



COMMUNITY VOICES IN MEDICAL ETHICS, INC.

November 21, 2013

LouAnn Stanton, Esq.
Office of the General Counsel
Department of Public Health
250 Washington Street
Boston, MA 02108

Commissioner Cheryl Bartlett and
Members of the Public Health Council
Department of Public Health
250 Washington Street
Boston, MA 02108

RE: Draft Regulations - 105 CMR 130.000, 105 CMR 140.000, and 105 CMR 150.000
Information and Counseling about Palliative Care and End-of-Life Treatment Options

Dear Commissioner Bartlett, Attorney Stanton, and Members of the Public Health Council:

I am writing on behalf of a community group called Community Voices in Medical Ethics, Inc. As part of our mission to include the community's voice in the dialogue of medical ethics which occurs within the Boston health care institutions, I helped form the Community Ethics Committee (CEC) in 2007. We are a volunteer group of eighteen members who are representative of the population served by the Harvard teaching hospitals. We are diverse as to socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Of the eighteen members, ten are men and eight are women; we range in age from our teens to our seventies. Some of us have advanced degrees and some of us do not yet have high school diplomas. Among us are two high school administrators, a high school teacher, and two high school students; a retired rabbi, a Muslim woman lawyer, a Latino Pentecostal student, and a professor at a local Protestant seminary. We include two gentlemen specializing in IT solutions – one originally from East India and the other from Taiwan; and we are individuals some of whom have disabilities and some who are parents of children with ongoing medical issues. We are students and writers and small business owners. We belong to eight different religious traditions, in addition to atheism, and we speak seven different languages. We are truly a representative community group and we have had the privilege to share our voice in discussions with the Harvard teaching hospitals as they developed policy initiatives on topics as diverse as caregivers' use of social media, pediatric organ donation on cardiac death, withholding non-therapeutic CPR, palliative sedation, organ transplant recipient listing criteria, and medical futility. All of our Reports (available online at medicalethicsandme.org) have included a strongly worded and unanimous recommendation to expand and enhance the public's access to palliative care, finding great value in palliative care teams' expertise in sensitive communication surrounding end-of-life and chronic illness issues and in proficient pain and symptom management.

RE: DPH Draft Regulations Regarding the
Information and Counseling about Palliative Care and End-of-Life Treatment Options
November 21, 2013
Page 2 of 6

With our diverse community backgrounds and with our experience in tackling some of the most thorny end-of-life policy-making issues, the Committee is eager to lend our voice to the public comment on the Department's Draft Regulations. We believe hospitals, clinics, and long-term care facilities should have an obligation to provide information on palliative care and end-of-life treatment options and we applaud the Department's efforts to ensure that happens.

Our comments on the Draft Regulations focus on three areas – (i) the definition of palliative care; (ii) the determination of which patients are “appropriate,” triggering the required delivery of written informational materials and end-of-life counseling; and (iii) the community's concerns about how this information is provided.

PALLIATIVE CARE – The Committee is aware that “palliative care” is a very broad category which encompasses much of what medical care is all about. We observed in our Report on Palliative Sedation that a timely dose of Benadryl could be viewed as palliative care – the goal of pain and symptom management does not necessarily imply or require a diagnosis of a terminal or chronic illness. Because of the confusion in the use of the phrase “palliative care,” we would suggest adding in the definitional section of the Regulations a statement that “Palliative care is continued compassionate care provided near the end of life or during treatment of a chronic condition or when, in the judgment of the patient's health care practitioner, it provides a benefit to the patient.” It is our understanding that hospice care is a subset of palliative care.

One of the primary concerns voiced by the Committee is the confusion that arises with the introduction of palliative care and the assumption that all curative treatments are withheld or withdrawn once palliative care has begun. Pervasive misunderstandings about the interaction of various medical orders - DNR (do not resuscitate), DNH (do not hospitalize), DNI (do not intubate), and DNT (do not treat) – is a concern to the community to the extent individuals who may want to continue some forms of treatment perceive palliative care as precluding all other types of medical interventions. A very real impression among many in the community is that a transition to palliative care, and more particularly entry into the hospice care system, means no further medical treatment options will be provided, imposing a “death sentence.” Although the introduction of the MOLST form may help to address some of these concerns, it does not completely eliminate the need for clarity among the public, health care providers, and institutions. We suggest that the definitional section of the Regulation included a statement that “Palliative care does not mean the cessation of all other medical treatments and does not preclude other treatment options being provided.” Both the written informational materials required to be distributed under the Draft Regulations and the end-of-life counseling must address the distinctions among these various medical orders and must reassure the patient and their family that a transition to palliative care means that compassionate care will continue. The lack of understanding in this regard has long-lasting adverse effects on public health policy and individual patient decision-making.

RE: DPH Draft Regulations Regarding the
Information and Counseling about Palliative Care and End-of-Life Treatment Options
November 21, 2013
Page 3 of 6

“APPROPRIATE PATIENTS” – The Committee has concluded that the sooner end-of-life discussions occur, the better. In an ideal world, “appropriate patients” receiving information under these regulatory requirements would include everyone who enters the medical system. In all events, those patients with a diagnosis of terminal and chronic illness should be deemed “appropriate patients” who are entitled to both an informational pamphlet and end-of-life counseling in the form of a careful conversation. A patient’s prognosis, whether it be a six month terminal illness or a lifetime of medical interventions to address a chronic condition, should not limit the appropriateness of initiating this discussion or providing this information. We would therefore suggest the Draft Regulations include within the definition of “appropriate patient” those individuals with chronic illnesses. From the community’s standpoint, the broader the definition of “appropriate patient,” the healthier the health care system will be.

CONTENT AND MANNER OF COMMUNICATION – The Committee has three primary concerns about the provision of information on palliative care and end-of-life treatment options. That information must be sensitive to cultural and religious perspectives; it must be in a form that assumes face-to-face conversations with a member of the patient’s health care team; and it must be provided in the context of continued and compassionate care.

As members of diverse communities within the Boston area, the Committee is aware of the varied approaches different ethnic cultures and religious groups take to end-of-life discussions. Even within those cultural and religious groups, individual patients and families are not uniformly agreed on what should or should not be communicated and what may or may not be helpful to medical treatment decision-making. As a result, the written informational materials that are distributed and the conversations that follow must be sensitive to the values and social structures important to the patient. Regardless of cultural and religious sensitivities, every patient must be reassured that their health care providers and the regulated institutions will continue to provide compassionate care and a transition to palliative care does not in any way connote abandonment.

A pamphlet that introduces the subject of palliative care and end-of-life decision-making is a good starting place. We find it important to note the Draft Regulations require end-of-life counseling and we recommend the informational pamphlet to be distributed to appropriate patients contain contact information for follow-up, providing an authentic opportunity for conversations about the patient’s wishes and beliefs surrounding end-of-life care. Training must be provided to health care providers so that these conversations can be had in culturally and religiously sensitive ways that acknowledge the patient’s and family’s values and focuses on the patient’s overall goals of care. The Committee addressed this issue in its Report on Medical Staff’s Use of Social Media, concluding that the “gold standard” of any kind of shared medical decision-making, but most particularly end-of-life decision-making, is a face-to-face conversation with a respected and well-trained health care provider. Any other form of communication is merely a prelude to “the real thing.”

RE: DPH Draft Regulations Regarding the
Information and Counseling about Palliative Care and End-of-Life Treatment Options
November 21, 2013
Page 4 of 6

The Committee acknowledges that placing a legal responsibility on health care providers to initiate these challenging and uncomfortable conversations may be perceived as unreasonably burdensome within a system that is becoming more regulated all the time. We are sensitive to the fact that such burdens may appear to take away from a professional's calling - the practice of medicine. And yet, we are convinced that the very heart of medicine resides with the patient and his or her values, goals, and voice. The Committee discussed the fact that the decision to donate organs is documented at the RMV and not in one's doctor's office. Perhaps end-of-life conversations could occur outside the medical system, sparing health care providers yet another task and obligation? Admittedly, end-of-life conversations should occur among all of us in every setting, but the one relationship that has the most at stake, the relationship uniquely positioned to help a patient transition to a "good death," is uniquely the health care provider/patient relationship. There is no way to delegate this responsibility to anyone else – it rightly resides in those health care providers working in hospitals, clinics, and long-term care facilities. It follows that the mandated reporting and compliance responsibilities should also reside in the health care providers who are interacting with patients and their families – those who are having the end-of-life conversations that are the ultimate objective of these public health regulations.

The Department's regulatory goal of providing patients with both information and counseling on palliative care and end-of-life treatment options is one the Committee fully and enthusiastically endorses and supports. Clearly, the broader public health goal is to ensure we all engage in conversations about our wishes and beliefs so that our individual voices are heard when treatment decisions are made at the end of our lives. To that end, the Committee recommends:

- The regulatory definition of "palliative care" be explicitly focused on continued compassionate care.
- The regulatory definition of "appropriate patient" be expanded to include all patients who have terminal or chronic illnesses, in addition to those who might, in the health care practitioner's professional judgment, benefit from palliative care services.
- The requirement that end-of-life counseling occur include assurances that follow-up conversations with the patient will be sensitive to cultural and religious differences and focus on eliciting information about the patient's individual values and goals of care.

RE: DPH Draft Regulations Regarding the
Information and Counseling about Palliative Care and End-of-Life Treatment Options

November 21, 2013

Page 5 of 6

In order to facilitate the incorporation of the Committee's recommendations within the Draft Regulations, we have provided language below which we suggest be added to the definitions section of each Regulation.

We greatly appreciate the opportunity to be heard on this important issue of palliative care and end-of-life treatment options - an issue central to the protection of public health, the provision of compassionate medical care, and the preservation of individual well-being.

Sincerely,

Carol L. Powers, President
Community Voices in Medical Ethics, Inc.
on behalf of the Community Ethics Committee

Carol L. Powers, Chair

Herman Blumberg

Alex Gamez

Yvonne Joyner

Neville Lee

Paul C. McLean

Shukong Ou

Patrick Smith

Shehla Syed

Julian Willard

Christine Mitchell, Advisor and Liaison to the
Harvard Ethics Leadership Group

Barbara Foot

Molly Johnson

Kathleen Kaditz

Rachel Liu

Paresh Motiwala

Gayle Robertson

Adam Sonnenschein

Frank Tipton

Please address correspondence to:

Carol L. Powers, c/o Harvard Medical School, Division of Medical Ethics

641 Huntington Avenue #207, Boston, MA 02115

or email carollpowers@gmail.com

RE: DPH Draft Regulations Regarding the
Information and Counseling about Palliative Care and End-of-Life Treatment Options
November 21, 2013
Page 6 of 6

The Committee's suggested definitional revisions and additions are:

Appropriate patient means a patient whose attending health care practitioner has (1) diagnosed a terminal illness or condition which can reasonably be expected to cause the patient's death within six months, whether or not treatment is provided, **or (2) diagnosed a chronic illness or condition which can reasonably be expected to require medical treatment over more than twelve months**, or (3) determined that the provision of palliative care services is consistent with the patient's clinical and other circumstances and the patient's reasonably known wishes and beliefs.

End-of-life counseling means an oral conversation with appropriate patients, occurring after the distribution of an informational pamphlet, regarding palliative care and end-of-life treatment options, including but not limited to: (i) the range of medical treatment options appropriate for the patient; (ii) the prognosis, risks and benefits of the various options; and (iii) the patient's legal rights to comprehensive pain and symptom management at the end-of-life. End-of-life counseling shall be done with sensitivity to cultural and religious differences, consistent with the patient's reasonably known wishes and beliefs, and with the purpose of eliciting the patient's individual values and goals of care in order to inform end-of-life decision-making.

Palliative care means a health care treatment, including interdisciplinary end-of-life care and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient's quality of life, including hospice care. **Palliative care does not mean the cessation of all other medical treatments and does not preclude other treatment options being provided. Palliative care is continued compassionate care provided near the end of life or during treatment of a chronic condition or when, in the judgment of the patient's health care practitioner, it provides a benefit to the patient.**