On Being a Catholic Physician

Sonnet XXX: Love, dignity, and dying[†]

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All of us in medicine who care for patients who are chronically critically ill, dying of incurable illnesses, will be faced with discussions about the value of their lives and about the appropriateness of ongoing supportive care. Such discussions are good and true, and they must always be done within the context of the sanctity of every human life and the promise of God that we are His children, each and every one of us. In this article, I explore the end-of-life path of a patient with amyotrophic lateral sclerosis (ALS) and the courageous faith that she demonstrated in the face of her illness. I explore with you, the reader, the hard-core conversations that took place at her bedside and their meaning in light of Catholic moral teaching. This story is not meant to indicate that we should always do all interventions at all times for all patients. That would be a teaching counter to Evangelium vitae. This story is meant to help you think through the path of your patients and of you as a physician or other type of healthcare professional in serving your patients. Primum non nocere. Ad maiorem Dei gloriam.

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The first time I saw Jessa, she lay crumpled in the ICU bed, paralyzed, expressionless, and unable to speak. A military veteran, she had fought in Desert Storm, but she now was facing a deadlier and more inexorable foe: amyotrophic lateral sclerosis (ALS), aka Lou Gehrig's disease. This disease causes progressive loss of muscle control, and Jessa was unable to speak, eat, or breathe on her own. Her only means of communicating

was through small facial movements—opening and closing her eyes or mouth, raising her eyebrows.

A dozen people made up her ICU team: three interns, three residents, a pharmacist, a nurse, a respiratory therapist, a social worker, a hospital chaplain, and myself—the lead physician, or intensivist. My intensivist mind, trained to seek solutions, skitters down a patient's problem list in search of answers. And Jessa's list was extensive: she needed a feeding tube, IV fluids, diapers, and a special bed to prevent bed sores, antibiotics for a newly contracted pneumonia, intermittent sedation to ease anxiety, narcotics for chronic back pain.

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Pulse voices granted permission to reprint this longer version of the same piece, which adds further discussion about euthanasia and physician-assisted suicide, the quality-of-life gap, redemptive suffering, and Maslow's hierarchy.

As I listened to the respirator pumping air into Jessa's lungs and felt her intense cobalt gaze on me, one thing was clear: any concerns about antibiotics or nutrition took second place to a larger question: "What do we know of Jessa's wishes about staying on a ventilator, now and in the coming weeks and months?" I asked the team after we had stepped outside of the room to confer. "Her chart says that she wanted to be placed on a ventilator when she couldn't breathe on her own," one resident said. "Look how long Stephen Hawking has lived that way," the nurse chimed in. "I don't think we should look at other people's lives," another resident burst out, clearly frustrated. "She's suffering. I'd never want to live like this. She probably didn't know it would be this way when she requested life support." Up till now, I had had no opinion on the subject. My knee-jerk reaction as a younger physician would have been in agreement with the resident, though I now see my younger self as too brazen and confident to "insert my oar." This time I was thankfully able to suspend judgment.

At that moment, Jessa's husband Zach walked into the ICU. We shared our concerns about Jessa's situation and asked him about her wishes. Calmly, he replied, "Doctors, while it wouldn't necessarily be my choice, Jessa does want life support, so she can have as much time as possible with me and the people around her. She was raised to believe that all life, however frail, is sacred. I know it might seem paradoxical, but that was a key reason she joined the military—to defend life and freedom. Also, she was raised Lutheran and remains strong in her Christian beliefs." Later that morning, he shared his own wishes: "Just make sure Jessa knows that she's not a burden, and that serving her is our privilege."

This conversation led to others over the next 2 weeks, and they sparked what I

now see as a transformative period in my growth as a physician and in my understanding of patients like Jessa. The next day, Zach told us more. "Jessa was born in Germany; she's bilingual. We've been married for twenty-seven years. We have no living children—we had several miscarriages. I'm all the family she has."

It had been Jessa's dream to serve as an American soldier. After they married, she enlisted and was deployed to Iraq as a diesel mechanic—one woman among over one thousand men. "She got caught under a tank once and smashed her head getting out," Zach said. "They flew her to an army hospital in Germany, and she recovered and went back. She's tough as nails."

More than twenty years later, she was diagnosed with ALS. "I've learned a ton from her about serving without concern for self," Zach said. "And now I'm learning even more. The amazing way she adjusts to whatever life throws at her ... She's constantly recalibrating my vision of how to make the most of every moment. Like today, she's on that breathing machine, and she just 'smiled' at me with her eyes."

In those few minutes, Zach revealed our silent, nearly motionless patient as a heroic person—someone I admired not only for her technical skills but for her pioneering attitude and her resolve to fight for freedom and life. I got an inkling of why she was fiercely holding onto the time she had left.

Still, some team members continued to view her quality of life (or QOL) as unacceptable. More than once, they described her situation as "hellish." When I told Zach this, he said, "Jessa once said she believes hell to be the absence of hope, just as cold is the absence of heat and darkness the absence of light. Now that you're getting to know her, can you see that she doesn't consider her illness hellish?" He whispered, "She's surrounded by love."

These discussions, as difficult as they were, marked a major shift in my

understanding. I began to see how often I impose my own QOL standards onto patients—a fundamental clinical error. Empirical data, I learned as I read more studies specifically about ventilation in ALS, show that ALS and other “locked-in” patients often rate their QOL as acceptable despite their physical debility. Their focus shifts to less tangible qualities—transcendence, spirituality, and security. Pondering this, I realized more and more clearly that it was Jessa’s values and perceptions in this particular situation that mattered, not mine.

Our role, I saw, was to dive into the chaos of Jessa’s life and offer her care and comfort despite our inability to cure her. Over the next week, we worked with our palliative-care team to ease Jessa’s pain, anxiety, and delirium (which receded along with her pneumonia). Every day, I made a point of remembering bioethicist Edmund Pellegrino’s words: “Healing can occur when the patient is dying even when cure is impossible.”

With this in mind, I asked Zach if Jessa would enjoy being read to, as our team had done with other patients. “Doc, she loves poems and the Psalms,” he said immediately. We began to take turns reading to her every day. On Jessa’s last day with us before she was to leave for a long-term care facility, I chose Edna St. Vincent Millay’s Sonnet XXX. “Love cannot fill the thickened lung with breath, nor clean the blood, nor set the fractured bone; yet many a man is making friends with death, even as I speak, for lack of love alone...”

As I read, Jessa’s mouth opened wide in a smile brighter than any we had yet seen from her. The medical student across the bed from me began to cry. “From joy and amazement,” the student later said. Seeing Jessa’s smile and the student’s tears, I felt my mind stop in its tracks; time stood still.

Jessa had lifted us above the physical realities of our existence and into

something mystical. I cannot explain it, and I almost do not want to try. Let’s just say that she gave us a private treasure, one that I will always savor as a gift I never expected or deserved. I squeezed Jessa’s hands, holding her eyes with mine.

Finally she looked away and up to the ceiling, and I stood in thought beside her. Although my team and I loomed over Jessa as she lay in her bed, I knew that, in spirit, she soared high above us.

REFLECTIONS AND TEACHINGS FROM A CATHOLIC PERSPECTIVE

Euthanasia and physician-assisted suicide

Patients such as Jessa often spark discussions of hot button issues regarding withholding and withdrawing life support, which in this situation led us to conversations about euthanasia and physician-assisted suicide. Over the days we cared for Jessa, we discussed many ethical tenets, such as how there is no ethical distinction between withholding and withdrawing life support. We also discussed data about euthanasia in the ICU. None of them were aware of the Belgian statement on end-of-life care (EOL) in the ICU (Vincent et al. 2014) that shockingly stated “shortening of the dying process with use of medications such as analgesics and sedatives may sometimes be appropriate even in the absence of discomfort.” To be clear, this statement is saying that we can keep giving morphine, for example, even with no apparent pain, explicitly for the purpose of ending the person’s life when we “judge it appropriate.” A European elder-statesman and ICU professor educated me in Brussels, “Where I come from, we call that murder,” summarizing others’ thoughts that have been published as a rebuttal to this same Belgian statement (Kompanje et al. 2014). This

sentiment is supported by the WELPICUS investigators who reported that a majority (79%) of the international group of critical care leaders gathered to garner consensus for EOL practices in the ICU considered “active shortening of the dying process with the intention to hasten death not permissible even if allowed by law” (Sprung et al. 2014).

As a human being, a doctor, and a Catholic, actively ending someone’s life is anathema to me. Indeed, the cornerstone of Jessa’s trust in me as her physician is that I will have 100 percent incentive to benefit her and 0 percent incentive to harm her. In our discussions, the ICU team members worried about how our oath of “*primum non nocere*” (discussed below) could be breached if similarly vulnerable patients without someone like Zach to speak for them might be “helped to die” sooner either by premature removal of life support or use of medications to shorten the dying process in carrying out some rationalization or mistaken attempt at compassion.

This should not, of course, be confused with the morally appropriate action of removing life support in circumstances in which an intervention (e.g., a ventilator or dialysis) is judged by the patient, the family, and the team to be disproportionate or excessively burdensome. To persist in providing life support in that circumstance could (depending on the details of the situation, which because of space I will not attempt to unpack here) also constitute a breach of the Hippocratic Oath by providing care that is not indicated and against the wishes of the patient.

How a physician handles such considerations over a patient’s evolving clinical course is why the term “provider” is inadequate, even inappropriate, in one’s lexicon. The decisions to start or stop complicated medications and life support are so nuanced that one cannot merely

order them as though in a cafeteria line. The perspective of society and public opinion is changing rapidly, with pressures mounting to avoid excess spending and futile interventions for patients like Jessa. Yet the Oath of “*primum non nocere*” (first, do no harm) remains intact and must be considered in all its complexity for every person. In Jessa’s case, it would be “harmful” (thus, breaking the oath) to remove her from life support against her wishes. This is not to say that all patients’ wishes must be heeded, for there are circumstances in which a patient might request that “everything be done” and it be aptly judged that life support is not indicated. Likewise, if someone asks for an intervention with the intent to kill, even with the purpose of relieving suffering, such a “request” would be considered unethical on grounds that it is the measured killing of another human (the definition of euthanasia). The U.S. Conference of Catholic Bishops (National Conference of Catholic Bishops, Administrative Committee 1991) and Saint John Paul II (John Paul II 1995) have both written extensively defining euthanasia as follows: “Euthanasia is the action or omission which by intention causes death, with the purpose of eliminating all suffering. Euthanasia’s terms are found in the intention of the will and are a grave violation of the Law of God, since this act is the deliberate and morally unacceptable killing of a human person” (John Paul II 1995, n. 65). Whenever I consider the rightness of the Hippocratic Oath in avoidance of doing harm, the sentiments of St. Augustine, William Penn, and Fulton Sheen reverberate in my mind: right is right if even nobody is right, and wrong is wrong even if everybody is wrong.

Walking to the bedside of dying patients makes most of us nervous, and this step toward Jessa was a worst case scenario. At least the majority of ventilated patients can use muscle groups to move

their extremities and communicate, but ALS had stripped Jessa of nearly all voluntary movements save blunted facial expression. The key in this situation, for you as for me, is actually no different than approaching a suffering person on the street: to look vastly deeper than the face and body into the complex and unique person in our midst. Thus, we must seek to understand the person who is Jessa, complete with her expectations and goals, to serve her best.

The “quality of life gap” between expectation and reality

QOL is of utmost concern, of course, in evaluating Jessa’s life circumstances. For people with very depersonalizing illnesses like ALS or locked-in syndrome, physicians may impose their values of QOL onto their patients, thus judging that if they would not want to live like that, neither would others. As mentioned above, such projection onto others is a crucial error, since empirical data show that such patients often rate their QOL as good and even similar to normal controls (Rousseau et al. 2013; Simmons 2014). Such unexpectedly high ratings of QOL may be due to many factors, including strong family support, patient–computer communication devices (as used by Stephen Hawking), and spiritual values. This can also be achieved by the patient matching his or her hopes with the reality of his or her life. The “QOL gap” between a person’s expectations and their actual experience is the key determinant to perceived QOL. Thus, if the QOL gap between expectations and reality is narrow, then a person’s perception or rating of his or her QOL is better (higher) than when the gap between expectation and reality is wide (Calman 1984). Calman reminds us, “It is *not* possible to make value judgments

about other people’s QOL. It is their own perception which matters.”

Redemptive suffering

Caring for Jessa was less confusing after I had thought so much about all of these separate yet related aspects of her situation as my patient. I understood better her devotion to life and her fighting spirit, and my purpose as her physician had new meaning and inspiration. I must first relieve her suffering (e.g., pain, anxiety, delirium) to the best of my ability. Beyond that, I discovered she believed in redemption through suffering. Because of her difficulty in communication, we maintained potent analgesia to maximize pain relief. Pope John Paul II wrote about redemptive suffering, teaching us: “Praise may be given to a person who voluntarily accepts suffering by forgoing painkillers in order to remain fully lucid to share consciously in the Lord’s Passion, but such ‘heroic’ behavior cannot be considered the duty of everyone” (John Paul II 1995, n. 65).

As this topic generates a lot of confusion both between Catholic and Protestant circles as well as within individual denominations, a bit more on the Catholic understanding of redemptive suffering is worthy of comment. This is a very hard concept for us to understand, especially while in the midst of suffering (i.e., it is easier to digest at a distance). Think of this as “suffering with meaning,” wrote Sister Mary Diana, a Dominican sister and physician member of the Nashville Guild of the Catholic Medical Association. She went further, “All of us, if we understand a reason for our suffering, can ‘do it’ better. For example, post-abdominal surgery we know why things hurt, and that we have to get through it to get to something better. Parents suffer through sleepless nights to

raise their children (whether infants or teenagers).” Such parental suffering prompted this prayer for parents with wounded hearts to link directly into the teachings of the Church (Ely 2014). George Isajiw, a Catholic physician and CMA faithful commented, “There is no empirical evidence that death ends suffering.” Consider this comment from the Apostle Paul, “It makes me happy to be suffering for you now, and in my own body, to make up all the hardships that still have to be undergone by Christ for the sake of His body, the Church” (Col 1:24).

As Catholics we believe in purgatory and that by accepting suffering on earth and uniting our sufferings to the cross of Christ, we can in fact help our own maturation as Christians and the ultimate purification of our souls here on earth so that we can be spared some of the suffering of purgatory, where we will be completely refined and de-stained for Heaven. Jesus allows us to share in His sufferings on the cross, as we are His body, the Church, and thus to participate in our salvation. By uniting our sufferings to His on the cross, we share in the merits of His redemptive suffering. Importantly, regarding redemptive suffering, no amount of our own suffering will ever equate to our “redemption” in terms of justifying our entry into Heaven, so what would be the purpose of our voluntarily enduring or embracing inevitable suffering? Consider this: If your child was going through something in the way of suffering, you would feel his or her pain, right? You would not want to separate yourself from that pain but want to join in with him or her in the suffering as his or her parent. In this way you enter into a spiritual and human facet of our existence, which you would never want to bypass. This is what it means to be fully human and a son of God. The suffering allows us to enter into the understanding of the process of redemption. It does not earn redemption. We join closer to God. It helps us in our

faith to become more Christ-like, which is the entire process and point of conversion. Put simply, redemptive suffering is a powerful tool in our own conversion.

Maslow’s hierarchy and concluding thoughts

Jessa’s team and I also considered the sixty-year-old psychological concept of Maslow’s hierarchy (Maslow 1943), which states that there are five levels of needs that must be satisfied to promote healthy well-being. The first two are the most basic and primal: physiological needs (e.g., food, water, shelter) and safety. Once these needs are met, a person moves up the hierarchy to psychological needs, including love and belonging, esteem and dignity, and finally self-actualization and incorporation of spiritual values into care. Maslow’s teachings have recently been reconsidered in light of modern day circumstances of critical illness in order to improve ICU and post-ICU care (Jackson et al. 2014). This helped Jessa’s team focus on her dignity. My daughter, Taylor, told me one day, “Daddy, we learned in school that every person has his dignity, and we respect that by taking care of one another until life is over.” Caring for Jessa was not a question of futile care or of nudging a woman and her husband to accept the end. This understanding on my part as her physician ushered in a time of flooding her days with unadulterated, childlike love.

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