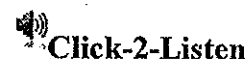


Medical guidance from the church

In Gonzales case, church teachings are interpreted differently



By Eileen E. Flynn
AMERICAN-STATESMAN STAFF
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The mother says it's murder. The doctors call it mercy. Each claims that Catholic teachings on end-of-life care support their positions.

In the case of Emilio Gonzales, the 17-month-old boy with a terminal disease at Children's Hospital of Austin, the decision over whether to remove him from a respirator has been steeped in legal maneuverings and court rulings.

But because both Emilio's mother, Catarina Gonzales, and the Seton Family of Hospitals rely on the Roman Catholic Church for guidance, theological questions on the boy's care have generated another layer of debate over Catholic doctrine that permits ending medical care for dying patients.

Gonzales brought her son to the Seton-run Children's Hospital with a collapsed lung on Dec. 27.

Emilio was put on life support in the pediatric intensive care unit the next day, then doctors told her that Emilio suffered from a rare, incurable disorder that causes the central nervous system to break down.

Since then Gonzales, doctors and hospital officials have clashed over how to care for Emilio, with Gonzales seeking more aggressive treatment and doctors recommending withdrawal of life support.

In trying to weigh the sanctity of life against the desire for a dignified death, Bishop Gregory Aymond supports the doctors' decision.

"It is my responsibility as a shepherd to make sure we are respecting human life and that we are not in any way carelessly taking human life or not respecting the dignity of human life," he said.

Meanwhile, Gonzales has said that she's sought counsel from her Lockhart priest and believes that God will take her son when it's time. Her conscience tells her to keep fighting to keep Emilio alive until that time comes. And she's found support from organizations that say Catholic teaching backs her position, not the hospital's.

The conflict is now before Travis County Probate Judge Guy Herman, who has scheduled a hearing for

Thursday to decide whether to require the doctors to continue treating Emilio while his mother looks for another facility that will take him.

As medical technology evolves, the church continually reviews its position on medical ethics, striving to balance the Catholic view that life is sacred with the desire to provide dignity in natural death.

In 1980, the Congregation for the Doctrine of the Faith, the Vatican department that oversees Catholic doctrine, released a declaration on euthanasia that said it's morally acceptable to discontinue extraordinary, or disproportionate, care when a patient's death is imminent.

In his 1995 encyclical "The Gospel of Life," Pope John Paul II wrote that such a step was not equivalent to euthanasia or suicide, that "it rather expresses acceptance of the human condition in the face of death."

The U.S. Conference of Catholic Bishops echoes those sentiments in its directives for health care services, the guidelines Seton's ethics committee used in its review.

Abortion, euthanasia and assisted suicide clearly violate Catholic teaching, the document states, but the rules on withdrawing treatment reveal the complexities of weighing medical technology, family desires and what's best for the patient.

"The use of life-sustaining technology is judged in light of the Christian meaning of life, suffering, and death," the directives state. "Only in this way are two extremes avoided: on the one hand, an insistence on useless or burdensome technology even when a patient may legitimately wish to forgo it and, on the other hand, the withdrawal of technology with the intention of causing death."

Determining when not to use available technology is the difficult part, said the Rev. Tadeusz Pacholczyk, a neuroscientist on staff at the National Catholic Bioethics Center in Philadelphia, who has been following the Gonzales case closely.

"There is a clear downward trajectory here," he said. "This child is dying. The question is what do we have to do in order to provide proper care to a dying individual."

In cases like these, he said, the church teachings are clear that removing Emilio from life support would be morally acceptable.

Though some have drawn comparisons between Emilio and Terri Schiavo, the brain-damaged Florida woman whose feeding tube was removed in 2005, the church sees the situations as distinctly different, Pacholczyk said.

"Terri Schiavo was not dying of anything," he said, which is why church leaders rallied to try to prevent ending her care. She was a disabled person who died because she was denied nutrition and hydration, a step the Catholic Church would never sanction, he said.

But that's what Emilio's doctors are proposing, argues Burke Balch, director of the Robert Powell Center for Medical Ethics, which handles euthanasia issues. The boy is receiving nutrition and breathing assistance, which he believes the church would consider ordinary care.

"In Catholic teaching, if you omit treatment with the intent of bringing about death, that is considered euthanasia, which is forbidden," he said. "And in this case, that seems to be the object aimed at."

On Feb. 19, Emilio's doctors consulted with the pediatric and neonatal ethics committee, a group of people from the community who review difficult cases and make sure Seton adheres to Catholic teaching in its health care practices.

The hospital was founded by the Daughters of Charity and preserves the mission of those nuns.

The committee first advised doctors to pursue more options for the boy. But the following month, after Emilio's condition worsened, members determined that continued treatment was futile.

Between meetings with doctors and the Gonzales family, the committee also met with Aymond, said Michael Regier, general counsel for the Seton hospital system.

"We regularly consult with the bishop," he said, "particularly on issues where we think there may be some likelihood that the issues could be (the topic of) public discussion or debate."

Aymond turned to national and international bioethicists and theologians and said he tried to weigh the details of Emilio's situation against the overall philosophy issued from the Vatican.

Aymond said he's satisfied with the hospital's conclusion.

"From the documentation I have read from the doctors and the ethics committee," he said, "the hospital staff and administration have acted responsibly and what they are suggesting to do is in accordance with church teaching."

But he would not say that Catarina Gonzales is wrong to seek continued treatment, and he said he would like to meet with her to talk about the church's teachings.

"The difficulty that we always run into is that very often for any of us, whether it's a bishop, a priest, a lay person, we may understand something theologically and theoretically, what we feel about it is very different," Aymond said.

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Terminally ill child's case has far-reaching effect

Hospital installs hotline, guard; case has international reach



By Mary Ann Roser
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The rhythms of hospital life have been anything but normal since the plight of a 17-month-old boy on life support captivated people across the country and cast a white-hot spotlight on Children's Hospital of Austin.

The hospital has been so inundated with phone calls — more than 100 a day — that it set up a hot line March 20 to take messages about doctors' plans to disconnect Emilio Gonzales from his respirator against his family's wishes. The story has been covered by media outlets across the country as well as in England and Canada.

Hospital officials also have posted an armed guard in the pediatric intensive care unit to deal with unauthorized visitors, including out-of-towners who say they want to visit or pray with Emilio, said Dr. David Anglin, the chief doctor treating the child. And ICU staff members, known for their high morale, receive group therapy twice a week to cope with the stress, Anglin said.

"This is a once-in-a-lifetime thing," said Anglin, who is 53 and has been a pediatric intensive care doctor for 25 years. "This has been hard on everyone."

Although doctors and families sometimes differ over treatment decisions, Emilio's case has been particularly contentious. And because it's playing out as end-of-life issues are being debated in the Texas Legislature, Emilio's case could influence how future cases are handled statewide.

"The fact that it's a child and it's getting a lot of media" has made the case all the more compelling, said Robin Chandler, an aide to state Rep. Eddie Rodriguez, D-Austin, co-author of a bill to change state law dealing with decisions on end-of-life care. The other author, Bryan Hughes, R-Mineola, appeared with Emilio's mother, Catarina Gonzales, in meetings with the hospital's ethics committee to discuss the child's case.

Their bill would require doctors to continue treating severely ill patients until another hospital agrees to provide the care.

At issue is a debate over who should have the final say on treatment decisions at life's end when doctors

and family members can't agree and the patient is too incapacitated — or too young — to express his or her wishes.

Doctors at Children's diagnosed Emilio with Leigh's disease, a neurometabolic disorder that causes the central nervous system to collapse. They said Emilio, who has been blind and unable to hear since birth, has no hope of recovering.

An MRI last week showed "his brain is rotting . . . and it's filled with giant holes," Anglin said. "He's as close to brain dead as you can be without being brain dead. He has no control of his bodily functions.

"He's lost human dignity," Anglin said.

Under Texas law, doctors who determine that ongoing treatment is futile can start a process that gives a family 10 days to find another facility to care for their loved one or face the withdrawal of treatment.

Doctors planned to disconnect Emilio's respirator last week, but Travis County Probate Judge Guy Herman extended the time and appointed a lawyer to act as Emilio's guardian. Herman scheduled another hearing for Thursday, when he will get a report from the guardian and hear witnesses on both sides.

Anglin sat in Herman's courtroom last week and is watching efforts to change the 10-day rule.

He said he thinks that requiring doctors to treat a patient like Emilio indefinitely denies the person a peaceful, dignified death.

"It's almost like we're being asked to become the abusers," Anglin said, echoing testimony doctors gave on a Senate bill last week that is a companion to the Hughes-Rodriguez bill.

But advocates for the disabled, family caregivers and others say doctors are not infallible and have too much power under current law.

"Let us err on the side of life," said state Sen. Bob Deuell, R-Greenville, a doctor sponsoring the Senate bill.

Gonzales, Emilio's 23-year-old single mother, told the senators at Thursday's hearing she wants everything possible done to keep her son alive, and said she believes that's what Emilio wants and what God wants.

Emilio's care is being covered by taxpayers through the government-sponsored Medicare and Medicaid programs.

The case has weighed heavily on the hospital staff, Anglin said. Attempts to transfer the child haven't worked, despite contacting more than 30 other facilities over two months. All have refused because they can offer nothing more to Emilio, said Michael Regier, general counsel for the Seton Family of Hospitals, which runs Children's.

Gov. Rick Perry, who has no authority in Emilio's case but could sign the proposed legislation into law if it passes, has received more than 200 e-mails and letters in the Gonzales case — the vast majority from out-of-state writers. Most urge Perry to save Emilio, but Perry has not publicly taken a position.

"This is a heartbreaking tragedy and a very difficult situation and certainly the governor's heart goes out to Emilio's family," Perry spokeswoman Krista Moody said.

Much of the mail to Perry's office has been fueled by organizations involved in the case, including the disability rights group Not Dead Yet and right-to-lifegroups, which oppose abortion and euthanasia. They are posting media reports from national and regional news outlets on the Internet along with comments from their members, bloggers and others who believe Emilio should be kept alive.

Anglin said he and the medical staff have been advised not to read the commentary. Although some have praised the doctors' stance, "some incredibly hateful things have been said" by those who disagree with the doctors, Anglin said.

"We do the best we can,"but not every life can be saved, he said.

"This is not a natural death," Anglin said. "It's prolonging death and preventing a natural death."

In the 1970s, doctors had too much power to make treatment decisions, he said. Now, the pendulum has swung the other way, Anglin said, and families can force treatment on loved ones that is painful, not beneficial and prolongs the process.

Gonzales, who has admitted calling staff members murderers, has been verbally abusive to the staff, Anglin said, and that is stressful.

"There are nurses who asked to not be on this case," he said.

Gonzales, who has said she can't have more children because of complications during childbirth, said all she wants is for her son to receive a tracheostomy, a hole made in his windpipe so he can breathe without a machine, and a feeding tube in his stomach so he has a better chance of being accepted by a long-term care facility. Anglin and other doctors said his lungs are too weak to be weaned from a respirator and he needs the intensive care of a hospital to survive.

"Many families don't want to let go," he said. "It's our job to help families with these tough decisions."

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COMMENTARY

Aymond: Like life, death is sacred

Bishop Gregory Aymond, DIOCESE OF AUSTIN

Sunday, April 15, 2007



The heart-wrenching situation regarding Emilio Gonzales, a 17-month-old child at Children's Hospital, has garnered national attention. Beside the heavy emotions, the issue of determining the use of extraordinary medical treatment in the face of such difficult situations is not a new dilemma. In my own family, I have been part of making end-of-life decisions for both of my parents and for my 24-year-old nephew, who was involved in a traumatic vehicle accident a few months ago. I empathize with Emilio's mother as she attempts to do what is best for her child and I remember her in prayer daily.

The terms "extraordinary" (disproportionate) and "ordinary" (proportionate) care are used by Catholic moral theologians in defining ethically required medical care and ethically optional medical care. Generally, if a medical procedure carries little hope of benefit and is excessively burdensome, Catholics — and Catholic institutions — are not morally obligated to pursue that procedure. Even Pope John Paul II was adamant that he would not accept extraordinary medical care as his health declined.

Suicide, euthanasia and assisted suicide are not morally acceptable; they violate the very sacredness of human life. We hold the teaching on the sacredness of life as fundamental. And we believe that our lives do not end with death, that we are called to everlasting life. Catholic teaching on ethically required medical care states that we should use all reasonable means to preserve human life and to promote the profound dignity that belongs to it. Yet we recognize that sometimes we should not use technology if it inflicts greater suffering on loved ones and holds them back from being able to go home to God.

The decision to forego extraordinary medical care must be made by the patient or the patient's proxy with a great deal of prayer and consultation with ethicists, spiritual mentors and health care professionals. In some situations, we would be obligated to use extraordinary medical care. There is no "one size fits all."

Physicians have stated that Emilio's condition is irreversible and will result in his death. There is great concern that continued extraordinary treatment will only result in greater pain for Emilio, without curing or improving his condition. Based on this information and a review of the case by ethicists, moving to a "comfort care" plan for Emilio would be morally acceptable. Emilio would still receive food, water, pain medication and other "ordinary" treatment. Some compare Emilio's situation to Terri Schiavo's. They are very different; in the Schiavo case, ordinary means — food and water — were withdrawn, which caused her death.

In 1995's "The Gospel of Life," Pope John Paul II wrote, "To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death."

The late pope's teaching is carefully reflected in the "Ethical and Religious Directives for Catholic Health Care Services," a document used by Catholic hospitals in the United States.

Our first concern must be the well-being of Emilio, physically and spiritually, and that appropriate pastoral and spiritual care is offered to his family. I have offered to meet with Catarina Gonzales to offer my support and explain the teachings of the Catholic Church regarding end-of-life issues. I ask everyone to join me in praying for Emilio, his mother and those responsible for his care.

I cannot imagine the pain that Catarina Gonzales is experiencing as she faces terrible questions no mother wants to face. As Catholics, we believe in the sacredness of life from the moment of conception to natural death. The journey toward death is sacred, but often it is also painful and lonely.

Perhaps the most important gift that Emilio and his family offer to the rest of us is an opportunity to reflect on our own beliefs and concerns for how we — and our loved ones — live the last days of our natural lives and prepare to return to the loving God who created us.

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