

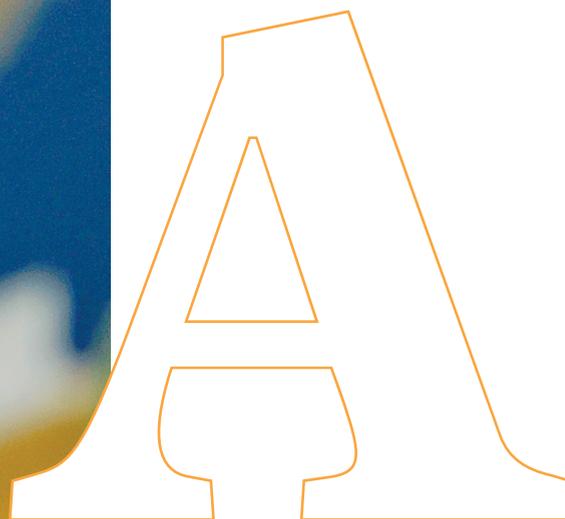




MARIA AND JOSE AZEVEDO HAD TO CHOOSE: ALLOW THEIR BABY TO DIE A PREVENTABLE DEATH OR SAVE HIM WHILE ACTING AGAINST THEIR RELIGION. THE DOCTOR WHO HELPED GUIDE THEM SHARES THEIR STORY.

WHEN SCIENCE MEETS THE SOUL

BY DR. DARSHAK SANGHAVI
PHOTOGRAPHS BY TANIT SAKAKINI



ALTHOUGH MARIA AND Jose Azevedo didn't know it back then – after all, they were children who lived on separate continents – their lives would be both changed and linked by the most mundane of events: a knock at the door.

As a daughter of Portuguese immigrants, Maria was raised a devout Catholic (her step-grandmother, named Trinity, used to teach catechism), but her family life growing up in New Jersey was marred by an abusive father. When Maria was 8, her mother invited a Jehovah's Witness proselytizing door-to-door into the home. Soon, her mother, Maria, and her sister began studying regularly with Witnesses, who questioned the existence of the Trinity and hell. Maria's father was not happy about that. "Whatever rage he had just became worse," Maria says. Still, Maria formally declared herself a Witness when she turned 13.

Thousands of miles away on the Ivory Coast in West Africa, Jose grew up in a French-speaking family that later immigrated to Connecticut. Jose's father had converted years earlier, also after a Witness came

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to his door, and Jose became baptized as a Witness at 17. Several years later, he met Maria at a convention for Witnesses in Monroe, New York. Soon they were writing letters back and forth and dated for two years. At Maria’s high school graduation party in 1993, Jose proposed. She said yes. They had a son, Giovanni, and later moved to Fitchburg, where Jose started a floor-sanding business.

Last winter, when the family was preparing for a trip to Italy, Maria learned she was pregnant again. In the doctor’s office, Maria remembers the shock of seeing “two circles” on the ultrasound monitor: She was having twins. Later came terrifying news – one of the fetuses could have a heart problem. By then five months pregnant, Maria and Jose rushed to the UMass Memorial Medical Center to see the pediatric cardiac specialist on call. That’s when we met.

FOR AN HOUR that day, I glided an ultrasound probe over Maria’s abdomen and gazed at snowy images on a digital monitor. My own heart sank. Normally, a heart pumps blood first to the lungs, where oxygen percolates into red cells. Then, the heart sends the oxygen-rich blood to the body. But the connections in one twin’s heart were all wrong, so none of the blood could get to the lungs (a condition called “transposition of the great arteries”). That’s not a problem in the womb, since the mother’s umbilical cord sends all the necessary oxygen to the baby’s body. But shortly after birth, when the umbilical cord is cut, the newborn would suffocate and die. Unless, that is, an emergency open-heart surgery was done then to repair the heart defect.

Stunned, the Azevedos listened as I drew diagrams to review the diagnosis and treatment options. The outlook was excellent, since the corrective surgery had been developed more than 20 years earlier. Soon after birth, the baby would need to be placed on a heart-lung bypass machine, containing donated blood, and undergo the surgery while the heart is purposely stopped.

But based in part on a literal biblical reading of Acts 15:28-29, which exhorts the faithful

Darshak Sanghavi is a pediatric cardiologist at the University of Massachusetts Medical School and the author of A Map of the Child: A Pediatrician’s Tour of the Body. E-mail him at sanghavi@post.harvard.edu.

to “abstain from meats offered to idols, and from blood,” Jehovah’s Witnesses categorically refuse all red-blood-cell transfusions. We discussed various options – including using parental blood or even the child’s own blood salvaged from the placenta at birth for the bypass machine – but none of these was acceptable to the Azevedos.

The couple faced an impossible choice: allow their baby to die a preventable death, or save their baby and forfeit a chance at eternal life in paradise. In a sense, their ordeal recalls one of the most troubling passages of the Old Testament. In the Book of Genesis, God without explanation commands Abraham to sacrifice and burn the body of his only son, Isaac, at an altar atop Mount Moriah. Abraham binds his son with ropes, lays him on the altar, and raises a knife to slay him. At the last moment, an angel descends to stop the violence. “Now I know that you fear God, because you have not withheld from me your son,” the angel says, and promises that “all nations on earth will be blessed, because you have obeyed.”

But what if no angel from heaven came to stop the Azevedos from letting their baby die?

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OT INFREQUENTLY, parents and physicians disagree about the proper medical management of young children, especially those with life-threatening conditions where the

therapy is highly invasive or the prognosis is uncertain. These conflicts often do not arise from parental misconceptions – in the Azevedos’ case, they understood the medical issues quite clearly – but from fundamental ethical and moral disagreements about a child’s quality of life.

In 1990, for example, a woman named Karla Miller went into premature labor at 23 weeks of gestation in Houston. Because a child born that early has a 75 percent chance of death or severe disability, the husband chose not to sign a consent form that would allow resuscitation. But the neonatologist resuscitated the girl, who grew up severely retarded, legally blind, and quadriplegic. The parents sued the hospital for ignoring their wishes, but in 2000

the Texas Supreme Court ruled for the hospital. George Annas, a medical ethicist at Boston University, later attacked the decision in the *New England Journal of Medicine*, since “the court implies that life is always preferable to death for a newborn . . . no matter how unlikely their survival is without severe disabilities.”

This tendency toward avoiding a baby’s death at all costs – without considering a family’s physical, emotional, or spiritual needs – has created some confusing and contradictory practices. Consider how physicians approach Down syndrome, which often results in mental retardation, heart defects, a higher risk of leukemia, and other problems. Last year, the American College of Obstetricians and Gynecologists recommended that all pregnant women, regardless of age, be offered screening for the condition before 20 weeks of pregnancy – a time frame clearly determined by the availability of legal abortion. Yet since 1984, federal law forces a child born with Down syndrome to receive almost any necessary surgery to preserve life. Therefore, aborting an otherwise normal fetus with Down syndrome for any reason is legal; however, allowing natural death for newborns with not only Down syndrome but also severe spinal and gastrointestinal defects is forbidden.

Things are even more complicated when severe heart defects are detected prenatally. In her moving memoir *Waiting With Gabriel*, Amy Kuebelbeck describes the birth of her son, who had “half a heart” (a condition called hypoplastic left heart syndrome, or HLHS). Kuebelbeck refused surgery and held her baby as he died. “We wished for his life to be free of pain and filled with love,” she once wrote to me. “And it was.” Given the same scenario, only one-third of doctors would want treatment, according to a 2003 report. That’s surprising since the survival for the condition after surgery is 85 to 90 percent, and many survivors have normal cognitive abilities.

Ultimately, the laws regarding highly invasive medical treatment for babies don’t have a coherent moral foundation. To further complicate matters, even savvy people (like physicians in sub-specialties) given a standard diagnosis may choose very different paths. If the law lacks nuance, and the doctors themselves are divided, perhaps the religious beliefs of parents, no matter how foreign to their child’s caregivers, shouldn’t draw judgment. Nobody, it seems, has a handle on all the right answers.



PALL IN THE FAMILY For Jose and Maria Azevedo, here at home with their first son, Giovanni, their religious beliefs left them little choice as they agonized over their second child's health. The Bible text that tells the faithful to "abstain from meats offered to idols, and from blood," to them meant that Jehovah's Witnesses must refuse red-blood-cell transfusions.

ONLY A FEW pregnancies in a thousand yield identical twins, and only one in a thousand pregnancies are complicated with potentially fatal cardiac defects – which meant that the probability of the Azevedos' situation was about one in a million. A few days after conception, the Azevedos' embryo split into two parts, and each fetus grew separately while sharing a single placenta. The developing children possessed identical genes, environments, and parents – yet the natural origami of one child's heart failed to unfold normally. It is entirely unknown how, so to speak, two identical seeds growing in the same soil can give rise to such different harvests. It's equally intriguing how the Azevedos and I differed so much in our approach to that event.

At our first meeting in April, each fetus weighed a pound and had completed 21 weeks of gestation. In later visits, we spoke for hours. Jehovah's Witnesses have helped pioneer many blood-sparing procedures, and with the input of a medical liaison from the church, we researched and discussed countless real and imagined scenarios for the baby, including the use of artificial blood (not yet available), open cardiac surgery without a bypass machine (nearly always fatal in neonates), and even bypass with salt solutions instead of blood (which would thin the child's blood excessively). Each time, Jose and Maria were hopeful we'd find some way to save their baby without blood. Yet

no alternatives emerged, despite my arranging for a second opinion at Children's Hospital in Boston. I grew to like the Azevedos; they were intelligent, friendly, and reasonable. But as the weeks ticked by, we remained deadlocked.

Sometimes we were all frayed. As a not-very-religious Hindu father of two young boys, I had difficulty understanding how parents could allow a child to die, just to avoid a transfusion. My feelings no doubt showed. For their part, Jose later told me: "We were not going to consent, no matter what. [It] was the most frustrating, difficult thing in our lives." Unknown to me, the family was considering plans to fly overseas for the birth to avoid transfusion.

Unlike parents choosing not to resuscitate extremely preterm infants or to withhold surgery for babies with half a heart, the Azevedos weren't worried about the risk of death or chronic disability; their concerns were mainly religious. In contrast to some congenital heart defects, transposition of the great arteries is eminently treatable. Most newborns are discharged within a few weeks of the surgery and require no subsequent invasive procedures. The Azevedos, though, had fundamentally different priorities – priorities that were rooted in their faith.

Originating in the 1800s from a Pittsburgh Bible study group that rejected the concept of the Trinity, modern Jehovah's Witnesses adopted their name in 1931, and today are head-

quartered in the offices of the Watch Tower Bible and Tract Society in Brooklyn. In the mid-1990s, the group's magazine, which claims a worldwide circulation of 37 million, had a cover story featuring 26 "Youths Who Put God First" and died after refusing transfusion. In one issue, a photo of a young girl picking yellow flowers in a meadow reads, "Saving life with Jesus' blood" – rather than transfusion – "opens the way to endless, healthy life in an earthly paradise." According to James Pellechia, a senior spokesman for the Watch Tower Society, a Witness who "willfully and without regret" accepts blood has "ceased being one of Jehovah's Witnesses."

Official Witness sources hedge on the subject of transfusions to save newborns when all other options are exhausted. One pamphlet reads, "Loving parents are responsible to weigh risks, benefits, and other factors and then to make a choice." Pellechia says: "It's a difficult situation for any parent." Although transfusion "would be a violation of God's law," he says, "it's up to the individual to decide whether they want to apply that law or not."

Thus, I hoped the Azevedos might ultimately allow the surgery. Since the closest pediatric cardiac intensive care unit was in Boston, the Azevedos arranged to deliver at Brigham and Women's Hospital. One summer day, Maria called me to say she was in labor. The twin boys, Miqueias and Jacob, were → PAGE 38

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born on August 15. Jacob was rushed to the intensive care unit, and the family met with Dr. Emile Bacha, the cardiac surgeon on call at Children's Hospital. After some discussion, the medical team initially came away thinking the family would proceed with the surgery.

But on the eve of the procedure, Bacha went to see Maria and Jose about the written forms to obtain official permission. After a quiet discussion, Bacha emerged from the room. "I don't think they're going to sign the consent," he said.

THE FIRST AMENDMENT of the US Constitution guarantees, "Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof." However, in 1944, the US Supreme Court ruled in *Prince v. Massachusetts* that a Jehovah's Witness could not force her 9-year-old niece to preach in downtown Brockton in violation of child labor laws. With deliberate punch, the court wrote, "Parents may be free to become martyrs themselves. But it does not follow that they are free, in identical circumstances, to make martyrs of their children." Currently, however, the federal Child Abuse Prevention and Treatment Act has been weakened so that medical neglect motivated by parents' religion cannot be prosecuted under its provisions.

Rita Swan, a literature scholar in Sioux City, Iowa, has committed her life to ending any religion-based exemptions to healthcare for children, which is ironic, since those very exemptions protected her from going to jail. Her toddler had a slow, agonizing death from a curable disease. And she let it happen.

Raised a Christian Scientist, Swan told me she was taught to "bend over backward" to avoid any knowledge of life sciences (to pass her college biology requirement, she made a leaf collection) and never took her older daughter to a doctor. (Christian Scientists avoid conventional medical care and believe prayer heals illnesses.) Then in 1977, her son Matthew developed a fever shortly after his first birthday. Over a 12-day span, the infant experienced racking sweats and convulsions and gnashed his teeth.

During prayer visits, she said, one practitioner would shout at the infant, "You can't be sick! You are God's perfect child!" So deep was the denial of the boy's suffering that Swan proceeded with a T-shirt decorating party for her 7-year-old daughter while Matthew lay upstairs convulsing. "It's just so sick," Swan says now. It turns out the infant had bacterial meningitis, an infection whereby the brain becomes covered with pus. Swan finally broke down and

took Matthew to a hospital. By then, the infection was too advanced, and Matthew died. Later, the practitioners weren't empathetic; Swan says that one of them told her, "Life on earth is such a pinprick, what does it matter?"

Swan and her husband left the faith and founded CHILD Inc., a nonprofit group to educate the public about medical neglect of children for religious and cultural reasons. In a heartbreaking 1998 report in the journal *Pediatrics*, she helped collect case reports of 172 children who – like her son – died from medical neglect. (Caroline Fraser, another former Christian Scientist, profiled cases in a 1995 *Atlantic Monthly* article and subsequent book, including the death of 12-year-old Elizabeth Ashley King, whose parents refused medical attention for a cancer on her leg that grew to 41 inches in circumference.) In Massachusetts, 2-year-old Robyn Twitchell died of intestinal obstruction at home (vomiting "excrement and portions of his bowel before he died"); his parents, Christian Scientists, were acquitted of wrongdoing in 1993, though they watched him suffer over five days. That year – helped by lobbying from Swan's group – Massachusetts became one of only five states that no longer exempts medical neglect of children for religious reasons from prosecution.

Philip Davis and Kari Mashos, spokespersons for the First Church of Christ, Scientist, insist the church allows "complete choice" and "no coercion" to dissuade parents from conventional medicine. "I think it's terrible to have a child suffer," Davis says. When I asked if, in retrospect, Robyn Twitchell should have been taken to a hospital, he answered: "It just feels like a slot I don't want to be put in, in that particular case."

Many states still specifically allow religious refusal for pediatric vaccines, lead screening, vitamin K shots for newborns, tuberculosis testing, bicycle helmets, and routine physical exams. And politicians are loath to criticize religious practices that doctors would deem dangerous. In 2005, for example, three infants in New York were infected with herpes virus after circumcision by the same rabbi, and one died. Presumably carrying herpes in his mouth, this rabbi practiced a rare Orthodox Jewish form of circumcision called *metzitzah b'peh*, in which the rabbi places his mouth on the neonate's penis to suck off blood following circumcision. When alerted to the outbreak, Mayor Michael Bloomberg didn't condemn the ritual. Instead, he called for more study and stated it "is not the government's business to tell people how to practice their religion."

Terry Craven is an associate justice in the Suffolk County Juvenile Court who's familiar with many cases like Jacob's.

What would happen in Massachusetts if a woman carrying a baby with a known severe heart defect avoided the hospital, had a home birth, prayed for divine healing, and watched the child die? A district attorney, Craven says, “is less apt to take that case. They want to be able to believe they can prosecute.”

IN JACOB AZEVEDO’S situation, thankfully, no medical harm had yet occurred and no criminal charges needed to be filed. On the contrary, Maria and Jose thus far had done everything possible for their son’s health; they just refused to sign the consent form. What happened next was at once ordinary and profound.

When a child is suspected of being in medical danger, doctors can ask the courts to mediate disagreements and, in certain cases, make binding decisions on behalf of the child over parents’ objections. Under this law a hospital lawyer named Ellen Majdloch on August 19 urgently requested a hearing. Craven, who hears perhaps a

his chest was sewn closed. Hopefully, no one would lay eyes on the heart ever again.

Weeks later, Jacob, who has honey-colored hair and an easy smile, was feeding and growing like a healthy infant. I asked Maria what she thought might happen to Jacob’s soul. “My conscience is clear,” she said. She felt that the doctors, not the child or the parents, would have to answer for the transfusion. “It wasn’t Jacob’s decision,” she said. “We took our stand and never compromised. Jehovah knows that I did not compromise my faith. What [the doctors] decided to do, that’s between them and God. We don’t judge them.” Jose agreed: “God will have to analyze the situation. I cannot speak for him, but I know that God is a merciful God, and he does forgive.”

Tacitly, the Watch Tower Society seems to endorse this end run around the transfusion ban for children. Its statement on blood products includes the following: “On occasion . . . medical personnel have sought court backing to give blood. Of course, Christians agree with laws or court

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half-dozen such cases yearly, was assigned to the case (that’s how we met), traveled to the hospital, and convened court in a small conference room steps away from the intensive care unit. The judge appointed lawyers for the family, a guardian to advocate for Jacob, and a Jehovah’s Witness liaison to help articulate the Azevedos’ religious views. Just before entering the room, Craven recalls, one of Jacob’s grandparents, who is a Witness, clutched her hand, looked in her eyes, and said, “Save my grandson.”

The hearing took hours. The judge listened patiently to everyone’s testimony and suggested a solution. The Azevedos could honor their beliefs and refuse to sign the consent. However, Craven herself would “authorize” – she was very careful, she said, to avoid the term “order,” even though Jose and Maria had no choice – the surgery, and her name would appear on a separate authorization form. The Witness liaison supported this compromise, assuring the Azevedos that “if the judge orders it, then you are not going against the church teaching.”

On August 20, Jacob was wheeled to an operating room at Children’s, where Bacha’s team opened the child’s chest, cooled his body to 72 degrees, and connected him to the bypass machine, primed with donated blood. Jacob’s heart lay still for a few hours as the surgeons performed the delicate switch of the great arteries. Repaired, the heart sprang to life when rewarmed and

action to prevent child abuse or neglect.” Pellechia, the spokesman, says, “Under pressure, if a person caved in and made a decision that others would not have made, I believe there would be an understanding [and] empathy shown.”

IT’S TEMPTING TO call this kind of rationalizing a “pathetic moral spectacle,” as the author and outspoken atheist Christopher Hitchens does, pointing to Orthodox Jews who pay others to work on the Sabbath, Shiite Muslims who offer temporary marriages for men visiting prostitutes, or papal sales of indulgences to fund projects like St. Peter’s cathedral. To Hitchens, creating elaborate rituals to circumvent religious dogma is hypocritical; he would prefer just tossing the rules. Of course, those diametrically opposed to that line of thinking might dismiss compromise just as vehemently. How, then, should people make progress when they don’t see eye to eye?

Occasionally, rational discussion prevails. Stanley Baum, the former chairman of radiology at the University of Pennsylvania, recalls that a decade ago, the Dalai Lama asked Baum’s friend and noted neuroscientist Robert Livingston to travel to India and lecture on the origins of the human nervous system. Livingston mentioned how sperm reside in the fallopian tubes from a day to a few weeks prior to fertilization. A murmur went up among the monks. That’s not pos-

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sible, they said, since Tibetan culture teaches that the soul is transferred to an embryo during orgasm. Livingston politely persisted. To Livingston's amazement, the Dalai Lama conceded, "All we can say is that our original concept must be wrong."

But people are rarely shaken so deeply. Instead, many of us cling to scaffolds of faith that – somehow – support the structure of our moral and spiritual lives. We make small changes here and there, rather than take a wrecking ball to it all. And that's ultimately the best for which we can hope. (Over the last decades, for example, the Watch Tower Society has stated that vaccinations may be acceptable for observant Witnesses. Interestingly, changes often concern diseases of children.)

In the end, neither the Azevedos nor I shifted our beliefs much. We just agreed on a ritual that allowed us all to move on. Recently, the Azevedos invited me over for dinner, and we talked for hours. I marveled at the contradictions we embodied: An Indian physician born in the Bronx who still puts up a Christmas tree and is married to a Philadelphia-born Jew who believes in ghosts was warmly invited to break bread and talk faith in the Fitchburg home of a couple of Portuguese and Ivory Coast descent raised as Jehovah's Witnesses, even after I'd helped force a surgery on their baby against their most deeply held convictions.

Somehow we'd all worked together to save Jacob's life. And after it was done, the Azevedos and I could listen to him coo contentedly nearby as we ate and talked as friends. ■



COMPROMISING POSITION

The solution offered by the judge was ideal. Jacob (with Maria, as Jose holds Miqueias) was saved and the parents never went against their church.

PHOTOGRAPH BY TANIT SAKAKINI