Learning From Ervin's Care: Ethics, Health Care Finance, and Human Connection

Amy C. Denham, MD, MPH

Department of Family Medicine, University of North Carolina at Chapel Hill School of Medicine, Chapel Hill, North Carolina

ABSTRACT

A 70-year-old man with complex multimorbidity and intellectual disability was my patient for the last 5 years of his life. He taught me important lessons about the challenges of practicing medicine as a primary care physician. He embodied all the complexities of multimorbidity, the ways in which clinical decision making can be fraught with uncertainties and tradeoffs. He raised difficult ethical questions for his care team, questions about how to respect the dignity of patients who lack decisional capacity and who do not have surrogate decision makers. The gaps in his care revealed shortcomings of the US health care system, but his care in his final years also showed some of the bright spots in coordinated, team-based care. Most importantly, caring for this patient taught me about the rewards of the human connections that primary care physicians establish with their patients.

Ann Fam Med 2024;22:565-567. https://doi.org/10.1370/afm.3182

It is often the most challenging patients that you learn the most from, and Ervin's care was challenging in so many ways.

Ervin was a 70-year-old man who I cared for over the last 5 years in a Program of All-Inclusive Care for the Elderly, or PACE, a model of interdisciplinary team-based care for medically complex, disabled older patients. (Names have been changed to protect the patient's privacy.) Ervin was intellectually disabled but lived independently in an apartment. He had no living family members. His mobility was limited due to arthritis. He had multiple severe chronic conditions, including cirrhosis, heart failure, and chronic kidney disease. In his final weeks of life, Ervin was admitted to the hospital and diagnosed with a pulmonary embolism (PE). Because he had struggled with medication adherence for many years, the hospital team recommended that he stay in a nursing home while completing his anticoagulation therapy. The stakes were high, and the consequences of a mistake could be catastrophic.

When I visited him at the nursing home after hospital discharge, Ervin told me he was scared. He had trouble articulating his symptoms, but said he felt like "all the medicines are bouncing off of each other and blowing up inside me." His vital signs and exam were unremarkable, with no clear indication for further work-up. The next morning, I got a call that he had started vomiting and then became unconscious. The nursing home sent him to the emergency department, where he was diagnosed with an intraventricular hemorrhage.

As I reflect on the years that I cared for Ervin and the time that I spent with him in his final days, several stories emerge that contain lessons about how we deliver health care for older, medically and psychosocially complex patients and how that care can build human connections.

Conflicts of interest: author reports none.

CORRESPONDING AUTHOR

Amy C. Denham
Department of Family Medicine
University of North Carolina at Chapel Hill School of Medicine
590 Manning Drive
Chapel Hill, NC 27599
amy_denham@med.unc.edu

THE CLINICAL STORY

Ervin's story is about the risks of medical care in a frail, medically complex patient. Sometimes patients with multimorbidity have a fragile equilibrium. Sometimes medical care, even when correctly applied, can upset that fragile equilibrium. Adverse drug events are common. Hospitalizations to treat one problem cause or exacerbate other problems.

Was it the right decision to start anticoagulation for Ervin? The medical decision making was complex, as it usually is with patients with multimorbidity.

Definitive diagnosis of PE was challenging. A computed tomography (CT) angiogram was contraindicated because of chronic kidney disease. A ventilation/perfusion (VQ) scan showed "high probability of acute pulmonary embolism," but his underlying lung disease reduced the specificity of the study. We were in a realm of uncertainty, as we often are with multimorbidity. Anticoagulation posed risks, but there were also risks of not treating what may have been a PE. We were in a position of balancing risks, burdens, and tradeoffs, as we often are with complex multimorbidity.

THE ETHICS STORY

Ervin's story is also about ethics, about navigating complex clinical decisions in an adult with intellectual disability. Ervin did not have the capacity to fully comprehend the decisions he was facing, but he maintained his legal competence. He had no next of kin or health care power of attorney to make decisions on his behalf. Our team had wrestled for years with finding the most ethical path forward with Ervin.

As his medical and functional status declined, managing Ervin's care in the community became increasingly untenable. Chronic conditions often went untreated because Ervin could not manage medications on his own. Although his functional impairments interfered with his ability to complete activities of daily living, he was steadfast in his preference to live alone. He declined home care services. He adamantly refused assisted living or nursing home care. Independence and autonomy were at the core of his identity, but he often could not demonstrate decisional capacity, unable to articulate the nature of health care decisions or their consequences.

Was it ethical to continue to care for Ervin in the community when we had significant concerns about his safety? Would he be better off with a court-appointed guardian who could make the decision to move him to a safer setting of care? Would a move to a more supported setting degrade his quality of life, given the blow to his personhood and autonomy that it would represent? Would it even improve his safety, considering emotional and psychological safety as well as the very real physical risks of institutional care?

Ervin had a friend Michael, who had served as his social worker prior to PACE enrollment and who continued to take an interest in his well-being and who sometimes helped him navigate consent for care. Ervin expressed that he trusted Michael to help with decision making, and our team began to talk with Michael about pursuing guardianship. Michael was starting that process when Ervin was admitted to the hospital for PE.

THE HEALTH CARE FINANCE STORY

Ervin's story is also about health care finance, about how health care spending crowds out everything else about our social safety net, how the health care system is the safety net of last resort for people who may be better served by other social supports. It is widely known that the United States spends far more on health care per capita than other nations but by many measures achieves poorer health outcomes.[1] What may be less commonly understood is that the US combined per capita spending on health and other social care is comparable to other wealthy nations. The difference is that the United States spends a greater proportion of its social spending on medical care, so spending on other social services is proportionately much less.[2]

Prior to PACE enrollment, Ervin had visits to the local emergency department (ED) at least once a month. He often called 911 for non-urgent complaints. He had frequent ED visits for gout flares, flares that may have been prevented if he had social support to assist with medication adherence. He also had many visits for purely social concerns—an apartment that was too hot due to broken air conditioning, difficulty getting to the grocery store for food. The ED was the only place he knew to go, the only place that would take him in when he was in crisis.

How would Ervin's care have looked different if he had a robust social safety net, a system of support that could adequately address his social needs? Instead, he relied on the health care system, so his needs became medicalized. Would his medical comorbidities have become so severe if he had more social support to help him manage his care?

THE STORY ABOUT ALTERNATIVE MODELS OF GERIATRIC CARE

Ervin's story is also about alternative models for organizing geriatric care. Seeing Ervin within a Program of All Inclusive Care for the Elderly (PACE), a model that is financed on a capitated basis rather than fee for service, our team had the latitude to organize care in ways that best met his needs. With capitated payment models, payment is organized around the patient and their needs, rather than by the individual visit.

Capitated payment models open the door to restructuring care in ways that best serve the patient. More complex patients can have longer clinic visits. Physicians can have the flexibility to make home or hospital visits. The team member who is most appropriate in the moment, whether a social worker to address psychosocial needs or an occupational therapist to address functional deficits, can provide the care that is needed, rather than needing to focus on which team member can provide a billable visit.

Prior to Ervin's enrollment in PACE, the primary care physician who cared for him in a fee-for-service model often felt overwhelmed with trying to meet his needs in 20-minute visits. It was not feasible to keep him out of the ED or to connect him with enough resources to meet his social needs. Once Ervin enrolled in PACE, he had a broader interdisciplinary care team with greater flexibility to address his concerns. He attended a day center, where he had frequent contact and developed trusting relationships with his social worker, occupational therapist, driver, physician and many other team members. There were still gaps in his care, and his needs still sometimes felt overwhelming, but when we were not constrained to a series of 20-minute physician visits, we were much better equipped to support him and to facilitate his desire to remain living in the community.

THE HUMAN STORY

In the end, Ervin's is a story about human connection. Health care professionals come into close relationships with individuals whose paths we might be unlikely to cross in our everyday lives. Despite our myriad differences—economics, education, cognitive status, disability, gender, race—Ervin and I formed a connection, albeit an asymmetric one. Over the 5 years that I cared for Ervin, I saw him in clinic almost every week. I could hear his boisterous greetings and laughter as soon as he entered the building. He sometimes became agitated and angry if he was frustrated, but he could also be generous and kind, bringing food from home to share with others, bringing me a lottery ticket every year as a Christmas gift.

Sometimes I felt helpless caring for Ervin. He had so many somatic complaints, so many sources of pain. With his difficulty keeping track of medications, managing both acute and chronic conditions rarely went smoothly. Sometimes his clinic visits were not about clinical concerns at all. He might pull out a stack of mail and ask me to help him understand the letters he had received from the utility company or the social security office.

Ervin had congenital foot deformities that caused chronic pain, and we could always return to foot care for relief and comfort. As Ervin and I talked, I would soak his feet in warm water, shave his calluses, apply lotion. These sessions gave us time to get to know each other and build trust. I heard the same stories again and again—about the time his apartment complex flooded, about how he used to help care for the horses on his uncle's farm. Over the years, my visits with him became less stressful, more relaxed.

Perhaps it was due to failings in our national social safety net that Ervin's primary care physician became his family, but that is what happened. He would often comment on how the PACE team was his family, and I sometimes joked with our team that I was his mom and Steve, his PACE social worker, was his dad. So, when Ervin had a severe intraventricular hemorrhage, when it was clear that he would not survive, Steve and I showed up at the bedside in the neurosurgical ICU because that is what families do. Together with his friend Michael, Steve and I sat with him for a few hours that evening as he lay unconscious, sharing stories about him, passing around photos. We told him what we had learned from him about patience, humor, resilience. As the respiratory therapist removed his endotracheal tube I sat and held his hand, felt his pulse slow and then stop altogether.

That evening, I had entered into a new kind of relationship with Ervin. It is generally not part of a physician's professional role to sit at the bedside and hold the hand of the dying person. We provide support but also space, so that family can do the work of connecting and grieving. But with Ervin, I had truly become his family.

Read or post commentaries in response to this article.

Key words: multimorbidity, medical ethics, physician-patient relationship, health care finance

Submitted June 9, 2024; submitted, revised, August 14, 2024; accepted August 20, 2024.

References

1. Gunja MZ, Gumas ED, Williams RDUS. Health care from a global perspective, 2022: accelerating spending, worsening outcomes. The Commonwealth Fund. Published 2023. Accessed Apr 2, 2024. https://www.commonwealthfund.org/publications/issue-briefs/2023/jan/us-health-care-global-perspective-2022
2. Bradley EH, Sipsma H, Taylor LA. American health care paradox-high spending on health care and poor health. *QJM*. 2017;110(2):61-65. 10.1093/qjmed/hcw187