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**DOI:**

[10.1016/j.socscimed.2020.113377](https://doi.org/10.1016/j.socscimed.2020.113377)

**Document Version**

Accepted author manuscript

[Link to publication record in Manchester Research Explorer](#)

**Citation for published version (APA):**

Henry, C. (2020). Palliative Space-Time: Expanding and Contracting Geographies of US Health Care. *Social Science & Medicine*, 268, 113377. [113377]. <https://doi.org/10.1016/j.socscimed.2020.113377>

**Published in:**

Social Science & Medicine

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## Palliative Space-Time: Expanding and Contracting Geographies of US Health Care

Accepted (Sept 2020) to *Social Science and Medicine*

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### Abstract

Two important changes are happening in health care in the US. As hospitals close in high numbers, the geographies of health care services are changing. Also, the ageing of the population brings about new and complex care needs. These are not discrete trends, as ageing impacts the who, what, and where of care needs, and hospital closures remakes the geographies of where people overall access care. Developed out of research on the impacts of hospital restructuring on workers, patients, and communities, this paper aims to understand how health care financing, care needs for the ageing, and new geographies of health services are intertwined. To do so, I look back to 1980s policy changes to Medicare, the federal health insurance program for the elderly and disabled. In 1982, Congress made two important changes to Medicare. The program began covering hospice services, constituting an expansion of care, and the government drastically changed the way it reimburses providers, effectively a contraction of the program. I trace the impacts of these changes over the next decades through analysis of media coverage and secondary research on hospital budgets. Drawing on the concept of palliative space-time, I identify a contradictory logic of death at the center of this expansion and contraction of the health care system. This death logic works to destabilize an already uneven geography of health service. Yet, this crisis has the potential for more just geographies of health and care.

**Key Words:** hospital closures; Medicare; death; health finance; health geography

### Highlights

- The ageing of the US population poses new challenges for caring for people as they age.
- Dozens of hospitals have closed across the US in the past decade, altering how and where people receive care.
- Palliative Space-time is concept for showing systems that struggle to exist but also have radical potential
- The concept is useful for analysing health systems, focusing on death, care, and potential alternatives in the health system.

## Introduction

Like many Global North countries, the US population over 65 is growing, as baby boomers age and Americans live longer lives, forcing attention to how societies can support thriving in old age. Individuals, governments, families, and institutions are considering new ways of meeting the care needs of elderly people throughout the last decades of their lives, including age-friendly cities, new collective living arrangements, new institutional forms of care, and an increased focus on home care especially (Poo 2015). As activist Ai-jen Poo (2015, 3) explains, ‘people getting older is not a crisis; it’s a blessing. We’re living longer; the question is how we should live.’

The demographic shift comes with a cultural shift around the end-of-life. This is visible through the growing popularity of the death positive movement and Caitlin Doughty’s ‘As a Mortician’ series (The Order of the Good Death n.d.), as well as countless books and podcasts exploring the meanings and practicalities of dying. Furthermore, COVID-19’s disproportionate impact on elderly and people vulnerable due to health conditions or the strains of systemic oppression, has heightened this conversation. People are asking what a ‘good death’ could be in a socio-economic system that is threatening to many lives and devalues entire demographics (Beech 2020; Fraser et al. 2020).

Simultaneously, the health care service landscape has changed dramatically since 2000. Hospitals have closed across the country, transforming health care labour markets, how and where people access health care services, and the role of health facilities in communities and the built environment (Buchmueller, Jacobson, and Wold 2006; Colliver 2015; Henry 2015; Alexander 2018). Overall, hospitals are concentrating within and to wealthier urban and suburban centers, meaning both rural and some urban populations are

quite far from a hospital. An excellent collaboration on the impacts of facility closures between the *Milwaukee Journal Sentinel* and *Pittsburgh Post-Gazette* on the impacts of facility closures found that ‘nearly two-thirds of the roughly 230 hospitals opened since 2000 are in wealthier, mostly suburban areas’ while the number of urban hospitals has been nearly halved since 1970 (Thomas 2014). Rural and disadvantaged communities are greatly impacted and left uncertain what health services will replace the shuttered facility (Tribble 2019).

Hospitals are closing for multiple reasons. Their role in the health system is changing, with more care shifting away from hospitals and towards outpatient and home care (Landers et al. 2016; Batra, Betts, and Davis 2019). More importantly, hospitals are increasingly financially unstable and unsustainable institutions (Goldsmith and Bajner 2017; Lovelace Jr 2018). Just as aging populations are not exclusive to the US, hospitals are unstable across the West. Canada and the UK are also downsizing hospital systems, even while wait times for care are high or increasing and aging populations are requiring more chronic care (Howlett and Morrow 2014; Ewbank, Thompson, and McKenna 2017). Every country’s health system is unique, but trends in financial stress, care deficits, and inequalities are strikingly consistent across the West.

Closures raise questions about the built environment when the health care landscape changes, because of the large size of hospital properties, the myriad services they house, and their historic role in urban development (Henry 2015; Day 2016). This is not to be romantic regarding hospitals but to highlight the importance of hospitals in the social reproduction of individuals, communities, and the health care system (Stevens 2007). It means thinking

beyond the impacts of a hospital closure on mortality rates (e.g., Joynt et al. 2015) to consider health and health spaces more holistically

This article posits that these two changes are not discrete, as health care is undergoing dramatic spatial and financial changes in the US. Thus, the driving question of this article is, what does the convergence of these two simultaneous trends in health care – the remaking of the health service landscape through hospital closures and the growing number of older people needing chronic and eventually end of life care – mean for the wellbeing of the entire health care system? How relational are these two trends? For answers, I turned to Medicare and Medicaid, the government-provided health insurance for, respectively, people over 65 and low-income people. Specifically, I examined the legislative history of Medicare to better understand the role of these programs in hospital financing. In the early 1980s both programs underwent their biggest changes since implementation. In the early 1980s, Congress passed the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) and the Social Security Amendments of 1983 (SSA). This legislation made hospice care become a covered service for the first time and the fee structure for reimbursing health care providers.

These two moments help explain the current transformations in US health care delivery. The closing of hospitals – the backbone of the health care system – and the ageing of the population are two intertwined trends, tied together through Medicare's financial structure. These policies of the 1980s are contradictory. While the hospice benefit expanded coverage, the new payment scheme reduced financial stability. The 1982 and 1983 changes to Medicare constituted an expansion and a contraction of Medicare and, arguably, the health care system. Together, they enacted a contradictory logic that is pervading the current health crises. More specifically, two different approaches to death – a care-full death for

individuals accessed through hospice and an abandonment (or the dying) of the health care system via financial destabilization. In turn, these legislative changes, while not the only factor, have helped facilitate the transformation in the health care landscape that is unfolding today.

To make sense of these legislative moves, I turn to feminist care ethics and Eric Cazdyn's (2012) concept of 'palliative time' – a state of existence that foregoes cure and marches towards, but does not always reach, death. I argue that with these structural changes to Medicare, death permeates the entire health care system but in different ways. The dying of a health system has radical potential to destroy the system and create something new. In sum, this article contributes to historicizing understandings of the current transformations in US health care needs and services, adding nuance to understandings of the shape and impacts of hospital closures, care needs, and demographic shifts.

This article draws on research from a broader project on the process and impacts of remaking of the hospital landscape in the US. I situate hospital closures and changing needs of an aging population in the historical context of health care funding. I use a textual analysis of media coverage in the 1980s from four major newspapers – *Wall Street Journal*, *New York Times*, *Washington Post*, and the *Los Angeles Times* – to trace debates about and impacts of these legislative changes. I chose these newspapers because of their wide readership, differing perspectives, and depth of coverage. Through LexisNexis, I searched for articles discussing Medicare and either hospice or prospective payment from 1980 to 1990, generating over 400 articles. I analyzed the articles in two ways. First, I used them to assemble a timeline of events. Second, I analyzed them for how different writers and actors characterized the needs – both financial and care – of Medicare and its relationship to the

health system more broadly. I paired this news analysis with a review of secondary literature (primarily from health economics and public health) focusing on studies done since 1982 on the impacts of the prospective payment system on hospital financing and the use and cost effectiveness of hospice.

In the next section, I turn to feminist care ethics and Eric Cazdyn's concept of palliative time, which I will later use to understand the implications of these legislative changes. Building on these literatures, I propose the concept of palliative space-time (PST) as a useful tool for understanding the contemporary state of health systems. Then, after outlining the two changes made in 1982 and 1983, I trace legacies of these changes in the decades since. Finally, I apply the idea of palliative space-time to these contradictory changes, to reveal a death-focused logic at work in US health care today and consider what alternative possibilities exist.

I focus primarily on changes made to Medicare, the federal program providing health insurance to the elderly, as well as some people with disabilities. When relevant I mention Medicaid, the joint state and federal program providing health insurance to the poor. While these are different programs, they are hardly discrete. Policy decisions around one often affect the other, and for patients, these programs sometimes work in tandem to ensure access to care (e.g., Medicaid, rather than Medicare, covers stays in nursing homes).

### **The Temporality and Spatiality of the Palliative**

In *The Already Dead*, Eric Cazdyn (2012) draws on his experiences managing chronic leukaemia to analyse medicine's increasing focus on maintenance over cure. This approach

prioritizes important life-maintaining care, Cazdyn argues, over lifesaving cures. He describes patients as stuck in palliative time: a time of persistent sickness, hanging on near death. He invokes palliative care, which is comfort care most often delivered when one is near death, to argue that people become trapped in the end-of-life care phase.

Importantly, this new temporality also describes a political economic condition: the maintenance of a sick and sickening system. Cazdyn pairs his critique of medicine with reflections on the impacts of globalization, arguing that globalized capitalism is a broken system, working well for the few and harming the many, that keeps a world lurching along, always near but never reaching death. He draws an analogy between economics and medicine that forces consideration of medicine's approach to chronic care in the political economic context of the health care system, as palliative time is a descriptor for patients as well as a global economic system.

Palliative time is not simply a temporal label. It is also an analytical tool that highlights the paradox at the center of the health care system: a near-death sphere of possibility, as Cazdyn calls it, referring to the possibility of something new and more just coming out of deadly and also frail system. On the one hand, being stuck in the palliative means forgoing cure. No longer searching for cures, the focus shifts to maintenance. People are expected to live with chronic illnesses both social and medical rather than searching for the end of those illnesses, be they through cure or death. Medicine resists death, viewing it as a failure rather than a part of life. For Cazdyn, living with sickness means living, but always near death. On the other hand, palliative and hospice care is an ideal practice of care. It is attentive to needs of both individuals and communities, treating death with respect, reverence, and care. It foregrounds the nuances that nursing brings to health care, rather than the colder, more

clinical approach of medicine. Hospice faces death directly, without losing complexity of human experiences and approaches to death. In death, hospice patients and their loved ones often access the best care they have ever received. Thus, palliative time captures a paradox in health care related to care and death, simultaneously holding two different, contradictory philosophies towards the end of life. The paradox describes a deadly system that also promotes, at times and in certain places, very care-full experiences of dying. These contradictory approaches to death offer different ways forward – one that maintains the deadly status quo and another, more progressive way that embraces death and dying as a meaningful part of life that deserves more attention.

Thus, this paradox sparks possibility, Cazden (2012, 46) argues, ‘with the radical time of the palliative released, moreover, new ways of caring for and investing in the present open.’ Drawing on palliative philosophies means adding in the perspective that death is part of human existence that needs attention and honoring. He continues, explaining ‘a radicalized palliative model that reconfigures the time of living and dying as well as the chronic and the terminal might turn out to be the most productive model for engaging the acute challenges of the present’. This approach asks for ‘new ways of caring for the dying that refuse to understand death as defeat or as an economically unproductive stage of life’, and these logics can be applied to other aspects of life, politics, and systems. Centering the paradox that palliative time reveals – that of embracing death to become free of a deadly system – puts death in a different light. It considers death in terms of living, thriving, and caring through the *entirety* of the life course, at the scale of the individual and collective.

Feminist interventions (e.g., Tronto and Fischer 1990; Atkinson, Lawson, and Wiles 2011) on care ethics are useful for adding clarity to the paradox of palliative time. Because of

his foregrounding of health care and invocation of palliative care, Cazdyn's concept of palliative time is an ethic of care. As Puig de la Bellacasa (2011, 100) explains, care 'is both a doing and ethico-political commitment that affects the way we produce knowledge about things...Care eschews easy categorization: a way of caring over here could kill over there. Caring is more about a transformative ethos than an ethical application'. Care is an ethico-political approach to living committed to transforming unjust social organizations of life. It presents a different epistemology of death, life, and care.

Importantly the act of care is an inherently spatial matter. As Mitchell, Marston, and Katz (2004, 417) explain, subjects are constituted both 'through time and in space'. This constitution is a care-full and social reproductive process, as 'how we live in space' is how we maintain and reproduce ourselves and communities (2004, 418). Massey's (2005, 10–11) explanation of space is helpful, arguing that space is a 'sphere of possibility' always in process. Taken together, space is a sphere of making, caring, reproducing, and creating new. Thus, a palliative temporality is also spatial; it can be called *palliative space-time* (PST). As an ethic of care is both an indictment of present inequalities and a call for a future in which people thrive and are cared for through the entire life course, PST similarly has this dual temporality. By centering possibility, palliative space-time is a tool for evaluating unequal access to the conditions for thriving, as well as offering a different way forward. It focuses attention on ways to better value care and body work, new intergenerational living arrangements, more accessible designs in the built environment, and different forms of institutional care. It also requires attention and correctives to oppressions that foster premature death and mean some people are not allowed to thrive or even reach old age. Each of these changes center an ethic of care in approaching space-making and design.

PST is, therefore, an analytic tool that foregrounds care, death, and futurity in analyses of health systems. It is a descriptor of the workings and implications of actions, systems, policies, and relations. It holds care and death at the centre of the analysis, in relation, tandem, *and* opposite to each other. Thus, PST could be used to understand the implications and workings of a health care system in financial dire straits, as I will show here. Or, one could use the concept to consider other aspects of globalised capitalism; after all, Ahmed (2014, no page) reminds us that ‘racial capitalism is a health system’. As a description of a state of existence, PST is a tool for shedding light on the unevenness of experiences and access to care, and the contradictions that have been built into the health system as it exists now. With the care-full principles of the palliative at its heart, PST centers a commitment to doing things differently in recognition of the failings of the status quo. This article explores legislation that has helped create those contradictions and fostered the increased unevenness, and I employ PST as a descriptor of the impacts of this legislation and a way to think through the near-death sphere of possibility of accessing health care under these conditions throughout the life course.

Applying a lens of PST reveals a complex relationship between care and death and decline at work at multiple scales. The qualities of PST are apparent at the national scale, shaping health care systems and access to care for the entire population through changes to the literal spaces that house provisions. Death and care operate in contradictory ways at the scale of the community, as hospitals – community anchors – close or shift meaning and role in regions, cities, and rural areas. Finally, PST describes the differential access to care individuals experience in life and in death.

PST is useful for understanding the implications of those two legislative changes of the early 1980s: the callous palliative state of the health care system, with the care-full service of hospice. While more money is invested in death care, the simultaneous restructuring of Medicare financing destabilizes an entire health care system. As a solution, Cazdyn (2012, 163) explains that ‘reclaiming our own deaths, not in a suicidal way, but in terms of our emotional and political consciousness regarding death and dying, therefore is tied to the reclaiming of utopia’. Facing death as an important part of life that needs care-full attention, systemically, can pave the way for a more just health system.

In sum, the health care system has shifted its orientation towards space and time, and this shift is rooted in a new approach to the life course and death. In tracing the impacts of these two changes in the rest of this article, I will show how these possible futures are animated by a dual logic of death. The legacies of 1982 and 1983 reveal health care system, both in its care-full and carelessness, working in palliative space-time.

### **Expanding Medicare: 1982**

The two legislative changes I examine here are contradictory. One expanded the services Medicare recipients had a right to receive, while the other was a change aimed at reigning in an out of control entitlement. The first change, in 1982, involved hospice care. Hospice provides comfort care to the terminally ill, generally wherever the person calls home, be that a house, a nursing home, or a hospital bed (NHPCO n.d.). Modern hospice began in the UK in the late 1940s, through the work of physician Dame Cicely Saunders, a nurse-turned-doctor who opened the first modern hospice, St Christopher’s in London in 1967 (Clark 1998). In the 1960s, American nurse Florence Wald, trained with Saunders, and

established the first hospice in the US in Branford, CT in 1974, providing both home hospice and inpatient care (Adams 2010). Over this same time, other hospice programs, largely volunteer-driven, began to appear across the country (Buck 2011; Freudenheim 1983).

Hospice is a philosophy of care that foregrounds the patient's goals and values. Saunders and other hospice pioneers' goal was for medicine and health care to approach death differently, as a part of life, not as a failure of a body or the medical profession, and to understand it holistically, involving mind, body, community, and family, and attending to a patient's 'total pain' (Clark 2007; Livne 2014). In hospice, the patient is more than themselves, because 'although death [is] a solitary event, hospice advocates insisted it must not be lonely' (Abel 2013, 169).

Congress first voted on adding hospice services to Medicare in 1974 (NHPCO n.d.; Buck 2011). Although the bill failed, in 1978 the Department of Health, Education, and Welfare declared that the federal government should support hospice because of its high quality care and potential for reducing health care costs. The Health Care Financing Administration then initiated a study of 26 hospices across the US to define hospice care and test cost effectiveness.

The Medicare Hospice Benefit passed as part of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA). As a three-year pilot program, TEFRA expanded coverage of hospice care for Medicare-certified facilities. Hospice providers could now receive reimbursements for services through Medicare, and patients with a prognosis of six months to live could now access hospice care when they ceased curative treatments. The bill's sponsors, Leon Panetta (D-California) and Willis D. Gradison (R-Ohio), argued for the benefit as humane, but also as cost-effective, seeing it as a solution to the supposed problem of

elder care (Buck 2011; Rich 1983c; 1983a). In 1986, Congress made coverage permanent and expanded hospice funding. The inclusion of hospice allowed Medicare patients to access expanded services and benefits, such as prescription drugs not usually covered under the program. Though most major insurance companies had some sort of hospice provision by 1982 (Torrens 1985), the inclusion of hospice in Medicare was a significant step in standardizing and legitimizing it as a way of care for those at the end of life (Quinn 1983). This enacted a new ethic of care by establishing hospice as an insurable service.

### **Contracting Medicare: 1983**

The second legislative change of the early 1980s constituted a contraction of the services, justified by the Reagan Administration claiming that Medicare could be bankrupt by 1990. When created in 1965, Medicare needed buy-in from physicians and hospitals in order to succeed. Partly to win support from a hostile medical establishment, the program's fee structure paid well. As Starr explained, the medical profession quickly learned '[Medicare] was a bonanza' (1982, 370). The federal government also 'agreed to rules for calculating [reimbursement] costs that were extremely favorable to the hospital industry' (1982, 375). For its first 18 years, Medicare reimbursed providers retrospectively for the actual cost of care according to a test of 'reasonable cost', meaning Medicare and Medicaid paid hospitals very well (Guterman and Dobson 1986; Stevens and Stevens 2007, 124).

Welfare programs have always first served the worthy poor, a population seen by state and society as worthy of assistance, compared to other populations deemed lazy or otherwise unsympathetic, generally according to racialized and gendered norms (Garland 2014; Piven and Cloward 1993). Central to this categorizing, Piven and Cloward explain, is

welfare's role in encouraging people into the workforce as the market demands through denials or granting of benefits, plus the role of employer-provided health insurance (Thomasson 2002). Medicare and Medicaid are major parts of the welfare state apparatus. They provide patients with vital access to care and funnel financial support to providers through reimbursements. They also operate like other welfare programs: providing (selective) support while disciplining recipients. Developed out of decades-long struggles over national health coverage, legislators designed these programs for uneven access (Starr 1982; Stevens and Stevens 2007; Quadagno 2004). By the 1960s, 'the aged could be presumed both needy and deserving, and the contributory nature of Social Security gave the entire program legitimacy' (Starr 1982, 368). For Medicare and Medicaid, this includes certain poor people, people who qualify as disabled, and retired people who already made their societal contributions through a lifetime of work or raising children/future workers. Therefore, while many welfare programs regulate people *into* the workforce, Medicare is a benefit for *after* the workforce. It is a universal program, granted after a lifetime of labor, with age as the only condition for qualifying, and no conditions for kicking one off the rolls.

This question of the worthiness of recipients is important in considering the threats to Medicare and Medicaid in the early 1980s. Over this first 15 years of the programs, health care costs grew not only from inflation, but at a rate beyond inflation (Pear 1982b; Schwartz 1982; Waldholz 1982; Merry and Schorr 1983). Some of this expense came from improvements in health care which includes more expensive procedures and equipment. Some of this increased expense, claimed health care economists and legislators, also came from a fee structure that did not encourage cost controls (for example, see coverage by Rich 1982). As Stevens and Stevens (2007, 117) argue, while Medicare grew into a widely

accepted program, Medicaid remained unable ‘to escape the debilitating effect of its welfare parentage’. The introduction of *prospective* payments for Medicare came after Reagan’s administration had already cut billions from America’s suite of welfare programs. While Medicare was and remains wildly popular (Norton, DiJulio, and Brodie 2015), the financial strain on the program made it into a potentially untenable luxury and justified it as a problem that needed solving.

As part of TEFRA, Congress implemented some ‘interim changes to the Medicare reimbursement system’ (Guterman and Dobson 1986) and tasked the Centers for Medicare and Medicaid Services (CMS) to develop a new payment scheme to replace the reimbursement system. By the end of 1982, the Department of Health and Human Services (HHS) outlined a prospective payment system (PPS) which came into effect with the Social Security Amendments of 1983. The PPS was meant to rein in costs and save Medicare from a predicted bankruptcy coming at the end of the decade. PPS ‘would reward hospitals for efficient delivery of care,’ rather than paying for what they have spent, according to Richard Schweiker, then Secretary of HHS (Pear 1982a). This was a decidedly different purpose for Medicare payments.

The new payment scheme created set amounts to reimburse providers for every health care product (services, inpatient stays, and physical products). Rather than billing for the cost incurred, the PPS set per-patient and per-day billing rates as well as a scheme for the reimbursement price for each service or product. Rates are set through calculations based on a standardized payment, the area’s wage index, and a diagnosis-related group (DRG) classification system, plus variations for urban and rural contexts and regional differences. Guterman and Dobson (1986, 99) identify an important characteristic of PPS: ‘each hospital

keeps, or loses, the difference between the payment rate and its cost for that unit of care.’ In other words, the program expected providers to pick up any slack. This is the same payment structure Medicare uses today.

### **Legacies of 1982 and 1983**

From the beginning these legislative programs contradicted each other, constituting an expansion and contraction in care. The months the federal government spent working out the details of the hospice benefits implementation reveal the challenges of expanding care access in an era overall hostile to public services. The hospice benefit proved contentious immediately after its passage. In the preparations for the hospice benefit, a dispute ensued between the members of Congress who sponsored the bill and Congressional Budget Office (CBO) over the rates at which providers were to be reimbursed. When passing the bill, the House Ways and Means Committee set a payment ceiling of \$7600 per patient (Rich 1983c). This figure was based on estimates lawmakers received for the average amount Medicare pays in the final six months of a person’s life. Medicare would pay hospice providers up to 40% of this average. When the CBO costed the program, it relied on a different figure and arrived at a different cap to the benefit payout – one over \$3500 lower than lawmakers’ cap. Over the following months, debates between Congress and representatives of the Reagan Administration in the HHS and Office of Management and Business (OMB) continued. The crux of this debate was whether or not – or if – hospice could save the government money. Stockman, head of the OMB, argued that claims that hospice would save money were misleading, as the program would actually cost the government hundreds of millions of dollars in its pilot phase (Rich 1983a), something that would be deeply unpopular given the

panic around health care costs (Pear 1982b). Lawmakers argued that lowering the rate was a violation of the agreement reached in the initial legislation and would cripple the program (Rich 1983c; 1983b). Ultimately, while HHS did set a lower rate than what lawmakers initially wanted, the final payout cap was much closer to the original figure through a series of compromises and amendments. These early months of the program demonstrate not only that the 1980s laws were contradictory, but also reveal the complex financial role of hospice and the trouble with the dominant ways of valuing health care. When health care is seen first and foremost as (too) expensive, the necessity of it takes a back seat.

From these rocky early days emerged a landmark program as ‘TEFRA has remained the most central piece of US hospice legislation’ (Livne 2014, 898), fueling the expansion and standardization of hospice services. After Congress made the hospice benefit permanent in 1986, funding was expanded in 1989 (NHPCO n.d.). By the mid 1990s when Clinton was attempting to reform health care, hospice was taken as an integral part of health care (NHPCO n.d.). Since TEFRA, hospice has become a more standardized set of services with clear criteria for when patients can or should access the care (Buck 2011; Livne 2014). For example, Carney et al (1989) found that, with the implementation of the Medicare Hospice Benefit, patients received more care from registered nurses, less care from volunteers and patients accessed care when they were sicker, which they credited to the six-month provision.

The standardization-via-Medicare took time. Uptake of certification was slow in the early years of the program, with only 20% of eligible hospices becoming certified (Buck 2011, s41). At TEFRA’s passage, hundreds of hospices were operating in the US but few received Medicare benefits; for facilities to qualify, ‘major reorganization will be necessary to conform

with the centralized administration required by the congressional act' (*Los Angeles Times* 1983). As *The Washington Post* reported, interviewing John J. Mahoney, president of the National Hospice Organization, 'some hospices say Medicare rates are too low to justify going through the difficult certification process. Others, he said are too small to justify the costs and trouble of certification,' and others were waiting to see if the program would exist after 1986 (Rich 1985; see also Buck 2011).

Over the 1980s, and especially after the program became permanent part of Medicare in 1986, more programs opted to become Medicare certified and funding increased (Davis 1988; Gilinsky 1988). The numbers of hospices both in general and Medicare-certified have grown at a rate of 10-20% each year since TEFRA (Livne 2014, 897–98). In 1985, hospice became reimbursable under Medicaid as well, and now, all states include the benefit (Kaiser Family Foundation 2019). By the mid 1990s, most commercial health insurance plans included coverage for hospice care (Buck 2011, s41). Annually, government spending on the Medicare Hospice benefit has grown 5-6% annually (MedPAC 2015, 325). As of 2016, Medicare has become the largest payer in the country, paying for 90% of hospice patient care days.

Hospice was attractive to lawmakers in 1982 for its potential to save Medicare money (Bayer 1983; Greenberg 1983). Cost effectiveness was based on patients staying at home, in de-institutionalized care (*The Washington Post* 1982). In general, however, the literature on the cost savings of hospice are mixed. According to the Medicare Payment Advisory Commission (2015, 327), beneficiaries can incur fewer costs in the last two months of life when on hospice. Yet studies from the past three decades offer a range of estimations regarding cost savings (e.g., Kidder 1992; O'Hare et al. 2018; Raphael, Ahrens, and Fowler

2001; Riley and Lubitz 2010). Smith et al's (2014) literature review of studies of palliative care in the Global North indicates that hospice care is generally cost-effective care. Medicare may find savings, at least, with some patients, depending on their diagnosis and when they opt for hospice care (Powers et al. 2015; Zuckerman, Stearns, and Sheingold 2016; MedPAC 2015). The *fact* of savings may be less important than the *belief* that hospice care is cost effective. As Livne's (2014) study of hospice in California shows, the belief in thrifty hospice agencies providing low-cost care is a powerful force shaping how providers care for patients and families.

Regardless of cost savings, hospice is of growing importance as the population ages. The blunt truth is that a lot of people will die in old age over the next few decades. This is, therefore, an important social and cultural moment in both ageing and the end stages of the life course, as a significant portion of the population ages and encounters the end stages of life, new questions emerge with urgency: what care is needed at the end of life? How can the system ensure access to such care? As hospice has grown over the past 30 years, more spaces have become palliative. Homes take on new caring roles, and new spaces specifically designated for palliative care open (Brown 2003; Turner et al. 2016). Legislative and financial support for hospice care opened up new possibilities spatially, temporally, politically and economically for relationships to death that foreground care and attention to death.

The prospective payment system reflects the other side of the palliative space-time paradox. Following 1983, the system expanded over the next two decades to cover physician fees as well as skilled nursing and long-term care facilities (*The Washington Post* 1989; Wodchis, Fries, and Hirth 2004). Nearly every state uses a prospective payment system for Medicaid reimbursements.

Recall that financial instability is the major driver behind hospital closures. Early on, PPS impacted hospital finances (Phillips 1984). In 1984, the first full year of the program, 18% of all hospitals saw a loss of revenue, while 44% of for-profit hospitals saw revenues increase (Guterman and Dobson 1986). This means that public and non-profit hospitals, which generally serve deprived communities, felt the impacts of PPS more. Facilities serving vulnerable populations became more vulnerable. Additionally, with PPS hospitals found it challenging ‘to pass along the costs of free care to the medically indigent’ (McLafferty 1986, 1080). By its own accounting, the federal government states that PPS was partially responsible for many rural hospital closures in the mid-1980s (CBO 1991). As well, facilities serving a high proportion of Medicare patients were more vulnerable to closure over the 1980s (Williams, Hadley, and Pettengill 1992). PPS is not the sole cause of closures, but it is an essential structural factor in their instability.

Most hospitals operating on break even budgets. Approximately one third operate on negative profit margins (AHA 2018). Hospitals are dependent on a fee structure that does not ensure financial stability. A hospital’s revenue comes predominantly from insurance reimbursements. But hospitals serve patients with a mix of insurance – private plans, government-provided insurance, and no coverage. Hospitals depend on having a payer mix that earns enough revenue to stay open and provide care to everyone. Privately insured patients are key to this, as their plans pay well.

A closer look at the breakdown of payments is instructive. Over 60% of all care hospitals provide is covered by Medicare and Medicaid Association (AHA 2019). While private insurers generally overpay at a rate of 144%, Medicare and Medicaid generally underpay by 10%, sometimes more (Cunningham et al. 2016). Medicare patients are both desirable (they

have reliable insurance) and undesirable (Medicare does not reimburse well enough).

Medicare is thus integral to a facility's survival but also risky. Then there are the patients who are uninsured and cannot pay for the care they receive. Though hospitals try (aggressively) to recoup those costs, they are left to eat the expenses. It is commonly assumed that hospitals cost shift shortfalls from other patients on to private insurers (Frakt 2011). Facilities facing financial shortfalls actually do not rely on cost shifting, but instead cut staffing and operating costs per patient (Hadley et al 1987; White and Wu 2014). As White and Wu (2014, 28) explain, 'over the long run, Medicare price cuts do not result in hospitals shifting costs to other payers or more profitable services; they instead constrain overall operations and resource use'. Without enough insurance reimbursements, and especially from private insurance, hospitals may not stay open. In addition, not only is a hospital's very existence at risk, but also, quality of care and labor conditions directly bear the brunt of the payment scheme's impacts of a facility's struggle to balance the budget. Spaces of care thus change or disappear.

PPS has implications for access to care that extend beyond hospitals, shaping access to care in multiple ways. For example, long-term care facilities often limit the number of Medicare and Medicaid patients they will accept, reserving more beds for people who can pay better through private and supplemental insurance (Mor et al. 2004; D. B. Smith et al. 2007). Medicaid, which uses a PPS, is the largest funder of long-term care, creating another fragility in the system providing care for older people and those with chronic health needs. Echoing Cazdyn, the health care system is stuck in palliative space-time. Applying the lens of PST shows a geography of PPS impacts as deadly to systems and spaces of care.

## Productive Contradictions: A Health Care System in Palliative Space-Time

In the wake of the legislative changes, the health care system is permeated by death and possibility. Hospice care is expanding, increasing access to comfort care for dying people and their families. The role of hospitals in the health care system is shifting, from improvements in care, pressures from insurance companies, and increased financial precarity.

Rather than stabilize Medicare, the PPS structure maintains the status quo of uneven and precarious access to services and an increasingly uneven geography of services. This continued with the Affordable Care Act, implemented in 2014: importantly, the program slowed the rise of health care costs and gave people greater access to health care through insurance regulations and expansions to Medicaid. Yet while hospitals saw net gains, especially in states that expanded Medicaid access, the Kaiser Family Foundation (Cunningham et al. 2016) has reported that hospitals expect changes to Medicaid policy and the high volume of Medicaid payments to actually offset some of those gains. Increased reliance on a system that reimburses poorly is not a prescription for good financial health. Instead, applying a PST lens, the system itself is dying but never allowed to die and not healthy enough to ensure sufficient care for all.

This deterioration takes on additional meaning as demographics change. With more people aging, more people will both qualify for Medicare and need more care. This means a growing number of Medicare patients accessing chronic and hospice care. The demographic and political economic contexts together brings connections between generations, spaces of care, and health care provisions into sharp relief. While hospice is not causing the closure of hospitals, these systems are far from separate, tied together through Medicare.

This interconnection is apparent when considering intergenerationality in the health care system. The 1980s have afterlives, creating a special relationship between the care of a select population and the care needs of the entire population. A logic of death and dying connect these two concerns. Because of the importance of Medicare to the financial wellbeing of hospitals, an entire system becomes dependent on a health care system for a single age group. There is an intergenerational dependence (society, health care facilities that everyone uses) on one group of people (seniors) because of their access to a specific program (Medicare). A program for some supports an entire system for all; Medicare has become the program keeping spaces of health care open *and* precarious. As the US population ages, the number of people over 65 – and beneficiaries of Medicare – is expected to reach 84 million by 2050 (Kaiser Family Foundation 2017). The financial implications of PPS and any changes to it will become even more important. While access to health care in the US has never been universally guaranteed, the death that pervades the health care system destabilizes the entire system. PST helps name the important expansion of care but also the structures that destabilize care for all, holding them together in the same frame.

Importantly, while the remaking of health care spaces threatens everyone's access – even those with private insurance – it is most acutely felt by those on the margins: people unable to drive great distances to the next nearest hospital, people without cars whose neighborhoods lack transit, people who suffer heart attacks and wait an hour for the ambulance to take them to the hospital an hour away, people already suffering in an anti-feminist, racist, and anti-poor system. The precarity of the system means premature death and logics of PST permeate the health care system. PPS makes life precarious until a person reaches 65, when they might have better access to good care at the end of life. The life

course, though, unfolds in myriad ways, and people access and need chronic and death care at all ages. Depending on a single demographic's program to support an entire system has significant implications beyond that demographic, especially when the general population that more care everywhere in an often-brutal socio-political economic system.

The reach of PPS is far, with the legislative changes of 1982 and 1983 working in tandem. As Livne (2014, 901) explains the different payment systems for hospital and hospice care incentivise a quicker move to end-of-life care. Time and space converge, holding different meaning for each service. Hospitals are paid per diagnosis under PPS, making a longer hospital stay potentially more costly for a facility (threatening self-sufficiency). Hospitals are incentivized to send people home as soon as possible, but also face steep penalties from Medicare for quick readmissions (Henry 2018). In contrast, hospices are also paid prospectively, but done so per diem, meaning a longer stay earns more money (increasing self-sufficiency). In other words, 'the hospice ethic therefore converges with [hospice's] financial interests, hospital's financial interests, and the overall effort to reduce spending on end-of-life care' (2014, 902) as the last year is typically the most expensive of a person's life. Death care is rewarded, while care at other times in life is rolled back and made precarious or harder to access.

PPS, as understood through PST, is a program that no longer cures ill in the health system, but maintains a fragile and sick system, with communities losing hospitals – anchors of services, economic activity, and built environment. Dying is, therefore, at the center of this remaking of health system, spatially, over the life course, and through death itself. Instability in the system through financial precarity leads to instability of health care spaces and

geographies; this in turn leads to greater instability in the health care system and loss of access to care, as what replaces hospitals is not always clear.

Importantly, the palliative is political, and placing death at the center of these politics is a contradictory move towards something new. The system is failing people, and as Cazdyn argues, addressing the manifestations of palliative space-time head on in a radical way means forcing a change; this might be risky, but the system is already deadly. The care needs and changing approaches to those specific needs are a twin transformation occurring in the health care system. Hospice and its increasing importance over the past 40 years, represents the emancipatory and utopian side of palliative space-time – a reclaiming of death and life in a health system that centers death.

Alternatives and the potential for action are abundant. Medicare recipients will grow to become a significant voting block in coming decades, as will the very politically engaged Generation Z. The sandwich generation of adults taking care of aging parents and children of their own have a stake building a robust and stable health system to support their own care pressures. Increasing discontent and attention is turning to hospital closures, with communities protesting closures, such as the outrage over the closure of a hospital in Brooklyn that culminated in its closure, but also legislation mandating better consideration of community and public health needs before allowing hospitals to shut (Frost 2015). As well, increased media coverage of the impacts of closures is increasing, for example, with Kaiser Health News's series on the a small Kansas town coping with the loss of their hospital (Tribble 2019). Furthermore, fed up with the growing care deficit and expense of the health system, public opinion towards universal health care has shifted dramatically in the past ten years.

Each of these trends have great potential to create more just health systems, making it all the more important to understand the implications of a health program's financial structure.

## Conclusion

In many ways, these changes to the health care arm of the welfare state do not represent a new process. The hospital system has undergone a series of downsizings since hitting its peak after the passage of the Hill-Burton Act in 1946, the federal funding program that poured money into building more hospitals across the country in the post-war era. Geographer Sara McLafferty (1986) demonstrated that the wave of hospital closures from the late 1960s to the mid 1980s most impacted smaller facilities serving communities of lower socio-economic status. Uneven access is always filtered through difference. This is apparent in the impacts deindustrialization had on public long-term care (Winant 2018). As well, closures of the 1960s-1980s must be understood in the context of integration, or the period when nearly all Black hospitals closed (Sanford III 2012). Legacies and patterns of uneven access to care and good health persist.

Given this history, what is special about the changes in the early 1980s? The changes of 1982 and 1983 signify a movement towards a systematic death drive, towards operating in palliative space-time for the health care system. It is a *systemic* shift in the system towards a form of care with necropolitical goals – focused on not just making live, letting die, and making die at the level of individual and population, but also at the health care system. Palliative space-time names not only a withdrawal of services or an increase of stress on caregivers. It describes a shaking of the entire system through closures of physical locations

of care, but with the potential to remake the system out of the ruins of closed facilities. For what replaces a hospital could be something wholly different and just.

Systems and practices of care change, evolve, improve. This article ultimately is arguing for critically centering the impacts of such changes. What happens in a hospital's wake? Where do people receive care? Where do workers work? What does the loss of tax dollars, a space of care, and an anchor of community mean for workers, communities, economies, politics, health care systems and provisioning? And how does a payment structure reveal what people actually value? Centering these questions might open up a way towards utopia, or at least a more just and equitable health care system.

## Acknowledgements

Thank you to Patrick Vitale and Clayton Rosati for organizing the AAG 2019 session where I first presented this paper, as well as to the UoM Geography Seminar Series in which a version was also presented. Thank you to Katie Mazer, Nick McGee, and Nate Millington for advice on drafts.

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