

5 (2020): e188-89; T. Burki, “Prisons Are ‘in No Way Equipped’ to Deal with COVID-19,” *Lancet* 395 (2020): 1411-12.

38. A. Maxmen, “California’s San Quentin Prison Declined Free Coronavirus Tests and Urgent Advice—Now It Has a Massive Outbreak,” *Nature*, July 7, 2020, <https://www.nature.com/articles/d41586-020-02042-9>; Brief on Behalf of Amici Curiae, San Quentin Consolidated Writ Proceeding, August 13, 2020, [https://www.scribd.com/document/472497973/AmiciCuriaeBriefMarinConsolidatedFinlwPOS-2#from\\_embed](https://www.scribd.com/document/472497973/AmiciCuriaeBriefMarinConsolidatedFinlwPOS-2#from_embed).

39. See, for example, J. Rich, S. Allen, and M. Nimoh, “We Must Release Prisoners to Lessen the Spread of Coronavirus,” *Washington Post*, March 17, 2020; E. Wang, B. Western, and D. Berwick, “COVID-19, Decarceration, and the Role of Clinicians, Health Systems, and Payers,” *Journal of the American Medical Association* 324 (2020): doi:10.1001/jama.2020.22109.

# In This Together: *Navigating Ethical Challenges Posed by Family Clustering during the Covid-19 Pandemic*

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As the Covid-19 pandemic shifts to a “new normal” in hospitals and clinics, health care professionals—especially in clinical ethics, critical care, and palliative care—are observing new impediments to shared decision-making, family-centered care, and quality end-of-life care.<sup>1</sup> One such impediment is a phenomenon we refer to as “family clustering,” which is our term to describe the situation when multiple members of a household or extended family unit contract Covid-19 concurrently, such that the infections occur in a cluster, or grouping, at roughly the same time and location.<sup>2</sup> Family clustering can be distinguished from a cluster of infections in a congregate living facility, like a nursing home, or in a group of employees, for example, in an emergency department or meat processing plant. Working in Southern California hospitals hit hard by the pandemic, we have seen this phenomenon up close and believe it deserves attention because of the way family clustering can affect ethical health care.

Family clustering creates at least three important ethical problems. Surrogate decision-making can become exceedingly challenging for patients with severe, life-threatening

Covid-19 in the context of family clustering. Unique presentations of increased guilt and denial for family members of stricken, hospitalized loved ones can emerge from family clustering, inhibiting shared decision-making and increasing suffering. Family clustering also exacerbates existing health inequities that disproportionately affect and burden people of color, and many of the current strategies for addressing the practical and ethical challenges associated with Covid-19 are insufficient to deal with these moral and social problems. We conclude by offering five strategies to address the effects of family clustering during the pandemic.

## **A Lack of Available Surrogates**

Family clustering is a confirmed phenomenon associated with Covid-19,<sup>3</sup> and harrowing stories of this disease ravaging families continue to be reported by American media.<sup>4</sup> Even the forty-fifth president of the United States and his family were affected. In an extreme example, twenty-eight extended family members in California reportedly tested positive for Covid-19. Two of the family members who quarantined together required hospitalization, and one of them died from the infection.<sup>5</sup> In family clustering cases, multiple loved ones may suffer from the symptoms of Covid-19 and be hospitalized, in quarantine, or recovering; and family members may also have died from the infection.

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*Surrogates often feel conflicted about their roles and the demands of decision-making after learning about the poor prognosis of a critically ill loved one. What is new is that some surrogates experience themselves to be the immediate cause of the life-threatening illness.*

In such circumstances, one can readily imagine how the typical practice of identifying a surrogate decision-maker can generate real ethical challenges. One challenge we have experienced many times is that nearly all potential surrogate decision-makers for a patient were rendered unavailable. This occurs because potential surrogates are too sick themselves to take on that role or too overwhelmed from tending to other sick family members to adequately participate in the shared decision-making process.

Many state statutes regarding surrogate decision-making describe required or preferred attributes for filling the surrogate role, such as having the ability to engage in complex medical decision-making.<sup>6</sup> Even in typical circumstances, it can be a challenge to identify well-qualified surrogates, meaning those who meet these attributes or criteria described in the bioethics literature. In the setting of family clustering, additional difficulties may arise because clinicians, out of necessity, engage with less qualified surrogates to fill a gap in the decision-making process. In nonpandemic conditions, norms for surrogate decision-making guide clinicians and surrogates to make decisions according to one of three approaches: the stated-preferences standard, the substituted-judgment standard, and the best-interests standard.<sup>7</sup> The first two standards are used most often, as each relies on a surrogate who knows the patient's preferences and values, and quite often patients have at least one person in their lives who does.

However, family clustering can create circumstances in which a surrogate who is unfamiliar with the patient's preferences, wishes, and values is put in the position of participating in difficult decisions—including end-of-life decisions. To make matters worse, they may participate in shared decision-making without the benefit of adequate family support and without being able to visit the patient. These conditions may render a marginally qualified surrogate even less capable of adequately representing the patient. For example, a potential surrogate may be so minimally able to engage in complex medical decision-making or so uninformed about the patient's values and preferences that the health care team rightly questions whether that person can legitimately serve as the patient's surrogate at all. And yet there may be no one

else to replace a poor candidate for surrogate decision-maker and, thus, no one left to fill the role.

These challenges can have a presentation that is similar to that seen with challenges to medical decision-making that emerge when hospitals severely restrict visitation, as many across the United States have.<sup>8</sup> When family members of patients with Covid-19 are restricted from having direct interaction with the patient and may not be allowed to visit the hospital at all, surrogate decision-making becomes much more difficult. These effects are profound when surrogates, who are unable to interact with patients or health care professionals in person, are asked to support decision-making about continuing intensive care treatment, possibly withholding life-sustaining interventions, or withdrawing treatments and transitioning their loved ones to comfort-focused, end-of-life care. For some, the inability to visit their loved one is a nonstarter for the shared decision-making process. For example, we encountered surrogate decision-makers who were reluctant to even consider discussing a do-not-resuscitate order without visiting the patient first. Family clustering magnifies these problems, as the few surrogates who are permitted to visit may be unable to do so due to home caregiving responsibilities for other family members with Covid-19 or because they are ill.

In other situations, family clustering so devastates a family that there are no healthy, qualified surrogates available to support shared decision-making, even though the patient has intimate family and friends who would otherwise be well-qualified surrogates. In these cases, the health care team may treat the patient as unrepresented and use a fair process to make treatment choices for them.<sup>9</sup> While we support decision-making for unrepresented patients regularly under normal conditions, this is the first time we have encountered that need because all members of a family are simultaneously incapacitated by the same infectious disease. We do not ordinarily use this process for patients with loving family members who are too ill themselves to participate in decision-making, but we have needed to do so repeatedly during the pandemic. We can easily imagine that this kind of situation could increase in frequency elsewhere if areas of the country again experience widespread infection and historic levels of hospital admissions.

## An Increased Burden on Surrogates

In addition to reducing the availability of capable surrogates, when surrogates are available, family clustering renders the emotional burden of decision-making almost unbearable, as it must now be borne in near isolation. Family members who can play the surrogate role may be asked to make difficult medical decisions for multiple loved ones simultaneously and without the benefit of the family to support their coping. Or they may make decisions for incapacitated loved ones while also suffering from Covid-19, which often includes chronic fatigue or neurological symptoms that impede the necessary cognitive functions for decision-making.<sup>10</sup>

Family clustering can also create a unique and significant combination of guilt and denial, phenomena that can influence surrogate decision-making. We have encountered a guilt among loved ones concerned about the role they believe that they played in how the patient became infected. We are aware of specific cases resulting in death, for instance, when a floor nurse unwittingly transmitted Covid-19 to her elderly father, when an urgent care physician unknowingly transmitted it to his elderly mother whom he lived with and cared for, and when an airport worker transmitted it to his wife, who in turn inadvertently transmitted it to her elderly father. In cases like these, we observed family members experience guilt and shame, stemming from their belief that they caused their loved one's infection and death. Feeling blameworthy is significant in the Covid-19 environment because it increases suffering for these family members and creates barriers to rational decision-making. When they are called upon to serve as surrogates for incapacitated patients, potent emotions of guilt, shame, and grief fuel a kind of distress that compounds the already very difficult emotional and moral experiences associated with surrogate decision-making and end-of-life care. While it is common for surrogates to feel conflicted about their roles and the demands of decision-making after learning about the poor prognosis and impending death of a critically ill loved one, what is new is that some surrogates experience themselves to be the immediate cause of that life-threatening illness.

We also have encountered a particular expression of denial during decision-making with surrogates who are sick with Covid-19 or have recovered from it. In some scenarios, multiple moderately or mildly ill family members of a patient have recovered from their own infections and thus cannot fathom that the critically ill hospitalized patient will not do the same. Likewise, there have been family members who reject poor prognoses described by clinicians because they believe that the very same infections they recovered from cannot possibly cause their loved ones to die. Although disagreement with prognosis made by the medical team is not unusual for surrogates of critically ill patients,<sup>11</sup> it is unusual for a surrogate to have recent, firsthand experience of the very same infection, to have survived it, and for this to be not merely the evidentiary but also the embodied basis of

their denial of or disagreement with their loved one's prognosis. Family clustering makes disputes about prognosis more understandable and, at the same time, more incorrigible because it makes it harder for surrogates to accept limits placed on providing ineffective treatments or proposals to increase comfort measures, even when patients are actively dying. They believe that the patient will recover, just as they did. Visitation restrictions compound this problem, as surrogates are unable to see firsthand the differences between their own illness and that of their much sicker loved one. As a result, there seems to be a unique sense of "Covid-19 denial" arising in these scenarios that clinicians must support family members in working through during decision-making for incapacitated patients.

Finally, family clustering creates challenges when implementing the family-centered-care paradigm for shared decision-making. In this model of care, family members are usually at the bedside to help establish trust and collaboration between the patient, family, and health care team. This reinforces a sense of clinical reality, family integrity, and unity—all essential elements of family-centered care that contribute to shared decision-making.<sup>12</sup> Yet the challenges created by family clustering can persist even in settings where visitation restrictions are relaxed or where exceptions to restrictions are made because exceptions are unlikely to be extended to sufferers of family clustering due to concerns about infection risk. And in some cases of family clustering, caregivers are unable to leave other sick family members alone at home to come to the hospital for family meetings. After all, the hospitalized family member is being adequately cared for by the nursing staff, while family members at home may be dependent on just one caregiver. Hence, interactions integral to family-centered care and high-quality shared decision-making may be nearly impossible to realize. Family members cannot gather at the bedside in the usual fashion, and their inability to interact with the patient and observe the severity of their illness can compromise the family's willingness to build trust with the health care team.

## Family Clustering and People of Color

The harms of Covid-19 have been disproportionately borne by Black, Indigenous, and other, especially Latinx, people of color. The many burdens of Covid-19 on these populations include higher prevalence of disease, earlier age of onset of serious illness, more severe complications from infection, and increased mortality.<sup>13</sup> Many explanations related to racial and social injustice have been offered for why Covid-19 harms Black people, Indigenous people, and other people of color (BIPOC) more than White people. These inequities include discrimination, education and income disparities, the kinds of "essential" work many in these communities are relegated to, crowded or poor housing, and lack of access to health care. For example, research has shown that unequal access to hospital care and lower health insurance rates drive racial differences in mortality.<sup>14</sup>

Higher community prevalence of certain comorbidities like severe obesity within BIPOC populations are strongly associated with Covid-19 mortality in younger adults and males, driving racial differences in Covid-19 death rates.<sup>15</sup>

Adding to this, BIPOC populations have been identified as most at risk for experiencing family clustering, which we believe compounds the stress in dealing with the illness and disproportionately exposes them to the many other ethical challenges tied to family clustering. People of color are more than twice as likely to live in multigenerational households, which makes spreading the virus easier.<sup>16</sup> Thus, in a cruel irony, a normally positive and admirably common attribute of non-White cultures—the extended communal experience of raising, living, and caring for one another in what are often multigenerational homes—has been warped by Covid-19 into yet another risk factor for poorer outcomes. Covid-19 not only reduces the availability of loved ones to support decision-making for seriously ill patients but also increases the risks of infection stemming from living together.

In addition to being part of the causal story of how inequities in care arise, family clustering, we believe, magnifies preexisting disparities in how critical care is experienced by patients, surrogates, and family members of color. Research suggests that the burdens on family members of seriously ill patients are also likely to be greater for BIPOC than for family members of White patients in the same situation, given disparities in access to, the quality of, and experience of advance-care planning and end-of-life care.<sup>17</sup> In a study comparing a White population to BIPOC populations, non-White patients were more likely to lack an advance directive appointing a surrogate and describing health care preferences, were more likely to receive aggressive interventions at the end of life, and were perceived by physicians to exhibit more interfamily conflict.<sup>18</sup> A likely set of contributing factors for these observations is the discrepancies in the quality of care that BIPOC populations receive compared to White patients if they have a serious illness.<sup>19</sup> In another comparative study, Black Americans rated the quality of care at the end of life far lower than did Whites, including giving lower ratings in relation to shared decision-making, being adequately informed of the treatment plan, receiving sufficient family support during a patient's hospitalization, and having one doctor primarily involved in care who is aware of the patient's medical history.<sup>20</sup> This finding has been supported by newer studies showing that physicians communicate poorly with Black patients when discussing end-of-life care with them.<sup>21</sup> Aside from socioeconomic status, other disparities such as those concerning attitudes toward death and dying, trust in the medical system, beliefs about autonomy versus interdependence, satisfaction with one's doctor, and direct experiences with the death of significant others have been posited as additional explanations for why BIPOC groups are less inclined to participate in advance-care planning, which, in turn, leads to disjointed care at the end of life.<sup>22</sup>

Altogether, these data remind us that barriers to surrogate decision-making already exist for BIPOC communities. Family clustering compounds the disparities in how they experience critical care as patients, loved ones, and surrogate decision-makers in multiple ways. Our experiences suggest that this increases the suffering people of color experienced on account of the Covid-19 pandemic. And because other barriers to effective surrogate decision-making already exist for patients from these communities, the impact of family clustering on the surrogate decision-making process is likely to be more pronounced and common for these same patients and their loved ones.

### Navigating the Challenges Posed by Family Clustering

We believe that the ethical implications of family clustering for hospitalized patients and their loved ones have not received as much attention as they deserve. Others have analyzed problems associated with restricted visitation during the pandemic. While we agree that the proposed solutions to these problems are relevant for family clustering, they remain insufficient. Some proposals emphasize technological fixes, creating virtual interpersonal connections, such as family member videoconferencing to “visit” patients. Nontechnological solutions include permitting visitation for patients at the end of life, although with restrictions that sometimes remain significantly burdensome for patients, their loved ones, and nursing staff.

These attempts to resolve issues related to restricted visitation are inadequate as responses to family clustering. While technology or limited visitation may allow a surrogate to visit or interact with the patient, and perhaps gain a better understanding of their medical condition, it will not allow them greater understanding of the patient's wishes, values, and interests. Likewise, that is not sufficient to provide for the family support needed to render the burdens of medical decision-making tolerable. Technology may facilitate a reasonable proxy for a certain kind of interpersonal closeness, but virtual visits are often ineffective substitutes for in-person conversations when the goals are to identify patients' values and preferences and support family members as they participate in decision-making.

Other strategies are needed to respond specifically to the challenges of family clustering. We conclude by offering a few. The first, though largely preventive in nature and described by others, remains important. For patients who are hospitalized with Covid-19 or at risk of becoming hospitalized due to relevant risk factors, advance-care planning should be both recommended and facilitated by the medical team.<sup>23</sup> Patients at risk of infection and serious complications should make their wishes known to their loved ones and should identify primary, secondary, and perhaps even tertiary health care decision-makers. While advance-care planning is not a panacea and may not be equitable across different racial, ethnic, and socioeconomic patient popula-

tions, it is likely to be an effective tool for mitigating some of the devastating impacts family clustering has on surrogate decision-making in the absence of well-supported and healthy surrogates. We encourage providers who support advance-care planning to consider how best to respond to family clustering. There is a need to increase planning for doing so in this new context and likewise to advocate to hospital administrators for the resources necessary to support this work immediately.

Next, the health care team should be prepared to provide greater and more involved support to surrogate decision-makers than is typical. A surrogate decision-maker who is affected by family clustering will require additional support with the decision-making process, preferably from a health care professional trained in facilitating decision-making for others. Research suggests that, in situations where surrogates experience poor communication with clinicians, including when the clinicians rotate often and require the surrogate to communicate with many different providers, this confuses and upsets surrogates.<sup>24</sup> Nurses and nurse leaders can also provide support, perhaps by using a limited rotation of nurses to improve continuity of care and allow the surrogate decision-maker to form connections with a smaller group of care providers, or consider another model of nurse-led interventions to improve communication and surrogate decision-making.<sup>25</sup> In addition to support for the medical decision-making process, the emotional support of a social worker or chaplain is strongly recommended. Emotional support has been shown to both increase decision quality and improve surrogates' psychological outcomes.<sup>26</sup> In short, when surrogates have no family, we believe that the care team becomes obligated to provide this support for them so that quality shared decision-making may move forward.

Third, family clustering may lead to situations where patients lack surrogate decision-makers completely or where available family and friends are willing to participate in the decision-making process but are incapable of serving as independent, unaided surrogates. State laws regarding surrogate decision-making vary significantly, which can make it even more difficult to involve available loved ones in decision-making if they fail to meet the minimum qualifications required of a surrogate by the state.<sup>27</sup> As states and counties pass emergency declarations and regulations in response to Covid-19, they should incorporate guidance on decision-making for unrepresented patients where this is lacking in existing regulations. These could include additional funding for underresourced public guardians or language that authorizes mechanisms for supporting decision-making for hospitalized, incapacitated, unrepresented patients.<sup>28</sup> Such mechanisms might include statutes or guidelines with more permissive language about who may serve as a surrogate decision-maker, who may participate in the process without being identified as a surrogate, or how surrogates may be replaced in situations where individuals have become de facto decision-makers due to the absences of family members caused by family clustering. Such regulatory and policy

changes would support health care teams in pursuing non-traditional, innovative approaches to ethical medical decision-making without fear of legal or professional liability.

Fourth, patients who are severely critically ill and whose surrogate decision-makers experience Covid-19 denial may receive undignified attempts at resuscitative services or other potentially inappropriate treatment at the end of life if their surrogates continue to request full, aggressive, critical care despite the patient's exceedingly poor prognosis. We recommend that, in circumstances like these, members of the care team consult clinical ethics services or the ethics committee to support conflict resolution and appropriate use of medical therapies. When responding to requests for potentially inappropriate treatment, we have used and can recommend a process like that outlined in a multisociety statement that supports both family members who dispute a poor prognosis and members of the care team.<sup>29</sup>

Finally, while this recommendation is hardly limited to the problem of family clustering and surrogate decision-making,<sup>30</sup> it bears repeating here: health care professionals should educate and inform themselves about the existing racial and social disparities that pertain to both Covid-19 and surrogate decision-making and make attempts when possible to correct these imbalances and overcome their biases. It is the confluence of these factors that renders family clustering disproportionately burdensome for people and communities of color, and this burden cannot begin to be addressed unless health care teams are sensitive to the disproportionate impact these factors have for a particular subset of their patients. Health care professionals should recognize their duty to help those who have disproportionately suffered from this pandemic, who are likely to be those who suffer the most from family clustering. Lacking sophisticated ways to do this, we recommend a simple one. Cultivate disproportionate attentiveness to the suffering of Black people, Indigenous people, and other people of color; when you see their disproportionate suffering, provide them with disproportionate care and support.

Family clustering is but one of the many ethical challenges posed by the Covid-19 pandemic. While technological resources have some potential for alleviating some of the problems that these challenges have created, the barriers associated with family clustering are not fully addressed by these alone. Rather, by providing greater support for the patient and family, whether in the early stages of illness via advance-care planning or later in the illness when the health care team may become quasifamily for an isolated surrogate, appropriate shared decision-making in the setting of family clustering, though still difficult, is rendered less burdensome for all involved.

#### Notes

1. J. L. Hart et al., "Family-Centered Care during the COVID-19 Era," *Journal of Pain and Symptom Management* 60, no. 2 (2020): e93-e97; Á. Estella, "Compassionate Communication and End-of-Life Care for Critically Ill Patients with SARS-Cov-2 Infection," *Journal of Clinical Ethics* 31, no. 2 (2020): 191-93.

2. T. Arango, “‘We Are Forced to Live in These Conditions’: In Los Angeles, Virus Ravages Overcrowded Homes,” *New York Times*, January 23, 2021.
3. A. Lowe, D. D. Chang, and G. Creek, “Multiple Fatalities in a Family Cluster of COVID-19 with Acute Respiratory Distress Syndrome,” *Ochsner Journal* 20, no. 2 (2020): 134-38; I. Ghinai et al. “Community Transmission of SARS-CoV-2 at Two Family Gatherings—Chicago, Illinois, February–March 2020,” *Morbidity and Mortality Weekly Report* 69, no. 15 (2020): 446-50.
4. See, for example, J. W. Cox, and S. Georges, “They Depended on Their Parents for Everything. Then the Virus Took Both,” *Washington Post*, July 20, 2020; T. Tully, “Coronavirus Ravages 7 Members of a Single Family, Killing 4,” *New York Times*, March 18, 2020; and Arango, “We Are Forced.”
5. K. Jones, “California Family Lost a Father to Coronavirus and 28 Family Members Got Infected, Son Says,” CNN, June 29, 2020, <https://www.cnn.com/2020/06/28/us/california-coronavirus-28-family-members/index.html>.
6. E. S. DeMartino et al., “Who Decides When a Patient Can’t? Statutes on Alternate Decision-Makers,” *New England Journal of Medicine* 376 (2017): 1478-82.
7. T. V. Cunningham et al., “How Do Clinicians Prepare Family Members for the Role of Surrogate Decision-Maker?,” *Journal of Medical Ethics* 44, no. 1 (2018): 21-26.
8. A. H. M. Antommaria, L. Monhollen, and J. K. Schaffzin, “An Ethical Analysis of Hospital Visitor Restrictions and Masking Requirements during the COVID-19 Pandemic,” *Journal of Clinical Ethics* 32, no. 1 (2021): 35-44.
9. T. M. Pope et al., “Making Medical Treatment Decisions for Unrepresented Patients in the ICU. An Official American Thoracic Society/American Geriatrics Society Policy Statement,” *American Journal of Respiratory and Critical Care Medicine* 201 (2020): 1182-92.
10. M. Wadman et al., “A Rampage through the Body,” *Science* 368 (2020): 356-60.
11. D. B. White et al., “Prevalence of and Factors Related to Discordance about Prognosis between Physicians and Surrogate Decision-makers of Critically Ill Patients,” *Journal of the American Medical Association* 315 (2016): 2086-94.
12. J. E. Davidson, “Family-Centered Care,” *AACN Advanced Critical Care* 28, no. 2 (2017): 136-37.
13. J. M. Wortham et al., “Characteristics of Persons Who Died with Covid-19—United States, February 12–May 18, 2020,” *Morbidity and Mortality Weekly Report* 69, no. 28 (2020): 923-29; Z. Raisi-Estabragh et al., “Greater Risk of Severe COVID-19 in Black, Asian, and Minority Ethnic Populations Is Not Explained by Cardiometabolic, Socioeconomic or Behavioural Factors, or by 25(OH)-Vitamin D Status: Study of 1326 Cases from the UK Biobank,” *Journal of Public Health* 42, no. 3 (2020): 451-60; Y.-H. Chen et al., “Excess Mortality in California during the Coronavirus Disease 2019 Pandemic, March to August 2020,” *JAMA Internal Medicine* (December 21, 2020): doi:10.1001/jamainternmed.2020.7578.
14. B. R. Yehia et al., “Association of Race with Mortality among Patients Hospitalized with Coronavirus Disease 2019 (COVID-19) at 92 US Hospitals,” *JAMA Network Open* 3, no. 8 (2020): doi:10.1001/jamanetworkopen.2020.18039; E. R. Berchick, J. C. Barnett, and R. D. Upton, *Current Population Reports, P60-267(RV), Health Insurance Coverage in the United States: 2018* (Washington, DC: U.S. Government Printing Office, 2019).
15. S. Y. Tartof et al., “Obesity and Mortality among Patients Diagnosed with COVID-19: Results from an Integrated Health Care Organization,” *Annals of Internal Medicine* 173 (2020): 773-81.
16. D. A. Lofquist, “Multigenerational Households: 2009-2011,” U.S. Census Bureau, American Community Survey Briefs, October 2012, <https://www2.census.gov/library/publications/2012/acs/ac-sbr11-03.pdf>.
17. S. P. Wood, “Covid-19 Underscores Racial Disparity in Advance Directives,” *Hastings Bioethics Forum* (blog), May 26, 2020, <https://www.thehastingscenter.org/covid-19-underscores-racial-disparity-in-advance-directives/>.
18. S. Muni et al., “The Influence of Race/Ethnicity and Socioeconomic Status on End-of-Life Care in the ICU,” *Chest* 139 (2011): 1025-33.
19. M. A. Clark et al., “Racial and Ethnic Differences in Advance Care Planning: Results of a Statewide Population-Based Survey,” *Journal of Palliative Medicine* 21 (2018): 1078-85.
20. L. C. Welch, J. M. Teno, and V. Mor, “End-of-Life Care in Black and White: Race Matters for Medical Care of Dying Patients and Their Families,” *Journal of the American Geriatrics Society* 53 (2005): 1145-53.
21. A. M. Elliott et al., “Differences in Physicians’ Verbal and Nonverbal Communication with Black and White Patients at End of Life,” *Journal of Pain and Symptom Management* 51 (2016): 1-8.
22. D. Carr, “Racial Differences in End of Life Care Planning: Why Don’t Blacks and Latinos Prepare for the Inevitable?,” *OMEGA* 63, no. 1 (2011): 1-20.
23. B. L. Block, A. K. Smith, and R. L. Sudore, “During COVID-19, Outpatient Advance Care Planning Is Imperative: We Need All Hands on Deck,” *Journal of the American Geriatrics Society* 68 (2020): 1395-97.
24. E. K. Vig et al., “Surviving Surrogate Decision Making: What Helps and Hampers the Experience of Making Medical Decisions for Others,” *Journal of General Internal Medicine* 22 (2007): 1274-79.
25. A. M. Torke et al., “Communication Quality Predicts Psychological Well-Being and Satisfaction in Family Surrogates of Hospitalized Older Adults: An Observational Study,” *Journal of General Internal Medicine* 33 (2018): 298-304; D. B. White et al., “Nurse-Led Intervention to Improve Surrogate Decision-Making for Patients with Advanced Critical Illness,” *American Journal of Critical Care* 21 (2012): 396-409.
26. A. M. Torke et al., “The Family Navigator: A Pilot Intervention to Support Intensive Care Unit Family Surrogates,” *American Journal of Critical Care* 25 (2016): 498-507.
27. DeMartino, “Who Decides?”
28. Pope et al., “Making Medical Treatment Decisions for Unrepresented Patients.”
29. G. T. Bosslet et al., “An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units,” *American Journal of Respiratory and Critical Care Medicine* 191 (2015): 1318-30.
30. See, for example, K. R. Lang et al., “Calling Out Implicit Racial Bias as a Harm in Pediatric Care,” *Cambridge Quarterly of Healthcare Ethics* 25 (2016): 540-52.