Whose Good Death? Valuation and Standardization as Mechanisms of Inequality in Hospitals

Katrina E. Hauschildt[1] ⓘD

Abstract

Although most clinicians have come to perceive invasive life-sustaining treatments as overly aggressive at the end of life, some of the public and greater proportions of some socially disadvantaged groups have not. Drawing on 1,500+ hours of observation in four intensive care units and 69 interviews with physicians and patients' family members, I find inequality occurs through two mechanisms complementary to the cultural health capital and fundamental causes explanations prevalent in existing health disparities literature: in valuation, as the attitudes and values of the socially disadvantaged are challenged and ignored, and in standardization, as the outcomes preferred by less advantaged groups are defined as inappropriate and made harder to obtain by the informal and formal practices and policies of racialized organizations. I argue inequality is produced in part because wealthier and White elites shape institutional preferences and practices and, therefore, institutions and clinical standards to reflect their cultural tastes.

Western medicine's approaches to death and dying have changed over time (Anspach and Halpern 2008; Glaser and Strauss 1965; Livne 2019). During the "golden age of doctoring" (Starr 1982), physicians paternalistically dictated care for terminally ill patients, favoring aggressive life-prolonging interventions and sometimes not even disclosing to patients they were dying (Glaser and Strauss 1965). Doctors' authority was challenged over the next four decades by patients, other professional groups, and social movements, who argued patients were entitled to open communication about dying without substantial medical interventions (Anspach and Halpern 2008). This dovetailed with policy efforts to contain costs and particularly to limit end-of-life (EOL) expenditures perceived as ineffective (Livne 2014). This shift has come to be seen as a beneficial turn toward quality over quantity at the end of life by many in bioethics, social sciences, and clinical medicine (Kaufman 2015; Livne 2019). Contemporary

studies of EOL care identify greater intervention (e.g., hospitalization, intensive care unit [ICU] admission, cardiopulmonary resuscitation [CPR], and/or inpatient deaths) as evidence of lower quality care (Marik 2014; Mullins et al. 2021; Sallnow et al. 2022), sometimes even labeling these interventions "inappropriate." Greater use of these interventions among marginalized racial and socioeconomic groups are labeled disparities and a problem to be fixed.

[1]Johns Hopkins University School of Medicine, Baltimore, MD, USA

Corresponding Author:
Katrina E. Hauschildt, Division of Pulmonary and Critical Care Medicine, Johns Hopkins University School of Medicine, 1830 E Monument St, #520, Baltimore, MD 21205, USA.
Email: hauschildt@jhmi.edu

While there may be new consensus among clinicians against aggressive EOL care, recent surveys have shown a doubling since 1990 in the percentage of Americans who would *prefer* aggressive interventions if they had a terminal illness (Pew Research Center 2013). These attitudes vary by race and class. Only 20% of White respondents and 18% of college graduates felt clinicians "should always do everything possible to save a patient's life"—but 59% of Hispanic respondents, 52% of Black respondents, and 43% of respondents with a high school degree or less favored that (Pew Research Center 2013). Qualitative studies on EOL planning highlight differences in advance care planning and preferences stemming from differences in attitudes about death, religious beliefs, and fears about discriminatory treatment (Blackhall et al. 1999; Cain 2021). Rosoff (2013) found that hospital futility policies and related state laws disproportionally constrained decision-making for minority patients and families.

Unknown is how these dynamic and diverging preferences are enacted and influence inequality in EOL care. To understand this, with specific attention to the ways it might produce good or bad deaths and for whom, I conducted observations in four ICUs and interviewed patients' family members and physicians. I used abductive analysis to examine how differences in EOL communication, decision-making, and treatment were experienced by those involved and identify mechanisms leading to inequities in experiences.

BACKGROUND

Theorizing Good Deaths and Obtaining Them

Existing theories provide leverage explaining how some systematic differences in health and health care develop. Socioeconomic status (SES) and racism are theorized as fundamental causes of health disparities because they shape access to varied resources for pursuing ideal health outcomes (Clouston and Link 2021); differential access to hospice services and advanced care planning by SES and race have indeed been found (Carr 2012; Silveira et al. 2011). Theories of cultural capital, and Shim's (2010) cultural health capital (CHC) specifically, argue that differences in the interactional navigation of institutions lead to unequal outcomes despite shared values (Bourdieu 1986; Shim 2010). Cultural capital suggests that certain cultural knowledge and habits are seen as markers of status and competency and thus help individuals accrue resources and opportunities (Bourdieu 1986). Shim's (2010) CHC theory provides rich description of how this unfolds in health care settings, explaining disparities through how patients interact with providers. Empirical studies find differential navigation of health care networks, styles of advocacy, and patient reporting impact whether and how quickly treatments are obtained (Dubbin, Chang, and Shim 2013; Gage-Bouchard 2017; Gengler 2020). Gengler (2020) observes parents of terminally ill children who feel knowledgeable enough to "captain" their children's care and know "they did everything" experience greater peace than parents with less CHC who rather "entrust" decisions to clinicians. However, fundamental cause and CHC research largely do not explain how institutions themselves develop definitions of "good" clinical practices, attitudes, and goals of care.

Contested "Good Deaths"

At the end of life, while all patients will experience the same objective health outcome (death), patients may desire different subjective experiences: to "be made comfortable" or "to prolong life as much as possible." Also contested are the validity of cost considerations and moral arguments about what constitutes "a life worth living" (Cain and McCleskey 2019; Jenkins 2015; Livne 2019). We can examine at the end of life whether and how subjective differences in interpretations and valuations shape care delivery and create inequalities through institutional practices, beyond the impact of patient CHC and resources.

I suggest that incorporating the sociology of valuation and standardization (Lamont 2012; Timmermans and Epstein 2010) with insights from Victor Ray's (2019) theory of racialized organizations provides complementary tools to explain the alignment of institutions with particular cultural tastes. Ray (2019:35) theorizes that racialized organizations are meso-level structures that link racial schemas to resources and, in doing so, "help launder racial domination by obscuring or legitimating unequal processes." Occupational segregation is one mechanism through which power and agency are constrained for racial minorities in medicine (Nguemeni Tiako, Ray, and South 2022). Organizations expect conformity to norms of deeply White-dominated spaces without naming Whiteness, and thus, "much racial inequality is produced through relatively passive participation in racialized organizations" (Ray 2019:40).

Valuation and standardization provide possible mechanisms of creating these racialized organizations. Valuation refers to the processes and judgments used to determine the worth of an entity (a treatment action or outcome, in this study). Standardization refers to how these valuations are legitimated by institutions (Lamont 2012; Thévenot 2009; Timmermans and Epstein 2010). Standardization refers not just to operationalizing a particular valuation to an entity but also operationalizing processes that determine how value is assessed. Lamont (2012) hypothesizes inequities resulting from valuation and standardization are more likely in spaces with fixed hierarchies (i.e., when clinical judgment outranks other considerations; Hauschildt and De Vries 2020). Timmermans, with Berg (2003) and with Epstein (2010), argues that standardization processes are ubiquitous in medicine.

I suggest that in the context of coalescing attitudes about good death among clinicians, processes of standardization reinforce the valuations of those with more power and agency within racialized health care organizations. In EOL care, the valuation and provision of particular treatments is assumed to reflect valuations of particular goals, and this translation is conducted by clinicians. Standardized care pathways and norms around "appropriate treatment" that default to providing care aligned most with the values of White and wealthier patients are another manifestation of racialized, and conceivably "classed," organizations. I suggest a derivation of Ray's (2019) conceptual work here: "Classed" organizations would similarly reproduce class-based inequities by prioritizing the opinions and experiences of higher-SES groups in treatment valuation and standardization.

In sum, past scholarship demonstrates that socially marginalized patients are less likely to share EOL valuations with their physicians and suggests that marginalized patients often possess fewer resources and less CHC in navigating health care institutions. I build on this work by arguing that clinicians tend to devalue aggressive EOL treatment goals and also interact differently with patients who value this different care in ways not fully explicable by patients' or families' ability to deploy material resources or CHC in negotiating treatments. In addition, I posit that aggressive treatment goals are often made pragmatically harder to implement despite patients' material resources or CHC because standardization processes empower clinicians and constrain patients in demanding devalued care. Finally, I theorize that valuation and standardization reinforce health organizations' racialization and reproduce class-based inequities by giving authority to elite and White values in EOL care.

DATA AND METHOD

Using Lutfey and Freese's (2005) exploration of diabetes risk as a model, I conducted ethnographic observation and interviews to understand how differences in EOL health care emerged *and* how these different EOL health care experiences were evaluated. Lutfey and Freese (2005:1329) argue that through ethnographic observation, "one can see in individual interactions evidence of more systematic disadvantages." I sought to identify the mechanisms that contributed to systematic disadvantages in EOL health care experiences. This study did not set out to establish if race and class differences in preferences and care exist, because population-level studies had already done this. Instead, I set out to explore *how* differences mattered in the care delivered, the interactions patients, families, and physicians had, and how participants felt about what occurred. I sought to understand when and how differences became inequities in the context of EOL health care (Rathore and Krumholz 2004).

The Context: EOL Decision-Making in the ICU

Treatment decision-making in ICUs is complex, value-laden, and ongoing. The contemporary move toward advanced directives has failed to improve goal-concordant EOL care or the perceived quality of that care (Fagerlin and Schneider 2004; Morrison, Meier, and Arnold 2021). Many patients still experience acute health problems, and their preferences are unknown, nonspecific, or not documented. In the ICU, I could observe frequent and ongoing processes of choosing (or not choosing) life-sustaining treatments and arguments made for or against such interventions.

Setting: Greenville and River City

"Greenville" (a pseudonym) was home to two hospitals. College Hospital, the adult hospital associated with State University Medical School, and Truman Medical Center (TMC), a large Veterans Affairs (VA) hospital. Both were staffed by medical faculty and trainees from State University Medical School. Trainees included medical residents and "fellows" pursuing specialization in critical care medicine. During my observations, 86% of patients in the College Hospital Medical ICU were White, 7% were

Table 1. Focused Observation Sample, Patient Demographics (*N* = 203).

	N
Race-ethnicity	
Black	90
White	102
Hispanic	6
Asian or Middle Eastern	5
Gender	
Women	67
Men	136
Age	
< 65 years old	87
65+	116
Total	203

Black, and 7% were from other racial-ethnic backgrounds. Most patients were from middle- or working-class backgrounds, and many had private insurance. The Medical ICU at TMC served veterans from across the state; 85% of TMC ICU patients were White, 13% were Black, and 2% were from other racial-ethnic backgrounds—few were high-income, although patients and their families varied in SES.

Nearby "River City" included two other hospitals in a for-profit health system. Memorial Hospital and North General Hospital were physically adjacent and were staffed by attending physician faculty employed by the River City Medical School and trainees employed by the for-profit health system. In North General's ICU, 82% of patients were Black, 16% were White, and 3% were from other racial-ethnic backgrounds. Most patients were from poor- or working-class backgrounds, some lacked any insurance, and very few had private insurance. Memorial Hospital's ICU included more privately insured patients than North General; 79% of Memorial ICU patients were Black, 15% were White, and 6% were from other racial-ethnic backgrounds.

Ethnographic Observations in the ICU

To capture EOL communication and decision-making, I observed more than 1,500 hours in these ICUs between June 2018 and February 2020. I focused on treatment decision-making for patients with terminal conditions who medical professionals defined as potentially at the end of life. I took detailed field notes on the decision-making processes and communication and attempted to approximate a verbatim transcript when possible.

All physicians and medical students on these units during observations agreed to participate and signed written statements of consent (N = 160). I received verbal consent from patients before observing them or family members in cases where patients could not participate in decision-making.

I observed clinical teams discuss over 500 patients. While I took notes on all cases, my observations focused on the 40% (N = 203) for whom doctors discussed the risks and benefits of continuing, starting, or withdrawing life-sustaining treatments, either among themselves or with the patient or their family members. Demographic information for patients in the focused observation sample is in Table 1. I employed a sequential case study logic (Small 2009) in my observations; the endpoint of continued observation was saturation, where later cases or observations provide little or no new information about the processes in question.

Interviews

To deepen insight into patients' and family members' experiences, I approached for follow-up interviews 66 family members who had multiple and/or significant conversations with the physicians regarding life-sustaining treatments. I asked about perceptions of their relative's care and how they made choices about treatment. Interviews took place after each site's observation period—5 to 18 weeks after patients' ICU stays. All but one was conducted by telephone; all were recorded and transcribed. Interviews were conducted with 39 patients' family members (59% of those recruited). I also conducted in-depth interviews with 30 physicians about their experiences and approaches to life-sustaining treatments. These interviews took place in person or by phone and were audio-recorded and transcribed (see the online Supplemental Appendix for additional information on data collection and interview sample demographics).

Data Analysis

All data were analyzed for themes and patterns (Emerson, Fretz, and Shaw 2011). I read through all field notes and interview transcripts, open coding and writing short memos about potential patterns. I analyzed how life-sustaining treatments were discussed and evaluated by physicians, patients, and family members, both across different patients and over time for the same patient. I used abductive analysis to identify variation between cases and then traced patterns to develop theoretical arguments

about observed variation (Tavory and Timmermans 2014). Using multiple methods of inquiry helped to validate patterns across different perspectives and methods (Giacomini and Cook 2000). Additionally, I used member-checking with clinicians and other experts to assess these interpretations and further clarify the processes identified (Anspach 1997).

RESULTS

In these observations, traditional mechanisms of health inequality were certainly at play. I will show, however, cases also demonstrated the production of inequality through other mechanisms. When physicians and patients had differing valuations, physicians often repeatedly questioned the patient and family's values, assuming they misunderstood medical information, or treated families with suspicion. Where physician values had coalesced around treatment standards, nonaligned patient values were seen as causing arbitrary paradoxes and led to intense physician resistance and restrictions of care. Formal standards also imposed rigid distinctions between, for example, hospice and curative care, and formal policies that appeared value-neutral gave physicians power to override patient preferences. Finally, I show these processes could interact with fundamental causes and CHC to reinforce inequality but also operate independently of these traditional mechanisms.

Traditional Mechanisms

Inequalities in EOL health care trajectories developed through numerous pathways and at multiple points in patients' ICU stays. Well-known mechanisms—differences in flexible resources (e.g., money, social support) and the amount of CHC patients or their families possessed—explained some of these inequalities. For example, Mr. Crosby, an 80-year-old Black retired factory worker, was limited in his options for transitioning to comfort care due to a lack of resources.

Attending Physician: What we do in the ICU, that's just prolonging life. Hospice is something you could choose that would allow you to have your symptoms managed outside the hospital. They won't do things to prolong your life through artificial means, like dialysis, but will focus on managing your discomfort: any pain, any shortness of breath.
Mr. Crosby: That sounds real nice. I'd like to go home.

Attending Physician: You live alone?
Mr. Crosby: Yes.
Attending Physician: You might need to receive hospice care in an inpatient unit or perhaps a nursing home. You might need more care than patients can receive at home.
Mr. Crosby: I just want to go home.

The ability to enact Mr. Crosby's care preferences was hindered by the lack of social and material resources needed to supplement home hospice services. After 10 days, the hospital social worker still could not identify a workable solution for home hospice.

By contrast, the family of Mr. Crest, an 83-old White retired office manager with a terminal cancer diagnosis, nimbly adapted to changes in his care by drawing on flexible resources they possessed as well as their familiarity with health systems. Mrs. Crest displayed a nuanced understanding of both his medical needs and the transition of coverage between traditional insurance and hospice benefits, asking detailed questions about his care needs, such as nutritional supplement supply and equipment for managing his chest tubes, to make sure hospice would provide necessary supplies. The hospital social worker coordinated equipment delivery the same day Mr. Crest decided to transition to hospice care because Mr. Crest's son received his supplies while his wife and daughter were at the hospital to coordinate discharge and emotionally support Mr. Crest. Thus, Mr. Crest and Mr. Crosby wished to have the same sort of death, but only Mr. Crest could access it because of his greater financial and social resources, his wife's CHC, and her ability to coordinate care to get him home faster than even the system expected.

In the aforementioned instances, patients and their families reached agreement with clinicians about appropriate treatment and had similar ideas about good deaths. When such concordance occurred, it led to more empathic care and facilitation of nonmedical goals. Physicians evaluated these outcomes more positively. However, when patients or families disagreed with clinicians, new pathways to inequities emerged.

Differing Valuations

Patients and families whose values differed from their clinicians were more likely to experience interpersonal and communication challenges with clinicians. In these instances, clinicians often assumed patients did not understand a treatment and its out-

comes rather than believing patients simply had different values.

Clinician disbelief and constant queries. The case of Mr. Haynes, a 65-year-old White retired truck driver, demonstrates how preferences for aggressive life prolongation—perceived as abnormal—led to conflict because his values did not align with those of his clinical team. Mr. Haynes was dying from leukemia and experienced worrisome drops in blood pressure during his second day in the ICU. He was awake, able to participate in decision-making, and had close friends at his bedside daily. The resident treating Mr. Haynes explained to him that there were medications to raise Mr. Haynes's blood pressure, but they would not reverse his dying from cancer. They would require placing a central line, a large intravenous line through the neck. After the resident described the procedure, noting it would only give the patient a couple more days, Mr. Haynes said he wanted it.

During the procedure, the resident told me he asked Mr. Haynes at each step if he "was sure" he wanted this: "Why do you want me to do this? What will be different in one to two days?" Mr. Haynes replied, "I'll have two more days." As explained to me, the resident could not understand why Mr. Haynes would want to continue suffering, now with an invasive line, for two additional days. Mr. Haynes's friends told me, "He knows he is dying, but we come [to the hospital] each day, and we talk, and watch shows [on television] together, and I just know he is scared. He is not ready to go."

These exchanges revealed the difference between the resident and Mr. Haynes in the value they placed on two more days of life in the ICU. The resident remarked, "I don't know why you'd want to be here [in the ICU] if you had no chance of leaving." The resident saw a patient suffering and was unable to cure what was killing Mr. Haynes. He understood additional interventions as extending suffering rather than offering benefit. Mr. Haynes, however, was not ready to die—and found value in time in the company of his friends and family, even suffering from pain and fatigue.

A day later, due to a complication, the resident needed to move the line to the other side of Mr. Haynes's neck. Again, the resident asked Mr. Haynes repeatedly whether he wanted the procedure to continue. After the resident's third appeal for reassurance, Mr. Haynes, frustrated by repetitive questioning, requested the resident stop asking. Talking with the resident and fellow after the second line, the fellow observed, "He [Mr. Haynes] is just done having conversations. It makes sense,

everyone coming to talk to you about how you're dying. But, it's like, you're really dying, right now." The fellow and resident felt Mr. Haynes's frustration with these conversations was due to denial of his impending death. They reasoned by accepting life-sustaining interventions, Mr. Haynes was denying his fate. Two days after the second line was inserted, Mr. Haynes told the resident he was tired and "ready to go." He requested the central line be removed. He died the next day with his friends at the bedside.

Physicians often described life-sustaining treatments for terminally ill patients as "less than ideal" or of "little to no value." One attending physician described *continuing* use of vasopressors as providing no "mortality benefit" and therefore "futile treatment." When I inquired why physicians would prescribe the medication if there were no benefit, the physician explained "vasopressors are only useful as bridge to another life-saving therapy. If no additional therapy can be provided, vasopressors are a bridge to nowhere." This phrase was used often for therapies that would not reverse the primary cause of the patient's dying (e.g., heart failure or cancer). Such therapies did have a physiologic effect and could sometimes extend patients' lives for days—but this was not considered a mortality benefit because patients would still die. Providing therapies physicians felt were futile was often described as bad medicine and imbued with negative moral weight. This meant some patients' and families' values were also judged and invalidated by the clinical team because those families' wishes did not align with the valuations embedded in clinicians' judgment. Mr. Haynes experienced this valuation difference and perceived this judgment when his values were repeatedly questioned by his ICU team.

Clinician suspicion and resistance. During Mr. Glendale's ICU stay, in addition to interpersonal conflict, we see how nominally value-neutral but intentionally coercive processes can be deployed to prioritize the clinicians' values about appropriate treatment. Mr. Glendale, a 65-year-old Black disabled man, presented to the ICU following a cardiac arrest at the nursing home where he resided. He was placed on a hypothermia protocol in which doctors strategically cool a patient's body hoping to reduce brain damage. After three days, neurology concluded Mr. Glendale was not brain dead but nonetheless had a very poor neurologic prognosis. A family meeting took place six days later, and his family was told Mr. Glendale was not brain dead but would not wake up; hospice care was recommended. The family asked for a few days to discuss and

decide. During this time, clinician suspicion and resistance toward the family's goals became a driving force in interactions with his family.

The next week, the resident told me he called the family at least once a day, but they did not return his calls. The attending physician noted "they were supposed to get back to us on Monday. It's been three days. He's just occupying a bed in ICU." The team consulted the hospital's clinical ethics service to consider removing decision-making power from Mr. Glendale's family. In the afternoon, the resident learned that palliative care spoke with the family, and they had decided Mr. Glendale would want to have a tracheostomy and be transferred to a long-term acute care facility. The resident remarked, "The family can't make us do something, just because they ask for it. Also, he is using a lot of resources, so we'll have to discuss on rounds."

The following day, Friday, the surgery team called the patient's sister to obtain consent for the tracheostomy, and she asked them to wait until Monday, her day off, so she could be present during the surgery. The same day, the ICU team unilaterally changed the patient's code status to do-not-resuscitate (DNR) based on the ethics consultant's recommendation. Over the weekend, a new fellow on the ICU service told the family about the team's DNR decision and recommendation against a tracheostomy and percutaneous endoscopic gastrostomy (PEG) tube. The family were distraught.

Brother: That's not what he wants. They started all of this by asking what he wants and now you're just deciding what you want to do.
. . .
Sister: You called just a few days ago and you offered a trach[eostomy] and PEG.
Fellow: A trach and PEG is not being offered.
Sister: They did call and ask, on the phone—
Fellow: To talk about a trach and PEG.
Sister: No, they asked for my consent.

Disagreement between the medical team and Mr. Glendale's family persisted. The team questioned the family's beliefs about Mr. Glendale's wishes and their motives. For example, an earlier request by the family to have guardianship formally assigned to them so they could pay Mr. Glendale's bills was interpreted with suspicion by the team, who suggested the family wanted to collect Mr. Glendale's Social Security checks. A few days following the fellow's meeting, a different attending physician took over ICU service and met with the family.

Sister: This is the third family meeting. I'm very irritated. I already talked to the chief of staff. And for me to keep going over the same thing, is very irritating.
Brother-in-law: And we keep hearing different things.
. . .
Brother-in-law: Do you see how this comes across? Like you're railroading us. This should be our decision. I have never seen a hospital try so hard to take his life and control this man's body, and let's not pull any punches here—you are talking about ending his life.
Sister: He is still here. Please let us do what we want to do, and we will take him away.

The ICU attending physician ultimately agreed to take the family's wishes to the Chief Medical Officer, who told the ICU team to do the tracheostomy so Mr. Glendale could be transferred elsewhere. Although the Glendale family eventually received the treatments they wanted, they did so by deflecting many efforts to dissuade them. While others in the hospital had at one point offered different treatment, the values of Mr. Glendale's ICU clinicians had a substantial impact on this experience in the hospital. When his family described Mr. Glendale's wishes for aggressive treatment, even with a very poor prognosis, they were disbelieved and clinicians viewed the family with active suspicion. Communication between the team and Mr. Glendale's family broke down multiple times, and physicians assumed these breakdowns meant his family did not care about his well-being, rather than contemplating that they may have felt berated and ignored.

The cases of Mr. Haynes and Mr. Glendale highlight how outcome and treatment valuations can differ between patients and providers. When these valuation differences occur, physicians often expressed distrust of patients' or surrogates' choices and revisited decisions often. Patients and families experienced these endless queries as challenges to their values, and some developed real fear they would be denied care.

Converting Values into Standards

Physicians' values regarding appropriate end-of-treatment could also lead to more rigid treatment pathways, could be codified as formal hospital policies, and were used to define appropriate medical treatment.

Translating values into treatments and valuation inflexibility. There is no trivial process in which values become treatment plans, although clinicians often act

as if that were so. The ways in which some values have been translated into "standard" treatments may lead clinicians to perceive patients as having contradictory values—not because the values are inherently contradictory, but because standardized translations of those values remove the nuance present in the patients' and families' articulations. Mr. Todd's case demonstrates how such standardized translations led to some of his wishes remaining unaddressed when physicians interpreted them as contradictory. A 77-year-old Black retired autoworker, Mr. Todd came to the ICU multiple times. He was alert and making treatment decisions and was eventually discharged to the rehabilitation unit. However, two weeks later, he returned to the ICU, again needing higher-level oxygen support. The resident reevaluated Mr. Todd's code status and the likelihood he would need intubation. Mr. Todd said he desired intubation if needed and would also want resuscitation attempted. Later, a respiratory therapist stated he was "not excited" about intubating Mr. Todd given his comorbidities, including severe pulmonary hypertension. The therapist also suggested Mr. Todd likely would not survive the intubation itself.

Mr. Todd's nurse soon told the residents that Mr. Todd was asking for food. One resident replied, "Mr. Todd cannot eat anything, including broth." The nurse described Mr. Todd as very hungry and whimpering and asked the resident to explain to Mr. Todd their decision to withhold food. The resident said, exasperatedly, "Tell him he can have food if he goes to hospice!" A nearby medical student seemed surprised (as was I), and the resident clarified, "He is at a massive risk for aspiration and if his goal is to live, [food] is not compatible. He needs to display some internal consistency with his goals—he wants us to intubate him and keep him alive, then he can't eat something and aspirate." The resident's translation of values into treatments employed organizational logics that often viewed curative and comfort-focused goals as contradictory and led to treatments being similarly bifurcated.

I asked if patients thought these things were contradictory—wanting to live and also not be hungry—and the resident replied, "I think most don't. It is the most frustrating part of being a doctor. We are doing a lot to keep him alive." The resident felt he was doing his best to prolong Mr. Todd's life and was frustrated Mr. Todd would want to eat—increasing his risk for needing an aggressive intervention—when his clinicians were "doing a lot to keep him alive." The resident's focus on Mr. Todd's desire for life prolongation led the resident to see Mr. Todd's desire to eat as contradictory rather than

see Mr. Todd's perspective, which included separate but common human desires: to live, but also to relieve discomfort from hunger and enjoy the pleasure of food. Operationalizing values via standardized treatment pathways, in which patients who wanted to "try to live" should not also receive (or desire) some comfort-focused treatments, was not unusual. Some physicians described requests for pain medication from patients who would accept intubation as contradictory—if they wanted to do everything possible to live, including being intubated if necessary (which most physicians saw as objectively unpleasant and to be avoided), they should not receive medications that might depress their respiratory function, which many pain medications do.

Physicians often acknowledged that most patients fell somewhere between solely valuing comfort and solely valuing life prolongation. However, when it came to providing treatments, institutional processes of operationalizing specific treatments as manifestations of specific values made it difficult for them to manage patients without a singular goal. When patients had more complex goals or had goals physicians were trying to change, patients sometimes did not receive treatments they wanted and perhaps needed.

Valuations become informal standards. Treatment also became constrained when informal standards developed around physicians' values of not "being overly aggressive" or "providing futile care," as in the case of Ms. Rosset, a Black 48-year-old pharmacy technician with metastatic breast cancer. Ms. Rosset came to the ICU delirious. The resident explained to Ms. Rosset's parents, who remained at her bedside for hours each day, that cancer metastases in her liver could be causing liver failure, so toxins built up that affected her brain, or alternatively, that she could have an infection and that they were treating what they could. Ms. Rosset's parents shared that her teenage son was on a school trip, and they did not want to tell him about the possibility her cancer had advanced until he returned.

After a few days, Ms. Rosset was intubated and stopped producing urine as her kidney function deteriorated. During rounds, the resident suggested that they consult nephrology, but the fellow disagreed, saying, "No, I don't want her to get dialysis; she needs hospice." Over the next weekend, Ms. Rosset's potassium began to increase dangerously because of her kidney failure.

Nurse: I think we may need to start dialysis.
Fellow: We're not offering it.

Nurse: I thought we were trying to keep her alive until Wednesday?

Fellow: Yes.

Nurse: Do you think she will make it?

Fellow: I do not.

Despite Ms. Rosset's kidney failure and her family's desire to prolong her life, the physician team would not offer dialysis, even to reach the family's goal of having her live until her son's return. This example illustrates how physicians would sometimes constrain treatment options, including not seeking consultation that might offer additional treatments, to adhere to perceived professional and organizational norms to avoid inappropriate care (e.g., wasting resources, prolonging dying, providing futile care). As valuations of particular EOL care become normative within an organization as "good" or "bad" care, physicians come to see and informally enforce restrictions on treatments believed to be "objectively not in the patient's interest" regardless of the patients' stated goals or desires for said care.

The morning of her son's arrival, a newly on-service ICU attending physician spoke to the family on rounds, hoping they would be ready to withdraw life support and transition to comfort care. However, Ms. Rosset's parents stated they were not ready yet and requested dialysis. When they were told it would not be offered, her mother asked how long they could continue what they were currently doing, and upon being told "her heart would eventually go out," her parents said they would like to "just wait it out."

After the meeting, the team discussed being surprised by the family's desire to continue treatment. The attending physician said he felt "uncomfortable not having nephrology as an ally" in their dialysis decision. He asked the resident to see who was on call for nephrology service. When informed of the name, the fellow warned, "They burned us on [another patient], they recommended CRRT [dialysis]." The resident asked if he should consult nephrology, and the attending physician declined, saying, "No, because I don't want them to offer [dialysis] (laughs)."

When I interviewed Ms. Rosset's mother, she reported being hurt by the attending physician's attitude and comments. She explained her rationale for her choices:

> I told him I was going to wait, because the way he was talking—he wanted to pull the plug—and I told him no . . . I didn't want it to be on my conscience that if I had them remove it, then maybe she would have lived longer. I didn't

want that to be in the back of my mind. She always thought that she would come through it, and I did too. I didn't want to have no doubts in my mind. If she was thinking that everything was going to be all right, I wanted to be on the same page she was.

In Ms. Rosset's case, her parents valued treatments for reasons the ICU did not also value: the allowing for her son's return, avoiding feeling Ms. Rosset might have lived longer if they had not given up, and honoring their daughter's values. While the clinicians allowed Ms. Rosset to remain on the ventilator until she died, they did not offer dialysis even when they felt without dialysis she was unlikely to survive until her son's return. Ms. Rosset's family attempted to fight the imposition of a standardized "good death" they felt she would not want, revealing the varied impacts of differing valuations in emotionally charged interactions.

"Bridges to nowhere": Treatment frames as informal standards. Concerns over providing treatments that were "bridges to nowhere," a phrase used often to refer to treatments that would not cure underlying disease, led ICU physicians to avoid these treatments even when it was not always clear at the time these treatments would be ineffective. Physicians did not want to be perceived as wasting resources, prolonging the dying process, or providing futile care—all of which were understood as contrary to patients' interests regardless of what patients said. They thus enforced among each other informal standards prioritizing a particular "good death" and used nominally value-neutral processes, such as requesting consultations (or not) that made that kind of death easier and other kinds of death harder. Phrases such as "bridges to nowhere" cue team members to use specific frames in evaluating the efficacy and benefit of treatments.

ICU physicians also passed judgment on other colleagues for being too optimistic, insisting the ICU continue life-sustaining treatments, or encouraging patients' families to continue treatments. One attending physician described agonizing over the care of a cancer patient he had recently treated and frustration with the oncologist's approach:

Attending Physician: [The patient] was on the maximal doses that we use here, for propofol, fentanyl and Versed, and he was still awake and in pain . . . having him go through that every day, that was a tough one. . . . Unfortunately, oncology wanted to give him some time to see if he made it through this and the family was there.

The oncologist's acknowledgment of the patient's likely poor prognosis but desire to continue life-sustaining treatments caused moral distress for the ICU physician, who was tasked with overseeing these interventions. This case, and others like it, served as warnings about being overly optimistic and providing potentially futile care.

More experienced physicians acknowledged that the opposite also occasionally occurred when junior physicians, with little experience with very sick patients, pushed patients and families to decline life-sustaining treatments that may have been beneficial.

> Attending Physician: We've seen times where, especially, less experienced trainees who may not be aware of what fully to expect of the clinical course may start to make recommendations to not pursue therapy that may frankly actually be beneficial . . . we have to be very careful not to be in a position where we're recommending people not get things that could help them live the way they want to live. . . . As opposed to saying, "Oh my God, this person is sick. I think they're going to die. I wouldn't want this for me, so I'm going to recommend that we don't do this."

However, most physicians expressed greater concern about the dangers of overly optimistic prognostication and subsequent treatments. In my observations, there was only one instance in which an attending physician or fellow expressed concern that a resident had painted an overly bleak picture of a patient's prognosis; even then, they did not revisit the decision to withdraw life-sustaining treatment.

Standardization through formal policies. Formal hospital policies also codified cultural valuations of treatments. Futility policies provide guidelines for when physicians could refuse to provide or could withdraw a particular treatment. Most commonly, these hospital-specific policies stated such an action was allowed if two physicians agreed the treatment was futile. This policy was invoked in the case of Mr. Glendale, described previously, to refuse to provide CPR if he suffered another cardiac arrest. While such policies often defined futility as providing no physiological benefit, some hospitals used a broader definition of futile care termed *nonbeneficial care*. These policies defined nonbeneficial treatments as those that may provide a physiological benefit but for which the benefits did not outweigh the costs—as assessed "from the perspective of two physicians." Such a policy could be used to deny a patient intubation, dialysis, or other life-sustaining treatments that required significant resources but would not address patients' underlying illness, although many would indeed sustain that patient's life for some time.

Physicians explained how these polices were used to make patients DNAR (do not attempt resuscitation) or to remove life-sustaining therapies, such as mechanical ventilation. After Mr. Mosley, a 58-year-old Black man, suffered a cardiac arrest and was resuscitated after 30 minutes of CPR, an ICU fellow remarked, "This state really protects doctors; we don't have to provide care that is futile." When discussing whether Mr. Mosley should receive a tracheostomy and PEG tube, given that he had not regained consciousness, the fellow replied, "People don't know what futile is. It doesn't mean they'll die either way. It could also mean—there is no benefit. I don't have to make someone a vegetable." In an interview, another physician described this dynamic more bluntly:

> Attending Physician: Your positive rights, your right to demand treatment, are limited to those that I deem as the ones likely to benefit. If you and I have a disagreement on what's going help you, at the end of the day, I'm the physician. I get to say what I think. You can find another doctor if you want to get a second opinion, by all means, but you can't force me to provide treatment that isn't going help. . . . We have this fundamental disagreement, and I win.

In another instance, while a resident was training a medical student in having code-status discussions, he remarked, "I don't think CPR should be offered if the chance of success is exceedingly small." When I asked whether CPR would be futile, even with very low odds of success, given not doing CPR would result in death, the resident said, "There are things worse than death." Multiple doctors feared resuscitative efforts would bring someone back, but only for a brief time (hours to days), to a minimally conscious state, or would "make the person a vegetable." How physicians valued these possible outcomes influenced whether they considered CPR to cause more harm than benefit and therefore its futility. Assessments of futility incorporated the clinician's valuations of outcomes, such as a prolonged hospitalized dying, and their valuations of risk, such as a 20% likelihood of a desired outcome. These policies then standardized physicians' valuations as the metric to be used in evaluating futility.

Internal Medicine Resident: As a health care professional, we might feel that the potential benefits are not worth the potential harms. Because the potential harms are a very high chance for this patient, and the potential benefits are very low for this patient. Whether or not to offer it in the first place is something that we negotiate.

It became clear hospital policies reflected organizational and individual clinician values while appearing procedurally "value-neutral." Processes of valuation and standardization impacted the experiences of patients similarly in all four hospitals. Across hospitals, physicians' attitudes toward appropriate EOL care for patients were similar, and similar structures, such as futility policies and ethics consultation, were invoked when clinicians disagreed with patients and families.

Formal standardization through hospice care pathways. Rigid distinctions in care pathways were also formalized. Patients enrolling in formal Medicare hospice benefits are no longer eligible for curative treatments for their terminal illness or related conditions. On top of formal coverage limitations are also perceived limitations, which are dependent on hospice providers' interpretations of "related conditions" and covered services. The daughter of Mr. Wilden, an 84-year-old White man, described her father's devaluation of hospice and palliative care as based on what he felt were broader treatment limitations implemented in his wife's care when she changed her resuscitation status.

Daughter: Once they had my mother change her wishes to DNR, then that DNR, in our opinion and in my father's eyes, became do not treat rather than do not resuscitate. Then my mother passed away because they quit giving her antibiotics and so forth . . . [that] was very upsetting to my father.

Mr. Wilden's daughter also described her mother's death at home as without sufficient pain management, leading to her father further avoiding palliative care and hospice suggestions.

Interactions between Valuation, Standardization, and Existing Theories of Disparities

Traditional mechanisms of inequality production could interact with valuation and standardization pathways to amplify inequalities. Mr. Ortiz's case provides an example of how CHC could interact with standards of care. Mr. Ortiz, a 70-year-old Hispanic man being treated for liver cirrhosis, and his family advocated for aggressive treatment yet generally accepted his physicians' treatment recommendations. When physicians communicated they were not using dialysis despite his acute kidney injury, his daughters did not question this decision. Although they resisted multiple efforts by the clinical team to transition their father to comfort care, their limited CHC prevented their recognition of the ways in which treatments were already being limited.

The role of marginalized experiences in valuation. Differences in valuation between patients and physicians—such as how serious hospitalizations were and how strenuously they be avoided—emerged among poor White patients, too. The lived experience of poverty and the lived experience of chronic illness led to differing valuations that were instead interpreted by physicians as failures to process information. Mrs. Cleary, a 55-year-old White woman, had been transferred from a rural hospital when it became clear she needed ICU respiratory care. When I asked Mr. Cleary, a retired truck driver, about the choices he made for his wife, he said:

Mr. Cleary: She had said if she was ever gonna be in a coma, "Don't kick me to the curb 'til I got a chance to come back." . . . I was like, "What I want—only thing Debbie said was, 'If there's a shot at me comin' back, yeah, let's do everything we can.'"

Mr. Cleary revealed his wife had struggled with illness for a long time, after contracting hepatitis C from a blood transfusion in her 20s. Detailing his and his wife's medical history, he described how they both came to see hospitalizations as regular, but survivable, occurrences. Given their rural home, he did not find value in always being at bedside; regrettably, hospital staff instead interpreted Mr. Cleary's requests for more information before "giving up" and his absence from the hospital as incongruent and evidence he "wasn't getting it":

Mr. Cleary: I think some of these hospitals feel like, "Well, if you're that interested why don't you just come here?" I'm like, "A) I'm old, and B), why come there every day, drive an hour and a half to a hospital and an hour and a half home when I can just call you?" . . . That's just how we

are. We ain't gonna do nothin' but be a pain in everybody's [expletive]. Stay home.

Mr. Cleary's care entrusting behavior and perception he would be underfoot and bothersome in the hospital reflected a lower level of CHC that exacerbated clinicians' frustration with his desire to continue aggressive treatment.

Resources, values, and the limits of CHC. Mr. Parker's case is an example of how the availability of flexible resources shaped families' values and decisions and the limits of deploying CHC when patient and family valuations differed from clinicians. Mr. Parker, a Black 84-year-old retired teacher, had dementia and lived in a nursing home. While visiting him, his daughter found him vomiting and lethargic. She brought him to the hospital, and he was admitted to the ICU with sepsis. The team treated Mr. Parker's infection, and he improved dramatically in a few days.

The ICU and palliative teams both had multiple meetings with Mr. Parker's daughter and repeatedly expressed concern Mr. Parker would continue to get infections and his daughter would continue to bring him back to the hospital. The clinicians felt allowing an infection to "take its course" would be in Mr. Parker's best interest, sparing him from worsening dementia. Mr. Parker's daughter, herself a nurse, felt obligated to treat reversible health problems. Similar to other patients and families confronting inadequate care in nursing homes, Ms. Parker felt his care and environment were often better at the hospital than at his nursing home, conflicting with clinicians' views of hospitalization as inherently worse. Acutely aware of the need to deploy CHC, Ms. Parker described using medical jargon and phrasing when she felt she was not heard but also explained its costs, saying, "That's when I tend to act more like a nurse, when [they're] not listening . . . I don't want to be the nurse; I want to be the daughter and a concerned family member."

Valuation, standardization, and social advantage. Finally, Mr. Wilden's case, described earlier around resistance to hospice, suggests that even material resources and CHC cannot always overcome the momentum of valuation and standardization. Mr. Wilden had a PhD and his daughter a JD; at 55, she was retired from her legal career and possessed full legal documentation of his care preferences. Her interactions with clinicians avoided euphemisms, and yet her ability to describe her father's wishes

did not mean they avoided judgment and hassles across multiple hospitalizations.

> Daughter: We do have [durable power of attorney] paperwork, and I have given it to them several times at the hospital [but when they request to speak with my siblings, again] . . . do I drive home, or do I just say, "Look, let's call my siblings and save myself two hours."

She described repeatedly sensing "that air of not wanting to treat, regardless" and experiencing disbelief from providers. Valuation and standardization are mechanisms of inequality because those most likely to experience consequences are from marginalized groups—but anyone who desires treatment perceived as inappropriate can face negative impacts.

DISCUSSION

Today's Good Death

Clinicians often believe it is best to limit life-sustaining treatments and decrease interventions as the end of life approaches. By contrast, I observed numerous patients and families wish to live as long as possible and see value in trying treatments with low odds of success, consistent with survey data. I find that cultural attitudes toward less aggressive intervention for terminally ill patients have become incorporated into and are framed as clinical judgments, evidenced in the ways doctors talk about "appropriate" EOL care and the formalization of these attitudes into standards and hospital policies. The good death preferred by most clinicians is characterized by a valuation of *comfort* and *control* over the circumstances of dying, evidenced in the perception that life-sustaining interventions and even simply being in the ICU are inherently undesirable. While clinicians sometimes acknowledge patients' different values, clinicians mostly believe their own perceptions of appropriate care are defined by their clinical knowledge rather than cultural—and thus classed and racialized—preferences.

Clinical attitudes and practices toward death and dying have shifted to advance a new form of good death (Livne 2019; Marik 2014). For many, the emergence of an alternative to aggressive care at the end of life is indeed a much-needed choice (Kaufman 2005), and medicine's shift toward the promotion of palliative care and withdrawal of intensive technologies is seen as positive and a presumed move toward patients' values. Earlier scholars have examined the lack of patient agency and the

uncritical use of high-technology treatments and interventions (Fox 1981; Glaser and Strauss 1965). This earlier research sought to "improve experiences of death and challenge the power of professionals" (Howarth 2007:426). However, current narratives of good deaths also privilege the cultural tastes of White, middle-class, and college-educated individuals over others (Cain et al. 2018; Hart, Sainsbury, and Short 1998; Zaman et al. 2017), and new policies reassert medical authority in decision-making (Hauschildt and De Vries 2020).

Mechanisms of Inequality

Across settings, socially advantaged groups more deftly navigate interactions with institutional players and accrue advantages toward preferred outcomes. Looking at how parents of children with serious illness navigated health care providers, administrators, and insurers, Gage-Bouchard (2017) and Gengler (2020) demonstrate that certain styles of interaction are more effective in eliciting positive responses from physicians and in obtaining efficient and effective care, and similar patterns are also noted outside of health care, including in schools (Calarco 2018) and criminal courts (Clair 2020). Shim's (2010) theory of CHC clarifies how the interactional styles of patients and families play out at the end of life, such as when Mr. Crest's wife's familiarity with hospice benefits enabled her to ensure coverage of all of Mr. Crest's needed supplies and care.

Yet CHC is not omnipotent (Gengler and Jarrell 2015). Ms. Parker's background as a nurse and Mr. Wilden's daughter's law degree provided ample CHC but were insufficient when coupled with a desire to extend their fathers' lives with terminal conditions. Valuation and standardization provide mechanisms for understanding how the treatment preferences of patients are ultimately seen as inappropriate and even prohibited in the name of patient-centered care. Moreover, these processes reproduce racialized and classed patterns in whose treatment preferences are devalued. My findings demonstrate how processes of valuation and standardization among clinicians and within racialized and classed organizations account for the emergence of additional inequality in EOL communication, decision-making, and outcomes in ways past literature has not fully explained.

In these data, the determination that less aggressive treatment should be prioritized left those who favored life-sustaining treatments more likely to experience tension, conflict, or distrust in their interactions with physicians and less able to receive the interventions they desire. Timmermans and Epstein (2010:84) emphasize "every standard inevitably implies an evaluation at the expense of some other, and often obfuscated, devaluation." In valuing good deaths characterized by symptom management, hospice, less time in the hospital, and the chance to return home, physicians devalue "doing everything" to maintain hope or faith or simply prolong a patient's life—as in the cases Ms. Rosset and Mr. Haynes. The organizational standardization of specific values is evident in how physicians speak about futility and their application of rigid treatment pathways, as in the cases of Ms. Rosset, Mr. Ortiz, and Mr. Todd. Limited institutional tolerance for diverse values inevitably discounts marginalized perspectives (Lamont 2012).

Race, Class, and Marginalized Perspectives

Organizationally devalued preferences are not randomly distributed (Cain et al. 2018; Pew Research Center 2013). Patients who were mostly White, college educated, and middle-class or higher were more likely to share the preferences of their physicians for comfort-and-control-focused EOL care. Individuals with marginalized backgrounds were more likely than advantaged peers to favor treatments physicians considered aggressive, including being in the ICU, being mechanically ventilated, and delaying death through all possible means. The different valuations of treatment made by many marginalized patients are not only different tastes but also informed by the material resources they possess (Abramson 2015) and the implications of those resources for the types of comfort and control they can provide, as it was for Mr. Parker; the frequency and depth of their experiences with illness and pain (Cockerham, Hamby, and Oates 2017), as it was for Mr. and Mrs. Cleary; and ongoing (and often racialized) experiences of trust and conflict in medical spaces (Ashana et al. 2022; Hansen, Hodgson, and Gitlin 2016; Jaiswal and Halkitis 2019; Smith 2010), as it was for Mr. Glendale and Mr. Parker.

The hospitals' valuation and standardization of "good deaths" preferred by those with the most power represent organizational mechanisms through which unnamed Whiteness and wealthiness become obscured or decoupled from expectations, processes, and decision-making resulting in clear racial and SES inequities (Lamont 2012; Ray

2019). For example, hospital futility policies and unilateral "do-not-resuscitate" orders, whose use expanded during the COVID-19 pandemic, are disproportionately used to deny agency to patients and families who are already profoundly marginalized in health care spaces (Rosoff 2013). The idealization of home hospice is another example of how EOL care often ignores the experiences of marginalized groups (Russell et al. 2017). Throughout these data, we also see examples of attending physicians excluding from care or consultation those who they do not trust to enforce the deaths those attending physicians value as good. In this way, we see processes of valuation and standardization working both against some patients and to police professional practices in ways that suggest credible mechanisms by which Ray's (2019) racialized organizations also enforce Whiteness at the interactional level.

Limitations

There are limitations to this study's methods and data. First, observations were conducted in a single geographic region, and there may be geographic heterogeneity in patient/family and provider interactions and in clinical practices. However, when I queried clinicians, they did not note differences about life-sustaining treatments compared to other institutions where they trained or practiced. Differences across regions, especially those with distinctive legal frameworks such as New York, should still be explored. Second, data elicited directly from patients in this study is limited because I did not explicitly seek out conversations with patients. Religion beliefs and practices, which can also be racialized, were not explored explicitly in this analysis, although patients and physicians held a variety of religious/spiritual beliefs. Given this article's focus on interactions between patients/families and providers, I have largely not discussed how training and professional development contribute to valuation practices, or biases, among clinicians. Finally, data collection was completed just prior to the start of COVID-19 pandemic in the United States. COVID-19 has had a disproportionate impact on low-income and marginalized groups and a worrying effect on family visitation and communication (Valley et al. 2020).

CONCLUSION

These findings demonstrate the reproduction of inequality in health care may occur through two additional mechanisms: in *valuation*, as the attitudes and values of the socially disadvantaged are challenged and ignored, and in subsequent *standardization*, as the outcomes preferred by less socially advantaged groups are defined as undesirable in formal hospital policies. Furthermore, these mechanisms can be seen as evidence of the ways in which organizations are racialized and classed and allow inequities to reproduce even while espousing commitments to diversity or patient-centeredness (Ray 2019). Other research, in medicine and beyond, has often focused on how individuals' institutional knowledge and cultural dispositions allow them to accrue advantage or fall further behind (Calarco 2018; Clair 2020; Gage-Bouchard 2017). My research extends our understanding on inequities, focusing on how organizations and institutions themselves reflect the values of socially advantaged groups. I demonstrate that medical institutions reflect the preferences and attitudes of the socially advantaged. Inequality is reproduced not just because socially advantaged individuals know the rules of the game but also because they design the rules to support their values.

ORCID ID

Katrina E. Hauschildt [iD] https://orcid.org/0000-0002-1000-2275

SUPPLEMENTAL MATERIAL

The Appendix is available in the online version of the article.

REFERENCES

Abramson, Corey. 2015. *The End Game: How Inequality Shapes Our Final Years*. Cambridge, MA: Harvard University Press.

Anspach, Renee R. 1997. *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery*. Berkeley: University of California Press.

Anspach, Renee R., and Sydney Halpern. 2008. "From Cruzan to Schiavo: How Bioethics Entered the Culture Wars." Pp. 33–63 in *Bioethical Issues, Sociological Perspectives*, edited by B. Katz Rothman, E. M. Armstrong, and R. Tiger. Oxford, UK: Elsevier Ltd.

Ashana, Deepshikha Charan, Adina Jan, Alice Parish, Kimberly S. Johnson, Karen E. Steinhauser, Maren K. Olsen, and Christopher E. Cox. 2022. "Interpersonal Perception: Family- and Physician-Reported Conflict in the Intensive Care Unit." *Annals of the American Thoracic Society* 19(11):1937–42.

Blackhall, Leslie J., Gelya Frank, Sheila T. Murphy, Vicki Michel, Joycelynne M. Palmer, and Stanley P. Azen. 1999. "Ethnicity and Attitudes towards Life Sustaining Technology." *Social Science & Medicine* 48(12):1779–89.

Bourdieu, Pierre. 1986. "The Forms of Capital." Pp. 46–58 in *Handbook of Theory and Research for the Sociology of Education*, edited by J. Richardson. New York: Greenwood Press.

Cain, Cindy L. 2021. "Valuing Black Lives and the 'Good Death' in the United States." *Sociology of Health & Illness* 43(8):1840–44.

Cain, Cindy L., and Sara McCleskey. 2019. "Expanded Definitions of the 'Good Death'? Race, Ethnicity and Medical Aid in Dying." *Sociology of Health & Illness* 41(6):1175–91.

Cain, Cindy L., Antonella Surbone, Ronit Elk, and Marjorie Kagawa-Singer. 2018. "Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision-Making." *Journal of Pain and Symptom Management* 55(5):1408–19.

Calarco, Jessica McCrory. 2018. *Negotiating Opportunities: How the Middle Class Secures Advantages in School*. Oxford, UK: Oxford University Press.

Carr, Deborah. 2012. "The Social Stratification of Older Adults' Preparations for End-of-Life Health Care." *Journal of Health and Social Behavior* 53(3):297–312.

Clair, Matthew. 2020. *Privilege and Punishment: How Race and Class Matter in Criminal Court*. Princeton, NJ: Princeton University Press.

Clouston, Sean A. P., and Bruce G. Link. 2021. "A Retrospective on Fundamental Cause Theory: State of the Literature and Goals for the Future." *Annual Review of Sociology* 47:131–56.

Cockerham, William C., Bryant W. Hamby, and Gabriela R. Oates. 2017. "The Social Determinants of Chronic Disease." *American Journal of Preventive Medicine* 52(1, Suppl. 1):S5–12.

Dubbin, Leslie A., Jamie Suki Chang, and Janet K. Shim. 2013. "Cultural Health Capital and the Interactional Dynamics of Patient-Centered Care." *Social Science & Medicine* 93:113–20.

Emerson, Robert M., Rachel I. Fretz, and Linda L. Shaw. 2011. *Writing Ethnographic Fieldnotes*. Chicago, IL: University of Chicago Press.

Fagerlin, Angela, and Carl E. Schneider. 2004. "Enough: The Failure of the Living Will." *The Hastings Center Report* 34(2):30–42.

Fox, Renée C. 1981. "The Sting of Death in American Society." *Social Service Review* 55(1):42–59.

Gage-Bouchard, Elizabeth A. 2017. "Culture, Styles of Institutional Interactions, and Inequalities in Healthcare Experiences." *Journal of Health and Social Behavior* 58(2):147–65.

Gengler, Amanda M. 2020. *"Save My Kid": How Families of Critically Ill Children Cope Hope and Negotiate an Unequal Healthcare System*. New York: New York University Press.

Gengler, Amanda M., and Megan V. Jarrell. 2015. "What Difference Does Difference Make? The Persistence of Inequalities in Healthcare Delivery." *Sociology Compass* 9(8):718–30.

Giacomini, Mita K., and Deborah J. Cook. 2000. "Users' Guides to the Medical Literature: XXIII. Qualitative Research in Health Care: A. Are the Results of the Study Valid?" *JAMA* 284(3):357–62.

Glaser, Barney G., and Anselm L. Strauss. 1965. *Awareness of Dying*. Chicago, IL: Aldine Publishing Company.

Hansen, Bryan R., Nancy A. Hodgson, and Laura N. Gitlin. 2016. "It's a Matter of Trust: Older African Americans Speak about Their Health Care Encounters." *Journal of Applied Gerontology: The Official Journal of the Southern Gerontological Society* 35(10):1058–76.

Hart, Bethne, Peter Sainsbury, and Stephanie Short. 1998. "Whose Dying? A Sociological Critique of the 'Good Death.'" *Mortality* 3(1):65–77.

Hauschildt, Katrina, and Raymond De Vries. 2020. "Reinforcing Medical Authority: Clinical Ethics Consultation and the Resolution of Conflicts in Treatment Decisions." *Sociology of Health & Illness* 42(2):307–26.

Howarth, Glennys. 2007. "Whatever Happened to Social Class? An Examination of the Neglect of Working Class Cultures in the Sociology of Death." *Health Sociology Review* 16:425–35.

Jaiswal, Jessica, and Perry N. Halkitis. 2019. "Towards a More Inclusive and Dynamic Understanding of Medical Mistrust Informed by Science." *Behavioral Medicine* 45(2):79–85.

Jenkins, Tania M. 2015. "'It's Time She Stopped Torturing Herself': Structural Constraints to Decision-Making about Life-Sustaining Treatment by Medical Trainees." *Social Science & Medicine* 132:132–40.

Kaufman, Sharon. 2005. *And a Time to Die: How American Hospitals Shape the End of Life*. Chicago, IL: University of Chicago Press.

Kaufman, Sharon R. 2015. *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line*. Durham, NC: Duke University Press.

Lamont, Michèle. 2012. "Toward a Comparative Sociology of Valuation and Evaluation." *Annual Review of Sociology* 38:201–21.

Livne, Roi. 2014. "Economies of Dying The Moralization of Economic Scarcity in U.S. Hospice Care." *American Sociological Review* 79(5):888–911.

Livne, Roi. 2019. *Values at the End of Life: The Logic of Palliative Care*. Cambridge, MA: Harvard University Press.

Lutfey, Karen, and Jeremy Freese. 2005. "Toward Some Fundamentals of Fundamental Causality: Socioeconomic Status and Health in the Routine Clinic Visit for Diabetes." *American Journal of Sociology* 110(5):1326–72.

Marik, Paul E. 2014. "The Cost of Inappropriate Care at the End of Life: Implications for an Aging Population." *The American Journal of Hospice & Palliative Care* 32(7):703–708.

Morrison, R. Sean, Diane E. Meier, and Robert M. Arnold. 2021. "What's Wrong with Advance Care Planning?" *JAMA* 326(16):1575–76.

Mullins, Megan A., Julie J. Ruterbusch, Philippa Clarke, Shitanshu Uppal, Lauren P. Wallner, and Michele L. Cote. 2021. "Trends and Racial Disparities in Aggressive End-of-life Care for a National Sample of Women with Ovarian Cancer." *Cancer* 127(13):2229–37.

Nguemeni Tiako, Max Jordan, Victor Ray, and Eugenia C. South. 2022. "Medical Schools as Racialized Organizations: How Race-Neutral Structures Sustain Racial Inequality in Medical Education—a Narrative Review." *Journal of General Internal Medicine* 37(9):2259–66.

Pew Research Center. 2013. "Views on End-of-Life Medical Treatments." https://www.pewresearch.org/religion/wp-content/uploads/sites/7/2013/11/end-of-life-survey-report-full-pdf.pdf.

Rathore, Saif S., and Harlan M. Krumholz. 2004. "Differences, Disparities, and Biases: Clarifying Racial Variations in Health Care Use." *Annals of Internal Medicine* 141(8):635–38.

Ray, Victor. 2019. "A Theory of Racialized Organizations." *American Sociological Review* 84(1):26–53.

Rosoff, Philip. 2013. "Institutional Futility Policies Are Inherently Unfair." *HEC Forum* 25(3):191–209.

Russell, David, Eli L. Diamond, Bonnie Lauder, Ritchell R. Dignam, Dawn W. Dowding, Timothy R. Peng, Holly G. Prigerson, and Kathryn H. Bowles. 2017. "Frequency and Risk Factors for Live Discharge from Hospice." *Journal of the American Geriatrics Society* 65(8):1726–32.

Sallnow, Libby, Richard Smith, Sam H. Ahmedzai, Afsan Bhadelia, Charlotte Chamberlain, Yali Cong, Brett Doble, et al. 2022. "Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life." *The Lancet* 399(10327):837–84.

Shim, Janet K. 2010. "Cultural Health Capital: A Theoretical Approach to Understanding Health Care Interactions and the Dynamics of Unequal Treatment." *Journal of Health and Social Behavior* 51(1):1–15.

Silveira, Maria J., Stephen R. Connor, Susan D. Goold, Lawrence F. McMahon, and Chris Feudtner. 2011. "Community Supply of Hospice: Does Wealth Play a Role?" *Journal of Pain and Symptom Management* 42(1):76–82.

Small, Mario Luis. 2009. "'How Many Cases Do I Need?' On Science and the Logic of Case Selection in Field-Based Research." *Ethnography* 10(1):5–38.

Smith, Sandra Susan. 2010. "Race and Trust." *Annual Review of Sociology* 36:453–75.

Starr, Paul. 1982. *The Social Transformation of American Medicine*. New York, NY: Basic Books.

Tavory, Iddo, and Stefan Timmermans. 2014. *Abductive Analysis: Theorizing Qualitative Research*. Chicago, IL: University of Chicago Press.

Thévenot, Laurent. 2009. "Governing Life by Standards: A View from Engagements." *Social Studies of Science* 39(5):793–813.

Timmermans, Stefan, and Marc Berg. 2003. *The Gold Standard: The Challenge of Evidence-Based Medicine and Standardization in Health Care*. Philadelphia, PA: Temple University Press.

Timmermans, Stefan, and Steven Epstein. 2010. "A World of Standards but Not a Standard World: Toward a Sociology of Standards and Standardization." *Annual Review of Sociology* 36:69–89.

Valley, Thomas S., Amanda Schutz, Max T. Nagle, Lewis J. Miles, Kyra Lipman, Scott W. Ketcham, Madison Kent, Clarice E. Hibbard, Emily A. Harlan, and Katrina Hauschildt. 2020. "Changes to Visitation Policies and Communication Practices in Michigan ICUs during the COVID-19 Pandemic." *American Journal of Respiratory and Critical Care Medicine* 202(6):883–85.

Zaman, Shahaduz, Hamilton Inbadas, Alexander Whitelaw, and David Clark. 2017. "Common or Multiple Futures for End-of-Life Care around the World? Ideas from the 'Waiting Room of History.'" *Social Science & Medicine* 172:72–79.

AUTHOR BIOGRAPHY

Katrina E. Hauschildt is on the faculty of the Division of Pulmonary and Critical Care Medicine at The Johns Hopkins University. After receiving her PhD from the University of Michigan Department of Sociology, she completed an Advanced Fellowship in Health Services Research at the Veterans Affairs Ann Arbor Health System. Her research interests include health care organization and delivery, health disparities, and qualitative methodologies. Her current work focuses on identifying and addressing drivers of inequity in and after critical illness.