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Rethinking the Role of Advance Care Planning in the Context of Infectious Disease

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ABSTRACT

Advance care planning (ACP) for medical decision-making at the end of life has developed around the expectation of death from long-term, progressive chronic illnesses. We reexamine advance care planning in light of the increased probability of death from COVID-19, an exemplar of death that occurs relatively quickly after disease onset. We draw several conclusions about ACP in the context of infectious diseases: interpersonal and sociostructural barriers to ACP are high; ACP is not well-oriented toward decision-making for treatment of an acute illness; and the U.S. health care system is not well positioned to fulfill patients' end of life preferences in a pandemic. Passing the peak of the crisis will reduce, but not eliminate, these problems.

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COVID-19; death and dying; living will; medical decision-making; social disparities

As social gerontologists who study death, dying, and bereavement in later life, we have based most of our work on the assumption that 21st century death is a product of non-communicable diseases, usually chronic conditions such as cancer and heart disease, or to a lesser extent, injury. Three-quarters of deaths in the U.S. each year occur to older adults and are caused by long-term, progressive, chronic diseases (Boerner et al., 2018; Boerner & Schulz, 2009; Moorman, 2020). The end of life, we have argued, is a prolonged life course stage like infancy or adolescence, and this period – lasting months if not years – provides a time and space to discuss one's treatment preferences, prepare family members for life after loss, and even make preparations for one's own funeral, creating a “post-self” in the process (Carr & Luth, 2019).

But then the COVID-19 pandemic struck, reorienting our attention and forcing us to reevaluate what we thought we knew about how people die, and how they and their families prepare for and adapt to loss. We had overlooked the observation by microbiologists over a decade ago that human infectious diseases have been emerging at the rate of three per year (Woolhouse & Gaunt, 2007). They attribute this rise to the intensifying ways in which humans

encroach upon the natural world, such as deforestation, the market for wild game and livestock, urban sprawl, and the exotic animal trade. Although the spread of COVID-19 will eventually taper off, other infectious diseases will inevitably follow. Rising rates of deaths that occur relatively quickly after the onset of illness raise important questions about how dying patients and their families can prepare for the end of life.

Our collaborative work has focused primarily on advance care planning (ACP), the legal and medical process of documenting one's preferences for health care in the final stage of life (Boerner et al., 2013; Carr et al., 2013; Moorman et al., 2014). Although ACP may be most salient to older adults who have one or more illnesses, all adults should complete ACP periodically to be prepared in case of sudden injury, illness, or incapacitation. Adults of any age can complete a living will, which is a document establishing one's values and specific preferences for end-of-life medical care. People can also designate a durable power of attorney for health care (DPAHC), an individual who is empowered to make medical decisions on behalf of an incapacitated patient. These legal mechanisms are most effective when preceded and accompanied by conversations, both with one's health care providers and with loved ones, which helps them to enact a patient's wishes. The premise underlying ACP is that patients and their families, together, will decide whether they desire potentially life-extending interventions like feeding tubes and mechanical ventilation, or whether they lean toward palliation and comfort care. Yet this concept of *choice* – the assumption that treatments are available as needed – has been challenged in the COVID-19 era, as health care providers struggle with shortages of ventilators and hospital beds, and debate whether rationing is necessary (Emanuel et al., 2020).

We maintain that ACP is as essential as ever, yet COVID-19 has forced us to reflect upon and reevaluate the use of ACP, and to speculate about changes in ACP should there be future resurgences of death from infectious disease. We offer four reflections regarding ways that current thinking about ACP poses problems for what we anticipate to be a rising number of infectious disease deaths in the decades to come.

Interpersonal barriers to ACP are high

Interpersonal barriers to ACP are especially high in a time of pandemic. In our studies based on large population-based samples of older adults, we have found that loneliness and social isolation hinder planning because isolated people lack a readily accessible person to assist in these efforts (Boerner et al., 2013; Carr et al., 2013). The social distancing and self-quarantining necessary to stem the spread of COVID-19 has made us more socially isolated than ever before, especially older adults. Our research also shows that supportive family relationships promote ACP, whereas family conflict can prevent it (Moorman

& Boerner, 2018). The added psychosocial and economic stressors of the pandemic, as well as limited personal control over where and with whom one spends one's time, are likely to intensify family tensions which may impede effective ACP. Additionally, living wills and DPAHC appointments ideally follow conversations with loved ones (Carr & Khodyakov, 2007; Moorman, 2011). Simply having legal documents, in the absence of conversations with people who must make the medical decisions, is ineffective. However, the rapid decline many COVID-19 patients experience may cause conversations to occur too late to be meaningful, or prevent conversations entirely.

Sociostructural barriers to ACP are high

Sociostructural barriers to ACP are also especially high in a time of pandemic. Persons with fewer economic resources, with lower levels of education, and of racial and ethnic minority backgrounds tend to be more vulnerable to most major illnesses, and these disparities have been glaringly evident in the COVID-19 era. The coronavirus crisis has cast light on the health risks incurred by nursing home aides, grocery store clerks, prison guards, bus drivers, factory workers, and people in other manual occupations (Baker et al., 2020). Work-at-home is a privilege, one that is frequently unavailable to persons of color, given their clustering in service occupations (Yancy, 2020). Inequalities such as these underscore the importance of promoting discussions and formal ACP among these potentially vulnerable populations, and doing so “early and often” before aggressive infectious disease strikes. Unfortunately, our research shows that race and class disparities extend to ACP, such that persons of color, persons with lower levels of education, and those with fewer economic resources have ACP rates dramatically lower than their more advantaged counterparts (Carr, 2011, 2012a, 2012b, 2016). The low rates of ACP found among Black and Latinx persons, in particular, partly reflect their preferences for aggressive life-sustaining treatment, which is often the standard course of care unless a patient refuses it (Portanova et al., 2017). This desire for treatment is a product of institutional racism and ensuing mistrust of the health care system which have historically deprived people of color of timely and high-quality care (Sanders et al., 2016).

ACP processes are structured for chronic, not infectious, diseases

ACP tools are poorly structured for decisions required when the underlying cause of death occurs quickly or without advanced forewarning. ACP is best approached as an ongoing process that evolves alongside the relatively slow progression of most chronic illnesses like cancer, congestive heart failure, and Alzheimer's disease or related dementias (Sudore & Fried, 2010). COVID-19,

by contrast, progresses rapidly from symptoms to death, especially for older adults who have comorbid conditions. Because COVID-19 is an emerging disease, health care providers do not yet have sufficient data to predict how a person's disease will progress in the next days or weeks, making advance decisions difficult. Reports recount patients who are on ventilators mere hours after they were talking with friends (Brown & Beasley, 2020). This is in stark contrast with deaths from chronic illnesses, which generally follow one of three trajectories: terminal disease, major organ failure, and frailty (Lynn, 2004). For this reason, older adults who have already done ACP may need to reassess their plans and preferences because they may have quite different feelings about the treatment they would want for COVID-19. Similarly, older adults who complete ACP during this time of crisis may need to revise their documents later, once the peak of the COVID-19 pandemic has passed. COVID-19 is a stark reminder of a persistent reality: ACP demands continuous engagement to stay current through changing circumstances, at a time when people are already inundated with fears of death.

The health care system lacks capacity

The current overload of the health care system may limit practitioners' capacities to enact patients' advance care plans. Hospitals with a large number of patients and an insufficient supply of resources may be forced to perform triage, and may not be in a position to dedicate ventilator care to every patient who wants it (Emanuel et al., 2020). Likewise, patients who desire palliative care may not have access to it, as palliative care settings are temporarily converted into COVID-19 wards to meet the surge of patients (Arya et al., 2020). These problems are particularly acute in the United States, where health care is a consumer good sold on the private market. In 2013, for example, 55% of hospitals failed to earn a profit (Bai & Anderson, 2016). These businesses respond to market forces, and cannot afford to stockpile extra ventilators or maintain empty beds when no pandemic is in sight. As a result, when a pandemic did occur, the U.S. was poorly prepared to meet the treatment preferences of patients and their families in such large numbers. These capacities may be further undermined in the future. According to some estimates, hospitals' operating revenues dropped by nearly 50% during the pandemic, as revenue-generating outpatient departments closed and elective visits and procedures were postponed or canceled so that facilities could meet the demands of COVID-19 care (Khullar et al., 2020).

Conclusion

The emergence of COVID-19 has strained the efforts of individuals to complete ACP and the efforts of health care professionals to meet the preferences

of dying persons and their families. The disease outbreak highlights the ways in which ACP is oriented toward non-communicable chronic disease. We argue that the policy solution is not to simply emphasize the importance of completing ACP. Rather, efforts to increase the rate of ACP need to account for interpersonal and sociostructural barriers to the practice. National organizations including Compassion & Choices (2020) and Respecting Choices (2020) have already begun developing useful tools to adapt ACP for the epidemic. Practitioners will need to develop innovative ways to establish older adults' treatment preferences, and discuss with them whether their preferences might vary based on the particular health condition from which they are suffering. Health care providers also should meet with patients, and ideally a family member or informal caregiver within the short period of time available before death from acute illness or injury.

Key Points:

- Enforced social isolation is a barrier to advance care planning.
- Racial and socioeconomic inequality are barriers to advance care planning.
- Advance care planning is currently designed around death from chronic illness.
- Health care system overload makes patient preferences unlikely to be realized.

Disclosure statement

No potential conflict of interest was reported by the authors.

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