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Responding to Intractable Terminal Suffering

TO THE EDITOR: Quill and Byock's paper (1) is a significant contribution to the end-of-life care discussion. However, I continue to question the use of the phrase *terminal sedation* by the medical profession, particularly in light of Quill and Byock's paper favoring this treatment. Whether used to describe the purposeful administration of sedation under the clinical guidelines summarized in this paper or to describe the unintended side effect of high-dose opioid therapy (a scenario that the authors choose to distinguish from their guidelines), the phrase implies intent. For health care providers who are understandably fearful of judicial interpretation and who therefore may underprescribe in the treatment of intractable terminal suffering, I submit that the alternative phrase *palliative sedation* would be far less conflicting and thus far more desirable.

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Reference

1. Quill TE, Byock IR. Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids. ACP-ASIM End-of-Life Care Consensus Panel. *Ann Intern Med.* 2000;132:408-14.

TO THE EDITOR: I applaud Quill and Byock's thoughtful discussion of options for responding to intractable terminal suffering (1). However, the term *terminal sedation* is confusion, misleading, and potentially harmful. First, the term is contradicted by the authors' own discussion of it. They write that *terminal sedation*, defined as "the use of high doses of sedatives to relieve extremes of physical distress," "is not restricted to end-of-life care." If the patient has a prospect of recovery, then the sedation may be used for intractable distress but is not necessarily "terminal." Second, the term *terminal sedation* inevitably connotes sedation intended to terminate, or euthanasia (2)—precisely what the authors say it does not mean. According to their description, it is a treatment intended only to relieve suffering by inducing unconsciousness in the rare cases when suffering cannot be relieved by any other means. In keeping with the principle of double effect (3, 4), terminal sedation is not intended to end the patient's life yet may have the foreseeable side effect of hastening death. Because of the connotation of euthanasia, the term may be upsetting to many patients and clinicians and therefore may hinder discussion and provision of appropriate palliative care.

Following Chater and colleagues (5), I propose that the term

terminal sedation be abandoned and replaced with *sedation for intractable distress of a dying patient*, abbreviated as SIDD Pat (2). This term minimizes the possibility that it will be misunderstood as euthanasia. In addition, it makes explicit the indication or proportionally grave reason for using this extraordinary treatment: the intractable distress of an individual dying patient. Thus, this designation may help remove barriers to optimum palliative care for patients whose suffering is most severe.

I strongly endorse the authors' general guidelines for use of this treatment.

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TO THE EDITOR: We are deeply troubled by a recent pair of papers on terminal sedation and "voluntary refusal of food and fluids" (1, 2) and the process by which they were accepted and published in *Annals*. These papers appear to convey the mistaken and perhaps dangerous impression of a genuine consensus among experts and official policy endorsement of these practices. At the request of the editors, we address the issues raised by the first of these papers in this letter and address related issues separately (3, 4).

It is true that terminal sedation (perhaps better called *sedation in the imminently dying*) is being discussed and evaluated by palliative care specialists as a therapy intended to relieve the refractory symptoms of patients suffering at the end of life. We do not disagree that it could potentially be appropriate therapy when performed in carefully selected cases by a well-trained internist or palliative care specialist who understands the ethical and medical issues involved. We also recognize that patients are entitled to refuse artificial hydration

and nutrition. However, Quill and Byock (1) propose as standard practice the use of “terminal sedation” intended to make patients unconscious and unable to eat so that they may die more quickly, and the use of “terminal sedation” for patients who “voluntarily refuse” to eat. We do not believe that there is anything approaching a consensus among palliative care physicians, bioethicists, or the membership of the American College of Physicians–American Society of Internal Medicine that such practices are morally, legally, and clinically appropriate.

While some might even agree that sedation was appropriate in the specific case they describe, this does not mean that one should endorse the authors’ general conclusions, which would justify a much wider range of “indications” for terminal sedation. “Suffering” is a very broad term, and it is unclear what sorts of suffering might represent appropriate indications for terminal sedation.

None of us, the undersigned, feel that the practices the authors recommend represent a settled approach to palliative care. It therefore seems inappropriate for them to be urging “professional bodies [to] help by adopting policy statements that attest to the ethical and professional acceptability of these components of palliative care” (1).

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IN RESPONSE: Yanow and Krakauer are concerned about misinterpretation of the term *terminal sedation*. This term was chosen after considerable discussion within the College’s End-of-Life Care Consensus Panel. Dr. Yanow rightly sees that we are distinguishing terminal sedation from the usual situation of “double effect,” in which death is unintended but the increased risk for death is foreseen (1). He fears that adverse judicial interpretation of a physician’s intention in cases of terminal sedation may cause physicians to underprescribe in other settings.

Dr. Krakauer notes that “palliative sedation,” sometimes called “heavy sedation,” is used to relieve severe symptoms in other circumstances (for example, burn patients who require extensive, painful debridement) (Goldstein-Shirley J, Jennings B, Rosen E. Total sedation in hospice and palliative care. In preparation). The expectation for survival and the use of other life-prolonging therapies help to distinguish “palliative sedation” or “heavy sedation” from the subcategory of “terminal sedation.” Terminal sedation usually precludes the concomitant use of life-sustaining therapies such as artificial ventilation and hydration. The expectation is that the patient will remain sedated until death.

“Terminal sedation” does not connote an intention to hasten death, nor does it imply that the sedative medication is the causative agent of death. The word *terminal* applies because death is the expected end point of the treatment. The physician’s purpose in administering sedative medications is to ensure relief from intractable suffering, rather than causing death (2). Some patients and families accept terminal sedation with the hope of an earlier death, whereas others focus exclusively on the relief of suffering. The terminology finally selected should foster respect for and understanding of the gravity of the intervention, while making it accessible to those in need (3).

Sulmasy and colleagues erroneously report that our article suggests using sedation “to make people unconscious and unable to eat so that they may die more quickly. . . .” Instead, we explicitly stated that “The purpose of the medications is to render the patient unconscious to relieve suffering, not to intentionally end his or her life.”

Patients in the terminal phase of illness can refuse to eat and drink and have the right to refuse artificial nutrition and hydration. These decisions by autonomous patients must not preclude the use of terminal sedation should intractable suffering subsequently develop.

The guidance proposed is intended to restrict these “last resort” practices to the relatively rare patients whose suffering does not adequately respond to standard palliative care measures. A second opinion is required by a palliative care specialist and by a mental health specialist (if there is uncertainty about the patient’s mental capacity). Although they require no changes in the law, these practices are erratically available and are not subject to any oversight or monitoring. Policy statements by professional bodies could help ensure that these decisions are made with care and caution.

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Palliative Treatment of Last Resort and Assisted Suicide

TO THE EDITOR: We are deeply troubled by a recent pair of papers on terminal sedation and “voluntary refusal of food and fluids” (1, 2) and the process by which they were accepted and published in *Annals*. At the request of the editors, we address the issues raised by the second of these papers in this letter, while addressing related issues separately (3, 4).

Quill and colleagues, representing the Consensus Panel of the Finding Common Ground Project (2), first observe that patients, even those “who do not have imminently terminal conditions,” may stop eating and drinking “as a variant of stopping life-sustaining treatment.” They then aver that physicians may sedate such patients if the process becomes “uncomfortable” and that this “terminal sedation” could be undertaken with the specific intention of hastening death.

Although the authors state that there is a “growing” ethical consensus about this type of induced sedation, the specific practice they describe is actually highly controversial and replete with unresolved moral and legal questions. Most palliative care specialists underscore that terminal sedation (better termed *sedation in the imminently dying*) should be reserved for highly selected patients and when

the explicit intention is the relief of suffering and not the hastening of death. Do these practices, as described by the authors, really differ from assisted suicide and euthanasia? If the patient’s primary purpose is to hasten death, is this a legitimate medical indication for total sedation? Is it appropriate to completely sedate a patient whose only refractory physical symptoms are those associated with having refused to eat or drink?

Almost no research about these practices has been done. We are concerned that the adoption of these interventions by inexperienced physicians who mistakenly perceive a consensus could harm patients by reducing access to specialized palliative care approaches and limiting the options for informed decision making on the part of patients and families. In inexperienced hands, it would also have the potential to be applied inappropriately to patients with treatable conditions in which suffering and problems with appetite are intimately connected, such as major depression and anorexia nervosa.

None of us, the undersigned, currently believe it is appropriate to propose these as standard practices. Issuing a consensus statement urging that patients be informed that they may elect to stop eating and undergo sedation if they believe they are suffering at the end of life seems at best premature and at worst potentially detrimental to optimal patient care.

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IN RESPONSE: As palliative care practitioners have struggled to find ways to respond to intractable end-of-life suffering without resorting to physician-assisted suicide, terminal sedation and voluntarily stopping eating and drinking have been suggested as morally acceptable alternatives that do not require changes in the law (1, 2). We agree with Sulmasy and colleagues that these practices are much more morally and clinically complex than is ordinarily acknowledged (3). For this reason, we support guidance for those who might participate in these practices even though it may not be legally required (4); the University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel also supports providing this guidance. We agree that the practices should be rare and restricted to highly selected patients and that the primary intention of participating clinicians should be relief of severe suffering. However, requiring that the intent must never also be to hasten death may at times create an impossible dilemma for the care of patients who are near death, are suffering terribly, and are psychologically prepared to die. Under the rule suggested by Sulmasy and colleagues, if the patient consents to terminal sedation exclusively to escape suffering, then the intervention may be permitted. If a patient's intent is also to hasten inevitable death, then suddenly the same intervention would become impermissible.

Guidelines can reinforce careful decision making and ensure access to standard palliative care before terminal sedation and the voluntary refusal of food and fluids are seriously considered. Without such guidance, "inexperienced hands"—the term used by Sulmasy and associates—might consider these options of last resort to be part of standard palliative care. With guidelines, the primary physician must document that standard palliative care has failed, that the patient is competent, and that all meaningful alternatives have been considered. Furthermore, these findings would have to be corroborated by a specialist in palliative care and by a mental health specialist if there is uncertainty about the patient's mental status. The question posed is whether appropriate access and oversight are promoted by formally accepting such guidelines, or whether the practices should remain solely at the discretion of individual providers.

In the current environment, we know that the use of terminal sedation varies from 0% to 50% of deaths in palliative care programs (5). Such variation by program suggests that current practices are driven more by the values of practitioners and programs than of patients and families, when just the opposite should be true.

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TO THE EDITOR: I was horrified and angered by the papers on assisted suicide (1–5). These papers acted as an apology for physician-assisted suicide.

Each year, I give my medical ethics students a copy of the Oath of Hippocrates—the original oath, not the watered-down version. The oath states, “I will follow that system of regimen which, according to my ability and judgment, I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous. I will give no deadly medicine to anyone if asked nor suggest any such counsel, and in like manner I will not give to a woman a pessary to produce abortion.”

The assumption underlying physician-assisted suicide is that life is a commodity in some way owned by the patient. The Hippocratic oath assumes that life is a divine stewardship, owned by neither the patient nor the physician. In this world view, physician-assisted suicide and abortion are the moral equivalent of murder. They usurp a divine privilege by taking a life that does not belong to the patient or physician. Tinkering with this world view, in place for more than 3000 years, invites catastrophe for the profession and for society.

When physicians abandoned their principles 25 years ago by performing legal abortions, a bright moral boundary was erased. Warnings that we had stepped onto a slippery slope were ridiculed as alarmist. After years of unrestricted abortion on demand, we now face the barbaric practice of partial-birth abortion. This would have been unthinkable 25 years ago. If we accept physician-assisted suicide now, we progress down another slippery slope. In another 25 years, we may be endorsing euthanasia for people with serious disabilities or painful terminal illness because “surely no one would want to live like this.”

Like abortion, physician-assisted suicide expands and reinforces the lesson that it is permissible to kill individuals who are inconvenient. Our actions have clear repercussions well beyond the profession. Medicine is more than applied biological science—it is a profession with a moral framework and underpinning. When we abandon moral principles for the gratification of making ourselves and an individual patient feel good, we contribute to the decay of the profession and society.

I call on all College members to reject physician-assisted suicide. We must re-establish a moral authority in the practice of medicine and dedicate ourselves to renewal of the principles of the Hippocratic oath. If we do otherwise, I fear for civil society, the profession, and our very souls.

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IN RESPONSE: Dr. Gates provides an impassioned reaction to the papers on assisted suicide, which we edited for the Finding Common Ground Assisted Suicide Consensus Panel convened by the University of Pennsylvania Center for Bioethics. He calls the issue “an apology for physician-assisted suicide.”

The University of Pennsylvania series, in fact, takes no position on the morality of assisted suicide or physician-assisted suicide. The goal of the project was not to argue for or against. Instead, believing that legalization was coming, as it did in Oregon and as it may in other states, we sought to examine how to guide practices and create

safeguards that would keep assisted suicide rare, voluntary, regulated, and an option of last resort. In doing so, we questioned the usual assumptions. One of the papers explicitly debates, for example, whether assisted suicide necessarily should mean physician-assisted suicide. Dr. Gates does not successfully make a case that there is an inherent bias or prejudice on the part of those who tried to do what is so rarely done with respect to this issue—engage in dialogue despite strong ethical differences of opinion.

As it happens, we are both opponents of the legalization of physician-assisted suicide, as were others who participated in the project and contributed to the papers in the series. The panel membership was national and multidisciplinary and was deliberately composed of individuals with diverse viewpoints. Panel membership, any dissents from a particular paper by a panel member, and the goals of the project were clearly identified. The preceding letter by Sulmasy and colleagues on palliative treatment of last resort implies otherwise. This letter also misrepresents several issues, most importantly by characterizing terminal sedation and voluntary refusal of food and fluids as measures recommended for standard practice when they were actually considered absolute last resorts for rare cases by the panel. The project was called Finding Common Ground because that is what we were attempting to do on the difficult issue of assisted suicide. As the abortion debate has demonstrated, avoiding polarization is not easy. Worse still, polarization of the sort reflected in these letters can be counterproductive to the positions that Drs. Gates and Sulmasy and others hope to advance.

The project we undertook tried to benefit from the diversity of opinion its members brought to the table in proceeding cautiously in an area of great controversy. But we wanted to proceed, to advance the debate. Groups in the past who have tried to write guidelines have failed when the discussion shifted from how to do so back to whether to do so. In the process, important policy considerations about how to keep physician-assisted suicide rare, alternatives to the practice, the implications for the patient–physician relationship, who should write guidelines, and how to regulate it were not getting addressed. The *Annals* papers help break this logjam—an important step now that physician-assisted suicide is legal.

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Publication of Papers on Assisted Suicide and Terminal Sedation

TO THE EDITOR: We are deeply troubled by a recent pair of papers on terminal sedation and “voluntary refusal of food and fluids” (1, 2) and the process by which they were accepted and published in *Annals*. At the request of the editors, we address the issues related to the development and publication of these papers in this letter, while addressing issues of content separately (3, 4).

One paper was called a “Position Paper” and was produced by the Ethics Committee of the American College of Physicians–American Society of Internal Medicine (ACP–ASIM) (1). We understand that this designation was a mistake. However, even though an erratum has been published, the damage has been done, since most *Annals* readers will already believe it is official College policy.

Members and staff of the ACP–ASIM Ethics Committee played a prominent role in both projects. One carries the endorsement of the 1998–1999 membership of this committee (1). The only qualification, buried in the fine print, reads, “this does not represent official ACP–ASIM policy” (1). This paper was “received by” yet not “endorsed by” the ACP–ASIM Board of Regents, giving it status without debate. The second, the report of a “Consensus Panel” (2), was published with a group of papers that gave it a degree of prominence generally afforded only to official statements. Further, no editorial representing an alternative to these controversial views was included. All these factors would encourage even a careful reader to believe that there was a substantial consensus about these issues and that the College had given its official policy endorsement to such a consensus.

Consensus panels should not be used to make definitive judgments regarding issues about which there is obviously little agreement. Whose consensus is this? None of us, the undersigned, accept as a settled matter the views presented in these papers. This suggests that if the purpose were to achieve a true consensus, then the panel composition seems to have been less than optimally representative.

We urge the editorial staff to make it very clear to the readers that these articles are not positions of *Annals* or the College and merely represent one group’s controversial viewpoint. *Annals* and the College may also wish to reconsider the manner in which consensus papers and position statements are developed and to review how such “labels,” even mistakenly, came to be placed on these controversial publications.

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4. Sulmasy DP, Ury WA, Ahronheim JC, Siegler M, Kass L, Lantos J, et al. Palliative treatment of last resort and assisted suicide [Letter]. *Ann Intern Med.* 2000;133:562-3.

IN RESPONSE: Sulmasy and colleagues express concerns about recently published papers on terminal sedation from two projects. The process used to develop these papers has been provided in past descriptions of the projects, but I will provide a brief review here.

“Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids” was developed by the ACP–ASIM End-of-Life Care Consensus Panel. It is one of a series of 14 by the College panel of national physician experts on important topics related to care of the dying. Those papers are approved by the College’s Ethics and Human Rights Committee but are not presented for approval by the Board of Regents and are not official College policy. Not all College products receive Board approval as College policy—notable examples are the Medical Knowledge Self-Assessment Program and the ethics case study series. The end-of-life care papers include clear language about their status. It was merely a mistake, corrected when identified, that the terminal suffering paper was accidentally published under the heading “Position Paper.”

Further, all papers in the end-of-life care series receive rigorous internal and external review. Drafts are developed after intensive discussion within the ACP–ASIM End-of-Life Care Consensus Panel and go through numerous rounds of review over the course of many committee meetings. They are then reviewed by outside experts and also by internists who do not consider themselves palliative care experts. They undergo review (but not approval) by the College’s Education Committee, Board of Governors, and Board of Regents and are both reviewed and approved by the College’s Ethics and

Human Rights Committee. On journal submission, the papers are then subjected to another round of external peer review.

The other paper to which Dr. Sulmasy and colleagues refer is “Palliative Treatments of Last Resort: Choosing the Least Harmful Alternative,” by the University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. My academic affiliation is with the University of Pennsylvania Center for Bioethics, and I worked on that project in that capacity. That affiliation was clearly noted.

This was one of a series of papers by that group published along with introductory material that clearly described the University of Pennsylvania group and its purpose. The series was the culmination of 3 years of work by a national panel of experts on the subject of assisted suicide. The panel membership was multidisciplinary—with representatives from medicine, nursing, psychology, hospice, patient advocacy, law, philosophy, the clergy, and bioethics. It was deliberately composed of individuals with diverse viewpoints on assisted suicide, proponents and critics. Our purpose was to come together to see where we could develop consensus on difficult issues related to assisted suicide. Dissent, if any, was noted on each paper.

A few individuals served on both groups. As is often the case, leading experts work with various organizations, institutions, and projects.

Concerns about process are understandable on matters of considerable debate. Regarding the papers that appeared in these pages, the process was sound and identified. We welcome continuation of the substantive debate around terminal sedation with the voluntary refusal of food and fluids, and other issues. It was, of course, not that long ago that the right of patients to refuse artificial nutrition and hydration was established, when fluids and nutrition were determined to be like any other medical treatment that may be withheld or withdrawn with patient refusal—according to the consensus that had developed.

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IN RESPONSE: Because the papers written by the ACP–ASIM End-

of-Life Care Consensus Panel were “received” rather than endorsed by the College, we made the editorial decision to publish them in the Academia and Clinic section of *Annals* rather than under the heading of “Position Paper.” The latter section is generally reserved for papers that have been formally endorsed by established medical organizations. In fact, all of the papers in the End-of-Life Care series that preceded the paper by Quill and Byock (1) appeared in the Academia and Clinic section. Publication of that paper (1) under the heading of “Position Paper” was purely a technical mistake, and an unfortunate one, that occurred during journal production. We apologize for the error, and have published a correction notice (2). As pointed out by Sulmasy and colleagues, readers were unambiguously notified on the title page that the paper does not represent official ACP–ASIM policy; the correction notice also contains that information.

The papers from the Assisted Suicide Panel of the University of Pennsylvania Center for Bioethics, including the paper by Quill and colleagues on palliative treatments of last resort (3), were published in the Medicine and Public Issues section, which does not contain official positions. The source and status of the papers were clearly labeled. After considerable thought, we decided to let these papers speak for themselves rather than trying to accompany them with one or more editorials on the many other possible points of view on the subject—an almost endless task—in the same issue of the journal. Part of the purpose in publishing these papers was, however, to stimulate continuing debate outside these pages on this extraordinarily complex and difficult topic.

Frank Davidoff, MD
Editor

References

1. Quill TE, Byock IR. Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids. ACP–ASIM End-of-Life Care Consensus Panel. *Ann Intern Med.* 2000;132:408-14.
2. Correction: end-of-life care paper. *Ann Intern Med.* 2000;132:1011.
3. Quill TE, Lee BC, Nunn S. Palliative treatments of last resort: choosing the least harmful alternative. University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. *Ann Intern Med.* 2000;132:488-93.