

# Reflections on “Aid in Dying” and the Paradox of “Achieving Death”: Avoiding the Confluence of Language and Ideology at Life’s End

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## I. Introduction

The subject of aid in dying has been front and center in New York for several years in the context of legalization debates that have been spearheaded principally by two advocacy organizations, End of Life Choices New York and Compassion & Choices. These debates have intensified in light of activity in other states and high-profile media attention to individual cases, such as that of Brittany Maynard. New York has seen the introduction of an aid in dying bill,<sup>1</sup> as well as litigation in the case of *Myers v. Schneiderman*.<sup>2</sup> The New York Court of Appeals handed down its decision in the case in September 2017, ruling that there is no fundamental constitutional right to aid in dying in New York as defined by the plaintiffs. A recent article in this New York State Bar Association *Health Law Journal* reviewed in detail legislative efforts in New York to establish medical aid in dying as a right.<sup>3</sup>

The focus of our particular commentary is to address in a non-ideological manner bioethical, clinical, and public policy issues about aid in dying that have not received sufficient attention in public forums to date, or have perhaps been given an ideological and libertarian slant. Drawing on interdisciplinary perspectives, the authors seek to reframe the debate about a complicated problem not amenable to technical or simplistic fixes that will not meet the need of most patients and families.

## II. From Ideology to Understanding

Proponents of aid in dying have framed the goals of the movement as an extension of patient self-determination that would encompass a right to aid in dying, also known as physician-assisted suicide (PAS).<sup>4</sup> In this article, we address ethical issues related to the practice known as physician or medical aid in dying. Under either term, this practice involves physician-prescribed lethal medication to a terminally ill, competent patient for the purposes of such patient’s self-administration of such medication to end his or her own life as he or she chooses. (Other practices that would involve intentional acts by a third party to bring a physically or mentally ill person’s life to an end through administration of lethal medication or injection, such as euthanasia, are legally permitted in some countries, but are not legal or under active consideration in the United States at this time and will not be discussed here.)<sup>5</sup>

Often motivated by libertarianism or neoliberal ideology,<sup>6, 7, 8</sup> which may be less progressive than it seems, this expansion of patient autonomy represents an illusory desire to control the timing and manner of death. But it is

a hollow quest. Physician aid in dying will neither negate the dread of death nor its sad aftermath. As the bioethicist Daniel Callahan has wisely written, no matter the desire for control, we cannot escape our mortality.<sup>9</sup> It is simply out of our hands.

Moreover, death is not an atomistic event affecting only the patient taking her/his own life. Most of us are embedded in families and larger social and cultural contexts, and there can be consequences for complicated bereavement when aid in dying occurs and there is unresolved conflict over the action.

All this complexity is obscured by the language of those who favor aid in dying. At a conference held at the Sandra Day O’Connor Law School focusing on dementia, brain injury and disorders of consciousness, a national proponent of aid in dying spoke rather eloquently and convincingly not about dying, but rather what was described as “achieving death.”<sup>10</sup> It was not clear what this meant, and whether the speaker intended to frame death and dying as a type of accomplishment.

Efforts to reduce aid in dying to an individual achievement or “good death” fail to account for the complexity in experience of suffering and death, dying, and bereavement. Dying is not a usual sort of achievement, but a passage with consequences. Changing the language leads to connotations that obscure differences with serious implications both for professional practice and for patients. For example, PAS is represented as aid in dying, seeking to conflate the multiple ways in which doctors help patients die, such as withdrawal or withholding of life-sustaining therapies (LST) and DNR orders. Indeed, language in the New York State Bill on “Medical Aid in Dying” suggests that PAS is no different from other ways that patients receive care at life’s end. This obscures important differences that we need to explicate.

Previously, each one of us has argued that there is a valid distinction between PAS and decisions to withhold or withdraw life-sustaining therapies.<sup>11, 12</sup> While this itself warrants an essay-length explication and is not the subject of our article here, suffice it to say that the argument hinges on causality and intent. Consider the example of two patients on a ventilator. The first has Acute Respiratory Distress Syndrome (ARDS) and respiratory failure. The second had general anesthesia for an operative procedure. If the ventilator is removed from both patients, once the second patient has recovered from anesthesia, death will occur in the first but not the second case. In this case, the mere removal of a ventilator is necessary for the first pa-

tient to die but insufficient in the second. In the first patient, extubation removes an impediment to death, allowing a natural process (ARDS) to proceed to its biological conclusion. The same action in the second patient leads to the recovery room because there was no longer a need for ventilation once the patient's level of arousal returned to normal. Thus, a withdrawal of LST only leads to death in patients who continue to need LST. A similar argument can be made for decisions to withhold LST. Only patients who are having a cardiac arrest need resuscitation.

Contrast these actions, whose outcomes are predicated upon specific biological realities (ARDS and cardiac arrest), with assisted suicide. When a patient is given a lethal dose of medication to self-administer, the medication, versus an underlying disease process, is the proximate cause of death. While one could argue that medication is only provided to patients who have a terminal illness, this stipulation does not address the causality question, which is further compounded by the challenge of accurate prognostication at the end of life as carefully explicated by Nicholas Christakis.<sup>13</sup>

Another key distinction is that of intention. In the context of intending to treat pain with escalating doses of medication necessary to achieve analgesia versus a fixed dosage that is known to cause death, the former action may have a double effect, a foreseeable but not intended consequence of death, but the latter is meant to unambiguously cause death. In sum, both causality and intentionality distinguish PAS from decisions to withhold or withdraw LST and the provision of high doses of pain medication to alleviate significant patient distress.

There also is an attempt here to say that the public needs aid in dying because we have no other remedy to "achieve death," as many proponents would assert. Indeed, the New York State Bill suggests that medical aid in dying is an *alternative* to palliative care. This seems to undermine the importance of palliative care and its known efficacy. Such conflation only breed fear, and prompt people to support desperate measures because they worry that they will be abandoned and die in pain.

We can mitigate these fears with good palliative care by teaching it well in New York State<sup>14,15</sup> and not undermining its legitimacy as the New York State Bill seems to do by casting PAS as an equal alternative. Medicine is not powerless. We can control the pain and symptom burden that may occur at life's end. We can temper the use of aggressive, but disproportionate, medical technology. We can talk with patients and families about forgoing resuscitation and opting for comfort measures.

We can even withdraw LST when it no longer serves a patient-centered purpose. And, if the pain is too great, we can sedate patients with strong medications to ease their passage. These palliative care interventions are distinct from deliberately ending one's life and consistent with long-established medical and ethical norms. In a

moral universe where *intent and intentionality matter*, these decisions must be distinguished from physician-assisted death.

### III. *Vacco v. Quill* and *Washington v. Glucksberg*

This concern about intent was notable in the 1997 U.S. Supreme Court assisted suicide cases, *Vacco v. Quill*<sup>16</sup> and *Washington v. Glucksberg*.<sup>17</sup> In rejecting a constitutional right to assisted suicide, the Court—Chief Justice Rehnquist himself—affirmed a right to palliative care, including pain medications, which might secondarily hasten death. Notably, it was asserted that pain management efforts were not intended to cause respiratory cessation, but that because this outcome was secondary to the goal of pain management, it was morally acceptable. This became known as the doctrine of "double effect," which clarifies that such instances are not assisted suicide but appropriate palliative care. The late Robert Burt, then Sterling Professor of Yale Law School, made this point in a *New England Journal of Medicine* at the time.<sup>18</sup>

*Quill v. Vacco*<sup>19</sup> was also important because the litigants sought to conflate withholding and withdrawing LST (which law and ethical consensus support) with PAS. Invoking the Equal Protection Clause of the Fourteenth Amendment, litigants in the Second Circuit *Quill v. Vacco*<sup>20</sup> case asserted that if there were a right to withhold or withdraw LST, there should also be a right to PAS. The Second Circuit agreed and SCOTUS reversed, rightly noting that the Equal Protection Clause only guaranteed equal protection to folks who were *similarly situated*.<sup>21</sup> As noted, patients on a ventilator that might be withdrawn, or those who are in imminent need of LST that might be withheld, are in quite a different position than those who need an affirmative action to end a life with PAS.

There is another potential consequence to conflating PAS with LST. Should the political tides change, one could see the rejection of PAS extending in a retrograde fashion to decisions to withdraw or withhold LST. Here the false invocation of the Equal Protection Clause would have a regressive effect. It would paradoxically erode liberties by bringing additional scrutiny to decisions at life's end that are now more routinely approached.

An expansion of rights to include assisted suicide could also undermine well worn rights at the end of life by forcing a more critical examination of motivations for acts that might either be construed as falling under "double effect" or a proper withdrawal of LST or as assisted suicide. This concern is more than hypothetical if we consider arguments made by Supreme Court Justice Neil Gorsuch in his volume, *The Future of Assisted Suicide and Euthanasia*.<sup>22</sup> In the book's final chapter, arguments are made that might either be construed as falling under double effect or as relitigating well-established rights of surrogate decision makers at the end of life. While Gorsuch accepts the right to refuse LST, he does so with the provision that these refusals are only acceptable when

death is not the goal, that is, when it is not sought. He argues that any decision or action that would involve the intentional taking of human life would contravene what he describes as “the inviolability-of-life principle.” Those who seek to expand rights to include assisted suicide should be careful not to engender regressive responses that would undermine the liberties that have been hard won at life’s end.<sup>23</sup>

The risk of constricting rather than expanding rights in the current environment is further complicated by the tragedy of the current opioid epidemic. We already see how access to opioid pain relief for people with chronic pain and at the end of life has been adversely affected by the national epidemic of opioid abuse and how this has been politicized. Those who live by the proverbial ideological sword can also have their arguments undercut when the same logic is applied in reverse. Hannah Arendt called this the error of logicity, in which acceptance of a first false premise can lead to logical conclusions that are wrong because of the initial predicate being erroneous.<sup>24</sup> Here the false conflation of PAS with other end-of-life choices leads to the potential error of logicity.

The best remedy to avoid such errors is to be sure that the application of these principles fits the evidentiary predicate in the first place. Patients receiving or in need of LST are different from patients who are fearful of future distress and want to invoke a negative right to be alone. Those who would forgo treatment in order to die are in a fundamentally different position than those who want, and request, an affirmative action so as to die.

#### IV. The Language of Good Intentions

The ideological manipulation of language at life’s end to achieve political goals has important clinical repercussions because it recasts how doctors think about their obligations. It will become easier to jump to unexamined conclusions about patient wants and needs, sometimes distorting the very autonomy that “death with dignity” seeks to protect. While this is speculation, this is an arena for potential abuse.

Consider the case of a patient with endocarditis secondary to intravenous drug abuse who was hospitalized in the intensive care unit with a spinal cord abscess involving cervical spine level c3-c5.<sup>25</sup> He had septic emboli to his brain and lungs, compromising both his level of arousal and his respiration. Because of cervical cord compression at the origin of the phrenic nerve, the patient needed to be ventilated.

Unconscious and in critical condition, the patient’s mother consented to a DNR order. A few weeks later the patient regained consciousness. Essentially locked in because of his spinal cord lesion, he began to communicate with his eyes. His doctors called for an ethics consult because he had indicated that he wanted to die and have

his endotracheal tube removed. They asked for an ethics consultation to validate this request so that they could honor his wishes and allow a “dignified death.”

When the consultant met the patient, he was alert and clearly able to signal *yes* and *no* with his eyes. After some preliminary questions to ensure that he could follow instructions and answer consistently by blinking his response, and after some additional neutral queries, he was asked if he wanted to die as had been indicated by the clinical team.

He answered, *No*.

The consultant sought to confirm that this was his answer and continued to ask about his endotracheal tube. *Do you want the tube out?*

*Yes*, he responded with his eyes.

*You would like the tube out?*

*Yes*, again with his eyes.

*You know that if I take the tube out you could die?*

*Yes*, he said looking directly at the consultant.

*So you still want it out?*

*Yes*.

*So you want to die?*

*No*, he responded.

The consultant repeated the sequence several times and in different ways and came to the conclusion that the patient wanted the tube out, understood that taking it out would cause him to die, and that he did *not* want to die.

There was an inconsistency and the consultant felt obliged to offer an explanation. After all, all the patient could do was to respond to his questions. He could neither generate his own questions nor explain himself. He was voiceless and at the mercy of others.

*So, let me summarize. You don’t want to die, but you want the tube out? Correct?*

*Yes*.

And then the consultant’s hypothesis, *Does the tube hurt you?*

The question was met with a massive swooshing of downward gaze of his eyes and even something of a grimace, which would be fair to translate as an emphatic, *Yes*.

*So, the consultant suggested, You want the tube out because it hurts?*

Another expressive, *Yes*.

Adopting a more prudential stance, the consultant suggested that if he wanted to live, then the tube would

be kept in place until it was safe to take it out or place a more comfortable tracheostomy tube. That option was not currently possible because he was on a significant amount of pressure support so the procedure could not be done safely.

The patient and consultant agreed to a number of things now that his goals were clear. First, the DNR order would be rescinded as he wanted to live. Second, he would be put under general anesthesia for a week to see if his lungs would heal thereby making tracheostomy placement possible. If that became an eventuality, he would be awakened to obtain his consent for that procedure. On the other hand, if his condition worsened and he were unable to come off the tracheostomy tube he asked that the DNR order be reinstated and that a terminal extubation be performed.

For comfort relief, the patient was placed under general anesthesia and continued to receive antibiotic treatment for his systemic endocarditis. He emerged a week later as a candidate for tracheostomy placement. This was done and he eventually went to rehabilitation.

A fortuitous outcome, but whatever had occurred it is important to return to how the case was too easily framed as a right to die case and how this changed. Over the course of 40 minutes of “discussion” with this patient, a “routine” withdrawal of care—presented by the patient’s medical team with much self-satisfaction—had become something quite different. Through a deeper exploration of the patient’s narrative, the consultant was able to clarify that the patient *never* wanted a withdrawal of life support and did *not* desire death. His request to have his tube removed, too easily interpreted as a euphemism, “like pulling the plug,” was actually a call for pain relief in a patient who had become voiceless due to his paralysis and intubation.

The desire to provide this patient a “dignified death” also suffered from a lack of credible evidentiary information about the patient’s prognosis. His fate was presumed by the treating team to be far worse than his actual prognosis. After additional consultation, it was estimated that he had a 50% chance of independent respiration after the abscess was drained and treated with antibiotics. Why the “treating” team so quickly saw the patient’s situation as terminal can only be surmised. We might speculate that it may be related to prejudicial views towards his substance abuse and the “self-inflicted” nature of illness or be a cognitive bias stemming from a framing about paralysis and disability. Whatever the explication, unexplored attitudinal biases were working upon this case in a manner that distorted decision making to the point of almost sacrificing a patient’s life.

We view these possibilities as antithetical to the origins of palliative care as means of providing comfort and relief, an evolving tradition dating back to the Irish Sisters

of Charity who opened Our Lady’s Hospice in Dublin in 1879.<sup>26</sup>

According to an account by Dame Cicely Saunders, herself the founder of the modern palliative care movement, the Sisters’ sole focus was on the care of the dying.<sup>27</sup> Describing their hospice, it has been said that the Sisters observed, “It is not a hospital, for no one comes here expecting to be cured. Nor is it a home for incurables, as the patients do not look forward to spending years in the place. It is simply a ‘hospice’ where those who are received have very soon to die, and who know not where to lay their weary heads.”<sup>28</sup> Here the Sisters capture the distinction between the balance of cure and care, the epitome of hospice and palliative care as contrasted with hospital acute care.

That phrase, “lay their weary heads,” lingers in the heart and mind, embodying that empathy, that compassionate care that had so informed the palliative care movement as it marched through the 1990s fighting for legitimacy in clinical circles and fighting off those who more narrowly sought to use the movement as an ideological means to advance the case for PAS.

As practiced by its most thoughtful proponents, palliative care originated from a patient/family-centered stance that focused on relief of distress and closure, as well as an appreciation that patients and families came to their decisions in their own way and in their own time. Each patient’s trajectory would be unique, and the key to formulating a smooth glide path to a peaceful death was to help articulate goals of care. Decisions to withhold or withdraw care were never goals in that framework. They were the means, meant to be derivative of a prior articulation of goals, desires and aspirations, some of which could be satisfied in other ways.

In the intervening decade, much has changed. In too many cases, the clinician’s angst of an impending death and sense of causality, or even responsibility, for a patient’s demise has been replaced by the consolation that those who withhold or withdraw LST are acting in a progressive fashion, invariably in the right, acceding to patient or family wishes. And if such consolation is wanting, then the default is clinical decision-making based on the superior judgment on such matters that is expected to come with medical practice. There is a certainty to these decisions replacing the ambiguity of clinical intentions and the moral angst that used to be felt. In short, this ideological belief becomes a prescriptive way to die that has taken some of the gravitas out of dying, and not in a manner that either benefits or consoles patients and families.

No longer is it just about securing a right to die. Practices and beliefs have morphed so that a timely death has become proper and prescriptive. When patients don’t die as expected, or on time, one hears house staff using the phrase, “failure to die”—an echo of the earlier geriatrician’s, “failure to thrive”—to describe terminally ill

patients who lingered and refused to die. A failure to die ... *we used to call that survival*. Now that is being seen as a failure, a strange twist since Wanzer wrote of death as a medical failure back in 1989.<sup>29</sup> That classic essay will celebrate its jubilee in 2019, but so much has changed. From death as medical failure to a failure to die: *Everyone is in such a hurry*. The risk of rushing to judgment at life's end could be further accelerated by having a PAS option.

## V. Fears of Abuse: Oregon

Some will counter and say that the New York State Task Force's unanimous reservations about the legalization of assisted suicide articulated in its 1994 *When Death Is Sought*<sup>30</sup> have not been realized. The evidence in states where it has been legal has not shown tremendous abuse.

There is much to say here, but let us focus on one clinical and epidemiological issue. First is the question of how we would determine that a patient has the capacity to make a voluntary decision about PAS. This hinges on the dual questions of capacity and voluntariness. In Oregon, capacity is not the threshold—instead they use a vaguer term about being capable. The statute reads:

(3) "Capable" means that in the opinion of a court or in the opinion of the patient's attending physician or consulting physician, psychiatrist or psychologist, a patient has the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available.<sup>31</sup>

There is the need for a concurring physician. Also, there is no mandate for a psych referral unless a psych disorder is suspected. "Capable" is the threshold and not formal decision-making capacity, which is usually the predicate for competence to make medical decisions. A decision to willfully end one's life would seem to require legal competence, not mere capability, which seems to be a term of art. This is a rather low threshold.

How applicable would this be to our highly regulated context in New York State? This was a point recently made by the Bar Association of the City of New York in its examination of the proposed legislation.<sup>32</sup> Tellingly, New York State regulates surrogate decision-making *more* rigorously than Oregon regulates PAS.

All kinds of questions arise about the regulation of PAS. We presume the law would continue to be limited to adult competent patients. But beyond that are several important questions: What illnesses would qualify? Who would evaluate patients for their ability to make decisions and determine their medical eligibility? What sort of training would these practitioners require? Would they need to be certified or credentialed? Could a hospitalist just meeting a patient make this judgment? Would these

assessments require that a patient have an ongoing doctor-patient relationship? Would that limit this service to those without access to primary care? Speaking of the poor, would this further limit their equitable access to care or make them more vulnerable?

Let us return to what exactly can be inferred from Oregon's experience and examine the epidemiological evidence. There has not been a high incidence of cases in Oregon. No matter how normative proponents of PAS want to make the act out to be, it is still but a small fraction of cases. From 1998-2017, only 1,967 patients obtained a prescription for lethal medication under Oregon's Death with Dignity Law. This is against the backdrop of 30-35,000 adult deaths per year in Oregon over this 20-year span.<sup>33</sup> That would equal approximately 0.28 to 0.32% of all adult deaths in the state. These data suggest that assisted suicide remains an exceptional action, chosen by a very small minority of dying patients, with an even smaller number bringing their decision to completion. And of the 1,967 who obtained a prescription since 1997, only 1,275 patients died from a legal ingestion, just under two thirds of patients who obtained medication.

This experience suggests that the needs of most dying patients cannot be addressed by pharmacology alone. Legalization of PAS is not a remedy for the vast majority of patients who will never consider, much less avail themselves of, this option. In Oregon, 99.7% of patients did not take advantage of the law. These data suggest that the focus on PAS is misplaced and constitutes a distraction from more compelling clinical need. Good end-of-life care is more complicated than having a stash of pills in the medicine cabinet. Patients need comprehensive palliative care, including psychological support to address their suffering and fears.

Whatever one thinks of PAS, it is *not* a population-based public health remedy for the vast majority of patients. Nonetheless, it consumes a disproportionate amount of our attention, at the expense of more productive conversation. This begs the question, why?

## VI. Brittany Maynard and the Need for Better Palliative Care

If we think of the Brittany Maynard case, we can begin to understand assisted suicide's appeal.<sup>34</sup> The images are heart-wrenching: A young woman, newly married, in her prime, dying of a *glioblastoma multiforme*. She decided not to seek treatment for her tumor, convinced it would be burdensome, if not futile. Moving to Oregon where physician-assisted suicide is decriminalized and regulated, she bravely expressed her desire to die. She wanted to end her life on her own terms before the tumor made a free choice impossible. But at the end she wavered, taken over by ambivalence. It is hard not to admire Ms. Maynard's courage and to mourn this tragic loss.

Yes, we feel for Ms. Maynard, but does that make her choice a good one? Does her compelling narrative make for good public policy?

The great jurist Oliver Wendell Holmes, Jr. once said that, “hard cases make bad law.” He worried about the misinterpretation of facts and the miscarriage of judicial reasoning, “... because of some accident of immediate overwhelming interest which appeals to the feelings and distorts the judgment.”<sup>35</sup> Such is true in the Maynard case. Her youth, the tragedy of her circumstances, and yes, the media appeal of her story, can distort judgment and lead us to conclude that what seems right for her is good for others.

But it is not so simple. The care of the dying is a challenge that American medicine has yet to fully embrace. In 2014, the Institute of Medicine (IOM) of the National Academies of Sciences issued a report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*,<sup>36</sup> which outlined the clinical, financial and cultural barriers to good palliative care and made constructive recommendations for reform. An endorsement of physician-assisted suicide was not one of them.

In the 19 years since the last IOM report,<sup>37</sup> progress at the end of life has been spotty. Although medical education has improved and palliative medicine became a nascent medical specialty, we have a long way to go to ensure that all Americans die well, or as well as can be expected. We remain wedded to ever-more medical technology, often in the face of futility.<sup>38</sup> Intensive care has become more *intense* fueled by a medical arms race, unthinkable even a decade ago.

We still have inadequate access to hospice and palliative care. Referrals are difficult and length of stay an issue.<sup>39</sup> Families may be insensitively asked about discharge plans upon arrival to in-patient hospice even when death is imminent.<sup>40</sup> Such callousness is prompted by CMS regulation of in-patient hospice length of stay with fiscal claw-backs.<sup>41</sup> These policies make hospice hard to access substantively and in a timely fashion. This becomes more complicated as most hospice care is provided at home, and that requires a home and an unpaid caregiver. So what happens if you're dying and single, or homeless, how do you get hospice care?

It shouldn't be that way, and as long as it remains so difficult to get competent and accessible palliative care, people will be susceptible to easy answers like assisted suicide, which now sounds so much more appealing when dressed up with polished phrases like “achieving death.” It is also cheaper, creating a perverse conflict of interest in times of scarcity.

## V. Conclusion

In the aggregate, these tensions illustrate the true complexity of end-of-life care, a complexity not subsumed by a solitary position on PAS. More fundamentally, Amer-

ica remains deeply divided. We remain a country that denies death.<sup>42,43</sup> Instead of planning for end-of-life care with sensible interventions such as advance care planning and goals of care discussions, we become enmeshed in ideological debates about so-called (and fictional) “death panels.” The force of denial is also part of the appeal of assisted suicide. By pursuing this agenda, we gain psychological reassurance that somehow we can avoid life's final chapter.<sup>44</sup> It will provide the illusion of solace, but if the Oregon demographics are dispositive about utilization, this change in law will do little more for the vast majority of New Yorkers, and as noted potentially will have unintended consequences for decisions at the end of life.

*Dr. Joseph J. Fins presented remarks on aid in dying to the New York City Bar Association Bioethical Issues Committee on December 5, 2016. The City Bar issued a commentary on aid in dying in June 2017, citing Dr. Fins' remarks before the Bioethical Issues Committee. This article draws on Dr. Fins' presentation to the Bioethical Issues Committee. Both Dr. Fins and Dr. Morrissey gratefully acknowledge the comments of members of the Bioethical Issues Committee for their fruitful dialogue.*

## Endnotes

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