

# The power of suggestion

## Disclosure ideologies and medically assisted death

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### Abstract

This article examines an ethical controversy that has received relatively little attention in public debates about the legalization of medical aid-in-dying (AID): should physicians inform patients that they have the option of hastening death? Drawing on ethnographic research about the implementation of AID in Vermont, I argue that how we understand the moral stakes of this debate depends on divergent views regarding language use in social interactions. Some stakeholders in this debate view a physician's words as powerful enough to damage the patient-physician relationship or to influence a patient to hasten her death, while others believe that merely informing patients about AID cannot move them to act against their own values and preferences. I illustrate how these divergent perspectives are tied to competing language ideologies regarding clinical disclosure, which I call 'disclosure ideologies'. My analysis of these two disclosure ideologies surrounding AID highlights disclosure practices in medicine as a rich site for medical anthropological theorizing on linguistic performativity and the social power of clinical language.

### Keywords

clinical communication, medical aid-in-dying, assisted dying, assisted suicide, disclosure, language ideologies, United States

In 2015, Beth Neill's ninety-year-old mother was hospitalized at a rehabilitation center in Berlin, Vermont, for recovery from a fall. During her four-month stay, clinicians at the facility regularly informed Neill's mother that she had the option of ending her life under Vermont's Patient Choice and Control at End of Life Act, or Act 39, as it's known in the state. The law, similar to statutes in six other United States jurisdictions, permits physicians to write a lethal dose of medication to a mentally competent and terminally ill adult patient for the purpose of ending the patient's life. According to Neill, her mother clearly indicated that she was not interested in Act 39 and felt pressured by the staff's repeatedly introducing the topic. Even after her mother was transferred to a different assisted-living facility, she remained deeply suspicious that health care workers there would try to push assisted dying on her.<sup>1</sup>

This story was recounted to me no less than five times during my first few weeks of ethnographic fieldwork in Vermont. In my project, The Vermont Study on Aid-in-Dying (Vermont SAID), I followed the social life of Act 39 across a variety of medical, legal, and advocacy settings between 2015 and 2017. The account circulated rapidly through advocacy circles and attained a remarkable notoriety after Neill shared it with a state legislator who had opposed Act 39. It offers a cautionary tale regarding an ethical question that has received relatively little attention in the ongoing public conversation about medical aid-in-dying (AID, also known as 'assisted suicide')<sup>2</sup> in the United States: should physicians inform patients that they have the option of hastening death if their state has legalized AID? In Vermont, debates over this issue culminated in a 2016 lawsuit by several conservative physicians' groups against the Vermont Board of Medical Practice and Office of Professional Regulation. The plaintiffs alleged that Act 39 required physicians to inform terminally ill patients that AID was a legal option in Vermont, and that this violated their constitutionally protected right to

<sup>1</sup> Neill was quoted on the website of True Dignity Vermont (2015), a Vermont-based grassroots advocacy organization that opposes assisted suicide (in their terms).

<sup>2</sup> Historically, what I call here 'aid-in-dying' was known as physician-assisted suicide (PAS), but proponents introduced alternative labels, such as 'death with dignity' and 'physician aid-in-dying' (PAD), because they found the language of suicide offensive and inaccurate in cases in which death is inevitable. Opponents view such labels as euphemistic and misleading, and continue to use 'PAS'. These labels thus index meaningful social, political, and moral values for advocates on both sides of the debate. Because I have tried to maintain a neutral stance on the ethics and politics of assisted dying and I remain somewhat ambivalent about the practice, this fraught language has presented me with a conundrum in my research. Ultimately, I use the term 'AID' out of deference to AID advocates, for whom the stakes of avoiding suicide stigma seem more consequential, in my view, than the moral stakes of their opponents. I also prefer 'AID' to 'PAD' because it decenters the role of physicians in medical aid-in-dying and acknowledges that other health care providers play a role in helping patients navigate the process.

free speech. Although the lawsuit was eventually dismissed – because the state argued that Act 39 held no such affirmative duty to inform – questions remain about physicians’ clinical and moral responsibilities in the evolving landscape of medically assisted death.

For opponents of AID, the fact that Beth Neill’s mother was ineligible for Act 39 – she had no terminal diagnosis and was in relatively good health for her age – served as alarming evidence that AID laws are ripe for misunderstanding, abuse, and the coercion of vulnerable groups, such as the elderly.<sup>3</sup> For proponents, the story represented a sensationalized account that likely reflected misunderstanding on the part of the rehab center’s employees or Neill’s mother herself. However, even some proponents of AID are ambivalent about whether physicians should inform patients that AID is an option. Regardless of whether or not Neill’s story is true, its circulation and performative effects highlight the cultural significance of the debate about the ethics of informing patients about AID.

Many physicians who support AID argue that communication about AID should always be initiated by patients because they believe that informing patients about AID may be harmful in certain circumstances. Patients may view this information as communicating the physician’s endorsement of AID or signaling a loss of hope or abandonment, and may cause patients who hold conflicting values to lose trust in their physician; in addition, physicians may worry that simply introducing the option could constitute undue influence on patients’ decisions (Buchbinder 2017). From this perspective, informing patients about AID may not be in the patient’s ‘best interest’ (Rodriguez 2018), despite widely shared views in US medicine about patients’ rights to health-related information.

In this article, I argue that how we understand the moral stakes of physician-initiated conversations about AID depends on local theories of language as social action – that is, ideas about what speech can do in the clinical arena – that are not adequately addressed through a bioethical frame. For some, the view that a physician’s words could be powerful enough to damage the patient-physician relationship or influence a patient to hasten her death is a potent deterrent from recommending that a physician ever initiate a discussion of AID unless a patient first requests it. For others, however, merely informing patients about AID cannot move them to act against their own values and preferences. My aim here is not to adjudicate these viewpoints and determine whether or not informing patients about AID is ethical. Instead, I illustrate how divergent perspectives on the duty to inform reveal key metalinguistic claims about the social function of language (see Carr 2006). These claims, in

<sup>3</sup> Bioethicists worry that elderly patients may be vulnerable both to pressure from family members to hasten death involuntarily and to the influence of physicians.

turn, underlie competing language ideologies regarding clinical disclosure, which I call ‘disclosure ideologies’.

In the next section, I discuss the concept of disclosure ideology, integrating relevant anthropological scholarship on disclosure in biomedicine with theoretical perspectives on linguistic performativity. Then, after providing some background on my research methods, I discuss health care providers’ views on informing patients about AID and show how their perspectives are tied to competing disclosure ideologies and metalinguistic claims. Finally, I turn to two ethnographic cases in which physicians chose to proactively inform a terminally ill patient about AID, with starkly different results. My analysis highlights a disjuncture between two distinct views of clinical communication, as either a neutral vehicle for sharing information or as a dynamic context for the performative act of informing.

## Disclosure and language ideologies in biomedicine

Medical anthropological perspectives on clinical disclosure – the act of naming disease or offering a prognosis – have highlighted how clinical practices surrounding disclosure are culturally and historically situated. As such, they reflect broader values and assumptions regarding privacy, relationality, autonomy, and medical authority. In 1927, the physician Joseph Collins published a provocative essay in *Harper’s Magazine* in which he argued that diagnostic disclosure practices in medicine should be governed by a strong paternalism. Citing numerous examples of patients whose health quickly deteriorated following the disclosure of a life-limiting diagnosis, Collins concluded that withholding the truth is not only compassionate but also protective. He mused, ‘The longer I practice medicine the more I am convinced that every physician should cultivate lying as a fine art’ (Collins [1927] 1999, 502).

Medical perspectives in the United States have evolved considerably since Collins’s time, particularly since the 1990 Patient Self-Determination Act established that patients have a right to make decisions about their medical care, and, therefore, to be informed about their medical conditions. Outside the United States, clinical disclosure practices surrounding cancer and HIV have also changed over the past several decades, from unilateral concealment to nuanced indirection (Wood and Lambert 2008), heterogeneous practices within the same society (Gordon and Paci 1997; Elwyn et al. 2002), and events that evolve over time and across multiple clinical encounters (Brada 2013; Dima et al. 2014). However, Collins’s ([1927] 1999) underlying point – the idea that clinical disclosure may have powerful social and embodied effects – still holds tremendous cross-cultural currency.

Social scientists have examined the social power of clinical disclosure, showing that receiving a serious diagnosis can transform one’s understandings of self and identity; afford one

certain bureaucratic, social, and economic entitlements; and reshape one's vision for the future (Aronowitz 1998; Dumit 2006; Jutel 2011). Genetic diagnosis, in particular, can medicalize kinship and cause dramatic shifts in subjectivity for presymptomatic persons (Konrad 2003; Lock et al. 2007), turning them into 'patients-in-waiting' (Timmermans and Buchbinder 2010). Yet nowhere is the social power of clinical disclosure more pronounced or feared than in the realm of terminal illness.

In *Death Foretold*, the sociologist and physician Nicholas Christakis (1999) observes that many American physicians adhere to an implicit norm of not communicating predictions unless asked to do so. They follow this norm because they believe – like Collins – that predictions can affect therapeutic outcomes through a type of self-fulfilling prophecy. One young general internist in Christakis's ethnographic study reported, 'The words coming out of my mouth feel like a proclamation. They can make things happen' (Christakis 1999, 179). Christakis identifies several possible mechanisms for such effects, including changing the physician's attitudes or behaviors, changing the patient's attitudes or behaviors, and a quasi-magical mechanism, similar to 'voodoo death' (Cannon 1942), to which many physicians subscribed. Ultimately, Christakis argues that a belief in the self-fulfilling prophecy is a major cause of what Fox (1988) has called the 'ritualization of optimism' in American medicine: the tendency for medical professionals to express optimism about the likelihood of therapeutic efficacy, even when a positive outcome is extremely unlikely.

Because clinical disclosure is credited with the power to transform the patient's experience of illness, for better or worse, its practice invites us to consider theoretical perspectives on linguistic performativity. The concept of linguistic performativity acknowledges that language, more than just a neutral container for transmitting ideas, is also a form of social action (see Duranti 1997, 214–44). According to the philosopher of language J. L. Austin ([1962] 1975), in saying something we are always also doing something. This pragmatic view of language asserts a distinction between a statement's meaning and force. For clinical disclosure, this distinction is between the propositional content of a diagnostic utterance and the action performed by uttering it within a clinical encounter.

To the extent that language can act in the world, however, such actions are always constrained by language ideologies: culturally informed, common-sense beliefs and assumptions about language use within a particular context (Irvine 1989; Woolard and Schieffelin 1994). Anthropologists have critiqued Austin's speech act theory for failing to acknowledge its contextual specificity with respect to English-language ideologies and Western cultural models of the person (Rosaldo 1982). In this way, language ideologies reflect much more than understandings of language per se. Their enactments also provide a

rich source of information about social norms, hierarchy, identity, and social reproduction and change within a cultural system.

As a ‘mediating link between social structures and forms of talk’ (Woolard and Schieffelin 1994, 55), the concept of language ideology has been particularly useful for bridging micro-interactive and macro-structural analytic perspectives on clinical communication and the performative effects of biomedical language (Briggs 2005; Pigg 2001). In this article, ‘disclosure ideology’ refers to a specific subset of language ideologies governing clinical disclosure, and ‘the power of suggestion’ denotes a particular disclosure ideology about the potentially negative effects of informing patients about AID.

Brada (2013) describes a practice of ‘disclosure catechism’ in which children with HIV in Botswana were expected to engage in repeated paired question/response sequences about the biological mechanisms of HIV.<sup>4</sup> Children recited disease-related knowledge with increasing sophistication and specificity over time, as clinicians gradually replaced euphemisms with scientific terminology in a stepwise progression, until they eventually acknowledged that the ‘bad guy’ of their earlier catechisms was HIV. According to Brada, this practice was motivated by two underlying ideological assumptions: that accurate self-knowledge would combat stigma and arm children to take better care of themselves, and that using the term ‘HIV/AIDS’ too early was dangerous and could potentially stymie self-care (see also Black 2015). These assumptions were driven in turn by a US-centric HIV-treatment agenda that viewed Botswana’s culture of silence around HIV as an inciting factor in its epidemic.

Underpinning Brada’s analysis are two disclosure ideologies common in US medical cultures. First is the notion that narrativizing one’s distress and suffering produces self-understanding and, in turn, clinical benefits; this idea asserts a metacommunicative claim about the therapeutic power of language. Carr (2006, 245) observes that ‘the talking cure is based on the assumption that words can do much more than refer to sick selves; they can also produce healthier ones’. The corollary of this idea, that ‘secrets keep you sick’, informs therapeutic approaches across a variety of clinical settings (see, for example, Carr 2006, 2011; Shohet 2007; Young 1993; Waldram 2012). As Young (1993) points out, however, the power of narrative to produce recovery lies in the ideological nature of the relationship between mental disorders and self-knowledge. From this perspective, language itself does not necessarily heal; instead, people learn how to tell the right narratives to present themselves as therapeutically transformed.

<sup>4</sup> See also Fainzang (2016, 28) regarding the role of repetition in diagnostic disclosure in a French clinical context.

I encountered the second idea – that clinical disclosure might be dangerous and even injurious to patients – in my earlier study of the politics of scripted speech in state-mandated abortion counseling; there, abortion providers expressed concerns that some of the required disclosures were explicitly designed to produce fear and shame in women seeking abortion (Buchbinder 2016). Similarly, in her ethnographic study of lying in a French hospital, Fainzang (2016) found that French physicians frequently hesitated to give patients bad prognoses because of concerns about their potential psychological responses, including the possibility that patients might commit suicide if they were to find out the truth.

The tension between these two prevalent ideologies, which respectively favor revealing and concealing, highlights that disclosure is delicate and interpersonally fraught. Drawing on research in India, Van Hollen (2017, 67) argues that it is more important to understand the relational dynamics responsible for either sharing or withholding information than it is to know whether or not physicians disclose a prognosis: ‘My research suggests that whether cancer patients or their family members looked favorably or critically on the practice of nondisclosure, *their primary concern was about the quality of care that nondisclosure symbolized* rather than about the content of the information and its usefulness for health-seeking decision-making purposes or the trauma that it might produce’ (emphasis in original). Gordon and Paci (1997) similarly argue that apparent contradictions in disclosure practices may arise from multiple conflicting ideological frames; therefore, they suggest that the cultural meaning and intent of disclosure matter as much as outcomes.

These insights regarding the relational context of clinical disclosure are particularly instructive for my purposes here. Bioethical debates about a patient’s ‘right to know’ pertinent health information often turn on considerations of individual rights, including the protection of people who may wish not to know (Konrad 2003; Sperling 2008). Yet anthropologists and sociologists have argued that models of bioethical decision making tend to privilege patient autonomy above other values and, in doing so, construe patients as isolated individuals decontextualized from their webs of social relations (Fox and Swazey 1984; Kleinman 1997). If autonomous decision making is privileged, threats to patient autonomy and vulnerability to coercion are most in need of protection in AID-related disclosure. However, as I will show, other relational factors may be equally significant.

In what follows, I shift attention from the question of whether or not there is such a ‘right to know’ that AID is a legally authorized option. Instead, I explore how disclosures of information, like the option of AID, are shaped by the power dynamics of the clinical encounter and reverberate through the social and moral worlds of terminally ill people. Because eligibility for AID requires that one be deemed terminally ill, such disclosures are always already embedded in broader prognostic judgments about ‘time left’ (Kaufman 2009).

I argue that the moral stakes of such disclosures are more complex than the question of one's 'right' to information, and instead depend on uncertainties surrounding the performative context of informing.

## Background and methods

Vermont passed Act 39 in 2013, becoming the fourth state in the United States to legalize AID. Other states include Oregon (1997), Washington (2008), Montana (2009), California (2015), Colorado (2016), and Hawaii (2018), as well as the District of Columbia (2016). Act 39 defines a terminal illness as one in which death is expected within six months. The law also contains several provisions and safeguards to ensure that participation is voluntary for both patients and physicians, and that the patient's choice remains stable over time. In addition, patients must be capable of making an informed decision; patients must be Vermont residents; patients must make two oral requests, spaced fifteen days apart, as well as a written request signed in the presence of two witnesses; the patient's prognosis and eligibility must be confirmed by a second physician; and the medication must be self-administered.<sup>5</sup> The Vermont Department of Health has released limited information about the utilization of Act 39 in its first four years. During this time, paperwork for fifty-two cases was filed, and twenty-nine people had utilized the lethal prescription as of January 2018; forty-eight had a death certificate on file, meaning that nineteen had died without ingesting the medication (Vermont Department of Health 2018). The most common diagnoses were cancer (n=43) and amyotrophic lateral sclerosis (ALS) (n=7). The number of physicians who have participated has not been published.

My primary data include in-depth interviews with 144 Vermont residents – including physicians, nurses, patients, caregivers for terminally ill patients, activists, legislators, and other policy stakeholders – about their perspectives on and experiences with the law. Included among my participants were twenty-seven caregivers of eighteen terminally ill patients who sought to use Act 39 (twelve of whom ultimately ingested the medication), and eighteen physicians who had participated in Act 39 as a prescribing or secondary physician. I also conducted participant observation at professional conferences and workshops, judicial hearings, and community education and advocacy events.

A professional transcriptionist transcribed interview recordings verbatim, after which two research assistants and I deidentified interview transcripts and ethnographic fieldnotes and

<sup>5</sup> Vermont Patient Choice and Control at End of Life Act (Act 39), VT Statutes Annotated Sec. 1. 18 V.S.A. chapter 113. <http://www.leg.state.vt.us/docs/2014/Acts/ACT039.pdf>.



analyzed them using an inductive, thematic approach and NVivo 11 Software. We organized emergent themes into a structured coding dictionary that included a definition for each of forty-four codes. Codes were then assigned to excerpts of interview text that matched the code definition by two coders, each blinded to the other's work. Research design and methods are described in more detail elsewhere (Buchbinder 2018a, 2018b). For this analysis, I focus on the 'duty to inform' code. The study received Institutional Review Board Approval from the University of North Carolina at Chapel Hill.

## The power of suggestion

In February 2018, I participated in a workshop at the National Academies of Science, Engineering, and Medicine designed to explore the evidence base and research gaps pertaining to the clinical implementation of physician-assisted death in the United States. A key message of my brief presentation was to challenge conventional approaches to communication about assisted dying. Professional medical guidelines on AID are often premised on an unstated assumption that any conversation about AID ought to begin with a patient's request; this is evident in the guidelines' focus on responding to requests, rather than communication about AID more generally (Quill, Back, and Block 2016). I had grown suspicious of this starting assumption because my research had demonstrated stark inequalities in access to Act 39, including different levels of awareness of AID as a legally authorized option (Buchbinder 2018a). Having had multiple opportunities to explain to strangers or acquaintances with no connection to Act 39 just what I was doing in Vermont over the course of my fieldwork, I knew that the general public was not well informed about Act 39's requirements or affordances. As a medical anthropologist, I also knew that power imbalances in the patient-physician relationship might make patients from racial/ethnic minorities or socioeconomically marginalized groups feel uncomfortable initiating such requests (Dubbin, Chang, and Shim 2013; Kuipers 1989; Lazarus 1988). For these reasons, it seemed likely to me that waiting for a patient to request AID would reinforce access disparities by making it more available to affluent, well-educated, white patients (Buchbinder 2017).<sup>6</sup> While I acknowledged the potential sensitivity of a physician initiating a conversation

<sup>6</sup> It is worth noting here that Vermont's population is 95 percent white, so racial diversity among patients accessing AID is not to be expected.

about hastening death, I suggested that there might be situations in which it would be appropriate for a physician to do so.<sup>7</sup>

I recognized that my ideas would be controversial, not only because US physicians are notorious for avoiding death talk but also because the notion of mitigating access barriers for the poor challenged the logic of longstanding concerns that socioeconomically marginalized groups may be vulnerable to coercion in the context of AID. Nevertheless, I was surprised when a member of the planning committee said, as part of his summary remarks, ‘it was clear from the presentations . . . that patients must opt in rather than be offered these services by providers’ (NASEM 2018, 7-3). I understood his point about ‘offering’ to mean that physicians should not inform qualifying patients about AID, but should rather wait for them to ‘opt in’, presumably by making a request. This comment seemed to disregard the central thrust of my remarks, quoted in the summary report for the meeting, that ‘we need to be thinking about “circumstances in which it might be ethically permissible for physicians and nurses to inform qualifying patients about aid-in-dying”’ (NASEM 2018, 3-14). Conventional disclosure ideologies around AID, it appears, are quite tenacious.

In my interviews, physicians and nurses articulated a range of reasons for avoiding such discussions unless initiated by a patient, yet most of their concerns focused on the potential for harm to the patient-provider relationship or the potential to influence the patient’s decision-making process. Ruby Cooper, an oncology clinic nurse coordinator, explained to me, ‘We never bring it up. It’s something that somebody else brings up with you’. When I asked her why, she elaborated:

I think you have to be careful about how people feel about this. And let’s say, for example, that you have a relationship with the patient and the family, and it’s a comforting, trusting relationship and they happen to be individuals who are completely against this. If I bring that up and it’s something that they wouldn’t even consider, that could create a huge scar in that relationship. And so, again, they can bring it up and then you know that the door is open to that conversation. But unless that door was opened, I would not bring it up to a patient.

<sup>7</sup> While this position will likely strike some readers as overly prescriptive, I see my contribution to this debate as a form of anthropological critique – insofar as I have drawn attention to the unexamined assumptions inherent in the conventional wisdom around waiting for a patient’s request – and not as taking a moral stance on the practice of AID itself. The view that physicians should potentially, under certain circumstances, inform patients about AID in jurisdictions where it is legal is not incompatible with my underlying ambivalence about whether AID constitutes good public policy.

Ruby suggested that mentioning AID as an end-of-life option with a patient who opposed the practice could irreparably damage the patient-provider relationship. If this conversation was a kind of a passageway to a new stage of end-of-life counseling, Ruby would not step over the threshold unless the patient first welcomed her in.

Dr. Alanna Reynolds, a hospice physician who had prescribed under Act 39 and described herself as an AID advocate, was more ambivalent than Ruby.<sup>8</sup> Ultimately, however, she came down on the side of not informing patients due to concerns about her potential influence.

I'll think to myself, 'Should I bring up Act 39?' And then I feel conflicted about it because I feel like it's a really patient-driven thing, and so I don't want to bring it up to them. I don't want them to feel like what they're going through isn't valuable. So, I don't typically – I will bring it up if people are asking questions that kind of indicate that they've reached a point – I try not to bring it up directly, actually, because I don't want to influence people.

Both Ruby and Dr. Reynolds were committed advocates; their objections were not to Act 39 itself, but rather to informing patients about it. While Ruby focused on the relational implications of introducing a culturally and morally contested topic, Dr. Reynolds worried about potentially contaminating the decision-making process. Although she stopped short of describing such conversations as coercive, the specter of coercion nevertheless threads through her remarks. In both cases, concerns about the performative effects of clinical language and the possibility for harm, which I gloss here as 'the power of suggestion', animate their moral reasoning and their stance on informing.

On the other hand, many of the physicians I interviewed indicated that there were circumstances in which they might initiate a discussion of AID as an option in the absence of a patient's request.<sup>9</sup> While some indicated that these circumstances would be somewhat unusual (for example, a patient threatening to shoot himself), others brought it up more regularly, as part of the 'slate of options', as one physician put it. In justifying this approach, several providers specifically mentioned concerns about patients' access to information. Dr. Lila Maupin, a family physician, said, 'Sometimes different topics make me, as a provider,

<sup>8</sup> See Buchbinder (2018b) for a fuller discussion of hospice policies around Act 39.

<sup>9</sup> Out of twenty nurse practitioners and physicians in the Vermont study sample who discussed their informing practices in their interviews, twelve indicated that they initiate discussion about AID with patients at least some of the time (Brassfield and Buchbinder, n.d.).

uncomfortable to bring [it] up, but I know I need to, and it's [in] the best interest [of] the patient. . . . With really obese patients, I bring up bariatric surgery, but they won't bring it up sometimes, but I feel obligated to offer them that'. While Dr. Maupin acknowledged that AID and bariatric surgery are very different, she suggested that physicians may avoid both topics due to their own discomfort, which might not be in the patient's best interest.

These divergent perspectives on informing patients about AID are tied to competing language ideologies surrounding clinical communication. Some physicians, like Dr. Maupin, focus on the content of clinical communication, emphasizing their responsibility to convey information to patients so that they can make informed decisions about their care. This perspective regards language as a relatively neutral vehicle for transmitting health-related information. Others, like Ruby Cooper and Dr. Reynolds, view clinical communication as an arena for a dynamic, performative act (informing), expressing legitimate concerns about the possibility of harm.

That these divergent perspectives denote distinct ideologies of clinical speech is underscored by the different language employed by representatives of each viewpoint. Notice that the physician at the National Academies workshop maintained that assisted death cannot be 'offered' to patients. In defending the same position, Cohen-Almogar (2003, 97) poses the question of 'whether a physician should *suggest* euthanasia to his or her patients' (emphasis added):

With respect to professional ethics, talking about euthanasia upon a patient's request is different from suggesting it to the patient. By suggesting euthanasia to a patient, the physician implicitly includes euthanasia in the canon of proffered rational treatment options. In light of the professional authority that she is offering, she thereby establishes euthanasia as a rule, and not as an exception. This conduct conflicts much more with the role of the physician as a healer than it is the case if the physician talks about euthanasia upon the patient's request.

In this account, Cohen-Almogar casts informing as suggesting and concludes that 'suggesting' communicates an implicit endorsement, thereby changing the scope of the physician's role as healer. At the same time, it appears that discussing euthanasia 'upon a patient's request' is morally uncomplicated for him. Yet Cohen-Almogar does not address the power dynamics that might constrain the patient's capacity to initiate a such a request. I would argue that professional authority is not 'offered' by the physician, as Cohen-Almogar proposes. Instead, it is structured into the power dynamics of the clinical encounter, in which a terminally ill patient is inescapably vulnerable. Such dynamics can make it very challenging for a patient to make such a sensitive and potentially stigmatizing request. If physicians are concerned about the relational fallout of introducing the option of AID, it is

important to remember that such consequences could easily cut both ways; a patient's request might ultimately be just as damaging to the patient-provider relationship as a physician's introducing the topic.<sup>10</sup>

Moreover, 'informing', 'offering', and 'suggesting' are distinct speech acts that differentially construe the speaker's agency and intentions with respect to the information being conveyed. While a physician may 'inform' patients about an option to which she remains neutral, to 'suggest' something implies a preference for a certain outcome, and 'offering' implies a gift, which comes with an expectation of acceptance. The selection of each of these terms thus encodes a bias about the metacommunicative function of clinical language. In other words, to speak of 'offering' or 'suggesting' AID implies that the physician can never merely inform because of her social influence.

Austin's ([1962] 1975) distinction between illocutionary and perlocutionary acts can help to illuminate this point: informing is an illocutionary act with a conventional force, while the perlocutionary act is an action we bring about by informing. For example, suggesting may be the perlocutionary act brought about by informing. As Austin ([1962] 1975, 110) explains: 'We must distinguish the illocutionary from the perlocutionary act: for example we must distinguish "in saying it I was warning him" from "by saying it I convinced him, or surprised him, or got him to stop"'. Aligning with Austin's argument, many physicians and bioethicists are skeptical that one can inform patients about AID without uncontrollable perlocutionary effects.

On the other hand, if we accept that clinical communication about AID must begin with a patient's request, we must acknowledge that a request, too, is a specific kind of speech act that may be more felicitous in certain circumstances and among certain kinds of actors. Fainzang's (2016) ethnography of lying in a French hospital reveals that, while doctors may believe that patients should only be informed to the extent that they want to be, many patients report not knowing whether or how to ask for such information. Waiting for patients to make a request only makes sense within a context in which patients feel empowered to make such requests of their health care providers – and one in which providers are willing to listen and respond.

<sup>10</sup> For example, several activists from my study commented to me that they had broached the topic of AID with their primary care physicians, although they were not currently ill, and knew that they would eventually need to find new physicians due to their physicians' opposition. Such examples make clear that asking about AID is morally loaded, with potentially powerful consequences.

In order to understand the social, ethical, and linguistic stakes of informing patients and families about Act 39 in Vermont, I now turn to two ethnographic cases that showcase what happened when a physician informed a patient of the option of an assisted death. In neither case was the patient inclined toward AID, and in both cases family members responded with serious concerns. Therefore, these are cases in which concerns about the potential for harm were warranted. Nevertheless, their outcomes illustrate that quite different possibilities are created when people are exposed to information. This underscores that informing patients about AID may yield different perlocutionary effects. As I will show, these possibilities depend on the relational context of informing as much as the referential content of the information expressed.

### ‘God’s time’

The first thing that I noticed about Cora Tremblay when she opened the door to her cream-colored single-story home was that she was not dressed in the plain, utilitarian style I had come to expect from Vermonters. Rather than sandals and jeans, Cora wore a calf-length fit-and-flare dress, hosiery, and a light cardigan sweater. Her outfit was finished with a lightweight patterned scarf, a pearl-encrusted necklace, and bright lipstick. She smiled warmly and led me through the kitchen, where a simple wooden cross adorned one wall, to a sunlit sitting room at the back of the house. There, she recounted the story of her husband’s illness and death over an emotionally charged two-hour interview.

Cora’s husband, Arnold, had died from terminal cancer the previous spring, after outliving his initial prognosis by many months. Arnold had been proud of reporting that he had ‘flunked hospice’. Following a protracted hospitalization and near-death experience, his symptoms stabilized and he returned home to Cora’s care, and was even disqualified from hospice. Eventually, however, the cancer spread to his brain and bones. Arnold’s primary care physician, Dr. Greg Wright, warned Cora that a steep decline was likely, with a strong possibility of seizures and falls in the weeks leading up to death.

Around this time, Cora recalled, Dr. Wright ‘presented [Act 39] as an option’. At a time when Arnold was running out of options, he was reassured to have a fresh one. Cora explained:

When it was presented, Arnold said, ‘it is an option’ – and he had explored every option available. Experimental research, anything the doctors told him, chemotherapy, radiation, surgeries, medication at home, injections, and he was in four different hospitals. . . . So, it was an option and I agreed to have – Arnold said, ‘We could have it in the house, I just, I just want it as an option. I may not exercise the option. It’s an option’.

For Cora, who hailed ‘from a family of faith’, the idea of hastening death was inimical to her conservative Christian worldview. She explained, ‘I believe in a natural – that, to let God take [Arnold] up in His time. I’m a religious person’. Cora and Arnold had both opposed Act 39. However, Cora’s commitment to her husband and her strong desire to honor his wishes outweighed her reservations. With a great deal of reluctance, she filled the lethal prescription and agreed to keep it in the house. She knew that Arnold found it reassuring to have the medication in the house, and she herself was reassured by the possibility that he might never decide to use it. To forestall such a decision, Cora made sure that Arnold’s pain was well medicated. She protected his dignity by helping him use the bathroom, so that he could avoid wearing diapers, and bathing him in an intimate manner without help from a home health nurse – an act that was physically taxing due to his large size, and that resulted in a long-term injury for Cora. Ultimately, Arnold died in his sleep, without taking the medication. Cora recounted: ‘He just went to sleep very peacefully. He had a very beautiful peaceful death and I’m comforted by that and it was a natural death and we did not use the Act 39’.

After hearing Cora’s story, I was surprised that Dr. Wright would have initiated a conversation about AID with such a deeply religious couple. It was very unlikely that he would have been unaware of Arnold and Cora’s faith; it was evident to me within minutes of meeting Cora. Furthermore, Cora had told me that when Arnold had been receiving hospice services, and Dr. Wright had shared his uncertainty about how much time he had left, Cora had countered, ‘Well, we’re praying for Arnold, and he’ll die in God’s time’. Given the number of physicians who had reported to me that they would avoid discussing AID with a religious family out of fears of damaging the relationship, I asked Cora whether she was upset with Dr. Wright for mentioning Act 39. She responded:

Oh, when he brought it up, was I upset? I was upset, but only as a conservative Christian. And then when Arnold said to me afterwards, ‘He’s just presenting an option’. Then I went back and read it online, and he’s a doctor in Vermont, so he’s presenting it as an option. And he’s a compassionate man. There’s no doubt he’s a compassionate man. I have no issues with Dr. Wright. I felt he was doing his job. No. The answer’s ‘no’.

Cora firmly rejected my presupposition that Dr. Wright might have provoked harm by mentioning AID to her husband. Her response offers a striking rejoinder to the claim of some of my interlocutors that the topic of AID should be altogether avoided with religious patients. Concerns about the potential for harm to the patient-provider relationship were mitigated in Cora and Arnold’s case by their understanding that Dr. Wright was a compassionate and supportive physician. There was something unmistakably compassionate

about Dr. Wright's giving Arnold more options (and perhaps some hope) at a time when other options were dissipating. And, it was because Dr. Wright was compassionate that Cora viewed the act of informing as within the scope of 'doing his job' and not an attempt to push his values on them.

Given that much of the bioethical concern about informing crystallizes around the potential for undue influence, Cora and Arnold's framing of Dr. Wright's disclosure about Act 39 as 'presenting an option', rather than 'suggesting' or 'offering', is reassuring. This linguistic choice suggests that they perceived Dr. Wright as having a neutral orientation to the information at hand, and to Arnold's potential choice to hasten death. On the other hand, Cora also indicated that Arnold 'did everything that was suggested to him' by his doctors. For Arnold, AID was just one more health care option extended to him by a caring clinician, and he was averse to declining it. From this perspective, filling the lethal prescription was similar to countless other health care decisions over which physicians like Dr. Wright can exert a powerful influence.

At the same time, having AID as an option restored Arnold's capacity to make an active choice at a time when terminal illness was otherwise stripping away his agency. In this respect, the performative effects of informing were quite the opposite of those imagined by critics: rather than influencing Arnold to make a particular choice, Dr. Wright's informing Arnold of this option helped to restore Arnold's decisional agency. Ultimately, the availability of Act 39 enabled Arnold to choose against hastening death in a context in which few choices were desirable or possible (see also Norwood 2009).<sup>11</sup>

## Unintended effects

'Are you my interviewer?' a bright-eyed, middle-aged woman asked warmly, sticking her head out from around the corner of the reception desk. It was a Monday at noon and the waiting room of the community-based neurology clinic had emptied out for lunch. She seemed amused by the fact that she had an interviewer, as if doubting that she had a story worth documenting. I said that I was, and she invited me into her office, which was small, yet homey, with antique furniture and a petite leather loveseat where I perched myself.

<sup>11</sup> The reassurance offered Arnold by having the medication on hand without ever ingesting it mirrors the findings from Norwood's (2009) important ethnography on euthanasia in the Netherlands, in which she argues that euthanasia discourse only rarely culminates in euthanasia death, and that the cultural value of euthanasia functions more as a social discourse about control, independence, and the prevention of social death.



Dr. Terri Nichols was a strong proponent of Act 39, a fact that was well known in her local community. She did not have moral objections to AID, and believed that it was part of her job to ensure that it was done correctly. 'If I can do it for a patient who really seeks it out and wants to do [it], I think it's their right', she explained. At the time of our interview, she had initiated the process three times, but in two cases it was not completed because the patient's disease progressed too quickly.

Dr. Nichols was frank about her commitment to informing patients about AID as a matter of routine practice. 'I think I want my patients to understand everything that's available and I don't think it's fair to leave a patient in the dark. Whether or not they want to do it or ethically agree with it is not the issue', she said. The issue, instead, was the patient's 'right to know'. She subscribed to a disclosure ideology that emphasized the physician's responsibility to convey all relevant information to patients. Her commitment to this viewpoint did not waver even after a challenging encounter in which a family member threatened her for initiating a conversation about Act 39. Dr. Nichols told me about the case of Ernestine Andrews, an elderly woman with cancer that had metastasized to her brain. After her oncologist told her that the brain tumors were inoperable, Ernestine came to see Dr. Nichols for control of her seizures. The doctor recounted the story for me as follows:

She came with her little husband, they're a very cute couple, and we're talking about how to control the seizures, and what we might try, and what's going on. And I said, 'You understand what this is, right, and you understand what the prognosis is, right?' And they did, and we went over that before I even brought up the topic, and I said, 'So you need to also understand that in Vermont we have a law that should you feel that you want to access this law it's there for you, and here is what the law is, right'. I didn't say, 'I think you should do this', I didn't say, 'this is what I want you to do', I didn't say, 'this is the right thing to do'. I said, 'You could get hospice, but this is where we're headed'. And it seemed like no one had made it really clear to this woman, even though they sent her to me after she had seen oncology, and neurosurgery, and had regrowth of tumor. No one had really, it seemed, made it very clear to her that you're not going to live six months at this point, right, we're at the end here and you've got to figure out what you've got to do and be prepared.

This narrative reveals how the decision to introduce AID as an option is always embedded in larger decisions about prognostic disclosure, insofar as being eligible for Act 39 requires an acknowledgment that the patient is expected to die within six months. In this case, the Andrewses did not seem to have fully grasped her prognosis before Dr. Nichols mentioned AID. The couple did not signal a strong interest in AID, but they thanked her and said they would think about it. They decided how to treat the seizures and scheduled a follow-up

appointment. They had spent an hour and twenty minutes talking, and Dr. Nichols thought that they had established a good rapport. Several days later, however, Dr. Nichols received an angry telephone call from the couple's daughter, which she recalled as follows:

[Ernestine's] daughter, who had found out [that I had mentioned AID] later from the daughter's primary care doctor – the daughter is wacky – called me up, verbally threatening me on the phone, screaming at me on the phone. So I got on the phone and I heard her out that I'm the world's worst doctor, and how dare I do this to her mother, and I ruined the rest of her mother's life, and now her mother's going down the tubes and it's my fault, and, you know, she wants to know exactly what was said to her mother when her mother was here. So I said, 'Okay if there's a release signed by your mother or your father and they want me to talk to you about this, otherwise I can't talk to you about this'. I heard everything she said, and I just kept saying, 'if you get a release'. So she sent us a fake release that the mother didn't sign, and she threatened to be outside waiting for me when I got out of the office. We had to get a restraining order against her. It was horrible. So she said, 'I'm never letting my mother come back to see you'. They didn't come back. But they also didn't sign a release for her to talk to me. So it was really horrible. And, you know, so I really wished she had been with the parents the day they were here. So she could have heard, but I'm not allowed to say, 'this is what happened'. So it was a really bad experience.

The reaction from Ernestine's daughter offers a critical challenge to the practice of affirmatively informing patients about AID prior to an explicit request. It is unclear whether Ernestine's daughter was reacting to the suggestion that her mother might wish to pursue AID or to the upsetting realization that her mother's death was imminent. In this respect, initiating a discussion about AID raises challenges similar to initiating a discussion of hospice, which can elicit negative reactions from patients and families because it signals the foreclosure of hope (Mrig and Spencer 2018). Even though Dr. Nichols apparently presented the information carefully, avoiding value judgments, the information took on a life of its own when it traveled outside of the clinical encounter. Despite Dr. Nichols's sensitivity and the superficially successful clinical exchange, Ernestine never came back for help with her seizures, and Dr. Nichols was compelled to obtain a restraining order against Ernestine's daughter. I wondered whether this experience had made Dr. Nichols more cautious about introducing the topic of AID, and asked her as much, but she said, 'no'. 'I don't think it's going to change what I do', she said. 'But it's a little scary when people are threatening you'.

Dr. Nichols felt she had a moral obligation to inform patients about what she viewed as an appealing end-of-life option:

My feeling is we see a lot of ugly death, we see a lot of suffering at the end of life. . . . I go to the people's houses when they die, right? And so, having seen it, like I told you, with my friend, the ninety-two-year-old man who died, you're very sure, you know, I wouldn't do this to someone. I wouldn't want another human being to suffer through this. They're going to die anyway. Like if they had the choice to not have to do that, how dare I not offer that to them, right?

This statement highlights how, for her, informing terminally ill patients about AID is not only a matter of upholding the possibility of choice but also of conveying compassion. In much the same way that Cora and Arnold extolled the benefits of having 'an option', Dr. Nichols's disclosure ideology positions sharing information about AID as critical to supporting patients' autonomy in end-of-life decision making and allowing them to avoid unnecessary suffering at the end of life.

Nevertheless, the social and ethical risks of informing are high, and her account validates critics' concerns regarding the risks of doing so. Informing Ernestine about AID set off a ripple of events that Dr. Nichols could hardly have anticipated, culminating with a legal intervention against her patient's daughter. Given that Ernestine never returned, informing may also have caused irreparable damage to the patient-provider relationship.

What lessons ought we to draw from this case? When we compare this clinical encounter to the long-term relationship between Dr. Wright and Arnold and Cora, it becomes clear that Dr. Nichols was missing pertinent information about the relational context of her disclosure. Because it was her first time meeting the couple, she was not attuned to the daughter's absence as a possible source of relief or tension. When the daughter contacted her following the appointment, Dr. Nichols had no way of knowing whether or not Ernestine would have welcomed her daughter's participation in the discussion about AID. The stressful aftermath of this encounter underscores the importance of carefully considering who is included in the clinical context of disclosure and with what possible effects. Conventional disclosure ideologies may overlook the fact that individuals are embedded in social relationships, and that information may come to be absorbed by social worlds beyond the discrete moment of the clinical encounter. Moreover, the fact that Dr. Nichols required a signed release to discuss this conversation with Ernestine's daughter highlights that health care providers confront multiple medico-legal constraints on disclosure beyond contested ethical norms. Informing patients about AID is never isolated from the broader regulatory complex that governs contemporary biomedicine.

The figure of the enraged daughter also exemplifies cultural concerns regarding older persons as particularly suggestible, and hence more vulnerable. The insinuation that

Ernestine went ‘down the tubes’ because of the clinical disclosure (and not because of her terminal cancer) aligns with cultural concerns about the power of suggestion. The notoriety and fears that attached to Beth Neill’s narrative of abuse underscores how older adults in the United States are often cast as particularly vulnerable to such influences. However, the type of influence at stake here does not assume a conventional bioethical form. The daughter’s concern was not that her mother was influenced to choose AID, but instead that she fell prey to a subtler form of suggestion: the self-fulfilling nature of a terminal prognosis (Christakis 1999). From this perspective, the performative function of clinical disclosure had collateral effects beyond expanding Ernestine’s choices or extending her agency.

## Discussion

Medical anthropologists have long been concerned with understanding how moral agendas, state power, and other structural forces are imbricated within the clinical encounter (see, for example, Cooper 2015; Gammeltoft 2014; Lazarus 1988; Maternowska 2006; Rivkin-Fish 2005). I have argued here that linguistic anthropology offers another set of perspectives and tools for enhancing medical anthropological theorizing in this arena. Disclosure practices in medicine are a particularly productive site for the integration of medical and linguistic anthropologies because they reflect cultural norms, values, and assumptions regarding clinical communication and communicability. Briggs (2005) introduced ‘communicability’ to refer to the productive processes by which disease-related knowledge is differentially communicated and received, and the ideological processes that shape and naturalize such patterns of distribution. While Briggs is principally concerned with journalism as a form of health discourse, public debates on bioethical matters constitute another communicative form through which health-related knowledge circulates. My analysis shows that a linguistic approach can enhance understandings of these communicative processes and their implications for health care, broadly conceived.

Physicians, bioethicists, and anti-AID activists in Vermont SAID expressed a range of concerns about proactively informing patients about AID. They worried that doing so might lead to a cascade of harmful consequences, such as damaging the patient-provider relationship or influencing the patient’s decision making. These concerns underpin a disclosure ideology widely held in contemporary medical ethics that discourages informing patients about AID. Beth Neill’s story exemplifies such conventional bioethical concerns insofar as it suggests that informing patients about AID can lead to a slippery slope in which ineligible patients are repeatedly and inappropriately offered AID in a way that could become coercive.

The two ethnographic vignettes presented here offer a contrasting perspective on the social, linguistic, and moral stakes of informing. The Tremblays viewed their physician as simply

‘presenting an option’ regarding Arnold’s medical treatment. Cora did not seem concerned about the power of suggestion, even though she acknowledged Arnold’s suggestibility. And despite Cora’s moral opposition to AID, for her, the foremost disclosure ideology was a belief in the patient’s right to information and the importance of retaining end-of-life choices. These values were similarly reflected in Dr. Nichols’s disclosure ideology. She felt an ethical imperative to maintain the possibility of choice in the face of death, particularly given the realities of what she called ‘ugly death’, and was far less concerned with the productive potential of such disclosures, even after experiencing harmful effects firsthand.

In order to understand the risks of disclosure, we need to look beyond the information at hand and examine how informing can yield quite different effects across different communicative contexts. This point echoes previous anthropological studies highlighting how the relational context of medical disclosure can shape and challenge understandings of the putative ‘right to information’ (Konrad 2003; Sperling 2008), as well as Norwood’s (2009) research affirming the central role of families in euthanasia discussions. Conceptualizing disclosure as a performative clinical process reveals how the social effects of disclosure unfold in time and space beyond the clinical encounter, in ways that challenge conventional bioethical concerns regarding abuse, threats to autonomy, and vulnerability to coercion. My analysis suggests other productive possibilities for the power of suggestion, not all of them negative. Informing may produce relational challenges outside of the patient-provider dyad, as we saw with Dr. Nichols. Yet, as we saw with Arnold Tremblay, it may also expand one’s range of choices and bolster decisional agency, irrespective of whether the patient ultimately pursues AID. Such stakes of disclosure are poorly served by traditional bioethical models of moral deliberation and decision making, which emphasize patient autonomy above other relevant factors. Instead, an ethnographic approach reveals how the moral stakes of disclosure may be marked by ambiguity and uncertainty, inviting a less decisive stance on disclosing the option of AID.

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