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Naomi Richards & Marian Krawczyk

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Classic Anthropological Theories to Help Understand Caregiving and Dying during the COVID-19 Pandemic

Naomi Richards  and Marian Krawczyk 

The COVID-19 global pandemic engendered a new social order, the ultimate shape and permanence of which is still unknown. What *is* known is that in the short term, experiences of caregiving and dying were profoundly reshaped in reaction to this new contagious threat and the effects of that reshaping are still being felt. Though these changes have been unprecedented, foundational anthropology theories continue to have relevance and can aid understanding. Our own expertise is in researching and theorizing how societies organize death and dying — their “death systems”¹ — and the cultural beliefs that emerge to make sense of people’s experiences.

Here, we summarize some classic anthropological theories that can contribute to our understanding of how dying, and caring for the dying, was affected during this pandemic. Even after the global rollout of vaccines, leading to a decrease in COVID-19-related mortality, we continued to see different countries struggle with how best to care for those with the disease, how to “count” those who died and how to minimize risk through regulating the movement of bodies locally and internationally. We believe that a postpandemic world will continue to contain similar or novel infectious disease outbreaks, either regionally or globally, and that the classic theories we outline here can help us to navigate the future terrain of end-of-life care in the Global North.

Pollution and Taboo

During the first waves of the pandemic, people who were severely ill with and/or dying from COVID-19 faced isolation at home or in hospital because of government-enforced restrictions on social contact and fears of contagion. The idea of sick, dying and dead bodies being polluting and considered socially taboo and with contact being strictly regulated is a long-standing theme in the anthropological literature.

The British anthropologist Mary Douglas published her famous book *Purity and Danger* in 1966 about how societies deal with dangers and perceived threats to the social order.² She memorably defined pollution as “dirt” or,

CONTACT Naomi Richards  Naomi.Richards@glasgow.ac.uk

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symbolically speaking, “matter out of place.” Threatening substances become polluting when they cross a literal or symbolic boundary, at which point they become dangerous. All societies commonly create boundaries to distinguish between healthy and sick, living and dying and clean and polluted bodies. Blood, feces and other bodily fluids are commonly considered forms of pollution or matter out of place. People who come into contact with such bodily fluids can also become polluting by association.

Dying bodies are considered potentially polluting in most societies. Even within hospitals where so much death takes place, dying bodies are matter out of place. Well before COVID-19, dying and dead bodies, as well as bereaved family members, were segregated within hospitals into separate, and often specialist, areas: palliative care units, family meeting rooms, the morgue. Those deemed closer to death were positioned closer to the nursing stations. The same is true in long-term aged care facilities. In an ethnographic study of an English care home in the late 1980s, anthropologist Jennifer Hockey found that residents with dementia who were incontinent and bedbound were designated “frail” and moved downstairs to the “frail” corridor nearer to the sick bays.³ Those designated “fit,” on the other hand, were supposed to congregate in the upstairs “living” area. Even in a “condensed world” of aging and dying, those closer to death needed to be demarcated and kept separate.

A decade later, anthropologist Julia Lawton argued that modern British hospices functioned as containers for the worst cases of “dirty dying” — dying that involves bodily decay considered too polluting for mainstream society.⁴ In her ethnography she writes about “unbounded” and “leaky” bodies and recounts disturbing stories of patients’ bodily disintegration. The sights and smells of dying bodies could “penetrate right through the building” with staff ineffectually burning aromatherapy oils and other patients complaining that the smell made them want to vomit.⁵ The role of the palliative care professionals in large part was to deal with the rupture and breakdown of the surfaces of a patient’s body that were deemed too repellent by families.

Contemporary Western medicine strictly regulates the actual touching of bodies, and professional status is marked out in terms of distance from the body. Consequently, the physical work of caring for those who are nearing the end of their lives across all care settings can be seen as a form of “dirty work.” This is low-status, low-pay work attending to intimate parts of the human body as it is dying. This is physically demanding work that brings people into daily contact with noxious sights and smells. It continues to be done predominantly by women, many of whom are from minority ethnic groups. Fisher and Kang’s study of three California nursing homes found that the female nursing assistants were from the Philippines, Mexico, India, the Pacific Islands and various African nations.⁶ Similarly, in Anne-Mei The’s ethnography of a nursing home in the Netherlands, the largely white Dutch residents were cared for by black

carers from the former Dutch Caribbean colony of Surinam.⁷ In these homes, the “dirtiness” of dealing with dying or dead residents was further exacerbated by the less-than-ideal working conditions — pay and benefits at or near poverty levels and no collective representation.

Whereas the dying body is often only symbolically polluting, the person dying of COVID-19 posed an immediate contagious threat. Consequently, we have seen these issues exacerbated within the pandemic where the vast majority of deaths in the first and second waves in the Global North took place in long-term care. People with COVID-19 were at their most contagious when they were at their sickest. Long-term care residents ostensibly became *doubly* polluting, where they were dying *and* they were dying of a highly contagious disease. Staff — predominantly female, often migrants — shouldered the “dirty work” of caring for dying residents with COVID-19, all too frequently with little or no personal protective equipment.

The prospect of contagion fundamentally challenges carers’ abilities to engage in boundary maintenance between clean/unclean, contained/uncontrolled bodies, and between self/other. Caregiving in this scenario required that carers don protective equipment and behave differently than with other patients. One doctor publicly compared coming into contact with COVID-19 patients to being exposed to radioactivity at Chernobyl.⁸

Social Death

The American ethnomethodologist David Sudnow pioneered the concept of “social death” in his landmark study on hospital dying in mid-20th-century America.⁹ Social death denotes the ways in which clinical staff may regard and treat certain patients who are nearing death “essentially as a corpse, though perhaps still ‘clinically’ and ‘biologically’ alive.”⁹ In these instances, the body and its post-death processing became the central focus, where death certificates were prefilled, next-of-kin were contacted for autopsy requests and, in some instances, patients’ sheets were switched to those used for wrapping the dead, even while people were still biologically alive. Through his ethnographic work, Sudnow found that certain groups were more likely than others to be treated as socially dead: older patients, patients judged to be of so-called poor moral character and patients who held little value for clinical teaching.

A subsequent study of resuscitation decisions by Stefan Timmermans and David Sudnow in the 1990s showed that despite voluminous biomedical protocols and legal initiatives, “whether care providers will aggressively try to save lives still depends on the patient’s position in a moral stratification.”¹⁰ In other words, both ethnographic works showed that little had changed between the 1960s and the 1990s. Sudnow’s theory of social death continues to be very influential in highlighting the social inequality that is an intrinsic part of the professional management of dying in institutions. This includes understanding

critical care resource allocation during the pandemic when at the various peaks, ventilators and space in ICUs became scarce resources, and age and existing comorbidities were used as social determinants for whether or not a person was given access to critical care while in hospital, or even whether they were admitted to hospital in the first place. In Lombardia, Italy, for example, a virus hotspot in the first wave of the pandemic, physicians adopted an ad hoc distributive justice approach where intensive treatment was rationed to those “deemed worthy of intensive care” — those under 65 years with no preexisting comorbidities.¹¹ An international survey of intensivists across 31 European countries highlighted the ubiquity of this reasoning, with the vast majority prioritizing younger patients for ventilator allocation.¹²

Social death is also a useful concept to throw into relief how health care infrastructures devalue entire populations of people outside of the acute care setting. In both Europe and North America during the first wave of the pandemic, older people were discharged from hospitals back to long-term care facilities despite having the virus. Given the contagion profile of COVID-19, returning “polluted” residents back into long-term care facilities, where there was little or no capacity to minimize the spread of the disease and where people were most vulnerable to dying from it, evidences how health care systems enact the social death of care-dependent older people as a whole, whether or not they have COVID-19. The consequences of this have begun to reverberate through legal systems. In 2022, the High Court of Justice in England found the policy of not testing or isolating people discharged from hospitals to care homes early on in the pandemic unlawful as well as “irrational.”¹³ Employing the concept of social death, however, allows us to understand the intangible calculus that underpinned these actions.

Liminality

The concept of liminality originates with ethnographer and folklorist Arnold Van Gennep’s famous *Rites of Passage*, written in 1909.¹⁴ Van Gennep identified that, around the world, there were rites that accompany “passages from one age to another and from one occupation to another.”¹⁴ Seeking out commonalities across these rites, he identified a near universal underlying three-part structure: (1) passage out of a previous phase or social status, (2) an ambiguous time and space betwixt and between social positions, and (3) re-entry into a new social position or period. Death is one of the biggest life transitions and across all cultures is marked by rites of passage with this same tripartite structure.

When dying is clinically recognized, a person is typically separated in space and time and enters the ambiguous liminal or betwixt-and-between phase. A dying person can thus be classified as a liminal being — as can a bereaved person. They both occupy a marginal space from which they are separated

from their pre-existing roles, identities and everyday activities. In the Global North, rites of reintegration predominantly occur with burial or cremation, after which the bereaved undergo a slow reintegration into society and the dead formally become ancestors.

During the pandemic, this liminal phase was much less certain for those dying of COVID-19. The typically sudden onset of the disease, rapid worsening of symptoms and escalation of medical intervention in the form of admission to critical care and, in some cases, intubation disrupted the ability to time and plan death. And timing and planning are key markers of a so-called good death. Though the last stage of life is often marked by extreme precarity, this was made even more severe in cases of COVID-19 where people might have teetered on the brink of death before recovering or dying. This makes the liminal phase for those who were dying potentially extremely chaotic and disorientating for all those who were navigating this passage. Those who survive with long COVID also face ongoing liminality, no longer a fully active member of society but not yet in receipt of a new socially legitimated identity. People experiencing long COVID have been shown to face medical “gaslighting”¹⁵ and/or disbelief from employers, family and friends.

Important rites that traditionally mark the transition from alive to dead were also severely disrupted during the pandemic. In many countries, the number of family members and friends permitted to perform the bedside vigil for loved ones who were dying in hospitals, hospices and long-term care facilities was severely restricted. In many early instances, these important cultural practices were not permitted at all. Funerals were also reconfigured, with limits on the number of mourners present and a prohibition on mourners physically comforting one another and touching or even seeing the dead body. In Belfast, the customary viewing of the remains was prohibited and, as in the rest of the United Kingdom, mourners were limited to 10, forced to stay 5 meters from the grave and prevented from throwing soil or flowers into the grave. As a Belfast funeral director said: “We can hear the pain in their voices — ‘Why can’t we do this?’ they ask ... it feels so barbaric, so strange.”¹⁶ Bedside vigil and funerals are powerful rites of social re-integration, needed to mark the end of the dying person’s liminal status and to create new relationships between the living and the newly dead. The disruption of these rituals has generated experiences of grief so severe that it has been conceptualized as its own pandemic.¹⁷

Gift-Giving and Reciprocity

Caregiving entails relations of exchange that anthropologists have long conceptualized as a form of gift-giving.¹⁸ Within families, caregiving is ideally premised on the notion of reciprocity, designed to establish bonds of mutual obligation and sentiment over time and even over generations. In

anthropological terms, caregiving can be understood as the cornerstone of familial bonds and generative for all concerned.¹⁹ As we have argued elsewhere, it could be argued that “caregiving at the end of life, when caring can be particularly intensive, is a debt which is accrued, serviced and settled in a long line of dying humans.”²⁰

Professional caregiving can also be conceived as a form of gift-giving. For the anthropologist Ann Russ carrying out fieldwork in San Francisco in the 1990s, professional caregiving in hospice programmes involved “care, touch, stories, and love,” which were conceived as gifts within a moral economy.²¹ The transcendental gift of being present and emotionally available for those who were dying was a choice that was made by these nurses, who perceived that they were doing relational work which could not be monetized. This has kinship with what the anthropologist Elana Buch identifies as the dual moral components embedded within the term “care” — both affective concerns (caring with) and practical action (caring for).²² But what happens when this gift of care becomes an existential threat posed by coming into close contact with the dying? And when the dying person themselves are aware of the dangers they present to others? As the pandemic unfolded, we also saw the devaluation of this gift, where health systems relied on and treated health care providers’ care as an endless good that could be drawn upon without additional supports or consequences. In the United Kingdom, this was reflected in the weekly “clap for carers” where neighbors stood out on their doorsteps every Thursday at 8pm banging pots and pans in a public display of gratitude. This ritual demonstration, encouraged by government ministers, quickly came to be viewed as a “hollow gesture” given the lack of resourcing and underinvestment in the national health service and successive governments’ failure to provide nurses with fair pay.²³

During the pandemic, many of the actions and relations that make up care at the end of life — physical contact, bedside vigils, saying final goodbyes — were severely curtailed for all those dying during this time. This means people were not able to be present with, witness or offer solidarity to the dying or, indeed, to their primary caregiver(s), across a range of care settings. Even for those dying at home, or caring for those dying at home, sustaining the continuity and dependability of day-to-day life through simple daily rituals such as cooking meals, doing laundry or running errands²⁴ was not possible. At a minimum, these gifts became sources of risk and anxiety-provoking. At worst, if the care recipient dies due to caregiver transmission, it may give rise to feelings of culpability.²⁵ An employee at a long-term aged care facility in the United Kingdom where 12 residents died confided anonymously to a journalist: “You start to get obsessive about particles. You think about all the different ways they can get spread, deposited on surfaces. ... You talk to your colleagues and they give you a bit of perspective and they say it might not

have been you ... [but] there's a voice in your head saying you've killed these people."²⁶ The anthropological literature highlights that this fissure in our ability to provide or receive care is more than an individual or organizational challenge. It represents the loss of the gift-giving rituals and relations through which our very humanity is cultivated through the generations.

Conclusion

Classical anthropological theory has contributed greatly to our understanding of the ways in which death and dying are managed and organized in societies around the world. These theories have been built on ethnographic fieldwork that found remarkable cross-cultural similarities in the social taboos that exist around the dying and dead body, discerned fundamental markers and rites of passage signifying the transition from alive to dead, identified the way some people are treated as socially dead while their bodies are alive and theorized the ways in which caregiving can be understood as a reciprocal gift to be passed down through the generations.

Though experiences of dying during the pandemic may be viewed as extraordinary or extreme, anthropological theories highlight pre-existing challenges around death and dying. At the same time, the classic anthropological theories highlighted here can help to show why dying from COVID-19 is interpreted as a quintessential "bad death," particularly during the first waves of the pandemic (see [Box 1](#)). Despite valiant attempts by palliative care professionals to

Box. 1 Ways in Which Dying of COVID-19 Fulfills Many Cross-Cultural Attributes of a "Bad Death"

- **Pollution and Taboo:** The contagious dying individuals are a source of pollution and danger for professional and lay caregivers and need to physically isolate from the caregiver; for their own well-being, caregivers must wear personal protective clothing, which limits facial recognition and human touch.
- **Social Death:** Older people with COVID-19, particularly those in long-term care facilities, are treated "as good as dead" because they are seen as lacking social viability.
- **Liminality:** The liminal dying phase is made more uncertain and the liminal phase of bereavement is protracted due to disruption in funeral rites of passage and widespread experience of complicated and disenfranchised grief.
- **Gift-Giving:** Caregiving entails relations of exchange that can be conceptualized as a form of reciprocal gift-giving. The caregiving rituals that provide meaning and significance to the end of life are severely attenuated and/or become sites of risk and caution.

construct a narrative around dying well with COVID-19,²⁷ cultural norms and dying scripts take generations to form and cannot be reconfigured overnight.

En masse, these bad deaths created huge social ruptures, the full consequences of which are still to be felt. We see early impacts in the form a mass exodus of health care workers citing burnout and PTSD, a rise in complicated and disenfranchised grief among the bereaved and political movements spearheaded by angry, grieving relatives calling for public inquiries and forms of political accountability. There are also indications that the expected social rupture has not been as seismic as the incalculable loss of life indicated it would be. This is likely to have something to do with the fact that the people more likely to die from COVID-19 were “older, sicker, poorer, Blacker or browner”²⁸ and their lives considered less “grievable.”²⁹ We can also speculate, along with historian Yuval Noah Harari,³⁰ that as a result of the fear provoked by the pandemic, death and dying will be further resisted with even more investment in medical technologies and extreme efforts to protect human lives — in other words, more blind faith in medical rescue and continued denial of human fragility and transience.

As we submit this essay, more than six and a half million people have died worldwide from COVID-19, with global excess deaths estimated at double or even quadruple that figure. Though we have seen the massive success of vaccines, new waves and different variants continue to shape and reconfigure our world, and we do not yet know, as the pandemic continues to evolve, how we will organize and give meaning to future COVID-19 deaths. The classical anthropological theories discussed here therefore hold both retrospective and prospective value.

Going forward, these theories will help us to understand how different countries are negotiating what societies consider acceptable prospective mortality rates and predicting what groups of people will be most affected in the future. They also provide insight into how we value those who continue to work with and care for the dying. At the same time, tensions about how to regulate risk through behaviors such as social distancing and the use of masks become understandable when viewed as an existential struggle about how to regulate a potentially polluting body capable of endangering others by its very existence. It is our view that the world will continue to contain similar or novel infectious disease outbreaks and there will be a continuing need to seek out theories that can help us understand what it means to die and care for the dying during such times.

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ORCID

Naomi Richards  <https://orcid.org/0000-0002-3029-5132>

Marian Krawczyk  <http://orcid.org/0000-0002-8830-6236>

Notes on Contributors

Naomi Richards is director of the End of Life Studies Group and senior lecturer in social science at the School of Interdisciplinary Studies, University of Glasgow.

Marian Krawczyk is lecturer in social science and programme lead for the End of Life Studies Programme (MSc/PGDip/PDCert) at the School of Interdisciplinary Studies, University of Glasgow.