic Doctor is In: The legacy of a special child

On Sept. 7, 2010, a baby boy was born in a hospital in Missouri. His mother named him Simon and proclaimed “he was absolutely perfect to our family.” This was despite the fact that Simon was born with congenital heart defects and a cleft lip. A few days later Simon was diagnosed with an uncommon genetic defect called trisomy 18. At this particular time, Mom and Dad did not understand all the ramifications of trisomy 18. What they did know is that God had given them a special child that they loved dearly, and they were completely dedicated to providing the care that their son needed.

It turned out Simon was a lot sicker than they had first realized. He had to remain on oxygen at all times. Because he could not suck effectively, he was fed via a small tube going through one nostril down into his stomach. After the diagnosis of trisomy 18 was officially made, Simon’s parents began to notice the doctors were less attentive to his care and tried to minimize communication with them. One day when Simon’s mom was at lunch, she returned to find that one of the doctors had deliberately removed his heart monitor. There was an awful moment when she thought her son was actually dead, since there were no heartbeats coming from the bedside monitor.

Simon’s clinical course was one of gradual deterioration, until one day his oxygen saturations fell dangerously low. They were told by the nursing staff that nothing could be done. There was no effort to resuscitate Simon as he was taken into God’s hands.

Months later, Simon’s parents obtained and reviewed his medical records from the hospital stay. They found an order in the chart that stated Simon was a DNR — do-not-resuscitate. The attending physician had made this decision unilaterally. This particular hospital in Missouri had what is called a “Futility Policy” in place, which means that if a physician believes aggressive care of a given patient should not continue (because in his opinion it is futile) this order can be written without necessarily discussing it with the parents.

Simon’s parents were devastated when they found out that care had been withheld from their child. During further review of the records they discovered that their son’s feedings were only comfort care and he was not getting enough nutrition to sustain growth and life. Finally, on the day he died, a doctor had ordered Ativan, a sedative that suppresses breathing and could have contributed to his death.

Simon’s mom subsequently went on a crusade to pass legislation in Missouri to prevent doctors from ever again limiting medical care without the parent’s permission. During testimony in front of the state’s legislature, Simon’s mom said this: “You see, it was a battle we fought to defend our son’s life and dignity. Not only were Simon’s rights violated, but also our parental rights were taken away. When our son, Simon was a

living, breathing human being, who brought incredible joy to his family; and he experienced love and joy from us ... did he not deserve the right to live?"

Simon's Law, as it is coined, has two basic components. First it ensures a health care facility inform patients and family if they have a futility policy. Second, a do-not-resuscitate order cannot be validated without the parents or legal guardian's permission.

I did some research on babies with the diagnosis of trisomy 18 for a better understanding of the overall prognosis. It is a complex disease with an overall poor prognosis, but death soon after birth is not a fait accompli. With aggressive medical treatment, one study reported a 1-year survival of 25 percent. Further research on the subject led me to a journal where many doctors get up-to-date information on many of the diseases they treat. It said this when discussing Trisomy 18: "A noninterventional paradigm of withdrawal of intensive treatment has been recommended for trisomy 18 ... although acceptance of this paradigm is not universal."

Nor should it be! The world, as well as this country, continue to head in the direction of a "culture of death". Parents have every right and obligation to make prayerful and sound decisions about their minor child's medical care.

I have very recently had the opportunity to talk with Simon's mom, Sheryl Crosier, to get updated on her efforts to get Simon's Law passed in as many states as possible. It turns out that in 2014 a committee chairman blocked the law from proceeding to the Missouri state legislature, and therefore it never had a chance to pass. She has a champion that she is working with in the Missouri legislature, and is hopeful it will eventually get passed. In 2016, Kansas passed Simon's Law in the senate, 37-3; but ran out of time to vote on it in the House. They are starting over in this year's legislative session.

Sheryl Crosier wrote a book in 2012, called "I am not a Syndrome — My Name is Simon". To read more about Simon's life and Sheryl's efforts to prevent future violation of parental rights, visit www.simonismyname.com.

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