Humanities: Art, Language, and Spirituality in Health Care

A Gift Twice-Given is Truly Received”

Charles R. Nolan, MD

Medical Director, LIFE Care – Palliative Medicine and Hospice, Guadalupe Regional Medical Center, Seguin, Texas, USA

Key Words

Transplant, gift-of-life, cirrhosis, alcoholism, addiction, palliative care

Key Message

Transplant Nephrologist turned Palliative Care – Hospice physician recounts personal experience in palliative care of patients with end-stage liver disease validating his conviction that Palliative Care is not just for dying patients.

A Gift Twice - Given is Truly Received

Today at Christmas mass, the Catholic priest's homily was about giving and receiving gifts. Newly ordained, his first assignment was in Albuquerque, NM. While there, he learned of a Native American wisdom verse which he translated as “A gift twice given is truly received,” a more eloquent version of the popular “paying it forward”. I'm inspired to share my own Christmas story about ***Gifts Re-Given and Truly Received***.

I realize now that from my earliest days in medical school, though I eventually specialized in Internal Medicine and Nephrology, I'd also embarked on a circuitous journey to becoming a Palliative Care – Hospice physician. For over three decades as a transplant physician at an academic medical center, I'd witnessed many miracles whereby critically-ill patients received the “Gift of Life” in the form of an organ transplant. However, I gradually came to understand that something crucial was missing in the treatment we offered. The Transplant Team often did not provide truly sufficient care for the many patients who didn't survive long enough to make it to transplant, those who literally “died waiting”. And of course, this profoundly affected their families too. Regrettably, I was all-too-often a coconspirator in the exclusively high-tech care of patients who were too sick to survive a transplant, yet unable to survive without one. That conundrum could drag on for weeks and ultimately bankrupt the patient and family both financially and emotionally. Such heart-wrenching experiences led me to transition to a second career in Palliative Care and Hospice.

A year and a half ago, I met a 45-year-old man with cirrhosis due to alcoholic liver disease and hepatitis C. JAL had recently been hospitalized with a life-threatening variceal hemorrhage. He was referred to our LIFE (Lifelong Intensive Family Emotional) Care – Palliative Care team to discuss beginning hospice. We met with JAL and his devoted daughter for the first time at his home. He described how he'd been a heavy drinker since his teens, was still actively drinking, and had no medical insurance; he said he had no hope of recovery. We discussed the potential benefits of hospice. But I also told him there was still hope of recovery. I outlined a difficult journey he could embark upon. He could work through to sobriety, apply for Social Security disability and so get insurance through Medicaid. If he could achieve all this, I'd refer him to a Transplant Center to be considered for a new liver. To the astonishment of the team, JAL immediately accepted the challenge. He stopped drinking, began to regularly attend church and AA meetings – and is now 18 months clean and sober. In short, he became the model patient, returning regularly to the Palliative Care clinic with a meticulous log of his daily weights and blood pressure readings and strictly adhering to the diet and medication regimen I prescribed. Though still terminally-ill with decompensated cirrhosis, his lab values (MELD score), overall health and physical

Resubmission of revised manuscript with revisions suggested by reviewer.

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Description of Changes in response to reviewer's suggestion:1) In the initial resubmission in the first sentence the word “Father” was changed to Catholic Priest to provide clarity for non-Catholic readers.2) In this second resubmission the grammar and syntax have been revised and improved to enhance readability.

Address Correspondence to: Charles R. Nolan, MD, Guadalupe Regional Medical Center, 1215 E. Court Street; Seguin, TX 78155, USA. E-mail: Nolch@grmedcenter.com

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appearance improved dramatically. Former drinking buddies would stop and ask him how he did it because they "wanted some of that". Eventually JAL did receive disability and Medicaid and I referred him for placement on the liver transplant waiting list. Around Thanksgiving, he presented with sudden worsening of his liver failure (MELD score 25) and we were afraid he would die from a complication. But then a Christmas Miracle occurred. JAL received a call that a deceased-donor liver had become available.

Yesterday, I visited him at the Transplant Center ICU. Smiling broadly, he told me about that long-anticipated call from the Transplant Coordinator and how he was immediately overwhelmed with a profound sense of sadness and guilt that some family was suffering the loss of a precious loved-one at Christmas. I've cared for hundreds of kidney, liver and lung transplant recipients over the years, yet this is the first time I can recall one of them verbalizing the kind of things JAL did yesterday. We talked about how something good had come of another family's tragedy and that after a few months he could anonymously write to the donor family to express his gratitude. I suggested that he could also volunteer with our LIFE Care team to serve as a coach and mentor for others suffering from liver failure. I envisioned a "**JAL Palliative Care Liver Transplant Club"** of which he has just become the charter member. Beaming, he told me he'd love *to pay forward* his gift in this way.

Still, I am painfully reminded that not all the patients that desire to follow in JAL's footsteps make it to a successful transplant. This very week, two young men who weren't candidates for a liver transplant died on our inpatient hospice service with complications from end-stage liver disease. I had recently had the "JAL Club" conversation with one these young men as he sat in a wheelchair in my office for the first time, accompanied by his terrified family. I outlined the difficult path to sobriety, disability, medical insurance coverage and a possible liver transplant. Later that day in a meeting with my team, I shared that except for his deep jaundice, he was the spitting-image of my own son, who's also struggled with mental illness and the serious health sequelae of addiction since early adolescence. Sadly, less than a week later, I was present with this young man's grieving family at his bedside as they held vigil for his impending death. His liver disease had already reached end-stage, complicated by onset of hepatorenal syndrome, such that time and circumstances precluded his even embarking on JAL's journey. I reminded his family that his untimely death was the result not of some weakness of character or moral failing but instead the consequence of the all-too-real disease of addition, which is no more the person's fault than cancer or any other illness is. I told the family of many an open Alcoholics Anonymous meeting where I'd listened to the incredibly tragic stories of young people whose first taste of alcohol or an illicit drug had suddenly and irrevocable changed their lives, not to mention the lives of their families. My own eyes welling with tears, I explained that they didn't fail their loved one, but that the disease simply prevailed.

Cancer may be the "Emperor of All Maladies" but addiction and substance abuse are surely also high-ranking members of the Royal Court. I'm convinced that God's grace in helping me through the many years of my son's illness ultimately led me to a career in Palliative Care and has provided me a strange gift that I often give again, and which can make a real difference in the lives of the patients and families I have the privilege to care for.