

Access to Aid-in-Dying in the United States: Shifting the Debate From Rights to Justice

Much of the literature on aid-in-dying (AID) has drawn heavily on rights-based ethical and legal frameworks that emphasize patients' rights of self-determination in end-of-life decision-making. Less attention has focused on how terminally ill people actually experience such putative rights once they are legally authorized.

This analytic essay draws on findings from the Vermont Study on Aid-in-Dying, an ethnographic study of the implementation of AID in Vermont (2015–2017). First, I show that terminally ill people can face a range of barriers to accessing AID in permissive jurisdictions, and that access to AID is mediated by various inequalities endemic to US health care, as well as some that are unique to AID. I then build on these findings to examine the utility of the concept of justice for public health scholarship on AID.

By integrating empirical, ethical, and policy analysis, I reframe rights-based frameworks that emphasize the role of individual choice and decision-making at the end of life. In doing so, I draw attention to health care justice as a neglected issue in public health perspectives on AID. (*Am J Public Health*. 2018; 108:754–759. doi:10.2105/AJPH.2018.304352)

Mara Buchbinder, PhD

Over the past 2 years, 3 new state laws have authorized aid-in-dying (AID) in the United States. Seven jurisdictions now permit physicians to prescribe a lethal dose of medication to a mentally competent, terminally ill adult patient: Oregon (1997), Washington (2008), Montana (2009), Vermont (2013), California (2015), Colorado (2016), and the District of Columbia (2016). Much of the public conversation and scholarly literature on AID has drawn heavily on rights-based ethical and legal frameworks that emphasize patient autonomy.^{1,2} The American Public Health Association exemplified this approach in expressing support for patients' rights of self-determination in end-of-life decision-making: “having the option of [Oregon's Death with Dignity Act] provides important psychological benefits for the terminally ill because it gives the terminally ill autonomy, control, and choice.”³

Less attention has focused on how terminally ill people actually experience such putative rights once they are legally authorized. Advocates often presume a standard script in which a terminally ill patient desiring to hasten her death requests assistance from a trusted physician, who accedes to the patient's wishes. However, findings from The Vermont Study on Aid-in-Dying (SAID), an ethnographic study of the implementation of Vermont's AID statute, indicate that terminally ill people can face a range of barriers to accessing AID in

permissive jurisdictions. I draw on data from Vermont SAID to show how patients' access to AID is mediated by various inequalities endemic to US health care, as well as some that are unique to AID. By examining the structural constraints on individual access to AID, I reframe rights-based frameworks that emphasize the role of individual choice and decision-making at the end of life. In doing so, I draw attention to health care justice as a neglected issue in public health perspectives on AID.

In developing this argument, I draw inspiration from recent scholarship on reproductive justice.⁴ This framework has been proposed as a critical response to the reproductive rights framework, which is grounded in concepts of individual choice and autonomy that do not adequately account for the structural forces that shape women's reproductive lives, particularly low-income women and women of color.^{5,6} Reproductive justice scholars have issued a call to look beyond the “right to choose,” noting that choice itself is often a privilege; this point parallels similar critiques regarding the role of individual choice in end-of-life decision-making.⁷ Although justice encompasses rights, the

presumed universality of certain core rights (e.g., self-determination) masks critical disparities based on race, class, and other key social identifiers.⁴ The reproductive justice framework also highlights the gaps between laws as written and laws as practiced.⁸ In making this connection to reproductive justice, I aim to underscore that the legalization of AID does not guarantee practical access and that well-intentioned policies designed to protect vulnerable groups may at times reinforce or exacerbate health care inequalities.⁹ In this regard, perspectives from reproductive justice scholarship can enrich understandings of the consequences—including unintended ones—of US AID policies.

In the next section, I illustrate how rights-based frameworks have dominated scholarly and advocacy discourses on AID. The remainder of the article addresses 2 interrelated objectives: first, to report on findings from Vermont SAID regarding access barriers, and second, to build on those findings to examine the utility of the concept of justice for public health scholarship on AID. My overall aim is to integrate empirical, policy, and ethical analysis to advance a novel perspective on

ABOUT THE AUTHOR

Mara Buchbinder is with the Department of Social Medicine and the Center for Bioethics, University of North Carolina at Chapel Hill (UNC).

Correspondence should be sent to Mara Buchbinder, Department of Social Medicine, University of North Carolina at Chapel Hill, 333 S Columbia St, 341A MacNider Hall, Chapel Hill, NC 27599 (e-mail: mara_buchbinder@med.unc.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

This article was accepted January 23, 2018.
doi: 10.2105/AJPH.2018.304352

the public health dimensions of AID.

THE “RIGHT” TO DIE

Rights-based ethical and legal frameworks have been central to the sociopolitical movements underlying AID legalization in the United States.^{1,2} A central premise of these movements is that patients should have the right to seek AID to control the time and circumstances of their death when death is imminent because of terminal illness. Although some have questioned the appropriateness of such arguments,¹⁰ they have been persuasive because they mirror dominant bioethical perspectives that privilege patient autonomy above other competing ethical principles.^{11,12} Legal arguments have centered on the assertion of a constitutional right to die with the assistance of a physician, under the Fourteenth Amendment’s Due Process Clause and Equal Protection Clause. Two Supreme Court decisions in 1997, *Washington v Glucksberg* and *Vacco v Quill*, rejected the constitutional basis of this claim, but left open the door for individual states to authorize AID.

In the context of AID implementation, the autonomous rights of individual patients must be balanced against public health concerns for possible harms to vulnerable patients, as well as the autonomous rights of physicians to opt out of providing morally contested medical services. As a consequence, US statutes share certain safeguards designed to ensure that participation is voluntary for both patients and providers. (Montana, which legalized AID through a state Supreme Court ruling but neither has an assisted dying statute nor regulates the

practice, is an exception.) All require that 2 physicians certify that expected survival is less than 6 months and assess the patient’s mental capacity; all mandate a waiting period between oral and written requests; and all require that a patient self-administer the medication. All likewise grant physicians the right not to participate. States vary in their requirements regarding waiting periods, state residency, and reporting practices.^{13–15}

These safeguards illustrate the inherent tension in any AID policy between imposing regulations to protect patients against abuse and coercion on the one hand and creating undue burdens to accessing AID on the other. They also demonstrate the limitations of rights-based frameworks for AID: an individual’s right to access AID is necessarily constrained by societal obligations to ensure that she does so voluntarily and that the policy does not have harmful consequences for others. Furthermore, although AID advocates emphasize patients’ rights, much of the US legislation is actually focused on protecting physicians from civil or criminal liability or professional disciplinary action, as well as their rights to act in accordance with their conscience.¹⁶

Research on patients’ reasons for pursuing AID have reinforced rights-based frameworks for AID by showing that patients’ primary motivations include the loss of autonomy and dignity (or the perceived threat thereof) and a reduced capacity to engage in enjoyable activities.¹⁷ For some, such data at least partially mitigate concerns that the desire for AID may emanate from shortcomings of the American medical system and inadequate access to palliative care.

RESEARCH BACKGROUND AND METHODS

In this article, I build on emergent findings from Vermont SAID. During qualitative data analysis, barriers to accessing AID surfaced as a key study theme. Qualitative analysis is ongoing and findings from the larger study have not yet been reported elsewhere. Therefore, my purpose is not to present a comprehensive overview of Vermont SAID findings but rather to advance an empirically grounded conceptual analysis of the role of justice in AID.

Sample and Methods

The primary aim of the larger project was to ethnographically document the implementation of Vermont’s 2013 Patient Choice and Control at End-of-Life Act, also known as Act 39, and analyze its social, cultural, and ethical consequences. I targeted Vermont because Act 39 had been enacted recently, providing a valuable opportunity to observe emergent responses to the law as they unfolded longitudinally and to document the law’s effects in lay, medical, and legislative settings. Data collected across the state of Vermont over 2 years (2015–2017) included (1) 144 semistructured, in-depth interviews with physicians (n = 29); nurses, chaplains, and social workers (n = 22); terminally ill patients (n = 9); caregivers (n = 34); activists, legislators, and other policy stakeholders (n = 37); and additional Vermont residents without a direct stake in Act 39 (n = 13) and (2) participant observation in community-based advocacy and educational events and professional medical conferences.

The findings discussed here draw from physician interviews.

During a preliminary research phase, I modified a semi-structured interview guide used previously to study clinical adaptations to a new state abortion law¹⁸ for use with Vermont clinicians. The interview guide included questions about the respondent’s

1. professional background,
2. ideas about a “good death,”
3. views on the physician’s role in end-of-life care,
4. attitudes toward AID,
5. interactions with patients and families about AID, and
6. views on the consequences of Act 39.

I recruited participants via an opportunistic and non-probabilistic sampling approach that included direct contact, e-mail list announcements, public flyers, and snowball sampling. Individuals who supported Act 39 were overrepresented in the clinician, patient, and caregiver samples because the study’s focus on the implementation of the law required participants who had direct experience with it.

Analysis

With the assistance of three research assistants, I analyzed de-identified interview transcripts by using an inductive, thematic approach guided by the tenets of grounded theory.¹⁹ First, we read transcripts closely to identify themes, which we organized into a structured coding guide. The final coding guide includes 44 codes, one of which is “access.” Using NVivo 11 Software (QSR International, Melbourne, Australia), we assigned codes to chunks of text that matched the code definition. We reviewed all coded transcripts and resolved discrepancies so that understandings of concepts and

codes remained in agreement. Two coders coded each transcript to ensure that all relevant interview excerpts were captured.

BARRIERS TO ACCESSING AID-IN-DYING

Of the 29 physicians interviewed, 18 had participated in Act 39 as a prescriber or secondary physician. They were thus well-equipped to speak about the actual experience of utilizing Act 39. Fifteen of these physicians reported barriers to accessing AID, as did an additional 4 physicians who had not participated in Act 39. In the next paragraphs, I describe key access barriers that emerged in qualitative analysis: safeguards, cost of medication, access to physicians, and access to information. Quoted interview excerpts should be treated as specialized knowledge of key expert stakeholders rather than as representative views. However, insofar as the Vermont SAID sample is biased toward physicians who have participated in Act 39, and many patients who encounter access barriers are unable to find a willing physician, it is likely that access barriers are even more pronounced than is suggested by these data.

Safeguards

Pursuing AID under Act 39, as in all permissive US jurisdictions except for Montana, requires patients to clear several regulatory hurdles (e.g., making 2 oral requests to a physician spaced at least 15 days apart, submitting a written request signed in the presence of 2 witnesses, and having a prognosis confirmed by a second physician).²⁰ Of the physicians interviewed, 5 suggested that the Act 39 safeguards are appropriate, 5 suggested that they are

overly restrictive, and 1 suggested that they are insufficient. The remaining 18 did not make an evaluative judgment about Vermont's safeguards.

Patients who followed the Act 39 protocol successfully drew on their social networks to identify physicians willing to participate and received help from caregivers in completing the protocol. Several physicians who had participated in Act 39 suggested that it would be impossible to utilize without a robust support network. One physician noted: "They need a good advocate for them, if that's what they really want" [0125].

The requirement that patients self-administer and ingest the lethal medication, a safeguard designed to ensure that participation in AID is voluntary, was a major barrier for some patients who hoped to pursue AID. Such obstacles were most pronounced for patients with neurologic conditions such as amyotrophic lateral sclerosis (ALS), which results in progressively declining mobility and often entails swallowing difficulties in its later stages. Patients with ALS represent a major subgroup of patients seeking AID.²¹ One physician lamented:

Why can't a hospice nurse administer the medicine for the patients if they can't do it themselves? That doesn't make sense to me. It seems like it puts undue stress on my patients and it also prevents a patient who really needs this program from being able to access it. I feel like it was designed with the cancer patients in mind [0118].

Caregivers and health care providers indicated that the self-administration requirement sometimes motivated patients to hasten death sooner than they otherwise would have so that they retained the capacity to

ingest the medication. It is important to note here that nothing in Act 39 or in other state laws expressly prohibits patients from ingesting medication via a gastrointestinal tube, an intervention that is routinely offered to ALS patients who lose the ability to swallow. In Oregon, the self-administration requirement has been interpreted to permit caregivers to put medication into the patient's g-tube to be ingested, as long as the patient commits the last act of ingesting the medication.²² Data from the Vermont SAID suggest that similar interpretations have been applied in Vermont.

Cost of Medication

Other access barriers track along more familiar lines of US health care inequalities. The exorbitant cost of Seconal, the most common barbiturate prescribed for AID, was a significant deterrent for some patients. In 2015, 1 month after California proposed AID legislation, the Canadian pharmaceutical company Valeant bought the rights to Seconal and raised the prices dramatically; a standard lethal dose now costs approximately US\$3000.²³ Although some insurance companies have agreed to pay for Seconal, others will not; federal funding, including Medicare, cannot be used for AID medications or services. The California state legislature budgeted for Seconal to be covered by the state's Medicaid program (Medi-Cal),²⁴ but Vermont has not done so.

To address these cost barriers, alternative drug protocols have gained in popularity, but physicians' knowledge about such alternatives is uneven, despite informational resources such as Compassion & Choices' Doc2Doc program. Many physicians

continue to view Seconal as the safest, most effective choice. One explained, "It's kind of like a medical frontier just 'cause it's [not] done that much. And if they can't afford the more expensive but more effective medication, that doesn't feel right. So that kind of feels like a discriminatory burden. If you're not wealthy you get the cheap stuff" [0113].

Access to Physicians

Although data about physicians' willingness to participate in AID in permissive jurisdictions are limited, support is generally lower among physicians than among the general public.¹⁷ Access to those physicians who are willing to prescribe for AID is mediated by broader health care inequalities. Vermont SAID physicians reported that patients living in certain counties have had an easier time finding a physician willing to participate. These differences often, but not always, parallel broader socioeconomic differences in access to care. For example, patients living closer to the University of Vermont Medical Center in Burlington, Vermont's biggest city, have tended to have a relatively easier time accessing AID, although certain rural areas stand out for meeting patient demand successfully. In the southern part of the state, many patients receive medical care from Dartmouth-Hitchcock Medical Center, which is located in New Hampshire, where AID is illegal. Veterans are likewise excluded from AID unless they can afford private medical care because of federal law prohibiting Department of Veterans Affairs physicians from participating.

Access to Information

Finally, access to AID is also shaped by patients' differential

access to information on the basis of variation in physicians' communication preferences and institutional policies. Many physicians will not discuss AID with terminally ill patients unless the patient initiates such a discussion. One physician explained, "I don't know of anybody who would put that on the table before somebody asked about it." She continued, "They're a savvy population. They're people who really want control, they're going to know about it, they're going to ask" [0101]. Hospice policies likewise vary in the extent to which they permit staff to provide information about AID.²⁵ Many physicians and bioethicists view such practices as an important safeguard to ensure that AID is voluntary and not subject to health care provider influence.²⁶ However, patients may not know enough about AID to inquire about it: data from Oregon suggest that public knowledge can lag far behind legislative developments.²⁷ Because more-educated patients are more likely to be informed about AID and initiate a conversation about it with a physician, access is stratified along socioeconomic lines.

Differential access to information also applies to physicians. Physician knowledge about different medication options and the Act 39 protocol itself varied. In 1 case, a patient was dismayed to have to begin the process anew because the physician had not documented the patient's request with the proper paperwork. The patient ultimately died before completing the protocol [reported by 0145]. In another case, a patient stopped pursuing AID after his physician told him that the medication would cost \$3000 [reported by 0141]; the physician was unaware that alternatives to Secondal exist.

Stratified Access to Aid-in-Dying

Taken together, these findings suggest that access to AID depends on cultural health capital, the tacit cultural knowledge, resources, and behaviors that predispose certain patients to more optimal health care encounters.²⁸ In the words of one physician: "There is a savviness that is also necessary. There's almost a doggedness on a patient's perspective that is necessary" [0125]. Insofar as referring to patient "savvy" is often an indirect way of speaking about socioeconomic privilege, such statements suggest an implicit stratification in patients' access to AID. Another physician reflected:

The situation is very elitist. Someone has to have the intellectual wherewithal to track down a physician who's willing to prescribe and follow through with that. They have to be able to track down a pharmacy that's willing to dispense medication and they have to be able to afford it, and most people who are in the last 6 months of life who meet the criteria to go through with this don't have the resources intellectually, cognitively, emotionally, financially. So it limits it to a very, very small group of people. It seems not fair that way, too [0123].

Recent media reports from California and Colorado have demonstrated that these access barriers are not unique to Vermont.^{29,30} In the next section, I build on these findings to analyze the role of justice in AID.

JUSTICE IN ASSISTED DYING

When justice has been discussed in the AID literature, it has typically been in the context of

distributive justice arguments mobilized to justify legalization. In climates of scarce health care resources, this logic goes, terminally ill patients desiring to hasten death should be permitted to do so if they act voluntarily, to free up limited health care goods for other patients in need.^{31,32} Yet implementation introduces another set of concerns regarding broader considerations of public health justice and patients' access to health care resources. These issues are gaining traction in media reports, but have received far less scholarly attention.

Considering justice in relation to AID access is rife with conceptual challenges. When unequal access to health care raises concerns about justice, it typically does so because health care is seen as a social good to which all members of society ought to have access. In the context of AID, the relationship between justice and access is more complicated because AID is not universally viewed positively. Some racial and ethnic minority groups, particularly African Americans, harbor deep mistrust of hospice and palliative care and prefer aggressive end-of-life treatment.^{33,34} Among patients holding such views, access to AID will not be desirable, and different patterns of access will not raise justice concerns. However, even among those who do believe that AID should be a legal end-of-life option, some believe that access to it should not be too easy. According to this view, safeguards impede access but are necessary to ensure that the choice is voluntary and emanates from a preference that remains stable over time. While ethical arguments regarding safeguards for AID have focused on considerations of autonomy and coercion,³⁵ less acknowledged in these contentious debates is

that safeguards are consequential for justice as well.

A second conceptual challenge is that AID advocates tend to invert standard arguments about health inequalities, justice, and access to medical services by socioeconomically marginalized groups. Historically, socioeconomically marginalized groups—along with women, the elderly, and people with disabilities—have been viewed as vulnerable to coercion in the context of AID. Advocates have countered such claims about vulnerable groups with data showing that AID utilization is highest among the socioeconomically privileged.^{17,36} However, such utilization patterns might plausibly reflect unequal access to AID rather than a stronger preference for AID among those with higher socioeconomic status. In the absence of nuanced qualitative data that examines how terminally ill patients from a wide range of socioeconomic and racial/ethnic backgrounds think about AID and seek it out (or not) in permissive jurisdictions, it is difficult to draw definitive conclusions about patient preferences from utilization differences between sociodemographic groups.

On a more practical level, it is important to be clear that although justice may require that terminally ill patients have access to AID in permissive jurisdictions, this does not mean that individual physicians are obligated to provide it. This tension may create additional challenges for health care administrators in developing policies that facilitate patients' access to physicians willing to participate in AID while also respecting physicians' privacy and their right not to participate. Lawmakers and policymakers should appreciate that legalizing AID without the critical support of physicians and

other health care providers is likely to create downstream obstacles to patient access.

Moreover, increasing access to AID without ensuring access to other end-of-life options, including hospice and palliative care, is ethically problematic and raises justice concerns. Fortunately, data from Oregon suggest that the legalization of AID can facilitate increased access to palliative care services: hospice enrollment rates grew following the passage of Oregon's Death with Dignity Act.³⁷ Equally concerning for justice would be a situation in which health insurance programs authorize reimbursement for AID while rejecting coverage of life-prolonging treatment, as was the case for Oregon resident Randy Stroup until the Oregon Health Plan reversed its decision.³⁸

Understanding how different types of access barriers affect patients seeking AID is critical for developing a broader framework for justice in assisted dying. The access barriers described here raise the possibility of at least 2 distinct kinds of injustice. First, the self-administration requirement raises justice concerns regarding discrimination against patients who are not capable of self-administering death-hastening medication. Although this requirement may be justified to protect vulnerable patients from coercion, some have argued that it creates an unfair barrier for certain patients.²² The Supreme Court of Canada's 2015 decision in *Carter v Canada* authorized voluntary euthanasia in addition to lethal prescriptions to address such concerns for equality.³⁹ The second type of injustice concerns access barriers resulting from geographic or socioeconomic inequalities, such as the cost of medication and access to

physicians. These inequalities seem more obviously unjust: state laws should not privilege patients from certain geographic regions or higher socioeconomic status backgrounds; these sociodemographic characteristics are irrelevant to AID eligibility requirements. It is less clear that waiting periods on their own raise justice concerns: delayed access to AID is different from not having access to AID at all.

The Vermont SAID data raise difficult questions about assisted dying and health care justice. Is AID explicitly designed for use by people with higher socioeconomic status and, if so, is this ethically sound public policy? How should we think about public health justice with respect to a clinical practice that many people believe should be difficult to access—a practice of last resort? What are the societal harms of legally authorized end-of-life options that many people cannot reasonably access, particularly when such access is stratified along socioeconomic lines? How ought we to account for the fact that efforts to increase access may come at the expense of provisions that protect patient and physician autonomy? These are vexing questions without simple answers, yet they offer some helpful starting points for shifting the rights-based paradigms that dominate current scholarly work on AID. To be clear, I do not mean to suggest that justice ought to override other ethical concerns, such as the protection of patient and physician autonomy and the importance of non-maleficence. Rather, critically examining the role of justice in AID opens up richer avenues for ethical and policy analysis than have historically been offered through dominant rights-based approaches.

CONCLUSIONS

Legislatively authorizing AID is very different from ensuring access to the death-hastening procedure. I have demonstrated here that equal access to a legal health care practice may be complicated by entrenched injustices in the US health care system. In some ways, the situation in Vermont mirrors the way abortion care has evolved in certain parts of the United States, insofar as there is a 2-tiered system in which the socioeconomically advantaged can travel and access care, while others cannot, despite having the “right to choose.” These findings offer a cautionary tale regarding the advocacy narratives suggesting that AID legislation offers a right to self-determination in end-of-life decision-making. At the same time, we still know relatively little about the social, ethical, and regulatory challenges of AID implementation, despite some important exceptions.^{24,40} As the momentum for legalization of AID in the United States continues, this issue warrants further investigation from public health scholars of how AID is implemented, regulated, and practically accessed in the aftermath of legalization. **AJPH**

ACKNOWLEDGMENTS

This research was supported by a UNC Junior Faculty Development award, a Greenwall Faculty Scholars Award, and a research grant from the National Science Foundation (1630010).

The author is grateful for constructive suggestions from attendees of the 2017 UNC Center for Bioethics beach workshop and the fall 2017 Greenwall Faculty Scholars meeting, 5 anonymous reviewers, and *AJPH* Department Editor Mark A. Rothstein. Research assistants Elizabeth Brassfield, Manisha Mishra, and Dragana Lassiter also provided helpful support.

HUMAN PARTICIPANT PROTECTION

The Vermont Study on Aid-in-Dying received institutional review board approval from UNC. All participants

provided written informed consent before the interviews.

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