Articles

Physician-Hastened Death

Advisory Guidelines for the San Francisco Bay Area From the Bay Area Network of Ethics Committees

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Recent high court opinions and pending Supreme Court rulings on the legality of physician-hastened death necessitate a pragmatic response from the medical profession. Adopting a "harm reduction" perspective on this contentious topic, the Bay Area Network of Ethics Committees developed practice guidelines for responding to a patient request for hastened death. The guidelines will be offered to the local medical community for use by individuals and health care institutions if the practice of physician-hastened death becomes legal. A multidisciplinary consensus process was used in developing the guidelines, which address clinical, ethical, and procedural concerns.

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Debates over the ethics and practice of physicians' hastening the death of patients—whether the practice is spoken of as "euthanasia," "aid-in-dying," or "assisted suicide"—appear to be almost as old as medicine itself. In the past few decades, and particularly in the past few years, those debates have intensified. Two 1996 Circuit Court of Appeals rulings invalidating laws prohibiting physician-assisted suicide present a potential revolution in the legal status of physician involvement in aiding terminally ill, mentally competent adults to end their lives, a practice which has long been prohibited by legal and professional codes.[1]

This is not the place to examine the many complexities in this debate; the literature is voluminous and growing exponentially, and an excellent selected bibliography on the topic has recently been published for those who wish to examine the issues in more detail.[2]

Development of the Bay Area Network of Ethics Committees (BANEC) guidelines was spurred by the possibility that "society," by the means of our nation's legal system, might well sanction some sort of physician involvement in hastening a patient's death. If so, many feel that procedural guidelines for those clinicians faced with a patient's request for a hastened death should be available.[3–7]

BANEC has attempted to approach the topic in a nonpartisan manner, borrowing the concept of "harm reduction" from the field of addiction medicine and epidemiology.[8,9] First, it is recognized that a potentially dangerous behavior is occurring and will likely continue regardless of legal and social prohibitions. Then interventions or other policies are offered that might lessen the negative consequences of the behavior without sanctioning the behavior itself. The classic example from the addiction field is the use of methadone in the treatment of heroin addiction; a more recent example is providing sterile injection equipment in the effort to quell the spread of HIV infection.

The practice of hastening death in various forms has occurred throughout the history of medicine, albeit cloaked in secrecy and ambiguity; negative consequences in terms of increased suffering or abuse also have sometimes occurred. In addition, some manner of hastened death may become legalized soon, since a majority of both the general public and American physicians, including those practicing in the jurisdictions covered by the Ninth Circuit court, appear to support some degree of liberalization of existing prohibitory policy.[10–13] Some medical associations (although not the American Medical Association) have begun to reflect this division of opinion in their official policies on the topic, thus ending the historically uniform condemnation of hastening death by the medical profession.[14] Without sanctioning the practice of hastening death, it is reasonable to develop procedural guidelines that aim to improve the care of the terminally ill and avoid unnecessary suffering—perhaps also pre-

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ABBREVIATIONS USED IN TEXT

BANEC = Bay Area Network of Ethics Committees

venting some avoidable instances of hastened death as well.[15,16] Additionally, any hastened death should be the last resort for patients with intolerable suffering who have been provided adequate and high-quality palliative care and for whom every other option has been fully explored. Also, guidelines for responding to requests for a hastened death might improve existing practice and communication in areas where shortcomings in the care of the dying have been identified.[17]

Even the most optimal set of procedures addressing this topic is unlikely to satisfy all perspectives. The BANEC guidelines were developed as a blueprint for suggested policy, to be reviewed and adopted by individual practitioners, medical institutions, and organizations as appropriate.

Methods: Developing Consensus Guidelines

Immediately after the Ninth Circuit ruling, members of BANEC decided that, should this practice become legal soon, clinically oriented practice guidelines would be needed, and that locally generated advisory guidelines would be useful. The group, which included experts in medicine, oncology, hospice care, and ethics, reviewed the court decisions and existing guidelines and prepared a first draft of procedural guidelines, including informed consent and reporting forms. Those draft guidelines were introduced and distributed for comment at a meeting of approximately eighty BANEC participants in June 1996. Comments from attendees and others were gathered for the next few months, a second draft was prepared, and another smaller community meeting was held in September. Additional comments from that meeting were incorporated in a third draft, which was then distributed to all attendees of a consensus development conference on care of the terminally ill convened Sept. 27 and 28, 1996, by the Stanford University Center for Biomedical Ethics.

In drafting guidelines on this issue, we strove to strike a balance between overly onerous restrictions and the existing laissez-faire, "underground" practice. Unavoidably, some practioners will feel that "bureaucratic" requirements are counterproductive and might serve to keep the practice undergound, even if legal; others fear that only the most strict and extensive procedural "safeguards" will prevent abuses of ethical practice. Issues to be discussed include categories of patients eligible for hastened death, mandatory waiting periods after first requests for assisted death, assessment of pain relief and palliative care, assessment of the patient's psychological state, types of procedures allowed, and informed consent, witnessing, and reporting requirements. In each case, the authors of the BANEC guidelines sought to reach a balanced consensus, advocating stronger safeguards where substantial differences in opinion persisted. Complete consensus on such issues was rare, even among the working group and especially among the greater number of BANEC participants, and "majority rule" was adopted as a deciding factor in revising certain sections.

Bay Area Network of Ethics Committees: Guidelines for Comprehensive Care of the Terminally Ill

Background

The public's fear of suffering at the end of life has led to extensive debate about physicians aiding terminally ill patients to hasten their death, a practice that has long occurred underground, without standards or scrutiny by the medical community. On March 6, 1996, laws prohibiting physicians from responding to a request for a hastened death by an adult, mentally competent, terminally ill patient, were declared unconstitutional by the Ninth Circuit Court of Appeals (with jurisdiction including California). The case has been appealed to the US Supreme Court, and a decision is anticipated in summer 1997.

These recent court actions may increase the available options in end-of-life medical decisions for adult, mentally competent patients who are terminally ill. Therefore, institutional guidelines of medical practice, policies, and procedures should be updated to accommodate these potential changes in care, within the context of a high general-care standard for patients with terminal illnesses.

The Bay Area medical community should be prepared for the reality that a terminally ill patient may soon have the right to ask a physician for aid in hastening death, and that providing such aid may be legal. In response, BANEC offers these guidelines. No medical procedure exists as an isolated option for any patient; these recommendations take into consideration the full and comprehensive care of terminally ill patients.

It should be noted that these guidelines emphasize safeguards and quality of care for patients with terminal illnesses. For certain recommendations, when safeguards are weighed against what may seem to be cumbersome documenting procedures, the guidelines emphasize the safeguards.

This document is a blueprint for potential policy, to be used as appropriate by individuals or organizations. The Bay Area Network of Ethics Committees provides a forum for open, independent discussion of ethical issues in health care. Opinions and guidelines proffered via BANEC are not necessarily representative of or

endorsed by any individual or organization participating in BANEC discussions, and are nonbinding.

Guidelines for Comprehensive Care of the Terminally Ill

BANEC

(Note: These guidelines are intended for use regardless of a patient's residence—home, hospital, hospice, clinic, or extended care facility—as he or she approaches death.)

Principles

I. The ultimate responsibility for the care of the patient pertaining to end-of-life decisions and treatments resides with the patient's physician. The actual informed decisions, however, are to be made by the patient.

II. The primary care physician is qualified to provide appropriate care, with or without consultation, for the great majority of patients who are dying.

III. The care of patients experiencing "difficult deaths," those undergoing (in their own judgment) intolerable or prolonged suffering as they die, or patients who are making complex and irreversible decisions about end-of-life care (including the decision to hasten death) may fall out of the range of skills of many primary care physicians.

Hospice programs have extremely effective teams that provide medical care and help patients with decisions about end-of-life treatment. Certain physicians in the medical community are also recognized to have special expertise in palliative, end-of-life care. For those patients who face difficult deaths, or those who are making complex and irreversible decisions about terminal care (including a request for physician aid in hastening their death), THE BANEC GUIDELINES URGE REFERRAL TO A HOSPICE PROGRAM AND/OR CONSULTATION WITH A PHYSICIAN EXPERIENCED IN PALLIATIVE CARE (including, but not limited to, pain control). Many patients, given appropriate and skilled end-of-life care, will withdraw their requests for a hastened death.

IV. At times, in spite of skilled physical, psychological, spiritual, and social care, an adult, mentally competent, and terminally ill patient will desire a physician's aid in hastening death.

V. These guidelines urge that, when a physician aids a patient to hasten his or her death, the following occur (with specific documentation in the patient's hospital chart and/or outpatient medical records).

(Note: No physician, nurse, physician-assistant, pharmacist, or other health care worker is required to participate in the act of hastening a patient's death or in the patient's evaluation for such an act. These guidelines recommend, however, that practitioners who exclude themselves from such participation advise the patient of his or her right to obtain consultation from other practitioners and facilitate the transfer of care should the patient so request.)

A. The primary care physician has ascertained the following (Figure 1).

1. The terminal diagnosis (a reasonable certainty of death within six months provided the disease runs its expected course, ascertained by review of the medical records and pertinent history and physical examination).
2. An assessment to confirm that, in the best judgment of the physician, the patient is mentally competent and not suffering from a depression that impairs decision-making capability. (IT IS HIGHLY RECOMMENDED THAT PHYSICIANS NOT EXPERIENCED WITH SUCH AN EVALUATION SEEK APPROPRIATE AID, WITH THEIR PATIENT'S CONSENT, FROM OTHER PRACTITIONERS IN THE MEDICAL, PSYCHOLOGICAL, OR SOCIAL SERVICES COMMUNITY.)
3. High-quality palliative care, by hospice and/or a physician recognized to have expertise in palliative care, has been made accessible to the patient.
4. To the best of the physician's knowledge, the patient's choice to hasten death has been freely made, independent of finances, family, health care workers, health insurance, or other coercion.

B. A second opinion to confirm the four points noted above by the primary care physician. These guidelines strongly recommend that the second opinion be obtained from a physician recognized to have expertise in palliative end-of-life care.

C. The patient has been evaluated by a hospice program and/or physician with palliative care expertise (Figure 2) [this can coincide with the second opinion noted above in B]. Documentation should also be made of the palliative-care recommendations resulting from this evaluation, and the ways in which they have or have not been followed.

Alternatively, documentation should be made that the patient declines an evaluation for improved palliative care. The guidelines recommend that these patients sign a form (see following example) to indicate an understanding that they have waived a medical evaluation that could offer care with significant potential for improving their quality of life as they die.

D. The patient has been counseled that a decision to hasten death should, if at all possible, be discussed in detail with family members, loved ones, and others who are likely to be significantly affected by this decision. The patient has also been counseled that the hospital and hos-

pice medical ethics committees are available and willing to discuss his or her care and the decision to hasten death with the patient and the patient's family.

E. A witnessed consent form (Figure 3) has been signed by the patient, including full disclosure of the illness, the procedure to aid the patient in hastening death and the associated risks, and a statement that other medical options exist (including hospice care) that might provide further comfort without hastening death.

The witnessing procedure should be in accordance with that now established for the signing of a Durable Power of Attorney for Health Care Decisions: "(1) Two qualified adult witnesses who are personally known to the patient (or to whom the patient provides evidence of his or her identity), and who are present when the patient signs and acknowledges the signature, or (2) acknowledged before a notary public in California. If the witness is other than a notary public, the law provides that none of the following be used: (1) a health care professional or an employee of a health care professional, (2) an operator or an employee of a community care facility or residential care facility for older adults. Additionally, at least one of the witnesses cannot be related to the patient by blood, marriage, or adoption, or be named in the patient's will. For patients in a skilled nursing facility, one of the witnesses must be a patient advocate or ombudsman."

For patients or witnesses not able to understand the consent form in English, the forms have been provided in a language they can understand or the signatures are accompanied by that of a competent translator.

F. A second witnessed signature by the patient has been obtained, no sooner than 48 hours after the first signature.

G. The patient has been counseled that he or she has the right, at any time, to change his or her mind and to return to care that includes the involvement of a hospice team or another physician experienced in palliative care.

H. The physical process of hastening death was initiated and completed by the patient: these guidelines emphasize that the physician may aid the patient in the process of hastening death (e.g., by provision of oral or injectable medication or the starting and maintaining of intravenous access), but it should be the patient's own physical effort that initiates and completes the process.*

I. Although it is the patient who undertakes the proximate action that leads to the hastened death, a physician or a person designated by the physician to be responsible for the care of the patient remain immediately and continuously available to the patient and family until death has occurred.

J. The cause of death on the death certificate is listed as the underlying disease.

K. Reporting: BANEC suggests that system similar to that of the California Tumor Registry (including the confidentiality of information) be established to which all cases of physician aid in the hastening of a patient's death be reported (Figure 4). This registry would be able to request for review the full medical records of the patient, including details of the hastened death, would track complete demographic information, and would issue an annual report, accessible to the public, detailing its findings.

BANEC also recommends that existing hospital, hospice, and community clinic peer-review organizations include cases of aid in hastening deaths in their mandate of review.

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*In the BANEC discussions of this document, a significant minority felt that section H draws an artificial mechanical boundary between a "patient-initiated" hastened death and a physician's act of administration of drugs once other guideline recommendations have been met. Since the Ninth Circuit Court addressed only physician-assisted suicide, however, the final BANEC guidelines reflect this limitation and refer only to a "patient-initiated and -completed" process.

Physician Checklist in Assisted Death Cases
(to be completed before the hastening of a patient's death)

Patient's name:_____

Physician's name: _____ Date:_____

Before assisting in the death of a patient, please confirm the following:

1. ❑ The patient is an adult resident of California.
2. ❑ As the patient's physician, I am well aware of the patient's medical history, condition, diagnosis, and prognosis.
3. ❑ The patient's condition is terminal, with death reasonably expected to occur within six months of this date.
4. ❑ A second physician has confirmed this terminal diagnosis.
5. ❑ The patient is mentally competent and able to exercise rational thought processes in making decisions regarding his or her health care.
6. ❑ High-quality palliative care, by hospice and/or physicians qualified to provide such care, has been offered to the patient, with full understanding that such care might result in an improved quality of life in the patient's remaining days.
7. ❑ If such care has been refused by the patient, such refusal has been documented by signed consent form.
8. ❑ To the best of my knowledge, the patient's choice to die has been freely made, independent of finances, family, health insurance, or other sources of coercion.
9. ❑ The patient has been offered consultation with an ethics committee.
10. ❑ The patient has been offered counseling by a psychiatrist, therapist, social service worker, clergy member, or other (blank line).
11. ❑ The patient has been counseled to discuss his or her decision with family members, loved ones, or others who will be affected by this decision.
12. ❑ The patient has made the required two signed, witnessed requests, at least 48 hours apart, for a hastened death.
13. ❑ The patient has been offered appropriate means of ending his or her life, with full disclosure of the process and pros and cons of each, and has made an informed choice of which intervention will be used.
14. ❑ At the time of the procedure, the patient is still competent, has made a third, final request, with witness(es) present, and has been advised that the procedure may be halted at any time upon the patient's request, with a return to optimal palliative care as an option.
15. ❑ A health care professional (physician or nurse) with expertise in this area has been identified who will remain immediately and continuously available to ensure that distressing symptoms are minimized via appropriate palliative means.

After death, the usual confirmation and reporting requirements are in effect, with the addition of the reporting form for physician-assisted death.

Narrative section (optional): Please use the back of this form and/or additional pages to add any comments deemed appropriate regarding this patient's case.

_____ _____
Physician's signature Date

Figure 1.—BANEC's Physician Checklist in Assisted Death Cases.

Documentation of Offer of Consultation and Services by Hospice or Other Palliative Care Expert

NAME _____

My physician, _____, has recommended that I be evaluated by a hospice program and/or another physician, both of which have special expertise in controlling the emotional, spiritual, and physical suffering that can be associated with dying. It is my understanding that hospice programs and such physicians can provide the optimal treatment for terminally ill patients such as me, and that such treatment might include improved treatment for the pain associated with my illness and treatment and counseling for possible depression, other psychological or social issues, or other problems related to my condition. I further understand that while such treatments will not cure my condition or significantly extend my life, they do have the potential to improve my quality of life. It has been explained to me that a consultation with hospice is readily available to me, and that hospices can make arrangements that will not place additional financial burdens on me or my family while they provide such services.

After due consideration of this information and offer of referrals, I hereby certify that:

- ❑ I have accepted the referral and have consulted with (check one or more):
  - ❑ Hospice representatives
  - ❑ Another physician as referred by my primary physician
  - ❑ Other: _____
- ❑ I decline the recommendation of a consultation with hospice personnel or physician.

_____ _____
Signature of patient Date

_____ _____ _____
Witness, print name Signature Date

_____ _____
Signature of primary physician Date

_____ _____ _____
Translator (if applicable), print name Signature Date

Figure 2.—BANEC's Documentation of Offer of Consultation and Services by Hospice or Other Palliative Care Expert.

Informed Consent—Request for Physician-Assisted Death

I, _____, being of sound mind, have of my own free will and in consultation with my physician and others close to me, decided that it is my desire to end my life. I hereby certify that:

I am an adult resident of the State of California;

I believe, and my physicians agree, that I am mentally competent to make decisions regarding my life and death;

I have a confirmed terminal diagnosis with a reasonable prediction that, if the disease runs its expected course, I will die within six months of this date;

I am making this choice to hasten death of my own free will and have not been convinced or coerced to do so by any other persons or party, including any insurer or payer involved in the finances of my health care;

I have been offered full use of medical and hospice services and expertise for the improvement of my condition and quality of life, including management of my pain and discomfort, and have either availed myself of such consultations or have declined to do so;

I have also been offered consultation with an ethics committee of a hospice or hospital and have or have not undertaken this consultation in accordance with my best judgment;

I have, in accordance with my best judgment, discussed (or chosen not to discuss) this final decision with members of my family or others who will be affected by my death;

I have discussed the process to be used to hasten my death, its risks, and alternatives and have chosen this method as my preferred means of ending my life;

I retain the right at any time to change my mind and withdraw my request to die. I understand that all other options for care, including hospice and other measures that are likely to make me more comfortable, continue to be available to me at all times.

First request:

_____	_____	_____
Signature	Date	Time

(Note: The selection of witnesses is in accordance with the regulations now established for the signing of a Durable Power of Attorney for Health Care Decisions.)

_____	_____	_____
Witness #1, print name	Signature	Date
Witness #2, print name	Signature	Date
Translator (if applicable), print name	Signature	Date

Second request:

_____	_____	_____
Signature Date Time		

(Note: The selection of witnesses is in accordance with the regulations now established for the signing of a Durable Power of Attorney for Health Care Decisions.)

_____	_____	_____
Witness #1, print name	Signature	Date
Witness #2, print name	Signature	Date
Translator (if applicable), print name	Signature	Date

Figure 3.—BANEC's Informed Consent—Request for Physician-Assisted Death.

Report of a Physician-Assisted Death
(to be completed by the patient's primary physician)

(Note: All cases of assisted death should be reported to an appropriate organization. Until such a time as an official reporting entity has been established, the BANEC guidelines recommend reporting to the local Health Department, hospital, or hospice ethics committee, or an established peer review or quality assurance committee.)

This information will be held confidential and will be reviewed only for compliance with recommended standards of practice. It is hereby agreed that the patient's complete medical records may be requested by such a review committee, and I hereby agree to provide these records if so requested.

_____
Patient name (or identifying code)

_____ _____ _____ _____
Patient's date of birth Age Sex Ethnicity

Physician: _____

Patient's diagnosis: _____

Second physician who confirmed terminal diagnosis: _____

Date of death: _____ Location of death: ❑ Institution ❑ Home ❑ Other: _____

Physician's relation to patient (check one):

❑ I have been the patient's primary physician for (blank line) months/years.

❑ Patient was referred to me to deal with the illness/symptoms which led to the request for a hastened death.
Date of referral: _____

❑ I believe patient was referred to me specifically regarding the hastening of death.
Date of referral: _____

First witnessed request for a hastened death: Date: _____ Time: _____

Second witnessed request for a hastened death: Date: _____ Time: _____

Diagnosis and symptoms leading to patient's request: _____

Was patient referred for palliative care/hospice consultation? ❑ Yes ❑ No

If not, why not? _____

If yes, did the patient accept this consultation? ❑ Yes ❑ No

If Yes: Date of consultation: _____

By whom: _____

Outcome: _____

Please attach copies of signed forms:

1. Documentation of Offer of Consultation and Services by Hospice or Other Palliative Care Expert
2. Informed Consent for Physician Assisted Death
3. Physician Checklist in Assisted Death Cases

Location of patient's medical records: _____

Mode of assisted dying used: _____

Other comments (use other side of form and additional pages as needed).

Figure 4.—BANEC's Report of a Physician-Assisted Death.

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* * *

Code Blue

I'm running,
running the way we all run
toward death,
sprinting through swarms
of *Pseudomonas* and *Serratia*,
the din of the soaps,
a demented man's scream.

And I run the code
serene as a monarch,
issue edicts and commands,
infusions, boluses, electric thumps
until I drop the paddles,
bent, breathless.

When I raise my eyes,
the body on the bed,
dusky blue, spreads
limp as twilight
on the wintry hills outside,
commuter traffic on the street
choked motionless,
the silent signal light beating
orange, red, green.

RICHARD M. BERLIN
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