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Harrison, Krista Lyn

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The Hidden Curriculum Of Hospice: Die Fast, Not Slow

Krista L. Harrison, PhD^{1,2,3}

¹Division of Geriatrics, University of California, San Francisco, San Francisco, CA

²Philip R. Lee Institute for Health Policy Studies, University of California, San Francisco, CA

³Global Brain Health Institute, University of California, San Francisco, California, USA

Abstract

Hospice provides palliative care at the end of life, but the model fails when patients die more slowly than expected.

I lost my faith in hospice care when my stepfather died. As a former hospice administrator and researcher in geriatrics and palliative care, I knew the ambition of hospice, the promise of what it could be. Our experience illustrated how hospice has become care for people dying fast, not for those trying to live well while dying slow.

On the first day of February in 2019, the hospice nurse called my mother and said “Good news! Larry is well enough we are discharging him.” This was not good news. Though my stepfather’s symptoms had started 10 years earlier, it had only been two years since he had been diagnosed with a rare neurodegenerative disease, Multiple System Atrophy (MSA), and not yet 6 months since he had been admitted to hospice after a hospitalization. Like Parkinson’s Disease, MSA includes profound autonomic dysfunction and problems with muscle control and coordination. Unlike Parkinson’s, MSA has a prognosis of five to nine years and rarely includes cognitive impairment. As with other serious illnesses where people are living while dying, best practice in care for neurodegenerative disease incorporates palliative care from diagnosis onward. Yet where Larry and my mom lived in Florida, home-based palliative care was not available and hospital-based palliative care was available only to people with cancer.

We knew Larry would likely need hospice at some point; the question was always when. Unbeknownst to me, doctors had been gently recommending hospice to my parents for months. Prior to his hospitalization in late 2018, Larry was six foot two, 187 pounds, and could walk around the house with a wheeled walker and my mother’s stabilization, though he fell many times a day. To get outside the house, he (reluctantly) used an electric wheelchair and wheelchair van. An intense Florida “red tide” algal bloom released aerosol toxins and caused such respiratory irritation that Larry began to drown in his own secretions, resulting in the week-long hospitalization. At discharge, we couldn’t get the equipment

Corresponding author: Krista Lyn Harrison, PhD, 490 Illinois Street, Floor 08, UCSF Box 1265, San Francisco, CA 94143, Tel: 415.502.4684, Fax: 415.514.0702, krista.harrison@ucsf.edu.

to manage symptoms at home. My parents were finally willing to consider hospice when Larry's primary care physician said the words "end stage disease" on speaker phone.

A Disconnect

I have researched hospice and palliative care – both the models of care and the organizations that provide it – for years, including working in a community-based hospice. My mother's most recent experience with hospice was my grandmother's death five years prior. We both thought of hospice as the best option for end-of-life care, with interdisciplinary support for the family in any care setting. According to federal regulations, hospice focuses on optimizing quality of life and minimizing sources of distress by providing 24/7 access to medical care; routine visits from nurses, social workers, chaplains, and home health aides; and home delivery of medication and durable medical equipment related to the terminal prognosis. Cost-containment efforts during the creation of the Medicare hospice benefit require physicians to attest that enrollees are likely to die within six months and require enrollees forgo hospitalizations and treatments with curative intent (such as cure-oriented chemotherapy for cancer). In theory, hospice enrollees are entitled to an unlimited number of days of hospice care. In reality, regulatory changes and increased oversight have led many hospices to preemptively disenroll enrollees before recertification of hospice eligibility at 180 days of service.

Larry wanted to be at home. We were prepared for his functional decline and anticipated that he might die within weeks of the hospitalization. For a few months, family or friends stayed full time to help. But, with a new regimen to support his lung function, Larry's strength improved enough that he could assist with transfers from bed to electric wheelchair to toilet, making it possible for him to stay at home with only my mother's full-time caregiving. Yet the overall picture was still one of decline. During his hospice enrollment, he began using the electric wheelchair full-time in the house until my mother needed to drive it for him. As he increasingly choked on solid food and aspirated liquids, my mother adjusted his diet. When the mechanics of eating became too challenging, my mother used her finger to help him move food around his mouth. Our best guess is that he lost 30 pounds in the 6 months after hospitalization.

Larry's trajectory of variable decline -- or what I think of now as punctuated equilibrium -- clashed with hospice. Though a six-month prognosis is required for hospice eligibility, it is often brink-of-death care. More than a quarter of hospice enrollees receive care for less than a week before death, while the median length of stay is only 18 days. The narrative among many hospice clinicians – echoed by family surveys - is that care is often initiated too late. Many hospice professionals say three months of care or more would be ideal to benefit from the interprofessional team's efforts to optimize quality of life. Our personal experience -- and my research -- indicates that the culture and regulations of hospice in the United States have not caught up to this aspirational narrative of optimizing quality of life for a longer period before death. The hospice we worked with was best suited to help people who are actively dying or ready to die, not those who are reluctantly dying.

Our family's efforts to maintain Larry's function (which allowed him to remain at home) and help him enjoy life while it lasted made the disconnect between hospice's words and practice apparent. We had several examples. One involved getting Larry access to a costlier, but for him, more effective medication. MSA results in constipation when slowed signals from the brain to the colon result in mistimed muscle contraction. After years spent trying every possible bowel regimen, Larry found that only the new long-acting treatments such as Amitiza worked. Insufficient management of his constipation had led to at least three Emergency Department visits over in the two years or so prior to him entering hospice, each visit following days of being unable to urinate from the degree of blockage. With a per-diem payment, hospice organizations need to manage costs so that clinician time, medications, durable medical equipment, and any other services are equal to the daily payment. Hospices with large daily censuses can use population management techniques to gain more flexibility in "right sizing" care, using patients whose needs are less expensive than the per diem to balance those who need more costly care. Constipation from opioids is a common hospice symptom that is often resolved with much cheaper regimens, so our hospice did not want to approve Amitiza. If Larry had been imminently dying, the effectiveness of the bowel regimen would have mattered less. It took months of arguing, purchasing out-of-pocket, and ultimately appealing to the executive vice president of the hospice organization, to get Larry the right care.

In another example, though hospice boasted about their wound care at enrollment, Larry developed pressure ulcers from his time spent in the wheelchair. Though the hospice physical therapist recommended a special cushion, the organization would not pay for it. The hospice nurses said, "that happens" and recommended morphine instead of a wound consult. This may have made sense if Larry had other sources of pain or was expected to die within days. Instead, Larry experienced substantial pain and discomfort for months while we advocated to obtain adequate bandages and oversight from a wound specialist.

Additionally, though hospice encouraged use of respite care, which provides caregivers a temporary break from caregiving, Larry's wounds dramatically worsened during his time in the hospice inpatient unit while my mother took her short break. He came home with injuries from improper use of his bipap and catheter. Because he was never allowed to bear weight during his 5-day stay in their facility, he also had substantial functional decline that made it much harder for my mother to care for him at home -- and less safe for both of them. Hiring additional paid caregivers was not a financial option for them. Thankfully, Larry slowly regained strength and function over subsequent weeks.

Finally, Larry was discharged alive from hospice a few days shy of the six-month mark. I had talked to my mother about the possibility that he could stabilize and be discharged, so she researched the signs of decline in MSA specifically and for hospice recertification generally. She tried to draw the hospice nurse's attention to Larry's weight loss, decreasing ability to stand independently or support his own weight, more frequent falls and bowel incontinence, and declining ability to eat independently, chew, or swallow. Perhaps they did not listen, perhaps they did not document his decline (a case manager reviewing his charts confirmed they did not document his weight loss). Perhaps the hospice nurses discounted the signs of deterioration because they did not witness the increasing efforts my mother made to

get Larry out of the house in the wheelchair and van – after all, he was not their more typical bedbound hospice enrollee with cancer. Perhaps they were simply providing suboptimal hospice care. Without much warning, the nurse called and said, “Larry is discharged. We will come by with the papers to sign tomorrow and pick up the equipment soon after.”

Traumatic Transition

The care transition was traumatic. The next six weeks were filled with efforts to enroll in skilled home health (which did not cover the most-needed service: an aide to help with bathing), replace medical equipment, and engage in what we jokingly called “Medicare Revenge Spending:” ambulatory visits with Larry’s primary care provider, neurologist, and pulmonologist. Mom and Larry re-told their story a dozen times to each person. The pulmonologist quipped “Didn’t die fast enough for them, eh?” The major causes of death in MSA are sudden death, aspiration pneumonia, urinary tract infection, or wasting. Any day could have been Larry’s last.

Six weeks after Larry was discharged, he sharply declined in conjunction with what we assume was an infection. My mother fought my recommendation to re-enroll with hospice, so deeply had they broken her trust. My hospice and palliative care colleagues assured me that re-enrolling was the wisest path, but I still second-guess. We spent valuable time and emotional energy handling the re-enrollment with the only hospice in the area. Staff seemed blithely unaware of our feelings. Hospice clinicians gave him an enema that made him desperately ill for six days. He stopped eating and drinking. The counterfactual is unknowable, but hospice failed their mandate to reduce suffering. Larry died three weeks later, April 2, 2019, eight months after his initial hospice admission.

We Need An Alternative

All humans die, yet we stubbornly fail to develop systems that make dying and bereavement less terrible. Hospice developed as an alternative to a death-denying hospital culture, an interdisciplinary care model to serve the person and family at end-of-life. Hospice has evolved into a business that relies on the extensive unpaid labor of family caregivers (and associated costs to caregiver physical, mental, and financial wellbeing). Between 2000 and 2016, use of hospice doubled while Medicare payments for hospice increased six-fold. Over 70% of hospice organizations are for-profit, with increasing involvement of private equity firms. There are widespread and ongoing concerns about quality of care in hospice. Market forces and regulatory oversight may pressure non-profit organizations to act like for-profits or to disenroll long-stay patients for fear of withheld payments.

The actions of Larry’s non-profit hospice diverged from the ideals of the hospice philosophy yet accorded with the incentives of the Medicare hospice benefit and oversight. The hospice philosophy aims to provide whole-person care, tailored to the preferences of patient and family, to relieve suffering throughout the dying experience. The benefit was designed around the relatively predictable course and symptoms of people dying of cancer: short prognosis with intense pain. Yet the vast majority of Medicare beneficiaries die of non-cancer serious illnesses. Capitated payments for all-inclusive care incentivizes cost-

minimization, as we experienced Larry's hospice declined to pay for expensive treatments like Amitiza and the wheelchair cushion (despite palliative benefit). Payment reforms are being attempted, but regulatory oversight intended to minimize inappropriate enrollment of low-need patients with prognoses longer than six months (to boost profits) has sometimes instead led to the early expulsion and abandonment of people with long trajectories of functional decline and hard-to-predict life expectancies.

Though I fundamentally believe my hospice colleagues are committed to caring for people like Larry -- and anyone with a serious illness -- the defaults and policies do not facilitate optimal care for the modern population of enrollees. While many hospice enrollees die too quickly (and this is a separate and valid concern), 20% of hospice enrollees receive care for longer than six months and 17% are disenrolled while still alive. Enrollees with neurological conditions have the longest average length of stay, and the second highest rates of live discharge. Yet this is the best option available -- end of life care is consistently rated higher when hospice is involved. No other existing Medicare benefit provides sufficient long-term interdisciplinary care (including integrated medical, functional, and social supports) through end-of-life wherever a person calls home.

The chasms of care are wide for the reluctantly dying. We need an alternative.

No revolt can come from the dying, their caregivers, or the recently bereaved: their energies are otherwise occupied. It falls to those of us left behind to advocate for policy change and models of care that mitigate rather than exacerbate the challenges of dying.

One option would be to build a payment model for care that supports patients – and caregivers – in the months and years *before* hospice eligibility. Potential seeds for this model include the Home-based Primary Care program within Veterans Affairs Center, the Program for All-Inclusive Care for the Elderly, the Independence at Home Demonstration and the Community-Based Palliative Care Demonstration. Each of these models would require adjustment to have been relevant to our family's situation. Larry was not a Veteran; he needed care informed by approaches from both palliative care and geriatrics, as well as aide services, durable medical equipment, pulmonary expertise, and wound care. He and my mother needed care continuity as well as to be recognized as experts in their rare disease experience. They needed ways to easily add additional layers of support as their care needs grew.

Another policy option would be to change the existing Medicare hospice benefit to better serve the characteristics and needs of beneficiaries. Changes would include removing prognostic requirements, facilitating payment for treatments with palliative benefit (even if expensive), adding more support from aides for personal care, adding more explicit support and care for family caregivers, and training hospice staff to care for a broader array of diseases. Given that nearly three-quarters of hospice enrollees are over age 65, this training should include an emphasis on principles from geriatrics such as minimizing functional decline, promoting adaptation, and managing multimorbidity. Such changes would likely increase the cost profile of hospice, but likely would simultaneously decrease costs in other areas of Medicare while decreasing often-ignored costs to family caregivers.

We will all die, and if we are fortunate, we will do so at advanced age. Self-interest alone should support the availability of high-quality, evidence-based, culturally humble end-of-life care that can be tailored to the preferences and need of those impacted. As a model of care in the United States, hospice has remained hobbled by efforts to minimize costs to Medicare. It is the only model of hospice in the world that asks physicians to guess whether or not a person will die in the next six months. The costs accrue to all of society, we simply do not measure the impacts. Change is needed for hospice (or its alternative) to reach its promise of helping people live however long they are dying.

Policy Checklist

The issue: There is no model of care available in the United States to provide wrap-around social, functional, and medical services for people with terminal illnesses with trajectories of slow functional decline (and their caregivers). Hospice is the best option available, but the regulatory structure and cost-containment measures have contributed to a culture that best supports people who are dying quickly.

Related reading:

- Boersma I, Miyasaki J, Kutner J, Kluger B. Palliative care and neurology: time for a paradigm shift. *Neurology*. 2014;83(6):561–567. doi:10.1212/WNL.0000000000000674 [PubMed: 24991027]
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