

**WITHHOLDING NON-THERAPEUTIC
CARDIOPULMONARY RESUSCITATION**

COMMUNITY ETHICS COMMITTEE REPORT

**Ethics Leadership Group for HMS Affiliated Hospitals and Institutions
Harvard Medical School
Division of Medical Ethics**

February 2009

**COMMUNITY ETHICS COMMITTEE REPORT to
ELLEN ROBINSON, RN PHD, and the
HARVARD ETHICS LEADERSHIP GROUP**

RE: **Withholding Non-therapeutic CPR**

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INTRODUCTION

The Community Ethics Committee (CEC) is a group of fifteen members living in the general Boston area who are representative of the population served by the Harvard teaching hospitals. The need for such a consultative group has been evident for a long time since individuals currently serving as community members on hospital ethics committees are not able to be broadly representative of multiple communities. Solicitation for membership on the Committee has been cast widely through community, business, and church groups, with a specific application process to ensure selection of a diverse and effective working group.

The Community Ethics Committee is comprised of members within the geographic region of the Harvard hospitals who are diverse as to socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Of the fifteen members, nine are women and six are men; we range in age from our twenties to our seventies. Some of us have advanced degrees and some of us have high school diplomas. Among us are a high school administrator and two high school teachers; a rabbi and a minister of a large downtown Boston church; individuals with disabilities and parents with disabled children. Two of us are retired, one from a large Boston law firm. We are students and writers and small business owners. We volunteer at a local rape crisis center, on an Institutional Review Board, in health care facilities. We belong to eight different religious traditions, including atheism, and we speak seven different languages. We all attended the Harvard Bioethics Course in June of 2007, where we first met and began our conversation as the Community Ethics Committee.

PROCESS

The Committee met throughout the spring and fall of 2008 to educate ourselves about the issue of “unilateral DNRs”. We came to the topic with the assumption that CPR is a uniformly effective treatment that will be provided automatically to someone presenting with cardiac arrest. We learned that CPR is rarely effective, even when administered in a hospital setting, and we learned that it can sometimes be an incredibly intrusive and violent procedure – not the gentle “tap tap” on the chest that our media exposure would have us believe. We learned about the medical community’s growing concern about providing such an invasive medical therapy at the point when patients are actively and irretrievably dying-- especially when CPR may only serve to increase their indignity, prolong their suffering, and draw out their dying process. We were faced with the realization that all deaths involve cardiac arrest. We struggled to define what

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medical treatments patients and families are entitled to expect, and we gravitated toward an approach which took into account the patient's overall goals of care which should be agreed upon after discussions with an informed patient and family. The goals of care then establish the entire context of a patient's encounter with the medical community, so that a decision about CPR can be made within that context. We were faced with the fact that perhaps and sometimes patients are dying - a sacred process which should be protected.

We corresponded by e-mail and shared articles we had found and information we had gathered. Our meetings were at a location on the Harvard Medical School site and, although scheduled to run from 6PM to 9PM, our discussions often continued much longer than that. We met in April, 2008 with Ellen Robinson, RN, PhD, a member of the staff at Massachusetts General Hospital. Dr. Robinson presented for the Committee's review existing hospital policies which support unilateral decisions by physicians and health care teams not to initiate CPR when, in their judgment, it was not medically indicated or deemed to be non-therapeutic, and she discussed the distress that medical staff feel when CPR is "administered in situations which defy common sense." Although such policies already exist in some hospitals, they are rarely applied, and she wondered what a community-based group of lay people would think about policies which authorize physicians to forgo using CPR when it would not be medically therapeutic despite the current widespread practice of seeking patient/surrogate consent for decisions not to perform CPR (typically called DNR orders).

We then met in June with Dr. Robert Truog, an anesthesiologist at Children's Hospital Boston and a prominent medical ethicist who has written about so-called "medically futile" treatment, and Martha Jurchak, RN, CS and PhD, who is a clinical ethicist at Brigham and Women's Hospital and Dana-Farber. Dr. Truog presented information about futility – explaining quantitative and qualitative futility and suggesting a focus on goals of care might be a more productive and better way to approach the issue. Dr. Truog spoke about the differences in decision-making when the focus of the discussion is changed – when the focus is on goals of care, the patient and family's values are included and accommodated; when the focus is on medical procedures, the medical team's expertise controls the discussion. In order to change the dialogue, he suggested the conversation with the patient and family begin with the question "What are you hoping for?" Then the issue of whether CPR should be offered or administered is placed in its rightful context – a physiological evaluation of whether it will be effective in meeting the patient's overall goals of care. And that physiological evaluation seemed to be rightly within the doctor's purview. The issues of whether the patient and/or family should be told about treatments that are not therapeutic and the preservation of patient autonomy were also discussed.

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As part of its process, the Committee reviewed hospital policies which deal with this subject either directly (as in the case of the MGH Life-Sustaining Treatment Policy) or indirectly (as in the BWH policy on Do Not Resuscitate (DNR) Orders and the BIDH Guidelines for Withholding, Withdrawing or Limiting Life-Sustaining Treatment, including resuscitation). Lastly and perhaps most importantly, the CEC members spoke about these issues with family, friends and colleagues – the community.

Based on our group discussions and in order to obtain everyone's viewpoints, our committee leadership developed a survey that solicited individual Committee members' thoughts on the questions initially presented by Ellen Robinson. Lastly, we met in September and November to review the survey responses and to focus our thoughts regarding the issue of "non-therapeutic CPR" and the public response to the suggestion that a decision can be made to withhold CPR without consent from the patient and/or family. (Some of the comments from that survey are included in this Report.)

RESOURCES and SURVEY

A Bibliography of articles and resources distributed to the CEC is attached as Attachment 1; and the Survey that was distributed to the CEC members is Attachment 2.

RESPONSES and COMMENTS

The CEC focused on three questions which arose in connection with this topic and which were presented by Ellen Robinson, as a member of the Harvard Ethics Leadership Group. In brief, those questions were:

1. What is the language that should be used to frame this area of medical decision-making?
2. How should this area of medical decision-making be presented to patients and their families? Or, in the alternative, should this area of medical decision-making be left entirely to the medical team, with no discussion with the patient and family expected or required?
3. Should a medical team perform CPR when the patient or family demands it, even when it is deemed not medically appropriate or therapeutic?

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The responses set forth below are necessarily condensed and cannot completely reflect the richness of the Committee's discussions or the care with which we wrestled with these issues.

1. What is the language that should be used to frame this area of medical decision-making?

The Committee was particularly sensitive to the fact that the language used in this Report would frame the underlying rationale for accepting or rejecting the concept of doctors' making medical decisions regarding CPR. The phrase "unilateral DNR" was felt to be "draconian and offensive" and easily misunderstood. The phrases "medically inappropriate CPR" and "medically futile CPR" were also deemed to be problematic, seeming to involve value judgments that extended beyond just medical evidence. We concluded that the phrases "CPR not medically indicated" or "non-therapeutic CPR" were most appropriate based upon our view that the only acceptable criteria for deciding not to perform CPR must be in the context of a patient's goals of care.

2. How should this area of medical decision-making be presented to patients and their families? Or, in the alternative, should this area of medical decision-making be left entirely to the medical team, with no discussion with the patient and family expected or required?

The presentation of this issue to the Committee included the recognition that CPR falls into a unique category of medical decision-making - currently patients must "opt out" of this treatment through the use of a DNR Order. Otherwise, the expectation is that CPR will be done; and, of course, the terminology drives that expectation - everyone wants to avoid death and be resuscitated. The expectation that CPR will be done in every instance of cardiac arrest has risen to the standing of a "right". The CEC was concerned that this bias in the public's view, that CPR would always be done, lost sight of two important facts - CPR is more likely than not ineffective in resuscitating a patient suffering from a cardiac arrest and CPR is a treatment option that may not be appropriate in the context of the patient's goals of care.

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In addition to the issue of the public's perception of the automatic availability and efficacy of CPR, the CEC also discussed at length the integrity of the medical profession and how much protection needed to be afforded to staff in situations where they may be required to participate in a procedure that violated their mandate to "do no harm." We believe the health care team's "moral distress" was not underestimated by the Community Ethics Committee.

Given these two perspectives – the public's "right" to CPR and the medical professional's "right" to opt out of procedures that do harm (i.e. do no therapeutic good) - the CEC felt that situations might reasonably present themselves when a physician could determine that CPR would not accomplish the patient's goals of care and would therefore be a non-therapeutic medical treatment. Determining the goals of care is rightly within the patient's decision-making control (or the surrogate decision-maker for the patient). The physiological evaluation of what procedures will accomplish those goals of care are necessarily within the physician's professional expertise.

The Committee felt very strongly that full disclosure of the medical conclusion that CPR would be non-therapeutic must be made to the patient and/or family and such disclosure was "essential to proper patient care." In addition, the Committee felt strongly that the decision should not be based upon individual characteristics of the patient such as age, race or even medical fragility, but rather be based upon identifiable physiological criteria. The decision should be based solely upon the probable medical outcome in the context of the overall goals of care for that patient. The decision should be "evidence based," meaning clear guidelines should be developed that would apply to all patients using identifiable criteria such as: whether the cardiac arrest was witnessed, whether the patient suffers from an underlying chronic terminal disease, and whether the patient has co-morbidities such as osteoporosis that might be contra-indicators for CPR . Finally, the discussion with the patient and family should include the option to transfer to another facility that would provide CPR as a medical treatment. The suggestion was made that a formal ethics consult should be made available to the patient and/or family if they rejected the physician's conclusion that CPR would be non-therapeutic.

The CEC concluded that, as soon as a decision is made that CPR is not therapeutic in the context of the patient's overall goals of care, the patient and family must be informed in a sensitive and fully descriptive way. The Committee was focused on the patient's good, as the patient and their family defined it, and wanted to ensure that CPR would not interfere with a dignified death. A significant amount of time was given to a discussion of the issue of providing a patient the option to transfer to another facility that would be willing to offer CPR, to ensure that the patient and/or family would not be abandoned. The concern on the Committee was widespread that, by offering a transfer option, the hospital and its staff might have less of an incentive to explain their concerns and engage the patient and family in a substantive conversation about the patient's goals of care and the therapeutic options that are available to accomplish those goals.

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One of the primary concerns the CEC expressed was the need to protect patients coming from different ethnic, racial or cultural backgrounds, since research supports the conclusion that those patients are more at risk for neglect and misunderstanding within the healthcare setting, making them especially vulnerable to decision-making that limits their therapeutic options. A suggestion presented by several members of the CEC was to include a cultural representative in the medical staff's discussions with the patient. In addition, it was suggested that data be kept so that trends could be monitored and bias could be minimized in patient populations for whom CPR was not offered.

Notwithstanding the concerns about how the decision is made not to provide CPR, and how that decision is to be communicated to the patient and family, the CEC recognized and was sympathetic to the moral distress expressed by the medical community. The Committee members were startled to learn both of the limited medical efficacy of CPR, even in "ideal" situations, and of the physical violence and intrusiveness which are sometimes involved. We understood how health care professionals, doing their utmost to provide the highest quality of care, are dismayed at being forced to pound on a dying patient's chest, to break ribs, to poke with needles, and generally to interfere with the body's natural process of dying. We could sympathize with their dilemma of continuing to work in a health care system that would not only condone such interventions, but demand them. The CEC felt its conclusion – to focus on the patient's goals of care and to withhold CPR after a physiological evaluation indicated such an intervention would be non-therapeutic – would accommodate the health care professionals' moral distress. Nevertheless, the CEC cannot emphasize strongly enough that its conclusion is based upon the express requirements that the patient and/or family be informed and that safeguards exist to ensure the patient's goals of care are carefully evaluated and protected.

Comments from the Survey include the following:

- Sometimes what we want is not what we should have.
- Ideally, the perception of CPR as a "right," as opposed to a medical intervention that is sometimes appropriate, sometimes not, and therefore not something the patient or surrogate can demand, will change.
- It would be the responsibility of the health care provider to sensitively and clearly communicate the risks and benefits of CPR administration, and if necessary, describe the process in some detail.

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- The conversation should be prompt, open, fulsome and frank and should include involved family members and religious or other family advisors requested by the patient to participate.
- I would argue for transparency, open and honest dialogue, and sharing of information in such a way that patients and health care professionals can work together to develop a plan that best meets the goals of the patient.
- The strain on the staff providing CPR is a high concern.
- Some families have no ability to make rational decisions; there aren't many, but I have met a few.
- I think the evidence that CPR is not nearly as effective as we would like to believe is helpful because it eases the urgency of performing it. If we know that it is often unlikely to be successful, then the harm/injury/damage done by the process can carry greater weight in the decision-making process.
- I chose the option where CPR should be attempted, but only if it is done ONCE. It should not be an endlessly repeated procedure when the patient is very unlikely to recover. Ask the family early on how their loved one wanted to live. And try to offer options based on that intention.
- I think it [withholding CPR] needs to be presented as medically not indicated, as interrupting the dying process, as even cruel to the patient.

3. Should a medical team perform CPR when the patient or family demands it, even when it is deemed not medically appropriate or therapeutic?

The CEC discussed at length the issue of whether it was ever appropriate for medical professionals to override the patient or family. The Committee focused on the adequacy and vigor of the communication with the patient and family, wanting to be sure the information was adequately conveyed regarding the benefits and burdens of CPR, being explicit in describing what happens during such an intervention. There was a sense that, once a patient and/or family understood the repercussions of a decision to go forward with CPR when it would not provide the hoped-for benefit, they would agree with the medical team to withhold CPR as a therapeutic option.

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Although both the CEC and the medical staff presenting this issue were concerned about the possible loss of trust that families might experience when the decision not to offer CPR was presented to a patient and/or his or her family, the CEC's concerns included the loss of trust incurred when the dignity of the dying patient is not vigorously protected. The CEC recognized that the impending death of a family member raises many different issues that affect medical decision-making. The CEC was particularly focused on what it perceived as the good of the patient – meaning each patient's dying process should be as dignified and respectful as possible. The Committee did conclude that medical staff could withhold non-therapeutic CPR even when the patient and/or family demanded it, when that decision was supported by the context of the goals of care given the patient's particular medical history and likely outcomes.

Comments from the Survey include the following:

- I would not feel comfortable with an order being placed in the chart if the family still objects after a candid conversation has taken place.
- I think this [a decision to withhold CPR against patient or family wishes] is a good thing. However it's obviously vital that the patient/family be sensitively informed if a decision to override their expressed wishes is taken.
- I think [such a policy] offers a by-pass for those who may be less than committed to patient and family-centered care; it's a disincentive to having those difficult conversations that are a significant part of healthcare. It feels too heavy-handed to me: "agree with me or I'm just going to overrule you".
- Sometimes the hard decisions are the right ones, and the hospital puts its public, professional and peer reputation on the line every time it does something bold which it deems correct and appropriate.
- No physician or nurse should be forced to perform medically inappropriate CPR and injure the patient they're trained to help.
- To the extent the [patient's] care plan doesn't change, the health professionals need to abide by the existing care plan until they can be replaced on the care team or the patient is transferred to another care provider who is more comfortable with providing CPR.
- While it should not affect the decision to provide CPR to a patient, staff may need ways to recuse themselves.

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- Unless such objection [the doctor's objection to administering CPR] is disclosed to the family and other medical staff and [hospital] administration in a timely manner, it would be unethical and possibly illegal to permit such a physician to affect the decision to perform CPR.

- The health professionals' conscientious objection ALONE should not affect whether a patient gets CPR. This leaves too much discretion to the health care provider, when not all health care providers are necessarily capable (or trustworthy) to make such decisions . . . This would be comparable to a physician withholding information/services for contraception, abortion or other reproductive health, simply because s/he has a conscientious objection to such practices. I would never support that, so I cannot support this!

SUMMARY of CEC CONCLUSION

The Community Ethics Committee was unanimous in their conclusion that CPR may be withheld by medical professionals when it is determined to be non-therapeutic for the patient. The decision to withhold non-therapeutic CPR must be made in the context of the patient's overall goals of care, supported by physiological criteria, and only when the patient and their surrogate and/or family are informed of the rationale for that decision as soon as practicable. The CEC concluded that withholding non-therapeutic CPR is supportable even when a patient and/or family disagrees with the health care team about the patient's overall goals of care and demands CPR. That being said, the members of the Committee felt strongly that the withholding of non-therapeutic CPR can only be supported when policies and practices are in place to ensure that patients' and their families' interests are protected. Those safeguards require that discussions with the patient and their surrogate and/or family be thorough and explicit and every effort be made to come to agreement on the patient's goals of care *before* withholding non-therapeutic CPR; that interpreters and cultural advocates be included, when appropriate, in discussions by medical professionals with the patient and their surrogate and/or family about withholding non-therapeutic CPR (and data be maintained as to which patient populations are included in these decisions); and that the opportunity to transfer to another healthcare facility be offered and facilitated.

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ASSUMPTIONS Leading to our Decision to Support the Withholding of Non-therapeutic CPR

The members of the Community Ethics Committee are grateful for the opportunity to contribute to the medical community's dialog about the decision to withhold CPR when it is determined to be non-therapeutic in the context of the patient's overall goals of care. Nevertheless, we find that withholding CPR when healthcare professionals conclude it is not a warranted medical intervention can only be justified when it is based upon a physiological evaluation based upon research-supported medical criteria. We have assumed that, without use of such medical criteria, the possibility exists of bias which could harm vulnerable populations, including those who are elders or of racial minorities or who are from different cultures or with disabilities. The CEC was unanimous in its concern that vulnerable populations will need protection and we have assumed two safeguards will be in place in situations where CPR is not offered by medical professionals because it is determined to be non-therapeutic in the context of the patient's overall goals of care: (1) open discussions with patients and families will occur, with the possibility of cultural representatives being present at those discussions, and (2) data will be reported so that these decisions to withhold non-therapeutic CPR can be closely monitored, to ensure formal protections will be instituted if discriminatory trends are found to exist.

It may be important to note that the CEC's discussions did include the issue of cost of care. The CEC was told that, in light of the overall cost of US health care, the costs of long-term care for those individuals who were resuscitated to a state requiring intensive and long-term medical interventions were not such a significant burden on the health care system as to require financial costs to be a factor in the decision whether or not to provide CPR. As a result, the CEC's decision to support the withholding of non-therapeutic CPR was not based upon a conclusion that health care costs would be saved thereby.

Comments from the Survey in relation to financial costs include:

- Financial considerations should, when feasible, be kept apart from decisions about sustaining/ending life.
- Economic bias should not enter into decisions until it is an agreed-upon factor in the medical profession, professional organizations and the national health care dialogue.
- As more and more decisions become economic, I think we have to figure out how to factor this in compassionately. Cost is not about the value of one's life, but part of the way we weigh whether to insist on continued treatment. Life may be priceless, but treatment is not.

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We also discussed the CEC's potential role in public education. We were unanimous in our concern about the media's portrayal of CPR, and we were all startled by our general lack of knowledge regarding the inefficacy of and the physical invasiveness that accompanies CPR. We all came to this issue misinformed by the media's portrayal of CPR as a highly effective and relatively non-invasive procedure. We were acutely aware of the resulting perception that, of course, everyone would want CPR and that, in fact, everyone feels entitled to CPR as a medical intervention. Given the pervasive misconceptions that the public brings to this issue, the information given to the patient and family when a decision is made to withhold CPR must be especially pointed and thorough.

One of the Survey comments applicable to the Committee's public education goals is:

- We have the opportunity to open the issue to greater public understanding just as we opened it to greater understanding among ourselves. I hope in the coming months and years that we will not only respond to the hospitals but also to the communities we serve.

Finally, we agree that this Report may be shared with other hospitals but we respectfully ask that these assumptions not be excluded when sharing CEC feedback with internal and external parties. We thank you for the opportunity to engage with you in such interesting and important deliberations.

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Non-Therapeutic CPR

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