Economies of Dying: The Moralization of Economic Scarcity in U.S. Hospice Care

Roi Livne

Abstract
As efforts are made to contain health care spending, the decision to stop trying to cure severely ill patients and focus on comfort care has become an economic as well as a moral issue. This article examines the intricate intersection of economics and morality in U.S. hospice care. Using historical, interview, and ethnographic methods, I explain the resonance between hospice practitioners’ moral motivations and policymakers’, insurers’, and providers’ efforts to economize near the end of life. Drawing on theoretical literature on morality in markets, I analyze the moralization of economic scarcity. I argue that rather than posing an external financial constraint on the achievement of moral goals, scarcity itself can bear moral meanings. In the case of hospice care, the view that “less is better” and the wish to save patients from over-treatment converge with financial interests to limit spending on end-of-life care and imbue financial constraints with positive moral meanings.

Keywords
morality and markets, death and dying, hospice, economic sociology, medicine, health care

How much money should be spent on sustaining the lives of terminally and severely ill patients? This disconcerting financial phrasing of a medical-ethical quandary has become commonplace in the United States over the past few decades. Between 1978 and 2006, Medicare spent more than a quarter of its budget on treating patients in the last year of their life, at a real annual cost that climbed from $13,401 to $38,975 per patient (Riley and Lubitz 2010). Utilization of intensive care in these patients’ treatment has risen, and so have the likelihood of hospitalization and the average number of physician consultations (Dartmouth Atlas Project 2013; Teno et al. 2013). Responding to this unsustainable growth, policymakers, insurers, and health care providers have sought to reduce spending on health care in general and on end-of-life care in particular (Rodwin 2011; Scott et al. 2000:194–96). With 17.9 percent of the U.S. GDP spent on health care, the U.S. health care system increasingly faces a problem of scarcity, which is especially challenging near the end of life: there exist finite financial resources to pay for an abundance of life-prolonging interventions. The perceived pricelessness of life thereby meets the finitude of economic resources. Morally charged decisions about whether to withdraw life-prolonging treatments and let patients die become entwined with attempts to economize.

*University of California-Berkeley

Corresponding Author:
Roi Livne, Department of Sociology, 410 Barrows Hall, University of California, Berkeley, CA 94720-1980
E-mail: rlivne@berkeley.edu
This article analyzes the complex relationship between economic scarcity and morality. Despite the centrality of scarcity in economic theory and policymaking, its relationship to morality has seldom been theorized sociologically. There are exceptions. Notably, E.P. Thompson (1971) analyzed the moral legitimacy of bread scarcity in eighteenth-century England as socially constructed. According to Thompson, scarcity was deemed morally legitimate under paternalistic social relations, when it was depoliticized and attributed to natural causes such as droughts. However, as capitalist markets developed, bread scarcity lost its moral legitimacy: it was attributed to profit-driven agents who acted independently of moral imperatives and provoked popular protest (Thompson 1971).

Scarcity is inherent in market economies, but it does not always provoke moral outrage. This article explores what Thompson’s account overlooked: how scarcity can be moralized as legitimate and even positive in markets. I use the case study of U.S. hospice care to illustrate a mechanism of positive moralization of economic scarcity in markets.

Scarcity is a persistent underlying problem in U.S. health care. Despite widespread acknowledgment that current spending trends will lead to bankruptcy, and despite criticism of medical over-treatment (Welch, Schwartz, and Woloshin 2011), end-of-life spending and health care utilization continue growing. Controlling spending is an ever-pressing policy issue: reforms in Medicare and Medicaid and increasing reliance on managed care are explicit attempts to make providers economize. Even when these attempts fail on the macro fiscal level, clinicians may feel them in declining reimbursement rates and shrinking hospital budgets (Rodwin 2011). Scarcity therefore manifests in end-of-life care in two interrelated forms: first, as an impending chronic problem of the entire U.S. health care system; second, in the form of budgetary constraints that limit health care delivery in individual organizations.

Structured by both scarcity and complex ethical predicaments, end-of-life care is a paradigmatic case for understanding scarcity and morality. Because the U.S. health care system has historically managed scarcity through market solutions (Starr 1982), this case study is particularly illustrative of the relationship between scarcity and morality in markets. My discussion focuses on hospice care—a comprehensive medical approach that, since the 1970s, has increasingly affected how U.S. society approaches death, dying, and end-of-life care. In 2009, the National Hospice and Palliative Care Organization (NHPCO 2010) estimated that “approximately 41.6 percent of all deaths in the United States were under the care of a hospice program”; over the course of one decade (1998 to 2008), Medicare’s expenditure on the hospice benefit increased more than fivefold, from $2.2 billion to $11.2 billion. Today, principles of hospice care are practiced and taught in a variety of health care institutions. Hospice ideas reverberate through public discourse and policymaking, playing an important role in reforming medical attitudes toward death, as well as in the effort to contain end-of-life spending and meet the limits of economic scarcity.

I argue that this success of U.S. hospice care owes much to the fact that, unintentionally, hospices have positively moralized scarcity around the end of life. In the realm of hospice care, scarcity is embedded in moral views on death and dying that cohere with the financial limits the health care market circumscribes. Starting in the 1950s, clinicians, academics, and other public figures promoted a medical ethic that attributed negative meaning to aggressive medical treatment at the end of life. As aggressive medical interventions became morally equivocal, spending less on them became ethical. Hence, from a hospice perspective, containing end-of-life spending is not an external cap imposed on clinical work; rather, in certain circumstances, containing spending is perceived as the moral thing to do and as a way to pursue the hospice ethic.

Hospice has never been an ideology designed to legitimize pecuniary interests: hospice work is morally driven, and the hospice practitioners this article follows are primarily motivated by the wish to do the right thing, medically and ethically. My argument, however, is that by
pursuing ethical ends, hospice practitioners may serve economic interests and present the effort to economize as morally virtuous. In this way, hospice ethics and economics are inseparably bundled together; they affect each other while being irreducible to one another. This is the main mechanism of positive moralization that this article outlines.

I begin with a theoretical overview of studies of morality in markets, focusing on commodification and valuation. I argue that this literature implicitly touches on the topic of scarcity, and that a systematic analysis of scarcity and morality may shed new light on it. I highlight three implicit approaches to the relationship between morality and scarcity: moral neutrality, immorality, and moral necessity. In the conclusion, I present a fourth approach that conceptualizes circumstances in which scarcity is moralized as positive. My empirical analysis relies on historical, interview, and ethnographic methods. I first outline the history of the hospice ethic and its evolving relationship to scarcity. I then focus on two key medical decisions that pertain to scarcity in end-of-life care: first, the decision to stop curative treatment, diagnose patients as “dying,” and restrict medical interventions to less costly hospice care; and second, the decision to limit the scope and level of treatment that patients receive after hospice admission.

Following Anspach (1993) and Zussman (1992), I do not evaluate the morality of these decisions. Rather, I analyze sociologically what makes people, whose work relates to these decisions, regard scarcity as moral or immoral. By adopting this approach, I examine how criteria of moral evaluation are constructed and how they sustain the hospice economy.

**MORALITY AND SCARCITY IN MARKETS**

Analyzing the moralization of scarcity in markets requires a conceptual break with a common critical intuition, which Zelizer (2011:5) termed “hostile worlds.” From a hostile worlds perspective, markets and morality represent two inherently contradictory logics; markets are domains of utilitarianism and selfishness—the ultimate antitheses of commitment to anything greater than one’s own economic interest. Markets therefore undermine collective moral values (Sandel 2012; Walzer 1983), replace altruism with profit-seeking (Titmuss 1971), and cause social disintegration (Polanyi [1944] 1956).

Diverging from this approach, a growing number of sociologists emphasize the cominling of morality and markets. Their insights resonate with Durkheim’s ([1893] 1984) classic definition of organic solidarity as the prototypical moral order of market societies and build on precursory economic sociology studies that focused on the moral agreements that enable market interactions (Macaulay 1963). Morals and markets scholars argue that far from being mere collections of self-interested individuals, markets are cultures “saturated with normativity” (Fourcade and Healy 2007:299–300) that share definitions of legitimate and illegitimate behaviors (Anteby 2010), rely on collective action (MacKenzie and Millo 2003), and may facilitate commitment and solidarity among their membership (MacKenzie 2006). These scholars provide ample evidence of cases in which moral views are expressed through market relations and discuss markets as domains where morality is formulated and materialized (Zelizer 2011). Research in this area has taken hostile worlds criticism of markets as its object of analysis; this work treats the very description of markets—as forces that reduce quality to quantity, reify meaning, and render sacred social values profane—as moral stances to be examined sociologically. The question asked is not whether introducing commodities, prices, and market relations to a certain domain is moral or immoral, but rather how the introduction of such features is moralized as positive or negative, virtuous or reprehensible, legitimate or contested.

Two interrelated discussions—on commodification and valuation—are particularly salient. First, “morals and markets” accounts of commodification typically analyze cases of contested commodities that became legitimate following the institutionalization of legitimizing narratives. The most thoroughly
researched commodity of this type is life insurance. Highly contested in the early-nineteenth-century United States, life insurance was seen as immoral, because it “threatened the sanctity of life by pricing it” (Zelizer 1978:605). In the mid-nineteenth century, however, narratives developed that associated life insurance with family values and care for one’s dependents, and this facilitated the growth of the life insurance market (Zelizer 1978). From a similar perspective, Quinn (2008) accounts for the moralization of viaticals by following the institutionalization of narratives that presented viaticals as a way to ensure a dignified death for poor, terminally ill people.

A second focus of morals and markets accounts is on valuation. As Boltanski and Thévenot (1999) discuss, valuation is a moral outlook: a judgment of the worth of various human or non-human qualities. The most common way to valuate things in markets is by assigning them prices; however, putting a price on objects and notions such as human life (Zelizer 1979), reproductive cells (Almeling 2007), or nature (Fourcade 2011) is often a controversial process and is widely criticized for reducing intricate, morally laden notions to standardized values (Espeland 1998; Espeland and Stevens 1998). Consequently, as Fourcade (2011) puts it, pricing poses three sociological puzzles about whether, how, and with what consequences money is used to express worth. As with commodification, economic valuation is a social process that epitomizes a moral stance on worth, virtue, and legitimacy (Stark 2009).

These accounts do not address scarcity directly, yet the moral question scarcity poses lurks throughout them. As Robbins (1945:16) contended, scarcity is the sine qua non of economics, “the science which studies human behaviour as a relationship between ends and scarce means.” Approaches to the morality of scarcity vary: we can distinguish between the treatment of scarcity as morally neutral, immoral, and a moral necessity. The case of hospice and its role in the U.S. end-of-life economy illustrates a fourth approach, which frames scarcity as a positive moral factor.

**Scarcity as Morally Neutral**

Robbns’s aforementioned definition of economics conceptualizes scarcity as morally neutral. Robbins uses scarcity as a metaphysical notion: the world’s resources are finite irrespective of human agency or socio-historical context. Consequently, moral views may influence demand for different goods under conditions of scarcity, but scarcity in and of itself is devoid of moral value. Demand for luxuries or ecclesiastical masonries may change according to the virtues that societies attribute to conspicuous consumption and asceticism, respectively (Robbins 1945). But, the finitude of resources is a defining feature of economic life that cannot be evaluated morally.

This view is shared inside and outside scholarly circles. In his ethnographic account of two intensive care units, Zussman (1992:100) documented clinical staff’s ethical concerns “about the ways in which resources are allocated. If there are only a limited number of beds in an intensive care unit, who should use those beds?” (see also Christakis 1999). Ethicists have treated the fact that “some beneficial health care services are simply too expensive to provide” (Asch and Ubel 1997:1668) as deriving from objective and unavoidable constraints. In line with Robbins’s framework, they do not apply moral judgment on scarcity itself, but rather on the choices made under the objective constraints of scarce resources. Moral debates emerge about how much to spend on different types of care given finite resources, but the finitude of resources is an arithmetic fact, uninfluenced by moral sentiments.

**Scarcity as Morally Negative**

In some cases, however, scarcity is itself moralized. Rather than an objective and natural constraint, it is understood as a social and political construction whose consequences are avoidable. In such instances, scarcity is often moralized negatively: when shortage can be avoided, it is hard to morally justify its existence. The historical transition that
Thompson (1971) describes illustrates this point: bread scarcity, which was initially perceived as an inevitable outcome of natural causes (e.g., droughts), became morally illegitimate once it was recognized as deriving from inflated prices.

Negative moralizations of scarcity often develop when people identify scarcity as an outcome of disputable social choices. Critical health care scholars, for example, argue that U.S. health care is rationed by ability to pay; consequently, although health care resources exist, the market makes them inaccessible to the economically disadvantaged (Hoffman 2012). This stance problematizes the otherwise-assumed inevitability of scarcity. As Mechanic and McAlpine (2010:153) observe, “the inclination to think of rationing solely as distribution of an unavoidably scarce supply . . . misses the large number of policy and service decisions that determine what care people can receive.” The moral value of scarcity is thus closely linked to the mechanisms used in allocating resources: when allocation is morally contested, scarcity is likely to be challenged as well.

The negative moralization of scarcity has implications for the moral attributes of markets in general, and for the moralization of prices and commodities in particular. Advocates of commodification rely on the theory that commodifying goods increases their availability and that this may be a way to avoid scarcity. Insurance companies, for example, positively moralized life insurance by presenting it as a way to ensure one’s family’s well-being after one’s death (Zelizer 1978). Conversely, critics of commodification present commodities as creating scarcity. Commodification of commons such as land (Marx [1867] 1976; Polanyi [1944] 1956) and non-market goods such as informal and unregistered housing (Mitchell 2005) are typically linked to political projects of dispossessions that create dearth.

The moralization of pricing and valuation is similarly connected to scarcity. Proponents of market solutions to natural resource management contend that pricing goods such as water would make people value them accurately and help address the water shortage facing many developing countries (Goldman 2005). Opponents of these solutions stress that assigning prices to previously non-monetized goods creates socially produced scarcity (Bakker 2007): conditioning access to goods on people’s ability to pay for them limits these goods’ availability (cf. Espeland and Stevens 1998).

Such moralization projects of prices and commodities are based on the assertion that scarcity is inherently negative and there is a moral obligation to avoid it, through commodification and pricing, or through de-commodification and the elimination of prices. Debates over the morality of commodification and pricing rely on a consensus regarding scarcity’s negative moral value.

**Scarcity as a Moral Necessity**

A third moralized form of scarcity is the moral necessity. Several accounts document cases where scarcity is construed as a morally necessary sacrifice that must be made to abide by certain moral principles. In these cases, scarcity is an outcome of moral views that determine the degree of scarcity—that is, the resources available in a certain economy.

Healy (2006), for instance, shows how moral critique and resistance to the commodification of bodily goods gave rise to a gift economy, in which whole blood and organs are donated rather than sold. This gift economy provides a scant supply of organs and blood, compared to what a fully commodified market economy would presumably provide. The moral concern over profaning the sanctity of the human body—and the appreciation for an economy that relies on donors’ altruism—limits the supply of organs and blood and establishes the degree of scarcity in this economy.

Fourcade’s (2011) account of the valuation of nature resonates with this insight. Comparing how French and U.S. litigants sought compensation for environmental damages, Fourcade shows that French litigants faced critical challenges in quantifying the value of nature and expressing it in monetary terms. The moral reluctance to convert a sacred and
sentimental notion such as “nature” into a dollar amount limited what could be demanded in monetary compensation for contaminated beaches and dead marine life.

In such cases, scarcity may have detrimental effects, but it is framed as a necessary moral sacrifice: better outcomes are relinquished because of the reluctance to commodify or price what is sacred. Yet, a pragmatic reading of these accounts would doubt the necessity of this sacrifice; Healy raises such doubts explicitly when proposing to carefully and moderately add certain market features to the donation economy of organ transplants to increase organ supply. Although taken as a moral imperative, scarcity in and of itself is considered negative. But can scarcity be positively moralized? And if so, how and under what conditions?

METHODS
I base my argument on historical analysis, ethnographic fieldwork, and interviews. First, I outline the history of hospices and their engagement with financial questions. I conducted an exhaustive bibliographic review of books published by hospice practitioners and advocates from the 1960s until the early 1980s. My examination begins with the early writings of U.S. hospice pioneers, which were published before the hospice industry developed. I collected their discussions on questions of budgeting, expenses, and financial management. I then analyzed these discussions and drew conclusions about how the hospice movement tackled financial questions in different periods. In addition, I reviewed congressional records—including reports, hearings, and laws—that dealt with end-of-life care in general and hospice care in particular.

My ethnographic fieldwork examines how one contemporary hospice addresses end-of-life decisions related to scarcity. I conducted a year of ethnographic fieldwork in Nubis Hospice, a California not-for-profit organization. Nubis is not representative of all U.S. hospices, yet its organizational characteristics match those of a significant portion of them. Nubis provides home hospice services: its clinicians visit patients at patients’ residences (homes or nursing facilities), and the hospice does not provide room and board. Nubis’s patients are usually cared for by family members, friends, or paid caregivers in addition to the hospice staff. Among U.S. hospices, 68.6 percent operated similarly in 2009 (NHPCO 2010). During most of my fieldwork, Nubis’s daily patient census fluctuated between 80 and 120; the national mean and median patient censuses were 90.2 and 51.8 patients, respectively. Finally, based on the available data, Nubis’s patient demographics are similar to hospice demographics nationwide (see Figures S1 through S6 in the online supplement [http://asr.sagepub.com/supplemental]).

Nubis is among the 48.6 percent of U.S. hospices that were registered as not-for-profit organizations at the time of my fieldwork (NHPCO 2008). A similar percentage registered as for-profit, and during the 2000s the number of for-profit hospices increased significantly. It is unclear to what extent for-profit hospices differ from their not-for-profit counterparts: quantitative analyses show little difference in the services provided (O’Neill, Ettner, and Lorenz 2008; Von Gunten 2008), and Rodwin (2011:117) notes that “markets led not-for-profit hospitals and insurers to compete with their for-profit counterparts by using similar strategies.” Still, there is much concern among hospice practitioners regarding the rising number of for-profit hospices (Cetti 2009).

As in every ethnographic account, one should be careful when generalizing specific empirical findings to other cases, let alone to other types of organizations. The key arguments of this article, however, refer to structural components that are relevant to all hospices in the United States—legislation, reimbursement policies, hospice ethical principles, and cost-efficiency considerations—and in this respect can shed light on the U.S. hospice market in general. Furthermore, the historical analysis puts the ethnographic data in historical context and helps highlight long-term sociological patterns of moral reasoning that persisted or were modified to match the challenges that hospices face today.
I started fieldwork as a volunteer at Nubis’s office. I was in charge of conducting “customer satisfaction” phone interviews and participated in the hospice’s volunteer training, where volunteers were introduced to the hospice’s various disciplines, to hospice ideology, and to Nubis Hospice in particular. I made numerous visits to patients’ homes and took detailed notes on all of my interactions with hospice workers. I took part in monthly volunteer meetings, a nurse training, staff meetings, staff and volunteer social meetings, and dozens of weekly interdisciplinary meetings where Nubis’s workers discussed their patients.

I complemented the ethnography with 20 in-depth, semi-structured interviews with Nubis’s staff, which provided me with access to the parts of their work I could not see in my observations. I interviewed representatives of all the hospice’s disciplines: seven nurses (including hospice liaisons and managers), six social workers, two chaplains, two hospice aides, one physician, and two bereavement coordinators. Questions addressed workers’ motivations, their everyday work, the influence that Nubis’s financial and organizational management have on their work, and their experience of this influence. I included quotes from as many interviewees as possible; to avoid idiosyncrasies, I chose quotes that were indicative of how Nubis operates as a system or that reflected clear patterns in the data.

**A SHORT HISTORY OF THE U.S. HOSPICE MORAL ECONOMY**

Understanding the moralization of scarcity in U.S. hospice care requires a historical analysis of how the moral principles of hospice developed and how their relationship to scarcity unfolded. Hospice was not envisioned as a way to positively moralize scarcity. The U.S. hospice movement developed in the early 1970s, when groups of idealist clinicians, who were critical of modern medicine’s approach to death and dying, sought to reform medical and cultural attitudes toward death and change how dying patients were cared for. Much of the clinical knowledge was brought from Europe, most notably from the experience of London’s St. Christopher’s Hospice—the first modern hospice facility, which opened in 1967. At first, U.S. hospices developed as a volunteer-based grassroots social movement; starting in the 1980s, however, they gradually transformed into an industry. A key catalyst for this growth was the relatively low cost of treating patients in hospice: hospice pioneers’ progressive ideological motivations merged with attempts to control spending on patients nearing the end of their lives (Arney and Bergen 1984).

I divide the history of U.S. hospices into three periods: the period of cultural critique and the hospice pioneers (1950s to 1970s), the social movement period (1970s), and the corporate period (since the early 1980s). In the first period, hospice pioneers hardly engaged economic issues. In the second period, different figures in the hospice movement adopted multiple—and at times contradictory—approaches to the economy of hospices, oscillating between “moral necessity” and “immorality” attitudes toward scarcity. In the third period, during the early 1980s, Medicare started reimbursing for hospice care, the corporatization of hospices began, and the hospice market developed. It was in this period that hospices laid the foundations for the positive moralization of scarcity.

**1950s to 1970s: Intellectual Origins of the U.S. Hospice Movement**

The social organization of death in modern societies presents an interesting paradox: although medicine assumed responsibility for managing the dying body, it remained fixated on prolonging life and hardly addressed death itself (Arney and Bergen 1984). For most of the twentieth century, little scholarly attention was dedicated to death, which many characterized as a cultural taboo (Faunce and Fulton 1958; Feifel 1959). Starting in the late 1950s, however, this taboo was challenged and developed into criticism of modern attitudes toward death (Steinfels 1974).
“For thousands of years, man has been the sovereign master of his death and the circumstances attending it. Today he no longer is” (Ariès 1974:9). In Western modernity, Ariès (1981:105) argued, death was “pushed out of the world of familiar things”; it was denied, hidden, and veiled. From a quintessential social occurrence—involving the dying person’s family, friends, and at times complete strangers—death transformed into a secret and secluded event, taking place in the medical sphere, far from the public gaze. Once an integral part of life, death became life’s antonym (Elias 1985).

Broadly characterized as “death denial,” this cultural pattern was thoroughly documented in U.S. health care. Reflecting on her groundbreaking study, Kübler-Ross (1969), one of the founding mothers of the U.S. hospice movement, noted how hostile clinicians were to the idea of studying death and dying. Similarly, Glaser and Strauss (1965) tackled death denial systematically by classifying four types of “awareness contexts” in hospitals. These contexts varied in patients’, families’, and clinicians’ awareness of death, as well as in their awareness of each other’s awareness. These accounts and others strikingly exposed the consequences of death denial: trapped in games of pretension, the terminally ill, their families, and the medical staff were unable to communicate, accept, or prepare for death.

The impact of this literature went beyond academic circles: its critique of modern Western attitudes toward death was a self-conscious effort to undermine these attitudes (Koff 1980:7). Hospices were connected to this effort: they aspired to challenge the denial of death, the consequent social isolation of the terminally ill, and the view of death as a medical failure. Hospices aimed to minimize the suffering of patients who lost hope of being cured and to save them from unnecessarily lengthy and aggressive treatment. As an alternative to conventional medicine, hospices offered specialized care for the dying: palliative, holistic care that simultaneously addressed patients’ physical, psychological, spiritual, and social needs (Hamilton and Reid 1980; Kübler-Ross 1969; Munley 1983).

Hospice ideology comprised two interrelated agendas: a medical and a sociocultural agenda. The medical hospice agenda concerned palliative care, focusing on symptom management and pain relief. Hospices challenged conventional medicine’s fixation on prolonging life and emphasized improving life’s quality rather than extending life’s length. Such treatment, it was argued, could only be given by treating death as a natural phase in life and acknowledging—rather than denying—the condition of dying patients. Herein lay the second, sociocultural hospice agenda: patients should be given the opportunity to accept their imminent death. Instead of fighting aggressively to seek a cure until the end, clinicians should help patients “let go,” support them through the process, and allow them to die comfortably and with dignity.

These two agendas of the hospice movement revolutionized the management of death and dying in U.S. health care. However, while hospices shared clear views about the virtues of accepting death and the importance of reforming the medical management of the dying body, they did not share an explicit vision about how hospices should manage themselves economically or about the general impact they should have on the U.S. health care economy.

This can partly be explained by the fact that during this period, health care spending did not constitute the problem it evolved into in the following decades; authors who wrote about health care were therefore less likely to address economic concerns. Furthermore, medical ethics has historically divorced itself from economic questions and “had little to say about broad questions of healthcare financing” (Zussman 1992:10). It is therefore unsurprising that an ethically dense field such as hospice care disengaged itself from finance.

1970s: Scarcity within Hospices—Between Moral Necessity and Immorality

The first U.S. hospice was incorporated in 1971 in Connecticut. Until the early 1980s, hospices were small, grassroots, volunteer-based organizations with few sources of
income. In a 1979 Comptroller General report, only two out of nineteen hospices that reported on their finances had income from Medicare, and only three were paid by private insurers and self-paying patients (Comptroller General 1979). The overwhelming majority of hospices relied on combinations of grants, donations, and volunteer work, with one hospice reporting annual operating expenses of $17,202 that were used to serve as many as 171 patients.

Many hospices during this period operated under extremely limited budgets, due to the precariousness of grant and donation-based financing (Stoddard 1978:41). At the same time, lacking a shared economic vision, hospice leaders disagreed about how to address this problem: they advocated for various strategies, ranging from a complete rejection of any form of monetized exchange to full support for corporatization and integration of hospices into the health care market economy.

Some hospice advocates adopted a hostile worlds approach, which translated into a view of scarcity as a moral necessity. Reluctant to mingle hospices’ ideological mission with money and markets, they sought to eliminate any monetized exchange from the hospice economy. The Hospice of Marin, for example, decided at a very early point not to charge any fees for hospice care. Reasons for this included: (1) we hoped to be able to establish the practicality of hospice home care without having to focus on reimbursement; (2) we were concerned that if we developed a billing program along conventional lines, hospice care might not be seen as a unique addition to the medical care delivery system. (Lamers 1978:54–55)

In a similar vein, McNulty and Holderby (1983:166) stressed that “community based, all volunteer programs . . . provide, perhaps, the purest form of hospice care.” Many advocates claimed that the economics of hospices should be restricted to donations and grants; and, as reflected in the 1979 Comptroller General report on hospices, this was the policy many hospices embraced (Comptroller General 1979). From this point of view, scarcity was a necessary result of an inherent incommensurability between morally laden hospice work and monetary value, even when commensurating the two could provide hospices with additional resources.

Yet this approach was not the consensus. Many hospice advocates propagated a more pragmatic stance that would expand this scarce economy: they presented hospices as adaptable to what they called the “mainstream of medicine” (Koff 1980:172; McCabe 1982). Wentzel (1981) claimed hospices should use federal and private insurance funding, and Cohen (1979) and Dubois (1980) listed multiple financial resources, both public and private, on which hospice economics should rely. Some advocates even suggested that hospices should become for-profit organizations:

> A financial management consultant, speaking recently at the Third National Hospice Conference . . . startled his audience with the comment that “now, the trouble with hospice people is that they think non-profit.”

This observation is consistent with the comments of other experts, who know that there is no such thing as a free service. Any health care must have a source of support. (Koff 1980:144)

These advocates presented the hospice movement’s volunteer and donation-based gift economy as a fetter. Rather than a moral necessity, they presented scarcity within hospices as a negative and immoral burden that should be eliminated. The solution to this scarcity within hospices was found in hospices’ ability to address a greater problem of scarcity that growth in health care spending was starting to create.

1980s: TEFRA and the U.S. Hospice Market

In the late 1970s, hospices started presenting their services as cheaper than those of conventional medicine. Kübler-Ross was quoted as saying that “when terminal patients are treated in hospitals, costs can run about $300 per day, but at home, using the Brompton...
cocktail for pain control, medication materials costs ran about 80 cents per week!” (quoted in Cohen 1979:85). Wentzel (1981:106–107) stressed that “it is the strong contention of its proponents that hospice support can appreciably lower the cost of dying in America.” Several reports were invited and written to determine whether hospices were indeed cheaper than hospitals, bringing mixed results (Brooks and Smyth-Staruch 1983; Comptroller General 1979; Hospice Project Task Force 1980). Even without conclusive evidence, hospice advocates argued for their cost-effectiveness in all of the congressional hearings on the topic (e.g., United States Congress 1982, 1983).

During the early 1980s, when the Reagan administration sought to cut spending on health care (Rodwin 2011), hospices’ attempts to access state funds proved successful (Mor and Masterson-Allen 1987; Timmermans 1999). In 1982, Congress approved Medicare coverage for hospice with strong bipartisan support: 242 representatives and 68 senators co-sponsored the original bill, which was later added to the 1982 Tax Equity and Fiscal Responsibility Act (1982, henceforth TEFRA). To ensure cost saving, TEFRA capped hospice reimbursement at 40 percent of the average expenditure on cancer patients, who were the main target population of hospice. When the Department of Health and Human Services tried to decrease the cap, representatives claimed it would discourage patients from choosing hospice and thus increase total spending on health care. Spending more on hospice, they insisted, would mean spending less overall (United States Congress 1983).

TEFRA funneled substantial amounts of money into hospices; health care corporations, which identified an economic opportunity, started acquiring hospice agencies, prompting the corporatization of U.S. hospices. Since TEFRA passed, the number of Medicare hospice patients has grown at an annual rate of 10 to 20 percent (Christakis and Escarce 1996). Apart from a short intermission during the late 1990s, this was also true for the number of Medicare-certified hospices (see Figure 1). With a stabilizing regulatory framework and an increasing number of actors (Fligstein 2001), the hospice market was gradually established.

The development of the hospice care market shifted the primary source of scarcity within hospices. Scarcity no longer derived from a moral necessity—that is, an outcome of hospices’ reliance on donations and volunteers. In a corporatized economy, in which workers are salaried and hospice care is a commodity paid for with money, the degree of scarcity within organizations is determined by corporate administrative decisions and insurers’ reimbursement levels. Hospices also have a role in attempts to address the impending problem of scarcity in the U.S. health care system: increasing utilization of hospice care replaces more expensive hospital care.

The following sections rely on ethnographic data to provide an in-depth view of the moralization of the looming scarcity in the U.S. health care system and the moralization of budgetary scarcity within Nubis. The empirical discussion focuses on two key end-of-life decisions: (1) the decision to terminate curative care and transfer patients to hospice, and (2) the decision about the extent of care given to patients while in hospice.

**FIRST DECISION: TRANSFERRING TO HOSPICE**

The decision to transfer patients from hospital to hospice care is extremely difficult, as it involves acknowledging one’s approaching death (Harrington and Smith 2008). As one of Nubis’s social workers told me, “Sometimes I feel at the end of [an admission] visit that I [have just] punched somebody in the stomach. Just in the course of having to talk about those things, they have to realize. . . . Well, this is not just home care.”

Such “punches” are embedded in hospitals’ economic interest to reduce patients’ length of stay (Pantilat et al. 2007), hospices’ interest to remain financially solvent, and insurers’ interest to lower their expenses. This
section explains why workers at Nubis consider this economy and the scarcity that it embodies to be a moral one. I begin by outlining the incentive system of hospice care and then discuss how these incentives relate to scarcity, how the market for hospice care operates, and how it interacts with hospice ethics.

**Economies of Dying: The Economics of Hospice Admission**

Since its enactment in 1982, TEFRA has remained the most central piece of U.S. hospice legislation. First, TEFRA’s reimbursement system structures hospices’ incentives and thus affects their economic agency. Second, TEFRA determines the criteria that define the scope of hospice care. It states that (1) Medicare pays only for patients with a prognosis of six months or less to live if their disease runs its normal course, and (2) hospice care includes only palliative care and is given in lieu of curative and life-sustaining treatments (Werth and Blevins 2002).

TEFRA’s reimbursement system was modeled after Medicare’s reimbursement system for nursing homes and home health services: Medicare pays hospices a lump-sum for every day they serve every patient, regardless of the services actually provided (Buntin and Huskamp 2002). When the daily expenditure on treatment exceeds this lump-sum, hospices absorb the loss; when it is lower, hospices extract a surplus.5

Operating under this funding mechanism, there are two main ways Nubis’s management can increase its surplus. First, it can increase the number of patients it serves and raise the surplus through an economies of scale strategy. In other words, it can use the same staff and resources to provide care to a larger number of patients:

Ann [the volunteer coordinator] tells me . . . that things have been hectic recently. [She says] it’s because . . . we’re admitting many new patients. I ask her why. . . . She says that we’ve been in the red for a long time, and now we are trying to get out of there. I ask her what counts as being in the red; she answers that it’s when there aren’t enough patients in the hospice. . . . “We can’t stay there for long periods.”

Tony, the hospice aides’ scheduler] looks very tired . . . says she’s been working very hard lately. She shows me the hospice census, which now includes 138 patients. This is a huge difference from the number Ann
With a short length of stay (solid black line marks Nubis’s daily expenditure)

With a longer length of stay

**Figure 2.** How *Economies of Dying* Strategies Are Practiced
*Sources:* Interviews with Nubis Hospice’s manager; Centers for Medicare and Medicaid Services 2012.

mentioned a couple of weeks ago, which was somewhere around the 80s. Tony says work has been very intense lately “coz my girls are fully booked.” (field notes, October 24, 2008)

Another strategy Nubis’s management uses to increase its revenue is what I call *economies of dying,* namely, extending patients’ length of stay in hospice. Most of the expenses for hospice patients are incurred in the first and last days of service. The first days following admission to hospice usually involve much work: equipment and medications are transferred to the newly admitted patient’s house; nurses, social workers, and chaplains visit the patient for evaluation; and a comprehensive care plan is formulated for the patient.

In most cases, work during the last days before a patient’s death is also intensive and expensive. Family crises and medical complications require more frequent visits. Consequently, Nubis does not profit from the first and last days of service: surplus is produced only in the middle period between them (see Figure 2).

Nubis’s management therefore tries to extend the average period its patients are on service. This is not easy:
Patients usually arrive here in the last stages of their illness, because their families don’t want to accept the fact that they are going to die. It is hard psychologically and this is what makes people’s stay in hospice too short and what causes us problems. (office worker, field notes, September 12, 2008)

Hospices are legally forbidden to be selective in their admission processes, and Nubis does not reject patients on the grounds that their life expectancy is too short to be profitable; instead, Nubis’s management tries to admit all patients earlier. This is done in several ways. First, investment in education and marketing:

It’s a matter of education, explaining to people that hospice is not such a bad thing. We’re trying to advertise ourselves; . . . we employ a marketing woman who goes to talk to doctors in their clinics and explains to them the services that we give, so that they are not afraid of sending patients to the hospice. (office worker, field notes, September 12, 2008)

Second, Nubis expedites the admission process by placing hospice nurses—hospice liaisons—in local hospitals. Hospice liaisons spend most of their time in the hospital, holding informational meetings with patients and families who are expected to be referred to hospice or who already have a referral. Liaisons make the admission process faster (which allows Nubis to bill for additional days of service) and give Nubis a competitive advantage over other hospices.

Admission, Competition, and Cost Saving

When hospital patients are referred to hospice, hospices begin to compete over the right to admit them. Hospice regulations require that patients who accept hospice referral are given the opportunity to choose a provider. In reality, however, most people do not know any of the hospice providers in their area. Still overwhelmed by the grim medical prognosis, they and their surrogate decision makers are often too shocked and confused to make their own choice (Kaufman 2005); many ask the hospital nurse to pick a provider for them, or simply choose the first name on the list.

The presence of hospice liaisons in hospitals is therefore extremely significant. A good liaison can develop personal relationships with hospital nurses, patients, and families. Unlike hospital nurses, who are often overworked and tired, hospice liaisons have much time. Even on their most intensive days, they usually do not hold more than five informational meetings, and there are days when they do not have any meetings at all. In some cases, the hospice liaison is the most available person on the hospital floor. The liaison has time to chat with patients and families, explain about hospice, and walk them through the difficult process of accepting a terminal diagnosis and forgoing curative care. In addition, liaisons often have the time to help hospital case-managers handle the paperwork of discharging patients and transferring them to hospice:

It’s competition. . . . Hospital [case-managers] doing the work to get people out are so overwhelmed and busy that if you say “oh, just call us, we’ll do it”—that’s who’s gonna get the referrals. (hospice liaison, interview)

Patients are more likely to choose Nubis after spending a few hours with an attentive and trustworthy liaison. Hospital staff are more likely to refer indifferent patients to Nubis when they know that Nubis’s liaison will help with the paperwork, or when they feel they owe the liaison a favor after having received help in the past:

The [hospital] case-manager is supposed to say, here’s a list of different hospices, . . . tell me which one you want. . . . [But] it all comes down to relationships, right? They know me, or they know one of the other people, they like us, they know that we do good work, whatever, we get along well. . . . So I think sometimes they don’t go out of
their way to say “here’s a big long list,” they say, “how about if I send someone from Nubis over to see you?” (hospice liaison, interview)

Besides the networks that develop among liaisons, hospital staff, patients, and families, there are also institutional relationships between Nubis and some hospitals. Aiming to increase the number of patients it serves, Nubis’s management cooperates with local hospitals that are owned by the same corporation that owns Nubis. Although these hospitals must allow patients to choose their hospice care provider, they can put Nubis at the top of the providers’ list given to families and patients, print “Nubis Hospice” on the list in bold letters, and refer patients who have no preference to Nubis. When local hospitals owned by this corporation started using these methods, the number of patients they referred to Nubis increased.

This cooperation is related to a perceived common economic interest that hospices and hospitals have. The per diem system that Medicare and other insurers use to pay hospices is different from the Diagnosis-Related Groups (DRGs) system that Medicare has used in hospitals since the early 1980s. Under DRGs, hospitals are paid per diagnosis: insurers provide them with the amount of money designated for the patient’s diagnosis, calculated based on the average length of hospitalization of patients with a similar diagnosis. If a hospital spends more than this amount, it has to absorb the loss. DRGs set a state of scarcity within hospitals, and many hospital administrations interpret their financial interest as discharging patients early to hospice to reduce their costs (Pantilat et al. 2007). Hospices, in contrast, have incentive to admit patients early, because under TEFRA, they are paid per diem: earlier admission of patients provides hospices with more resources. As one of Nubis’s managers explained:

Hospitals lose money on every Medicare patient. Hospice[s] . . . make money on every Medicare patient. That’s a match [made] in heaven—isn’t it? We take the patients, we take care of them, we survive, and the hospitals survive, and we provide good care without losing money! It’s like nirvana!” (manager, interview)

This economic cooperation is not the driving logic of hospice admissions. All the hospice workers I talked to mentioned that some people “aren’t ready” for hospice and emphasized that they would never try to admit them to hospice prematurely. Still, the institutional relationships between Nubis and hospitals led to more hospice admissions on the aggregate level. The effort to limit health care spending, which was the driving logic of TEFRA, indeed led to increased hospice utilization.7

Scarcity and the Hospice Ethic

This economy of end-of-life care involves the financial interests of multiple market actors. Nubis’s workers are aware of these interests and play an active role in pursuing them: in practice, they promote earlier diagnoses of people as “dying” than is done in conventional medical care.8 Yet workers do not consider this an ethical problem, because economization and the hospice ethic prescribe similar professional practices: admitting hospice patients early. Because the financial imperative and the hospice ethic correlate, Nubis’s workers, although not primarily motivated by pecuniary interests, address financial interests as they pursue ethical ends.

Nubis’s workers are acquainted with the hospice movement’s critique of conventional medicine, and they identify with it. In many conversations I had with workers, they presented themselves as facing the challenges and fighting the battles that hospice pioneers fought in the 1970s. Several clinicians who had worked in hospitals and clinics told me about their unease with conventional medical practices, which eventually made them move to hospice care:

I worked in this one [hospital] unit, we had people there that actually ended up being on
ventilators . . . for over a year, . . . and a lot of them were never even spoken to about hospice or end-of-life issues. So I started to develop a kind of an attitude and feelings about why are we doing a pacemaker in a 102-year-old person? You know, these kinds of issues started to crop up at work nightly. . . . It didn’t feel good too; I wasn’t really sure what kind of care I was providing at that point. (nurse, interview)

During a nurse training session I attended, a senior nurse described Nubis as fighting overly ambitious hospital doctors who refuse to acknowledge that some of their patients are terminal and thus continue unnecessary and painful treatments that cause much suffering:

“We realized that some patients manage to get only three or four days of hospice care before they die,” she says, “which is way too little, because usually you can know that the chances that the treatment will help them are very, very low.” The nurses nod in agreement.

“Sometimes oncologists are so ambitious,” she continues, “that they give up only a few days before the patient dies.” She says that they . . . have to make families and patients aware that there is an alternative option—hospice care—which provides palliative care and helps people die at home with dignity and relatively less pain. (field notes, September 29, 2008)

Hospice workers are therefore morally motivated to transfer patients from hospitals to hospice care earlier than is typically done. Earlier admission to hospice, they believe, can save patients from painful, aggressive treatment that has little chance to succeed. At the same time, early hospice admission is also lucrative for hospices, hospitals, and Medicare:

Hospice services are way less costly for Medicare than hospitals, so [Medicare] doesn’t want hospitals used, just from a financial perspective. And most patients feel like they’re gonna get better treatment at home . . . so we can provide better treatment in a place a patient would rather be for cheaper. For me, maybe this would even shine more light on [the] hospice benefit. You know? Not just the patient, but society as a whole. (social worker, interview)

Earlier transfer to hospice can also provide patients with more time to prepare for death and increases the chances the dying experience will be emotionally and existentially meaningful:

Getting [patients] on [hospice] as early as possible has a financial benefit, but it also has benefit for the patient and family. The more time they’re on hospice, the better they do; the shorter time they’re on can be much harder. If it’s been all of a sudden, and it’s just a new diagnosis and three days later they’re dead. . . . People never have time to . . . it’s more like the kind of sudden death experience, which is not the model for hospice. (hospice liaison, interview)

The hospice ethic therefore converges with Nubis’s financial interests, hospitals’ financial interests, and the overall effort to reduce spending on end-of-life care. Policymakers aim to control spending and create incentives for hospitals to transfer patients to hospice early. Hospitals operating under this incentive system generally aim to discharge patients early. Hospices such as Nubis try to increase their revenue by admitting as many patients as possible for the longest periods possible. In pursuit of its financial interests, Nubis’s management acts strategically, cooperates with hospitals whose economic interest is to discharge patients, and sends liaisons to network in hospitals and gain an advantage over competing hospices. The hospice ethic prescribes similar practices: patients’ well-being is achieved by saving them from invasive care in hospitals (Kapo et al. 2005; Rossman 1977). This is one underpinning of the positive moralization of scarcity by hospices.
SECOND DECISION: HOW MUCH SHOULD BE SPENT ON HOSPICE PATIENTS?

Care and Scarcity inside the Hospice

Perhaps the most contentious effect of scarcity on caregiving begins after admission to hospice. Nubis’s administration strives to limit its average spending on patients to the amount of money covered by insurance policies. For example, if Medicare pays Nubis $210 per day for each patient, Nubis aims to keep its average expenditure per patient below the $210 level.

In principle, hospice care is cheaper than conventional care, because it replaces invasive life-extending interventions with less costly comfort care. In practice, however, interpretation of what is considered comfort care is rather flexible and may include highly expensive interventions. Blood transfusions for leukemia, for example, can be interpreted as both curative (they slow the progress of the disease) and palliative (they make patients feel better). Radiotherapy, which is usually considered curative, can also be defined as palliative when used for certain kinds of bone cancer. Even chemotherapy, seemingly a quintessential curative treatment, can be defined as palliative, as it can reduce the pain a tumor causes by shrinking its size.

Whether such treatments benefit hospice patients and whether they are consistent with hospice care—that is, they provide comfort as opposed to life-extending care—is widely discussed (Albrecht et al. 2013; Prommer 2004; Reinbolt et al. 2005). In addition, this blurred boundary between curative and palliative treatments poses serious financial challenges to hospices. Such “boundary treatments” are costly and often involve travel to a clinic and, in some cases, hospitalization. Legally, Nubis is allowed to provide patients with many of these services; economically, however, its administration is reluctant to pay for them. Conflicts around this issue occur between patients’ families and Nubis’s workers regularly:

I had a patient, a really lovely lady. . . . She had leukemia. And, you know, . . . the transfusions weren’t really helping, . . . so she came on hospice. Well, we had a little bit of ups and downs, and then at one point she got very [tired] and the [husband] was very angry, saying “if you just give her the transfusion she’ll feel better.” So we did a lot of debate and I even called [the manager, who] said, well, she hasn’t had one for a while and if she wants one hospice will pay—we’ll say it’s a comfort measure at this point. But we can’t do this every week! So we did [one] transfusion. She felt a lot better. (nurse, interview)

Nubis’s general policy is not to approve such treatments, especially when they are needed for long periods. Nubis has an official formulary, a common way to control spending (Ubel 2000), that determines which medications are included in its services. This policy applies to all medical care provided at Nubis, including treatment of simple infections:

Generally speaking, we don’t treat patients with antibiotics. And if you keep getting pneumonia, because you’re swallowing the wrong way, it could be treated with antibiotics. If you keep getting UTIs, it could be treated by antibiotics. But if this keeps happening over and over, and the patient’s getting weaker and weaker, and the quality of his life is getting worse and worse, . . . hospice would say, “no, we’re not gonna pay for it.” (social worker, interview)

During admission, Nubis’s nurses check the medications admitted patients take regularly and see if they can take patients off the expensive ones that are not included in Nubis’s formulary. When an admitting nurse fails to remove an expensive non-formulary medication from a patient’s care plan, one of the hospice physicians or nurse-supervisors usually asks why this medication is still being used. In most cases, the medication is removed from the patient’s care plan and replaced with a cheaper medication from the formulary.
Many patients admitted to hospice have had long, challenging, and painful struggles with their illness, and some patients get used to certain medications and oppose any change in their prescriptions:

There’s . . . a drug for nausea—Zofran. Zofran, if you’ve been on chemo and nothing else works—Zofran works. But, according to [our medical director], once you come off chemo, Zofran doesn’t work as well. But, you try and tell that to a patient who has only had success with Zofran and has lived with nausea and vomiting! They don’t want anything else! They only want the Zofran, and it’s very expensive. (nurse, interview)

Nubis’s management thus directs workers to limit the care they provide. Meeting patients on a daily basis, workers have an unmediated experience of the effect this has on patients’ lives. What are the moral underpinnings of these practices? In the following sections, I point to two underpinnings: first, Nubis’s solvency and ability to provide hospice care depend on limiting care and spending; second, I show that budgetary constraints acquire a moral meaning that resonates with hospice ideology.

Solvency and Boundary Treatments

One important characteristic of the U.S. health care system is that health care providers function as individual business units that must keep their budgets balanced to stay afloat. Organizations that lose money are forced to cut back on their services and, at times, shut down (cf. Kornai 1980).

From the point of view of a care worker who sees her work as a moral calling, the economic success of the organization where she works is essential for the care she gives. While budgetary scarcity within an organization is viewed as an objective constraint, it is not morally neutral. Nubis’s management, in particular, presents scarcity as a moralized constraint: the organization needs to meet the constraints of scarcity to continue serving the dying. This is how a nurse training instructor explained the need to reduce Nubis’s expenses:

Look, we all want to keep our jobs, so we have to think about expenses [nurses nod]. There’s a simple rule: Morphine—cheap! [laughter] Methadone—even cheaper! Oxy-codone—not so good. Always try to go to Morphine [or Methadone]. (field notes, September 29, 2008)

In a staff meeting that dealt with cutting Nubis’s expenses, several workers said that some of the manager’s suggestions were inapplicable. The manager replied assertively:

We mustn’t end this meeting only with things we can’t do. We have to think about things we can do, otherwise we’ll end up like [another unit]. They told [the corporate management] “we can’t possibly function here,” and guess what? Soon there will be no [name of unit] anymore. So if you want that, then tell me all you can’t do and we’ll have that. But if you want to stay here, if you want the hospice to survive, then tell me what you can do. (field notes, July 22, 2009)

In a later interview with this manager, she told me,

You have to have money to stay in business, and I want to provide care to families. I think our service is one of the best services there is in the universe. We provide good care! Excellent care! . . . When I had that family just being so distressed, so upset . . . [I walked] in and that calmed them, because they knew they could do it. Just the little bit I was doing! And all the times I’ve gone into people’s homes and they [said], “oh, my God, I feel so much better, I feel like a burden has been relieved, lifted from my shoulders—I’ve heard that a million times.”

Workers sometimes become very emotional when they talk about Nubis’s financial
performance. In a luncheon dedicated to the hospice’s volunteers, a tearful Nubis volunteer coordinator spoke about the financial difficulties Nubis was facing. The altruistic realm of volunteering merged with details of Nubis’s economics; both were presented as meaningful parts of hospice work:

Ann gets back to the microphone and thanks us again, with tears in her eyes, for the last year. . . . This year wasn’t easy, she says, for quite long periods we were in the red. Our census dropped below 100 patients, and at some moments we had only 80 patients. . . . For a pretty long period we were losing money, and we should remember that even though we’re a non-profit, we are still a business. There were moments this year that we thought we would not be able to keep the hospice running and that the place would have to shut down. But now we managed to build back our patient population, cross the 100 patients, and the situation is a lot better. (field notes, April 25, 2009)

Workers speak about Nubis’s financial situation emotionally because they see it as a condition for providing care. The identification between limiting spending and the ability to fulfill the hospice ideology helps neutralize the possible tension between the two. In a health care system where hospices function as individual businesses, the alternative to conforming to the limits of scarcity is shutting down and not providing care. Hospices’ financial interests are therefore bound up with workers’ moral motivations.

Limiting Spending in the Pursuit of Hospice Principles

The second underpinning in the moralization of scarcity at Nubis is that workers rely on scarcity to pursue hospice principles. In particular, a repeating theme in the data is workers who describe limiting spending as a way to encourage patients to accept death, “let go,” and recognize the limits of what can be done to save a human life (cf. Callahan 1987). When I asked a Nubis physician if he felt Nubis’s financial considerations contradict the hospice ideology, he replied, “I would find it contradictory to pay for a lot more life-sustaining treatment inside hospice.” Similarly, in staff meetings, when patients or families were reported to be interested in boundary treatments such as palliative chemotherapy, they were often seen as denying death.

Boundary treatments were not rejected just on economic grounds; rejecting such treatments was also seen as a medical and ethical act. Economically, Nubis sought to reject expensive treatments. Medically and ethically, Nubis’s workers did not want to pay for treatments they felt signified death denial. Limiting spending was itself a way to acknowledge the limits of medicine and accept that death was approaching. By limiting spending, workers tried to help patients prepare for their death psychologically, emotionally, and spiritually:

It may sound a little paradoxical, but part of the spiritual aspect of hospice is that you talk about costs. People think “Money? Costs? How can that be spiritual?” But it is! Because, it’s forcing people to come down to earth and realistically confront what we can and can’t afford to do. And that automatically puts them into the spiritual realm, because it forces us to be real and to be present, and not to be off in some state of denial when we’re pretending . . . and we’re really not confronting what is here. (physician, interview)

More than just a method of budgetary austerity, Nubis’s workers use financial limits on care as a means to help patients and families face death. Here, capping spending is a form of psycho-social treatment, aimed at achieving some of the main goals of hospice care: establishing awareness and acceptance of death, helping patients and families prepare for death, and making death a meaningful experience. From this standpoint, providing patients with expensive medical care in hospice is contradictory. The hospice goal is to
give patients things beyond expensive interventions, and focusing on standard medical procedures interferes with this goal:

What hospice offers, is putting a time period around some things. . . . When you’re in hospice . . . that is the time for you to take care of [unfinished] business, . . . anything special you want to do, anybody you want to see, and it allows people to realize and take advantage of that. . . . If you’re not in that mode, if you’re in the mode of “let’s try some more therapy” or “let’s try some more chemo,” or let’s try this or let’s try this—you’re never in that period of looking at your life and reflecting on who is important to you. (social worker, interview)

Providing more medical care is ultimately seen as counter-productive (cf. Rossman 1977:205–208). A nurse who shared with me the personal story of her husband’s death illustrated this strikingly:

You know, my husband died several years ago. His last day was horrible. He just kept grabbing the side-rails and sitting up—“help, help!”—and I kept giving him everything, doing this, doing that, because I was so not present. Because I was not really present, I was . . . going “Oh, my God, what does he need? He needs this, he needs that!”—nothing. Nothing put him down. I gave him Morphine and Oxycodone. . . . I gave him a ton of stuff, . . . because he couldn’t let go. Finally, at two o’clock in the morning I realized what I was doing. I said “Oh my God, I haven’t released him.” And so I released him. I said, “It’s okay, I’m gonna be alright, you can go.” I said a bunch of stuff, but that was what I said. I said “I need [you] to just lay down, put your head down on the pillow and go to sleep, just let it happen. I’m gonna go right over here, lie in my bed. I’m right here if you need me, but let’s just both go to sleep.” He left. It was amazing. (nurse, interview)

In the hospice moral economy, providing much medical treatment, and expensive treatment in particular, is regarded as death denial. It is exactly by abandoning expensive medical procedures in the care for the dying that the most important elements in hospice care are realized: empathy, spirituality, compassion, and personal attachment. Scarcity is hence not an external financial limit imposed on morally driven care work—it is itself used in moral practices. Limiting spending is an existential statement that life is finite, people are mortal, and there is a limit to what can be done to extend life. By limiting spending, clinicians acknowledge the limits of human agency and invite patients to come to terms with their imminent death, to receive emotional and spiritual support, and to reach higher levels of personal connection. When spending less means caring, economic scarcity is valorized.

CONCLUSIONS

One of the cardinal ethical questions that modern medicine poses—when should we stop treating patients?—is tackled today as an economic question as well. The steady rise in health care spending confronts policymakers and health care providers with a problem of scarcity: a myriad of life-prolonging interventions curbed by finite financial resources available to pay for them. Hospices provide a moralized solution to this problem. The hospice ethic endows the dying process with new meanings and emphasizes the virtues of reaching acceptance and limiting treatment. Consequently, limiting spending near the end of life can be framed not only as morally acceptable, but also as morally virtuous. Limiting spending means helping people face their imminent death and avoiding prolonged aggressive treatment; in the context of hospice, it becomes a way of caring.

Historically, the hospice ethic has interacted with scarcity in various ways. In their theoretical form, hospice ideas were devoid of economic meaning; yet as ideas were applied and hospices grew in size and number, hospices had to confront the challenge of surviving financially. At first, the moral value
hospice advocates attributed to scarcity oscillated between “moral necessity” and “immorality.” In the late 1970s, however, the mainstream of hospice advocacy gravitated toward the immorality view, stressing that limiting hospices to a scarce volunteer-based economy was immoral and that opening hospices to markets was necessary. Through this transition, hospices also defined their position vis-à-vis the macro problem of scarcity that the U.S. health care system started confronting. Once hospices successfully contested the morality of aggressive medical interventions, refraining from spending money on such interventions could be framed as virtuous. This is the essence of the positive moralization of scarcity in U.S. hospice care.

The growth of U.S. hospice care owes much to its role in the effort to control health care spending. Yet as this article shows, the hospice ethic cannot be reduced to economic motivations: even if the hospice ethic legitimizes certain economic interests, hospice ideas are not post-hoc rationalizations of financial and political interests. First, hospice protagonists promoted radical views divorced from any economic interest, and they did so nearly two decades before hospices were industrialized and corporate interests in the area were formulated. Rather than being an economy that developed moral ideas to legitimize itself, hospice was a moral idea that developed an economy to sustain itself. Second, as the case of Nubis Hospice demonstrates, the pursuit of hospice ideology and care for the severely and terminally ill are the prime motivators of hospice clinicians. Limiting medical interventions is practiced out of conviction in their immorality. Moral and economic acts are inseparable parts of a single moral economy; typically, pursuing one is pursuing the other.

This elective affinity between the hospice ethic and spirited scarcity demonstrates a fourth pattern of moralized scarcity: positive scarcity, in which the finitude of resources acquires a positive moral meaning. Specific cases in which scarcity resonates with moral principles have been documented before. Heimer and Staffen’s (1995, 1998) study of neonatal units (NICUs) shows that scarce budgets may decrease the likelihood that NICU staff will completely marginalize parents whom staff members label as deviant. The high cost of hospitalization, and NICUs’ rigid budget constraints, lead NICU staff to depend on parents. Staff members are therefore likely to apply re-integrative rather than disintegrative sanctions on parents who behave “inappropriately,” and the impact of scarcity resonates with moral views on the sacredness of parental ties (Heimer and Staffen 1998:175). Similar to the juvenile court system, where the finitude of resources counterbalances oppressive apparatuses of social control (Emerson 1969:271–73), scarcity acquires its positive moral meaning from restraining morally disputed practices.

The case of hospices is particularly illustrative because of the moral indeterminacy that characterizes end-of-life care and the historical role that hospices have played in this area. The moral meaning of parenthood is fairly established, and NICUs have not played a significant historical role in redefining it. Hospices, on the other hand, developed in morally indefinite waters. As Weber (1946:144) famously observed, “whether life is worthwhile living and when—this question is not asked by medicine. Natural science gives us an answer to the question of what we must do if we wish to master life technically. It leaves quite aside . . . whether we should and do wish to master life technically and whether it ultimately makes sense to do so.” The hospice movement outlined a new morality of dying: it redefined what a “good death” means and consequently re-moralized scarcity around the end of life as positive.

This discussion of morality and scarcity sets the stage for further investigation of the moralization of quantities in economic life. As a counterbalance to economics, sociological discussions of morality in markets predominantly focus on analyzing economic qualities. Scholars have followed how people establish moral orders by earmarking special types of money (Zelizer 1994), consecrating commodities and gifts (Healy 2006; Zelizer 1978), and separating different categories of
social relations (Zelizer 2005)—all qualitative categorical distinctions between objects, means, and modes of economic exchange. Less attention has been given to the moral attributes of quantities, that is, the moralization of *how much* is spent, invested, or allocated toward certain moral ends. Discussion of the moralization of quantities could inspire reflections on myriad economic projects, ranging from progressive initiatives to restrain capital (cf. Wuthnow 1996) to conservative attempts to legitimize austerity.

The intensity of moral questions near the end of life, and their embeddedness in the effort to economize, reflects the profundity of moral economies that structure our intuitive sense of right and wrong, even at the hour of our death.

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**Notes**

1. I thank an *ASR* reviewer for helping me clarify this point.
2. Names and identifying details about the organization, its workers, and its patients were changed.
3. Nubis, for example, is owned by one of the biggest U.S. health care corporations, which has capital estimated at $8.5 billion. Although not able to pass profits to shareholders, this corporation’s profits exceeded $580 million in 2007.
4. There can be alternative interpretations of this decision from the perspective of hospices. For an account of how such decisions are made in hospitals, see Kaufman 2005.
5. The cap TEFRA sets on the total annual reimbursement it pays for hospice (Hospice Care Regulation: Title 42(IV) §418.309) is too high to form a significant constraint for the majority of hospices today (90 percent according to one estimate [Sack 2007]). Yet there is some concern among hospices that it could become a constraint in the future (Xanthopoulos 2007).
6. There can be alternative interpretations of this interest. Hospitals may try to discharge patients without hospice care and then readmit them under a new DRG. However, this strategy may be risky, because these patients’ hospitalizations could gradually become longer and more costly (Panttila et al. 2007). In 2012, Medicare began penalizing hospitals with high 30-day readmission rates, which further prompted hospitals to cooperate with hospices.

7. This article discusses this decision from the perspective of hospices. For an account of how such decisions are made in hospitals, see Kaufman 2005.
8. In 2009, the national average and median length of hospice service were 69 and 21.1 days, respectively (NHPCO 2011). Figures at Nubis were similar or slightly lower (see Figure S7 in the online supplement). In a 2009 sample of Medicare fee-for-service patients, 28.4 percent of patients who died in hospice used hospice for three days or less (Teno et al. 2013); 25.4 percent of Nubis’s patients stayed in hospice for five days or less.
9. Yet scarcity has the opposite moral value in other areas: lack of welfare budgets, for example, compromises parents’ ability to fulfill socially expected roles of parenting, particularly when their children are severely impaired and require much care (Heimer and Staffen 1998).

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Roi Livne is a PhD candidate in the Department of Sociology at the University of California-Berkeley. His dissertation analyzes the intersection between the moral predicaments of end-of-life care and the health care economy. He is currently writing on end-of-life decision-making in hospitals, drawing on an ethnography of palliative care clinicians. He is interested in theoretical discussions of morality in markets and seeks to apply them to contemporary U.S. health care politics.