NOT DYING ALONE: THE NEED TO DEMOCRATIZE HOSPITAL VISITATION POLICIES DURING COVID-19

MAAYAN SUDAI

Faculty of Law and Faculty of Humanities, Women and Gender Studies, University of Haifa, Haifa, Israel

ABSTRACT

Of the many adverse outcomes that may result from the spread of the severe acute respiratory syndrome coronavirus 2, known as COVID-19, one stands out as particularly vile: the experience of dying alone. Many healthcare facilities in the US and elsewhere adopted 'No-Visitor Rules' in an effort to contain the virus, but these rules mean that the countless people in nursing homes and hospital wards were isolated during their final hours of life. There is no epidemiological or US federal or state requirement to prohibit visitation to (and thereby isolate) dying patients—even those with COVID-19. Instead, constructing pandemic-specific visitation policies is usually left to the discretion of hospitals and healthcare providers. Such policies aim to limit the risk of exposure but fail to account for the individual and social costs associated with dying alone for patients, families, and frontline healthcare workers. As a result, the policies may be overly restrictive and actively cause harm. This article argues that US hospital visitation policies need to be democratised to include the perspectives of community members and patients. By drawing on existing patient rights frameworks, this article outlines several legal strategies to reconceptualise hospital visitation policies as a civil rights issue.

KEYWORDS: COVID-19, democracy, end-of-life, expertise, hospitals, visitation rights
I. INTRODUCTION

The majority of older adults indicate that they would prefer to die at home, without pain, and surrounded by friends and family. However, due to the ongoing COVID-19 pandemic, many people who died of the virus did so in isolated hospital wards. In this article, I use ‘isolated deaths’ and ‘dying alone’ to underscore the absence of family members and close friends from the patient’s deathbed. These terms do not mean that people have died without anyone by their side, as it is important to acknowledge the presence of healthcare and social workers who have provided compassionate end-of-life care to dying patients, within the barriers of providing care during the pandemic.

In the USA, many hospitals enforced strict no-visitation rules for all patients—whether they had COVID-19 or not. Although many hospitals had end-of-life exceptions in place, these often did not apply to those who were infected with the virus. It is not clear how many people in US hospitals and nursing homes were affected by such rules, but evidence suggests that the experience was widespread. News reports indicate that people died alone in hospitals and nursing homes in a number of states and territories, including New York, Washington, California, and Wisconsin. During the early days of the pandemic spread in the USA (March 2020), various media outlets presented the voices of those who experienced the immense pain and sorrow associated with such visitation policies.

Despite public outcry about isolation in death, hospitals were slow to relax their policies, if they did so at all. Strict no-visitor rules seemed to be viewed as an ‘unavoidable reality’.

1 Nancy R. Hooyman, Kevin Y. Kawamoto and H. Asuman Kiyak, Social Gerontology: A Multidisciplinary Perspective (10th edn, Pearson 2017) 477.
2 Lucy Mitchinson and others, ‘Missing the Human Connection: A Rapid Appraisal of Healthcare Workers’ Perceptions and Experiences of Providing Palliative Care during the COVID-19 Pandemic’ (2021) 35 Palliat Med 852–61; Chris Raftery, Ebony Lewis and Magnolia Cardona, ‘The Crucial Role of Nurses and Social Workers in Initiating End-of-Life Communication to Reduce Overtreatment in the Midst of the COVID-19 Pandemic’ (2020) 66 Gerontology 427–30; Joyce Oi Suet Cheng and Edwin Li Ping Wah-Pun Sin, ‘The Effects of Nonconventional Palliative and End-of-Life Care during COVID-19 Pandemic on Mental Health-Junior Doctors’ Perspective’ (2020), 12 Psychol Trauma S146–47.
3 Anon, ‘Too many People are Dying Alone’ A New York Doctor’s Story’ RochesterFirst (27 March 2020) <www.rochesterfirst.com/coronavirus/too-many-people-are-dying-alone-a-new-york-doctors-story/> accessed 09 March 2021; Daniel Burke, ‘Coronavirus Preys on What Terrifies Us: Dying Alone’ CNN (29 March 2020) <www.cnn.com/2020/03/29/world/funerals-dying-alone-coronavirus/index.html> accessed 09 March 2021.
4 Scott Simon, ‘Opinion: 1 Unfathomable Toll of the Coronavirus Outbreak — Dying Alone’ NPR (7 March 2020) <www.npr.org/2020/03/07/813113958/opinion-1-unfathomable-toll-of-the-coronavirus-outbreak-dying-alone> accessed 09 March 2021.
5 Julia Prodis Sulek, ‘Grieving in the Time of Coronavirus: Forbidden from Dying Dad’s Bedside’ The Mercury News (19 March 2020) <www.mercurynews.com/2020/03/19/coronavirus-gilroy-family-forbidden-from-dying-dads-bedside-broke-my-heart-into-a-million-pieces/> accessed 09 March 2021.
6 Ella Torres ‘He Died Alone’: Son of Navy Veteran Describes Shock of Losing Father to Coronavirus’ ABC News (25 March 2020) <https://abcnews.go.com/US/died-son-navy-veteran-describes-shock-losing-father/story?id=69780107> accessed 09 March 2021 (‘He Died Alone’).
7 Discussed in Section III.
8 Kamilah Mitchell, ‘No Visitors Allowed: Potential Legal Ramifications of Restricted Visitors Policies In the Midst of COVID-19’ Jackson & Campbell, PC (21 April 2020) <https://www.jackscamp.com/no-visitors-allowed-potential-legal-ramifications-of-restricted-visitors-policies-in-the-midst-of-covid-19/> accessed 09 March 2021.
necessary in service of the ‘greater good’. The public’s early submission to no visitation policies seemed to reflect the perception that hospitals were the best decision-makers on this issue, given that they had the knowledge and expertise needed to quantify risk and accurately assess the situation. I, however, argue that drafting hospital visitation policies should not be treated as a strictly epidemiological challenge, but should, instead, be conceptualised as a task of balancing different types of harm and benefit to distinct groups in the context of scarce resources (mainly personal protective equipment (PPE)). Examining this challenge through civil and patient rights frameworks will contribute to more democratic medical policy making that better represents the interests of non-medical stakeholders.

This article begins with Section II, where I review a selection of hospital visitation policies that were in place between the first and third waves of the pandemic in the USA (March 2020 and February 2021, respectively) and then discuss their different levels of restrictiveness, classifying each as strict, vague, or lenient. In Section III, I portray documented adverse outcomes associated with strict and vague visitation policies, especially for patients, their families, and frontline medical staff. Given the immense pain and sorrow associated with strict visitation policies, I then attempt, in Section IV, to explain how and why hospitals continued to ban visits to COVID-19 patients, almost a year after the pandemic started, even for those who were approaching the end of their life. I identify an excess in hospitals’ discretion, meaning that despite state and federal guidance, hospitals were not meaningfully limiting their decisions to ban visits altogether. I also examine three justifications that hospitals have used for strict visitation policies, and argue that epidemiological justifications and legal liability concerns are insufficient to explain hospitals’ strict no-visitation policies. I draw a complementary explanation from the social history of dying, and argue that, in our modern era, deathbed companions are not considered vital or assistive participants and are, therefore, easier for hospital administrators to dismiss as inessential.

Finally, in Section V, I discuss the need to democratise hospital visitation policies during COVID-19 (and, possibly, regardless of the pandemic). I join others who argue that the social and psychological costs of people dying alone—including those incurred by their families and loved ones, as well as by frontline medical staff—should be included in the cost-benefit analysis, which currently overlooks different community stakeholders and is mainly intended to reduce the risk of further exposure to the virus. This part examines three legal frameworks to use in this argument: hospital visitation rights, informed consent, and death-related rights as established in US federal regulation and state laws. Such legal frameworks can help to democratise the process of hospital policy making by posing a challenge to its legality and enforcement.

This article offers an opportunity to critically reflect on the status of patients and their families in the US healthcare system in the current moment. Ultimately, I seek to underscore the value of legal frameworks in re-examining complex socio-

---

9 Hector C Ramos, Nathan Hashimoto and Lisa Henry ‘No One Should Die Alone on Our Watch’ (2020) 4(4) Int J Care Caring 595–98.

10 For a debate about the advantages and perils of medicalising civil rights, see eg Craig Konnoth ‘Medicalization and the New Civil Rights’ (2020) 72 Stanford LR 1165–267; Rabia Belt and Doron Dorfman ‘Reweighing Medical Civil Rights’ (2020) 72 Stan L Rev Online 176; Alison K Hoffman ‘How Medicalization of Civil Rights Could Disappoint’ (2020) 72 Stan L Rev Online 165.
epidemiological challenges that have been gradually medicalised to the point that we submit to them without a struggle. I suggest that we reconsider that submission and work to rebalance the cost-benefit analysis of patient visitation policies.

II. NO-VISITOR POLICIES: STRICT, VAGUE, AND LENIENT POLICIES

In the final weeks of March 2020, US hospitals announced that they were adopting restricted visitation policies as a way to mitigate risks related to the COVID-19 pandemic. These new rules either limited or altogether denied visits to hospital patients to prevent patients, employees, visitors, and medical staff from contracting the virus. Under these rules, providers commonly screened visitors for particular symptoms (such as fever) and prohibited those who displayed such symptoms from entering the facility. Hospitals also required visitors to follow a particular hand-hygiene protocol, wear a face mask, and restrict their movement within the hospital.

A review of revised visitation policies that were published on hospital and healthcare provider websites in March 2020, revealed that no-visitation policies were applied across all units and were not restricted to COVID-19 patients. General visitation policies usually included a list of exceptions, such as for child patients and patients in labour, who were allowed to be accompanied by at least one healthy adult. The other common exemption related to end-of-life care: many hospitals had explicit end-of-life exceptions that allowed one or two visitors to stay at the bedside of a dying patient. Providers that did not have an explicit exemption for this situation sometimes included discretionalexceptions for ‘special circumstances’, which could apply to such cases.

Despite the fact that end-of-life exceptions were common, the visitation policy specifically for dying patients who tested positive for COVID-19 remained largely undefined. For COVID-19 wards overall, rules were stricter. Some providers, particularly during the first wave, enforced a strict no-visitation rule. They explicitly stated in their policies that there would be no visitation for patients who tested positive for, or who were believed to have, COVID-19.

11 See Supplementary material.
12 Katie Hafner, ‘A Heart-Wrenching Thing’: Hospital Bans on Visits Devastate Families’ (The New York Times, 29 March 2020) <www.nytimes.com/2020/03/29/health/coronavirus-hospital-visit-ban.html> accessed 9 March 2021.
13 See eg Johns Hopkins Hospital, ‘Learn How Your COVID-19 Self-Screening Tool Works’ <https://www.hopkinsmedicine.org/coronavirus/digital-screening.html> accessed 9 March 2021. 
14 UMass Memorial Medical Center Memorial Campus, ‘Visitor Restrictions due to Coronavirus (COVID-19)’ (2020) <https://www.umassmemorialhealthcare.org/healthalliance-clinton-hospital/patients-visitors/patient-resources/visitor-restrictions-due-coronavirus-covid-19> accessed 9 March 2021.
15 I looked at 25 revised policies found online using the search terms ‘hospital + visitation + Covid’. Children’s hospitals generally allowed visits regardless of condition, but limited the number of visitors and the times of visitations, see Supplementary material.
16 See Supplementary material.
17 For example, in email correspondence with one medical centre that did not include an explicit end-of-life exemption in their policy, they explained that they had a general visitor restriction in place but that at this critical time, they would allow family onto the unit to say goodbye. Correspondence on file with author.
permitted end-of-life visitations to such patients, some providers replied that they did not.\textsuperscript{19} Such policies were also reported by hospital physicians in articles and op-eds.\textsuperscript{20} Indeed, many medical writings, news reports, and social media posts by patients’ family members and medical staff confirmed that, as of March 2020, hospitals and healthcare facilities in the USA and elsewhere barred visits to patients who tested positive for COVID-19, even during end-of-life circumstances.\textsuperscript{21} Other hospitals, at the time, enforced vague policies by not clearly stating their guidelines regarding visitation to COVID-19 patients, or by enforcing a no-visitation rule with discretionary exceptions (decided on a case-by-case basis).\textsuperscript{22}

In February 2021, almost a year after the virus outbreak, things were somewhat different. Many hospitals were enforcing a lenient visitation policy that allowed visits to COVID-19 patients. Although these were restricted and monitored, healthcare institutions, nevertheless, facilitated them and also included explicit end-of-life exceptions for COVID-19 patients.\textsuperscript{23} Despite this general relaxation of visitation policies between the first and third COVID-19 waves, many hospitals still enforced a vague policy by not explicitly addressing visitation rights of hospitalised COVID-19 patients.\textsuperscript{24} Some also continued to enforce a strict policy and state on their websites that COVID-19 patients will not receive visitors, even during end-of-life circumstances.\textsuperscript{25}

Because we are still moving through waves of the pandemic, vaccination optimism is often overshadowed by concern about the virus’s variants.\textsuperscript{26} As a result, it remains unclear whether visitation policies will gradually return to their pre COVID-19 standards or whether they will remain, or become even more, restrictive. Given this uncertainty, the reality of people dying alone in isolated COVID-19 wards in hospitals cannot be treated as a passing episode resulting from a limited public health emergency. As isolated deaths in COVID-19 wards become the ‘new normal’,\textsuperscript{27} administrative decisions regarding visitation policies must be critically examined and evaluated.

\textsuperscript{18} See Supplementary material.
\textsuperscript{19} Email correspondences with the author (on file). See also a similar review of thirteen hospitals in Michigan showing that hospitals almost never included exceptions to the no-visitor policy for COVID-19-positive patients: Hillary S Weiner and others, ‘Hospital Visitation Policies During the SARS-CoV-2 Pandemic’ (2020) Am J Infect Control <https://www.sciencedirect.com/science/article/pii/S0196655320308877> accessed 9 March 2021.
\textsuperscript{20} Glenn K. Wakam and others, ‘Not Dying Alone—Modern Compassionate Care in the Covid-19 Pandemic’ (2020) New Eng J Med <www.nejm.org/doi/full/10.1056/nejmp2007781> accessed 9 March 2021; Daniela J. Lamas, ‘I’m on the Front Lines. I Have No Plan for This.’ The New York Times (24 March 2020) <www.nytimes.com/2020/03/24/opinion-coronavirus-hospital-visits.html> accessed 9 March 2021.
\textsuperscript{21} See Section III.
\textsuperscript{22} See Supplementary material; Weiner and others (n 19). Also, Mitchell (n 8).
\textsuperscript{23} See Supplementary material.
\textsuperscript{24} ibid.
\textsuperscript{25} ibid.
\textsuperscript{26} Center for Disease Control and Prevention (CDC), ‘About Variants of the Virus that Causes COVID-19’ (2020) <https://www.cdc.gov/coronavirus/2019-ncov/transmission/variant.html> accessed 09 March 2021.
\textsuperscript{27} Thomas H Lee, ‘Creating the New Normal: The Clinician Response to Covid-19’ (2020) New Engl J Med Catalyst <https://catalyst.nejm.org/doi/full/10.1056/CAT.20.0076> accessed 09 March 2021; Rajesh Sagar, Nishtha Chawla and Mahadev Singh Sen, ‘Preserving the “Human Touch” in Times of COVID-19’ (2020) 54 Asian J Psychiatr 102224 (2020).
III. THE COSTS OF STRICT AND VAGUE NO-VISITOR POLICIES

Hospital visitation policies can produce a certain distribution of authority, money, safety, health, sense of security, and other things that people value. For example, a lenient policy that allows visitors for COVID-19 patients during end-of-life situations may decrease a hospital’s supply of PPE and increase the risk of virus transmission. It would, however, be more satisfying for patients, families, and frontline healthcare workers. A vague policy that relies on case-by-case decisions may provide hospital management with more flexibility, at the price of placing excessive pressure on families to make the case for a visit and forcing managers to make difficult decisions without clear guidance or support. Vague policies may also result in unfairness from inconsistent implementation. A strict visitation policy that prohibits all visits to COVID-19 patients, including in end-of-life situations, might save hospital PPE supply and increase safety to some degree, but it can wear down medical staff’s emotional resilience, increase their already heavy workloads with the painful task of facilitating remote goodbyes, and cause harm to patients and families, who report feeling deeply helpless and like they have no sense of closure.

My analysis will focus on the costs of strict and vague visitation policies that ban visits to COVID-19 patients at their end-of-life. All stakeholders in this analysis—patients, their families and loved ones, hospital administrators, and frontline medical staff—have an interest in being safe and protected from the virus. Indeed, many restrictive visitation policies ground their justifications in the need to protect public health.\(^\text{28}\) Despite these real concerns, this heightened standard of protection comes at a price.

A. Current and Future Patients

Although the experiences of people who have died in isolation have not been collected, we know that when asked what they fear most about death, older adults often mention loneliness.\(^\text{29}\) In the face of the COVID-19 crisis, in particular, some have said that they were more afraid of dying alone than of the actual virus.\(^\text{30}\) Others avoided going to hospital for other potentially life-threatening medical conditions as a result.\(^\text{31}\) Even those who did not feel that fear, said that dying in such a way would be like losing a chapter of their lives—leaving the world as a statistic and not as a whole person.\(^\text{32}\)

Young people, too, have died from the virus and so may have had similar experiences. An international study that examined 39 survivors of COVID-19 between the ages of 20 and 95 years, reported fear of dying alone as a major concern of participants.\(^\text{33}\) During the first wave of the pandemic, children’s hospitals across the US secured lenient visitation policies of one or two caregivers per child.\(^\text{34}\) However, for

---

\(^\text{28}\) Weiner and others (n 19).

\(^\text{29}\) ibid.

\(^\text{30}\) John Leland, ‘At 89, She Fears Dying Alone More Than the Coronavirus Itself’ The New York Times (7 April 2020) <www.nytimes.com/2020/04/07/nyregion/dying-alone-coronavirus.html> accessed 09 March 2021.

\(^\text{31}\) ibid.

\(^\text{32}\) ibid. The fear of being reduced to numbers and figures on death seems to be addressing what Daniel Sperling has called ‘symbolic existence’, people’s interest to be represented as ‘whole’ and ‘distinct’ human beings after their death: Posthumous Interests: Legal and Ethical Perspectives (CUP 2008) 41–42.
COVID-19 positive children, policies were often vague and may have resulted in isolated deaths for children too.35

B. Frontline Medical Staff
Medical staff who were and are on the frontline treating COVID-19 patients, have and are suffering because of highly restrictive visitation policies. Although the added stress on them from seeing people die alone has not yet been empirically evaluated, commentary by clinicians in academic literature and in news reports indicate that these policies increased stress and added heavy emotional burdens to an already intense work atmosphere. Indeed, in the USA and around the world, family members and doctors have reported that seeing people say farewell remotely and die alone has been the hardest part of the crisis.36 One New York City physician said that due to strict visitation protocols, ‘too many people are dying alone with no family around them . . . this is one of the most horrific things’.37 An ICU physician from Boston said that the new visitation policy was ‘a tough decision that leaves our patients to suffer through their illnesses in a medical version of solitary confinement. And I’m worried for them’.38 She acknowledged that the images of COVID-19 patients dying alone in Italy hung over all healthcare professionals, and ‘Talking with one of the nurse practitioners in our hospital’s new COVID-19 ICU one recent night, I asked what worried her most. “Patients dying alone”, she replied quickly’.39

Clinicians and hospitals staff have described being compelled to keep families away from their loved ones as ‘the darkest experience of their professional life’, and they have said that having a relative present could ease their workload and even provide crucial information that they otherwise would not be able to access.40 With hospitals encouraging patient–visitor communication via technological means,41 frontline workers have found themselves having to facilitate an eternal farewell via goodbye phone call or a videoconference with a loved one who was likely intubated, anxious, and not dying alone.

33 Isaac Iyinoluwa Olufadewa and others, “I Was Scared I Might Die Alone”: A Qualitative Study on the Physiological and Psychological Experience of COVID-19 Survivors and the Quality of Care Received at Health Facilities’ (2020) 8 Int J Travel Med Glob Health 51–57 (2020).
34 See Supplementary material.
35 Anon, ‘Coronavirus: 13-Year-Old with Covid-19 “Died Alone” without His Family around Him, Friend Says’ ITV News (1 April 2020) <https://www.itv.com/news/2020-04-01/coronavirus-13-year-old-victim-died-alone-friend-says-ismail-mohamed-abdulwahab-kings-college-hospital/> accessed 02 October 2020).
36 ibid. Flavio Lo Scalzo, ‘Watching Patients Die Alone Breaks Doctors’ Hearts in Provincial Italy Hospital’ Reuters (20 March 2020) <https://www.reuters.com/article/us-health-cornavirus-italy-hospi-tal-idUSKBN2163ML> accessed 08 July 2021; Maria Grazia Murru “‘Everyone Is Dying Alone’: Italy’s Coronavirus Crisis Taking Double Toll on Families’ Global News (6 April 2020) <https://globalnews.ca/news/6782647/coronavirus-italy-death-toll-families/> accessed 02 October 2020; Harry Howard, ’Italian Doctor Describes Dying Patient’s Last Moments as They Plead to See Their Loved Ones for a Final Time’ The Daily Mail (21 March 2020) <www.dailymail.co.uk/news/article-8135907/Italian-doctor-describes-dying-patients-moments-plead-loved-ones-final-time.html> accessed 02 October 2020.
37 Anon (n 3).
38 Lamas (n 20).
39 ibid.
40 Hafner (n 12).
41 Elizabeth Kelley, ‘Patient Visitors in Hospitals during the COVID-19 Outbreak’ (Bureau of Health Care Safety and Quality, 16 March 2020) <https://www.mhalink.org/MHADocs/Communications/COVID19/20-03-16C19dphvisitation.pdf> accessed 09 March 2021.
unable to communicate in any usual way. Reports have attested to the alienating and technologically awkward nature of these digital goodbyes. Based on such experiences, several US physicians reported that restrictive visitation policies prevented them from providing ‘humane, family-centered care, particularly during critical illness and at the end of life.’

Vague visitation policies that make frontline staff and managers responsible for deciding whether to allow visits, may cause ‘moral injury’ to medical staff. This can be understood as the ‘profound psychological distress which results from actions, or the lack of them, which violate one’s moral or ethical code’, and may be triggered by the lack of an essential supply and the need to make difficult decisions regarding that supply’s allocation. Data on moral injury to frontline healthcare workers during the COVID-19 pandemic are accumulated, and bioethicists have suggested that ‘the moral conflict among health care providers when they see their patients dying alone can be unbearable and lead to ongoing grief and sadness’.

Anecdotal evidence supports this view. Several Detroit ICU physicians have described the hardships of negotiating between hospital administrators and family members who asked, begged, and even threatened to come onto the ward to say goodbye. Physicians in Michigan have contended that strict visitation policies caused severe trauma among frontline staff, who worried about making the wrong predictions regarding a patient’s chances of survival and thus sending away a family member. If the patient eventually died, then ‘there is no metric for such suffering’. Additionally, there is a risk of moral stress and injury for bedside physicians who are the frontline implementors of restrictive policies, despite having had little say in constructing them. In a few exceptional instances, nurses and physicians actually created alternative visitation protocols in order to allow dying patients in COVID-19 wards to be accompanied.

42 Jennifer Levitz and Paul Berger, ‘I’m Sorry I Can’t Kiss You’—Coronavirus Victims Are Dying Alone” (Wall Street Journal 10 April 2020) < www.wsj.com/articles/im-sorry-i-cant-kiss-youcoronavirus-victims-are-dying-alone-11586534526> accessed 1 October 2020.

43 Erica Andrist and others, ‘Paved With Good Intentions: Hospital Visitation Restrictions in the Age of Coronavirus Disease’ (2020) Pediatr Crit Care Med 21(10) e924.

44 Matthew Roycroft and others, ‘Limiting Moral Injury in Healthcare Professionals during the COVID-19 Pandemic’ (2020) 70 Occup Med 312–14.

45 Stella E Hines and others, ‘Initiation of a Survey of Healthcare Worker Distress and Moral Injury at the Onset of the COVID-19 Surge’ (2020) Am J Ind Med <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7404965/> accessed 09 March 2021; Lauren M Borges and others, ‘A Commentary on Moral Injury among Health Care Providers during the COVID-19 Pandemic’ (2020), 12 Psychol Trauma S138–40; Victoria Williamson, Dominic Murphy and Neil Greenberg, ‘COVID-19 and Experiences of Moral Injury in Front-line Key Workers’ (2020) 70 Occup Med 317–19; Suet Cheng and Ping Wah-Pun Sin (n 2).

46 Lisa K Anderson-Shaw and Fred A Zar, ‘COVID-19, Moral Conflict, Distress, and Dying Alone’ (2020) 17 J Bioethic Inq 777–82.

47 Wakam and others (n 20).

48 Andrist and others (n 43).

49 ibid.

50 Ramos, Hashimoto and Henry (n 9).
C. Family Members and Loved Ones

Perhaps most commonly recorded in the news were the perspectives of family members and friends who had lost their loved ones. For many, being unable to say goodbye in person, hold their loved one’s hand, or even see the person after their death, bred feelings of isolation, helplessness, guilt, and inability to reconcile with the situation. One woman who lost her father to the virus said that she was not allowed to visit him in isolation, and when he was brought into the ICU, she watched him through glass doors: ‘It broke my heart into a million pieces. I didn’t want him to feel alone.’

Some described the process of watching their loved one die without being able to offer support as being like watching them drown from a distance: ‘We are watching from the shore and not being able to do anything . . . it is a very helpless feeling.’

Another woman described this experience as ‘devastatingly isolating.’

Some family members emphasised the difficulty of not being able to touch their loved ones or hold their hands. Others have reported that being physically separated from a dying loved one made it difficult to recognise what had happened and to grieve properly. Because of strict social distancing measures, people have been unable to hold in-person cultural rituals around mourning, such as funerals and shivas, or to receive physical comfort from their close community. Experts have suggested that the loss of these rituals of saying goodbye leaves survivors with ‘a sense of deprivation’.

Last but not least, as reported by families and frontline physicians, strict and vague visitation policies also burden families with the job of petitioning hospital administration to make an exception in their case.

While this in not a complete comparison of the costs and benefits of strict, vague, and lenient visitation policies, this section has provided an overview of the harms associated with strict and vague visitation policies, as recorded in reports, letters, comments, and studies published in academic journals and news outlets. This preliminary assessment of costs and benefits aims to open a conversation regarding paths to...
redistributing harms and benefits between different stakeholders such as hospital administrators, frontline medical staff, patients and their family and friends. In the next section, I argue that hospitals enjoy superfluous discretion to restrict visitations without any meaningful legal limitation; a condition that leads many hospitals and healthcare providers to enforce overly restrictive no-visitor policies.

IV. HOSPITALS’ SUPERFLUOUS DISCRETION

The decision to ban visits to COVID-19 patients was mostly a hospital one and was not required by US state or federal guidance. As hospitals were granted broad discretion to restrict visits as they saw fit, even beyond recommended state and federal guidance, in this section I argue that hospitals enjoy an authority ‘surplus’. This surplus allows them to ban visits regardless of whether doing so is necessary or proportional to the risk. I also suggest that epidemiological and financial explanations cannot account for the fact that some hospitals devised more restrictive policies. I offer an alternative explanation related to the medico-legalisation of death and the weak legal status of community members at the deathbed.

A. Top-Down Restrictions, Regulations, and Guidance

During the first wave of the pandemic, federal agencies, states, and municipalities in the US issued executive orders that outlined important considerations for hospitals in devising their visitation policies. None of these, however, mandated that hospitals ban visits to COVID-19 patients. In fact, many of them acknowledged the necessity of end-of-life visitation to COVID-19 patients. For example, the Centers for Disease Control and Prevention (CDC) interim Guidance called on facilities serving communities in which COVID-19 had spread to limit visitors to COVID-19 patients—not to ban them. The CDC’s guidelines for long-term facilities and nursing homes were more restrictive and recommended ‘aggressive visitor restrictions’ even before COVID-19 was identified in a community or a facility. However, even within this framework, the CDC excluded ‘compassionate care situations, such as end of life situations’ and recommended evaluating such visits on a case-by-case basis. It also explicitly addressed ways to manage and control visitation of those with COVID-19, such as by instructing visitors to maintain hand hygiene, use protective equipment, limit surface touch, and restrict their movement within the facility. The Centers for Medicare & Medical Services (CMS) guidance to nursing homes aligned with that of the CDC: restrict visitations except in compassionate care situations, such as when a patient was at the end-of-life and was in a controlled environment.

59 I am following the distributional analysis schema offered in Janet Halley and others, Governance Feminism: An Introduction (University of Minnesota Press 2018) 253–66.
60 CDC, ‘Healthcare Facilities: Preparing for Community Transmission’ (2020) <https://www.cdc.gov/coronavirus/2019-ncov/hcp/guidance-hcf.html> accessed 26 April 2020.
61 CDC, ‘Preparing for COVID-19: Long-term Care Facilities, Nursing Homes’ (2020) <https://www.cdc.gov/coronavirus/2019-ncov/hcp/long-term-care.html> accessed 26 April 2020.
62 ibid.
63 ibid.
64 Center for Clinical Standards and Quality/Quality, Safety & Oversight Group Services, ‘Guidance for Infection Control and Prevention of Coronavirus Disease 2019 (COVID-19) in Nursing Homes
Similar guidance was issued at state and municipal levels, as governors and public health departments issued orders that called upon healthcare facilities to revise their visitation policies. A review of such executive orders and guidance documents from states with among the highest numbers of confirmed COVID-19 cases in the first wave of the pandemic, reveals that nearly all such guidance recommended including compassionate or end-of-life exceptions to strict no-visitation rules, and some even specified how visitation of COVID-19 patients should take place. For example, in the state of New York, where numbers of reported COVID-19 cases were among the highest in the nation, the Department of Health issued guidance that called for suspending all visits ‘except for patient support persons, or family members and/or legal representatives of patients in imminent end-of-life situations’. The guidance further permitted patient support for paediatric patients, patients in labour and delivery, and patients with intellectual or developmental disabilities. It guided hospitals to accommodate the stay of essential support persons, ‘including when the patient is confirmed or suspected to have COVID-19’. Thus, not only did the state of New York not ban visits to patients confirmed or suspected to have COVID-19, it actually provided guidelines regarding how such visits should be managed.

Other states and municipalities also recommended including a discretionary exemption to the no-visitor rule. For example, in a memorandum from mid-March 2020, the state of Massachusetts called upon hospitals to urge potential visitors to defer visitation until further notice, but left room for hospitals to make case-by-case decisions in compassionate care situations. In San Francisco, the health officer issued an order to limit hospital visitors and allowed hospitals to authorise ‘necessary visitation’ on a case-by-case basis. According to the order, necessary visitations are ‘types of visits or contact that are time-sensitive or critical’. This order is in line with the State of California Department of Public Health ‘Visitor Limitation Guidance’, which defined visitors of terminal patients as essential to their mental health. The state of

65 According to CDC data, updated to April 7 2020, jurisdictions found to have the largest cumulative number of reported Covid-19 cases in ascending order were Illinois, Florida, Pennsylvania, Massachusetts, California, Louisiana, Michigan, New Jersey, New York, and NYC. See CDC, Geographic Differences in COVID-19 Cases, Deaths, and Incidence — United States, February 12–April 7, 2020’ (17 April 2020) <www.cdc.gov/mmwr/volumes/69/wr/mm6915e4.htm?s_cid=mm6915e4_w> accessed 02 October 2020.

66 New York Department of Health, ‘Health Advisory: COVID-19 Updated Guidance for Hospital Operators Regarding Visitation’ (10 April 2020) <https://coronavirus.health.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_041020-002.pdf> accessed 02 October 2020.

67 ibid.

68 Massachusetts Department of Public Health, ‘Hospital Visitor Restrictions Guidance’ (16 March 2020) <www.mass.gov/doc/hospital-visitor-restrictions-guidance-march-16-2020> accessed 02 October 2020. The Commissioner of public health issued an order that required hospitals to implement screening procedures and to restrict visitations: ‘Order of The Commissioner of Public Health’ (15 March 2020) <https://www.mass.gov/doc/march-15-2020-hospitalvisitor-restrictions-order/download> accessed 02 October 2020.

69 City and County of San Francisco, ‘Order of the Health Officer No. C19-06 (Limitations on Hospital Visitors)’ (13 March 2020) <https://sfgsa.org/sites/default/files/Document/OrderC19-06.pdf> accessed 02 October 2020.

70 California Department of Public Health, ‘Visitor Limitations Guidance’ (2020) <www.cdph.ca.gov/Programs/CHCQ/LCP/Pages/AFL-20-38.aspx> accessed 02 October 2020.
Michigan, which defined a very narrow list of exceptions, likewise allowed visits for patients ‘in serious or critical condition or in hospice care’.\(^1\)\(^\text{71}\) New Jersey issued mandatory guidelines that required administrators to prohibit visitors in the facility except for end-of-life situations,\(^2\)\(^\text{72}\) during which visits would be permitted only following screening and education of visitors.

As evidenced by this review of US federal, state, and municipal guidance documents in places where the pandemic erupted severely during the first wave, neither health specialists nor policy makers at these levels prohibited visiting dying COVID-19 patients. Many of these documents actually recommended including exceptions for end-of-life conditions. Why, then, did so many hospitals adopt more stringent rules? Epidemiological reasons and financial incentives offer only a partial explanation. I suggest that the historical diminishment in the status of community members at a dying patient’s side, is key to understanding the common and unnecessarily strict no-visitor rules that hospitals put in place for dying COVID-19 patients.

B. The Epidemiological Explanation

Hospitals that enacted strict visitation policies in the early days of the pandemic did not have data regarding actual virus transmission rates inside their walls. Even today, data related to transmission rates inside hospitals remain relatively difficult to gather due to the lag time between infection and the start symptoms, if they appear at all.\(^\text{73}\)

Studies that have attempted to evaluate and quantify hospital infections use different time frames to estimate which COVID-19 infections happened inside the hospital, and how.

Studies published between June and September 2020 that examined hospitals in the USA and UK, found that of all positive COVID-19 cases in a selected time frame, 6.8–15% were likely to have been infected while inside a hospital.\(^\text{74}\) These studies attempted to trace infection routes within hospitals and mentioned several possibilities. One study found that 88.9% of hospital-acquired cases resulted from sharing a ward with a confirmed COVID-19 patient before the patient was confirmed positive for COVID-19.\(^\text{75}\) A different study found that 55% of hospital-acquired COVID-19 cases had been in the same room with a confirmed patient, and 14% had been in the same ward as a confirmed patient.\(^\text{76}\) No other source was found for the remaining

\(^1\) State of Michigan Office of the Governor, ‘Temporary Restrictions on Entry into Health Care Facilities, Residential Care Facilities, Congregate Care Facilities, and Juvenile Justice Facilities’ (5 April 2020) <https://content.govdelivery.com/attachments/MIEOG/2020/04/05/file_attachments/1419769/EO%202020-37.pdf> accessed 02 October 2020.
\(^2\) State of New Jersey Department of Health, ‘Mandatory Guidelines for Visitors and Facility Staff’ (13 March 2020) <https://nj.gov/health/healthfacilities/documents/MandatoryGuidelinesVisitorsStaff_COVID19.pdf> accessed 02 October 2020.
\(^3\) Pippa Allen-Kinross, ‘The Problem with Coronavirus Transmission in Hospitals’ Full Fact (17 December 2020) <https://fullfact.org/health/coronavirus-transmission-hospitals/> accessed 10 March 2021.
\(^4\) Ben Carter and others, ‘Nosocomial COVID-19 Infection: Examining the Risk of Mortality. The COPE-Nosocomial Study (COVID in Older People)’ (2020) 106 J Hosp Infect 376–84; Rachel M Wake and others, ‘Reducing Nosocomial Transmission of COVID-19: Implementation of a COVID-19 Triage System’ (2020) 20 Clin Med e141–45; Hannah M Rickman and others, ‘Nosocomial Transmission of Coronavirus Disease 2019: A Retrospective Study of 66 Hospital-acquired Cases in a London Teaching Hospital’ (2020) Clin Infect Dis <https://doi.org/10.1093/cid/ciaa816> accessed 02 February 2021.
Another study found that of 697 COVID-19-positive hospital patients, only two cases were infected inside the hospital—one of them likely by an asymptomatic spouse who visited. These studies strongly suggest that improper placement of patients inside hospital wards—not outside visitors—was the primary source of hospital infections.

Additionally, studies emphasised that the risk of hospital infection can be controlled via ‘rigorous infection control measures,’ and practices such as consistent screening of medical staff and patients, classifying patients to risk groups, universal masking, screening visitors with symptoms, and following CDC guidance regarding PPE. Considering the centrality of PPE supply in preventing hospital-based COVID-19 outbreaks, one epidemiological explanation for restrictive visitation policies could be related to the PPE shortage that was widely reported among US healthcare facilities during the first and second waves of the virus. And yet, even a limited PPE supply is not sufficient to explain a blanket no-visitor policy because when the PPE crisis was still underway, some hospitals had already announced lenient visitation policies to dying patients in COVID-19 wards. How is that possible?

First, as we already know, although many hospitals experienced a shortage of PPE, some hospitals suffered less than others. Secondly, even while experiencing limited PPE supply, healthcare facilities could optimise their use of PPE and prioritise end-of-life visits when allocating hospital resources. The Israeli National Council for Bioethics, for example, devised a plan that balanced the risk of transmission, PPE supply, and the need to say goodbye in person. It advised hospitals to allow dying COVID-19 patients to say goodbye in a ‘humane’ way that included ‘direct contact’ with a close person (and a religious person, if they wished). In order to reduce the risk of infecting visitors and their secondary networks, the Council recommended...
limiting the physical farewell to one visitor and suggested that, when possible, chosen visitors should be family members who had contracted COVID-19, had recovered, and were possibly immune. Another way to manage the scarcity of PPE could have been to arrange for a stock of donations for visitors to use, as occurred with tablets and phones.

For these reasons, medical and public health experts in infection control have criticised hospital policies that restricted visits to COVID-19 patients. Some have argued that such policies ‘prioritize, above all else, containment of the coronavirus’ without considering other public goods, such as compassionate, family-centered care, reduction of fear, and improved health outcomes. Some infection control experts have argued that because visitation restrictions occurred in addition to other infection control measures, the actual contribution of those restrictions to minimising transmission is ‘unclear’, noting the successful experience of softening visitation restrictions in Singapore, for example. Accordingly, there have been calls to ‘reject the argument that the public good requires patients to die alone’. Many have noted that the risk from infection by visitors is contingent, can be successfully reduced with different means of infection control, and should be balanced against documented mental health harms of isolation, which affect patients, family, and frontline workers. Given all of this, facilities can and should accommodate the family presence in isolated wards, even in times of disease outbreaks.

To conclude, the absence of qualitative data on hospital transmissions in the early days of the pandemic likely led to overly restrictive visitation policies. Within a few months, it became clear that the epidemiological risk from such visits could be mitigated by using PPE and following the CDC guidance. Thus, although the shortage of PPE was a significant barrier to conducting visits safely, visitations could have been managed through balancing needs and prioritising PPE use. The epidemiological explanation thus cannot fully justify the continuation of strict no-visitation policies. An alternative explanation for this ongoing phenomenon may, however, lie in financial incentives, such as reducing legal liability.

86 ibid.
87 Jamie Ducharme, ‘Volunteers Are Collecting Tablets to COVID-19 Patients’ Time (24 April 2020) <https://time.com/5826220/covid-19-tablets/> accessed 10 March 2021.
88 Teck Chuan Voo, Zohar Lederman and Sharon Kaur, ‘Patient Isolation during Infectious Disease Outbreaks: Arguments for Physical Family Presence’ (2020) 13 Public Health Ethics 133–42; Alejandra Victoria Capozzo, ‘Dying Alone Due to COVID-19: Do the Needs of the Many Outweigh the Rights of the Few—or the One?’ (2020) 8 Front Public Health 593464 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7734051/> accessed 18 February 2021; Ramos, Hashimoto and Henry (n 9).
89 Andrist and others (n 43).
90 Siddiqi (n 58); ibid.
91 Liang En Wee and others, ‘The Impact of Visitor Restrictions on Health Care-Associated Respiratory Viral Infections during the COVID-19 Pandemic: Experience of a Tertiary Hospital in Singapore’ (2021) 49 Am J Infect Control 134–35.
92 ibid. This argument was made particularly with respect to paediatric intensive care unit departments.
93 Voo and others (n 88); Siddiqi (n 58); Andrist and others (n 43).
94 Voo and others (n 88); Wee (n 91); Teck Chuan Voo, Mathavi Senguttuvan and Clarence C Tam, ‘Family Presence for Patients and Separated Relatives During COVID-19: Physical, Virtual, and Surrogate’ (2020) 17 Bioethic Inq 767–72.
95 Ramos, Hashimoto and Henry (n 9).
C. The Liability Explanation

Several critiques have pointed out that the governments focus solely on the numbers of COVID-19 cases and deaths and neglect other facets of the situation, such as its effects on the economy, the poor, or domestic violence rates.96 Similarly, the social and individual anxieties that result from deaths in isolation are not represented in COVID-19 statistics. As a result, decision makers do not account for them when making important healthcare decisions.97 These observations might explain why hospital administrators adopted more stringent visitation policies than were actually necessary—because the social and mental health costs of strict visitation policies may not be reflected in their metrics. Take, for example, a hospital risk manager who evaluates patient visitation policies. In the healthcare context, risk managers are expected to proactively protect the safety of patients and the healthcare organisations’ interests, by detecting, monitoring, assessing, mitigating and preventing risks.98 However, anxiety and sorrow stemming from isolated deaths are not naturally translated into risk matrices and heat maps. Although risk management literature has advocated using risk-management tools to reduce patient suffering,99 and to address harms that are not only physical or economic but other harms including psychological harms and ‘avoidable suffering’,100 a fundamental objective of risk management is to reduce the institution’s liability exposure.101 From this conventional perspective, risk managers are incentivised (with all good intentions) to err to the side of caution and to produce strict policies that minimise liability from exposure to the COVID-19 virus.102

Yet, it is not clear that strict visitation policies do reduce liability exposure, a constant concern in the USA. First, even from the limited conventional standpoint of a hospital’s risk management department, isolated deaths may trigger a lawsuit. Adverse feelings that result from such events could be reflected in decreased ‘patient satisfaction’, which is understood to increase the likelihood of litigation caused by grievances.103 In these cases, such litigation could be grounded in contractual claims based on the hospital admission agreement,104 the pursuit of injunctive relief (such as a

96 Simon Lohse and Karim Bschir, ‘The COVID-19 Pandemic: A Case for Epistemic Pluralism in Public Health Policy’ (2020) 42 Hist Philos Life Sci 58.
97 Scott Simon (n 4).
98 Anon, ‘What Is Risk Management in Healthcare?’ (2018) NEJM Catalyst <https://catalyst.nejm.org/doi/abs/10.1056/CAT.18.0197> accessed 10 March 202.
99 Resulting, inter-alia, from restrictive visiting hours: see Alan J Card and Victor R Klein, ‘A New Frontier in Healthcare Risk Management: Working to Reduce Avoidable Patient Suffering’ (2016) 35 J Healthc Risk Manag 31–37.
100 Alan J Card, ‘What Is Ethically Informed Risk Management?’ (2020), 22 AMA J Ethics 965–75.
101 Anon (n 98); Department of Health and Human Services, ‘OIG Final Report: Risk Management at Health Centers’ (7 February 2005) <https://oig.hhs.gov/oei/reports/oei-01-03-00050.pdf> accessed 10 March 2021.
102 Although not identical, studies on ‘defensive medicine’ can be related to practices of ‘defensive administration’ in hospitals. On defensive medicine prevalence and incentives see eg Allen Kachalia and Michelle M. Mello, ‘Defensive Medicine—Legally Necessary but Ethically Wrong?: Inpatient Stress Testing for Chest Pain in Low-Risk Patients’ (2013) 173 JAMA Intern Med 1056–57; David M Studdert and others, ‘Defensive Medicine Among High-Risk Specialist Physicians in a Volatile Malpractice Environment’ (2005) 293 J Am Med Assoc 2609–17.
103 Anon (n 98).
104 Mitchell (n 8).
temporary injunction by patients),\textsuperscript{105} or intentional or negligent infliction of emotional distress.\textsuperscript{106} Given these possibilities, prohibiting visits might actually increase liability exposure. Secondly, when a hospital commits itself to strict and difficult-to-enforce standards, it might be more likely to be caught diverging from that standard. In this regard, vague policies are less risky from a liability perspective and thus ought to be more appealing to hospitals.

The viability of these claims has not yet been tested, so it is not clear whether and how liability exposure might have shaped COVID-19 visitation policies. Nevertheless, as long as risk assessments do not reflect the threat of litigation concerning visitation policies, this threat will probably not balance the hospital's incentive to disallow visits. Even if visitation policies are eventually taken to court, the history of timid judicial intervention in executive agencies’ risk assessments suggests that winning is unlikely.\textsuperscript{107} Furthermore, the risk of hospital liability during the COVID-19 pandemic has been minimised in the US state and federal laws that provide healthcare professionals and facilities with immunity protections for liability of certain kinds.\textsuperscript{108} In conclusion, liability concerns are likely driving many hospitals to adopt strict policies, but not universally, as evident from the divergence between policies.

D. The Cultural Explanation

A final explanation for strict no-visitor policies is rooted in the social history of deathbed rituals and of accompanying dying people in their final hours. This very brief history of such rituals demonstrates that the institutionalisation of death—it’s shift from the home to the hospital—has diminished the status and authority of family members and the dying person’s community. In our modern era, deathbed companions are not considered vital or assistive participants. They are, therefore, easier for institutions to dismiss. This explanation, I suggest, is key to understanding contemporary no-visititation rules.

In pre-industrial society, deathbed rituals were governed by religion and actively involved the community. For example, much has been written about the \textit{ars moriendi} (‘the art of dying’), the Christian manuals that instructed the dying on how to navigate the end-of-life.\textsuperscript{109} These manuals indicated that the hour of death was an occasion not just for the person nearing the end-of-life but also for the community and the public, who were invited to witness a holy death.\textsuperscript{110} As part of this process, the dying person would choose who would accompany and support them in their final hour.\textsuperscript{111} Such accompaniment through the dying process has been a well-regarded custom in many cultures and religions throughout history.\textsuperscript{112}

\textsuperscript{105} ibid.
\textsuperscript{106} ibid.
\textsuperscript{107} Sheila Jasanoff, \textit{Risk Management and Political Culture} (Russell Sage Foundation 1986) 32.
\textsuperscript{108} Ronen Perry, ‘Who Should Be Liable for the COVID-19 Pandemic?’ Harv J Legis (forthcoming 2021) <https://ssrn.com/abstract=3697283>.
\textsuperscript{109} Shai Joshua Lavi, \textit{The Modern Art of Dying a History of Euthanasia in the United States} (Princeton University Press 2005) 5.
\textsuperscript{110} ibid 27.
\textsuperscript{111} ibid 29.
With time, however, the process of dying has been medicalised. It has become a matter of medical and legal regulation, and both frames have sought to fight death and preserve life. Until the nineteenth century, when it became clear that a patient was going to die, doctors would leave the bedside and cede that territory to family and clergy. In contrast, the new ethic expected physicians to remain present at the deathbed and help patients achieve a good and easy death: ‘The law of the deathbed had shifted from religion to medicine’.¹¹³ This hospitalisation of death has dramatically changed dying rituals, as well as the place of community, family members, and loved ones within them. By the end of the twentieth century, death was taken largely out of the hands of communities and families and placed into those of doctors and medical institutions.¹¹⁴ Death changed from a community event to a segregated, personal, and psychological one.¹¹⁵

Although the historical transformation of dying rituals may sound barely related to contemporary visitation policies, they may help to explain current COVID-19 hospital visitation policies. The gradual expropriation of death from the community has produced a new reality: in it, death under the jurisdiction of hospitals has become the normative, neutral-seeming background against which visitation rules are created and accepted. In these settings, the community’s historical role as an active and essential participant in the ritual of dying is taken over by medical staff. From a medical perspective, community members are external—they are not considered to be essential to the biological processes that take place inside the hospital. From a legal perspective, community and family are merely ‘visitors’ and can be regulated as such. Thus, the relationship between hospitalised people who are dying and their loved ones is construed as being subject to the administrative apparatus of rights and privileges which hospitals can grant or withhold. Accordingly, the choice of hospitals in strict no-visitor rules merely reflects processes of modernity, particularly the ongoing medicalisation of death and the distancing of the dying patient from their community.

Supporting this view is the difference in how patients in labour have been treated in US hospitals during the pandemic. Experts have argued that obstetric care professionals are at a particularly high risk of infection due to the long duration of labour and the intensity of patient interaction.¹¹⁶ Writing on the visitation rights of labouring persons during the COVID-19 pandemic,¹¹⁷ Nofar Yakovi Gan-Or has described how in response to the attempts of New York City hospitals to bar spouses and other family members from accompanying birthing persons, the public and the city were quick to respond. A petition garnered more than 600,000 signatures,¹¹⁸ and the Governor issued an executive order to allow one support person in the delivery room.¹¹⁹

---

¹¹² See eg Avriel Bar-Levav, ‘Ritualisation of Jewish Life and Death in the Early Modern Period’ (2002) 47 Leo Baeck Institute Year Book 69–82. On dying vigils as an ancestral human ritual, see Ramos, Hashimoto and Henry (n 9).

¹¹³ Lavi (n 109) 6.

¹¹⁴ Philippe Aries, *The Hour of Our Death* (OUP 1991) 583.

¹¹⁵ ibid. Lavi (n 109) 31.

¹¹⁶ Noelle Breslin and others, ‘Coronavirus Disease 2019 in Pregnancy: Early Lessons’ (2020) 2 Am J Obstet Gynecol MFM 100111.

¹¹⁷ Nofar Yakovi Gan-Or, ‘Going Solo: The Law and Ethics of Childbirth during the COVID-19 Pandemic’ (2020) 7 J Law Biosci Isaa079.
Commentators observed the unequal treatment of labouring people and people dying alone:

By singling out pregnant people, the Governor’s executive order also seemingly fails to recognize the wider array of necessary triaging decisions that are already being made . . . Just as there are heartbreaking stories of people birthing alone, there are heartbreaking stories of people dying alone.120

The difference in the public and political responses to lonely births versus lonely deaths can be explained by the differing cultural transformations that have occurred regarding these two life events. Although both underwent a process of medicalisation and hospitalisation in the twentieth century, the destiny of labour partners has dramatically diverged from that of deathbed companions. According to Gan-Or, despite the tradition of labour as a ‘woman-only’ event, the transition to hospitals actually pushed spouses into the delivery rooms and not out of them.121 Their presence is now considered vital to the health and decision making of the birthing person and can also reflect their desire to be more involved in the delivery process.122 Gan-Or suggests that ‘the doors of the delivery room are now open not just to husbands’ but also to same-sex partners, adoptive parents, friends, siblings, or whoever the labouring person identifies as necessary.123 Accordingly, medical students are taught to manage a crowd next to the delivery bed, and obstetric departments pride themselves on their capacity to accommodate the stay of partners and support persons throughout the visit.124 As outlined earlier, the destiny of deathbed companions has been quite the opposite.125

Although epidemiological and financial explanations provide some rationales for hospitals that create restrictive visitation policies, I argue that the different treatment of labouring people affirms that such policies are also shaped by the modern medico-legal configuration of deathbed companions as non-essential persons.

V. DEMOCRATISING HOSPITAL VISITATION POLICIES

In its idyllic use, ‘democratisation of healthcare’ generally refers to patient participation in the process of biomedical policy making. This is based on the perception that a rational deliberation process, inclusive of patients’ perspectives, will lead to better

118 Jessica Pournaras, ‘Andrew M. Cuomo: Safeguard the Right of All Laboring People During COVID-19 Crisis’ (Change.org, 2020) <https://www.change.org/p/andrew-m-cuomo-safeguard-the-right-of-all-laboring-people-during-covid-19-crisis> accessed 10 March 2021.
119 Exec Ord No 202.12 (NY) <https://www.governor.ny.gov/sites/governor.ny.gov/files/atoms/files/EO_202.12.pdf>.
120 Louise P. King and Neel Shah, ‘The Ethical Argument Against Allowing Birth Partners in All New York Hospitals’ (Bill of Health, 2020) <https://blog.petrieflom.law.harvard.edu/2020/04/08/new-york-coronavirus-birth-partners/> accessed 11 March 2021.
121 Yakovi Gan-Or (n 117).
122 ibid.
123 ibid.
124 ibid.
125 See eg the failed attempt to pass ‘The No Patient Left Alone Act’ in North Carolina here: <https://www.ncleg.gov/BillLookup/2019/S730>.
and more legitimate political outcomes.126 Relatedly, the concept of democratisation in healthcare also signals values such as patient empowerment and emancipation through activism of patient movements.127 To democratise hospital visitation policies, patients and additional relevant stakeholders should be included in the process of making such policies.

There are many reasons to give hospitals discretion in managing their conduct, but there are also arguments in favour of including stakeholders’ perspectives when devising visitation policies. My analysis thus far has shown that medical experts and epidemiologists have acknowledged the need to balance the ‘unclear’ value of restrictive visitation policies with the policies’ adverse outcomes, such as delayed recovery, or psychological and moral harm to medical staff, patients, and their families.128 This lack of consensus regarding cost-benefit analyses justifies some level of public scrutiny. If we go further and argue that visitation policies are actually an allocation-of-scarce-resources challenge (PPE), rather than a pure epidemiological/medical expertise challenge, then stakeholder perspectives are arguably more essential in the process of ethical allocation. By further reconceptualising the challenges of hospital visitation policies using a civil rights framework, I seek to underscore the undemocratic and possibly unfair nature of COVID-19-related hospital visitation policies.

As others have expressed, there is a clear need to democratise hospital visitation policies during the COVID-19 pandemic. Although some do not agree with arguments in favour of limiting hospitals’ prerogative,129 others have called for the inclusion of more perspectives in the decision-making process, such as those of frontline doctors, patients, and the community.130 For example, Hillary Weiner and others have recommended that visitor restrictions are informed by the best epidemiological data and by ‘stakeholder input’.131 Policies should be transparent about who created them and restrictions should clearly explain the process of petitioning for an exception.132 In contrast, Erica Andrist and others have argued that visitation restrictions should be decided by an independent decision-making body that incorporates the perspectives of hospital administration, medical professionals from a variety of disciplines, and patients and their families.133

Legal strategies can foster the democratisation of healthcare. Although courts do not replace political deliberation, and may even hinder it,134 they have been effective

---

126 Phillip H Roth and Tommaso Bruni, ‘Participation, Empowerment, and Evidence in the Current Discourse on Personalized Medicine: A Critique of “Democratizing Healthcare”’ (2021), Sci Technol Hum Values 01622439211023568, 5–7; Beatrix Hoffman and others, Patients as Policy Actors: A Century of Changing Markets and Missions (Rutgers University Press 2011).
127 Steven Epstein, Impure Science: AIDS, Activism, and the Politics of Knowledge (University of California Press 1996); Charlotte Williamson, Towards the Emancipation of Patients: Patients’ Experiences and the Patient Movement (Policy Press 2010).
128 See Section IV.A.
129 King and Shah (n 120).
130 Sarah E Nelson, ‘COVID-19 and ethics in the ICU’ (2020) 24 Crit Care 519 (2020); Weiner and others (n 19); Andrist and others (n 43)
131 Weiner and others (n 19).
132 ibid.
133 Andrist and others (n 43).
134 Gerald N Rosenberg, The Hollow Hope: Can Courts Bring About Social Change? (2nd edn, The University of Chicago Press 2008) 12.
in striking ‘new balances’ between lay knowledge and expert authority in different contexts, including the biomedical one.\textsuperscript{135} Even while bearing in mind criticisms of legal activism, it does have some advantages.\textsuperscript{136} Moving the debate from the hospital to the court, for example, would require hospitals to diligently justify their policies and support them with sufficient evidence. Moreover, a court decision can have broad ranging material and symbolic benefits that last beyond the pandemic and spread across localities and institutions.

Despite the possible advantages of litigation for the democratisation of healthcare, legal strategies need to be considered more broadly—as a language of resistance that can produce political transformation outside the court, and in various types of deliberations with hospitals, governmental agencies, or commissions. Reconceptualising disagreements with medical authorities using legal concepts, principles, and frameworks, can effectively politicise issues that seem to be entirely medical or scientific.\textsuperscript{137} Legal language can introduce questions about fairness, equity, and other values that the medical/epidemiological approach do not address directly.\textsuperscript{138} Ultimately, legal language helps to make visible assaults to core values that are sanctioned in the law. The legal frameworks suggested in the following sections are, accordingly, not intended to pave a direct path towards litigation, but rather to offer concepts, frameworks, and anchors to form a resistance based in law—a ‘language of power’.\textsuperscript{139}

A. Hospital Visitation Rights

Hospital visitation rights appear to be intuitive and are derived directly from the civil rights and liberties that are firmly enshrined in US law and culture. Perhaps surprisingly, though, the ability of family and loved ones to stay connected with hospitalised patients is not obvious nor automatic; indeed, it has been at the heart of civil rights struggles since the beginning of the twentieth century.\textsuperscript{140} Or perhaps it is not surprising after all, considering the historical removal of family and community members from the patient’s bed and their replacement by medical professionals. Given this context, formal declarations of hospital visitation rights in US law can be a place from which to start looking for a formal right to receive visitations in hospitals.

The most explicit reference to hospital visitation rights and privileges on the national level appears in a 2010 presidential memorandum by then President Barak

135 Sheila Jasanoff, \textit{Science at the Bar: Law, Science, and Technology in America} (Harvard University Press 1995) 22.
136 Orly Lobel, ‘The Paradox of Extralegal Activism: Critical Legal Consciousness and Transformative Politics’ (2007) 120 Harv Law Rev 937–88; Michael McCann, ‘Law and Social Movements: Contemporary Perspectives’ (2006) 2 Annu Rev Law Soc Sci 17–38.
137 Maayan Sudai, ‘Revisiting the Limits of Professional Autonomy: The Intersex Rights Movement’s Path to De-Medicalization’ (2018) 41 Harv J Law Gender 1–54.
138 ibid.
139 Kenji Yoshino, \textit{Covering: The Hidden Assault on Our Civil Rights} (Random House 2006) 23.
140 George Annas, \textit{The Rights of Hospital Patients: The Basic ACLU Guide to a Hospital Patient’s Rights} (Discus Books 1975) 54; Meredith Fileff, ‘Hospital Visitation: The Forgotten Gay Rights Struggle’ (2012) 45 J Marshall L Rev J 939; Better Together - Parenting with Families, ‘Understanding the Historical Context for Visiting Policies’ \(<\text{www.ipfcc.org/bestpractices/Understanding-Historical-Context.pdf}>\) accessed 02 October 2020; Graham Mooney and Jonathan Reinarz, ‘Hospital visiting in Epidemics: An Old Debate Reopened’ (2020) History & Policy \(<\text{http://www.historyandpolicy.org/opinion-articles/articles/hospital-visiting-in-epidemics-an-old-debate-reopened}>\) accessed 02 October 2020.
This memorandum aimed to ensure equal visitation rights to patients from the LGBTQ+ community, who faced difficulties in receiving visits from loved ones to whom they were not related by blood or marriage. As a byproduct of this memorandum, then President Obama affirmed that all patients have a right to receive visits while in hospital and to choose their designated visitors. The memorandum praised states (such as North Carolina, Delaware, Nebraska, and Minnesota) that had taken measures to ensure the equal enforcement of patients’ visitation rights and asked them to expand these steps ‘to ensure that hospitals that participate in Medicare or Medicaid respect the rights of patients to designate visitors’. However, the statement also recognised hospitals’ authority to limit visitations ‘in medically appropriate circumstances as well as the clinical decisions that medical professionals make about a patient’s care or treatment’.

Ever since this memorandum was published in 2010, all US hospitals participating in Medicaid and Medicare have been required to comply with visitation policy regulations which were issued by the Department of Health and Human Services (HHS) that same year. This requires hospitals to have written policies and procedures regarding patients’ visitation rights, including any ‘clinically necessary’ or ‘reasonable restriction’ placed on those rights and the reasons for them. This regulation, along with visitation rights scattered throughout states’ public health laws and their patients’ bills of rights, creates a formal legal right to receive visits in hospitals.

Both federal regulation and state laws that formalise visitation rights, such as those outlined in this section, are possible sources of legal action against restrictive hospital policies in the era of COVID-19. In some cases, the federal regulation was not considered actionable for individual plaintiffs, but in other cases, the possibility of bringing such action was not overruled. The chances of winning such a lawsuit are

---

141 Presidential Memorandum, ‘Respecting the Rights of Hospital Patients to Receive Visitors and to Designate Surrogate Decision Makers for Medical Emergencies’ (15 April 2010) <https://obamawhitehouse.archives.gov/the-press-office/presidential-memorandum-hospital-visitation> accessed 02 October 2020.
142 See the case of Janice Langbehn who was barred by the hospital from her dying partner’s hospital bed: Langbehn v Pub Health Tr of Miami-Dade Cty, 661 F Supp 2d 1326, 1331 (SD Fla 2009).
143 ibid.
144 ibid.
145 Assistant Secretary for Health, ‘Access to Healthcare: Non-discrimination’ (15 August 2017) <www.hhs.gov/programs/topic-sites/lgbt/access-to-healthcare/nondiscrimination/index.html> accessed 02 October 2020. In some states, visitation rights are established in patients’ ‘bill of rights’ laws that were also provided a private cause of action: RC Miller, ‘Construction and Application of State Patient Bill of Rights Statutes’ (Originally published in 2001) 87 Am Law Rep 5th 277 [part 22.a].
146 42 CFR s 482.13 (Referring to s 1861 of the Social Security Act).
147 For example, Md. Code Ann., Health-Gen. s 19-342 (West 2020); Minn Stat Ann s 144.651 (West 2020).
148 The federal regulation is not always actionable to individual plaintiffs: Qualantine v. Newton Med. Ctr-Atl. Health Sys, Inc, No A-5005-14T3, 2016 WL 7176939 *3 (NJ Super Ct App Div, 9 December 2016); Anon, ‘Sick, Scared and Separated From Loved Ones: A Report On Nys Hospital Visiting Policies And How Patient-Centered Approaches Can Promote Wellness And Safer Healthcare’ (2012) <www.nypirg.org/pubs/201208/Sick-Scared-Separated_from_Loved_Ones_8-2012_full_report.pdf> accessed 02 October 2020. The 2018 report, however, indicates improvement in several parameters: Anon, ‘Sick, Scared & Separated from Loved Ones Third Edition: A Pathway to Improvement in New York City’ (2018) <www.nypirg.org/pubs/201801/NYPIRG_SICK_SCARED_FINAL.pdf> accessed 02 October 2020.
149 DeVito v Yale-New Haven Hosp, Inc, No CV156053915, 2015 WL 9242226 (Conn Super Ct, 23 November 2015).
unclear for two reasons: first, visitation rights are not well-founded in state or federal laws or in case law, and, secondly, courts tend to defer to medical judgement on questions deemed to be medical/professional in nature. Nevertheless, some COVID-19 restrictions are exceptionally strict and so may result in court decisions that would limit hospitals’ discretion in such cases.

An alternative path to taking personal action in court would be to file a complaint with the Department of HHS Office of Civil Rights (OCR). As the next section demonstrates, such a complaint could bring effective change with regard to visitation rights during COVID-19.

B. Informed Consent Rights

A classic patient rights framework that has already proven effective in challenging COVID-19-related hospital visitation policies is the doctrine of informed consent. According to this doctrine, hospitals are generally required to provide patients with timely and accurate information based on which they can make medical decisions. Thus, hospitals must disclose to the patient accurate and relevant information about their diagnosis, the nature of the proposed treatment, and the risks, benefits, and alternatives to that treatment.

The informed consent framework was used to override COVID-19-related hospital visitation bans following a complaint from Disability Rights Connecticut to the HHS Office for Civil Rights. According to the complaint, all hospitals in the state had strict no-visitor policies, with no exceptions for disability. This denied people with disabilities equal access to medical treatment by, for example, denying effective communication, the right to make informed decisions, and the right to informed consent. The complaint included details of three constituents (one of whom tested positive for COVID-19) who had suffered adverse medical outcomes because they could not communicate well with staff as a result of the restrictive policies. The complaint was successful and was followed by an order from Connecticut’s health commissioner, which required all hospitals in the state to allow patients with disabilities to have one designated support person with them to ensure effective communication during their stay, and to provide appropriate PPE.

150 ‘Filing a Civil Rights Complaint’ (NHS Org) <https://www.hhs.gov/civil-rights/filing-a-complaint/index.html> accessed 10 March 2021.
151 The duty to receive informed consent in medical care was established in the USA through court decisions and state laws. See eg Canterbury v. Spence, 464 F.2d 772 (DC Cir 1972), Schloendorff v Soc’y of New York Hosp, 105 NE 92 (1914) (New York), Salgo v Leland Stanford Jr Univ Bd of Trustees, 317 P.2d 170 (1957) (California).
152 Standards of disclosure change between jurisdictions following either a patient-oriented or professional-oriented standard: Barbara A. Noah and Neal R. Feigenson, ‘Avoiding Overtreatment at The End-of-Life: Physician-Patient Communication and Truly Informed Consent’ (2016) 36 Pace L Rev 736, 762–63.
153 Disability Rights Connecticut, ‘Illegal Disability Discrimination Concerning Hospital COVID-19 Visitation Policies’ (4 May 2020) <https://static1.squarespace.com/static/5952983059cc68f83ce3153/t/5eb187ff2da21b0620c52f65/1588692992532/HHS+OCR+Visitor+Policy+Complaint+FINAL+050420+-+with+exhibits.pdf> accessed 02 October 2020.
154 Ibid.
155 State of Connecticut, Department of Health, ‘Order’ (9 June 2020) <https://portal.ct.gov/-/media/Coronavirus/20200609-DPH-Order-regarding-patients-with-disabilities-in-health-care-facilities.pdf> accessed 02 October 2020.
Although this disability complaint relied on anti-discrimination provisions in the Americans with Disabilities Act, the Rehabilitation Act, and the Patient Protection and Affordable Care Act, the argument for accommodating effective communication could, theoretically, be expanded to critically ill COVID-19 patients based on informed consent obligations. Barring them from having a designated support person to ensure effective communication with medical staff, denies them their right to informed consent. This right, while relevant in all stages of care, is especially important during end-of-life situations, and scholars have argued that securing informed consent at such times requires the help, support, and mediation of family members and others with whom the patient is close.\textsuperscript{156} Indeed, in the USA, patients who lose decision-making capacity require the appointment of a surrogate decision maker (SDM), who, in some circumstances, needs to be able to communicate with the patient in person.\textsuperscript{157}

During the COVID-19 crisis, SDMs could well have an important role in end-of-life decisions from early in a hospitalisation, such as whether to connect the patient to a ventilator or move to comfort care.\textsuperscript{158} Their presence next to the patient’s bed is arguably even more critical at this time because of the pandemic-oriented nature of treatment. With medical teams reducing personal visits, moving their patient communications to telehealth, and communicating through a mask,\textsuperscript{159} the case for the presence of SDMs in the room becomes stronger. As we already know from the disability case, attempts to replace in-person human communication with technological versions cannot capture the nuanced gestures and signs that play such critical roles in complicated communication.\textsuperscript{160} Unsurprisingly, transitioning to a technological means of communication during the pandemic was reported to adversely affect communication of the medical staff with patients’ families and loved ones.\textsuperscript{161}

\textsuperscript{156} Noah and Feigenson (n 152); Mark Kuczewski, ‘From Informed Consent to Substituted Judgment: Decision-Making at the End-of-Life’ (2004) 16(1) HEC Forum 27; Sonia M Suter, ‘The Politics of Information: Informed Consent in Abortion and End-of-Life Decision Making’ (2013) 39 Am J Law Med 7; Rebecca S Allen and John L, Shuster, ‘The Role of Proxies in Treatment Decisions: Evaluating Functional Capacity to Consent to End-of-Life Treatments within a Family Context’ (2002) 20(3) Behav Sci Law 235–52.

\textsuperscript{157} Dragana Bolic-Jankovic and others, ‘Exploring Determinants of Surrogate Decision-Maker Confidence: An Example From the ICU’ (2014) 9 J Empir Res Hum Res Ethics 76–85.

\textsuperscript{158} I J Gold and S Ungerleider, ‘It’s Time to Get Serious About End-of-Life Care for High-Risk Coronavirus Patients’ Time (30 March 2020) <https://time.com/5812073/endof-life-coronavirus/> accessed 02 October 2020.

\textsuperscript{159} Mathias Schlägel and Christopher A Jones, ‘Maintaining Our Humanity Through the Mask: Mindful Communication During COVID-19’ (2020) 68(5) J Am Geriatr Soc <www.ncbi.nlm.nih.gov/pmc/articles/PMC7262056/> accessed 02 October 2020.

\textsuperscript{160} Sheri Fink, ‘Connecticut Hospitals Ordered to Allow Visitors for Patients with Disabilities’ The New York Times (9 June 2020) <www.nytimes.com/2020/06/09/nyregion/coronavirus-connecticut-hospitals-disabilities.html> accessed 02 October 2020 (the case of Joan Parsons); Disability Rights Connecticut, ’Illegal Disability Discrimination Concerning Hospital COVID-19 Visitation Policies’ (4 May 2020) <https://static1.squarespace.com/static/5952983059cc6883e3153/t/5eb187f2da21b12062c52665/1588692992532/HHS+OCR+Visitor+Policy+Complaint+FINAL+050420++with+exhibits.pdf> accessed 02 October 2020; Marianne Schmid Mast, ‘On the importance of nonverbal communication in the physician–patient interaction’ (2007) 67 Patient Educ Counsel 315; Bianca Nobilo, ‘Coronavirus Has Stolen Our Most Meaningful Ways to Connect’ CNN News (2020) <https://edition.cnn.com/interactive/2020/06/world/coronavirus-body-language-wellness/> accessed 02 October 2020.
In practice, filing an OCR complaint may be difficult to manage, as patients who test positive for COVID-19 and are dying are not (yet) recognised by anti-discrimination laws as subjects of discrimination. Nevertheless, claims that hospitals failed to obtain informed consent may trigger hospitals to allow the presence of SDMs at the patient’s bedside in different stages.

C. Death-related Rights

Another relevant legal framework to visitation policies is the set of laws and declarations that guarantees dying people the right to receive palliative or comfort care. The main goal of such care is to address the dying person’s individual needs, such as relief from pain and suffering, mental and spiritual support. Under comfort care principles, physical contact is considered to be soothing and helpful in easing stress and fear. Because of the centrality of touch in providing such care, it has been recommended that technological solutions in hospice care only be used to supplement face-to-face visits and not to replace them. The right to have family members serve as emotional support is essential when healthcare workers report the overwhelming emotional burden of working on COVID-19 wards. For example, one physician acknowledged that she could not effectively provide the emotional support her dying patients needed:

I don’t want to spend a moment longer in a Covid-19 patient’s room than I have to . . . I do what I need to do and then I leave. I don’t take the time to reassure, to explain, surely not to hold a hand. Truth is, I am scared.

Literature on palliative care suggests that family members and other loved ones are essential to comfort and minimise suffering for the dying person. The Dying Person’s Bill of Rights outlined a right ‘not to die alone’. Similarly, the Declaration on the Promotion of Patients’ Rights in Europe states that patients have ‘the right to enjoy support from family, relatives and friends during the course of care and treatment and to receive spiritual support and guidance at all times’. The British Secretary of State for Health even suggested giving families a ‘right to say goodbye’.

---

161 See Annachiara Marra and others, ‘How COVID-19 Pandemic Changed Our Communication with Families: Losing Monverbal Cues’ (2020) 24 Crit Case 297; Siddiqi (n 59); Niki R Kennedy and others, ‘Perspectives on Telephone and Video Communication in the ICU during COVID-19’ (2020) 18 Ann Am Thorac Soc 838.

162 Craig D Blinderman and JA Billings, ‘Comfort Care for Patients Dying in the Hospital’ (2015) 373 New Engl J Med 2549–61.

163 NIH, ‘Providing Care and Comfort at the End of Life’ <www.nia.nih.gov/health/providing-comfort-end-life> accessed 02 October 2020.

164 George Demiris D Parker Oliver and KL Courtney, ‘Ethical Considerations for the Utilization of Telehealth Technologies in Home and Hospice Care by the Nursing Profession’ (2006) 30(1) Nurs Adm Q 56, 62.

165 See Section III above.

166 Lamas (n 20).

167 Amelia J Barbus, ‘The Dying Person’s Bill of Rights’ (1975) 75 Am J Nurs 99.

168 European Consultation on The Rights of Patients, ‘A Declaration on The Promotion of Patients’ Rights in Europe’ (28 June 1994) <www.who.int/genomics/public/eu_declaration1994.pdf?ua=1> accessed 02 October 2020.
Some US states have laws which are meant to ensure access to, or to provide information on how to access, palliative and comfort care.\textsuperscript{170} Some laws, for example, mention the hospital’s duty to assess the dying patient’s ‘physical, psychosocial, emotional, and spiritual needs’ in order to promote their well-being in the dying process.\textsuperscript{171} Depending on the duties they impose on healthcare providers and the resolution mechanisms they provide, such laws may prove useful for families that wish to challenge visitation restrictions in the light of the duty/obligation to provide hospice care for dying patients in order to ease their pain and suffering. Given that many hospitals already have end-of-life exceptions in their restricted visitation policies, it may be possible to expand those exceptions to include COVID-19 patients who are dying, as some hospitals have.\textsuperscript{172}

VI. CONCLUSION

In this article, I have drawn a direct line between the seemingly narrow administrative issue of hospital visitation policies and the ways that the cultural ritual of dying has transformed over time. Even before the current pandemic, the institutionalisation of death had dramatically shifted dying rituals. Moving death from the home to the hospital has redistributed power and changed who is present by the deathbed. Daniel Callahan has argued that medicine’s promise of a domesticated, pleasant, and polished death has not been fulfilled.\textsuperscript{173} Instead, death remains fearsome, perhaps even more so when the process is prolonged. Isolated deaths in the COVID-19 era seem to be an extreme form of what Callahan terms ‘wild death’:\textsuperscript{174} people who die in this way are alone, surrounded by machines and strangers wearing heavy protective gear, isolated from their communities, and, with the elimination of post-death cultural rituals, then represented to the world through mortality statistics.

My arguments here have highlighted some key questions which require consideration: who should decide who can enter and leave a dying person’s hospital room, particularly during a pandemic, and how can we reconcile the need to control infection and the wish to be together at such critical hours and moments? Although

\textsuperscript{169} Peter Walker and Robert Booth, ‘Hancock Vows to Give Families ‘Right to Say Goodbye’ to Loved Ones’ (2020) <https://www.theguardian.com/world/2020/apr/15/families-to-be-allowed-to-say-goodbye-to-dying-relatives-in-care-homes> accessed 10 March 2021.

\textsuperscript{170} VT STAT ANN tit 18, s 1871 (2012) (Vermont); NY PUB HEALTH LAW s 2997-d (New York); For a thorough review of recent palliative care laws and the entitlements they provide, See Health Affairs, \textit{How States Can Expand Access To Palliative Care} (30 January 2017) <www.healthaffairs.org/do/10.1377/hblog20170130.058531/full/> accessed 02 October 2020.

\textsuperscript{171} For example, 25 Tex Admin Code s 133.42 (2007) – ‘patient rights require hospitals to acknowledg[e] the psychosocial and spiritual concerns of the patient and the family regarding dying and the expression of grief by the patient and family’; Okla Admin Code s 310:661-5-1.3 (2009) – ‘. The comprehensive assessment shall identify the physical, psychosocial, emotional, and spiritual needs related to the terminal illness that shall be addressed in order to promote the hospice patient’s well-being, comfort, and dignity throughout the dying process’.

\textsuperscript{172} UPenn Medicine Medical Center explicitly allowed patients dying from COVID-19 to have one support person physically present: UPenn Medicine Medical Center, ‘Inpatient End-of-Life Guidance for Clinicians: COVID-19 Pandemic’ <www.med.upenn.edu/uhpscovid19education/assets/user-content/documents/eol-faq-for-providers-3-30.pdf> accessed 02 October 2020.

\textsuperscript{173} Daniel Callahan, \textit{The Troubled Dream of Life: Living with Mortality} (Simon & Schuster 1993) 29–30.

\textsuperscript{174} ibid.
legislators and the public seem mindful of the suffering that results from isolated deaths, for the most part, they do not use that awareness to limit hospitals’ discretion in these cases. For their part, hospitals still err on the side of more restrictive policies for medical, financial, and cultural reasons. But hospital visitation policies as they currently exist should not be seen as inevitable. These policies can be challenged by groups and individuals and so trigger judicial scrutiny, legislative, or administrative action. Although any legal change could produce adverse outcomes—such as needing to direct PPE supply towards visitors and away from other needs, or burdening hospital administration with coordinating visits—the reality is that such difficult choices are already being made. At the moment, however, they are being made at the hospital administrative level, where there is no requirement to consider critical external perspectives. Instead, I advocate for redistributing hospitals’ discretion so that it is shared among additional stakeholders. To bolster the project of democratisation in medical healthcare, I suggest that community members use existing legal frameworks and rights to shape hospitals’ policies.

SUPPLEMENTARY MATERIAL

Supplementary material is available at Medical Law Review online.

ACKNOWLEDGEMENTS

I would like to thank I. Glenn Cohen, John Witt, Tammy Harel Ben Shahar, Itamar Mann, Y. Michael Bar Ilan, Lihi Yona, Doron Dorfman, Sagit Mor, Shira Shmuely, Oren Tamir, Yair Sagy, Orna Rabinovich-Einy, Amnon Reichman, Tal Zarsky, Ely Aaronson, Gad Barzilai, Alexander Kedar, Suzan Shapiro, Orna Alyagon Darr, and Yuval Moscovitz.

Conflict of interest statement. None declared.