INTRODUCTION

In their recent article in the *Hastings Center Report*, Tia Powell, Eran Bellin, and Amy R. Ehrlich raise a number of important issues concerning the coronavirus and its effect on older adults living in long term care facilities. They note, among other concerns, the way that ventilators were applied to no good effect for this population of infected and ill individuals. They end their paper with the following provocative claim:

> With great expense and effort, we organized deaths with ventilators for America's oldest people. We thought the ethical imperative was to get a ventilator for everyone. The real need was to provide care that helped. We can save more lives and make unavoidable deaths less painful if we will learn at last this simple lesson.¹

As they note, ethicists need to think through the ways in which older adults can live through this pandemic as well as possible and what it means for them to die well. Dying well—or, at the very least, experiencing an appropriate death—is the focus of this paper. Even before Covid-19 swept through nursing homes resulting in an overwhelming sickness and death rate, many of our elders had been denied an appropriate death. Thus, it is essential that advanced care planning occurs in a way that upholds the familial and relational aspects of elders’ lives that often matter to them the most. We invoke concepts from feminist ethicists like Hilde Lindemann and Eva Kittay and introduce Avery Weisman and Thomas Hackett’s concept of “appropriate death” to suggest better ways of planning for those deaths of our elderly that cannot be avoided. Our hope is to allow for deaths that are as meaningful as possible for both the elderly and the family members who survive them.

¹Powell, T., Bellin, E., & Ehrlich, A. R. (2020). Older adults and Covid-19: The most vulnerable, the hardest hit. *Hastings Center Report*, 50(3), 61–63, p. 63.
look like for them, has never been clearer. The concept of appropriate death helps flesh out questions that should be asked of elders and their loved ones in order to help elders die deaths that are as meaningful as possible.

We must take care to distinguish what we are arguing from the claim that the death of our elders might be an acceptable cost when weighed against the economic and practical costs of shutdowns. Our approach is not such a utilitarian cost-benefit analysis. Nor do we support the more conventional claim that since the elderly are near the end of life, their deaths are of less moral concern than the deaths of those who are younger. Nevertheless, our analysis recognizes that when they enter nursing homes, most old persons never leave; death is, indeed, the expected end point. We must, therefore, consider what circumstances might allow them to die better deaths. Some of the necessary steps taken to protect nursing home residents during this pandemic have complicated securing a decent death for those elders who have died. Our aim in this paper, then, is to consider from a relational and familial perspective how we have failed our older adults in providing care under Covid-19 and to specifically consider the call to “make unavoidable deaths less painful” by also ensuring they are as meaningful as possible. Although some of what we advocate for—in person conversations with elders and their loved ones—may not be possible during this pandemic, the situation faced by our elders over the past months has established the need to ensure that advance care planning and conversations about dying well happen early and often in nursing homes or even before admission to a nursing home occurs.

In the next section we adopt a feminist relational approach that is rooted in an ethic of care and a conception of the self as inherently social. While we endorse the principle of autonomy in our considerations, we adopt a relational approach to autonomy that has been advanced by a number of feminist philosophers. We believe that this approach is best suited to addressing persons in their vulnerabilities, relationships or not.

Relational autonomy matters because, as Jamie Nelson and Hilde Lindemann claim, families (and kin-like relationships) matter. It is by developing out of both the relationships we choose and the relationships and identities that are imposed on us. This is clearly reflected in nursing homes, where residents are connected to those who care for them physically and emotionally, connections that open the very identities of the elderly residents in place. Those who maintain residents’ sense of self include not only family members, but also nurse’s aides, nurses, and other employees (kitchen staff, activity coordinators, social workers, etc.). The work of maintaining others’ sense of self is a thus a privilege and a responsibility that evolves out of relationships of intimacy and care, whether they are familial relationships or not.

Relational autonomy matters because, as Jamie Nelson and Hilde Lindemann claim, families (and kin-like relationships) matter. It is by being embedded in (supportive, loving) relationships that we become fully fledged selves. As they assert:

> When we live in close and affectionate proximity with others, we can be seen and celebrated specially; we can be known more fully than our relationships in the workplace, in civic life, or in casual friendships. Being known well—being seen lovingly and particularly, in a way that singles us out from the billions of others who walk in the world—reinforces our understanding of who we are.

This desire for connection, for “close and affectionate proximity with others” has been significantly challenged in nursing homes by the
need to lock down facilities to prevent the spread of Covid-19. One of the saddest and most difficult aspects of the coronavirus in these settings is the inability for family members to visit their elderly loved ones and for the elderly residents to have access to those who love them and view them as special, particular individuals. While stemming the spread of communicable disease must be a high priority in nursing homes, so must the desire and human need for connection and relationship.7

We note that this is especially true for the elderly in nursing homes, where residents experience varying degrees of dementia, where chronic illnesses create the need for more dependence upon others, and where the residents’ sense of self may often be held in place by those in relationship to them. In his book At the will of the body, Arthur Frank addresses the connection between one’s bodily experience and its impact on one’s life. As he writes, “What happens when my body breaks down happens not just to that body but also to my life, which is lived in that body. When the body breaks down, so does the life.”8 When this is the case, we rely heavily on others to support us in caring for our physical bodies, but also in helping us to hold on to our identities; this identity “holding” is something that we all need to a degree, but it becomes more necessary as we lose bits and pieces of who we are.

This concept of “holding” one’s identity in place has been captured especially well by bioethicist and philosopher Hilde Lindemann, who has noted that “To have lived ... as a person is to have taken my proper place in the social world that lets us make selves of each other.”9 According to Lindemann, our way in philosophy of understanding individuals and their identities over-emphasizes requirements of agency and voluntarism and it overlooks the way that moral communities create, uphold—or, sometimes, unravel—who we are. As she notes, moral communities are capable of holding each other well or “clumsily,” or of failing to do this holding work at all; but in any case, it is largely others that determine how our identities and our personhood are formed, maintained, allowed to change, and even when it is time to let them go.

Similarly, Eva Kittay’s book Learning from my daughter: The value and care of disabled minds emphasizes that all people are naturally dependent on, not independent of, one another. Here, as in her previous writings, Kittay suggests that dependency and care are intertwined and that it is through these activities that people with severe cognitive disabilities (like her daughter Sesa, referenced in the book title) are seen as fully human in their moral status and standing.

Kittay identifies care “as labor, an attitude (or disposition), and a virtue” making it critical to human flourishing and to a robust appreciation of the way—as Lindemann puts it—that we hold one another in identity.10 Below we consider this relational view of the self, and the concept of “holding” one another in place in relation to concerns raised by the Covid-19 pandemic and nursing homes. As we will argue, the threats posed to older adults by the coronavirus include not only infection, illness, and death, but also the violation of their familial connections and relational needs that are essential to their well-being and identities.

3 NURSING HOMES AND COVID-19

As news reports are indicating, the group most adversely affected by the coronavirus has been the elderly, with those 65 and up accounting for 80% of the US deaths from the disease.11 In a Congressional report, 2.9% of residents at surveyed facilities were reported to have tested positive for Covid-19, a rate five times higher than the national rate. 2.1% of staff in these facilities tested positive for the virus, 3% had been hospitalized, and .4% had died of the virus.12 Additionally, nursing homes and assisted living facilities account for 38% of Covid-19 deaths, making them the least safe place to reside or work as a caregiver during this pandemic.13 The out-of-control rates of infection in congregate living settings speak to a number of problems that had already been in place before the coronavirus struck.14

The deep failings of nursing homes have been exposed with the advent of Covid-19, with some extreme examples of abandonment, abuse, and neglect that have garnered considerable media attention.15 Yet even in nursing homes where abandonment is not an issue and the provided care is of high quality, major failings are still apparent. Better-run and better-resourced facilities have done their best to make living—and dying—in their facilities during the time of Covid-19 comfortable, but they face many roadblocks that should be of concern for relational ethicists. For example, one widespread issue is that residents of nursing homes have often been shut off

---

1We recognize that not all individuals in nursing homes and other long term care facilities enjoy strong familial support. Our familial ethic in such cases can be extended to include kin-like relationships that can develop between resident peers and/or residents and staff in long term care situations. Indeed, as Tracy Karner has noted, paid caregivers can become “fictive kin” given the intimate aspects of the care relationship and the details of the residents’ lives to which workers become privy, and the extremely personal tasks in which they are engaged. This might place obligations on caregivers to take on the role of patient advocates when family members are absent or otherwise incapable of fulfilling their duties of care. See Karner, T. (1998). Professional caring: Homecare workers as fictive kin. Journal of Aging Studies, 12(1), 69–82.

2Frank, A. (1991). At the will of the body: Reflections on illness. Houghton Mifflin, p. 2.

3Lindemann, H. (2014). Holding and letting go: The social practice of personal identities. Oxford University Press, p. 159.

10Kittay, E. (2019). Learning from my daughter: The value and care of disabled minds. Oxford University Press, p. 171.

11Conlen, M., Ivory, D., Yourish, K., Lai, K., Hassan, A., Calderone, J., Smith, M., Lemonides, A., Allen, J., Blair, S., Burakoff, M., Cahalan, S., Cassel, Z., Craig, M., De Jesus, Y., Dupre, B., Faciolla, T., Fortis, B., Gorenflo, G., Harvey, B. (2021, March 31). More than 100,000 U.S. coronavirus deaths are linked to nursing homes, New York Times. https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html

12Conlen, M., Ivory, D., Yourish, K., Lai, K., Hassan, A., Calderone, J., Smith, M., Lemonides, A., Allen, J., Blair, S., Burakoff, M., Cahalan, S., Cassel, Z., Craig, M., De Jesus, Y., Dupre, B., Faciolla, T., Fortis, B., Gorenflo, G., Harvey, B., op. cit. note 11.

13Levine, S., Bonner, A., Perry, A., Melady, D., & Unroe, K. (2020). COVID-19 in older adults: Transfers between nursing homes and hospitals. Journal of Geriatric Emergency Medicine, 1, 7–14.

14Derfel, A. (2020, April 17). Records reveal chaos in the days before staff abandoned the Herron. Montreal Gazette. https://montrealgazette.com/news/local-news/records-reveal-chaos-in-the-days-before-staff-abandoned-the-herron
from those close to them, both in terms of proximity and relationship. The normal “goods” of nursing homes that allow for social connection and building community—the ability of residents to join interest groups, to participate in gym classes, to eat together in shared dining—have needed to be restricted because of fear of infection. Meals are now often isolated events in residents’ rooms and even what would normally be group activities are solo activities taking place under isolation. Bingo is played over speakers and musical acts perform outside residents’ windows. Although nursing homes are trying to keep a sense of normalcy and routine for their residents, as Rachel Chason and Rebecca Tan write, 

The grief, loneliness and fear [that have characterized the last 11 weeks for many Americans] are intensified inside these facilities...Every day the crisis persists, those in long-term care facilities are forced to confront the risks of living in close quarters with other vulnerable residents — and the possibility of dying alone.16

Residents have been unable to receive visitors because of concerns about the spread of Covid-19. At the beginning of the pandemic many nursing homes went into “lockdown” and did not allow for any visitors. At the time of this writing, many nursing homes are effectively still in lockdown in order to prevent the spread of the virus. Stories have proliferated of people visiting residents of nursing homes through windows to celebrate birthdays and anniversaries and offering embraces through “cuddle curtains.” As even small group gatherings and visiting continue to be banned in some nursing homes, some residents are experiencing a rapid decline in mental and physical health.17

Whether we should forsake the mental health of the old in the fight to protect their physical health is a question that we think deserves closer scrutiny. An increasing number of studies indicate that the impact of isolation, loneliness, and lack of human contact has deadly implications, especially for the elderly experiencing degrees of dementia.18 As our relational ethics framework suggests, humans suffer deeply from that lack; and this is exacerbated for our elders who may rely heavily on others to hold their identities and sense of self in place. As Jennifer Abbasi notes, the prolonged isolation for those in nursing homes relates to higher rates of mortality and morbidity. Citing Lea Watson, MD, MPH, a psychiatric consultant to more than 50 of Colorado’s long-term care facilities Abassi explains that “staff from multiple homes reported that residents had stopped eating and had ‘given up’ without family visitation.”19 Since the beginning of the pandemic, the value of “life at any cost” has prevailed in nursing homes; but this may be a value judgement that not all residents share. The benefits of allowing for limited visitation might outweigh the risks of exposure to the virus that this visitation brings. This is especially true when such visits allow elders to plan end of life care with their loved ones in face-to-face discussions about advance care planning.

The physical isolation and distance required to keep elders safe during the pandemic have made the everyday experiences of staff, residents, and their families more complex, but they have also led to a breakdown in compassionate and effective end of life care. The inability of families to visit with residents or to speak to care workers creates an additional complication when residents are dying. Powell and colleagues explain how nursing homes did their best to maintain contact and to discuss care plans with family members residents during Covid-19, but despite best efforts, they ultimately failed. Nuanced conversations about the relative benefits of palliative care versus life-sustaining treatments are impossible because they are being done under emergency conditions and families cannot directly observe the suffering of their loved ones. Thus, while containing the spread of the virus and preventing death is a key problem for nursing homes, one important relational lesson learned is the need to have structures in place to ensure that patients and families have some sort of end of life care plan in place. These structures are necessary to ensure that the identities and autonomy of elders, both of which are constituted in relationship with significant others, remain intact as much as possible, up to and through the dying process. In the rest of the paper, we will explore the concept of appropriate death, coined and championed by psychiatrists Avery Weisman and Thomas Hackett. By employing this concept with a relational ethics perspective we can illuminate ways to have more specific and fruitful conversations that will better prepare our elders for the process of dying, both during and after this pandemic.

4 | DYING WELL DURING COVID-19

The concept of appropriate death was originally conceived by psychiatrists Avery Weisman and Thomas Hackett. They “call[ed] attention to a group of patients who, without open conflict, suicidal intention, profound depression, or extreme panic, correctly anticipated their own deaths.” These patients were convinced that death was approaching and determined death was “desirable and appropriate.” Although in

16Chason, R., & Tan, R. (2020, May 28). Isolated and at risk. Washington Post. https://www.washingtonpost.com/graphics/2020/local/social-issues/coronavirus/nursing-homes-patients-voices-covid-19/
17Healy, J., Ivory, D., & Kovaleski, S. (2020, October 30). ‘A slow killer’: Nursing home residents wither in isolation forced by the virus. New York Times. https://www.nytimes.com/2020/10/30/us/nursing-homes-isolation-virus.html
18Manca, R., De Marco, M., & Venneri, A. (2020). The Impact of COVID-19 infection and enforced prolonged social isolation on neuropsychiatric symptoms in older adults with and without dementia: A review. Frontiers in Psychiatry, 11, 1-11.
19Abbasi, J. (2020). Social isolation—The other COVID-19 threat in nursing homes. JAMA,324(7), 619-620.
20Powell et al, op. cit. note 1, p. 62; Toner, E. (2020, December 3). Crisis standards of care: Lessons from New York City hospitals’ COVID-19 experience. Webinar from Health and Human Services Office of the Assistant Secretary for Preparedness and Response Technical Resources, Assistance Center, and Information Exchange (ASPR TRACIE), New York. https://files.asprtracie.hhs.gov/documents/aspr-tracie-csc-webinar-slides--final-508.pdf
21Weisman, A., & Hackett, T. (1961). Predilection to death: Death and dying as a psychiatric problem. Psychosomatic Medicine,23(3), 232-256, p. 232.
these case studies there was great variety—ages, genders, and temperaments of the patients differed, ethnicities and races differed, the circumstances leading up to the patients’ hospitalization differed, their family situations differed etc.—these patients’ attitudes toward their circumstances leading up to the patients’ hospitalization differed, their peraments of the patients differed, ethnicities and races differed, the death was not only inevitable, but desirable.”22

Weisman discusses four distinguishing features of a person who has an appropriate death: they understand that they are dying, they reach some level of acceptance, they feel the death is timely, and that their death is one they can “live with in terms of the values one has supported, and in terms of the groups whose respect and regard matter most.”23 What an appropriate death might look like will vary from individual to individual, but no one’s death needs to be ideal in order to be appropriate. Recognizing this is especially important during the ongoing Covid-19 pandemic.

The concept of appropriate death “put[s] legs under” the idea of a good death.24 Weisman and Hackett’s concept—with Weisman’s further development of it—offers operationalizable criteria for an appropriate death even in circumstances that are not ideal. For example, as we have seen during this pandemic, dying in nursing homes has become a lonely, fraught affair. Being isolated from loved ones has become standard procedure in nursing homes in order to protect all residents from a possible deadly infection. To assist in achieving appropriate deaths, conversations around the sort of deaths elders want to die, as well as determining what would make their own deaths acceptable to them should happen more frequently and regularly. The benefit of employing this concept is that it makes much clearer what specific questions might be useful to ask during end of life planning (see Table 125). These specific questions are also helpful to the care providers who care for their patients up to and through the dying process, many of whom are reluctant to have these conversations.

Covid-19 has made clear that there is a need to do better with helping elders to die well, and the concept of appropriate death offers a nuanced and detailed account of what such a death looks like. The application of this concept becomes richer still when we understand it through a relational ethics framework. Lindemann’s conception of “holding” each other’s identities in place is especially relevant here. When a person cares for someone unto death, especially when she stands with that person through months or years of illness and decline that interfere with identity-constituting activities and relationships, her care can help preserve that person’s identity. Even when the daily care of elders happens in nursing homes rather than at home, loved

25A very serious limitation of this table is that it assumes that the patients for whom an appropriate death is sought have no intellectual impairments. In an ideal world, conversations about an appropriate death would be had with most patients before cognitive decline. In a less than an ideal world, substituted judgment might need to suffice for patients who lack current capacity to participate in meaningful end of life conversations. An important question remains unanswered about how and if appropriate death standards can be ethically applied with persons who have experienced intellectual impairments throughout the course of their lives (e.g., patients with Down Syndrome).

### TABLE 1 Questions for end of life conversations that correspond with criteria for establishing appropriate death

| Criterion for establishing a death is appropriate | Examples of corresponding questions to ask patients |
|--------------------------------------------------|---------------------------------------------------|
| Patient understands that they are dying.         | *Is there any information you feel like you’re lacking, or anything you don’t understand about your illness?*  
|                                                  | *Do you feel like you’re involved enough in decision making about your care?*  
|                                                  | *If your health situation gets worse, what are your goals?* |
| Patient has reached some level of acceptance regarding their death and the circumstances of their death. | *Do you feel like you’ve contacted everyone you’ve needed to?*  
|                                                   | *Is there anyone you wish could be present with you right now?*  
|                                                   | *What do you want for and from your loved ones at your end of life?* |
| Patient feels the death is timely.               | *If your health situation gets worse, how much are you willing to go through to gain more time?*  
|                                                   | *Are there interventions that seem worse to you than dying?* |
| Patient feels the death is consonant with the life that they lived. | *Would you like to include a family member or loved one in these conversations?*  
|                                                   | *How much do your loved ones know about your wishes?*  
|                                                   | *What things in your life, if you could no longer do them, would make your life less meaningful?*  
|                                                   | *Have you ever had a friend or loved one who died whose death you thought was a good one? What did that look like?*  
|                                                   | *What sort of celebrations or memorials would you want your loved ones to hold after your death? What would be a fitting way to mark the end of your unique life?* |

22Ibid: 101.  
23Kastenbaum, R. (1993). Avery D. Weisman, M.D.: An Omega interview. OMEGA - Journal of Death and Dying, 27(2), 97-103, p. 100.  
24Ibid: 101.
ones help maintain elders’ identities when they visit, call, and other-

wise keep in relationship with them. Reminiscing about times spent

with family, bringing food to elders made from old family recipes, and

even introducing them to new additions to the family help to hold

older persons in place as part of a family, even as their living situation

changes. When a person enters a nursing home, if active steps are not

taken to preserve their bonds in the outside world, an elder can expe-

rience a sort of social death long before biological death takes place.

Social death becomes more probable during this pandemic.

The moral value of “holding” identities in place is especially evi-
dent as our loved ones approach the end of life. At such times there

is an even greater need to have early conversations about end of life

wishes and what kind of care they prefer. Yet over the past several

months stories of elders dying alone and neglected in nursing homes,

whether from Covid-19 or something else, proliferate.26 Not all of

these deaths could have been made less tragic with earlier and bet-
ter advance care planning, but clearly some might have. In cases in

which families were required to make end of life decisions for their

loved ones without being able to visit their elders because of

Covid-19 restrictions, the burdens on loved ones certainly could

have been made much lighter if detailed end of life conversations

took place well in advance of their elder’s death.

Dying well, even during the best of times, requires conversations

about what one values and how those values shape what one en-
visions as a decent death. Even under normal conditions in which health

care professionals, patients, and loved ones can meet together in per-

son, having end of life conversations is hard. Only 1 in 3 American

adults have completed an advance directive or living will, and this in-
cludes adults with chronic conditions.27 The numbers are better

among nursing home residents but are nowhere near 100%; only 65%

have an advance directive on file.28 This number is not surprising given

that more than 85% of doctors report difficulties in having end of life

conversations.29 However, from a relational ethics perspective, there

is good reason to have these conversations. When we care for some-

one who is dying, it is a care to up to, including, and after death.

The incidents of complicated grief that arise from the bad deaths of loved ones

show the truth of this. In order to allow our elders to exercise auton-
omy during their end of life, to die deaths they "see" themselves in,

conversations with those who care for them—health care practitioners

and loved ones—are essential to this exercise of autonomy.

The concept of appropriate death offers a guide to deeper conversa-
tions about what our elders want to see in their deaths. Without

adequate end of life conversations this becomes harder, if not impossi-
ble, to achieve. Elders need to know when to refuse treatment, as well as

what comfort measures are available to them wherever they reside.

Their loved ones need to know the wishes of their elders for the end of

life and to be ready to help guide health care providers regarding these

wishes if elders are no longer able to do so, upholding the autonomy and

identity of their elder when their elder cannot. Without the support of

carers in information gathering, the execution of a care plan that pre-

vents unwanted hospitalization and ensures comfort care when neces-

sary becomes very difficult. Although the percentage of nursing home

residents hospitalized at the end of life varies widely, what remains consis-
tent is that many of these hospitalizations are avoidable.30

Yet dying appropriately means more than avoiding unwanted hospitalization. It also means dying a death that is consonant with a person’s style of living. Ascertainment whether a death is appropriate for a person requires not only inquiring what medical interventions they desire or want to avoid, but some understanding on that person’s part of how the life they have lived, the identity they have cre-
ated, shapes those desires. Appropriate death, and the surrounding dis-

cussion to ensure it is achieved, delves into the realms in which rela-
tional ethics dwells. Conversations about appropriate death center

not only on questions about medical interventions, but also on mak-
ing amends before dying and what everyday activities and relation-
ships give meaning to the dying patient’s life. Just as relationships are an essential part of having a meaningful life for most people, so too are they necessary for a meaningful death.

In an ideal world, everyone would die a death that they would consider good. A “good death”—one in which a person died where they wanted, when they wanted, surrounded by who they wanted—is likely not possible for everyone living through Covid-19, but we can do more to ensure that people die in ways that are in keeping with their express wishes. Powell and coauthors write,

...decision-making for seriously ill patients [during Covid-19] was hampered by the exclusion of family members from the bedside. Family members could not witness the experience of a suffering loved one, nor was there time, as with a chronic illness, to accept that death was near.31

Although a good death might not be achievable because of Covid-19, deaths that avoid unwanted hospitalization and medicaliza-

tion are. As Atul Gawande writes, even before Covid-19 struck,

You [didn’t] have to spend much time with the elderly or those with terminal illness to see how often medi-
cine fails the people it is supposed to help. The waning days of our lives are given over to treatments that addle
our brains and sap our bodies for a sliver’s chance of

26Sedensky, M., & Condon, B. (2020, November 19). Not just COVID: Nursing home

neglect deaths surge in shadows. AP News, https://apnews.com/article/nursing-homes

-neglect-death-surge-3b74a2202140c5a6b5cf05c6f0e94f32

27 Yadav, K., Gabler, N. B., Cooney, E., Kent, S., Kim, J., Herbst, N., Mante, A., Halperrn, S. D., & Courtright, K. R. (2017). Approximately one in three US adults completes any type of advance directive for end-of-life care. Health Affairs, 36(7), 1244–1251.

28 Jones, A., Moss, A., & Harris-Kojetin, L. (January 2011). Use of advance directives in long-term care populations. NCHS Data Brief No. 54. https://www.cdc.gov/nchs/produ-
cists/databriefs/db54.htm

29Periyakoil, V. S., Neri, E., & Kraemer, H. (2015). No easy talk: A mixed methods study of doctor reported barriers to conducting effective end-of-life conversations with diverse patients. PLoS ONE, 10(4). https://journals.plos.org/plosone/article?id=10.1371/journ
al.pone.0122321

30Allers, K. Hoffman, F., & Schnakenberg, R. (2019). Hospitalizations of nursing home residents at end of life: A systematic review. Palliative Medicine, 33(10) 1282-1298.

31Powell et al., op. cit. note 1, p. 61.
benefit...Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology, and strangers. 32

Without engaging in tough conversations about how elders want to die, they will be subject to the whims of a system set up to identify them as bodies to be treated. They will be denied their individuality, not out of malice, but out of lack of preparation. We argue that where good deaths are not achievable, we should minimally aim as much as possible to achieve an appropriate death. When possible, this requires finding ways to allow for families and loved ones to be present at the bedside when an elder is dying, even if only virtually during this pandemic. This also means that providers and carers need to engage in conversations they have often sought to avoid. Conversations about dying appropriately need to happen even with healthy elders. We recognize that given limited resources, this increased effort may simply not be currently possible in all nursing homes. Shortages of staffing and technology required for these sorts of conversations are very real obstacles, and must be addressed. The lessons we have learned and are learning during this crisis only underscore the need to redouble our efforts around advance care planning when we find ourselves on the other side of this pandemic.

One other benefit of our relational account is its ability to address some aspects of dying and death that go beyond the medicalized death that Gawande notes we have constructed for patients. It allows us to consider as morally relevant those who are left behind after a loved one dies and medicine leaves the scene—how to memorialize the dead and how to mourn. Death has an impact on more than just the one who died. Those who witness—or, in the time of Covid-19, those who cannot witness but only imagine—the deaths of their loved ones will be harmed if end of life conversations are not held well in advance of death. Advance care planning brings with it better bereavement outcomes for caregivers, both familial and professional; and given the already complicated nature of bereavement during Covid-19, this has never been more important. 33

Conversations about appropriate death should include how elders and their loved ones might memorialize the life of the elder when the elder dies. When an elder desires, she should be involved in discussions about the planning of memorials and celebrations of life. Our rituals around death allow us to grieve the loss of those deceased loved ones who were central to the constituting of our own identities. End of life conversations allow families to decide with their dying loved ones how mourning will occur. Relational ethicists care about these rituals, and a relational approach emphasizes the social, emotional, psychological, and moral importance of the rituals surrounding death.

5 | CONCLUSION

The Covid-19 pandemic has brought to the forefront the inadequacies concerning end of life care and planning for older adults in nursing homes. In this paper we introduced a relational ethics framework for understanding some of the continued failings in end of life care for nursing home residents. Without a relational ethics lens, we miss important insights into the contextual considerations that make individuals’ lives rich and meaningful and the ways in which family members hold one another in identity. Joining this with the concept of appropriate death allows for the application of these relational insights through the process of dying. Covid-19 has shown us that the everyday particularities of our relationships—coffe with neighbors, dinner out with friends, visits with family—are what enrich our lives and help us fully realize and live out our identities. While our lack of preparedness around dying and death in nursing homes has been exacerbated by Covid-19, these concerns transcend the pandemic and require us to keep in mind the importance of relationships for living—and dying—well.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ORCID

Jennifer A. Parks https://orcid.org/0000-0002-3673-8264

AUTHOR BIOGRAPHIES

Jennifer A. Parks, PhD, is Professor of Philosophy and Director of the Undergraduate Bioethics Minor Program at Loyola University Chicago. Her areas of specialization include health care ethics with a special interest in reproductive technologies and aging and long term care. She is currently working on ethical issues relating to elder care and technology, and global issues in reproductive technologies.

María Howard, PhD, is an Assistant Professor of Philosophy at Gonzaga. Her primary areas of research are in the philosophy of suicide and the ethics of medically assisted dying. She serves as the ethicist co-chair of her county’s Disaster Clinical Advisory Committee and Eastern Washington’s Crisis Standards of Care Regional Triage Team.

How to cite this article: Parks JA, Howard M. Dying well in nursing homes during COVID-19 and beyond: The need for a relational and familial ethic. Bioethics. 2021;35:589–595. https://doi.org/10.1111/bioe.12881

32 Gawande, A. (2014). Being mortal: Ageing, illness, medicine, and what matters in the end. Profile Books.
33 Wright, A., Zhang, B., Ray, A., Mack, J., Trice, E., Balboni, T., & Prigerson, H. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA, 300(14), 1665-73; Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. BMJ, 340. https://www.bmj.com/content/340/bmj.c1345