

**Mara Buchbinder. *Scripting Death: Stories of Assisted Dying in America*.** Oakland: University of California Press, 2021. 248 pp. \$26.95 cloth, e-book.

Anthropologists are well-known for their tendency to think small (by focusing on local communities), engage in what Clifford Geertz (1973) called “thick description,” and grasp for broader insights and conclusions. In this respect, Mara Buchbinder’s ethnographic research on how patients, caregivers, health care providers, legislators, and activists have responded to Vermont’s 2013 Patient Choice and Control at End of Life Act is exemplary. As she explains, “One of the strengths of ethnography is its refusal to compromise between specificity and generality” (15). That is Buchbinder’s rationale for studying Vermont as a “microcosm of a larger national story, offering insights into cultural ideals, fears, and debates that will resonate across the United States” (15). She interviewed 144 Vermonters and participated, as an observer, in advocacy and educational events and professional medical conferences. Her book uncovers layers of complexity and depth in the area of medical aid in dying, otherwise known as death with dignity or physician-assisted suicide. It is well written and serves as a good example of how a wide range of concepts in the social sciences can be useful for interpreting detailed empirical material.

Many readers will turn away from a book about preparing for death; yet the topic should concern us all. Buchbinder begins her inquiry with the following quote from an advocate for medical aid in dying: “I’m going to start by stating the obvious: you are going to die.” As Yedidia and MacGregor (2001) note in one of the first studies of how patients at the end of life view their imminent demise, “Dying is one of life’s unique experiences, ubiquitous yet largely unexamined; talk about it is difficult for some to initiate and hard for others to hear.” We will never have an inside account—from the perspective of a decedent—of the experience of death. But Buchbinder has completed a remarkable study in weaving together first-person accounts of patients at the end of life (before death) together with first-person accounts of caregivers and third-person accounts that attempt to tell the story from the deceased person’s perspective. It is difficult, at least for this reader, to contain one’s natural curiosity about the issues most of us will have to confront at the end of life, regardless of whether we have the appetite and resources to contemplate, let alone pursue, some form of medical aid in dying.

An important theme to which Buchbinder returns throughout her book is the fact that assisted dying is more easily available to those from more privileged backgrounds. Acquiring greater control over the timing and circumstances surrounding one's death requires income, information, and social connections; it is therefore affected by socioeconomic inequalities and what Pierre Bourdieu (1984) called "cultural capital." In this sense, *Scripting Death* provides a rich collection of Vermont stories about the challenges of organizing medical aid in dying, which serve as a microcosm of the broader problems faced by Americans in gaining access to health care. One might object that focusing on medical aid in dying diverts attention to this most uncommon practice from important issues that most of us will face at some point in life. For example, should we write a living will or plan (advance directive) detailing the kinds of life-sustaining treatments we would wish or refuse in the event of terminal illness and probable death? Should we appoint others to make such decisions if we are unable to do so? Would we want to be part of a hospice program?

Buchbinder is well aware that her potentially misplaced attention on medical aid in dying may have "stolen time" from other pressing issues, notably the importance of ensuring access to palliative care for all those in pain (whatever their expected life expectancies) and to expanding hospice care, an area in which Vermont lags compared to many states. Indeed, she argues that "ensuring patients have access to hospice and palliative care is a necessary prerequisite to medical aid in dying, so that terminally ill people will not choose to die because they lack better options" (170).

In the field of health policy and health services research, there is already extensive literature on where Americans die and the range of alternative settings in which we may spend our final days. Over the past 15 years, place of death has moved away from hospitals and nursing facilities to the home (Cross and Warraich 2019), but as death nears, patient and family preferences for home death can change rapidly (Wachterman et al. 2022). The circumstances in which one dies within these places vary greatly from home hospice to palliative care, acute care, or intensive care units in hospitals. The problem of inequitable access to medical aid in dying raised by Buchbinder is typically studied by analyzing data on use of health services by place, occupation, or level of education. For example, about 50 years ago Wennberg and Gittelsohn (1973) documented unexplained variations in hospital admissions in Vermont that were not easily explained by patient needs or outcomes. More recently, Wennberg and colleagues (2004) highlighted significant regional variations in the intensity of medical care received by people treated in *U.S. News and World Report*-ranked "best" academic medical centers during the last six months of their life.

The final outcome—death—was the same for all of the Medicare beneficiaries in their retrospective study, but the number of days spent in acute inpatient hospitals and intensive care units, as well as the number of consultations with medical specialists, varied enormously.

The so-called Wennberg variations raise issues about whether they are explained by what economists call “supplier-induced demand” or uncertainty about what is best for patients or by differences among patient and family preferences. These variations also highlight the importance of shared decision making: involving patients and their families in health care decisions that are consistent with their values. Beyond people’s preferences for place of death and patterns of end-of-life care, clinicians have called for advance care planning and “multifaceted interventions to address the psychologically complex process of improving decision-making at the close of life” (Teno 2022). Guidelines have been issued to assist clinicians in their conversations with patients, yet there is little consensus on these issues (Berlinguer et al. 2013).

Buchbinder’s ethnographic research—her stories and the insights she draws from them—provides us with a deeper understanding of why it is so difficult for clinicians to arrive at anything but the broadest consensus and why the ways in which end-of-life care is organized vary so much. Her metaphor of “scripting death” suggests that the determinants of a “good death” are as multifaceted as those of a “good life.” In the case of death, they reflect the tensions between medical aid in dying as the ultimate enactment of personal choice and the ways in which agency—the capacity to act with intention—is socially embedded and relies on shared values and meanings. Buchbinder shows how these tensions are affected by the struggle to reconcile control and improvisation, uncertainty, and ambivalence. Such insights and how they emerge from her analysis of concrete cases are for me the most important contribution of her book.

Although Buchbinder’s stories are based on the experience of fewer than 50 Vermonters who sought medical assistance in dying, her deep interviews with caregivers, health care providers, and others shed light more generally on the complexity of issues surrounding end-of-life care. For example, Buchbinder reveals how patient and caregiver values act in concert with cultural norms and assumptions to affect how we choose to talk (or not talk) about death. For example, she highlights the dominant clinical and bioethical assumption that conversations about death should be initiated by the patient, not the caregiver. Likewise, she shatters Vermonters’ (and Americans’) pride in their rugged individualism, ingenuity, and determination that patients can just do it themselves, that is, die with medical assistance, by showing the complex collaboration required of physicians,

pharmacists, and caregivers. As she puts it, “Even if seeking a medically assisted death is an expression of autonomy and individual control in dying, those who pursue it cannot escape the fundamental sociality of living in the world” (173). The same could be said of all forms of care at the end of life and how they most often involve complex coordination between health care providers and our family and friends.

In summary, Buchbinder’s research provides a “thick description” on the process of dying and why, for most of us, it will not be an accident but more likely an end that reflects our deepest values, cultural predispositions, and the health system that cares for us. Indeed, one of Buchbinder’s central themes reinforces a classic 1960s report (NCCHS 1966), *Health is a Community Affair*. The same may be said of medical aid in dying and end-of-life care, as they are deeply embedded in our communities and in our health system with all of its technological accomplishments, bureaucratic complexities, and inequalities.

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