Whose Good Death? Understanding Inequality and the End of Life

by

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I am forever in awe of the generosity of my participants. Over 300 physicians, patients, and families allowed a stranger to observe and ask questions about profoundly emotional and trying moments in their lives. This dissertation is my attempt to learn from these moments, but the stories it contains are gifts from my participants. I sincerely hope there is something in here that honors these gifts.

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Dog walks and cuddles on the couch are the most basic and intense joys of any day, and their prints are on every page of this dissertation.

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ABSTRACT

Traditionally disadvantaged groups are more likely to want life-sustaining treatments and are the beneficiaries of greater spending and intervention at the end of life, yet these outcomes are considered disadvantageous by clinicians and scholars. This dissertation investigates how diverse individuals experience end-of-life health care, and how and when differences become disparities. First, I use Health and Retirement Survey data to demonstrate racial and socioeconomic differences in end-of-life preferences and decisions and demonstrate preferences for more aggressive treatment are correlated with a lower likelihood of congruent decisions. Second, I employ ethnographic and interview methods to examine communication and decision-making about life-sustaining treatments and find that population-level inequities arise through 1) clinical patterns of valuation and standardization in medicine, and 2) differences in institutional resources among hospitals that treat demographically different populations. Collectively, my findings reinforce the need for a nuanced understanding of the mechanisms that produce inequality when designing health care interventions focused on alleviating disparities. Further, this research reveals how cultural tastes influence the clinical valuation of treatments and provides clinicians and policymakers with strategies for improving the health care experiences of disadvantaged groups.

CHAPTER 1

Introduction

"Death is not a binary state or a simple biological fact but a complex social choice."
— Sandeep Juahar

Sandeep Juahar ended his *New York Times* opinion piece on the matter of brain death with these words, his essay one of more than 65 articles on the topic of death and dying published by the paper in 2019. Indeed, the topic of death and dying generates extensive discussion among clinicians, academics, and in the media, much of it centered on the inherently moral, and social, notion of "good deaths": What medical treatment ought to be provided, what ought to be said, where someone ought to be when they die. And like many complex social phenomena, it is also unsurprising that inequality, a defining feature of American social life, appears to shape an individual's experience of a "good death."

However, how inequality plays a role in death and dying remains imprecise, raising methodological and theoretical questions about how we define and measure inequality. Traditionally, health and health care disparities research has found socially advantaged groups are better able to access expensive and high-technology medical treatments (Agency for Healthcare Research and Quality 2017). Research on death and dying in the 1960s suggested

some evidence of this pattern at the end of life as patients with fewer financial resources or those perceived as lacking social worth were provided with less life-sustaining treatments (Glaser and Strauss 1965; Sudnow 1967). Drawing on ethnographic work in the early 1990s, Timmermans found similar patterns in resuscitative care. Although these studies either did not examine or find systematic differences by race, some other studies at the end of the 20th century did identify racial and socioeconomic differences in survival after cardiac arrest (Becker et al. 1993; Ebell et al. 1997; Hallstrom et al. 1993). This body of research pointed to two important contexts of end-of-life (EOL) treatment during this period: 1) doctors were the primary decision-makers about life-sustaining treatments, and 2) that such decisions may have led potential disparities in outcomes—who got more or less life-sustaining treatment.

More recent research, however, points to two important shifts in treatment at the end of life. First, a broader conversation about appropriate treatment for dying patients, which began around the same time as the publication of Glaser and Strauss' (1965) *Awareness of Dying*, has led to increased public attention to death and dying and the development of specialty medical treatment for terminally ill patients. Favoring hospice and palliative care for dying patients is increasingly normative among medical professionals and some members of the public (largely White, college-educated individuals) (Hauschildt and De Vries 2020; Livne 2019; Pew Research Center 2013). However, public opinion surveys and studies of advance directives suggest such attitudes are by no means universal, and Black and Hispanic patients and those with lower socioeconomic status (SES) are more likely to prefer more aggressive treatment at the end of life (Barnato et al. 2009; Frost et al. 2011; Pew Research Center 2013).

Second, social and demographic differences in EOL care have shifted. Black and Hispanic individuals, and those from lower socioeconomic groups, are now more likely to receive life-sustaining treatments in the last six months of life (Burgio et al. 2016; Muni et al. 2011; Quill et al. 2014) and more money is spent during this time on their care (Byhoff et al. 2016). Does this mean earlier disparities in outcomes have been addressed? Perhaps, yet the families of patients from social disadvantaged groups are also less likely to report satisfaction with their and the patient's EOL experiences (Gries et al. 2008; Lee et al. 2016; Teno et al. 2015). Given a robust field of research suggesting inequities in communication and biases in medicine contribute to the poorer health care experiences of racial minorities and less educated patients (Burke et al. 2017; Mack et al. 2010; van Ryn and Burke 2000; Smedley, Stith, and Nelson 2003), differences noted in satisfaction with EOL experiences may arise through disparities in doctor-patient interactions, apart from differences in outcomes or medical treatments. These findings suggest inequality at the end of life may be driven by disparities in processes, apart from outcomes.

A lack of social consensus around ideal treatment for the dying, alongside racial and socioeconomic variation in treatment decisions and satisfaction with health care experiences, complicates efforts to define and measure how and whether patients have "good deaths." Should good deaths be measured in treatment outcomes—i.e., which treatments patients receive? Should good deaths be measured processes of care – communication and decision-making between patients, families, and clinicians? Variation across processes and outcomes also hinders efforts to identify, measure, and ameliorate inequality. Without a clear understanding of how physicians, patients, and families feel about life-sustaining treatments and EOL health care, it is challenging to design interventions to improve this care. Who should make decisions about patients' EOL

health care, and to accomplish what ends? Most importantly, how does social inequality operate at the end of life in the setting of all this variation? Our understandings of inequality at the end of life remain murky.

This dissertation investigates how different EOL health care experiences occur, how participants in end-of-life decisions account for these different experiences, and the consequences of these accounts for the production of social inequality. I use a combination of methods and draw on national survey data, ethnographic observations in intensive care units (ICUs), and interviews with physicians and patients' family members to explore racial and socioeconomic differences in EOL experiences and identify the mechanisms that shape inequality at the end of life. I focus on the ICU setting because many forms of aggressive or life-sustaining treatments are primarily provided in the ICU and therefore communication and decision-making about these interventions takes place frequently in this setting. Additionally, many Americans will spend time in an ICU at or near the end of life; over 40% of Medicare recipients are admitted to an ICU in the last six months of life (Wennberg and Cooper 2020). In this introduction, I will provide an overview of the kinds of technologies and treatments considered for critically ill and dying patients in the intensive care setting, followed by a brief description of the original data collection and an outline of the dissertation by chapter.

Treatments for Critically Ill and Dying Patients
In trying to understand potential differences or disparities in EOL treatment and the decisions patients, families, and physicians may make about EOL treatment, it is helpful to understand the range of medical interventions and treatments considered for critically ill and dying patients.

Treatment options today include technologies whose primary goal is to extend or prolong life as well as treatments whose primary goal is the alleviation of unwanted symptoms caused by illness and the dying process, and thus are often considered part of distinct pathways in treating dying patients. The former category is often referred to as life-sustaining treatments or therapies (LSTs) and is defined as any "medical treatment that is intended to prolong the life of a patient who would be expected to die soon without the treatment" (Foglia et al. 2019, pg. 29). Most commonly, and particularly among acutely ill patients, LSTs include ventilatory support, hemodialysis, artificial nutrition, and cardio-pulmonary resuscitation (CPR).

Modern ventilatory support uses pressurized air to open the airway and inflate the lungs (Mehta and Hill 2001). Two forms of ventilatory support are delivered in the ICU and thus often considered LST for patients at or near the end of life. First, hospitals can provide heated high-flow oxygen via nasal cannula (HHFNC), which provides heated, humidified air with up to 100% oxygen concentration through a tube that sits just inside the nasal passage (Hyzy 2020). Although hospitals vary in whether this treatment requires intensive care unit (ICU) admission, the hospitals I observed for Chapters 2 and 3 all required HHFNC to be administered in the ICU, as patients requiring this amount of oxygen support have a high risk of acute complications.

Second, mechanical ventilation may involve intubation—i.e., ventilation may be administered through an endotracheal tube (entering the nose or mouth and into the trachea) or tracheostomy tube (through the skin directly into the trachea) (Walter, Corbridge, and Singer 2018). This more invasive ventilation allows for greater protection and suctioning of the airway, as well as generally greater control of the volume, frequency, and expiratory pressure of breathing (Walter

et al. 2018). Many forms of EOL planning specifically consider invasive ventilation, and patients may to choose "do not intubate (DNI)" instructions. Often, but not always, endotracheal intubation and ventilation are accompanied by sedation to minimize patient discomfort.

Hemodialysis is used to treat kidney failure and involves filtering metabolic waste out of the blood using an external machine (The National Institute of Diabetes and Digestive and Kidney Diseases 2018). Intermittent hemodialysis (IHD), often received at outpatient dialysis clinics, may allow patients to continue living for many years. Continuous renal replacement therapy (CRRT) provides uninterrupted dialysis for patients with acute kidney failure who are too sick to handle the fluid shifts that occur in traditional IHD (Golper 2020). CRRT requires close management by a critical care nurse and cannot be provided outside of an acute care setting. At the end of life, both IHD and CRRT may be considered life-sustaining treatments.

In the acute setting, artificial nutrition may include nutrition support delivered via a tube through the nose and into the stomach (a nasogastric tube) or via a tube through the abdominal skin and directly into the digestive tract (a PEG tube) (Seres 2019). It could also include total parenteral nutrition (TPN), which refers to nutritional support delivered via an intravenous line (Seres 2020). Patients may require artificial nutrition to continue living because of underlying illness or because another therapy, like mechanical ventilation, does not allow them to eat safely. For patients with terminal illnesses such as end stage cancer or dementia, artificial nutrition is considered an LST and may be part of EOL planning discussions (Marcolini, Putnam, and Aydin 2018).

The most commonly discussed life-sustaining treatment is cardiopulmonary resuscitation (CPR). CPR in the hospital, or advanced cardiovascular life support (ACLS), itself consists of multiple interventions including chest compressions, defibrillation (shocks), medications like vasopressors to raise the blood pressure, and the use of bag valve masks or intubation to maintain ventilation for patients who aren't breathing (Pozner 2020). Whether a patient would like CPR performed, referred to as code status, may be discussed or revisited at multiple points during a patient's hospital admission, including in the emergency department, upon admission to the ICU, prior to surgery, or when new diagnostic or prognostic information becomes available. Most electronic health records now have specific processes for documenting code status. For example, patients may elect to be intubated for surgical procedures or breathing complications but still choose to forgo resuscitative efforts, and this would be recorded as "do-not-resuscitate (DNR), okay to intubate." Clinicians generally discourage offering other aspects of CPR piecemeal or performing "partial codes" (Baumrucker et al. 2015); although among critically ill patients with DNR orders, aspects of ACLS, such as ventilatory support and vasopressive medications, may already be in use to treat the patient's acute illness.

Clinicians generally consider many the therapies described above aggressive treatment for critically ill and dying patients. These therapies are substitutes for fundamental organ function and without them patients will quickly die. Many of these therapies are hospital- or ICU-based therapies—meaning patients requiring these kinds of support are unable to leave the ICU or hospital. Physicians, patients, and families may feel differently about the acceptability of beginning or continuing therapies that will not allow the patient to leave the hospital, particularly if it becomes unclear or unlikely the patient could eventually live without that treatment.

Often but not always considered in contrast to LSTs are palliative care, comfort care, and hospice, or treatments whose primary goal is the alleviation of unwanted symptoms. Hospice care arose in the late 1960s and early 1970s and sought to challenge prevailing notions of care for the dying, to advocate for acknowledging the dying process, and to minimize physical and emotional suffering at the end of life (Livne 2014). Modern hospice care in the United States is available to patients expected to live less than six months and is primarily provided to patients in their homes (National Institute on Aging 2017). A hospice service provides all care management for the patient including medications, medical supplies, psychosocial treatment and spiritual support. While hospice staff are available by phone around the clock, home hospice requires family caregivers to provide much of the day-to-day care patients need (National Institute on Aging 2017). In the US, the Medicare hospice benefit also requires patients who choose hospice care to forgo curative treatments for the condition which led to their enrollment in hospice.[1]

Palliative medicine as a distinct medical specialty arose out of the hospice movement and includes treating the physical and psychosocial symptoms of serious illness in patients and their family members prior to and at the end of life, primarily in the hospital setting (Livne 2019). Palliative care treatments include medications or other treatments to address pain, shortness of breath, nausea, anxiety, or any other symptoms patients experience, as well as spiritual support and/or psychosocial support for family members (Kelley and Morrison 2015). Palliative care can also include discussing goals of care with patients and families. Palliative care treatments can be

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[1] Few hospice providers will enroll patients who may need other expensive curative or life-sustaining care (i.e., a patient with advanced cancer who enrolls in hospice may still find it difficult to access treatment for end-stage renal disease) (Livne 2014).

provided by any clinician, including in the outpatient setting, but are also commonly provided by specialists certified in palliative medicine. While palliative care is ideally available for any patient with serious illness and can be provided concurrently with curative treatments, the limited availability of palliative care physicians suggests many specialists spend a significant amount of their time discussing treatments for patients at the end of life (Kelley and Morrison 2015).

Comfort care is a term generally used to refer to aggressive symptom management for patients who are imminently dying (Blinderman and Billings 2015). The specifics of comfort care may vary from patient to patient but involve assessing proactively what treatments are needed to provide comfort and what treatments should be removed if they do not contribute to making a patient comfortable. Comfort care often includes providing medications for pain, shortness of breath, nausea, constipation, and/or other symptoms, and may include palliative sedation leading to limited or no consciousness (Blinderman and Billings 2015). It may also include the removal of medications, tubes, lines or other treatments that are not seen as necessary for advancing a patient's comfort. While comfort care does not explicitly preclude the use of life-sustaining treatments, many LSTs are viewed as inherently uncomfortable and thus considered incompatible with focusing on comfort.

Decisions about life-sustaining treatments and palliative care are often seen as embedded within larger conversations about patients' values, goals, and wishes. These conversations are sometimes referred to as a kind of treatment in and of themselves: goals of care (GOC) conversations. Efforts to align this framing with documentation in the medical record and billing procedures resulted in a provision within the Affordable Care Act to allow physicians to bill for

advance care planning discussions (Carr and Luth 2017). While these conversations have achieved procedural status for billing purposes, the extent to which formal didactics and training consider communication about life-sustaining treatments a distinct procedure requiring supervision and sign-off remains limited and varies significantly by training program (Dickinson 2011; Litauska et al. 2014; Mills, Rhoads, and Curtis 2015).

Research Questions and Original Data Collection

Patients and families at or near the end of life thus face many choices about various treatments, including decisions about when to start, continue, or withdraw treatments. From previous research, we can see the myriad ways in which shifting attitudes about death and dying (Livne 2019), differences in patients' wishes (Pew Research Center 2013), differences in the treatment patients receive (Quill et al. 2014), and differences in communication between patients and physicians (Periyakoil, Neri, and Kraemer 2016; Shavers, Bakos, and Sheppard 2010; Welch, Teno, and Mor 2005) could lead to less than good deaths for less advantaged and/ or minority patients. However, in the context of this variation, understanding when differences should be interpreted as reflective of heterogeneous cultural attitudes towards death and dying versus disparities resulting from inequities in how patients from different social backgrounds are treated remains difficult (Rathore and Krumholz 2004). A more complete examination of inequality needs to articulate how differences in treatment take place – for example, through patient or family requests, or through physicians' recommendations or communication styles – and how these different trajectories are defined as good or bad by those involved. This dissertation sought to answer the following questions:

1) To what extent and how do the EOL experiences of patients of different race/ethnicities or SES differ?

   A) What differences exist in patients' and families' stated preferences and reported health care decisions?

   B) Are there differences in whether health care decisions align with patients' and families' preferences?

2) How do differences in patients' and families' EOL experiences arise?

   A) How do patients/ families pursue different kinds of EOL experiences?

   B) Do patients' sociodemographic characteristics, as well as patients' preferences and decision-making styles, impact physicians' attitudes about treatment and how they communicate with patients and families about EOL decision-making?

   C) Do patients' and families' EOL experiences vary between hospitals? Do racial and socioeconomic differences in EOL experiences vary between institutions? How do hospital-level factors influence EOL experiences?

3) How do physicians and patients' family members evaluate patients' EOL health care and the quality of that care? What is central to their recollections of their EOL health care experiences?

Survey Analysis

I begin this exploration of EOL differences by using quantitative analysis of secondary survey data to explore race and class differences in EOL preferences, decisions, and the congruency between those two outcomes. While this analysis is not sufficient to answer the questions posed

above, it is helpful in laying the groundwork for potential avenues of qualitative inquiry.

Qualitative methods were best suited to identifying the processes that took place in EOL

decisions and how these processes were interpreted by those involved in accounting for overall

EOL experiences.

Observations and Interviews

I conducted observation in multiple intensive care settings to observe the processes of EOL

treatment decisions and communication between doctors and patients and/or their family

members. I also conducted follow-up interviews with physicians and patients' family members. I

chose the ICU setting because I wanted to observe how decisions developed and were made in

the context of life-sustaining interventions. Although advance care planning (ACP) has been

advocated for decades, and efforts to facilitate the establishment of advance directives have

received substantial attention and funding (Carr and Luth 2017), many patients' wishes are still

unknown, unclear, and/ or not documented when their doctors and families are confronted with

making decisions about life sustaining treatment (Shapiro 2015). Observational methods allowed

me to witness interactions as they occurred, rather than relying on participants' recollections of

events (King, Keohane, and Verba 1994; Small 2009). I also conducted semi-structured

interviews with physicians and family members of ICU patients to better understand how they

approached communication and decision-making in the ICU. Interviews provided insight into

how family members and physicians experienced the use of LSTs and EOL communication and

decision-making (Pugh 2013; Weiss 1994). By combining interviews with observations, I gained

a more complete picture of communication, decision-making, and the meaning attached to what

was said and done in the ICU (Giacomini and Cook 2000).

Observations in the ICU meant shadowing the physician team on their morning rounds and throughout the day. I tried to attend any family meetings that were planned and to observe as much impromptu physician-physician, physician-patient, or physician-family member communication as possible, including listening to updates provided by phone. I took notes in a small notebook I could hold while standing and entered these notes into the computer when there were lulls in communication activity, such as after rounds when the ICU team wrote their notes and orders for the day, or when I returned home in the evening.2 Although I wrote down as much verbatim communication as possible, I refrained from extensive notetaking in family meetings when I felt it was obtrusive and then wrote or typed notes about the meeting immediately afterward.

Interviews with family members and physicians varied somewhat, as interviews with family members were focused on their specific ICU experience and the patient's care, while interviews with physicians asked about their thoughts and approaches to LSTs and EOL care more generally, supplemented by asking about specific anecdotes or stories that exemplified their experiences (Interview guides are available in the Appendix). I sought to recruit a diverse interview sample both across and within hospitals, although regardless of patient gender, family members most involved in communication and decision-making tended to be women, which is largely consistent with the findings of other studies of surrogate decision-making among hospitalized patients (Katz, Van Scoy, and Sherman 2012; Shapiro 2019; Torke et al. 2014).

2 At TMC, I was required to store data on VA network computers and in secure VA facilities; I therefore remained at the hospital each evening until I finished entering my daily notes.

How Data Collection Unfolded

When I proposed this project, I anticipated spending approximately 4-6 months observing

treatment decision-making for patients in 2-3 intensive care settings. I sought to identify

hospitals in different cities that served demographically distinct patient populations. Ultimately, I

conducted data collection at four hospitals: two in Greenville (Truman Medical Center and

College Hospital) and two in River City (Memorial Hospital and North General Hospital). These

cities and hospitals are described in more detail in later chapters.

However, identifying these sites and gaining access to their ICUs was not straightforward. First,

it always involved sponsorship from an attending physician. Beyond sponsorship, however,

hospitals proved to have unique requirements, often tied to Institutional Review Board (IRB)

application and approval. At the first hospital, Truman Medical Center (TMC) in Greenville, I

was required to become an employee, which required additional paperwork, training, and

background checks. After six months of preparation, I began data collection at my first field site

in June 2018. When I planned to start follow-up interviews, however, additional modifications

had to be made and approved by the IRB to accommodate conducting interviews over the phone.

Intensive data collection at the first field site occurred between June and August 2018, with

intermittent observations periods occurring through November 2018. I finished conducting

interviews with family members in February 2019.

TMC proved to be an ideal first site due to a smaller overall ICU patient population and because

fewer patients were very critically ill. The pace allowed to me to spend time learning aspects of

critical care medicine, the jargon that accompanied it, and the generic processes and hierarchies

of intensive care units, while also following closely the patients that were potentially at the end of life. This would have been substantially more difficult at the other hospitals I observed. My observation schedule varied depending on field site logistics, other time obligations, and honing over time the best practices for observation. Data collection at TMC informed how I carried out later observations, allowing me to conduct more focused, intensive data collection over a shorter period of time at later hospitals. That said, there were inevitably small communications I missed between physicians, or between physicians and patients or family members. I did my best to observe the breadth of communication that took place in each ICU and follow as many cases closely as possible.

Identifying later field sites meant gathering support from new physician contacts for referrals and introductions. Even with support, previously identified sites fell through, often early on (other research was already being conducted on EOL care, other researchers already observing in the ICU, etc.), but also later on, after IRB applications had been submitted. I made contact with the ICU director at my second and third field site in late September 2018 and completed simultaneous IRB submissions in late December: at my home academic institution, the academic institution of the field site's faculty physician service, and to the review committee of the hospitals. In early June 2019, I obtained IRB approval for data collection at the second and third hospitals and conducted two months of intensive observation at each hospital between July 2019 and October 2019. I completed interviews with family members from Memorial and North General hospitals in January 2020.

Mid-way through data collection at the River City hospitals, I felt additional observation in Greenville was necessary to clearly identify the mechanisms driving some differences observed between TMC and the River City hospitals. After multiple rounds of IRB applications, I had become more skilled at preparing applications and anticipating and addressing potential issues. I submitted my application for IRB approval in November 2019 and after a few contingencies were addressed, received approval in late December 2019. I conducted observations at College Hospital in January and February 2020. Interviews with family members were completed in March 2020.

I generally sought to contact family members 6-8 weeks after their ICU stays. Initially, I had planned to contact family members at 4 weeks, but given early delays in starting interviews at TMC, and the intensity of data collection at later hospitals, I found it easiest to schedule and conduct interviews when I was not in the field. I also aimed to be sensitive to and flexible with family members and didn't schedule interviews during the holidays. Family member interviews were ultimately conducted 5-18 weeks after the patient's observed ICU stay.

Physician interviews took place between June and July 2019 and between February and March 2020. I suspended physician interviews in mid-March 2020 as the coronavirus pandemic meant many critical care physicians and hospital residents were unable to take time away for interviews and because the pandemic altered the provision of ICU care and deeply changed processes of communication and decision-making about EOL care. In total, I conducted more than 150 days of observation in ICUs, 30 interviews with physicians, and 39 interviews with patients' family members between June 2018 and March 2020.

Positionality, Interaction, and Emotional Labor

In observations and interviews, my goal was to convey friendly professionalism; however, as a White, female, graduate-level researcher, I had varied levels of social distance from physicians, patients, and family members. First, processes designed to obtain informed consent were also demonstrations of competency and authorization. Research documents, by design, foregrounded my institutional affiliation and title in addition to the substantive goals of research. Introductions and informed consent paperwork contributed to establishing my credibility but also invoked positive and negative associations participants had with research broadly and with the University of Michigan specifically.

With physicians, my identity as a doctoral student seemed to help establish credibility and some early rapport, although physicians' comments reveal varied assumptions about my medical sophistication. Trainees often assumed I could sympathize with their experiences of medical school and residency, including the long hours and comparatively low pay, which further established connection. However, physicians were not equally comfortable with my presence, and sometimes I was not told about expected family meetings. These instances were few and did not follow any pattern of physician role or visible physician or patient identity (gender, age, race or ethnicity). My research occurred at teaching hospitals and in ICUs; patients and families appeared used to interacting with multiple staff and being observed by large teams as part of the hospital experience. I reiterated any time I met any new family member that I was not part of the medical team, and that my research was distinct from their medical care. And yet, patients and

families often viewed me as another member of the hospital staff and/or clinical team, even when I made my role clear.

In observations, I aspired to make patients, families, and physicians comfortable with my presence but also hoped they would attend to it as little as possible; I tried to position myself unobtrusively, either in a corner or to the side during meetings. During observations, patients and family members occasionally confused sociology with social work and asked for related assistance or information from me; I made sure in these instances it was clear I was a researcher but also did my best to pass along these requests to an appropriate staff person. If they asked for water, or tissues, I would get these items for them. I tried to make clear to families I was not medically trained.

How actively to participate during fieldwork posed an ongoing dilemma for me (Anspach 1997; Anspach and Mizrachi 2006; Rowling 1999). Should I give a resident feedback about a family meeting that just occurred when they asked for it? Should I correct a miscommunication in seeing information relayed from resident to attending or from medical student to family? If I saw a family becoming increasingly frustrated waiting to talk to a doctor, should I remind the doctor the family was waiting? Should I mention the family's frustration? I generally abstained, and for better or worse, I found when I did pass along information, its influence was generally minimal—for example, letting physicians know families were waiting didn't lead them to rush to the bedside or stop what they were doing. On a few occasions, family members asked what I would do in their situation. I did my best to deflect these questions, pointing out I had neither

clinical expertise nor personal expertise about their family member, but similar to clinicians'

feelings about these inquiries, I wasn't always sure this was the best response.

Prior to some interviews, family members had specific questions about what I planned to do with

the information that was shared. I explained that I hoped to understand and explain family

members' experiences for fellow researchers and clinicians, and that hopefully this work would

help identify ways to improve care. I emphasized that patients' and families' names, or other

unique or identifying details, would not be included in anything I wrote. While these questions

came up infrequently, more Black patients' family members raised them than White or Hispanic

patients' family members. In interviews, I also tried to be aware of how social distance might

impact what participants felt comfortable disclosing. I sought to explicitly ask about bias or

prejudice when family members described what they felt was inadequate or inappropriate

treatment or communication. In these instances, I specifically asked Black family members about

racial bias. In interviews with physicians, I asked about their thoughts on racial and class

differences in EOL health care at the end of interviews after we had established some

conversational rapport. My own biases and assumptions also likely shaped topics about which I

asked follow-up questions or chose to probe more deeply.

As others have noted, emotional investment and empathy are fundamental to the relational nature

of ethnographic and interview-based research (Gair 2012; Watts 2008). Such empathy is core to

"seeing things through another's eyes" or "walking in their shoes". At the same time, the

appropriateness of the visibility of researcher emotion to participants is the subject of robust

debate (Gair 2012). Rowling (1999) describes the paradox of "empathic distance": emotional

connection is essential to making participants comfortable with the researcher's presence during or when discussing deeply personal experiences, but the researcher must also maintain critical distance to focus on participant's experiences, emotions, and thoughts. I became more comfortable as the research progressed with my non-verbal responses to events in the ICU: a look of concern when families voiced their grief, tears in my eyes after the death of a patient, a supportive glance at a resident during a goals of care conversation. During observations, I realized these responses made participants more comfortable with my presence and in turn less likely to attend to it.

Like others studying critical illness, death, and dying (Burr 1996; Rager 2005; Rowling 1999), I found this research emotionally difficult. I did my best to maintain my role as researcher and to focus on understanding the thinking and feeling of all the participants, but transference inevitably occurred at times, both with staff and families. As the project progressed it required more emotional labor. As I sought to ensure I had observed a sufficient number of cases, the steady stream of human tragedy came to the forefront of my observations. At times I dreaded the early mornings, long drives in traffic, late nights, and the sadness I absorbed. I found the work exhausting, emotionally and physically. Mostly, I felt lonely: lonely in my observations and lonely in my thoughts about them. Occasionally, stories I found particularly upsetting, due to the grief of the families, the frustration of the team members, or the injustices of our health and social welfare systems, continued to bother me for days or weeks. I eventually sought mental health care to manage the emotional labor that accompanied this research, and I wish I had done this earlier. I am acknowledging this because I want to continue normalizing the need for

debriefing and external resources in the setting of conducting emotionally difficult research (Rager 2005).

How Data Analysis Unfolded

Data analysis began during data collection. I wrote brief memos on potential patterns and interesting events, and, drawing on Smalls' (2009) model of sequential case study, used this limited analysis to hone ongoing and future data collection. These brief, single page memos helped shaped case and site selection as observations progressed. For example, the addition of College Hospital was driven by a need to observe specific phenomena that varied between TMC and the River City Hospitals. That said, while I had hoped to collect and analyze data concurrently, rigorous data analysis occurred during the periods I was not in the field. It was challenging to balance the time required for detailed observation in the ICU with other tasks and responsibilities. Most observation periods meant 5-6 days/week of data collection; each day consisted of 10-12 hours in the ICU plus additional time to transfer and expand on any written notes I had gathered late in the day. Observations in River City also included an hour commute each way. At the same time, I was emotionally exhausted during data collection, and this impacted the bandwidth I had for the intellectual demands that more systematic analysis required.

When I was in between field sites, I read through my field notes in their entirety, began hand coding these notes, and began writing more detailed outlines on various themes and patterns I identified (Emerson, Fretz, and Shaw 2011). I also began analyzing interview data as I collected it, transcribing key passages and including these in the outlines derived from my field notes. All

interviews were eventually transcribed in full. I referred to Tavory's and Timmermans' (2014) description of abductive analysis to identify meaningful variation and patterns which could generate broader empirical and theoretical claims about the mechanisms which shaped inequalities. An abductive approach also meant I focused my analysis of the most recently collected data on evidence which supported, refuted, or refined the empirical and theoretical arguments I had developed from earlier data collection.

Summary of Chapters

Chapter 2, "Unequal Treatment(s)? Racial and Socioeconomic Differences in Preferred and Actual End-of-Life Outcomes," acts as starting point for this dissertation, providing a broad view of racial and socioeconomic differences in EOL preferences, decisions, and congruency between preferences and decisions using Health and Retirement Study exit interviews collected between 2002-2016. While much research has sought to document racial and socioeconomic disparities in EOL health care, little research has specifically examined disparities in whether EOL decisions align with patients' stated preferences. Recent survey research suggests people disagree about what health care should be provided to patients at the end of life, and that an increasing proportion of the public would choose aggressive treatment for themselves (Pew Research Center 2013). Yet the "good death" that has become increasingly normative among health care professionals emphasizes maximizing quality of life and minimizing aggressive interventions (Livne 2019). I hypothesize that individuals with preferences for more aggressive treatment are a) more likely to be racial minorities or those of lower SES and b) more likely to experience health care decisions incongruent with their preferences, and that these differences may help account for disparities in congruency. I find strong evidence of racial and socioeconomic

differences in preferences and health care decisions, but less evidence of differences in whether care is congruent with patients' written preferences. However, more aggressive treatment preferences are a consistent predictor of incongruent decisions. These findings emphasize the need for more research which explores a) how preferences may contribute to inequality in EOL health care experiences, and b) why and how decisions depart from patient's written preferences.

In Chapter 3, "Life Sustained or Death Standardized: Novel Mechanisms in the Reproduction of Inequality," I draw on the ethnographic and interview data I collected and focus on understanding the experiences of patients and families whose care preferences differ from the clinicians treating them. What are the implications of differing views on appropriate EOL medicine in how EOL health care is experienced by patients, family members, and physicians? I demonstrate that traditional mechanisms of health disparities, including flexible resources (Phelan, Link, and Tehranifar 2010) and cultural health capital (Shim 2010), impacted EOL care and that additional inequality emerged through institutional processes of valuation and standardization. Cultural values shaped clinical assessments, disagreements about valuation shaped communication with patients and families, and ultimately, the efforts to standardize appropriate care shaped the kinds of life-sustaining treatments that were available to patients at the end of life. These findings highlight the limitations of focusing on more easily measurable aspects of EOL health care, which draws attention away from the social processes of care that undergird the social experience of death and dying for patients and families.

In Chapter 4, "Miles Apart: Race, Socioeconomic Status, and Institutional Inequities at the End of Life," I expand on understanding differences in processes of care using a comparative lens

between hospitals in different communities shaped by longstanding patterns of segregation of care. Previous hypotheses for disparities in EOL care have focused on the receipt of interventions (Orlovic, Smith, and Mossialos 2019) and disparities in communication (Periyakoil et al. 2016; White et al. 2007). Both of these hypotheses emphasize individual choices and actors as pathways to inequities. I demonstrate that communication and decision-making about life-sustaining treatments are shaped by the built environment, structure of service, and investment in ancillary and support services. Beyond patient preferences and provider biases, the segregation of care by race and SES is implicated in racial and socioeconomic disparities in EOL health care experiences through variation in the structure of care between hospitals. Importantly, these findings suggest a need to move beyond surface-level measures of access to understand the nuanced impact of the structure of care on differences in EOL experiences and in efforts to alleviate inequities in health care more broadly.

In the final chapter, I summarize and expand on the empirical findings of these three chapters, as well as how these how these findings contribute to broader debates within sociology and in interdisciplinary work on the end of life. I also explore the unanswered and emerging questions of this research and identify areas for future study. Finally, I explore a range of policy and practice changes that could be considered to alleviate inequalities at the end of life and in health care experiences more generally.

CHAPTER 2

**Unequal Treatment(s)? Racial and Socioeconomic Differences in Preferred and Actual
End-of-Life Health Care Outcomes**

While increasing attention to end-of-life (EOL) experiences in public policy (Institute of

Medicine 2015) and the rise of hospice and palliative care services in US hospitals have focused

on improving EOL experiences (Meier 2011), not all patients appear to benefit equally. Evidence

suggests that racial and socioeconomic inequality persists at the end of life (Carr 2016; Lee et al.

2016; Muni et al. 2011).

Yet, pinpointing the ways in which inequality persists is complicated in practice. The quality of

end of life has been measured by patients' experiences of pain, the use of aggressive

interventions in the last month of life, the location of death, entry into hospice, and quality

ratings from bereaved family members (Meier et al. 2016; Mularski et al. 2007). Many

explorations of inequality at the end of life are often rooted in the conception that a "good death"

can be defined by what is or is not done when someone is dying, and that these measures are

mostly universal—that good deaths are, in some ways, the same for all (DelVecchio Good et al.

2004; Marik 2014; Ornstein et al. 2017; Zhang, Nilsson, and Prigerson 2012). What health care

should be provided to patients at the end of life constitutes a large part of the discussion around

good deaths. However, recent survey research suggests that people disagree about what health

care should be provided for patients at the end of life and that these opinions differ in patterned ways across social groups. Further, the proportion of people who would want "everything done" even if they had an incurable illness increased from 14% to 20% between 1990 and 2013 (Pew Research Center 2013).

To better understand inequality in EOL experiences, it is critical to explore the diversity of these preferences and how they map onto the care patients receive. With some notable exceptions, much of the research on differences in planning and preferences for EOL health care is divorced from research on differences in treatment and satisfaction with care (Carr 2016; Lee et al. 2016; Orlovic et al. 2019). This means the quality of patients' EOL care is largely defined by what researchers and clinicians feel is better or worse, rather than whether patients and families get the treatment they want. A more complete picture of racial and socioeconomic differences in EOL experiences, from preferences to outcomes and congruency between the two, will shed needed light on potential mechanisms of inequality in EOL health care (Hopp and Duffy 2000).

As I will show, people define good deaths differently and have different treatment preferences at the end of life in ways that vary by race and socioeconomic status (SES). Further, my findings indicate there is important variation in whether patients' preferences for EOL care and the decisions made about that care align. Research on inequality at the end of life, and assessments of the quality of EOL experiences, should therefore be contextualized by the preferences of the dying person.

Good Deaths

A burgeoning literature has sought to identify and describe what a good EOL experience looks like. Research has suggested that characteristics include pain and symptom management, a sense of control, preparation for death, and affirmation of the "whole person" (Carr 2016; Clarke, Korotchenko, and Bundon 2012; DelVecchio Good et al. 2004; Steinhauser et al. 2000). More recently, Livne (2019) has theorized that ideas about good EOL experiences are increasingly dominated by a turn to palliative care and hospice services, representing an alternate approach to medicine's traditional bias towards aggressive intervention and curative efforts. Livne (2019) posits that in this framing, EOL experiences are "economized": Patients should maximize their quality of life rather than the number of days they may live. There is evidence that this perspective has increasingly become normative among health care professionals (Hauschildt and De Vries 2020; Livne 2019; Weissman et al. 2016).

Research into public opinion, however, suggests there is far less consensus on what constitutes a good death. Systematic literature reviews of studies on good deaths and dying, while noting some agreement around specific outcomes, such as pain management, also find significant variance in how a good EOL experience is defined (Meier et al. 2016; Mularski et al. 2007). Meier and colleagues (2016) note differences depending on who is queried – patients, family members, or a variety of health care providers. Others contend that too much of this literature draws on the opinions of health care providers, White respondents, patients with particular diseases, or simply focuses on factors that are easier to describe and measure, such as pain management, use of a particular treatment, or location of death (Hales, Zimmerman, and Rodin 2008; Mularski et al. 2007). For example, a meaningful portion of the literature identifies aggressive treatment and heroic measures as inconsistent with a good death (DelVecchio Good et

al. 2004; Marik 2014; Orlovic et al. 2019; Ornstein et al. 2017; Zhang et al. 2012). However, some racial minority groups and individuals of lower SES were more likely than White and higher-SES individuals, on average, to prefer and pursue aggressive treatment (Barnato et al. 2009; Blackhall et al. 1999; Pew Research Center 2013). Thus, it is important to consider EOL outcomes that do not privilege the views of professionals or a given group of socially advantaged actors.

Differences in End-of-Life Experiences

Research shows that EOL experiences vary by race and SES. Welch, Teno, and Mor (2005) conducted survey interviews with a national sample of surviving relatives drawn from death certificates in 2000 and found evidence of racial differences in the perceived quality of care of the decedent and in whether the appropriate amount of life-sustaining treatment was given. More recent research also suggests racial and socioeconomic differences in EOL experiences, although many samples are either regional (Carr 2016; Lee et al. 2016; Muni et al. 2011) and/ or limited to patients with specific illnesses (Abdollah et al. 2015; Hernandez et al. 2015; Nayar et al. 2014; A. K. Smith, Earle, and McCarthy 2009). Black patients are more likely to receive cardiopulmonary resuscitation (CPR), to die with full life-support, and to experience reported discord between family members and clinicians (Burgio et al. 2016; Hernandez et al. 2015; Mack et al. 2010; Muni et al. 2011). Other research shows that lower-SES patients are more likely to die in in-patient settings rather than at home (Barclay et al. 2013; Carr 2016), and Nayar and colleagues (2014) report patients with lower SES are less likely than patients with higher SES to enroll in hospice. In an analysis of cancer patients, those who reported financial hardship were

more likely to receive resuscitation efforts or to be placed on mechanical ventilation than patients who didn't report hardship (Tucker-Seeley et al. 2015).

In addition to research documenting differences in EOL experiences, a small body of literature suggests preferences for aggressive treatment may contribute to racial differences in EOL experiences. For example, Lee and colleague (2016) find some evidence that the greater use of life-support by minority patients mediates the lower quality ratings of EOL experiences reported by surviving relatives. This could be because life-support itself decreases the quality of EOL experiences or because successful negotiation for such treatment is linked to greater conflict with clinicians. Other research suggests that a lack of congruency between wishes and care received could drive racial differences in ratings of satisfaction with care (Loggers et al. 2009; Silveira, Kim, and Langa 2010; Welch et al. 2005). Racial minorities are more likely to report that their preferences were not solicited in EOL experiences (Welch et al 2005). More recently, Loggers et al (2009) found that at one institution, among patients with advanced cancer who wanted aggressive treatment, White patients were more likely to receive it than Black patients. In a national survey of hospice patients, racial minorities reported numerous disparities in the quality of their hospice care, and Black and Hispanic hospice patients were less likely than White patients to have received care that was consistent with their wishes (Agency for Healthcare Research and Quality 2016).

This body of research provides some evidence that racial differences at the end of life may include disparities in whether patients receive EOL health care that is congruent with their preferences. Notably, in a representative sample of Medicare recipient deaths between 2011 and

2015, Sharma and colleagues (2017) examined bereaved family members' evaluations of the overall quality of EOL care received by their relative and found no significant racial differences. Orlovic and colleauges (2019), using the Health and Retirement Survey, separately examined racial differences in planning and health care outcomes, but did not examine whether planning or preferences mediated differences in health care outcomes. However, none of this research exploits a nationally representative dataset to examine whether preferences predict whether health care decisions and preferences are congruent—i.e., whether patients with reported preferences for more or less aggressive care are more or less likely to report decisions that aligned with that preference. Further, no research has yet determined whether preferences themselves may be related to potential racial or socioeconomic differences in congruent preferences and decisions.

Research Aims and Hypotheses

Using a large, national sample of adults over age 50, I describe differences by race and SES in EOL preferences and decisions and explore whether there are racial or socioeconomic differences in whether individuals' preferences align with the EOL health care decisions that are made. Drawing on sociological theory in death and dying, I hypothesize that preferences that are incongruent with an economized death are predictive of health care decisions incongruent with one's reported preferences. I also posit that incongruence between preferences and decisions is a potential avenue for understanding racial or socioeconomic differences in EOL experiences.

DATA AND METHODS

Dataset

The Health and Retirement Survey (HRS) is a nationally representative survey of adults over age fifty, sponsored by the National Institute on Aging and conducted by the University of Michigan. I use the consolidated HRS Rand longitudinal data file and exit interview files (Health and Retirement Study 2019, 2020).[3] I examine EOL experiences among all respondents who had exit interviews completed between 2002 and 2016.[4] Exit interviews were conducted with a respondent's proxy (most often a spouse or child) following their death. Much of the previous work using national samples has been limited to Medicare-enrolled populations which encompass the experiences of many, but not all deaths in the US. Many of these samples often exclude those whose deaths occur prior to age 65, individuals who become institutionalized prior to age 65, and others who are ineligible for Medicare (e.g., some immigrants). Including the EOL experiences of individuals whose deaths occur outside of the Medicare system is beneficial, particularly if examining inequality is a focus of the research. For example, nearly 23% of Black men alive at age 50 will die before age 65, compared to just over 8% of White women (Arias 2010). Using a younger, national sample provides a more accurate picture of EOL experiences across different groups. This descriptive paper will focus on three areas of potential differences in EOL health care experiences: preferences, decisions, and congruency between preferences and decisions.

Measures

EOL Preferences

[3] The RAND HRS Longitudinal File is an easy-to-use dataset based on the HRS core data. The RAND HRS Exit/Post-Exit Interview Files combine the Exit and Post-Exit Interviews into one dataset per survey year. The Finder File allows users to identify which years Exit and Post-Exit interviews are available for each respondent.
[4] Because some respondents lack data on some outcomes, sample size varies across analyses. See discussion for more information.

Preference questions were asked of proxy-respondents who specified the deceased respondent had written instructions about EOL preferences. Decedents whose proxies indicated they did not have written preferences were not asked the following questions about the nature of those preferences and were not included in any analyses which included these preference questions. In this analysis, EOL preferences were examined using three yes-no questions that asked whether the deceased respondents' written instructions expressed a desire "to receive all care possible under any circumstances in order to prolong life," "to limit care in certain situations," or "to have any treatment withheld."

EOL Decisions

EOL decision questions were asked of all proxy-respondents who responded "yes" to the question, "Did any decisions have to be made about the care and treatment of [the deceased respondent] during the final days of their life?" Proxy-respondents where then asked, mirroring the preference module, three yes-no questions about whether those decisions "involved a desire to give all care possible unconditionally in order to prolong life," "involved limiting care in certain situations," or "involved withholding any treatment."

EOL Congruency

Congruency outcomes were limited to deceased respondents whose proxy-respondents answered both the EOL preference and EOL decision questions. This measure was created by identifying whether the proxy-respondents' answers to the related preference and decision questions were congruent, i.e., the deceased respondents' written instructions specified a desire to have some

treatments withheld and a decision was made to withhold some treatments. Congruency could mean that responses to the preference and related decision questions were both yes or both no.

Independent and Control Variables

Race was reported at initial entry into HRS and recorded as non-Hispanic White, non-Hispanic Black, and Hispanic.[5] SES was measured by educational attainment (less than high school, high school diploma or GED, some college, and college degree or more), and household income at the previous wave (a summary measure of all income sources (Health and Retirement Study 2020)). Household income was measured in quartiles. I also controlled for age at death, year of death, and gender. In sensitivity analyses, I considered a dichotomous indicator of poverty and a summary measure of wealth instead of income; neither significantly altered the results presented below. I further considered indicators of partnership status (currently partnered or not), cause of death (cancer, cardiovascular, or other), and census region (Northeast, Midwest, South, and West), which also did not significantly alter the results presented. Finally, I considered a composite measure of preferences which includes responses to all preference questions[6]; including this composite measure versus individual outcomes assessed one at a time did not significantly alter patterns of race and socioeconomic differences in the models presented.

Analytic Approach

[5] The Rand HRS sample also includes respondents who reported other racial/ethnic identities; there were not sufficient respondents from other racial backgrounds for accurate statistical analyses.
[6] Proxy-respondents who indicated a preference to prolong life *AND* did not indicate a preference to limit care or have treatments withheld were categorized as having more aggressive preferences, proxy-respondents who indicated a preference to prolong life *AND* to limit care or have treatments withheld were categorized as having mixed preferences, and proxy-respondents who indicated a preference to limit care or have treatments withheld *AND* did not indicate a preference to prolong life were categorized as having less aggressive preferences.

I first calculated Pearson chi-square tests of significance to assess whether there were racial and socioeconomic differences between deceased HRS respondents with proxy-completed exit interviews and deceased respondents whose proxies specifically completed the preference and decision questions described above (See Figure 2.1). The total exit interview sample includes deceased HRS respondents who had a proxy complete an exit interview between 2002-2016 and for whom the core independent variables described above were available (N=10674). The preference sample consists of deceased respondents whose proxy indicated in the exit interview that the respondent had written EOL instructions and whose proxy answered yes or no to at least one of the preference questions (N=4386). The decision sample includes deceased respondents in the exit interview sample whose proxy indicated decisions were made about the treatment that the deceased respondent received in their final days and whose proxy answered yes or no to at least one of the decision questions (N=4380). The congruency sample consists of deceased respondents in the exit interview sample who answered yes or no to at least one set of corresponding preference and decision questions (N=2160).

I next compared the prevalence of each EOL outcome across racial/ethnic groups, educational attainment groups, and income quartile groups. Sample size varied slightly from above, as each substantive outcome (prolonging life, limiting care, or withholding treatment) was considered individually. In bivariate analyses, I calculated Pearson chi-square tests of the significance of between-group differences. Next, I examined racial and socioeconomic differences in EOL preference, decision, and congruency outcomes in logistic regression models that further controlled for age at death, year of death, and gender. I further controlled for preference when examining congruency outcomes. Non-Hispanic White respondents, respondents with less than a

high school degree, individuals in the lowest income quartile and female gender were the referent categories in these multivariable models. In congruency outcomes a "yes" response to the related preference question was the referent.

RESULTS

Differences in Respondent Samples

Because questions were asked of different segments of exit interview proxy-respondents, I first briefly describe the composition of each outcome group of deceased respondents and the larger population of deceased HRS respondents with completed exit interviews (See Table 2.1). Among deceased respondents with completed exit interviews, 76% were non-Hispanic White, 16.4% were non-Hispanic Black, and 7.6% were Hispanic. By income, 9% of deceased respondents in the exit interview sample were from the highest income quartile of all HRS respondents and 13% had a college degree or more, while 37% and 35%, respectively, were from the lowest income quartile of HRS respondents or had less than a high school degree. HRS respondents with higher SES appear under-represented in the exit interview sample, likely reflecting their lower likelihood of death at any given age.

There were clear racial and socioeconomic differences between decedents in the exit interview sample and the preference question sample, which includes only respondents whose proxies reported the decedent had written EOL instructions. Among deceased HRS respondents in the exit sample, proxy respondents indicated 49% of non-Hispanic White respondents had written advance directives, compared with 17% of non-Hispanic Black respondents, and 18% of Hispanic respondents. There were similar disparities between deceased respondents with higher

and lower SES: proxies indicated 33% of respondents in the lowest income quartile had written EOL instructions, compared to 51% of those in the highest quartile, and 31% of respondents without a high school degree had written EOL instructions, compared to 56% of respondents with a college degree or higher.

These demographic differences in proxy-reported written EOL instructions are reflected in the make-up of the preference and congruency samples, as shown in Table 2.1. Both the preference and congruency samples have a greater proportion of higher-SES and non-Hispanic White deceased HRS respondents. For example, over 90% of deceased HRS respondents in the preference and congruency samples are non-Hispanic White. The racial and SES backgrounds of deceased HRS respondents in the decision sample more closely approximate the larger exit interview sample, although there are still statistically significant differences.

Race and Socioeconomic Status Differences in End-of-Life Health Care Outcomes

I find evidence of racial differences in EOL preferences, health care decisions, and congruency between preferences and decisions, in bivariate analyses (Table 2.2). I also find strong evidence of socioeconomic differences in preferences and decisions, but not congruency, in bivariate models.

Differences in Preferences

In logistic regression models, I find that racial differences, and some socioeconomic differences, in preferences persist when controlling for both identities as well as age at death, year of death, and gender (Figure 2.2). Among those with written preferences, proxies reported Black

respondents were 14% more likely than White respondents to have written EOL preferences to prolong life, and 10% and 21% less likely than White respondents to have preferences to limit care in some situations or have treatments withheld, respectively. Proxies indicated Hispanic respondents were 7% more likely than White respondents to have a preference to prolong life, 8% less likely to report a preference to limit care, and 12% less likely to report a preference to have some treatments withheld.

There were fewer and smaller EOL preference differences by SES in the logistic models. Individuals of higher SES were less likely to express preferences aligned with prolonging life. Compared to deceased HRS respondents with less than a HS degree, those with some college, or a college degree, were 2% and 3% less likely, respectively, to have a proxy-reported EOL preference to prolong life. Proxies indicated deceased HRS respondents from both the 2nd and 3rd income quartiles were 2% less likely than deceased respondents from the lowest quartile to have written EOL preferences to prolong life, and both were also 3% more likely to have a preference to limit care in some circumstances. Deceased HRS respondents in the highest wealth quintile were 3% less likely than deceased respondents in the lowest wealth quintile to have proxy-reported written EOL preferences to prolong life, 4% more likely to have a preference to limit care, and 5% more likely to have a preference to withhold some treatments.

Differences in Decisions

Examining EOL decisions, I find racial and socioeconomic differences in EOL decisions in logistic regression models after adjusting for control variables (Figure 2.3). Deceased Black respondents were 24% more likely than deceased White respondents to have a proxy report that a

decision was made to prolong life, and 12% and 18% less likely, respectively, than White respondents to have experienced a proxy-reported decision to limit care in some situations or have treatments withheld. Deceased Hispanic respondents were 24% more likely than deceased White respondents to have a proxy report a decision was made to prolong life, 16% less likely to have a proxy-reported decision to limit care, and 16% less likely to have a proxy-reported decision to withhold treatments.

Socioeconomic differences in decisions were larger than socioeconomic differences in preferences. The trend remained similar; higher-SES respondents' proxies were less likely to report decisions aligned with more aggressive treatment. Deceased HRS respondents with a high school degree or GED were 4% less likely than those with less than a HS degree to have a proxy report a decision was made to prolong life and 5% more likely to experience a proxy-reported decision to limit care. Deceased HRS respondents with some college were 9% less likely than those with less than a HS degree to have a proxy report a decision was made to prolong life, and 4% and 5% more likely, respectively, to experience a proxy-reported decision to limit care or have treatments withheld. Deceased HRS respondents with a college degree or more were 8% less likely than those with less than a high school degree to experience a proxy-reported decision to prolong life, and 5% and 6% more likely, respectively, to experience a proxy-reported decision to limit care or have treatments withheld. There were fewer statistically significant differences by income in EOL decisions made; deceased HRS respondents in the 4th (highest) income quartile were 8% less likely than those in the 1st (lowest) quartile to have a proxy report a decision was made to prolong life, and 7% more likely to experience proxy-reported decisions to limit care or withhold treatments.

Differences in Congruent Preferences and Decisions

Finally, in logistic models of congruency outcomes there were few significant differences by race or SES when controlling for each other as well as age at death, year of death, gender, and preference. Although in bivariate analyses deceased Black and Hispanic respondents were 8% and 13% less likely, respectively, than deceased White respondents to have proxy-reported congruent preferences and decisions with regards to prolonging life, and deceased Hispanic respondents were also 13% less likely than deceased White respondents to have proxy-reported congruent preferences and decisions with regard to limiting care (See Table 2.3), these differences were not significant when other factors were included. In bivariate models there was also some evidence that higher-SES decedents were also more likely to have proxy-reported congruent preferences and decisions with regard to prolonging life, but these also were not significant when other factors were included.

In the fully adjusted model, deceased Black respondents were actually 9% more likely to have proxy-reported congruent health care preferences and decisions regarding withholding treatments at the end of life than deceased White respondents. This finding contrasts with my hypothesis and other research (Loggers et al. 2009; Welch et al. 2005) that Black decedents would be more likely than White decedents to experience care that departed from their stated preferences. Deceased respondents with a high school degree or GED were more likely to have proxy-reported congruent preferences and decisions with regard to limiting care than without a HS degree.

Preferences themselves were strongly associated with congruency (See Table 2.3). Deceased respondents with proxy-reported preferences consistent with less aggressive treatment were far more likely to have proxy-reported decisions that aligned with those preferences (Figure 2.4). Among deceased respondents whose proxies reported a written EOL preference to prolong life, 63% had a proxy report a health care decision was made that aligned with that preference; 89% of deceased respondents whose proxies reported they did not have a preference to prolong life experienced a proxy-reported health care decision that did not focus on prolonging life. In contrast to this pattern, 84% and 77% of deceased respondents whose proxies reported a preference to limit care or have treatment withheld experienced a proxy-reported health care decision that aligned with that preference; among those whose written EOL instructions did not express a proxy-reported preference to limit care or have treatment withheld, 52% and 54%, respectively, experienced an EOL health care decision that did not limit care or withhold treatment, respectively.

DISCUSSION

While much research has sought to document racial and socioeconomic disparities in EOL experiences, less research has explored how differences in preferences have influenced these disparities. The nature of a good, economized death presented by the contemporary palliative care and hospice fields appears to have become more normative among health care professionals (Hauschildt and De Vries 2020; Livne 2019), yet recent survey research suggests people hold divergent perspectives on what health care should be provided to patients at the end of life (Pew Research Center 2013). Connecting these two strands of study, in this study I examined race and socioeconomic differences in preferences, decisions, and congruency between preferences and

decisions in a national sample of US adults over age 50. I find strong evidence of racial and

socioeconomic differences in preferences and health care decisions, but less evidence of

differences in whether care is congruent with preferences. However, preferences contrary to

comfort-focused treatments are a consistent predictor of incongruent decisions. Although the

proxies of Black and Hispanic respondents, and respondents from lower-SES groups, are more

likely than the proxies of White and higher-SES respondents, respectively, to report preferences

aligned with aggressive treatment, and these preferences are associated with incongruency in

reported decisions, I did not find consistent evidence of racial differences in congruency. This

may be due to the small number of respondents, regardless of race or SES, for whom more

aggressive treatment preferences and decisions were reported.

These findings thus provide little evidence for the premise that decisions made "against" the

wishes of patients or their family members may contribute to racial and socioeconomic

disparities in the overall quality of EOL health care experiences, as reported in other studies (Lee

et al. 2016; Welch et al. 2005). However, incongruent preferences and decisions may not

necessarily be evidence that decisions were made against the wishes of a patient or their

surrogate decision-maker. Rather, they could also illustrate what Livne (2019) describes as one

of palliative care clinicians' main activities: drawing on patients' or their families' own values to

introduce and lead them to choosing an economized death that involves fewer interventions

and/or withholding some treatments at the end of life. Other studies suggest families may choose

to reject previously written directives because they feel the patient's written preferences have

changed, are not relevant to the current context, or are indeed persuaded by the medical team to

change course (Devnani et al. 2017; Shapiro 2019). Further complications to congruent decision-

making may be the result of changes in patients' preferences over time (Auriemma et al. 2014), and because surrogate decision-makers often have limited knowledge of patients' preferences (Fried et al. 2017; Shalowitz, Garrett-Mayer, and Wendler 2006), especially when asked to recall decisions made in the past. This study gauged congruency on the proxy-respondents' reported knowledge of the patients' preferences and their assessment of the decisions made, which may not have reflected patients' perspectives.

EOL planning itself may signal inequality in EOL experiences, both for patients and for family members. White respondents in the Health and Retirement Survey are much more likely to report written advanced directives (Orlovic et al. 2019) and as others have noted, there are stark differences by race and SES in formal advance care planning (Carr 2012a). Some advance care planning interventions have been linked to better quality EOL life experiences (Brinkman-Stoppelenburg, Rietjens, and van der Heide 2014) and lower levels of bereavement burden for surviving relatives (Carr and Luth 2017; Song et al. 2015). However, it is difficult to disentangle the contributing mechanisms to these differences; individuals with written advance directives are much more likely to prefer less aggressive interventions at the end of life (Brinkman-Stoppelenburg et al. 2014; Garrido et al. 2015). Given inequities in health care trust and resources, there are also racial differences in how written documents like living wills and DNAR orders are perceived and enacted (Johnson, Kuchibhatla, and Tulsky 2008; Rhodes and Teno 2009). These differences caution against assuming that differentially advantaged groups will benefit similarly from advance care planning.

Limitations

Survey design limits generalizability for EOL health care preference and experience outcomes. Because preference questions are only asked of those with written advance directives, I rely on a subset of respondents for, and am only able to compare, differences in preferences in that group of respondents. Decision outcomes are also limited to a somewhat different group of respondents, those whose proxies indicated that "decisions needed to be made about treatment in the respondent's final days." Consequently, congruency outcomes are further limited to a smaller sample of those respondents whose proxies answered both preference and decision questions.

Minority and lower-SES individuals who do have advance directives are arguably more likely to have similar preferences to White and higher-SES individuals than minority respondents without written advance directives (Braun et al 2008). This means that the racial and socioeconomic differences identified in my analysis likely underestimate differences in preferences in the US population. Given the analysis also shows that preferences appear to influence differences in whether respondents' proxies reported care that was congruent with respondents' written preferences, we could hypothesize that racial differences in congruency between preferences and treatment decisions are also underestimated in this analysis. There is certainly a need for more complete data on EOL experiences among respondents of nationally representative surveys. While other samples, such as the National Health and Aging Trends Survey, have begun collecting this data, many are limited to Medicare beneficiaries, and consequently individuals who die or become institutionalized before 65 are not included.

These findings cannot answer questions about how the EOL decision-making process unfolds and is understood by family members: how did surrogate decision-makers choices come to diverge from a patients' reported preferences? Did surrogates disagree with the patient's preferences and enact their own values (Shapiro 2019)? Were surrogates persuaded to choose differently? Were they ignored or overruled by health care providers or courts (Hauschildt and De Vries 2020; Rosoff 2013)? Qualitative research in this area would help identify how different EOL trajectories arise and how people evaluate whether a particular patient experienced a good death. Thus, while these findings are evidence of how preferences may influence EOL experiences and whether patients reportedly "get what they want"—and evidence of differences by race and SES—they leave open questions of how differences arise within decision-making and lead to different outcomes and are unable to answer how these different outcomes are evaluated by the physicians and family members involved.

Although limited by the scope of data available, these findings do suggest that shifting attitudes towards death and dying may be a future avenue for accounting for social differences in EOL experiences. Additionally, although numerous efforts to encourage advance care planning, particularly among racial and ethnic minorities, have been undertaken (Hong et al. 2018; MacKenzie et al. 2018), my findings suggest that there are limits to the effectiveness or usefulness of written preferences, and that preferences themselves may shape the quality of EOL health care in unanticipated ways. While inequality appears to persist at the end of life, the mechanisms that contribute to inequality deserve greater exploration in order to create effective health care and social policy for a diverse population.

Figure 2.1 Venn Diagram of Analysis Samples

Exit Interview Respondents
N=10674

Preference Sample
N =
4262-4355

Congruency Sample
N = 2092-2124

Decision Sample
N =
4278-4315
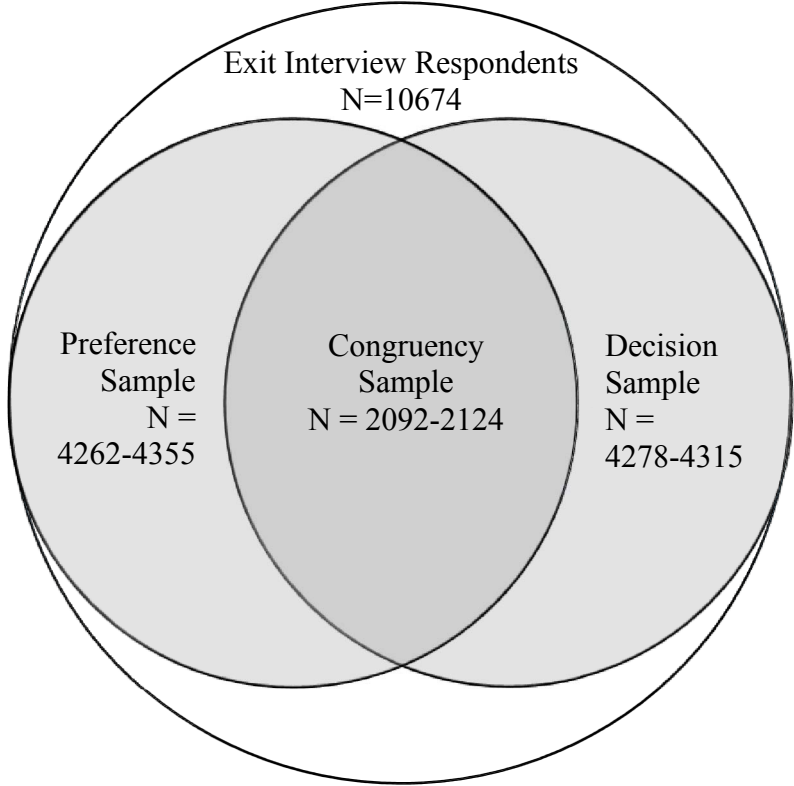
Table 2.1 Descriptives by Race and Socioeconomic Status of Outcome Samples

		Exit	Preferences	Decisions	Congruency
			Respondent Samples [a]		
Race	*White*	75.8	90.0	78.7	90.1
	Black	16.5	6.6	14.2	6.1
	Hispanic	7.7	3.4	7.1	3.8
			***	***	***
Education	*< HS*	34.8	26.0	33.1	25.1
	HS or GED	34.5	35.8	34.1	35.0
	Some College	17.7	20.5	18.2	20.9
	BA or more	13.0	17.7	14.6	19.0
			***	***	***
Income[b]	*1st Quartile*	36.8	29.5	35.5	28.5
	2nd Quartile	32.1	33.9	33.0	35.1
	3rd Quartile	21.7	25.0	21.6	24.2
	4th Quartile	9.4	11.6	9.9	12.3
			***		***
	N=	10674	4386	4380	2160

[a] Stars indicate that sample varies significantly from the larger exit sample
[b] Income quartiles are based on the HRS sample; higher income quartiles have had less overall mortality

Figure 2.2 Marginal Effects for Race and Socioeconomic Status on EOL Preferences
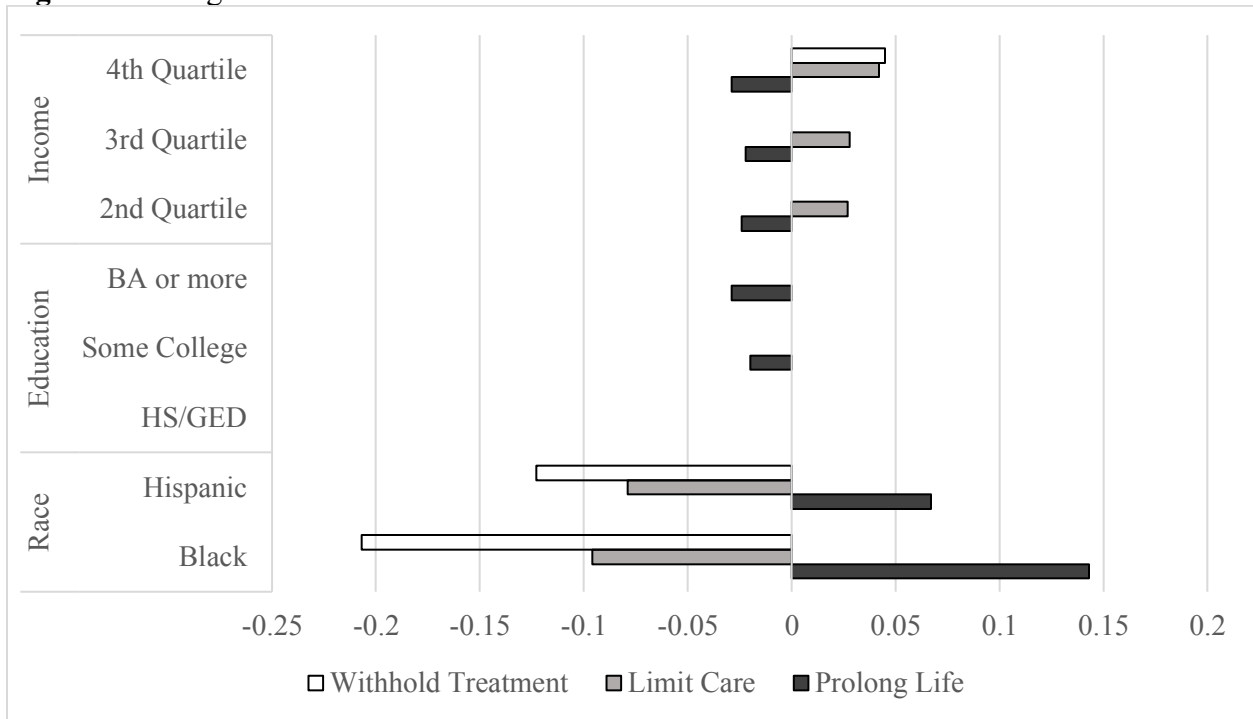
(Referent categories are the 1st (lowest) income quartile, less than a HS degree, and White race. Models include all control variables. All bars denote statistically significant differences.)

Figure 2.3 Marginal Effects for Race and Socioeconomic Status on EOL Decisions
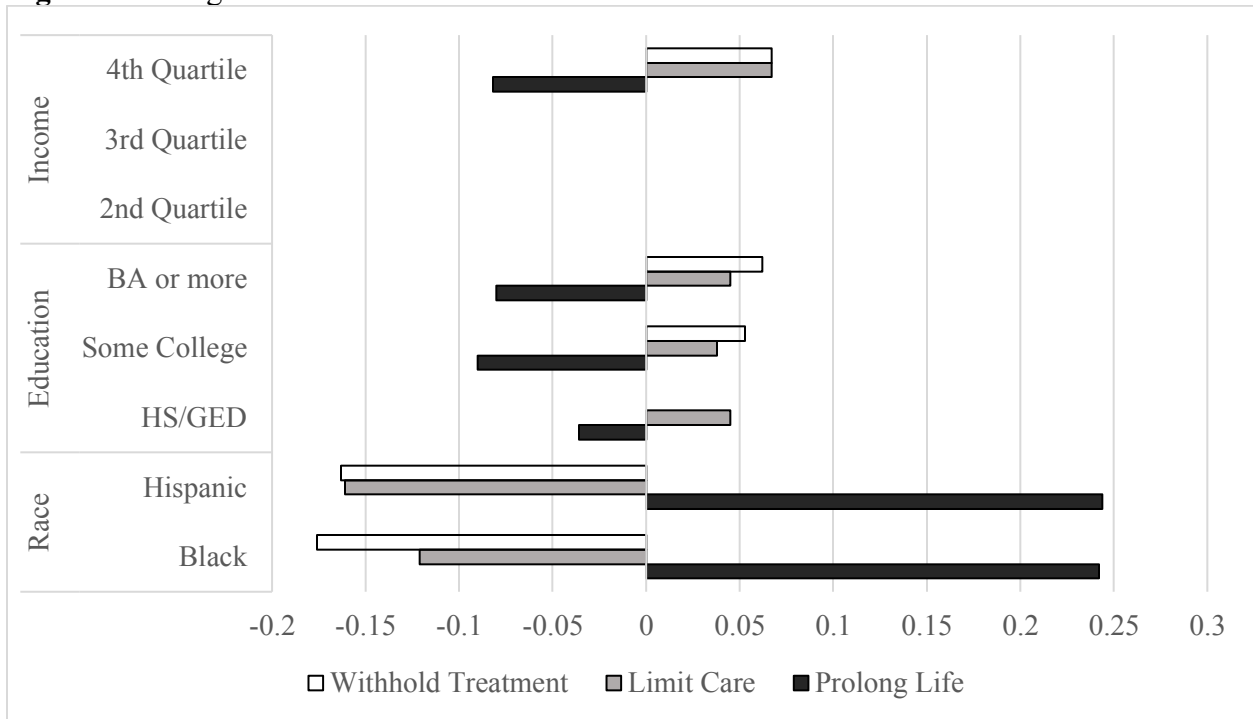
(Referent categories are the 1st (lowest) income quartile, less than a HS degree, and White race. Models include all control variables. All bars denote statistically significant differences.)

Figure 2.4 Predicted Probabilities of Congruent EOL Preferences and Decisions, by Preference
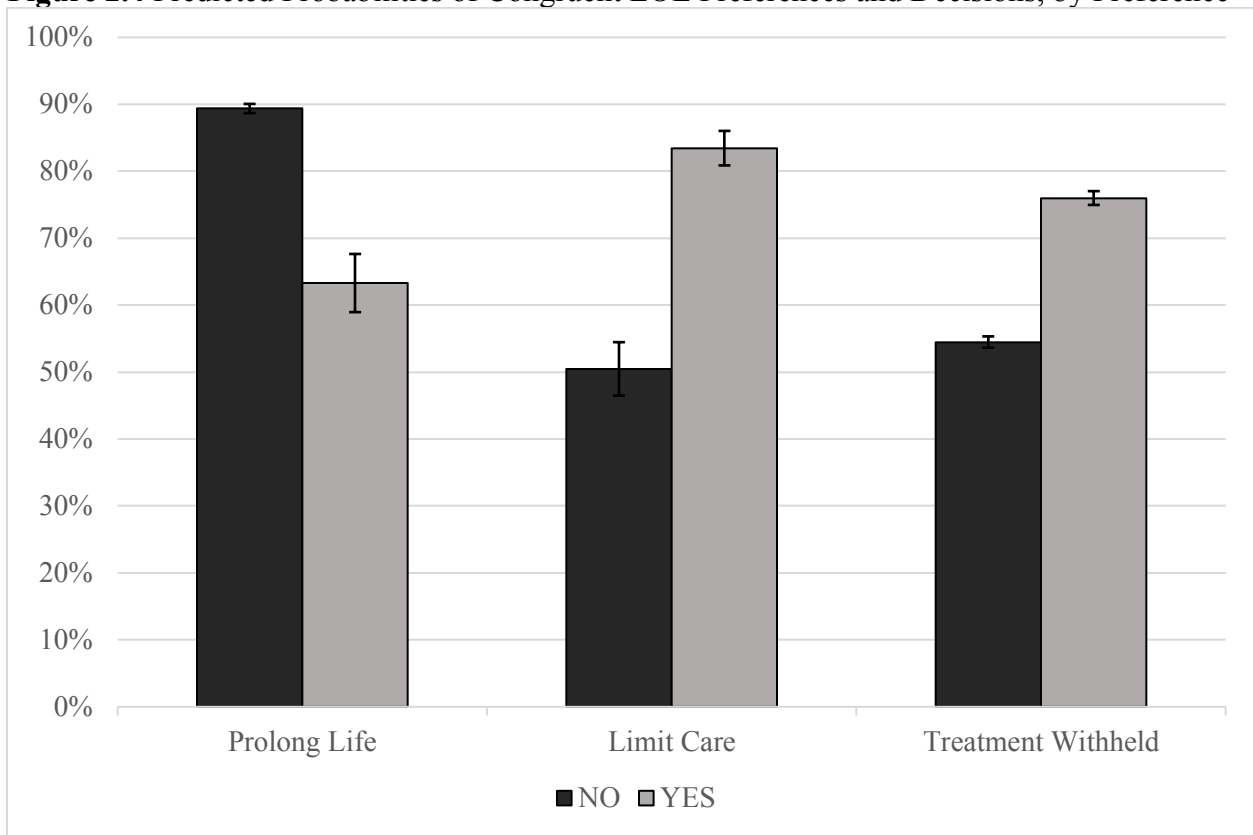
(Models include all control variables. Differences by preference are all statistically significant.)

Table 2.2 Bivariate Comparisons of Racial and Socioeconomic Differences in EOL Preferences, Decisions, and Congruency in Preferences & Decisions

	PREFERENCES			DECISIONS			CONGRUENT PREFERENCES AND DECISIONS		
	Prolong Life	*Limit Care*	*Withhold Treatment*	*Prolong Life*	*Limit Care*	*Withhold Treatment*	*Prolong Life*	*Limit Care*	*Withhold Treatment*
Race/ Ethnicity									
White	4.21	91.74	80.65	19.4	74.29	62.91	88.58	81.69	72.03
Black	23.69	79.51	57.95	50	58.77	42.16	80.77	75.97	75.76
Hispanic	16.44 ***	80.14 ***	65.97 ***	52.17 ***	53.69 ***	42.33 ***	75.32 ***	68.42 **	67.11
Education									
< HS	8.64	88.27	75.78	33.73	65	52.53	84.49	78.26	69.9
HS/GED	5.53	90.42	79.29	25.15	73.15	59.45	88.41	83.6	73.28
Some College	4.91	92.06	79.29	19.85	72.75	62.48	87.98	79.55	72.58
BA or more	3.77 ***	92.43 **	80.86 *	18.23 ***	75.12 ***	64.97 ***	89.9	80.69	72.22
Income Quartiles									
1st (Lowest)	8.05	87.9	77.42	31.3	67.13	54.21	84.95	79.5	73.53
2nd	5	91.37	78.4	24.6	71.38	59.06	89.05	82.81	72.5
3rd	5.32	91.46	78.86	23.61	72.53	61.41	87.74	79.3	69.25
4th (Highest)	4.36 **	92.89 **	82.02	17.25 ***	76.81 ***	65.73 ***	89.35	81.54	73.08
N=	*4355*	*4328*	*4262*	*4315*	*4278*	*4298*	*2124*	*2111*	*2092*

50

Table 2.3 Marginal Effects for Racial and Socioeconomic Differences in Congruency Between EOL Preferences and Decisions

	Models 1, 2, and 3			Model 4: Fully Adjusted		
	Prolong Life	Limit Care	Withhold Treatment	Prolong Life	Limit Care	Withhold Treatment
Race (*White is Ref*)						
Black	-0.078 **	-0.057	0.037	-0.003	-0.001	0.086 **
	(0.035)	(0.039)	(0.039)	(0.027)	(0.034)	(0.035)
Hispanic	-0.133 ***	-0.133 **	-0.049	-0.044	-0.049	0.006
	(0.050)	(0.054)	(-0.055)	(0.039)	(0.048)	(0.052)
Education (*< HS is Ref*)						
HS/GED	0.039 **	0.053 **	0.034	0.026	0.046 **	0.042
	(0.020)	(0.023)	(0.026)	(0.019)	(0.023)	(0.027)
Some College	0.035	0.013	0.027	0.019	0.014	0.042
	(0.022)	(0.026)	(0.029)	(0.022)	(0.026)	(0.030)
BA or more	0.054 **	0.024	0.023	0.032	0.019	0.045
	(0.022)	(0.027)	(0.030)	(0.023)	(0.028)	(0.032)
Income (*Lowest Quartile is Ref*)						
2nd Quartile	0.041 **	0.033	-0.010	0.022	0.022	-0.009
	(0.019)	(0.022)	(0.025)	(0.018)	(0.022)	(0.025)
3rd Quartile	0.028	-0.002	-0.043	0.015	-0.01	-0.039
	(0.021)	(0.024)	(0.027)	(0.021)	(0.026)	(0.029)
4th Quartile	0.044 **	0.02	-0.005	0.023	0.014	-0.01
	(0.024)	(0.029)	(0.033)	(0.026)	(0.031)	(0.036)
Yes Preference (*Ref is No*)				-0.164 ***	0.234 ***	0.189 ***
				(0.020)	(0.024)	(0.022)
	N=2124	N=2111	N=2092	N=2124	N=2111	N=2092

N=2124 N=2111 N=2092 N=2124 N=2111 N=2092 N=2111 N=2092 N=2124 N=2111 N=2092

(Model 1, 2, and 3 are bivariate logit models. Model 4 controls for age at death, gender, marital status, cause of death, and region of residence controls for preference.)

CHAPTER 3

Life Sustained or Death Standardized:
Novel Mechanisms in the Reproduction of Inequality

Sociologists have explored Western medicine's approaches to death and dying and demonstrated

changes over time in how physicians and the public think about the end of life (Anspach and

Halpern 2008; Glaser and Strauss 1965; Livne 2019). During the mid-20th century end-of-life

(EOL) experiences were characterized by aggressive, costly interventions, but increasingly a turn

towards palliative care and hospice has shifted away from such life-sustaining treatments. This

turn has been perceived by many in bioethics, social sciences, and clinical medicine as

improving medical treatment for the dying (Kaufman 2015; Livne 2019; Warraich 2017).

Overwhelmingly, contemporary studies of EOL health care identify greater intervention (such as

ER visits, hospitalization, ICU admission, CPR, and/ or inpatient deaths) as evidence of

inappropriate or lower quality EOL care (Abdollah et al. 2015; Bischoff et al. 2013; Marik

2014).

At the same time, scholars focused on inequality in health and health care demonstrate how

disparities in health care access, health literacy, adeptness in health care settings, and resources

for healthy living (re)produce disparities in health and health care. They generally find that when

compared to their more socially disadvantaged counterparts, those from socially advantaged groups tend to be better equipped to efficiently access health care, process and respond to health information, initiate and navigate interactions with health care and providers, and maintain resources that improve health (Dubbin, Chang, and Shim 2013; Gengler 2014; Phelan and Link 2013; Phelan et al. 2010; Shim 2010). Link and Phelan (1995; 2015) argue that this is because socioeconomic status (SES) embodies an array of "flexible resources" such as money, knowledge, and prestige that help individuals avoid risks and adopt protective strategies that promote health and wellbeing. Much of the research on differences in EOL care draws on this work, hypothesizing that disparities in health information and health care access, from knowledge about advance directives to access to hospice services, lead to disparate EOL experiences (Carr 2012b, 2016; Silveira et al. 2011).

Because views on what medical treatment should do, particularly for terminally ill patients, have changed over time, we know what counts as good medicine is not simply a reflection of objective physiologic knowledge, but socially constructed and reflective of cultural values—including cost considerations and moral arguments about what constitutes "a life worth living" (Anspach 1997; Jenkins 2015; Livne 2014, 2019). However, the role of differing social and cultural attitudes in defining and assessing disparities deserves greater attention, and we know little about how these definitions shape our perceptions of differences in care desired or received.

Nationally representative quantitative studies show persistent race and class differences in patients' preferences and values about EOL treatment, in the use of life-sustaining technologies in the last six months of life, and in families' reports of satisfaction with EOL treatment and care

(Frost et al. 2011; Lee et al. 2016; Muni et al. 2011; Pew Research Center 2013; Quill et al. 2014). Variation across these dimensions – preferences and values, treatment decisions, and satisfaction with EOL experiences – complicates efforts to define and alleviate social inequalities in EOL health care.

To avoid the normative assumptions of previous research, this paper asks what kinds of inequalities matter at the end of life, to whom they matter, and how they emerge. How do patients, families, and physicians reflect on the quality of EOL experiences? I employ ethnographic observation in 4 intensive care units (ICUs) and interviews with 39 patients' family members and 30 physicians and use an abductive approach to explores how differences in EOL communication, decision-making, and treatment are experienced by those involved and identify which mechanisms led to inequities in treatment experiences.

I found patterns of inequality that have been well-documented by prior research. Access to material resources and ease in speaking with physicians, for example, varied among patients and their family members in ways that explained some inequities: for example, why some patients accessed hospice or other services more quickly. However, these traditional patterns were only part of the story. When patients and family members disagreed with physicians about life-sustaining treatments, inequality emerged because of institutional actions of valuation and standardization of EOL care.

Patients and families from socially disadvantaged groups were more likely to experience a disconnect between the care and treatments they valued or desired and the treatments that

physicians felt were best, and thus were more likely to experience tension and conflict in their interactions with physicians. In some cases, valuation differences led to limitations on whether treatment requests would be honored. In these instances, physicians' attitudes towards death and dying influenced the value they assigned to particular treatments and led to additional burdens for patients and families requesting care physicians considered less valuable. Further, physicians' attitudes towards death and dying were increasingly incorporated into their assumptions about good medicine, and along with broader efforts to champion hospice and palliative care, led to the formalization of particular attitudes in standards of care and hospital policies. Given cultural differences between the majority of physicians and their patients from socially disadvantaged groups, these processes disproportionately negatively impacted patients and families from minority and lower-SES groups. In contrast with research which has primarily shown how the resources and abilities individuals bring to the health care encounter lead to disparities, I find institutions' own valuation and standardization processes are important and overlooked mechanisms by which inequality is reproduced.

Background

Evolving Practices in Treatment for the Dying

Early social theorists in medicine, from Parsons (1951) to Freidson (1988), contend that medical norms bias providers towards active, aggressive intervention. During the "golden age of doctoring," when physicians enjoyed substantial prestige and authority (Freidson 1988; McKinlay and Marceau 2013; Starr 1982), many terminally ill patients and their families were not positioned to challenge the recommendations made by their physicians, and in some cases were not even told they were dying (Glaser and Strauss 1965; Oken 1961). Life-sustaining,

aggressive interventions favored by providers in that era were gradually challenged over the next four decades by patients, other professional groups, and social movements (Anspach and Halpern 2008). In the 1970s, the growing field of bioethics raised questions of whether patients should have the right to refuse treatment and whether quality of life should be considered an important outcome in treatment decisions (Anspach 1997; Fox and Swazey 2008). A "death with dignity" movement also arose during this time, arguing that patients were entitled to open communication about death and dying and founding hospices as places patients could die a death free from medical interventions, with as little pain as possible (Kubler-Ross 1969; Livne 2019).

The development of palliative care as a medical specialization formalized this alternative to aggressive intervention *within* medicine (Livne 2019). Palliative care physicians championed the good death as one in which patients were able to prepare for and accept their death, decide where they would like to spend the end of life, experience as little pain as possible, and avoid inappropriate technological interventions. Growing concerns about aggressive interventions were also informed by efforts across medicine to contain costs and particularly to limit expenditures at the end of life that were perceived as evidence of ineffective spending (Livne 2019). Yet despite support for withdrawing/ withholding aggressive interventions amongst many physicians (Livne 2019; Zussman 1992) and policy efforts to document patients' wishes to decline aggressive interventions at the end of life (Patient Self-Determination Act 1990), it remains unclear whether and to what extent the American public has endorsed this definition of a good death.

The Evolving Good Death and the Public

Shifts in both societal values and professional attitudes towards aggressive interventions at the end of life were primarily led by White, middle and upper class, highly educated individuals. Religious conservatives still oppose both assisted suicide and the removal of many life-supporting medical interventions (Anspach and Halpern 2008; Pew Research Center 2013). Recent surveys have shown a doubling (since 1990) in the percentage of Americans who would prefer aggressive interventions if they had a terminal illness; over 1/3 of respondents would want doctors to do everything possible to a patient's life even in the context of an incurable disease (Pew Research Center 2013).

Differences in attitudes are more pronounced between racial and socioeconomic groups. While only 20% of White respondents and 18% of college graduates felt "medical staff should always do everything possible to save a patient's life", 59% of Hispanic respondents, 52% of Black respondents, and 43% of respondents with a high school degree or less thought everything possible should be done (Pew Research Center 2013). Qualitative studies on EOL planning have highlighted how differences in advance care planning (ACP) and preferences point to differences in cultural attitudes about death, religious beliefs, and fears about discriminatory treatment (Blackhall et al. 1999; Braun et al. 2008; Carr 2012a). Rosoff (2013) finds that despite attention to procedural justice in hospital futility policies[7] and state laws like the Texas Advance Directives Act, these policies disproportionally impact decision-making for minority patients and families. The literature above, demonstrating differences in the health care patients and their families favor, and the interactions patients and families have with health care institutions, suggest that inequality may be at work, but make it less clear which differences ought to be

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[7] Futility policies allow physicians to decline to offer treatments they believe are futile and lay out a procedure to do so.

counted as disparities and how they arise. For example, should differences in treatment be characterized as disparities, if and when patients and families pursue different treatments?

Theorizing Health and Health Care Disparities

I turn to existing theories on health and health care disparities, such as fundamental cause theory and the concept of cultural health capital, as starting points in hypothesizing how differences develop and how disparities are characterized in EOL health care trajectories. Link and Phelan suggest that SES is a fundamental cause of health disparities because it reflects the ability of individuals and groups to utilize flexible resources, such as money, time, and social connections, to avoid risks and employ protective strategies to maintain their health (Link and Phelan 1995; Phelan et al. 2010). Recent research has highlighted differential access to hospice services and advance care planning (ACP)[8] by SES and race, also suggesting that differences in knowledge and access to these kinds of EOL health care are the drivers of differences in outcomes (Carr 2012a, 2012b; Silveira et al. 2011). However, some argue that fundamental cause theory is limited in helping us understand differences when countervailing mechanisms are present which encourage individuals to prioritize other goals, for example *beauty* or *masculinity,* over *health and longevity* (Courtenay 2000; Lutfey and Freese 2005)*.* At the end of life, choices of more or less aggressive health care interventions are often characterized as choices between the goals of quality and quantity of life—i.e., pursuing health OR longevity. Consequently, flexible resources may differentially impact outcomes depending on what patients and physicians are pursuing and how interactions between patients, families, and physicians unfold.

[8] Advance care planning encompasses discussing and/or formally documenting one's preferences for treatment if one became acutely ill and could not speak for themselves at that time. ACP may include discussing one's wishes with a doctor or family member, assigning a durable power of attorney, or creating an advance directive specifying which treatments one would or would not like to receive.

Theories of cultural capital broadly, and cultural health capital specifically, argue that differences in the interactional navigation of institutions lead to unequal outcomes (Bourdieu 1986; Shim 2010). Cultural capital refers to the ways in which cultural knowledge and habits are seen as markers of status and competency and thus allow individuals with that cultural capital to accrue resources and opportunities (Bourdieu 1986). Cultural health capital is important in understanding how interactions between patients and providers may lead some individuals to obtain preferred treatments more quickly or more often than others (Shim 2010). Empirical studies find that differential navigation of health care networks, styles of advocacy, and patient reporting result in socially advantaged patients receiving more favor and attention from their physicians, which can lead to more effective and efficient care (Dubbin et al. 2013; Gage-Bouchard 2017; Gengler 2014). The EOL setting offers an opportunity to explore whether and how these interactional styles matter when patients, their families, and physicians may have fundamentally different ideas about what outcomes are best.

Despite the significant leverage that cultural health capital research has provided in understanding health and health care disparities, it does not adequately attend to how institutions themselves develop and reflect particular cultural preferences or tastes (Bourdieu 1984). The literature above makes clear the social attitudes and values shape ideas about good deaths and thus undergird clinical understandings of appropriate care. 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," for example (Pew Research Center 2013); see also (Blackhall et al. 1999; Zaman et al. 2017). The

end of life is thus an ideal setting to examine whether and how subjective differences in interpretations and valuations shape notions of appropriate medicine and reproduce inequalities through institutional practices, beyond the impact of patient resources and skills.

Turning to the sociology of valuation and standardization (Lamont 2012; Timmermans and Epstein 2010), I explore how these processes account for the emergence of inequality in EOL communication and decision-making. Valuation refers to the processes and judgements used to determine the worth of an entity (a treatment action, in this study) and standardization refers how these valuations are legitimated by institutions or fields (Lamont 2012; Thévenot 2009; Timmermans and Epstein 2010). Lamont (2012) hypothesizes that inequalities are more likely to advance in institutions or social spaces in which elements of organization and decision-making are in a fixed hierarchy—for example, when clinical judgment always outranks other considerations (Hauschildt and De Vries 2020). I hypothesize that in the context of coalescing attitudes about good death among clinicians, processes of standardization, exceedingly common in medicine (Thévenot 2009; Timmermans and Epstein 2010), may reinforce some cultural valuations over others, and reproduce patterns of social inequality in EOL care.

Data and Methods
Using the model of Lutfey's and Freese's (2005) exploration of the mechanisms that contributed to fundamental differences in diabetes risk, I conducted ethnographic observation and interviews in order to understand how differences in EOL health care emerged *and* how these different EOL health care experiences were evaluated. This study did not set out to establish that race and class differences in the kinds of care patients and families preferred and chose existed—as

quantitative, population-level measurement is better equipped to do—but rather to explore *how* differences mattered in terms of the health care patients used, the interactions patients, families, and physicians had with each other, and in how these participants felt about what occurred. I sought to understand when and how differences became inequalities in the context of EOL health care (Rathore and Krumholz 2004). Lutfey and Freese argue that through ethnographic observation "one can see in individual interactions evidence of more systematic disadvantages" (pg. 1329); following their example, this study sought to identify the mechanisms which contributed to systematic disadvantages in EOL health care experiences.

The Context: End-of-Life Decision-Making in the ICU

The end of life in intensive care units is an ideal place to study how multiple mechanisms impact inequities. Treatment decision-making in ICUs is complex, value-laden, and ongoing. While efforts across health care networks have begun to encourage patients to think about their EOL preferences earlier and complete advance directives, including with primary care providers, some research suggests that these efforts are not always successful in anticipating, and thus documenting, how decisions should be made in future, acute settings (Fagerlin and Schneider 2004; Perkins 2007). Further, many patients still experience acute or critical health problems and their preferences are unknown, unclear, and especially, not documented. The ICU setting allows for observing the processes of choosing (or not choosing) life-sustaining treatments and the arguments made for or against such interventions. Additionally, the patient population served by an ICU may be more diverse than primary care or other inpatient settings at the same site because the ICU provides more specialized and complex care, and patients may travel farther to receive this care. Thus, in many ICUs, this complex, value-laden, decision-making happens for a

diverse group of patients from different racial and socioeconomic backgrounds, providing

opportunities to understand how ambiguities are navigated differently and may lead to inequities.

Setting: Greenville and River City

My first field site, which I call Greenville, was home to College Hospital and Truman Medical

Center. College Hospital is the primary adult hospital associated with State University's medical

school and Truman Medical Center (TMC) is one of the state's larger Veterans Affairs (VA)

hospitals. Both are staffed by medical faculty and trainees from the State University medical

school. During my observations, 86% of patients in the College Hospital Medical ICU were

White, 7% were Black, and 7% were from other racial/ethnic backgrounds. Most patients and

families were from middle- or working-class backgrounds, and many had some private insurance

coverage. The Medical ICU at TMC serves Veterans from a broad region within the state. In

TMC's ICU, 85% of patients were White, 13% of patients were Black, and 2% were from other

racial/ethnic backgrounds.[9] Truman Medical Center sees very few high-income patients,

although during my observations, patients and their families still varied in SES.

The second field site, which I call River City, included two hospitals that are part of Promise

Health, a larger for-profit health system serving the region. Memorial Hospital and North

General Hospital were both located on a large medical campus in River City, and both were

staffed by attending faculty from the nearby River City medical school, while residents and

fellows were employed by Promise Health. In North General's ICU, 82% of patients were Black,

[9] As a Veteran's Affairs hospital, the overwhelming majority of patients at Truman Medical Center were men. In the context of ICU care, family members and other decision-makers were often involved in treatment conversations and decisions, and the gender of these individuals varied.

16% were White, and 3% were from other racial/ethnic backgrounds. Most patients and families were from poor- or working-class backgrounds, some lacked any insurance, and very few had private insurance coverage. Memorial Hospital's ICU saw a slightly different patient population, including more privately insured patients than North General. During my observations, 79% of patients were Black, 15% were White, and 6% were from other racial/ethnic backgrounds.

Ethnographic Observations in the ICU

To capture processes of communication and decision-making as they occurred, I conducted more than 150 days of ICU observation between June 2018 and February 2020. I focused on observing the processes of treatment decision-making for patients with terminal conditions whom medical professionals defined as potentially at the end of life. I attended morning rounds with the physician teams and observed conversations among clinicians and between clinicians and patients and/ or patients' decision-makers regarding treatment recommendations and consent for treatment decisions. Throughout my observations, I took detailed field notes on the decision-making processes and communication that occurred and attempted to approximate a verbatim transcript whenever possible. I refrained from notetaking when I felt it was distracting or upsetting, and then wrote down as much as possible after a meeting concluded.[10]

In observing physicians, I focused on how physicians talked with each other about diagnoses, treatment options, prognoses, and what kinds of care they thought were appropriate. I asked them about their assessments of prognosis, how well they thought family communication was going, and what they thought would happen next. I asked them what information they shared with

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[10] Block quotations or statements presented in quotations are direct statements recorded during interviews or observations.

patients or families and why. These observations and queries offered insight into how physicians

conceived of appropriate EOL care and the benefits and risks that motivated their thinking.

All physicians and medical students who served on these units during observations agreed to

participate and signed written statements of consent (N=160).[11] Prior to observing

communication between patients and clinicians, or patients' family members and clinicians, I

introduced myself, explained I was observing critical care communication and decision making

in the ICU, and asked for their permission to observe. Patients, or family members in cases

where patients weren't able to participate in decision-making, verbally consented to having their

interactions with physicians observed.[12]

Information about patients' and families' values was often solicited by physicians during

conversations about the goals of care. These conversations offered insight into patients' lives and

their assessments of the value of various treatments. In order to avoid interfering with patients'

and families' communication with physicians or increasing patient or family member burden in a

stressful environment, I refrained from initiating conversations or querying patients or family

members directly while in the ICU. However, patients and family members sometimes initiated

conversations with me; these informal exchanges were shaped by what patients or family

members wanted to share. When these conversations happened, I acted primarily as an empathic

listener and asked if I could draw on what they had shared for this study. Many agreed, although

[11] Some physicians were observed in multiple hospitals (N=8).
[12] At one site, in keeping with the specifics of IRB approval at that site, I obtained written statements of consent from the patient's primary surrogate decision-maker and up to one additional family member involved in decision-making if I observed direct communication between the physician team and a patient's family members.

in some instances patients or families asked that specific memories or thoughts be kept private, and I have honored these requests.

In order to gain additional insight into their experiences, I also conducted follow-up interviews with a subset of family members, recruiting patients' family members who had multiple and/or significant conversations with the physicians about the patient's preferences regarding the use of life-sustaining treatments.

Characteristics of ICU Patients in Observation Sample

I observed the clinical team discuss the care of over 500 patients during morning rounds. All 4 medical ICUs saw a variety of patients, including patients who needed close monitoring by nursing or respiratory therapists but who were generally stable, such as patients are who were going through alcohol withdrawal, or patients who required mechanical ventilation all the time, such as those with ALS (amyotrophic lateral sclerosis—a progressive neurodegenerative disease which affects the cells of spine and brain). There were also patients who came to the ICU due to the critical onset or exacerbation of a chronic condition and who required intensive care management of respiratory failure, high blood sugar, or an irregular heart rhythm. Some of these patients' critical condition resolved quickly or prior to observation of their care, or they were to be transferred to another service. While I took notes on how doctors discussed these cases during rounds, my observations were focused primarily on approximately 40% of the patients in these units (N=203) for whom doctors discussed the risks and benefits of continuing, starting, or withdrawing life-sustaining treatments, either among each other or with the patient or their family members. These patients were critically ill and the effectiveness of treatment was

unknown, such as in cases of septic shock, or were patients who had serious terminal illnesses or conditions, like cancer, liver failure, or lung disease. Of these 203 patients, 102 were White, 90 were Black, 6 were Hispanic, and 5 were of another racial/ethnic background. Patients ranged in age from 18-95 years old, and over 57% were 65 or older. Demographic information for patients in the focused observation sample are described in Table 3.1.

I employed a sequential case study logic (Small 2009) in my observations, through which the goal of continued observation was saturation, meaning that later cases or observations provided little or no new information about the processes in question. In this study, cases may refer to: 1) individual instances of communication or decision-making, such as morning rounds for a patient, or a family meeting, and/or 2) individual patient cases. As such, the analysis of early observations conducted at the first hospital informed the selection of cases for observation as data collection progressed, and case selection at the final hospital was informed by observations at three previous hospitals.

Interviews with Patients' Family Members

Interviews, while limited to retrospective accounts, offered additional insight into the thoughts and feelings of patients' family members who witnessed their relative's care, participated in communication about that care, and were often decision-makers for patients in the ICU. I recruited 66 family members/ decision-makers for follow-up interviews. I followed up with patients' relatives and/or surrogate decision-makers after their hospital visits and interviewed them about their perceptions of their relative's health care experiences and how they made

choices and decisions about treatment. Interviews took place after observations concluded at each site and were between 5 and 18 weeks after the patients' ICU stay concluded.

I asked family members about the patients' health prior to their hospitalization and what brought them to the ICU, and to describe what happened in the ICU: the conversations they had with physicians, the decisions that were made, and how they felt about the conversations and decisions that took place. All but one interview was conducted over the phone. Interviews ranged in length from 17 to 74 minutes[13], and all interviews were audio-recorded and transcribed.

Sample Characteristics of Interviewed Family Members

Interviews were conducted with 39 patients' family members (39/66, 59% of interview recruitment sample).[14] The patients' and family members' demographic information are detailed in Table 3.2. Interviews were conducted with the family members of 21 White patients, 16 Black patients, and 2 Hispanic patients. While patients and families often made decisions together, female family members were far more likely to act as the primary point of contact or surrogate decision-maker, and my interviews were overwhelmingly with female family members or surrogates (85%). Patients' educational attainment ranged from middle school to a bachelor's degree, and family members' educational attainment ranged from middle school to a masters' degree. Patients' and family members' occupational backgrounds were similarly diverse.

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[13] Four interviews were under 20 minutes, and four were an hour or longer. Most were between 25 and 45 minutes. There was not a consistent pattern by demographic characteristics or patient outcome in relation to the length of the interview.
[14] In one instance the patient was present, provided consent, and also participated in the interview. For one patient with multiple ICU visits, two family members were recruited and interviewed separately. Among those who did not participate, 20 were not reached after three messages were left, and 7 declined to participate.

Interviews with Physicians

I also conducted in-depth interviews with physicians about their experiences and approaches to the use of life-sustaining treatments. Topics included what factors they considered in whether they recommend a life-sustaining or palliative intervention, how they communicated with families about these treatments, how they handled conflicts or disagreements, and why they thought disagreements occurred. I also asked about EOL care generally, what they thought a good death looks like, the quality of dying in the ICU and how EOL care could be improved. Finally, I asked them about race and class differences in EOL care and why they thought differences arose. Interviews took place in-person or by phone, were audio-recorded and transcribed, and ranged in length from 28 to 93 minutes.[15]

Sample Characteristics of Interviewed Physicians

Interviews were conducted with 30 physicians who worked at one of the four hospitals I observed. Most interviews were conducted with residents, critical care fellows, or critical care attending physicians I observed; I also conducted additional interviews with specialists in palliative care and geriatrics. Information about the physician interview sample is provided in Table 3.3.

Data Analysis

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[15] Four interviews were under 40 minutes, and 12 were an hour or longer. In earlier interviews for each role and at each site, I asked respondents to describe a "typical day on service." In later interviews, I did not include this question as answers became redundant.

Both interview transcripts and field notes were analyzed qualitatively for themes and patterns (Emerson et al. 2011). Primary coding was done by hand; I read through all field notes and interview transcripts, open coding the data and writing short memos about potential patterns emerging in the data (Glaser and Strauss 1965; Tavory and Timmermans 2014). 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, member-checking with clinicians and other experts was utilized to assess whether these analytic interpretations made sense to others and further clarify the processes identified (Anspach 1997).

RESULTS

Traditional Mechanisms

Inequalities in EOL health care trajectories developed through numerous pathways and at multiple points in patients' ICU stays. Well-known mechanisms, such as differences in flexible resources (e.g., transportation, social support to assist with care, planning, etc.) and the amount of cultural capital patients or their decision-makers possessed, helped explain some of the inequalities that arose. For example, Mr. Crosby, an 80-year-old Black retired factory worker, felt limited in his options for transitioning to comfort care.

> Mr. Crosby: I am tired of being sick, I am not used to being sick. If my body can't sustain me then that's what's meant for me… Over the [recent] holiday I actually had to cut three people's lawns and I was able to do it. During my last hospital admission, I had a very high potassium, and they said I could have no salt. I tried to do that, but that's when I

started having these dips in my blood pressure. It's never been that low before… with my heart I know that no one can fix it so I'm just not going to worry about it… I'm 80. My father passed away of a heart attack.

Attending: How old was he?

Mr. Crosby: He was 72. I just thought I'd have a heart attack like that. No suffering.

Attending: That's where hospice comes in. 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: You live alone?

Mr. Crosby: Yes.

Attending: 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.

Attending: Do you have anyone to check in on you? Help you if things get worse?

Mr. Crosby: Maybe. I really want to go home. That's my goal. I don't have to decide now?

Attending: Of course not. Would it be alright if I had Macy, from palliative care, talk to you? She can help explain hospice options.

While Mr. Crosby was interested in hospice, his ability to take advantage of it was hindered by a lack of social and material resources needed to supplement home hospice services. After ten days, Mr. Crosby had stabilized enough to leave the ICU and the stepdown unit[16], but the hospital social worker had still not been able to identify a workable solution for home hospice.

In contrast, the family of Mr. Crest, a 53-year-old White manager with a terminal cancer diagnosis, was able to nimbly adapt to changes in his EOL care by drawing on the flexible resources they already possessed as well as their familiarity with health systems and clinicians. Mr. Crest's wife and children booked a local rental home when he entered the hospital for possible chemotherapy, and when Mr. Crest later elected to receive hospice care at home, she

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[16] The stepdown unit is an intermediary unit between the ICU and general hospital wards, characterized primarily by a decreased intensity of patient-nursing staffing ratios. At this hospital, nurses could cover 1-2 patients in the ICU and 3-4 patients in the stepdown unit.

requested hospital staff help her fill out paperwork to receive a refund for the duration of their reservation. Mrs. Crest also asked detailed questions about his specific needs at home, such as his nutritional supplement supply and equipment for managing his chest tubes, making sure the hospice would provide these necessary supplies. Anticipating possible aspects of care which might fall through the cracks or delay his return home required a nuanced understanding of both his medical needs and the transition of coverage between his traditional insurance benefit and the hospice benefit. The hospital social worker also mobilized his transition as rapidly as possible, coordinating with the hospice service to deliver the equipment needed for Mr. Crest to get home the same day he decided to transition to hospice care. Mr. Crest's parents were able to wait at his home for the delivery of supplies while his wife and youngest daughter remained at the hospital to coordinate discharge and provide emotional support for Mr. Crest.

Like others have noted (Gengler and Jarrell 2015), patients (and families) who can leverage more resources or build rapport with care providers through greater institutional knowledge can and often do receive better care, quicker access to treatments, or micro-advantages such as flexibility with scheduling and additional support.

In the instances described above, patients' and their families agreed, or reached agreement, with clinicians about appropriate treatment and had similar ideas about good deaths. Indeed, when patients and families shared similar opinions about EOL treatment with clinicians, this led to more empathic care and facilitation of non-medical goals or wishes. Physicians also tended to evaluate the outcomes in these cases more positively.

Mr. Kelley, a 74-year-old White retired fire station supervisor, presented to the ICU suffering from hypoxia (insufficient oxygen) caused by worsening interstitial lung disease (ILD). Mr. Kelley didn't want intubation, resuscitation, or "overly aggressive care" and acknowledged that his ILD would eventually cause his death. He was treated with heated high-flow (HHF) oxygen in the ICU because his pulmonologist thought he might get through this exacerbation (as he had recovered from past exacerbations). After a few days, the team felt he would not get better and that he would die in the ICU very quickly after his HHF oxygen mask was removed. Because Mr. Kelley's values around the use of aggressive care were seen as appropriate by his physicians, his use of ICU resources was accommodated. He spent three additional days on the HHF oxygen while family came to visit, and the attending assured Mr. Kelley that they would "make him comfortable" when he decided he was ready (to die). Mr. Kelley also voiced concern about his wife's financial well-being, even suggesting he wanted to make it to the first of the upcoming month so she would collect another pension check before he died. The team sympathized with Mr. Kelley's concerns, and reached out to social work to determine what benefits might be impacted by his death, as well as any death benefits his wife would receive to cover expenses. Multiple members of the team were emotional when Mr. Kelley died. Because Mr. Kelley's and his family's values aligned with those of the clinicians, they felt empathy, rather than frustration, towards him, and approved of his use of ICU resources to facilitate a good death.

In the instances described above, patients and families who shared similar opinions about EOL treatment with clinicians were more likely to receive more empathic care. Clinicians were more likely to accommodate patients' non-medical goals or wishes. Physicians also tended to evaluate the outcomes in these cases more positively. However, when patients or families disagreed with

clinicians, new pathways to inequalities emerged. As I discuss next, patients or families who wanted aggressive treatment and life-sustaining therapies despite having terminal illnesses were more likely to experience additional hurdles in their treatment and care.

Differing Valuations

Mr. Haynes and Vasopressors

Mr. Haynes, a 65-year-old White retired truck driver, was dying from AML (a form of leukemia) and began to experience worrisome drops in his 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 each day. The resident physician treating Mr. Haynes explained that the team could offer a medication to raise Mr. Haynes's blood pressure (a vasopressor), but that it wouldn't reverse the course of his dying from cancer. It would require placing a central line, which is a large intravenous (IV) line that enters through the neck, to deliver the medication. This procedure, and the resulting IV line, are more invasive and uncomfortable than a traditional IV line in the wrist or arm. After the resident had described the procedure, noting that it would only give the patient a couple more days, Mr. Haynes nevertheless said he wanted the medication. Prior to doing the procedure, the resident told me he asked the patient at each step if he "was sure" he wanted this done. The resident asked Mr. Haynes, "Why do you want me to do this? What will be different in one to two days?" The patient replied, "I'll have two more days." As he explained to me, the resident couldn't understand why Mr. Haynes would want to continue to suffer, 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 a fundamental difference between the resident and Mr. Haynes, and the value they placed on one or two more days of life in the ICU with a central line. When I discussed Mr. Haynes' case with the resident treating him, he 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 the length of suffering, rather than curing or alleviating Mr. Haynes' illness and symptoms. Mr. Haynes, however, was simply not ready to die—and he found value in having more time in the company of his friends and family, even in the ICU, suffering from pain and fatigue.

A day later, due to a complication, the resident needed to place another line on the other side of Mr. Haynes' neck in order to continue giving him the blood pressure medication. Again, the resident told me he asked Mr. Haynes multiple times whether he wanted the procedure to continue. After the third time the resident asked for reassurance, Mr. Haynes, frustrated by repetitive questioning, requested the resident stop asking him, and the resident completed the procedure. Talking with the resident and fellow after the second line was placed, 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 that 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 asked that 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 the use of *continuing* vasopressors as providing no "mortality benefit" and therefore "futile treatment." When I inquired as to why physicians would prescribe the medication if there was no benefit, the physician explained that "… 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 to describe therapies that wouldn't reverse the primary cause of the patient's dying—heart failure or cancer, for example. Such therapies did have a limited physiologic benefit and could sometimes extend patients' lives—if only for a matter of days—but this was not considered a mortality benefit, as patients would still die, and such therapy was thus labeled futile by this and other physicians. Providing therapies physicians felt were futile was often described as bad medicine by the physicians I observed and interviewed and imbued with moral and ethical weight. In conversations with patients and families, this sometimes meant that families felt their values and convictions were being challenged, judged, and invalidated by the clinical team.

The Glendale Family and a Tracheostomy

Mr. Glendale, a 65-year-old Black man, presented to the ICU following a cardiac arrest at the nursing home where he lived. He was placed on a hypothermia protocol, in which doctors seek to strategically cool a patient's body temperature to reduce brain damage following cardiac arrest.[17]

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[17] Therapeutic hypothermia is linked to decreased intracranial pressure and increased oxygen supply to areas that suffered ischemia, or a loss of blood flow (Varon and Acosta 2008).

After three days, neurology saw Mr. Glendale and concluded that Mr. Glendale was not brain dead but likely had a very poor neurologic prognosis. Due to the death of another family friend, a family meeting took place six days later with the neurologist, ICU fellow, and Mr. Glendale's sisters in attendance. The family was told Mr. Glendale was not brain dead but had a very poor neurologic prognosis and would not wake up; hospice care was recommended. The family asked for a few days to discuss and make a decision.

Later the next week, the resident remarked he was having trouble contacting the family. The resident told me he called the family at least once a day, but they did not return his calls. The attending noted that "…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 decided to consult ethics[18] regarding pursuing guardianship for Mr. Glendale. In the afternoon, the resident learned that palliative care spoke with the family and they decided they would like Mr. Glendale to have a tracheostomy[19] 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, surgery called the patient's sister to obtain consent for the tracheostomy procedure, but she asked them to wait a couple days until she had a day off, so she could be present during the surgery. The same day, the ICU team moved to unilaterally change

[18] The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) requires hospitals to establish a mechanism for resolving clinical ethics questions in order to be accredited. The hospitals I observed had slightly different variations on what this process looked like, but all involved consulting a designated ethics service staffed by a committee or faculty member.
[19] A tracheostomy refers to an opening secured through the neck and directly into the windpipe (rather than through the mouth) to provide longer-term ventilatory support.

the patient's code status[20] to do-not-resuscitate (DNR) based on the ethics consultant's

recommendation. Over the weekend, a new fellow was on the ICU service, and he met with Mr.

Glendale's sister and brother-in-law to tell them about the team's DNR decision and

recommendation that a tracheostomy and percutaneous endoscopic gastrostomy (PEG) tube not

be offered. The patient's sister and brother 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 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.

This meeting failed to produce a resolution, and disagreement between the team and Mr.

Glendale's family persisted. The team questioned the family's beliefs about Mr. Glendale's

wishes and their motives for pursuing life-sustaining treatments. For example, an earlier request

by the family to have guardianship 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. The internal medicine chief of staff also called the family to

recommend withdrawal of care. A few days following the fellow's meeting, a new attending took

over the ICU service, and met with the family for a third time.

> 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.
> …
> Attending: [He'd want this] if he knew that he would not be able to get up and walk, and
> would have pressure ulcers, and be fed through tube, and be in a vegetative state?

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[20] Code status refers to whether a patient would want resuscitation attempted if their heart were to stop
beating and/ or they were to stop breathing.

Brother-in-law: He would want us to decide. That is the issue. The hospital went behind her (gesturing to his wife) back to try and have guardianship assigned—would he have wanted that?

…

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 that Mr. Glendale and his family could receive care elsewhere. Although the Glendale family was eventually able to receive the treatments they wanted, they did so by deflecting many efforts to dissuade them. When they described Mr. Glendale's wishes for aggressive treatment even if he was given a very poor prognosis, they were often disbelieved. Communication between the team and Mr. Glendale's family broke down on multiple occasions, and physicians assumed that these breakdowns meant his family did not care about his wellbeing, rather than considering that they may have felt berated and ignored.

Frequent conversations meant to persuade families towards different treatment decisions often backfired. In an interview with another patient's daughter-in-law about their experience, she described how frustrating it had been to have multiple conversations focused on getting her father-in-law to choose comfort care and change his code status to do-not-resuscitate. Mr. White, a 72-year-old Black man who previously worked in building maintenance, had come to the ICU following a bout of respiratory distress because of a laryngeal mass and abscess. He had recently

been diagnosed with laryngeal cancer and had received a tracheotomy a few weeks earlier. The family had been hopeful he would be able to receive palliative chemotherapy.

> Mr. White's Daughter-in-Law: When we thought chemo or treatment was an option, it was almost like he was trying to talk him out of the option. [When her father-in-law] said, "Yep, this is what I want to do," [the doctor] says, "Well, you can't do it for your family…" It was just horrible to me… there has been a lot of loss in [our] family… so death, we're fully aware of, dealing with the sick and people being hospitalized, I mean that's almost like second nature to both sides of the family. It became frustrating to listen to this man try to talk them out of every decision… he gave him options, but it was like only one option, maybe in his eyes that's all he saw.

The cases of Mr. Haynes, Mr. Glendale, and Mr. White highlight how valuations of treatments – and the possible outcomes of those treatments – can differ between patients and providers. When these valuation differences occur, physicians often expressed distrust of patients' or surrogates' choices, and revisited decisions often, as happened in these cases. Patients and families, on the other hand, experienced these endless queries as challenges to what they valued and some developed real fear that they would be denied care. Mr. White later insisted his sister be present for all future conversations about treatment, and his sister confided to me she was "glad I was there, to document what was said."

Formalizing Life-Sustaining Treatments' Value

Importantly, differences in physicians' and patients' valuations of life-sustaining treatments didn't just lead to qualitative differences in patient's and family members' experiences. Physicians' attitudes about appropriate end-of-treatment could lead to more rigid treatment pathways, could be codified as formal policies, and could be used to define and measure appropriate treatment.

Mr. Todd and Intubation

Mr. Todd, a 77-year-old Black retired autoworker, presented to the ICU multiple times over the course of four weeks. Mr. Todd had first been transferred from another hospital following a COPD exacerbation which resulted in his being intubated, and eventually successfully extubated, before transfer. He was alert, making decisions about his care, and was eventually weaned from the heated high flow oxygen machine, which was only available in the ICU, to oxygen by nasal cannula. He was then sent to the rehabilitation unit in the hospital. However, about two weeks later, he returned to the ICU. He was again having trouble breathing and needed to be placed back on heated high flow oxygen. The resident met with him and discussed his code status and the likely possibility he would need to be intubated again. Mr. Todd said he would want to be intubated, if needed, and that he would also like resuscitation to be attempted. During rounds, the respiratory therapist commented that given the patient's comorbidities, including severe pulmonary hypertension, he was "not excited" about possibly intubating him, and that he felt there was a strong chance Mr. Todd wouldn't survive the intubation procedure itself.

During Mr. Todd's second day, his nurse approached the team of doctors at their desks and said that Mr. Todd was asking for food. A resident replied, "Mr. Todd cannot eat anything, including broth." The nurse described Mr. Todd as very hungry and whimpering and asked the resident to at least go talk to him and explain their decision to withhold food. As one of the residents got up to go speak with Mr. Todd, the other resident said, exasperatedly, "Tell him he can have food if he goes to hospice!" One of the medical students seemed surprised (as was I) and the resident clarified, "He is at a massive risk for aspiration and if his goal is to live, then that 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." I asked if patients' thought of these things as incompatible – wanting to live but also doing something about being 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's comments, borne of this frustration, were rooted in his desire to do his best to deliver the clinical outcomes he felt Mr. Todd wanted, even though the resident felt these outcomes would be difficult to deliver in the best of circumstances. The resident observed that keeping Mr. Todd alive would be very difficult if he required intubation, and he was frustrated Mr. Todd would risk worsening his prognosis by doing something, like eating, that increased his risk for needing an aggressive intervention, when he was "requesting so much" of the resident and his colleagues.

The resident's focus on the clinical outcome Mr. Todd hoped mechanical ventilation might possibly give him—extending his life—led the resident to see Mr. Todd's desire to eat as contradictory, rather than seeing things from Mr. Todd's perspective, which included separate but common human desires: to live, but also to relieve discomfort from hunger and enjoy the pleasure that came from eating.

Physicians' ideas about EOL treatments sometimes led to rigid treatment pathways, in which patients who wanted to "try to live" shouldn't also desire (or receive) treatments that might increase their comfort. Some physicians described requests for pain medication from patients who wanted to be intubated as contradictory – if they wanted to do everything possible to live – including being intubated if necessary (a state most physicians saw as objectively unpleasant) –

then they shouldn't receive medications that might depress their respiratory function (most narcotics can have this effect).

Physicians often acknowledged in discussions that most patients fell somewhere between solely valuing comfort and solely valuing prolonging life. However, when it came to providing treatments, they found it difficult to manage patients who did not express a singular goal. In cases where patients had more complex goals, or had goals physicians were trying to change, patients sometimes did not receive treatments that they wanted or perhaps needed. In one instance, Mr. Frazier, a 73-year-old White man with dementia, did not receive any nutritional support despite being in the ICU for five days as the team unsuccessfully tried to convince Mr. Frazier's wife that her husband was dying and that she should consent to comfort care. It was only after a nurse raised concerns about his nutritional status that the attending (who had just begun their rotation on service the day prior) insisted the resident start total parenteral nutrition (TPN – nutritional fluid given through an IV line).

Ms. Rosset and Dialysis

In addition to patients' requests that physicians felt were contradictory, treatment pathways could also be constrained by physicians' desires not to be seen as "too aggressive" or "providing futile care," as illustrated below in the case of Ms. Rosset, a Black 48-year-old pharmacy technician with metastatic breast cancer. Ms. Rosset came to the ICU because of confusion and altered thinking. The resident explained to her parents, who remained at her bedside for many hours each day, that she was able to follow commands but was not responding to questions. He explained that the cancer metastases in her liver could be causing liver failure, allowing toxins to

build up that affect mentation, or that she could have an infection, and that they were treating what they could. He said they hoped to do more diagnostic tests. Ms. Rosset's parents shared that her teenage son was on a school trip, and that they didn't want to tell him about the possibility her cancer had advanced until he returned.

After a few days, Ms. Rosset required intubation, and the next day, she stopped producing urine, suggesting that her kidneys had stopped working properly. During rounds the resident suggested they consult nephrology, but the fellow disagreed, saying, "No, I don't want her to get dialysis; she needs hospice." The attending also did not want to consult nephrology. "Now we're in worst case scenario. Her ammonia is trending down (suggesting any liver failure is resolving) but her mentation is not improving. No matter what we're doing, she's just getting worse."

The attending spoke with Ms. Rosset's parents to explain these new developments. He also advised her parents change her code status, saying, "I do have to recommend, I know we are keeping her here until her son can get here, but I have to recommend we don't do CPR or shocks if her heart was to stop. She can't take anymore." Ms. Rosset's parents agreed to make her code status DNR.

Over the next weekend, Ms. Rosset's potassium began to increase, another side effect of her kidney failure.

> Fellow: At some point we should stop labs.
> Resident: Is the family ready to do that?
> Fellow: That's not really their call.
> 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 concerns about Ms. Rosset's kidney failure and her family's desire to prolong her life,

dialysis would not be offered. Further, the team was considering stopping labs, traditionally part

of a transition to more comfort-focused care, although this had not been discussed with the

family. The morning of her son's arrival, a new ICU attending physician, who began service on

Monday, spoke to the family on rounds, hoping they would be ready to withdraw life-support

and transition to comfort care.

Attending: Have you made any decisions?
Father: We've discussed dialysis?
Attending: We're not going to offer that. It won't change any outcomes.
Father: We want to keep trying.
Attending: She's telling us she's dying. That's unfortunately the hard truth. We can't change that. Dialysis doesn't change the big picture. Dialysis doesn't bring kidney function back; it just replaces it.
Mom: That's her son, standing behind you.
Father: We aren't ready yet. There has to be something that we can try. We aren't ready for her to go. I understand that you may be ready, but we aren't yet.
Attending: I understand, I do. But I don't have anything to offer that will change the situation.
Mother: How long can we continue what we're doing?
Attending: I mean, we can continue indefinitely, likely eventually her heart will give out. It could be tomorrow; it could be a week from now.
Mother: Why don't we just wait it out. We'd like to wait.

After the meeting, the team discussed being surprised by the family's desire to continue

treatment. The attending remarked that he thought the family was ready for Ms. Rosset to die.

The fellow replied, "We thought that, too. We got the sense we were trying to get her son here."

The attending said that 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 the resident

stated who was on call, the fellow warned, "They burned us on [another patient], they

recommended CRRT[21]." The resident asked if he should put in a consult to the nephrology team, and the attending declined, saying "No, because I don't want them to offer it (laughs). We're not going to consult."

The next morning, Ms. Rosset was doing worse, and the team lamented that her parents would not withdraw the mechanical ventilator. The attending asserted that the parents just "don't get it," but that Ms. Rosset would at least die more peacefully without CPR. Ms. Rosset died a day later. When I interviewed her mother, she reported being hurt by the attending's attitude and comments and explained her rationale for choosing to keep her daughter on the ventilator.

> I believe he should have used different words to describe what was going on. 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 conscious 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 saw value in life-sustaining treatments the team felt were of little benefit, and also felt they were honoring their daughter's values. While the clinicians involved allowed Ms. Rosset to remain on the ventilator until she died, they did not offer dialysis, even when there was concern it might be needed for her to live until her son's return. The attending physician and fellow expressed concern about consulting other providers who might offer an intervention they felt was not appropriate. ICU physicians across the hospitals I

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[21] Continuous renal replacement therapy is a form of continuous dialysis that filters waste, sodium, and excess fluid from the blood more slowly than traditional dialysis. It is used for patients who cannot tolerate the hemodynamic changes that occur during traditional dialysis.

observed voiced wariness about consulting other clinicians who might be too optimistic with their patients or offer treatments they had decided not to offer.

On another occasion, dialysis was avoided for a patient with liver cirrhosis, although it was unclear whether the acute kidney injury (AKI – sudden episode of kidney failure) he had developed was linked to his cirrhosis. The nurse treating Mr. Ortiz, a 70-year-old Hispanic man, tried to advocate for dialysis, pointing out that delays in treating his AKI might be worsening his mentation, which was likely contributing to his need for breathing support. However, the team decided not to pursue dialysis, in part because they felt nephrology might demand evidence that Mr. Ortiz' liver cirrhosis was not the cause of his kidney failure and they did not want to push the nephrology service too hard for treatments that the nephrologists might consider futile.

In instances like those above, concern over providing treatments that could end up being "bridges to nowhere" led ICU physicians to avoid these treatments, even when it was not always clear at the time that treatments would have provided no benefit. On a few occasions I witnessed, and physicians described, judgement from other team members for providing futile or overly aggressive care. Physicians didn't want to be perceived as wasting resources, prolonging the dying process, or providing futile care.

Physicians in the ICU also passed judgement on other colleagues for being too optimistic and 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:

> ICU 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, but [the oncologist] kept on [going]—that was a tough one. I did also speak to [oncology], and I explained to them my concerns about it, about futile care, but they were like, "He may improve." Well, they did say to me, "Oh, he has a terrible prognosis, but let's see what happens."

The oncologist's acknowledgment of the patient's likely poor prognosis but desire to continue life-sustaining treatments caused moral distress for the ICU attending, who was tasked with overseeing these interventions. This particular patient was mentioned by multiple physicians I spoke with at this hospital, who had all heard about the case. 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 or fellow expressed concern that a resident had painted an overly bleak picture of a patient's prognosis, yet they did not revisit the patient and family's decision to withdraw life-sustaining treatment.

Formal policies could also be used to codify cultural valuations of treatments. Futility policies

provided guidelines for when physicians could refuse to provide, or could withdraw, a particular

treatment; most commonly, these policies stated such an action was allowed if two physicians

agreed that the treatment was futile. This policy was invoked in the case of Mr. Glendale,

described above, to refuse providing CPR if he suffered another arrest. While such policies first

defined futility as providing no physiological benefit, some hospitals used a broader definition of

futile care often termed non-beneficial care. These policies interpreted the types of treatments

that could be deemed non-beneficial more broadly, including those that did provide a

physiological benefit but for which physicians felt the benefits did not outweigh the costs. Such a

policy could be used to deny a patient intubation, dialysis, or other life-sustaining treatments that

required significant resources but wouldn't address patients' underlying health problem,

although many would indeed sustain that patient's life, at least for some amount of time.

Physicians explained how futility or non-beneficial care polices could be used to make patients'

DNAR (do not attempt resuscitation) or to remove life-sustaining therapies, such as mechanical

ventilation. In the case of Mr. Mosley, a 58-year-old Black man who 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 asked by the resident if he

was okay with Mr. Mosley receiving a tracheostomy and PEG tube, even though he had not

regained consciousness since his cardiac arrest, 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 even 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, "In the US, we let people decide (their code status) but in some other places it is appropriate to never offer it to people… I don't think CPR should be offered if the chance of success is exceedingly small. Physicians can decide not to offer a treatment that carries more risks than benefits – you wouldn't take someone's appendix out if they asked you to but they didn't have appendicitis. That would be futile." When I asked whether CPR would be futile, even in cases of a very low chance of success, given that not doing CPR would result in death, the resident said, "There are things worse than death." Indeed, multiple doctors feared resuscitative efforts that would bring someone back, but only for a very small amount of time (hours to days), to a minimally conscious state, or would "make the person a vegetable." How physicians valued these possible outcomes influenced their feelings about providing CPR, but in many instances also whether they considered resuscitation to cause more harm than benefit and therefore it's futility. The decision that a treatment was futile thus involved more than the clinician's objective assessment about the likelihood of certain outcomes. Rather, assessments of futility also incorporated the clinician's valuation of those odds and outcomes.

Although not all hospitals I observed had a formal futility policy, physicians across hospitals

spoke of avoiding offering life-sustaining treatments, and if patients or their families didn't

request them, being able to avoid providing what they felt would be futile care. Physicians

viewed offering treatments of low benefit as potentially inappropriate.

> 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.

> Attending ICU Physician: People will say yes to things because it gives them hope, and maybe we shouldn't be giving them options, like dialysis, that won't change their global picture. You could be offering someone a futile intervention; you don't know if it will help them.

These physicians, and others, felt that avoiding futile interventions was a clinical expectation or

standard, and that if you weren't sure an intervention would be helpful, it was better not to offer

it and not give patients or families what would turn out to be false hope.

Benchmarks and Standard-Setting

At one hospital, physicians' valuations of different EOL treatment trajectories were used by

administrators and other agencies to create benchmarks of success. A palliative care fellow told

me that the hospital tracked whether "they performed a consult" on any patient who died in the

ICU, and they planned to put a note in the chart for a patient who had refused to meet with them.

The fellow explained that if he died in the ICU without receiving a palliative care consultation,

this would be considered evidence of aggressive, and arguably inappropriate, treatment at the

end of life. In this instance, despite the patient's active choice not to be seen or receive treatment

from palliative care, the hospital planned to benchmark him as having received less satisfactory

care. By assessing physicians and clinical services based on standardized metrics, hospitals may further encourage clinicians to ignore patients' and families' preferences for care.

When quality metrics reflect ideas about EOL care that the majority of people agree upon, such as preferring to die at home, they inadvertently contribute to the marginalization of the choices of people who do not share these preferences. Further, when there are racial and socioeconomic patterns in ideas about EOL care, majority-driven measures of quality tend to dismiss the choices of already disadvantaged groups. Thus, efforts to standardize care, in the hopes of alleviating disparities, may instead marginalize socially disadvantaged groups by imposing the preferences of majority groups on their care.

Variation Between Hospitals

Other aspects of care delivery varied between hospitals, and hospitals served demographically different patient populations with varying levels of individual- and family-level resources, both of which independently influenced EOL health care experiences and racial and socioeconomic differences in care. However, processes of valuation and standardization impacted the experiences of patients similarly in all four hospitals I observed. Across hospitals, physicians' attitudes towards appropriate care for patients at the end of life were very similar, and similar structures, such as futility policies and ethics consultation, were invoked when clinicians disagreed with patients and families.

Race and Class Differences

The excerpts above described how patients whose values about life-sustaining treatments and more aggressive care differed from those of clinicians often had poorer interactions and poorer health care experiences than patients whose values aligned with those of their clinicians. Indeed, patients who desired aggressive treatments, especially patients and families who wanted resuscitation, regularly frustrated physicians, and physicians often expressed judgement or exasperation with patients who desired an aggressive intervention their treating team did not want to provide. Patients and their families who wanted aggressive treatments were called to frequent meetings and subjected to repeated conversations meant to readdress and potentially alter these preferences, received judgement from staff, and were constrained in their treatment pathways. Interviews with family members of patients who wanted aggressive treatment showed that many were aware that the medical team disagreed with their choices and that they felt they needed to reassert their desires for aggressive treatment multiple times.

In my observations, and in other studies on the topic (Barnato et al. 2009; Pew Research Center 2013), Black patients and their families were far more likely to express a desire for aggressive treatments than White patients and their families. In interviews, Black patients' family members were much more likely to express fear that the medical team "was giving up" or that care would be withdrawn. Many physicians were aware of this distrust but felt unsure how to address it.

> Resident: I think it comes from the long history of a lot of discrimination and injustice, similar to Tuskegee. There are a lot of people that have either hinted at it or openly said it to us—the reason we weren't offering something is because they were poor and African American. We didn't want to save their life, and if they were somebody else, we would value their life more. And that sucks. That sucks that people feel that way. That wasn't why we were doing it, but then when you hear that, you think "Oh, no." How do you convince someone?

Similar but more muted patterns emerged by social class; middle-class patients were far more likely to accept palliative care and refuse resuscitation than working-class or poor patients.

Interactions between Mechanisms

My findings also suggest that well-known mechanisms of inequality could interact with valuation and standardization pathways to amplify inequalities. For example, Mr. Ortiz' case, described above, provides an example of how cultural health capital could interact with standards of care. While his family, and Mr. Ortiz when he was alert, advocated aggressive treatment that would help him live longer, they generally accepted without question what Mr. Ortiz' physicians recommended to them. His older daughter, who lived with her father and was his primary caregiver, later told me she slept in her father's ICU room, next to his toilet, because she felt he wouldn't receive aggressive care if she wasn't there. She also felt the team was trying to undermine her choices by cornering her younger sister about Mr. Ortiz' care when she wasn't present. Yet, when physicians explained that they were trying to clear toxins from Mr. Ortiz' body but preferred not to start dialysis, his daughters didn't question this decision, although they resisted multiple efforts by the clinical team to transition their father to comfort care. While physicians described, and I observed, instances in which family members with more health literacy or cultural health capital questioned doctors about the specifics of how they were treating each failing organ, the working-class Ortiz family largely deferred to clinicians about specific treatment choices, although it was clear they wanted their father to receive every possible chance at recovery. Given the treating teams' ambivalence about dialysis, it is certainly possible advocacy by a more assertive family member would have pushed them to utilize it.

However, even among family members with some health literacy, physicians described a hierarchy of medical knowledge (Anspach 1997). Physicians explained that family members who were not medically trained but were somewhat knowledgeable about various treatments were more difficult than those without any medical knowledge because they pushed back and requested different kinds of life-saving treatments physicians did not feel would be helpful.

> Resident: I find that some people with some medical background can be challenging because they know some things, so they try to apply that sort of intellectualize things and don't really fully grasp the concepts. I'll say, high health care literacy, but not necessarily like physicians—somewhere in between there. I think that population or subset of people can be challenging because they—this sounds awful, but they think they know everything.

Patients' and families' health care literacy was appreciated when it aligned with physicians' own assessments of appropriate treatment, but often challenged when patients' or families' expressed preferences for more aggressive treatment that clinicians felt were inappropriate.

Mr. Parker and Recurrent Infections

The case of Mr. Parker, an 84-year-old Black man who presented to the ICU in septic shock, is an example of how flexible resources could themselves shape how families valued different treatment trajectories. Mr. Parker, a retired teacher, had dementia and lived in a nursing home; while visiting him, his daughter had found him clammy to the touch, vomiting, and lethargic. She brought him to TMC, and he was transferred to the ICU. The ICU team was able to address Mr. Parker's infection and over the course of a few days, he improved dramatically.

Both the ICU team and the palliative team had multiple meetings with Mr. Parker's daughter, and afterward, expressed concern that Mr. Parker would continue to get infections and his daughter would continue to bring him back to the hospital. They felt allowing an infection to

"take its course" might be in the best interest of Mr. Parker, rather than allowing his dementia to worsen. However, Mr. Parker's daughter, herself a nurse, felt a moral obligation to make sure his reversible health problems were addressed. She expressed frustration when he was neglected by staff at the nursing home, which she thought likely contributed to his recurring infections and other issues. For example, Mr. Parker was severely constipated when he presented to the ICU, suggesting he hadn't had a bowel movement in days, yet his nursing home hadn't given him any treatment for his constipation.

Because of the limited health care options available to Mr. Parker in his day to day life, his daughter told me she felt he often received better care when he was in the hospital than in a nursing home. Her concerns about reversible problems like infections, caused by neglect and poor care, motivated her to bring her father to the hospital when he was ill. Other families also described ways in which previous negative experiences with hospice care, including insufficient symptom management, contributed to their view of more aggressive treatments, and hospitalization in general, as preferable to nursing home or hospice care. In these instances, limited flexible resources for in-home care or in-patient hospice (which few could afford) shaped patients and families' EOL health care wishes, which in turn shaped their interactions and experiences with providers. Notably, Ms. Parker's own health capital from her nursing background made it easier for her to express her wishes but, combined with her differing values regarding treating recurring infections, contributed to increased conflict in her interactions with clinicians.

Discussion

Today's Good Death

My observations revealed that while clinicians often believed it was best to limit life-sustaining treatments and decrease interventions as the end of life approached, numerous patients and families felt strongly about living as long as possible and saw value in trying treatments that had a low chance of success. I also found that cultural attitudes towards less aggressive intervention for terminally ill patients had become incorporated into clinical judgements, evidenced in the ways doctors talked about appropriate EOL care and the formalization of these attitudes into standards and hospital policies. The good death preferred by most clinicians was characterized by a valuation of *comfort* and *control* over the circumstances of dying. While clinicians acknowledged differences in patients' values, they felt their own perceptions of appropriate care were defined by their clinical, rather than cultural, knowledge.

Clinical attitudes and practices towards death and dying have shifted to advance a specific form of good death (Bischoff et al. 2013; Marik 2014; Mcnamara 2004). For many, an alternative to aggressive care at the end of life has indeed been a much-needed choice (Kaufman 2005), and it may seem plausible to interpret medicine's shift towards the acceptance of palliative care and the withdrawal of intensive technologies (Livne 2019) as exclusively positive. Earlier scholars have examined the lack of patient agency and the uncritical use of high technology treatments and interventions (Clark 2002; Fox 1981; Glaser and Strauss 1965; Illich 1976). This earlier research sought to "improve experiences of death and challenge the power of professionals" (Howarth 2007, p. 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).

Mechanisms of Inequality

The end of life proves fertile ground for understanding social processes that contribute to inequality across institutions, reflecting that inequality emerges through multiple mechanisms. In their explorations of how parents of children suffering from serious illness navigated interactions with health care providers, administrators, and insurers, Gage-Bouchard (2017) and Gengler (2014) demonstrate that differential styles of advocacy in the health care setting are more effective in eliciting positive responses from physicians and in obtaining efficient and effective care. Similarly, other scholars have shown how lower, middle, and upper class parents' approaches to childrearing vary and how these approaches reinforce social class (Lareau 2003), or how White and Black defendants' differential reliance on their lawyers as their cases proceed through criminal court contribute to differing outcomes between these groups (Clair 2020). Across institutions, socially advantaged groups more deftly navigated their interactions with institutional players and accrued advantages towards preferred outcomes. Existing theories of health care disparities, and inequality in other institutional settings, help explain how the resources of individuals (financial, social, and interactional) produce inequalities in outcomes. Differences in material resources and cultural capital also contribute to unequal experiences in EOL health care. Further, by exploring how institutional actors evaluate good and bad outcomes, my findings demonstrate additional processes that impact the experiences of individuals in health care organization, and hypothetically other institutional settings as well.

I find that processes of valuation and standardization amongst clinicians and within an institution (Lamont 2012; Timmermans and Epstein 2010) account for the emergence of additional

inequality in EOL communication and decision-making. Medical institutions have increasingly come to accept culturally-driven preferences for less aggressive treatment at the end of life *and* support their positions by rationalizing that these views are clinically appropriate (Livne 2019), taking for granted the processes of subjective valuation that lead these views to be preferred (Berg 1997). In my observations, 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 desired. Timmermans and Epstein (2010) emphasize that "every standard inevitably implies an evaluation at the expense of some other, and often obfuscated, devaluation" (p. 84). In valuing giving patients good deaths characterized by symptom management, hospice, and the chance to return home, physicians often devalued trying treatments with low probabilities of success. The institutional standardization of particular EOL values was evident in how physicians spoke about futility, the application of rigid treatment pathways, and in benchmarks for receipt of palliative care consultation. Thus, limited institutional tolerance for diverse values frequently allowed marginalized perspectives to be discounted (Lamont 2012).

Race, Class, and Marginalized Perspectives

Important for understanding why these mechanisms reproduce inequality is an understanding of which patients were more likely to hold marginalized perspectives (i.e., to value aggressive treatment). Preferences for or valuing of aggressive treatment clearly shaped patients' and families' experiences. Taking into account established patterns by race and class in treatment desires (Cain et al. 2018; Pew Research Center 2013), processes of valuation and standardization thus became pathways which reproduce racial and socioeconomic inequalities in health care

experiences. Patients whose social identities and backgrounds were similar to those of their

clinicians – mostly White, college educated, and solidly middle-class or higher, were more likely

to share the preferences of their physicians for comfort-focused EOL care. Individuals and

families who favored more aggressive treatment contested physicians' assessments of the value

of these treatments and were more likely to experience conflict, tension, and distrust. The

outcomes individuals were pursuing[22], which vary meaningfully by race and class (Barnato et al.

2009; Frost et al. 2011; Pew Research Center 2013), led to disparate care experiences.

Limitations

Although this study makes novel contributions to understanding how cultural processes of

valuation and standardization can lead institutions to (re)produce inequality, there are some

limitations to the methods and data collected. First, this paper draws on observations in a single

geographic region. It is possible that clinicians in other hospitals, including those in other parts

of the country, have differing valuations of various EOL health care. I often queried clinicians

about whether their current hospital varied from other institutions where they received training or

practiced, and clinicians did not mention differences in how they or their colleagues felt about

many life-sustaining treatments. That said, future research should explore how valuation and

standardization processes in EOL care may occur in different hospitals and regions. Second, data

elicited directly from patients in this study is limited, as I did not explicitly seek out

conversations with patients. More data on how patients experience EOL trajectories in the ICU

setting is needed to fully account for their perspectives on EOL health care.

[22] Notably, I use "pursue" in a loose fashion here. As others have noted (Livne 2019), individuals who choose not to articulate particular plans for the end of life and "take things as they come" might be conveyed of as not pursuing anything in particular, but their rejection of the thinking that physicians would like them to engage in still manifests as contradictory to the ends desired by their physicians.

Conclusion

These findings demonstrate that the reproduction of inequality may occur through two mechanisms largely unexplored in the health and health care disparities literature – in *valuation*, as the attitudes and values of the socially disadvantaged are challenged, questioned, and ignored—and in subsequent *standardization*, as the outcomes preferred and chosen by less socially advantaged groups are defined as less optimal and crystallized as such in formal policies. Other research, both within medicine and in other institutions, has often focused on how individuals' institutional knowledge (or lack thereof) and cultural dispositions allow them to accrue advantage or fall further behind in health care experiences, schools, and the criminal justice system (Clair 2020; Gage-Bouchard 2017; Lareau 2003). This body of work highlights how socially advantaged individuals are better situated to know how to navigate institutional rules and expectations. My research extends our understanding of inequality by focusing instead on how institutions themselves reflect the cultural dispositions of socially advantaged groups. Rather than highlighting how individuals deploy institutional knowledge, 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 are part of the groups that "make the rules."

Table 3.1 Observation Sample: Patient Demographics

	TMC	College	Memorial	North General	All
Race					
Black	8	2	39	41	90
White	53	32	5	12	102
Hispanic	4	0	1	1	6
Asian or Middle Eastern	0	3	1	1	5
Gender					
Women	3	17	20	27	67
Men	62	20	26	28	136
Age					
< 65 years old	13	21	25	28	87
65 and over	52	16	21	27	116

Table 3.2 Interview Sample: Patient and Family Member Demographics

	TMC		College		Memorial		North General		TOTAL	
	PTs	FMs	PTs	FMs	PTs	FMs	PTs	FMs	PTs	FMs
Race										
Black	4	4	1	1	7	7	4	4	16	16
White	11	11	7	7	1	1	2	2	21	21
Hispanic	2	2	0	0	0	0	0	0	2	2
Gender										
Women	0	16	4	5	8	7	4	5	16	33
Men	17	1	4	3	0	1	2	1	23	6
Education										
<HS	2	3	2	0	1	0	0	0	5	3
HS	7	3	1	3	4	1	2	3	14	10
SC	4	6	3	2	2	5	4	3	13	16
BA or more	4	5	2	3	1	2	0	0	7	10
Occupation										
Managers OR Professionals	4	6	1	4	2	3	0	0	7	13
Assoc. Professionals/ Technicians	2	2	1	1	0	4	2	4	5	11
Clerical OR Service OR Skilled Craft/ Trade	4	5	3	2	2	1	1	0	10	8
Factory/ Machinery Operators OR Elementary Occupations	6	0	0	1	0	0	2	1	8	2
Homemaker/ Not Working	1	4	3	0	4	0	1	1	9	5

Table 3.3 Interview Sample: Physician Demographics

	Physicians
Race	
Black	2
White	19
Asian or Middle Eastern	9
Gender	
Women	14
Men	16
Position	
Attending	9
Fellow	10
Resident	11
Department/Division	
Internal Medicine	10
Emergency Medicine	1
Critical Care	15
Palliative Care	2
Geriatrics	2

CHAPTER 4

Miles Apart: Race, Socioeconomic Status, and Institutional Inequities at the End of Life

Health and health care researchers commonly show that socially disadvantaged groups are less likely to access expensive, technologically advanced medical care than their more socially advantaged counterparts (Buchmueller et al. 2016; Agency for Healthcare Research and Quality 2017). Yet, research on end-of-life (EOL) medical care suggests that Black and Hispanic patients are *more* likely to be treated aggressively (Brown et al. 2018; Davies et al. 2019; Orlovic et al. 2019). Still, despite this trend, these groups also report less satisfactory EOL experiences (Carr 2016; Khandelwal et al. 2014; Lee et al. 2016; Welch et al. 2005). These findings indicate that analyses that attend only to access may fail to adequately account for ways in which inequality functions at the end of life. Even when socially disadvantaged patients receive more medical care, they still might experience poorer outcomes. Identifying appropriate interventions to address social inequality in EOL care thus requires additional investigation.

Past research suggests two possible pathways to racial and socioeconomic inequalities in EOL experiences. Some research suggests that aggressive treatment itself at the end of life results in less satisfactory EOL experiences and high costs for families and insurers (Kaufman 2005; Marik 2014). This *intervention perspective* suggests aggressive measures are both costly and

traumatizing, and posits overtreatment among socially disadvantaged groups is to blame for the less satisfactory EOL experiences of minorities and patients with lower socioeconomic status (SES) (Marik 2014; Orlovic et al. 2019; Richards et al. 2019). Another possible explanation points to evidence that racial minorities face discrimination in health care experiences, including provider prejudices and patient-provider communication differences (van Ryn and Fu 2003; Smedley et al. 2003; Williams and Jackson 2005), and these may contribute to poorer EOL experiences. Clinicians' own ideas about appropriate care may negatively influence the experiences of patients and families who want more aggressive treatment (See Chapter 3). This body of evidence supports a *bias perspective* that suggests disparities arise when patients with lower-SES or minority patients and their families face discrimination and bias in communication and decision-making and experience poorer interactions about EOL care.

While both perspectives offer some analytic leverage over disparate experiences at the end of life, too often they are siloed from each other, and may overlook other structural factors. After conducting ethnographic observations in 4 intensive care units (ICU) and interviews with patients' family members and physicians, I found a complex interplay of factors, at multiple levels, likely inform broader population-level patterns of difference in EOL experiences. Notably, a comparative lens demonstrated how hospital-level variation in resources shaped EOL care trajectories and how they enabled or constrained communication and decision-making about life-sustaining treatment. This variation in resources structured the care provided, even when similar technologies were available at all hospitals. I found that variation in institutional resources, like the built environment of the ICU, physician staffing, and investment in ancillary and support services made communication and decision-making more feasible and swifter,

regardless of whether patients and families chose more or less aggressive care pathways. These hospital-level resources also had the potential to make it easier and more efficient to implement particular EOL care pathways or to facilitate the process of decision-making. Even when hospitals could provide similar technologies or services, institutional resources shaped how patients and families learned about and made decisions about those treatments.

In this paper, I demonstrate how the built environment of the intensive care unit, physician staffing, and hospital investment in ancillary and supportive services impacted different aspects of communication and decision-making in the ICU, leading to aggregate differences in the experiences of patients near the end of life in four different hospitals. In the setting of substantial demographic variation in the populations different institutions served, these institutional "structure of care" resources helped illuminate population-level disparities in EOL health care experiences.

Background

An Intervention Perspective: Differences in End-of-Life Treatments

Early work on social inequities in EOL experiences suggested that socially disadvantaged patients were more likely to have life-sustaining treatments, such as cardiopulmonary resuscitation (CPR) or life support, withheld or withdrawn (Glaser and Strauss 1965; Sudnow 1967). Sudnow's classic ethnography on the treatment of dying patients in the ER painted a disconcerting picture of how patients' social worth impacted how much effort, if any, physicians would put forth in resuscitating them. He found that patients deemed to have lower social worth due to age, class, or substance use received far less resuscitative treatment. Revisiting this line of

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research decades later, Timmermans (1999) examined resuscitative attempts following the implementation of evidence-based protocols for CPR. Despite such practice-based changes, he continued to find that resuscitation efforts were influenced by patients' age, social connections, and whether they had terminal illnesses or substance abuse problems—what he called the perceived "social viability" of patients. Further, he found clinicians felt the deaths of many of these patients were welcome and/or appropriate. These ethnographic studies provide some evidence of inequality in the aggressiveness with which some patients receive life-saving interventions.

Research since continues to document race-ethnic and socioeconomic differences in EOL experiences but reveals a different pattern: while the specific forms of intervention at the end of life have changed as new and different technologies have been developed,[23] evidence now indicates socially disadvantaged patients are more, rather than less, likely to receive greater intervention at the end of life. Black patients are more likely to die with mechanical ventilation and have CPR performed, and less likely to receive less aggressive treatment such as hospice care (Burgio et al. 2016; Hernandez et al. 2015; Mack et al. 2010; Muni et al. 2011; Nayar et al. 2014). Patients with lower SES are less likely than patients with higher SES to enroll in hospice (Nayar et al. 2014) and less likely to die at home (Barclay et al. 2013; Carr 2016). Further, Silveira and colleagues (2011) found that hospice care clusters around key SES measures: greater regional hospice availability was associated with increased community wealth and education.

[23] Life-sustaining treatments include aspects of cardiopulmonary resuscitation (i.e., administration and timing of chest compressions, administration of vasopressors, cardiac massage, and/ or inter-cardiac epinephrine) as well as intubation and artificial respiration.

Alongside work documenting differences in care received, some studies have also documented differences in satisfaction with care. Lee and colleagues (2016) found that the greater use of life support by racial minorities helped account for some of the lower EOL experience ratings among those respondents. Zhang, Nilsson, and Prigerson (2012) also find evidence linking aggressive treatment to lower satisfaction with EOL experiences as reported by patients' relatives and caregivers but note that most of the variance in these satisfaction ratings remained unexplained. On the other hand, in a more recent sample of Medicare recipient deaths, Sharma and colleagues (2017) examined variation in EOL treatments and bereaved family members' evaluations of the overall quality of EOL care and found evidence of racial differences in treatment but no significant differences in family member evaluations. Considered collectively, these findings showing difference in treatments received, particularly more recent differences, could be evidence of shifting inequality and be seen as at least partial support for the *intervention perspective*, linking greater intervention at the end of life for patients from lower SES or minority backgrounds with less satisfactory EOL experiences.

A Bias Perspective: Differences in Interactions and Communication
It is also possible, however, that differences in physician-patient communication contribute to race and socioeconomic differences in EOL experiences. Differences in physician-patient communication based on patients' race and class are well documented and have been shown to contribute to health care disparities (Smedley et al. 2003). For example, Anspach (1997) and others (Fisher 1988; Fisher and Groce 1985) noted that among less socially advantaged patients, clinicians conveyed information in an oversimplified style, and were more likely to tell or

persuade patients what to do rather than present them with options. White and colleagues (2007) found that the number of prognostic statements made by ICU physicians in family conferences was positively associated with the level of education of family members, suggesting more educated families received more frequent and specific information about prognosis than less educated families. While differences in clinicians' interaction styles may be explained in part by differences in health literacy of patients (S. K. Smith et al. 2009), they also may be a product of implicit and explicit racial bias (Chapman, Kaatz, and Carnes 2013; Green et al. 2007). Scholars show that physicians' beliefs about minority patients' ability to participate in decision-making and adhere to follow-up recommendations contribute to disparities in treatment (Burke et al. 2017; van Ryn and Burke 2000).

Other scholars have found that patients who are more educated or sophisticated are more able to get their way (Anspach 1997) because they are better able to articulate their concerns and wishes in a language and presentation that is palatable to health professionals—they have more cultural health capital (Shim 2010). In his ethnography of palliative care physicians, Livne (2019) finds evidence that good communication, driven by a patient's ability to articulate their wishes to the physician, was considered key to a good death, independent of the treatments administered and length and course of the patient's illness. This body of research provides some support for a *bias perspective*, suggesting bias and conflict in communication and decision-making with doctors contributes to poorer EOL experiences for patients and families with lower SES or patients from minority racial groups.

Broader Study of Disparities

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The mechanisms described above largely focus on how broader cultural processes shape individual-level factors, such as individual patients' preferences and providers' actions, in explaining patterns of difference. Although they point to structural patterns of difference, some scholars have criticized how these narratives may inadvertently contribute to a focus on individual-level solutions and interventions (Gee and Ford 2011; Golden and Earp 2012; Link and Garcia 2019). Link and Garcia argue that diversions in health inequities research have turned focus away from people and institutions with power and have preferred to identify answers that lead to solutions considered more easily modifiable or actionable. In light of these critiques, and because of the already complex patterns of difference by race and SES in EOL preferences, decisions, and satisfaction, explorations of inequality must be designed to capture multiple levels of difference and identify broader structural forces contributing to inequities. I hypothesize that exploring how processes of decision-making and communication vary across hospitals may shed new light on patterns of racial and socioeconomic differences in EOL health care experiences (White, Haas, and Williams 2012).

DATA AND METHODS

In this paper, I leverage observation and interview data from four hospitals in two cities to explore meso-level variation, or hospital-level differences in structures of care, and their impact on individual level experiences. I conducted observations in four medical intensive care units (ICUs) and follow-up interviews with 30 physicians and 39 patients' family members to identify how EOL experiences varied and how they were evaluated by those involved. Observations took place at two field sites and two separate hospitals in each site; I conducted over 150 days of ICU

observation between June 2018 and February 2020. I also conducted follow-up interviews with 30 physicians and 39 patients' family members.

Field Sites

Greenville, a mid-sized city of approximately 120,000, is home to State University and its associated medical school. The medical school provides medical residents and attending faculty to College Hospital and Truman Medical Center (TMC), Greenville's Veterans Affairs (VA) Hospital. Other clinical staff (nurses, respiratory therapists, pharmacists, etc.) at College Hospital were employed directly by the State University Health System; other clinical staff at Truman Medical Center were employed by the VA.

College Hospital mostly served the residents of Greenville and the surrounding region. Part of a large academic medical center, the ICU at College Hospital regularly received patients transferred from smaller regional hospitals, including ICU-level transfers. Over 70% of residents in Greenville and the surrounding county were White, 55% of residents over 25 years old had a college degree, and 85% had incomes at or above the poverty line (U.S. Census Bureau 2019b).

TMC served veteran residents from a broad region within the state, and its patient population reflected the state's Veteran population: fewer than 25% had a college degree and nearly 85% were White (National Center for Veterans Analysis and Statistics 2018). Patients were also frequently transferred to this VA hospital from satellite clinics and other VA hospitals for more complex inpatient care.

Because the TMC ICU served Veterans, men made up a very high proportion of its patient population. Patients in the observation sample at TMC ICU were, on average, older than patients at College Hospital, while patients at College Hospital were, on average, more critically ill. This was due in part to College Hospital's status as the region's major academic medical center as well as lower patient-to-nurse staffing ratios in other wards of the hospital, which meant patients requiring intermediate levels of care and supervision could remain on the general wards. Only the highest acuity patients were transferred to the ICU. College Hospital's patients were from higher-SES backgrounds than TMC, although there was variation in the patient populations at both hospitals.

River City is 40 miles away from Greenville and has a population of nearly 700,000. Memorial Hospital and North General Hospital are both located on a large downtown medical campus in River City. Both hospitals were part of Promise Health System (PHS), a large for-profit health system with numerous hospitals and satellite clinics in the area. River City also had a medical school, whose faculty were contracted to provide service at Memorial and North General Hospitals. Other clinical staff, including residents, were employed directly by PHS. Both hospitals mainly served residents of River City; nearly 80% of River City's population was Black, 36% had incomes at or below the poverty level, and 15% had a college degree (U.S. Census Bureau 2019a).

The ICUs at Memorial Hospital and North General Hospital served slightly different patient populations: North General housed one of River City's major trauma-receiving emergency rooms and was described by emergency medicine residents as preferred by local EMTs and

paramedics because of its easy unloading for ambulances. North General's medical ICU received a greater proportion of patients brought to the hospital by ambulance, including cardiac arrest and overdose cases, as well as patients arriving directly from the area's nursing homes, than Memorial Hospital. Likely because of this distinction in where patients came to the ICU from, Memorial had more privately insured patients than North General, and North General had more uninsured patients than Memorial. Both saw high proportions of Medicare and Medicaid patients, and the PHS medical center that included Memorial and North General provided over 1/5 of the entire state's in-patient Medicaid services.

Observations

I focused on observing processes of communication and decision-making about life-sustaining treatments for patients considered potentially at the end of life due to a terminal illness (e.g., cancer, end-stage liver or heart failure, etc.) or for patients whose acute critical illness came with a high risk of death (e.g., severe sepsis, acute respiratory distress syndrome, etc.). These patients were approximately 40% of the patients (N=203) who occupied ICU beds during my observation period. I attended morning rounds with the ICU team and followed them throughout the day, observing how they discussed patients' diagnoses, prognoses, and the risks and benefits of life-sustaining treatments, both amongst themselves and with patients and their families. When possible, I also asked physicians directly about their thoughts on patients' prognoses, family communication, and what they thought should happen next. I took detailed field notes on the communication and decision-making processes that took place and wrote down conversations about life-sustaining treatments nearly verbatim when possible. There were instances during family meetings when note-taking was clearly obtrusive to family members; during these

instances I refrained from taking notes and later wrote down as much as possible immediately following these meetings.

Institutional approval and informed consent were obtained at each hospital. Initially I worked with administrators, and I also obtained each clinician's informed consent. Consent was obtained away from supervising faculty, and physicians were also told they could ask me to refrain from observing at any point. All physicians and medical students on service in the ICU units during observations provided consent (N=160).[24] Prior to observing communication with patients or family members, I introduced myself, explained I was observing critical care communication and decision making in the ICU, and obtained their verbal permission to observe.[25] I also provided an information sheet with study information and informed patients and families that they could ask me to stop observing at any point. Demographic information for the observation sample is provided in Table 3.1 (pg. 99).

Interviews

Additionally, I conducted semi-structured follow-up interviews with physicians and patients' family members. I recruited family members of 66 patients for follow-up interviews. I selected interview subjects who engaged in multiple and/or lengthy conversations with the team focused on identifying the patient's preferences for and family's decisions about the use of life-sustaining treatments. I followed up with patients' family members after the patient's discharge from the

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[24] Some physicians were observed in multiple hospitals (N=8).
[25] At one site, in keeping with the specifics of IRB approval at that site, I obtained written statements of consent from the patient's primary surrogate decision-maker and up to one additional family member involved in decision-making if I observed direction communication between the physician team and a patient's family members.

ICU and interviewed them about their experiences in the ICU, their communication and decision-making with the ICU team, and what mattered to them in making decisions about the patient's treatment. All but one interview took place over the phone. Nearly 60% of patients' family members recruited in the ICU for follow-up completed an interview (39/66). Information about the interview samples is provided in Table 3.2 (pg. 100).

I also interviewed 30 physicians about their experiences and approaches to communication and decision-making about life-sustaining treatments in the ICU. Topics covered included positive and negative experiences with deaths in the ICU, how they handled disagreements or conflicts with patients and/or families, and their thoughts on EOL care and how it could be improved. I used convenience sampling, and spoke primarily with internal medicine residents, critical care fellows, and critical care attendings I had observed, but also conducted interviews with palliative care and geriatric physicians who had experiences with patients in the ICU. Information about the physicians interviewed is provided in Table 3.3 (pg. 101).

Data Analysis

Interview transcripts and field notes were analyzed qualitatively for themes and patterns (Emerson et al. 2011). I initially open coded the field notes and transcripts by hand and wrote short memos about potential patterns emerging in the data (Glaser and Strauss 1965; Tavory and Timmermans 2014). I used abductive analysis to identify variation between cases and then traced patterns to develop theoretical arguments about observed variation (Tavory and Timmermans 2014). Specifically, to make comparisons across institutions, I identified variation in how structures of care influenced EOL experiences and then determined how these structures mapped

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out in each hospital. Patterns of institutional variation were confirmed across multiple methods of inquiry—they were evident in family member and physician interviews as well as my observations (Giacomini and Cook 2000). Additionally, member-checking with clinicians and other experts was utilized to assess whether my interpretations about processes of care made sense to others (Anspach 1997).

RESULTS

The demographic differences in the patient populations served by College Hospital, Truman Medical Center, Memorial Hospital, and North General Hospital were stark. At Memorial and North General, 85% and 75% of ICU patients whose care I observed were Black, while only 12% and 6% of patients whose care I observed at TMC and College Hospital were Black. More generally, patients at Memorial and North General were more likely to rely on Medicare or Medicaid, or lack any health insurance coverage, than patients at College Hospital. TMC patients were often from lower-SES backgrounds than patients at College Hospital but were also embedded in the VA's interconnected health system.

The built environment, physician staffing, and investments in supportive services between hospitals simultaneously varied, with College Hospital having the most resources available to provide high-quality care for communication and decision-making about life-sustaining treatments and Memorial and North General having more constrained resources. TMC aligned with College Hospital in some aspects and with Memorial and North General in others. Differences in aspects of care provision are summarized in Table 4.1.

The Built Environment and Structure of Service

In all four hospitals, ICU service followed a similar pattern. All four hospitals had morning rounds where the team discussed the care of each patient on service. Teams began rounds by seeing patients admitted during the night, and then seeing the other patients on service. After rounds, residents and fellows spent the rest of the morning and afternoon placing orders for medications and other treatments, entering their notes into the electronic health record, updating families and discussing the day's treatment plan, and preparing for and completing any procedures patients needed. They were also responsible for seeing any patients being considered for admission to the ICU.

However, these tasks were differentially impacted by the built environment. The number of ICU beds (and thus number of patients), where the teams' patients were physically located ,and where team members worked (see Table 4.1) all impacted how long morning rounds took, whether families could anticipate and participate in rounds, and how easily and frequently other communication between physicians and family members took place..

Because the ICU service at College Hospital and TMC was located entirely within a single unit, the process and flow of morning rounds was clearer to patients and families. Families often could get a general sense of when the team would round on their family member. Rounds began at the same time each morning, and almost always ended before 11am. At College Hospital, families frequently listened to morning rounds and were afforded some face time with the attending on service.

At Memorial and North General, the physical layout of the ICU service often made communication with family members more difficult. Because of the location of ICU patients in multiple units, as well as the greater number of patients overall, morning rounds involved visiting multiple units, often more than once. This process meant rounds took longer, often lasting into the early afternoon. Unless families could be present for the entire span of morning rounds, they often did not know when the team would be by to discuss their family member's case. A similar pattern emerged at North General, where ICU patients were again located in multiple units, including the emergency department.

Further, the layout at College Hospital and TMC facilitated greater communication between patients and families and their physicians when compared to Memorial and North General. Given the public-facing workstations of clinicians in College Hospital and TMC ICUs, family members could readily locate and speak to a physician when questions emerged. Concomitantly, the public-facing workstations made it easier for residents and fellows to see when visitors arrived, and an effort was often made to provide an update to family members shortly after their arrival in the unit. The layout of the ICUs at College Hospital and TMC were not perfect for facilitating communication. Some family members complained about the size of the rooms and thus limited space for multiple visitors to receive updates simultaneously, and occasionally a private space for family meetings was difficult to find. However, overall, the visibility and accessibility of clinicians ensured a significant degree of open communication or something between clinicians and family members.

At Memorial and North General, the separate workspace for clinicians reduced accessibility and thus patient-provider communication. Patients and their family members frequently could not directly contact physicians, but instead relied on nurses to page them. Physicians might be slow to respond given other responsibilities, such as completing rounds or placing orders, as well as the low visibility of waiting patients and family members.

For example, in one instance typical of care on the busy Memorial ICU service, the ICU team had been asking the sister of Mr. Dunmore, a 59-year-old Black man who had required intubation because of large (likely cancerous) neck mass, to come to the hospital to discuss his diagnosis and treatment options. Two days later (on a weekend day), the fellow informed the resident that Mr. Dunmore's nurse paged him and said Mr. Dunmore's sister and aunt were waiting in his room for an update from the doctor. The resident replied that he would talk with Mr. Dunmore's family after attending to a new admission in the ER – another routine responsibility. Yet, after meeting with and admitting the new patient in the ER, the resident then went back to the workroom to enter notes regarding the admission. Two hours after receiving the page, the resident checked in on Mr. Dunmore's family, who were already gone – a pattern that repeated across many observations in Memorial and North General. Residents faced numerous demands on their time and the barrage of accumulating tasks meant talking to families located elsewhere was delayed or forgotten. This could happen at TMC and College Hospital as well, but the consistent presence of physicians in the open space of the unit made families more visible to physicians and made physicians' work—and delays related to that work—more visible to families.

Physician Staffing

Another key difference between these hospitals was the ratio of physicians to patients. Aspects of physician staffing, including day and night staffing, the use of "call shifts", the assignment of patients, and attending presence are summarized in Table 4.1. The overall number of physicians to very sick patients varied between hospitals, with College Hospital and TMC providing physicians with smaller patient loads. As a result, physicians at these hospitals could spend greater time with patients and their families. With this time, they could more thoroughly review treatment options and build therapeutic relationships, providing another avenue through which patient-provider communication was enhanced and EOL treatment trajectories improved.

Substantial patient loads were first and foremost a constraint on the time physicians had to speak with families. Physicians at Memorial and North General described feeling burdened by the high number of patients and the inability to allocate enough time to speak with family members. Occasionally, family members who wanted frequent conversations were interpreted as difficult. After a 20-minute conversation with the son of critically ill patient who had just failed extubation (the removal of a breathing tube), one fellow confided to me how challenging the patient's son was becoming. "It's really frustrating, when families are so demanding. I can't afford to spend 20 minutes talking to every patient's family each day." At first I was surprised to hear this, as 20 minutes likely seemed very short to the patient's son, but she explained, "If I did that for every patient – if I did that for half my patients – I'd spend my whole day having family meetings."

Another physician explained that the sheer number of sick patients at Memorial left little time to prepare for exactly the kinds of in-depth conversations required for family meetings about goals

of care. After a meeting with the daughter of Mr. Romero, a 73-year-old Hispanic man with recently diagnosed lung cancer, about treatment options for his cancer given his current functional status, a fellow reflected on feeling unprepared:

> Memorial Fellow: This is just too much here. Too many patients that are too sick. It's too hard. I feel like everything I do is reaction, reacting to this, let's do that. I don't have time to think about what we're going to do for each person. I don't have time to get to know people. If I were family, in that meeting, I'd be like, "This guy, he doesn't even know what's going on." I'd like to not look inept.

Another fellow, who described the importance of contacting family each day, and not only when you "have bad news" admitted most families didn't get updated as much as she would've liked.

> *I: How often do you think families get updated?*
> Memorial Fellow: I, mean, not as much as I or the families would like. There are a lot of components to working in an ICU that take priority—which are that if there is a sick patient, you need to attend to them first. Everything else is second. If you have 15 sick patients at one time, you need to attend to them. There may be patients who we may be withdrawing care from. There are just so many—there may be patients who need a study done or a procedure done now which may be lifesaving or may really change things for them at that very moment. We try to focus on those things, and that's why I feel sometimes the routine stuff gets pushed to the back. There are just so many hours in a day, unfortunately, as much as we would like to have more hours… More often than not, it is basically that our days are just so unpredictable, and we are trying to prioritize things that will change something—there just aren't enough hours in the day.

Multiple attendings also acknowledged how the ICUs at Memorial and North General varied from where they had trained. They felt the units were much busier and had more very sick patients than their previous institutions and recognized this demanded a lot from the fellows. One attending physician at North General described the patient loads as:

> "really hard on the fellows. When I was in fellowship, I had time to get to know the patients, get to know what was going on with them. We had more time for these conversations. It was a smaller unit and we had support staff. I mean, the patients were different, too, but I had so much time to learn. I don't think our fellows get as much of that. It's hard."

This contrasted with the experiences of physicians at College Hospital and to a somewhat lesser extent, those at TMC. For example, at College Hospital, when one resident-intern pair was carrying six patients, he asked the other pair on call for the day to take the next patient (which in alternating order, would have gone to his team). His fellow resident, part of a pair only taking care of two patients, happily obliged. Because of lower patient-physician ratios, trainees at College Hospital and TMC never expressed concerns that the number of sick patients they were treating would impact the level of care they could provide.

At Truman Hospital, residents described their ICU rotation as very manageable, and remarked that rotations on the general wards at TMC were sometimes more stressful than the ICU. In fact, on occasion residents complained there were too many trainees on service, and that they had too few opportunities to perform procedures that required supervision before residents were certified to perform them solo.

Beyond the ratio of patients to physicians, how patients were assigned to residents and how shifts were organized influenced EOL care. At College Hospital, patients were cared for by resident-intern pairs who took different days off each week, so there was always someone familiar with the patient's case, and familiar to the family, on service. At TMC, residents were also assigned patients for the duration of the patient's ICU stay. At Memorial and North General, however, patients were reallocated amongst the residents each morning to ensure the large number of patients was equitably divided among them. This reallocation meant patients (and their families) frequently experienced turnovers in the primary physician taking care of them.

Patients and families were frustrated by the turnover of residents, who were, ideally, supposed to be most familiar with the patient's care. For example, the husband of Mrs. Saunders, a 47-year-old Black woman, complained to the ICU attending about his wife's care after it was revealed that previously ordered tests were not completed.

> Memorial Attending: The husband is frustrated and doesn't want trainees treating her (his wife). He was upset because last time these tests weren't done. I told the husband about this (the missed tests) to be transparent. He told me his wife was a nurse for 25 years and deserves better care. I told him I treat all my patients the same.

While the delayed test did not substantially impact Mrs. Saunders' current treatment, her husband later explained to me he was more concerned by his communication with the ICU team.

> Mr. Saunders: I think people come in the room, and they don't know what's been done, and they don't know what's going on. I'm the one telling them that something has already been done. They weren't here yesterday. They're new. The nurse didn't know. That causes me distress, as a family member, that you don't know what's been done. People need to check the computer and check the chart. You don't know what questions I'm going to have, and I don't want to offend you by asking a question that you don't know the answer to. I need to know someone is following up, following along. Seeing 2-3 different doctors, who don't know, that distresses me.

Residents tried to take care of the same patients from day to day, but between overnight call shifts and the balancing of patients across residents, most patients ended up being cared for by multiple residents during their stay. Mr. Saunders' concerns, including what he perceived as a lack of continuity in his wife's care, were not uncommon. These concerns weakened trust in the ICU team and led to increased tension in communication with the team.

Early communication issues could later become barriers in important conversations about prognosis and goals of care. Physicians from each hospital emphasized the need for

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communicating regularly with families. Further, they emphasized this worked best when the same person provided updates and helped families through decision-making:

> Fellow, Memorial Hospital: It also depends that who is having those conversations subsequently. It may be different members of the ICU team; it may be different family members from their side. I feel if you have a relationship with the family early on, I think those conversations are a lot smoother than they are otherwise because—here is somebody telling you that, "Oh, your family member is dying, and we shouldn't do anything, and we've done everything we could," as opposed to when they were actually not doing well, and then they got better, and you worked through that with them, and now they're getting worse. It's a relationship—the sooner you start it, the better.

In the case of Mrs. Saunders, I received an update on her case during a physician interview after my observations had concluded. The physician told me that after a return trip to the ICU during her cancer treatment, she and her husband sought to transfer her care to another hospital, as they didn't trust the team's assessment of her prognosis.

Call shifts, too, impacted communication and decision-making. Residents were required to cover 24-hour "call shifts" every four or five days at Memorial and North General. During a call shift, a resident worked through the day, overnight, and then presented their patients on morning rounds the following day. Overnight call shifts were 28-30 hours on average, as residents arrived around 6am each morning, and morning rounds on the overnight resident's patients ended around 10am the next day, after which they would finish their notes before departing. Call shifts actually exacerbated the challenges of patient hand-offs between physicians. Residents often took their weekly day off following a call shift, which allowed them to have nearly two days out of the unit. When they returned, they were now two days removed from the care of their previous patients and unfamiliar with two days of new admissions.

Call shifts also exhausted residents, which impacted their ability and desire to provide updates to families. On call shifts, residents described having little time and energy to engage with patients and families in the evenings (when many families were more likely to be able to visit).

> Memorial Resident: I'm a black cloud[26], I swear. I'm exhausted. We had six admissions last night.
> {I: Do you think that impacts patient care?}
> Resident: How could it not? I guess they say it doesn't – they did a study. But they also started paying for residents to take Uber or Lyft home after call shifts. Someone got in an accident a few years ago. Being sleep deprived is like being drunk. I know my thinking is affected.

> North General Resident: I tried to talk to [the patient's] sister last night when they were here, but then I was called away [to see another patient]. There were too many other sick patients. I didn't even try to sleep last night.

Because Memorial and North General had only one fellow and one, often exhausted, resident caring for 20-30 patients in the evenings, family communication and goals of care conversations took a backseat to decompensating patients and other urgent tasks. For instance, after one overnight shift, a resident explained she'd had little time to discuss whether intubation was appropriate for a patient just admitted from the emergency room with trouble breathing. Ms. Berry, a 68-year-old Black woman, had advanced lung disease, and her family later revealed she did not want to end up stuck in the hospital.

> Memorial Resident: I don't know if that was the right choice for her. But she was just (imitates patient hunched over, heaving and struggling for breath) and the fellow was taking care of another patient upstairs. Of course, once the tube goes in, we can't ask her anything.

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[26] A 'black cloud' referred to someone who seemed to have very high admissions and comparably sicker admissions when they were on call.

In another case, Mrs. Rogers, a 51-year-old White woman with severe complications following a lung transplant removed her breathing tube in the middle of the night. The previous day she had told the doctors and her family "she was done" and they were planning to transition to comfort care the next morning when her family arrived. The on-call resident and fellow, panicked Mrs. Rogers would die before her husband arrived, called and asked him if they could put the breathing tube back in. Unfamiliar with the conversation that took place earlier, they ultimately provided care Mrs. Rogers had stated she did not want.

While the total number of patients at TMC was smaller, and some patients were often less critically ill, the overnight coverage by a single resident at TMC could also infrequently pose challenges. In one instance, Mr. Malone, a 54-year-old Black man with numerous comorbidities and acute cardiomyopathy, came to the ICU after his heart stopped beating properly and his implantable cardioverter defibrillator (ICD)[27] fired, resuscitating him. Over the next 24 hours, his ICD fired twice more in response to irregular heart rhythms, and unfortunately, the team was unable to determine the cause of his arrests. Early the next evening, he experienced another cardiac arrest which required CPR, including additional shocks from his ICD and chest compressions from the clinical team. He was successfully resuscitated, but in immense pain, and unsure when he would arrest again. Overnight, in significant pain and with no obvious treatments to fix the underlying problem, Mr. Malone struggled with the difficult choice of deactivating his ICD.

[27] An ICD is a medical device implanted under the skin with leads (wires) threaded directly into the heart. The device monitors a patient's heart rhythms for abnormalities (arrythmias). If it senses an arrythmia, it delivers a shock to get the heart back into a normal rhythm.

While the overnight resident was able to manage Mr. Malone's and the other patients' care medically, and explain his options clearly, she expressed concern about helping with decision-making. Mr. Malone and his family were struggling with notably complex EOL decision-making given his uncertain diagnosis, prognosis, and relatively young age. Mr. Malone appeared to change his mind multiple times about ICD deactivation. With no other physicians on service to consult, the resident asked me after some conversations with the family whether I thought she should formally change the patient's code status. At multiple points, the patient's brother informed her Mr. Malone had changed his mind, and she expressed uncertainty about whether she should change the patient's code status in the health record. Ultimately, a final decision regarding deactivation and a transition to comfort care for Mr. Malone was deferred until the following day, when the day resident and fellow taking care of Mr. Malone met with him and his brother to clearly confirm his wishes. Limited overnight coverage and call shifts contributed to poorer or delayed EOL communication and treatment.

How Physician Availability Plays out in Family Discussions

Greater and consistent physician availability can increase trust, facilitate decision-making over time, and lead to more positive evaluations of care by both physicians and families. The following two cases reflect how physician availability differentially impacted communication and decision-making. In both cases a patient suffered a serious cardiac arrest, was placed on a cooling protocol,[28] and was awaiting neurologic prognostication. In both cases, a decision was

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[28] Therapeutic hypothermia is used to cool a patient's body temperature to reduce brain damage following severe cardiac arrests. Studies show they decrease inflammation and increase oxygen flow to damaged areas (Varon and Acosta 2008).

also eventually made to either withdraw life-support or not escalate life-support, and the patient died in the ICU.

Ms. Elmina was an 88-year-old Black woman with advanced dementia. Following a serious bout of pneumonia and sepsis, Ms. Elmina spent 3 weeks at a long-term acute care facility (LTACH) for respiratory support and rehabilitation before being transferred to a nursing home. Two days after that transfer she had a cardiac arrest. CPR was started and she was sent by ambulance to North General. Ms. Elmina's heart started beating after 30 minutes of CPR, and she was taken to the ICU. She was placed on a cooling protocol and the fellow met with her two daughters for about 5 minutes to give them an update, explaining, "right now it's not looking good, she is not showing higher-level reflexes, and she is not responding to stimuli."

Two days later, the neurology attending and ICU fellow met with Ms. Elmina's daughters and explained that although she was not brain dead, they believed she had a poor neurologic prognosis. Ms. Elmina's daughters were upset and asked for more prognostic information. The clinicians reported two additional tests could be performed. The next day, Ms. Elmina's daughters asked to speak with the team, but by the time rounds finished, nearly three hours later, Ms. Elmina's daughters had left.

Before rounds the following day, the resident taking of Ms. Elmina explained to me that she wished the attending had spoken to the family yesterday. She thought that they might have responded better to the supervising physician. She also felt neurology "just signed off" without explaining the results of the additional tests to Ms. Elmina's daughters. During rounds, the team

discussed how to proceed with talking to the daughters. The resident taking care of Ms. Elmina

was on call overnight, so she would be off the rest of the day.

> Resident: I still think that if we talk to the family we might –
> Fellow: We can talk to them.
> Resident: Yesterday they were here until noon. I wanted to talk with them with you, but they didn't come back.
> Attending: If they are here, I will talk to them. Actually, I have clinic.
> Fellow: I will talk to them.

Unfortunately, the day became busier and after two hours the resident, newly caring for Ms.

Elmina, went to speak with her daughters.

> Resident: So, they did any EEG-
> Daughter (1): Yes, so we have been waiting on the test results.
> Resident: So, the results are back, and they show that her brain stem function is not as it is supposed to be. There is some activity, but it is not very good. Her ability to function is very low to be honest.
> Daughter (1): They also said they were going to do another test. Do you know the results of that test?
> Resident: They did that test, yes, they did a second test. It was an SSEP, and this showed that her function was very low. There is very severe injury to her brain. To be honest, the prognosis is just not very good.
> Daughter (1): We keep hearing that, but the thing is nobody is reaching out to us to tell us the results of these tests.
> Resident: Today's my first day [covering Ms. Elmina]. But that should have been conveyed to you, I'm sorry that that didn't happen.
> …
> Daughter (1): They say that they are going to give us information and we come for hours. We've been here for hours every day and nobody talks to us, unless we grab someone… This our mother, and it feels like no one cares… The other thing is there are so many of you. Have you heard the saying 'there are too many chefs?' We're dealing with our mother leaving this world and it just doesn't feel like people are working together.

On this day, Ms. Elmina's daughters waited another hour to speak with the neurologist, and then

briefly headed downstairs to get lunch. After returning and waiting another hour, they asked to

speak with the resident. The resident explained to the daughters that the neurologist came by, but

they were not in the room. The eldest daughter replied that they stepped away for lunch, but that

their phone numbers were written on the white board. She asked the resident why they were not

called.

> Resident: Let me ask, what do you think went wrong?
> Daughter (1): I have no idea what happens next, and I feel like she doesn't have people who care about her here.
> Resident: I do care about her; I care about all my patients. I am working hard to take care of her and pay attention to what she needs. Let me tell you, I have seven patients here just as sick as she is, they are all my patients, plus there are three more in the emergency department. I can't be available all the time. But the nurse at the counter—if you tell her you have a question or you need something, she pages me, and I come here just like I did.
> Daughter (1): That's not what I'm asking for, it just would be nice to know when we could speak with someone. Do you have too many patients?
> Resident: Yes, I do.
> Daughter (1): I am sorry about that. I know you are working hard, but between a 1 and a 10 I feel like we are at a 3—
> Resident: We are giving our best care; we are doing our best. But we don't have the pleasure to be available all the time.

Already, Ms. Elmina's daughters felt that communication was strained. When the resident spoke

about the high number of patients he was caring for, he reinforced their concerns that their

mother's treatment was not the best it could be. Two days later, Ms. Elmina's daughters spoke

with the attending on service for the first time. The eldest daughter explained that she understood

her mother was old but that she had beaten poor prognoses in the past. When the attending

explained he would be off-service on Monday, the youngest daughter replied with surprise, and

suggested he had barely gotten to know Ms. Elmina.

> Daughter (2): You didn't even get a chance to know her.
> Attending: You need a fresh doctor.
> Daughter (2): This is your first day.
> Attending: This is my 6th day. I work 18-20 hours a day. I get up at 5am to look at patient records and don't get home until midnight.
> Daughter (2): Okay. Well, we are just meeting you.

Ms. Elmina died four days later, while the eldest daughter was driving her sister to the airport. When the attending who took over the ICU service called the daughters to inform them that Ms. Elmina was declining, they became distraught and implied they wanted her care escalated. The attending deflected their requests and encouraged them to return to the hospital as soon as possible. Fifteen minutes later, after the attending had restarted rounding on other patients, the ICU fellow called Ms. Elmina's daughters and told them she had died. Her daughters said nothing and hung up the phone.

Ms. Elmina's daughters experienced compounding frustrations: lengthy waits to discuss concerns with clinicians; a lack of consistency in who provided and discussed their mother's care; and a failure of clinicians to meet even basic expectations, such as calling them when they briefly left their mother's room to eat lunch. Physicians in this context were doing their best: they often provided at least a brief daily update and tried to emphasize that they were in communication with other team members. However, brief conversations with rotating team members meant conversations rarely covered new ground and often led to confusion about whether and when information had been shared with the daughters. Further, there was a clear need for trust-building with Ms. Elmina's daughters, and the rotation of different physicians severely limited this process.

This can be contrasted with the experience of a critically ill patient at College Hospital. In an interview, an attending described the case of a young Black man on his service who suffered a cardiac arrest. Like Ms. Elmina, this patient was cooled to prevent further tissue damage, and the

attending described his conversations with the family during the process of prognosticating on

the patient's neurologic recovery:

> College Hospital Attending: You take about four days to prognosticate. You do all these neurologic tests. As this is going on, I'm having multiple conversations with Mom, Dad, sister, a couple cousins.
> Again, it's another family, African-American family, so there's that trust issue, but over time the family becomes, I think, more comfortable with the notion that we've done our best, that we're being honest with them, that we're not hiding anything, that we've got no agenda…

This attending recounted multiple family meetings, throughout prognostication, where he, as the

attending, was getting to know the patient and his family. He described this as building a

therapeutic relationship and building trust. He was able to take the time each day to talk with the

family without an agenda beyond establishing communication. He described trust increasing

between the team and the family during the patient's ICU course.

> Any independent functioning outside of an extended care facility was very unlikely. By the time I had the third sit-down meeting with the family, I knew everything about this kid; what he did in high school, what he did for work, what he enjoyed, how he got in jail, his girlfriend who was there. He had a baby, a little baby. You've got the father of a baby that you're talking about withdrawing care, and these are very heavily, emotionally charged conversations. In the end, after all these meetings, I made it clear, and they understood.

The College Hospital attending described how getting to know his patients built trust and also

allowed him to see the patient—and the decisions that needed to be made about his care—

through the eyes of his family members. Although this case had occurred nearly a year prior, the

attending's voice faltered when he discussed it, and he wiped his eyes and made a joke about

"allergies."

For this attending, the period between the patient's arrival in the ICU and official prognostication was an opportunity to build a relationship and get to know his patient. The family of this young man, like Ms. Elmina's daughters, needed multiple meetings and assurances before they were able to make a decision. By ensuring these meetings took place with the same physician each time, the College Hospital attending was able to more clearly convey his investment in the young man's case. The attending physician was able to personally take time to speak with the young man's family each day and gain a deeper understanding of his life and family outside of the hospital. This relationship allowed him to share in the family's anguish over the loss of their loved one. While the attending physician was emotionally affected by this patient and his family, he also felt proud of the care he provided, which led to a sense of accomplishment, rather than distress and burnout.

While the team at North General was also invested in Ms. Elmina's treatment, this was not as clear to her daughters. For Ms. Elmina's family, trust decreased as communication became strained and the family felt they had no physician who was consistently present in their mother's care. Further, physicians at North General commonly described an inability to continue engaging with families when cases became lengthy or contentious because, unlike at College Hospital, they faced greater institutional constraint and frequently burnout. In particular, they felt they had too many sick patients to have multiple lengthy conversations that they felt were unlikely to change a patient's course.

Here, it is important to acknowledge that having multiple family meetings, where a physician could, in theory, build the kind of therapeutic relationship described by the College Hospital

attending above, is dependent on the family's availability as well. Across my field sites, patients' family members were most available at College Hospital and least likely to be regularly available at North General. College Hospital patients more frequently had family members who could be present throughout the day, such as spouses or siblings who were retired or adult children whose jobs allowed them to take time off. They were also more likely to have access to transportation. In contrast, some families of patients at North General described multiple jobs, inflexible schedules, and limited access to transportation. Coordinating family meetings usually took more time for patients at North General.

However, family and physician availability were distinct contributors to the frequency and effectiveness of discussions about life-sustaining treatments. As evidenced in the case above by the breakdown in communication despite Ms. Elmina's daughters' frequent presence in the ICU, at North General, physician availability for relationship-building communication was far more limited, and the rotation of patients among residents and fellows meant less continuity in conversations.

How Level of Training and Physician Availability Intersect in Discussions of Life-Sustaining Treatments

As revealed in other studies (Dzeng 2019; Jenkins 2015), differences exist in how clinicians with more or less training handled conversations around life sustaining treatments, and this was also true at each hospital I observed. And at all hospitals there were times when the determination of who would lead a family meeting or give updates to a patient's family members came down to who was currently available, rather than who was most appropriate. Lastly, trainees were not

regularly supervised in conducting family meetings or goals of care conversations, and this was also true across hospitals.

However, the role of trainees in communication and decision-making resulted in disparities in care between hospitals because hospitals varied in the degree to which they relied on residents, fellows, or attending physicians to serve as the primary point of contact, lead family meetings, and in how much modeling and supervision trainees received. At College Hospital attending physicians frequently chose to lead family meetings and check in with families after rounds, while at TMC, Memorial, and North General, many attendings did not expect most family communication to require their involvement unless a case proved particularly contentious. Further, at Memorial and North General, it was simply not possible for them to be as closely involved given the sheer number of patients. Attending physicians were more likely to become involved when patients had been in the ICU for a long period of time. This was not infrequent at North General but meant that attending physicians were often stepping into conversations when trust and goodwill among the family members may already have diminished.

In my observations, and by many physicians' own admissions during observations and interviews, attending faculty were often better at conducting family meetings. This is not to say all attending physicians were best, but rather that most physicians acknowledged that exposure to more clinical situations, and observations of successful and unsuccessful meetings, helped refine prognosticating abilities and communication skills.

> Attending: I see residents and interns take these things really hard. They're in the unit for one month at a time, and think we're really hurting these patients, and it does feel that way when you're brand new to the system, and they have all this medical knowledge and

the patient and family have usually very little. They feel like they want to be more paternalistic in approach and that we should do this.

> Fellow: I think that, as a trainee in residency, you have a lot more grim perspective. I think your prognostication is probably inappropriately short. I think you're limited by the number of experiences you've had so your numbers will be off.

In interviews, physicians of all levels described watching more advanced or experienced clinicians to learn the nuances of successful conversations about life-sustaining treatments.

> Fellow: I took the opportunity to watch one of the attendings handle a conversation with a family. This wasn't a particularly difficult family but there was a lot of issues and you watch the body language. Listen to the verbal cues that were used. You're kind of like, "Oh, that really made sense. I see what happened in their demeanor after he used this phrase." …When you actually see it real-time and how it actually impacts, it really sinks in… It's a hard thing to simulate.

Many described that observing others often gave them new ways to describe similar phenomena, be it specific treatments, prognostic details, or probing questions to elucidate patients' wishes. Some recalled specific clinicians whose skill and compassion resonated deeply in developing their own approach.

Further, more advanced clinicians described greater comfort with prognostic uncertainty, which often translated into greater acceptance of varied patient and family preferences for care.

> Attending: The disagreement with regard to recommendations definitely affects the quality of patient care in what I've seen from trainees—where they don't agree with [the patient or family about] something from a goals of care discussion. Their ability to be cognizant and to care and just be more focused goes away. I don't think it's a conscious thing. I think it's a subconscious thing, where you just don't do the best you can do because well, you guys have a disagreement about stuff.

Not all physicians felt trainees were at a disadvantage in discussing life-sustaining treatments, and I also observed trainees who were particularly skilled at building trust and empathy with

patients and families and attending physicians who were less skillful. On the whole, however, more experienced physicians were both considered by other physicians and observed to be better prognosticators and more artful communicators than residents. Further, their role, as the supervisor of the unit, also elicited or increased trust from families and their perception that someone was in charge.

Thus, not only did patients at College Hospital benefit from the greater involvement of attending physicians in family meetings, residents and fellows there were provided with important opportunities to see high-quality family communication modeled by experienced physicians. Without feedback on how to better communicate with families, trainees often learned through trial and error, and sometimes at the expense of clear communication and trust with patients and families.

Residents and fellows at all hospitals rarely demurred when asked to handle a family meeting or give an update and rarely answered affirmatively when asked if the attending should be involved. Yet, as demonstrated in the case of Mr. Malone at TMC, caring for patients that were medically manageable by residents could still require more advanced communication and decision-making abilities than residents possessed, and neither residents nor fellows always personally perceived these kinds of deficiencies or saw them as sufficient reasons to involve supervising physicians, particularly when it meant asking them to be present in the unit during a time they would traditionally be elsewhere, including evenings and at night.

Further, trainees often handled family meetings precisely because a fellow or attending was unavailable, and therefore teaching and feedback were often tied to the outcomes of the meeting, rather than the process of communication that took place, which was not observed. For example, a resident at North General was told to update the family of Ms. Bishop, an 80-year-old Black woman who had suffered a cardiac arrest. The attending suggested that the resident "tell [the family] that she is having no spontaneous breathing but that she has some reflexes, and that we are doing testing. And tell them she is still in shock and her kidneys are worse and they need to come in." The resident called the patient's son, shared and explained the exact information the attending suggested, and asked the patient's son to come in; the son replied he would be in within the next couple days. When the attending asked about the family later that day, the resident told him, "I explained the worsening shock. I asked them to come in. I didn't want to give prognostic information over the phone, so I asked them to come today. They said they would be in the next couple of days." The attending grumbled in response, "If they say 'couple of days' that means they didn't get the message. We will call them again after this." Later, the resident expressed frustration with the case and told me he didn't know what he could have done differently. In instances like these, residents inferred they had failed to deliver the outcome the supervising physician wanted—family coming in sooner, a change in the patient's code status or goals of care, or approval for a procedure—but lacked information or insight into how they could have communicated with patients or families differently.

Availability and Burnout

In addition to the physical constraint of only being able to attend to one critically ill patient at a time, I also perceived that mental burnout from heavy loads of critically ill patients factored into

who was available for family meetings. Emotional and mental burnout was occasionally evident in a few physicians at every hospital. However, the burden of very sick patients at Memorial and North General was consistently high compared to the occasional wave of numerous dying patients I observed at TMC or College Hospital, and burnout and disengagement from difficult cases were more common at the River City hospitals.

For example, at one point there were nine patients who had experienced a cardiac arrest on the North General ICU service. During this time multiple staff expressed being overwhelmed by the need for goals of care conversations, prognostication, and some acknowledged that it might impact patient care. I spoke with the attending physician about his plans for the day, and asked about the family of Mr. Glendale, a 65-year-old Black man whose family had been considered hard to reach after the team disclosed his poor neurologic prognosis. From the desk where were standing, we could see they were present in Mr. Glendale's room that morning.

> Me: Are you planning any family meetings today for these patients?
> Attending: I had a long one yesterday. I thought it went well, but then right after the patient passed, some more distant family members were quite upset and got in a fight. They were yelling, and we had to involve security. Even though the daughter was comfortable with the decision that was made. Yeah, I'm not in the right place to have more family meetings today.
> (I glance in the direction of Mr. Glendale's room.)
> Attending: The fellow can speak with them.
> Me: Why do you think the Glendale family is not accepting the recommendation for comfort care?
> Attending: I think some people are just okay with small chance; if there is a 1% chance, they say that they'll take it. I think the other thing is that they get mixed messages.
> Me: What do you mean?
> Attending: I think, you know, when the resident has a conversation—they don't have the level of training that we do, and they may not be as clear. They may not say things as clearly as I would.

Mr. Glendale's case exemplifies how physician burnout, caused by heavy caseloads, impacted patients' EOL care. Despite suspecting that the family of Mr. Glendale may have not received the same prognostic information he would have shared, and that he might have been able to have a better conversation with them, the attending did not revisit the decision with the family because he was not in the right place to have another family meeting. He was at the end of his rotation, and he described being exhausted by the number of very sick patients on service. The meeting was handled by a fellow covering that weekend, and while he did his best to summarize Mr. Glendale's prognosis and the team's evolving approach to his care, he misstated that Mr. Glendale was brain-dead, further upsetting the patient's family.

Support Staff for Communication and Decision-Making

EOL care across hospitals also varied in terms of investments in support staff. At each hospital, social work and palliative care were considered key services in facilitating aspects of communication and decision-making, particularly around life-sustaining treatments and EOL care. Like physician staffing, there were differences across hospitals in the availability of ancillary service providers.

At College Hospital, the ICU had a dedicated social worker assigned to the unit. Her workspace was adjacent to the ICU entrance, and she introduced herself to every patient and family shortly after they arrived in the unit. There was also a second social worker, assigned to the surgical ICU, who would assist when there was greater need in the medical ICU. College Hospital had a palliative care service and fellowship program with 16 faculty members and 5 fellows each year; they provided both inpatient and outpatient palliative medicine. They also had a small inpatient

palliative care unit, which offered short-term inpatient care for patients at the end of life who could not be managed with home hospice care.

At TMC, the ICU was staffed weekdays from 9-5pm by a permanent social worker, although she also provided social work services for other units. She was very familiar with the broad array of VA benefits and services available for EOL care, long-term acute care, and death-related services. TMC also provided inpatient and outpatient palliative care, and many College Hospital faculty had dual appointments at TMC. TMC also had 5 dedicated in-patient palliative care beds located in the hospital's transitional care unit.

At Memorial Hospital, a social worker provided coverage for all 5 ICU units in the hospital. Like the social worker at TMC, she worked weekdays. At North General, a social worker covered the ICU and stepdown units. At neither Memorial nor North General was there a dedicated in-unit space for the social worker on service. Promise Health System intermittently hired palliative care physicians to provide palliative care for inpatients, but during my observations, inpatient palliative care consultation was provided by a single nurse practitioner (NP) who covered both Memorial and North General. This NP also worked for the separate, for-profit hospice provider who managed an in-patient hospice unit located within Memorial Hospital.

Having a dedicated social worker available in the ICU unit was particularly important in care transitions for patients and families, regardless of whether they chose more or less aggressive treatment pathways. They could help patients navigate a complex diagnostic and prognostic information, link families to other resources, like chaplains or support groups, and were key to

discharge planning. For example, identifying and selecting an LTACH or rehabilitation facility

was common for patients who needed to continue or recover from life-sustaining treatments like

mechanical ventilation, dialysis or artificial nutrition support.[29] However, different facilities

varied in restrictions, including types of care provided, accepted insurance plans, and current bed

availability. Moreover, families, whose prior knowledge and experience with facilities varied

considerably, had to navigate these restrictions as well as concerns about transportation and

distance from their homes. Social workers were essential for helping patients and families with

these care transitions.

College Hospital was best equipped to deliver support services effectively for critically ill

patients and patients at the end of life, as the social worker was available in the unit throughout

the workday. Her presence meant she could provide a list of options, answer questions, and then

begin and complete appropriate paperwork, often immediately after identifying an accepting

facility. Similarly, she was readily available to provide and ensure family members' medical

leave of absence paperwork was handled swiftly.

At Memorial and North General, these tasks were also often handled by social workers, but as

with physicians, delays and miscommunications were more likely to occur because of heavy

caseloads and because social workers saw patients in different units.

> Me: Mr. Marshall's cousin mentioned you had difficulties contacting the social worker?
> Mr. Marshall's Mother: Yeah, she called to talk about extended care places, and I just
> asked her to send the information in the mail. She said she wasn't sure she could do that
> and would need to consult her supervisor. I don't understand that. I just didn't want to
> write everything down, and I said that. She offered to text it to me. I said, "I guess that's

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[29] Artificial nutrition support could include nutritional supplement provided orally (i.e., through a naso-gastric tube), enterally (through an abdominal feeding tube into to the intestinal tract), or parenterally (intravenously into the blood).

ok, but it isn't great, it's not as easy to sit down and read texts and compare places." She did text it, but I haven't looked at it yet. I'm going to try to talk to her and try to build some rapport with her this week. I know I was frustrated and stressed out by all this. Maybe she was having a bad day, too.

In addition to having less availability, discharge planning at Memorial and North General often proved to be more difficult, and more time-consuming, for their social workers: many patients had more complex treatment requirements, their insurance was often more limited, and some families had more constrained travel and transportation options. While these factors were distinct from staffing, they exacerbated the social workers' already comparatively heavy patient loads. As with physicians, an institutional mismatch occurred: hospitals with higher-need patient populations in fact had fewer social work resources. For example, in the case of Ms. Reade, a 76-year-old Black woman suffering from ongoing delirium after a lengthy ICU stay, the social worker spent two weeks looking for an LTACH placement. The day after she had located an available bed in an accepting facility, the new attending on service suggested during rounds that he wanted to revisit Ms. Reade's goals of care, and the social worker expressed concern.

> Resident: She was accepted at Golden Hills (nursing home). She's going to be full code. It's policy.
> Attending: I don't want her to be full code.
> Social Worker: But she can go out today.
> Attending: She could just come back after an arrest if she's full code. I think it's wrong to code her. I mean, [if you're being coded] you're dead, so it's not the end of the world, but it's not the right thing to do. I am frustrated. I don't want to do that to her. Let's hold her, and get a family meeting?
> Social Worker: We're going to lose authorization.
> Attending: She's been here for weeks, what is 3 more days? I don't want her to go and get coded when she's dying. I can't do that. I couldn't sleep at night.
> Social Worker: We have meetings each week for patients that have been here more than 4 weeks and I have to explain why. I told them last week I was pursuing placement and that's why she was still here.
> Attending: You can put it on my name. It's my decision.

This exchange revealed two constraints on the social worker's time—1) the investment that she already made in locating a placement for this patient, who had a tracheostomy and required ventilatory support, and 2) institutional policies and procedures which required her to explain and implicitly carry some responsibility for lengthy ICU stays. In this case, trying to schedule another family meeting would mean the patient would "lose their spot" and she would have to start over in finding placement. The social worker had to manage contradictory obligations of facilitating communication and decision-making with the family and ensuring Ms. Reade's successful discharge from the hospital.

As a VA hospital, the coordination and familiarity fostered by the VA system meant support services could be more easily delivered and there were fewer missed connections and delays than Memorial or North General. Although the TMC social worker also had responsibilities for patients outside of the ICU, TMC was a smaller hospital, which meant general ward patients whose needs escalated to ICU-level were occasionally already being seen by the ICU-assigned social worker. Second, the social worker often had previous familiarity with TMC patients who ended up in the ICU because TMC's patients were Veterans and therefore received much, if not all, of their care at VA facilities, and often TMC specifically. Finally, because VA providers and facilities were part of an interconnected system, pathways to discharge and follow-up were more consistent and efficient.

The availability of palliative care at each hospital followed a similar pattern and impacted communication and decision-making towards less aggressive treatment pathways. At Memorial and North General, the palliative care NP was extremely busy providing consults across both

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hospitals. She always provided an excellent description of how patients and families might think about treatments in the context of goals of care, how hospice worked, and explained that patients and families could follow up and ask for more information about hospice providers. However, providing these initial introductions, and then connecting patients and families who opted for hospice services, took up all her time. She was not involved or consulted about symptom management, able to link patients to longer-term palliative care management, or able to re-visit with families who had initially declined transition to hospice.

In some instances, palliative care consultations (as described above) at Memorial or North General took an extra day or two to occur[30]. Weekends proved especially difficult, as families were often more likely to be able to gather for large meetings, but palliative care consultation was much harder to schedule. In a few instances, these weekend delays meant patients died in the unit before hospice could be arranged, or very quickly after transfer to the attached, inpatient hospice. Further, the palliative care NP's limited availability and busy schedule largely precluded the involvement of palliative care for specific symptom management and for patients and families who chose to withdraw life-sustaining treatments and therefore die in the ICU. While many ICU clinicians and nurses were familiar with and comfortable providing EOL care in the ICU, the extremely limited involvement of palliative care in these latter tasks contrasted sharply with the breadth of these services at TMC and particularly at College Hospital.

[30] The palliative care NP's limited availability and the limited availability of families at Memorial and North General often worked in tandem to produce delays in conversations about transitioning to hospice care.

Because of their robust palliative care staffing, College Hospital's and TMC's palliative care services regularly provided consultation on symptom management, suggesting changes to medications, dosages, and other treatment to better manage patients' symptoms. They also sometimes had ongoing relationships with patients who had received outpatient palliative care for serious lung disease, cancer, or other illnesses. They had time to continue visiting patients over the course of longer hospital and ICU courses, and a number of palliative care attending physicians told me they looked forward to following up with patients and families days or weeks later.

Because of better staffing, support staff were also able to better coordinate with the ICU team in these hospitals, which further improved EOL outcomes. Successful coordination between the ICU team, palliative care and social work was particularly helpful in transitions to hospice. At College Hospital, the ICU team, social work, and the palliative care team frequently worked together to help families choose hospice care and identify the best hospice or comfort care option (dying with comfort care in the ICU, transitioning to the inpatient hospice beds managed by palliative care, or receiving home hospice care).

Even for deaths managed well by the ICU team and nurses, palliative care staff often checked in to ask if the ICU team needed anything. For example, after the family of Mrs. Muller, a 65-year-old White woman, opted for comfort care, the team felt she might die quickly, and comfort care in the ICU was agreed upon. After two days, Mrs. Muller had stabilized at a lower level of support but was still expected to die within a few days. The ICU team re-consulted palliative care, and she was moved to one of the inpatient hospice beds, where her family would be more

comfortable. In another case, a patient with end-stage cancer became stable enough for a transfer home, and palliative care, social work, and the ICU team worked rapidly to help him and his family choose home hospice, identify his home care needs, choose a home hospice provider, fill out all the relevant paperwork, and transfer the patient home that same day. Because the unit's social worker could rely on help from the surgical ICU social worker, she was able to spend the entire day ensuring this transition occurred.

Palliative care was often involved in transitions to comfort care and the withdrawal of life-sustaining treatment in the ICU at TMC; however, there were instances when initiating these processes were delayed at TMC, often on weekends. Specific medications needed to begin safely and comfortably withdrawing support like mechanical ventilation were not kept in the unit and had to be ordered and sent up from the pharmacy, which sometimes took hours. While families rarely noticed, or at least commented, on these delays, ICU team members noted on multiple occasions that such transitions occurred more quickly at College Hospital and families exercised greater control over the timing of transitions. In one case, after waiting more than two hours for the narcotics needed for withdrawal of a breathing tube (extubation), a fellow grumbled, "Jesus, you can't even die 'stat' at TMC."

DISCUSSION

Observations and interviews with physicians and patients' family members demonstrated key ways in which EOL care can vary significantly despite hospitals providing access to similar technologies and services. Institutional factors influenced communication and decision-making about life-sustaining treatments and consequently, patients' and families' EOL health care

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experiences. The structure of care, including the physical environment, the schedule of service, physician staffing, and investment in supportive services, all impacted whether, how, and when communication and decision-making took place. Across hospitals these impacts contributed to cumulative differences in the experiences of patients and their families. Further, variation in institutional resources helped identify how disparities in EOL health care experiences might be linked to patterns of residential segregation and thus demographic variation in the populations different institutions serve.

Care Segregation as a Fundamental Cause

My findings reflect patterns of residential segregation and disparate access to greater-resourced hospitals and clinics; segregation is linked to the presence of fewer health care providers as well as more poorly-resourced facilities in predominantly Black communities (Ansell 2017; Schulz et al. 2002; White et al. 2012). In Lutfey's and Freese's (2005) classic study of disparities in diabetes management, differences in the quality of care that higher- and lower-SES patients accessed were influenced by the availability of providers, continuity of care, and additional resources like educational materials. Similarly, studies of critical care have shown that racial and socioeconomic disparities in outcomes most often emerge across, rather than within, hospitals (Barnato et al. 2008; Corl et al. 2019; Mayr et al. 2010; Taylor et al. 2018). I find that geographic segregation, implicated in other health and health care disparities (Phelan and Link 2015; Williams and Collins 2001) is also apparent in processes of EOL care. Gee and Ford (2011) note segregation within the health care system has continued, including in acute cardiac care and nursing home care, and point to a need for ongoing examination of health care segregation and how segregation impacts differences in care. This body of research suggests that in addition to

broad measure of access, differences in the nuanced structure of care delivery are also fundamental to the production of health care disparities. Further, given these disparities, it is unsurprising that racial inequalities in perceived quality of care have also persisted despite efforts to increase overall access to health care (Sommers et al. 2017). Measures of access may not consistently account for complex aspects of care delivery, like hospital layouts, levels of staffing and the extent of supportive care investments. Further, care segregation exacerbates inequalities through dual processes: socially disadvantaged patients obtain care at poorer resourced hospitals and these hospitals in fact require more resources to overcome other social inequities faced by disadvantaged patients, such as limited personal financial resources, access to transportation, and more limited social support.

ICU Staffing

My findings reveal another pathway by which care segregation impacts EOL experiences: ICU staffing. Previous studies of ICU staffing and patient outcomes have tended to focus on attending physician coverage and mortality and the length of patients' ICU stays (Kerlin et al. 2017). One survey of critical care attending faculty found that higher patient-to-physician ratios were perceived as negatively affecting patient care and teaching and increasing provider stress (Ward et al. 2012). Another found that 24-hour in-house attending coverage was associated with decreased time between ICU admission and the withdrawal of mechanical ventilation and do-not-resuscitate orders (Wilson et al 2013). I found that attending physician involvement in EOL communication and decision-making improved the quality of conversations and led to greater trust.

Even fewer previous studies have explored trainee ICU staffing ratios, and my findings suggest staffing ratios at all levels may be implicated in patient care. I found that the use of resident call shifts in the ICU increased trainee exhaustion and led to limited and poorer EOL communication and decision-making in the evenings. Others have shown frequent 24-hour shifts in ICUs have been associated with increased medical errors (Landrigan et al. 2004).

Further, my findings provide contextual support that lower physician-to-patient ratios allow physicians to be more involved in communication and decision-making, enable fewer handoffs (increasing continuity of care), and lead to lower levels of burnout. Burnout among critical care providers has been associated with poorer quality of care, lower patient and family satisfaction with care, and job turnover (Kerlin, McPeake, and Mikkelsen 2020; Moss et al. 2016).

Other studies on health disparities have also linked continuity of care to patient health and satisfaction (Lutfey and Freese 2005), and although ICU continuity of care has not been linked to mortality or length of stay (Ali et al. 2011), it may still be linked to communication and decision-making (Wilson, Rhudy, et al. 2013). My findings complement this literature and suggest that continuity of care, even within short periods of time, can provide patients and families with better communication, increased trust, and greater satisfaction with care. Numerous physicians felt EOL care could be improved if conversations about patients' wishes took place with long-term providers who had relationships with those patients. However, when such conversations do not occur with primary care providers or specialists managing patients' chronic illnesses, I find that establishing relationships and building trust, even in the context of comparatively short ICU visits, should be prioritized for high-quality ICU communication and decision-making.

Availability, Continuity, and Trust

These findings also reveal the ways in which EOL care is inhibited by structural resources which can further breed mistrust, particularly among those already positioned to experience it. Narratives of racial disparities in trust in the medical system often focus on the legacy of well-known historical violations of Black patients by medical providers and researchers, like the Tuskegee Syphilis Study (Brandon, Isaac, and LaVeist 2005). However, medical mistrust is also clearly rooted in experiences and expectations of current care (Armstrong et al. 2013; LaVeist, Isaac, and Williams 2009; Washington 2006). Among the patients I observed, Black patients more often voiced concerns about neglect and inadequate care than explicit discrimination[31], and like Ms. Elmina's daughters and Mrs. Saunder's husband, concerns about the quality of care increased mistrust in physician communication and treatment recommendations.

At the end of life, a successful recommendation to withdraw life-supporting treatments often hinges on full trust that every curative intervention has been considered and that physicians care deeply when a patient's life ends. One study of provider communication found that older African Americans felt limited time and a lack of recognition of patients as unique persons made it more difficult to build trust with doctors and felt that these factors reflected a 'broken system' of care (Hansen, Hodgson, and Gitlin 2016). Multiple factors at North General and Memorial, including

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[31] In my field observations, this may have been due to the social desirability (or lack thereof) for different kinds of claims. In interviews, when family members voiced complaints, I asked if they felt any biases or prejudices played a role in those instances. While acknowledging poorer treatment, family members more often linked this to aspects of structural racism, like disinvestment in community hospitals, rather than explicit interpersonal discrimination. However, social acceptability may have played a role in their responses to me as well, as a White researcher often perceived as associated with the hospitals in which I conducted my fieldwork.

consistency in providers, access to support services, and physician burnout, undermined trust in these aspects of care. Care segregation and decreased access to aspects of high-quality care were thus contributors to racial differences in trust in patients' and families' EOL experiences. While highlighting mistrust as a contributor to differences in health care experiences, my findings emphasize structural drivers of racial disparities in trust (Adams and Simoni 2016). Remedying and improving the aspects of care outlined above in minority-serving hospitals are thus crucial tasks for alleviating disparities in trust.

Limitations

Although this study leverages variation across four hospitals in two different cities to demonstrate how institutional variation contributes to inequities, it is still limited to variation within a single state. I am not able to speak to the processes of communication and decision-making at rural hospitals or in other states or regions of the country. How care is delivered in other hospitals, and to other patient populations, may reveal contradictory, expanded or novel impacts on population-level differences in EOL health care experiences. Additionally, this study draws on limited data directly from patients about their experiences, as many patients in ICUs are unable to speak or participate in care decisions. Future research could explore variation in communication and decision-making about EOL health care in different hospital or outpatient environments where patients themselves could participate more fully. Finally, future research could include quantitative analysis of hospital records to identify other factors or expand our understandings of variation in care processes, staffing, and service investments.

Conclusions

My findings demonstrate that institutional variation in the structure of care in medical ICUs, including the built environment, levels of physician staffing, and investment in supportive services like palliative care and social work, all contributed to variation in communication and decision-making about life-sustaining treatments. This variation led to observed substantive differences in the quality of patients' and families' EOL health care experiences. Further, this institutional variation may be implicated in broader patterns of racial and socioeconomic differences at the end of life. My research does not discount the impact of individual-level factors in influencing racial and socioeconomic differences in EOL health care, but draws attention to nuanced processes of care that, in combination with patterns of persistent residential segregation and socioeconomic inequality (White et al. 2012), may reproduce fundamental inequities between Black and White patients and between patients from higher- and lower-SES backgrounds. These inequities reveal a "broken system of care" (Hansen et al. 2016) in which predominantly minority-serving institutions maintain the surface-level appearance of equal access while often continuing to provide care with fewer resources. Thus, addressing racial and socioeconomic differences in EOL experiences, like other aspects of health care, will require adopting structural changes in the distribution of health system investments and dismantling segregation in access.

Table 4.1 "Structure of Care" Descriptives

	College	TMC	Memorial	North General
Unit(s)	20-bed unit, divided among two teams, occasional patients in other units	16-bed unit, shared with surgical critical care service	Patients located in (5) shared 10-bed units + dedicated coverage of 10-bed oncology ICU[1]	Patients located in (2) dedicated 12-bed units, frequent coverage of 2-3 patients in other units[2]
Service Census	6-18[3]	0-12	22-38	16-31
Morning Rounds	8:30AM-11AM	8-11AM, or earlier	8:30AM-1PM	8:30AM-12:30PM
Physician Workspace	In unit, visible to families	In unit, visible to families	Outside unit, not visible to families	In unit, not visible to families
Day Staffing	1 Attending 1 Fellow[4] 2-3 Residents[5] 2-3 Interns[4] 0-2 Medical Students[6]	1 Attending 1 Fellow[4] 3 Residents[5] 0-2 Medical Students[6]	1 Attending 2 Fellows[4] 3-4 Residents[7] 0-2 Interns[5] 0-2 Medical Students[6]	1 Attending 2 Fellows[4] 2-3 Residents[7] 2-3 Interns[5] 0-2 Medical Students[6]
Night Staffing	1 Dedicated Fellow[8] 3 Dedicated Residents	1 Dedicated Senior Resident	1 Dedicated Fellow 1 Call Resident	1 Dedicated Fellow 1 Call Resident
Call Shifts[9]	Fellow, up to 1/week	No	Fellows, up to 1/wk Residents, every 5 days	Fellows, up to 1/wk Residents, every 4 days
Patient Assignments	1 resident-intern pair for duration of visit	1 resident for duration of visit	Reallocated daily for balance; continuity of care attempted	Reallocated daily for balance; continuity of care attempted
Attending Presence[10]	Morning rounds + post-rounds family discussion + late afternoon check-in	Morning rounds + late afternoon check-in	Morning rounds + early evening check-in	Morning rounds + early evening check-in
Social Work	M-F, dedicated to ICU unit with assistance as needed	M-F, Shared with other units	M-F, shared with other units	M-F, shared with other units
Palliative Care	Dedicated inpatient and outpatient service, 2 inpatient PC beds	Dedicated inpatient and outpatient service, 5 inpatient PC beds	1 NP provider, M-F, shared with North General; separate outpatient hospice unit located in building	1 NP provider, M-F, shared with Memorial

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1 In the past, Memorial Hospital had distinct surgical, medical, cardiac and neurological ICUs. Over the past decade or so, these boundaries dissolved, the hospital no longer had a dedicated neurological ICU service, and the medical ICU service came to have patients spread across the previously distinct ICU units. The oncology ICU was part of a separate institution, and I did not follow patient cases in this ICU. I have included the patients in the oncology ICU in the total number of patients treated by the team.

2 One of two 12-bed units was step-down ICU unit. Patients in the medical ICU required either 1:1 or 1:2 nursing. In the step-down unit, nurses could care for up to 4 patients. The team also cared for patients in the 6-bed critical care unit in the emergency department.

3 For College Hospital, census and day staffing refer to the A-team only.

4 At College Hospital and TMC, fellows had Sundays off; at Memorial and North General, each fellow had one weekend day off.

5 Each resident and intern received one day off each week.

6 Medical students took 1-2 days off each week.

7 Each month there were 5 residents on service at Memorial and 4 residents on service at North General. However, residents received one day off each week and residents who had a call shift the prior day left after presenting their patients on rounds.

8 Dedicated refers to a fellow or resident who only covers nights while they are on service.

9 Call refers to a fellow or resident completing a 24-hour shift.

10 Attending presence varied based on preference, other obligations like clinic appointments, and where attendings had office space (in hospital or elsewhere).

CHAPTER 5

Conclusion

Despite a common refrain that death is the great equalizer of us all, social science research demonstrates that social inequalities endure even at the end of life (Anspach 1997; Sudnow 1967; Timmermans 1999). However, the end of life also reveals potentially puzzling patterns in racial and socioeconomic differences: national surveys demonstrate that traditionally disadvantaged groups are more likely to want life-sustaining treatments and receive greater spending and medical intervention at the end of life (Burgio et al. 2016; Hernandez et al. 2015; Pew Research Center 2013), but that these groups also report less satisfaction with end-of-life (EOL) experiences (Lee et al. 2016; Muni et al. 2011; Welch et al. 2005). At the same time, greater receipt of high-technology interventions and expensive treatments has been defined as disadvantageous by many clinicians and scholars according to more recent characterizations of a good death (Kaufman 2005; Livne 2019; Marik 2014). Consequently, the emergence and transformation of life-sustaining technologies and subsequent dialogues about appropriate treatment for dying patients underscore the importance of social values in developing and assessing the usefulness of medical treatments (Anspach 1997; Kaufman 2015; Livne 2014, 2019). This dissertation investigated racial and socioeconomic differences in EOL health care pathways, examining what differences existed and how these pathways were experienced by

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those involved. Additionally, this dissertation closely examined which differences were articulated and experienced as unfortunate or undesired by patients, family members, and physicians, and what this meant for our accounts of social inequality at the end of life.

In this concluding chapter, I will briefly summarize the empirical findings from each chapter and discuss the key contributions of these findings to interdisciplinary research on the end of life and to theorizing on health and health care inequalities. I will also consider the questions that remain unanswered and explore directions for future research. Finally, I conclude with a series of practice and policy recommendations for addressing and alleviating inequalities at the end of life.

Summary of Findings

In Chapter 2, I examined racial and socioeconomic differences in written EOL preferences, decisions, and congruency between these preferences and decisions using Health and Retirement Survey exit interviews completed between 2002 and 2016. The HRS is longitudinal, nationally representative survey of adults over age 50. Exit interviews were completed by a proxy (usually a spouse or child) after the death of each survey respondent. Preference were measured using a series of three yes-no questions that asked whether the decedent's written preferences expressed a desire "to receive all care possible under any circumstances in order to prolong life," "to limit care in certain situations," or "to have any treatment withheld." A series of three yes-no questions about health care decisions made for the respondent mirrored the exact language of these preference questions (i.e., if decisions involved "a desire to give all care possible unconditionally in order to prolong life"). Congruency measured whether the preferences and decisions reported aligned with one another.

My findings indicated clear racial and socioeconomic differences in preferences and decisions. Black and Hispanic respondents were more likely than White respondents to have reported written preferences and treatment decisions for life-prolonging care. In contrast, White respondents were more likely to have reported preferences and decisions for limiting care and withholding treatment. Respondents without a college degree or in the lowest wealth quartile were also generally more likely to report aggressive care preferences and decisions than respondents from higher socioeconomic status (SES) backgrounds. While I did not find racial and socioeconomic differences in congruency between preferences and decisions, my results did indicate that patients with more aggressive or life-prolonging care preferences were less likely to have reported decisions congruent with those preferences. My results also revealed that racial and socioeconomic differences in decisions were more pronounced than differences in written preferences, which may imply that racial and socioeconomic differences in written preferences are underestimates of differences in undocumented preferences (Barnato et al. 2009; Tarzian and Cheevers 2017). These results first and foremost reiterated a need to contextualize EOL health care decisions in light of patients' and families' preferences.

In Chapters 3 and 4, I explored racial and socioeconomic inequality using ethnographic and interview data that I collected in four medical intensive care units. Chapter 3 explored whether and how differing attitudes towards death and dying contributed to inequality. Building on previous work explaining how inequities arise in health care, my findings pointed to the ongoing occurrence of racial and socioeconomic disparities due to differences in flexible resources and cultural health capital. Further, my findings indicated attitudes about appropriate death and dying

held by traditionally advantaged groups were embedded in clinical assessments and shaped

communication and care pathways at the end of life, suggesting institutional processes of

valuation and standardization within medicine contributed to inequality. In seeking to deliver

appropriate care and good deaths, physicians and institutions reinforced some cultural attitudes

over others. This chapter highlighted a need for interrogating the development of clinical

standards in EOL care and the need for diverse representation in setting and identifying best

practices.

Chapter 4 transitioned from exploring mechanisms of inequality across hospitals to

understanding how inequities emerged between hospitals. I used a comparative lens to examine

processes of care around communication and decision-making and identified key variation in

how care was structured. I found that the built environment, physician staffing levels, and

investment in ancillary and support services shaped communication with patients and families

and impacted treatment decisions and experiences. This variation in structures of care across

hospitals contributed to racial and socioeconomic differences in EOL experiences because the

hospitals served demographically distinct populations. Segregation within health care and

inequities in access are linked to residential segregation (Gee and Ford 2011; Smith 2005; White

et al. 2012) as well as hospital closures (Bazzoli et al. 2012; Villa and Kane 2013; Walker et al.

2011). In hospitals which served primarily Black patients, I found that structures of care, like the

built environment and physician staffing, were clearly linked to family members' experiences of

mistrust. This chapter emphasized a need to extend our analyses of inequality at the end of life

beyond surface-level measures of access and attend to how structural differences also shape

nuances in the delivery of care.

Key Contributions

This dissertation contributes to important dialogues in sociology about inequality while also providing direction for research and interventions aimed at addressing inequality at the end of life. My findings underscore the complexity of EOL inequality and consequently the difficulties of assessing how it manifests and how to ameliorate it successfully. Over three decades ago, Crenshaw (1988) pointed out the limitations of anti-discrimination law bound by a restrictive, or process-focused, approach to inequities. The law restricted efforts to remediate differences in outcomes only to those that ensured access to a similar process of treatment under the law. Crenshaw argues that a more expansive approach would measure and provide remediation if outcomes remained unequal. A large body of research provides clear evidence that both processes and outcomes in health care remain unequal between advantaged and disadvantaged groups (van Ryn and Fu 2003; Smedley et al. 2003). Differences in processes and outcomes are also evident in EOL care, as shown by these findings and others (Carr 2016; Lee et al. 2016; Welch et al. 2005). My findings suggest that efforts to address inequities should seek to disentangle rather than dismiss either measure of potential inequality—attending only to equity in outcomes or only to equity in processes will be insufficient.

Questions of how to best approach inequality at the end of life cannot ignore individual, family, or community level differences in resources, attitudes towards death and dying, and variation in what constitutes appropriate treatment and good death. First, equitable outcomes are not likely to be achieved, and may not be appropriate, when structures of care and other aspects of treatment remain segregated and insufficient. For example, recommendations for hospice must be

contextualized by the current limitations of Medicare's hospice benefit, patient and family resources, and the limitations of symptom management in home hospice (Barclay et al. 2013). Second, at the end of life a focus on equalizing outcomes, such as treatment utilization, location of death, and hospice enrollment, must be contextualized by patients' and families' desires for EOL care. My findings collectively suggest that researchers, clinicians, and policymakers hoping to identify and address inequality in EOL health care experiences need to acknowledge that binary measures of treatments received are insufficient (Fischhoff and Barnato 2019; Walkey et al. 2017). At the same time, ascertaining appropriate measures of EOL outcomes should be linked to efforts to ensure equitable processes, structures of care, and attending to physicians' own values and potential biases regarding EOL care (Barnato 2017).

Beyond health care specifically, my dissertation also advances our understanding of how processes of valuation and standardization within organizations and institutions may contribute to inequality. Acknowledging the social and cultural underpinnings of good deaths and appropriate EOL treatment reveals that inequality is produced in part because socially advantaged groups are more able to define and then codify what good or appropriate EOL medicine entails. The way this medicine is practiced thus reflects their cultural preferences or tastes (Bourdieu 1984). Institutional standard-setting and development of best practices may represent opportunities for culturally dominant norms and preferences to shape access to care and be perceived as objective, neutral constraints on possibilities. For example, in exploring how defendants navigate the criminal court system, Clair (2020) finds that assumptions about preferred outcomes by the courts contradict the preferences of some defendants who preferred jail time over probation. These preferences stemmed in large part from the costs of probation and

the perception of defendants in highly-policed communities that probation was likely to result in more, rather than less, interaction with the criminal justice system—i.e., individuals might experience greater periods of surveillance and incarceration through probationary sentences and subsequent violations. Clair's findings create complexity around measuring probation as an equitable outcome, revealing how this benchmark neglects the experientially-driven preferences of Black defendants. My dissertation finds the standards and benchmarks developing in EOL practices and research may also prioritize the culturally- and experientially-driven preferences of advantaged groups, particularly when discussions about best practices and standards tend to happen in culturally homogenous spaces.

Finally, my dissertation emphasizes the methodological strengths of leveraging quantitative and qualitative analysis in an iterative research process (Creswell and Plano Clark 2017). This dissertation began with a puzzle discovered in quantitative analysis of numerous large survey samples and administrative data. Using quantitative analysis, I explored whether congruency between preferences and decisions might be part of understanding this puzzle. While I did not find evidence of racial and socioeconomic differences in congruency, I did find that congruency between preferences and decisions varied by preference. These findings laid the groundwork for the qualitative analysis used in Chapter 3, which specifically explored how preferences influenced EOL experiences, shaping interactions with clinicians and access to treatments. Chapter 4, while also qualitative, leveraged a comparative lens between hospitals to further explore variation in processes of care. Ultimately, the sequential design and analysis in this dissertation was both fixed and emergent (Creswell and Plano Clark 2017)—while initial quantitative and qualitative components were planned, they also shaped the trajectory of ongoing

analysis in unexpected ways. The development of my focus of inquiry, the methodological construction of this project, and the ways in which analysis led to iterative hypothesis generation underscore the importance of considering quantitative and qualitative information throughout the research process.

Future Research Directions

There are numerous unanswered and emerging questions from this research which are fruitful avenues for future study. First and foremost, there are limitations of both the quantitative and qualitative samples. Chapter 2 is limited to exploring differences in preferences and decisions between non-Hispanic White, non-Hispanic Black, and Hispanic respondents in the United States, and Chapters 2 and 3 largely examine the experiences of Black and White residents in a single US state. Other studies have demonstrated complex variation in EOL preferences among other racial and ethnic minority groups in the US (Krakauer, Crenner, and Fox 2002; Kwak and Haley 2005; Periyakoil et al. 2016) and globally (Cain et al. 2018; Phua et al. 2015; Yaguchi et al. 2005). Some evidence suggests hospitals that regularly serve racially diverse patients may invest in resources to improve communication and culturally-competent care (Weech-Maldonado et al. 2012). Thus, exploring the experiences of other racial and ethnic groups, and accounting for how different organizations attempt to provide culturally competent care, is an important area for ongoing work. At the same time, others have critiqued a narrow focus on cultural competency and suggest "cultural humility," characterized by self-reflexivity, attention to power imbalances is also needed (Greene-Moton and Minkler 2020; Tervalon and Murray-García 1998). A cultural humility framing may be particular useful in preparing clinicians for communication and decision-making in EOL health care.

Further, while some patients at the hospitals I observed may have traveled from rural areas, I did not observe how EOL communication and decision-making unfold in rural hospitals or hospitals serving Native-American communities. Many of these hospitals experience substantial resource constraints, many have closed in recent years, and access remains a persistent problem in the Indian Health Service (Joynt et al. 2011; Kaufman et al. 2016; Sequist, Cullen, and Acton 2011). Patient and family experiences accessing life-sustaining treatments and making decisions about EOL care are likely shaped by the unique constraints of these hospitals and by the closure of community hospitals (Freeman et al. 2007; Watanabe-Galloway et al. 2014).

Sociologists should also continue to critically interrogate our own investigations and measurements of disparities. Even the language used to describe EOL choices—values and preferences—itself reflects a particular way of approaching the end of life (Livne 2019). This language idealizes a notion of intrinsic, ruminative value construction that closely reflects the habitus of socially advantaged groups. A cornerstone of studying inequality is thus identifying when and which aspects of difference should be problematized and addressed. We should take a critical eye towards how the institutions we study identify ideal outcomes and best practices, investigating not only the processes that determined which outcomes are preferable, but also how standardizing practices demand conformity from institutional actors as well as the public(s) they serve. Other scholars have continued to do this in examining our courts, our schools, and our financial systems (Clair 2020; Grodsky, Warren, and Felts 2008; Krippner 2017; Poon 2007). Valuation and standardization present a useful theoretical framework for examining how inequality arises across different institutions and allows for comparative work between

institutions and more general concept development (Thévenot 2009; Timmermans and Epstein 2010).

This dissertation also points to future directions for work on race and trust in EOL health care. Reviewing enduring racial disparities in trust, Smith (2010) describes differences in both generalized trust, i.e., perceptions that most people are trustworthy, and particularized trust, i.e., perceptions that specific people are trustworthy in specific situations. Generalized trust in medicine (sometimes called institutional trust) may influence how and whether individuals engage with formal health care systems and particularized trust is foundational to the doctor-patient relationship. Both are likely essential to accepting recommendations to withdraw what clinicians consider non-beneficial medical treatments.

Studies of generalized trust in medicine provide insight into how individual and local contexts may shape racial differences in trust in medical providers (Armstrong et al. 2007; Sullivan 2020). Research demonstrates durable racial-ethnic differences in trust in medicine and health care providers and that historical and current violations, inequities, and discrimination within medicine contribute to racial differences in trust (Armstrong et al. 2007, 2013; LaVeist et al. 2009; Sullivan 2020). Research also shows that that racial-ethnic differences in trust are related to individuals' socioeconomic status, insurance status, and may vary by other local contexts such as level of segregation and health care gate-keeping (Armstrong et al. 2007; Douds and Wu 2018).

Understanding trust in specific health care encounters requires distinguishing the role of generalized trust in medicine and the role of particularized trust of specific providers and hospitals. My dissertation provides further insight into contextual factors which may contribute to racial differences in both generalized and particularized trust by identifying how processes of care may improve trust or further exacerbate mistrust in the specific context of beginning, maintaining, and/or withdrawing life-sustaining treatments. My findings point to a need for physicians to work to build particularized trust or interpersonal trust with patients and family members—that is, trust in them specifically—while acknowledging and addressing legitimate reasons for generalized mistrust of medical institutions by Black patients and their families.

Sullivan (2020) acknowledges this dilemma and details ways in which individual providers may demonstrate competence, care, and comprehension of mistrust in order to build trust with Black patients and families. However, my findings reveal that providers within critical care units and hospitals may lack the necessary resources to overcome generalized mistrust when they are not able to engender competence and care due to structural limitations. In this case, patients' and families' accurate assessments of systems which provide segregated and thus unequal care, and which require ongoing wariness and/or aggressive advocacy, may make interpersonal trust difficult if not impossible to achieve. Future research should further explore how trust across different levels—in specific providers, hospitals, and the medical system—interact and influence both patients and providers.

Physicians' trust in patients and family members also deserves further attention. In Chapter 3, my findings suggest that disagreement with physicians' recommendations may provoke distrust

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by physicians, and that this distrust may shape communication with patients and families. Other research suggests physicians' trust of patients and their surrogates is shaped by patients' identities, including race (Moskowitz et al. 2011), but also implicated in assumptions about medical sophistication, financial motives, and substance abuse (Anspach 1997; Goold, Williams, and Arnold 2000; Nelson 2003; White et al. 2007; Wilk and Platt 2016). Practice-focused work should explore how physicians' attend to and navigate their own feelings of trust in patients and family members and how this impacts their communication and treatment recommendations.

Another more practice-focused avenue for future work could explore training and supervision in communication and decision-making about life-sustaining treatment. Ongoing research efforts have documented and developed curriculum-based approaches to EOL conversations (Billings et al. 2010; Dickinson 2011); qualitative research may be particularly well-suited to make critical comparisons between different programs as well as explore how participants feel prepared for providing real world care. Similarly, qualitative methods may offer insight into ongoing training through modeling and supervision and how these efforts may vary across hospitals and residency programs. Physicians I interviewed and observed in my research reflected on the importance of modeling and receiving feedback on their communication with families. Better accounting for when and how modeling and supervision take place and contribute to skills development could allow programs to formally embed specific standards into training, but more research is needed to identify ideal moments and strategies.

Practice and Policy Implications

My findings suggest numerous opportunities to change practice and policy around EOL health care. First, discussing and choosing whether and when to initiate, continue, or withdraw life-sustaining therapies is a core task of intensive care provision (Iwashyna 2020). Like many technologies and treatments, effective communication and decision-making should be understood as a complex set of knowledge and practices that collectively are deployed to provide care. Effective training should include modeling early in training programs and supervision as training progresses to build competency. The patient-specific aspects that shape a procedure (physical size, comorbidities, etc.) and potential complications that might occur when, for example, placing an arterial line or chest tube, may be seen as metaphorically similar to the kinds of variation in important patient- and family-specific needs that will influence the outcome of a conversation. Residency programs may want to consider steps beyond curriculum, such as verifying trainees can and have successfully deployed the requisite knowledge and skills to navigate complex conversations that involve prognostication, communication of risk and benefits, and attention to patients' and families' needs. This form of supervision and certification is commonly done with other complex procedures and certification should further be grounded in ongoing training and supervision across residency and fellowships.

In the same vein, hospitals and providers should revisit and reflect on the emergence of rigidity in care pathways and narratives of intrinsic or unchanging goals and values about EOL care (Sudore and Fried 2010; Wittink et al. 2008). My findings, and the research of others (Fischhoff and Barnato 2019; Patel, Cohen, and Barnato 2016; Turnbull and Hartog 2017), suggest that goals, preferences, and decisions are multifaceted and context-specific. Opportunities for down-shifting in aggressive treatment pathways rather than complete changes of course from curative-

to comfort-focused care may be appropriate for some patients and families. Aligned with improving teaching for trainees, providing appropriate life-sustaining and/or EOL care should be deeply linked to ensuring that processes of communication and decision-making with patients and families are performed well, rather than linked to specific treatment decisions. For example, supervising faculty should be reflexive about using language which prioritizes outcomes (i.e., "getting the DNR" order) and should make efforts to observe and provide trainees with feedback on communication with patients and families.

Additionally, hospitals must acknowledge that EOL care transitions are time-intensive processes that require significant physician and ancillary support service resources. In acknowledging that transitions from aggressive to comfort-focused care will happen frequently in intensive care settings, hospitals should consider aggressive care for the dying as an essential service of the ICU, should consider counseling on and discussing care transitions as an essential service of the ICU, and should staff and train these units accordingly (Kruser et al. 2019). ICU staffing, including patient-physician ratios and continuity of care, are important for both patients who survive their acute health crisis and those who do not (Wilson, Samirat, et al. 2013). Although physicians are obviously limited in their ability to change the built environment of the ICU, attending to the impacts of the environment on patients' and families' experiences could prompt efforts to make other aspects of service more family-centered, including implementing family-centered rounds (Davidson et al. 2017; Netzer 2018). Further, most hospice service in the United States is dependent on the availability of family-level social and financial resources (Barclay et al. 2013; Boucher, Kuchibhatla, and Johnson 2017; Cross and Warraich 2019). Robust, person-centered hospice care cannot be provided in many patients' homes, nor in underfunded and

overwhelmed skilled nursing facilities without significant investment in those facilities and services. Hospitals and health systems should consider supporting greater access to in-patient hospice care. More importantly, Medicare's hospice benefit should be expanded to cover inpatient hospital- and hospice facility-based services.

Finally, it is exceedingly difficult to imagine the undoing of inequality in EOL health care experiences without dismantling larger patterns of segregation in health care (Gee and Ford 2011). Dismantling our segregated and unequal health care system would begin to move beyond addressing specific inequities and towards building a health care system focused on equal and robust access to care from birth to death. No rigorous study of inequality should fall short of acknowledging this reality.

A1. Family Member Interview Guide

First, I'd like to know a little bit more about your [patient's relation to respondent – father, brother, daughter, etc.].
Can you share with me a little about them?
>   *(PROMPTS: Where did they grow up? What kinds of work did they do?)*

Now I'd like to talk a bit about their health. What brought them to the hospital/ ICU?
>   *(PROMPTS: How would you describe [patient name]'s health before their hospital visit?*
>   *Did she/he have any ongoing health problems? When did they become sick? How had*
>   *they been handling their health/ illness?)*

Can you describe for me what happened when your [relation] came to the ICU?
>   *(PROMPTS: What do you remember happening first? What happened next?)*

What did the doctors tell you/ share with you?
>   *(PROMPTS: What did doctors/ nurses tell you was the problem/ diagnosis? What did*
>   *they say about his/her future? Was there anything you wanted more information about?*
>   *What was helpful? Not helpful?)*

Now I'd like to talk a little bit more about how you/ your [relation] made health care decisions.
During your hospital stay, were you or [patient] asked to make decisions about his/her treatment?
Did you make decisions for them (the patient) or did they participate in decision-making?

Can you tell me a little about the kinds of decisions you or your [relation] were asked to make?

What influenced the decisions you made? OR What do you think influenced the decisions
[patient name] made?
>   *(PROMPTS: How did your/ your [relation]'s beliefs influence your/ their decision(s)?*
>   *Did any previous health care experiences, experienced by [patient name] or others close*

to you, influence your/ their decisions? How so? Did you/your [relation] consult anyone else, like relatives, friends, clergy?)

Did the physicians' make recommendations about what to do? What did they recommend?

How satisfied were you with the communication from physicians during your [relation]'s stay? What was good/ bad about the conversations you had?

How had you or your [relation] planned for difficult health care decisions if they became seriously ill?
   (PROMPTS: Had they ever discussed with anyone what sort of care they would or would not want if they were in that situation? What did they want?)

Did your [relation] do any formal care planning for situations like this?
   (PROMPTS: Did they sign a document indicating what kind of treatment they would want if they became critically ill? Or who would make the decisions if they couldn't decide for themselves?)

(Question not asked if patient died during ICU stay) What happened after [patient name] was discharged?
   (PROMPTS: Have they/ Did they return home? Did they return to the hospital?)

Is there anything else I should know about your [relation]? Anything I should have asked about but haven't?

Demographic Questions

Please answer the following questions about your [relation].
   1) Patient's Race/ Ethnicity:
   2) Patient's educational attainment:
      Less than HS
      HS Degree/ GED
      Some College
      Bachelor's Degree or higher
   3) Patient's past/ current occupation:

Please answer the following questions about yourself.
   1) Relationship to Patient:
   2) Respondent's Age:
   3) Respondent's Race/ Ethnicity:
   4) Respondent's educational attainment:
      (Less than HS, HS Degree/ GED, Some College, Bachelor's Degree or higher)
   5) Respondent's past/ current occupation:

A2. Physician Interview Guide
Background/ General Questions
Tell me a little about yourself. Have you decided what you want to do next (after residency)/ what are your plans after residency? (residents) OR
Tell me a little about yourself. How did you choose this specialty? (fellows/ attendings)

Can you tell me a little bit about your experience in the ICU?
>   *PROBE: Walk me through a day when you were last on service.*

Use of Life-Sustaining or Life-Prolonging Treatments
I'd like to know more about how treatment decisions are made to use life-sustaining or life-prolonging therapies, like intubation, dialysis, or CPR.
>   *PROBE: When do you think life-sustaining or prolonging technologies should be used/ when should they not be used?*
>   *PROBE: Does it depend on the technology, or more on the patient?*

What practice standards/ guidelines/ policies (if any) have you heard about/ used?
>   *(For residents/ M4s) What training have you received about using LSTs?*

Can you give me an example of when you did not recommend an LST?

How do you talk to patients about their "goals of care" or how aggressively to use life-sustaining or life-prolonging therapies? Can you describe an example to me?

Will you describe another example to me? *(If they first described a "positive" example, then ask about one where maybe the conversation didn't go as well; If they describe a "negative" example, then ask for an example where things went better)*

Differences in Perspectives/ Disagreements about Life Sustaining Treatments
Have you dealt with differences of perspectives between family members or family members and patients? Can you tell me about a case where that happened?

What about differences of perspective between family/ patients and clinicians? Can you tell me about a case where that happened?

What practice standards/ guidelines/ policies help you navigate disagreements about using LSTs?

Do you think there are differences between attendings and trainees in how they handle these differences in perspective/ conflicts?

Life-Sustaining Treatments and End-of-Life Care
Next, I'd like to talk a little about how you think about life sustaining treatments in end-of-life care. What health care should people receive at the end of life?
>   *PROBE: What do you think a good death looks like?*

Can you describe an end-of-life case you've dealt with?

What makes that case stick out in your mind?

Can you describe another case to me? *(If they first describe a "good" case, then ask about a different case, maybe one where things didn't go as well; If they describe a "bad" case, then ask about a case where things went better)*

What made that case particularly memorable?

Disparities and Improvements
Research shows there are race and class differences in end-of-life health care. What differences have you noticed? What do you think contributes to those differences?

How well do you think the process of end-of-life care is handled in this hospital? What is working well and what if anything, would you want to see changed?

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