Article

After COVID-19: The Way We Die from Now On

ANNA MAGDALENA ELSNER

Abstract: Ethical issues raised by the outbreak of COVID-19 have predominantly been addressed through a public health ethics lens. This article proposes that the rising COVID-19 fatalities and the World Health Organization's failure to include palliative care as part of its guidance on how to maintain essential health services during the pandemic have exposed palliative care as an underlying global crisis. It therefore calls for a different ethical framework that includes a care ethics perspective and thereby addresses the ways in which the pandemic has triggered new difficulties in ensuring the delivery of appropriate end-of-life care for the dying. The article analyses the structural weaknesses of palliative care accentuated by the pandemic and proposes solutions that could set in motion lasting changes in the way it is delivered beyond COVID-19.

Keywords: COVID-19; end-of-life care; palliative care; care ethics; dying

Ethical issues raised by the worldwide outbreak of COVID-19 have predominantly been addressed through a public health ethics lens and a focus on questions of rationing and triage protocols. But the pandemic's rising fatalities have also exposed new difficulties in ensuring appropriate end-of-life care to patients. Indeed, the pandemic has rapidly changed the way we die and mourn across healthcare systems. The fast deterioration of patients has frequently rendered conversations about dying impossible. Hospitals, considered as sites of contagion, have restricted or prohibited visits to the dying. Patients have therefore often died alone, merely in the presence of a healthcare professional or supported by a tablet connecting them to loved ones. As funerals have been banned in some places and those in contact with COVID patients mandated to self-isolate, support systems have been upended, and many are grieving alone.

This situation has accentuated two issues in particular: first, that our belief in medical progress has not made us immune to mortality, and second, that our valuing of autonomy as an ethical principle cannot protect us from depending on others in the processes of dying and mourning. In facing the present challenges, we should seize the momentum to acknowledge some of the deeper roots of these issues as well as devising structural solutions that can shape the way we die and grieve beyond the pandemic. Ultimately, this may allow us to build a humbler culture of medicine, one that, through its acknowledging of scientific uncertainty and our mutual interdependence, turns dying into one of the cornerstones of medical care and medical education.

The Crisis of Care

Historically speaking, some of the current challenges to dying and grieving are not new phenomena and have numerous precedents in previous epidemics and wars.

Cambridge Quarterly of Healthcare Ethics (2021), **30**, 69–72.
© The Author(s), 2020. Published by Cambridge University Press.
doi:10.1017/S0963180120000572

https://doi.org/10.1017/S0963180120000572 Published online by Cambridge University Press

Irrespective of acute crises, however, the isolation of the aging and dying, the marginalization of mourning in public life, and the denial of death in medical culture have been widely documented in the 20th century. In his 1982 text *The Loneliness of the Dying,* for example, German-British sociologist Norbert Elias highlights the increasing lack of involvement of others in individual deaths. He understands this isolation as the result of stigma around aging and frailty; it springs from our overvaluing of independence and is disseminated by a culture of autonomy and self-determination that has defined Western societies from the 20th century onward. "Too often," Elias writes, "people today see themselves as isolated individuals totally independent of others. To further one's own interests—seen in isolation—then seems the most sensible and fulfilling thing for a person to do."[1] COVID-19 has caused an abrupt shift to dying and grieving alone. Yet, what seems a tragic, but temporary scenario due to the hazard of infectious disease, has merely carried to extremes an already existing reality.

Indeed, the dislocations of communities, triggered by increasing mobility and migration, has long meant that the involvement of family members in individual deaths has become the exception rather than the norm. Similarly, the disappearance of open caskets, visible bodies, and public mourning rituals has relegated expressions of grief to the private realm. Besides, the medicalization of bereavement—apparent in discussions around prolonged grief as part of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) and, more recently, the *International Classification of Diseases* (ICD-11)—has further contributed to the marginalization of mourning practices. To be sure, personal protective equipment, the absence of corpses, and funerals caused by COVID-19 will trigger new forms of complicated grief. As specific to COVID-19 as these will seem, they also provide a dystopian look into a future, when the ever-increasing use of technology, the further disintegration of communities, and the pathologizing of emotions, may have fully turned isolated forms of dying and mourning into the new norm.

Conceptually, ethical concerns associated with dying from COVID-19, as well as previous infectious disease outbreaks, have largely been understood through principle-based ethics frameworks. But the way in which the present situation accentuates an existing crisis of care—socially and conceptually long in the making, spurred further by austerity measures and the devaluing of care work—calls for care ethics to be included as a key response to the pandemic. In the short term, this will mean asking *what care can mean in the times of social distancing*, taking into consideration that substitute virtual contact can also cause distress to the dying and the mourning. At a fundamental level, however, it will mean rethinking the human being as interconnected, relational, and mortal in medical ethics. A shift is called for, one that is grounded in a recognition of vulnerability and our shared finitude beyond risk groups. Such an acknowledgment of our mutual dependence as individuals, communities, and societies may allow us to let care at the end of life take center stage in medical ethics.

Palliative Care in and beyond COVID-19

Despite precedents in earlier epidemics and wars, the present situation is unprecedented in the ethical context we have made for dying and mourning since the advent of palliative care. What gave the impetus to the formation of palliative care in the 1970s was the view that the care for terminal patients urgently had to be improved—

https://doi.org/10.1017/S0963180120000572 Published online by Cambridge University Press

in medicine and beyond. Against this background, the failure to include palliative care in the World Health Organization guidance on how to maintain essential health services during the pandemic has to be taken very seriously.[2] More than an "oversight,"[3] it is a symptom that testifies to the *existential crisis of palliative care*. Some structural weaknesses of the field have been further accentuated by the pandemic, and thinking about how to address them now might set in motion a lasting change in the way palliative care is delivered beyond the pandemic.

COVID-19 has thrown two issues corroding the subspecialty into sharp relief: First, the speed of deterioration and the ensuing impossibility to call on specialist teams in a timely manner has highlighted the need to break down palliative care silos. Some of the fundamental skills of the field, such as symptom management and communicating candidly about dying, should be acquired by all clinicians and nurses, even if they work within medical specialties with lower mortality rates or fewer emergencies. Due to the impossibility to rely on family support and a multidisciplinary team approach, the healthcare professional's role in caring for the dying will be particularly important during the pandemic. Quickly imparting these key competencies among all who care for the dying, as well as making sure that healthcare professionals' own physical and mental health is protected, is therefore a priority. By reframing death as a key issue within medicine generally, this will, in the longer term, make dying visible in the healthcare sector and beyond, potentially even redressing the gender imbalance of the field. Importantly, this should not be understood as turning dying over to medicine; rather, the sharing of palliative care competencies across healthcare professionals will be instrumental in framing dying as a societal issue at large.

Second, the absence of time for planning has highlighted the importance of thinking about ethical workarounds instead of categorically adhering to professional templates.[4] Further developing and integrating advanced care planning is an indubitably effective tool to ascertain that individual preferences are met. COVID-19–specific decision aids have been designed to provide patients with a structured approach of care options reflecting the specific end-of-life scenarios of the disease. While it will be necessary to ascertain that these decision aids are flexible enough to allow patients to change their minds, the larger goal in the aftermath of the pandemic will be to conceive of medical education beyond the imparting of technical skills. It will mean training healthcare professionals in the essential narrative skills involved in listening to patients and finding out when flexibility and need for improvisation are called for. It will entail highlighting the importance of cultural aspects in communicating at the end of life and resisting the erosion of the language of death and dying from palliative care, even if the field's focus on comfort care and symptom relief is no longer restricted to the dying.

To be sure, many of the characteristics of palliative care's version of the "good death," such as preparing for death, dying at home, supported by family and friends, who are themselves offered bereavement support, cannot be fulfilled during the pandemic. Yet, even stripped down to its basics, such as managing symptoms and talking openly about dying, a pandemic palliative care perspective has to play a key role in the discussion of ethical issues raised by the pandemic. In the short term, this means involving palliative care in ethical triage decisions, including it as an essential health service during the COVID-19 pandemic and as an integral part of any pandemic response and preparedness plan. In the longer term, the potential collapse of end-of-life care caused by COVID-19 may become a

https://doi.org/10.1017/S0963180120000572 Published online by Cambridge University Press

possibility to address the more deep-seated problem of what Daniel Callahan has called medicine's "war against aging and death" as well as the critical opportunity to rethink the triumph of autonomy in bioethics.[5]

Notes

1. Elias N. *The Loneliness of the Dying*. Jephcott E, trans. New York/London: Continuum; 2001 [1982], at 34.
2. For WHO guidance, see https://www.who.int/publications-detail/covid-19-operational-guidance-for-maintaining-essential-health-services-during-an-outbreak (last accessed 27 April 2020).
3. Editorial. Palliative care and the COVID-19 pandemic. *The Lancet* 2020;395:1168.
4. The term is borrowed from Berlinger N. *Are Workarounds Ethical? Managing Moral Problems in Health Care Systems*. Oxford: Oxford University Press; 2015.
5. Callahan D. Death, mourning, and medical progress. *Perspectives in Biology and Medicine* 2009;52:106.

https://doi.org/10.1017/S0963180120000572 Published online by Cambridge University Press