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OpEd

Death, economy, and the problem of excess

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Open nearly every book about the US healthcare system and the problem of excess would echo throughout. Healthcare accounts for some 18 percent of US gross domestic product, and the figure continues to rise. Pharmaceutical companies, medical device producers, insurers, hospitals, clinics, laboratories, and physician groups make up a profitable industry that develops, sells, and utilizes ever-more-advanced and expensive methods to diagnose and treat disease. Procedures that only two decades ago were deemed “extraordinary” are now being used as ordinary treatments, which physicians offer and insurers cover even when their benefit is minimal (Kaufman 2015). It is mind-boggling, indeed, that in a country where so many lack even the most basic access to medical services, many others face a persistent problem of *too much*.

This problem of excess is manifest when it comes to severe and potentially terminal illness. Treating people in their last year of life consumes a staggering quarter of Medicare’s annual budget

(Riley and Lubitz 2010). Money aside, critics have argued that US medicine’s aggressive treatment of severe illness prolongs debilitated, incapacitated, and agonized states of being, which can hardly count as meaningful lives. “The medical man,” Max Weber observed in his famous lecture at the University of Munich, “preserves the life of the mortally ill man even if the patient implores us to relieve him of life, even if his relatives, to whom his life is worthless and to whom the costs of maintaining his worthless life grows unbearable, grant his redemption from suffering” (Weber [1917] 1946, 143). A century later and thousands of miles away, this foreboding description seems to have materialized in a most extreme and palpable way: excessive spending on excess treatment leads to excessively long and unwanted lives.

For the past decade, I have studied the US movement for *hospice and palliative care* as a mobilization that identified, criticized, and attempted to curb excess near the end of life. With much inspi-

ration from the sociology of critical capacity (cf. Boltanski and Thévenot 1999), I am interested in the regimes that structure and condition this movement’s critiques. My main focus, however, is analyzing the social structures that these critiques have produced.

Modern hospice ideas originated in England and reached the US in the 1960s. US hospices first developed in the form of small, idealistic, and fairly marginal groups of clinicians who advocated minimalism and simplicity in end-of-life care. Dying patients, they argued, had no interest in having their lives prolonged with sophisticated and extraordinary technologies. If allowed to reflect on their condition and assisted in accepting their inevitable death, the dying would presumably prefer to experience a “good death” at home, surrounded by family, and without artificial life-prolonging interventions. Beyond claiming to represent dying patients’ wishes, hospice advocates promoted their more restrained medicine as morally and professionally superior: they stressed that when it comes to end-of-life care, *less is better*.

Some would find it ironic that by the 1980s, this iconoclastic and anti-institutional approach became the strange bedfellow of Reagan’s fiscal conservatism. Against the backdrop of increasing healthcare spending, Reagan’s administration sought ways to slash federal budgets. Hospice advocates were quick to recognize an opportunity and pitched hospices as a moral way to reduce healthcare costs. They argued that rejecting aggressive life-prolongation as excessive and unethical would help the government curb its expenditure (Livne 2014, 2019). Their reasoning was intuitive enough to make Congress approve hospices as a Medicare benefit in 1982. With a stable and reliable source of funding, US hospices grew into a

massive industry. By 2018, Medicare was paying hospices 19 billion dollars annually to treat over 48 percent of the dying patients it insured (NHPCO 2019). These enormous amounts of money feed a thriving economy, over two-thirds of it for-profit, whose *raison d'être* is limiting life-prolongation and monetary spending on it.

In my recent book, *Values at the End of Life*, I call this economy *the new economy of dying* (Livne 2019). Like many other economies, this one comprises monetary exchanges, corporate interests, and moral views that enable and legitimize them (cf. Zelizer 1979). The actors within this economy, however, face a major challenge: How can they mobilize both current and future patients to join the economy and relinquish life-prolonging care?

The ethnographic parts of this book follow how clinicians address this challenge. I conducted participant observations in the palliative care services of three California hospitals. In the US, palliative care services work inside hospitals and typically see patients whose illnesses fall in the gray zone between curable and terminal. These would include, for example, people with severe, incurable, and slowly progressing chronic diseases; patients with incurable cancers who still seek some life-prolonging options; and older adults who experience physical and cognitive decline without facing an immediately life-threatening disease. Most of palliative care services' work involves discussing with patients, their families, and the medical teams who treat them whether, how, and when to phase out medical interventions. Some, though not all, of these patients are referred to a hospice.¹

By shadowing palliative care teams in their day-to-day work, I could therefore follow how clinicians, families, and patients nego-

tiated what counted as "excessive" and "unnecessary," placed limits on medicine, and decided to let patients die. The medical staff never deliberately invoked money or financial interests in these conversations. In the few cases that a clinician (never from a palliative care team) carelessly mentioned the high cost of treatment to a family, the interaction quickly devolved into a heated exchange, with the infuriated family oftentimes demanding that the patient receive maximum treatment.

The accepted and far more effective way to curb medical utilization and spending drew on soft power. Palliative care clinicians encouraged patients and families to engage in existential and introspective reflections, articulate what values and personal traits defined them (or their relative), and discuss what medical decisions would best match these values. The palliative care teams did not force external economic and organizational constraints on patients and families; they rather infused patients' and families' own judgment with a moral approach that valorized limits and informed how patients thought of themselves and their condition. This led many people to voluntarily conclude that they preferred less treatment for themselves or their family members.

This soft power, however, was effective to different degrees when applied to different populations. Patients from relatively privileged backgrounds, who had access to healthcare throughout their lifetime and the course of their terminal disease, were likely to have illness experiences that resonated with critiques of excessive and aggressive medicine. By contrast, many patients of marginalized populations who had their diseases diagnosed late due to having little or no insurance coverage, were dismayed that, when they finally saw

a physician, the physician tried to convince them that less treatment was better. The new economy of dying, its moral views, and its pursuit of more economical dying trajectories is therefore a hierarchical social field, which valorizes and validates some experiences and biographies while marginalizing and remarginalizing others.

This project has several implications beyond the case of end-of-life care. First and most simply, it illustrates the value in applying an economic sociology framework to analyses of healthcare and medical practice. Despite being a major economic sector in all developed countries, healthcare has attracted relatively scant attention from economic sociologists. There is much work to do in the area. Second, it highlights how important it is to account for social hierarchies and inequalities when studying morality in economic life. Moral values and conceptions of legitimacy are crucial components in the formation and expansion of markets (Fourcade and Healy 2007; Zelizer 2011). Yet when studying them, one also has to account for the power of some groups to transform their particular experiences and views into general moral conceptions. Such conceptions may overlook, marginalize, and exclude other social groups.

Lastly, in my current work, I treat the case of end-of-life care as emblematic of an entire historical period. It is no coincidence that hospice and palliative care has proliferated since the second half of the twentieth century: this is a time when faith in the power of modern scientific progress gave way to discussions of progress's limitations and possible end. Similar discussions took place in other realms – economists warn of the exhaustion of growth (Gordon 2016; Hirsch 1978), and environmentalists highlight the finitude of Earth's resources and the impera-

tive to rein in production and industrial expansion (Meadows et al. 1971). If the search for limits and the attempt to control growth and

excess are defining features of the current historical moment, then end-of-life care and attempts to govern medical technologies may

serve as an illustrative case that sheds light on far broader social dynamics.

Endnote

1 By Medicare standards, in order to qualify for hospice care, two doctors have to

confirm that a patient has a life expectancy of six months or less.

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