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Unrealized Hopes, Unimagined Consequences: In-Hospital CPR and the
Critically Ill

By

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For my parents, who have made everything possible.

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A Review of the Literature

The history of resuscitation in the Western world can be traced back to the late 1700s, when Dutch, British and American Societies first described techniques for resuscitating near-drowned and anaesthetized patients who had suffered respiratory arrests.^{1,2} The advent of what we know as modern cardiopulmonary resuscitation (CPR), encompassing cardiac as well as respiratory arrests, however, is relatively recent, originating in the 1950s with the development and acceptance of three procedures: the termination of ventricular fibrillation through external defibrillation,³ mouth to mouth ventilation (originally developed by midwives to resuscitate newborns),^{4,5} and in 1960, the pivotal technique of closed chest cardiac massage (CCCM), developed by Kouwenhoven et al. At that time, cardiac massage was a known and accepted procedure, but could only be performed on the opened chest, through thoracotomy.⁶ The development of CCCM opened the doors to widespread attempts at resuscitation and ushered in the era of modern CPR. As Kouwenhoven wrote, "Anyone, anywhere, can now initiate cardiac resuscitative procedures. All that is needed are two hands."⁷

Despite these enthusiastic words, Kouwenhoven et al's report makes clear that CPR was intended to be applied only on a *select* group of patients: those in relatively good overall health and with good cardiac function. In their follow-up report published six months later, co-investigator Jude cautioned:

Not all dying patients should have cardiopulmonary resuscitation attempted... The cardiac arrest should be sudden and unexpected.

The patient should not be in the terminal stages of a malignant or other chronic disease, and there should be some possibility of a return to a functional existence.²

One can only speculate as to whether these cautions were based on purely physiologic considerations, or on their personal definitions of acceptable outcomes as well. In any event, because CPR held out the possibility of reversing a death in progress, the urge to attempt it on everyone suffering an arrest became irresistible. As one observer noted wryly, "Because we can, we think we should."⁸ Thus, in 1965, the American Heart Association, Red Cross, Industrial Medical Association, and U.S. Public Health Service called for a reclassification of CPR from a *medical* procedure to an *emergency* one.⁹ This shift in thinking eventually led to the current in-hospital standard of performing CPR on *anyone* who arrests except for those who specifically refuse it.¹⁰

As a result of its broadened application, survival rates following administration of CPR have plummeted from the 70% that Kouwenhoven et al reported in their initial study.⁷ Indeed, since 1960, medical providers worldwide have been unable to come *close* to reattaining that benchmark. A review of nine reports and meta-analyses which altogether combine the results of more than 300 in-hospital CPR studies revealed an overall world-wide survival rate of between three and 32.2%, with an average of roughly 15% - an average largely unchanged over forty years' time.¹¹⁻²⁰

What these studies have done, however, is provide consistent empirical evidence that patients whose arrests follow sudden, unexpected cardiac collapse, who are without multiple co-morbidities, and who enjoy a quick return of circulation, stand a relatively good chance of survival. Conversely, high risk patients - those with significant co-morbidities (e.g., metastatic cancer, AIDS, renal failure, sepsis, pneumonia), those who suffer an unwitnessed arrest, and/or present in asystole or pulseless electrical activity, stand less than a 5% chance of survival to hospital discharge.^{13 14, 15, 18, 21-25}

Many studies have gone on to show that if a patient's circulation is not re-established within five to six minutes, neurologic function declines sharply and rapidly. Thus, even if a patient *survives*, the longer the resuscitation effort continues, the greater the chance of suffering neurologic complications: impaired memory, loss of higher intellectual function, myoclonus, seizures, cortical blindness, spinal stroke, persistent vegetative state, and brain death.²⁴ Martin, et al found that only 5% of patients who remain unconscious after 48 hours regain full neurologic function. It is estimated that roughly 30% of in-hospital CPR survivors sustain some degree of neurologic deficit.²⁴

Other CPR outcomes studies have provided data on mechanical sequelae from CPR. CPR is a highly aggressive procedure. To adequately perfuse the coronary and cerebral vasculature, one must compress the patient's lower sternum one and one-half to two inches towards the vertebra at least 60 times a

minute.² High-pressure chest compressions applied in the wrong place will break bones -- particularly the bones of older, frailer patients. Numerous CPR-induced injuries such as broken ribs, sternal fractures, pneumothoraces, and lacerated trachea have been reported. Further, patients with certain co-morbidities are at risk for ruptured viscera following defibrillation and positive pressure compressions.²⁶⁻⁴⁵ In addition, most CPR survivors require prolonged mechanical ventilation and time in intensive care units¹⁰ where further invasive procedures are the rule, and where, for 85% or more of them, death comes in days to weeks.

For patients with significant co-morbid conditions at the time of arrest, then, a significant percentage will suffer mechanical injury from the effort, all will require intensive post-CPR hospital care, and only 3-15% will eventually leave the hospital alive. Of those, thirty percent will likely have incurred permanent neurologic deficits.

Beyond these possible consequences to the patient, CPR attempts on high-risk patients also impact patients' families, medical providers, and their resource-limited communities. Families and surrogates often bear painful witness to the unrelieved pain, dyspnea, and confusion commonly experienced by patients in the last days of their lives,⁴⁶ question whether they have made good choices for the patient, and find themselves faced with such agonizing decisions as when or whether to withdraw treatment for their loved ones. Medical providers as well agonize over their obligation to administer this very aggressive procedure and inflict more pain on already dying patients. In one survey, 70% of house officers

at five different hospitals reported that they had gone against their conscience in providing aggressive treatment to terminally ill patients. Fifty-five percent felt that they had provided overly burdensome care.⁴⁷ In response, some physicians have resorted to the problematic practice of providing only half-hearted or sham CPR efforts, so-called "slow codes," when they have not been able to prevail upon families or patients to forego the procedure.⁴⁸

Finally, CPR performed on patients with poor prognoses is expensive. One study estimated that the cost associated with in-hospital CPR increases exponentially as the rate of survival to discharge decreases. For patients in that study with a 10% chance of survival, the cost was estimated to be ~\$117,000 per life saved. This sum increased to \$248,271 for patients with a 1% chance of survival, and to \$544,521 for patients with a 0.2% chance of survival.⁴⁹ Another report from an international multi-center trial estimated the cost of CPR programs for six-month survivors of CPR to be \$406,605.00 per life saved (range \$344,314.00 to \$966,759.00), and \$225,892.00 per quality-adjusted-life-year (range \$191,286.00 to \$537,088.00).⁵⁰ Though one may argue the appropriateness or inappropriateness of assigning dollar values to lives, one wonders how long we can afford to spend such sums on persons with end-stage diseases while others in our communities are in dire need of health insurance and proven preventive care.

Clearly, then, CPR's benefits come with significant risks and costs, particularly for those with poor baseline medical prognoses. In the face of what we know, then, is there anything to be done to minimize the harm, while maximizing its utility? Is there any way to rein in its use?

Perhaps We Should Discuss This

As noted earlier, CPR has been deemed an emergency procedure. Thus, as the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research wrote in 1983, unless a patient or surrogate provides *specific* instruction [i.e. a Do-Not-Resuscitate-Order (DNR)], consent for CPR is presumed, and CPR must be administered in the event of an arrest, regardless of a patient's overall medical prognosis.⁵¹ Thus, if a patient does not explicitly order it to be withheld, and the physician does not record that order, the patient will receive it.

In fact, research has shown that many patients near the end of their lives prefer comfort care over life-extending measures.⁵²⁻⁵⁴ Unfortunately, however, individual patients' preferences have never been well documented or well known to either their families or physicians. Studies have shown that physicians' and families' predictions of patients' CPR preferences are no more accurate than what one could expect by chance alone,⁵⁵⁻⁵⁷ and that physicians tend to underestimate their patients' preferences for CPR, and surrogates tend to overestimate them. It would seem, then, that unless patients are directly involved in their own

treatment decisions, many are destined to receive more or less care than they actually desire.

On initial consideration, a fairly straightforward means of preventing unwanted and physiologically non-beneficial CPR would be through physicians' and patients' *discussion* of the matter. If doctors shared realistic information about CPR and elicited their patients' preferences early in the course of illness, when patients could still speak for themselves, many patients would rationally choose to forego CPR if it was unlikely to benefit them, or was inconsistent with where and how they wished to spend the remainder of their lives. Furthermore, if physicians spoke with their patients while they were still *healthy*, in routine outpatient office visits, conversations could be more thorough and extensive, and patients could record their preferences in advance directives or living wills, or assign legal proxies to speak for them in the event that they became unable to speak for themselves.

Curiously, though, in a society such as ours in which a patient's right to make and guide decisions about her medical care is so highly valued, (and affirmed by the United States Supreme Court,⁵⁸ the President's Commission,⁵¹ the Patient Self-Determination Act⁵⁹, and guidelines from the American Medical Association⁶⁰), such conversations rarely occur between patients and doctors at *any* point in the patient's illness.⁶¹⁻⁶⁶ Apparently, the solution is not as straightforward as it seems.

The Sound of Silence

Most doctors believe that eliciting their patients' preferences for life-sustaining treatments like CPR is important and necessary. Further, most physicians hold themselves responsible for initiating such discussions.^{67, 68} Nevertheless, many find these conversations uncomfortable and difficult to broach.⁶⁹⁻⁷¹ Some fear that they will depress their sick patients, and/or give them the impression that they have given up on them. Others fear that their patients will lose faith in them if their prognostications fail to be accurate.^{71, 72} Such fears cause many doctors to delay conversations about treatment plans and resuscitation preferences -- often until the patient is too ill to participate in the discussion. In such cases, physicians and surrogates are left to interpret their wishes. Unfortunately, as stated earlier, their interpretations have, by and large, been inaccurate.

Physicians have thus been urged to initiate these discussions when their patients can still speak for themselves - well before they are seriously ill. Unfortunately, no clear consensus or guideline exists as to when that should be. Many have advocated initiating them in the outpatient setting, with healthy adults of *all* ages.^{52, 73-75} Under these circumstances, and in the context of an established relationship with a primary care physician, it is thought that patients can consider the issues more thoughtfully, and revisit them over time as necessary.

Others, however, feel that such discussions, particularly resuscitation status (so-called "code status") discussions, can only reasonably be held with older patients, those who develop life threatening illnesses, or those who directly face

poor short-term prognoses.^{67, 76, 77} But while earlier discussions may be disorienting and overly abstract for some patients, delaying conversations until patients are seriously ill also incurs the risk of waiting *too long*, which, in fact, physicians often do. Research has shown that physicians grossly and systematically overestimate their patients' prognoses.^{78, 79} In one study, physicians overestimated their patients' probability of survival to discharge after CPR by as much as 300%.⁸⁰ In another, the highly regarded Acute Physiology and Chronic Health Evaluation III System (APACHE III) computer-generated prognostic scoring system (deemed to possess a positive predictive value of ~ 80% and negative predictive value of ~90%), predicted a 51% chance of two months or greater survival time for patients who actually died within the week.⁸¹

Have I Made Myself Clear?

A different set of communication difficulties arises even when physicians and patient *do* engage in conversations about resuscitation. Few medical students receive significant training in discussing end of life issues with patients.⁷⁰ The largest of the very few studies assessing such skills identified a number of shortcomings. From audiotaped discussions between doctors and patients, these researchers found, for example, that most doctors failed to specifically mention or quantify likelihood of survival after CPR. Instead, most focused on descriptions of specific technical procedures instead of eliciting patients' overall goals for care, life values, and concerns about their conditions. Most conversations were brief -- averaging ten minutes-- and dominated by the

physician.⁸² Another study demonstrated similar findings: conversations between patients and doctors regarding advance directives averaged 5.6 minutes, and again, were physician-dominated. Physicians rarely explored patients' life values, and in the majority of cases, presented patients with hypothetical scenarios which were too clearly dire or reversible to represent real-life clinical circumstances -- precisely the circumstances for which personal preferences are the least well-known, and of the greatest value to providers.⁸³ Another study found that some conversations were so vague that patients failed to realize that they had even *discussed* end-of-life care issues with their doctors.⁸⁴ Still other research has documented that physicians sometimes miss patients' verbal clues as to their emotional states and attitudes about their health.⁸⁵ Clearly, then, if physicians fail to convey meaningful information about the nature, uses, risks and benefits of CPR (and other life-sustaining treatments), while also failing to ascertain their patients' values regarding health and disability, though they may have "talked," they have hardly communicated.

Patient Preferences

So now, what *of* the patient's preferences? A great deal of research has gone into trying to determine what patients want from their medical care and providers at the end of their lives. Predictably, they want a great diversity of things.

One consistent finding is that patients invariably overestimate their medical prognoses^{86,87} and CPR's rate of success -- often by as much as 50%.⁸⁸⁻⁹⁴ Why

would they do so? Several studies have shown that many individuals' ideas about CPR are informed by television depictions of the procedure. Researchers in one study tabulated all occurrences of CPR on the popular television dramas, *ER* and *Chicago Hope* during the 1994-95 viewing seasons, and 50 consecutive episodes from the show *Rescue 911*. They found that 75% of patients on these shows survived their CPR attempt, and up to 67% survived to hospital discharge.⁹⁵ These percentages are wildly unrealistic, and to the extent that they serve as primary sources of information, are harmful. One can imagine that if a high-risk patient overestimates her prognosis, perceives that she has a 65% chance of surviving CPR, is unaware of what the procedure entails, or the possible sequelae she could suffer,^{94, 96} she could rationally view CPR as a very good bet. Indeed, the very term "Do-Not-Resuscitate" misleads the patient in that it implies that CPR *would* be successful if attempted.*

Encouragingly, however, numerous surveys have shown that while conversations about advance directives and code status can be disturbing to patients initially, they overwhelmingly desire such conversations, are comfortable discussing such matters, and are even relieved to have the discussions.^{74, 92, 94, 96-101} Furthermore, they, too, believe that their physicians should initiate the discussions⁵² and, in contrast to many physicians, believe that these conversations should occur in the

*More recently, this term has been altered to reflect the more accurate description of the procedure: Do-Not-Attempt-Resuscitation (DNAR).

outpatient setting, when they are still in relatively good health,^{92, 96, 98, 102-104} and *not* when they are very ill.¹⁰⁴

Furthermore, studies show that when patients receive accurate data involving CPR procedures, outcomes, and probability of survival -- that when they understand their probability of survival will be low, or that they probably will not be able to return to a similar level of functioning, the majority opts to forego CPR.^{73, 93, 98, 105⁹}

All told, there is a good deal of evidence, then, that patients are generally uninformed about the realities of what CPR entails and can engender, that they are responsive to new information, and that they do wish to speak with their physicians about resuscitation and life sustaining care. Research also indicates that physicians generally feel it their duty to speak with their patients about advance care planning, want to know their patients' preferences vis-à-vis code status and other life-sustaining measures, and wish for better algorithms to improve their prognostic capabilities. Surely, then, enhancing mechanisms for communication and prognostication would vastly improve a patient's and physician's ability to arrive together at informed, rational preferences regarding resuscitation and other life sustaining treatments. As the Study to Understand

⁹ A very important caveat, however, is that some patients' preferences remain unchanged by outcome data,⁹² declining health,¹⁰⁶ or perceived declining quality of life.¹⁰⁷ Several studies have shown that such patients continue to favor CPR regardless of whether the chance of survival is < 5%⁹⁴, or whether their lives can be extended by only a month,¹⁰⁸ or whether they face a hopeless prognosis,^{96, 105, 109} While it is unclear whether these patients were informed of sequelae or were presented with any meaningful alternatives, these data underscore the great diversity of preferences and priorities which exist.

Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) highlighted most dramatically, however, enhanced mechanisms for communication have proven woefully inadequate to achieve this goal.

SUPPORT and the Limitations of "Talking"

In 1989, the SUPPORT researchers began a four-year study of in-hospital medical care for seriously ill patients (n = 9105) in five academic medical centers around the United States. In the first phase of the study, they described a number of serious shortcomings in the care of seriously ill, hospitalized patients. Among a host of troubling findings, they confirmed much of the aforementioned research: doctors and patients very rarely discussed patients' prognoses or resuscitation preferences, and physicians were thus unaware of patient preferences: though 30% of interviewed patients wished no CPR, less than half of their doctors (47%) knew that. And of the 960 patients who *explicitly* indicated that they wished no CPR, only 49% had formal DNAR orders recorded in their charts.^{63, 86} Further, though patients' declines were deemed predictable, almost half of all DNAR orders were written only two days before the patient's death, when the order was almost surely more an acknowledgement of impending death than a reflection of the patient's values.⁶³

In the second phase of the study, they implemented an intervention designed to improve doctor-patient communication and mutual understanding in order to help them arrive together at patient-centered medical care. Thus, they provided

physicians with prognostic information about their patients, as well as information regarding their patients' treatment preferences. Further, specially trained nurses communicated repeatedly with physicians and patients in order to share information and encourage communication between doctors and their patients. Ultimately, these interventions were, in the assessment of the investigators, "completely ineffectual." There was no improvement in patient-doctor communication, no change in the incidence or timing of written DNAR orders, and no change in physician knowledge of their patients' resuscitation preferences.⁶³

This study dramatically highlights the reality that factors beyond the availability of prognostic data and an awareness of patient's preferences determine how we arrive at a patient's code-status and other treatment plans. For to focus exclusively on these factors is to assume that patients *have* resuscitation preferences which are stable and expressible, or that patients truly *want* to make a decision, and will readily comprehend and incorporate prognostic estimates in making that decision. To focus on these factors is also to assume that providers truly consider patients' preferences a priority, and that factors outside of the doctor/patient relationship do not exist or influence the course of treatment for individual patients. In fact, all of these assumptions are suspect.

First, many patients, even seriously ill patients, do not *have* a preference for or against CPR, and may not wish to form one. In a study of Swedish patients in

different stages of congestive heart failure, for example, most had never given thought to how they felt about CPR for themselves, and furthermore, did not consider their involvement in deciding their code status to be important. Though they welcomed a discussion, they felt it was ultimately the physician's job to decide the matter.⁹⁴ These patients' viewpoints were echoed in Beisecker and Beisecker's study of patient/physician interactions in an outpatient rehabilitation clinic, where patients uniformly expressed a strong desire for information, yet still expected and wanted the physician to make the decisions - though they welcomed knowledge, they did not welcome responsibility.¹¹⁰

Indeed, even patients who *do* have well-articulated preferences can change their minds over time, and the expectation that patients' preferences will remain stable across different states of health may be naïve. Some who express an unambiguous preference for limited care may feel very differently when very ill: one study suggested that patient desires for aggressive care may increase as their sense of vulnerability grows.¹¹¹ And in the SUPPORT study, no patient who stated that s/he would rather die than endure a particular outcome actually *sought* to die when that outcome actually occurred.¹¹²

Other patients with previously well-articulated preferences may find that they no longer *want* to decide. Studies have shown that as patients become older or more severely ill, their desires for autonomy seem to decrease.¹¹³ In SUPPORT, more than 70% of patients who had previously expressed resuscitation

preferences ultimately wanted their doctors or surrogates to make final decisions for them rather than adhere to their earlier expressed preferences.¹¹⁴ And in a study of dialysis patients, Sehgal et al similarly found that 31% were willing to have doctors or proxies override their advance directives *completely* if they became incompetent.¹¹⁵

Indeed, as highly valued as personal autonomy is believed to be, it is really only one of many factors that patients weigh in deciding code status and other end-of-life treatment plans. One qualitative study of hemodialysis patients showed that patients may view advance care planning not simply as a tool to exercise one's autonomy and control, but as a *social* process by which one prepares for death and strengthens personal relationships.¹¹⁶ Thus, as Puchalski et al point out, resuscitation preferences must be understood within a broader context of patient values, cultural traditions, spiritual beliefs, and social relationships.¹¹⁴

A broader context also helps explain why many surrogates may "fail" to make decisions about code status on entirely rational terms. SUPPORT researchers posited that surrogate decision-makers for terminally ill patients may have opted for all life-sustaining measures even in the face of dismal odds because they were more invested in fulfilling their roles as loving family members who, as such, would never deny their parent or spouse every opportunity to live.¹¹² Next, even physicians who *are* aware of their patients' preferences do not necessarily *heed* them. In a national survey of 879 critical care physicians, 34%

acknowledged continuing life-sustaining treatments over their patients' and surrogates wishes to have them discontinued. Eighty-three percent unilaterally withheld and 82% unilaterally withdrew treatments they judged to be futile, and acknowledged that some decisions were made without their patients' knowledge or consent, and others were made over their objections.¹¹⁷ In another study, Danis et al found that even preferences strong enough to have been recorded in advance directives were overridden, and that physicians seemingly respected patient preferences only to the extent that they agreed with them.¹¹⁸

There are, of course, legitimate reasons for overriding patients' preferences. Indeed, it is the physician's professional obligation to overrule or delay some patients' demands, pending further investigation. For instance, providers are not obligated to adhere to the wishes of patients who are mentally altered, or simply misinformed as to the uses of certain procedures or medications. Indeed, even in treating competent patients, physicians are expected to make clinical judgments based on risk/benefit ratios before offering treatment, as opposed to simply offering patients all treatments available, and letting the patients decide for themselves.

Nevertheless, researchers have documented a number of instances in which patients' genders, socioeconomic class, and level of education, as well as physicians' socioeconomic background and income have impacted doctor/patient interactions and influenced clinical judgments.^{84, 119, 120} In one study, Christakis, et

al, found that, controlling for other factors, physician age, area of practice, and religion impacted willingness to withdraw life support.¹²¹ Another study showed that, though patients' desires for discussing resuscitation did not vary by skin color, non-white patients were less likely to have discussed resuscitation with their doctor, and nonwhites with non-white physicians were more likely to have discussed it.¹⁰⁰ SUPPORT data also revealed that physicians systematically wrote DNAR orders earlier for patients over 75, regardless of prognosis. In addition, controlling for other variables, the use and timing of DNAR orders varied significantly among physician specialties - with internists and oncologists more likely to write DNAR orders, and surgeons less likely to do so.¹²² Indeed, in open acknowledgment of the fact that physicians' bases of judgment may be inappropriate at times, the Houston Task Force on Medical Futility has cautioned physicians never to act unilaterally in making patients DNAR, but to seek a second opinion, in the form of an ethics committee or some other review body.¹²³ Evidence suggests, then, that a physician's awareness of patient preferences for or against CPR will not in and of itself lead to a code-status decision that will be more patient-centered.

Finally, it would be naïve to believe that the decisions and will of the individual physician and patient wholly determine the patient's course of care in the hospital. Research has shown otherwise. For example, in their national survey of ICU care, Prendergast et al, reported extreme variation between sites. Across the country, they found, for example, that CPR attempts for dying patients in

different ICUs ranged from 4% to 75%.¹²⁴ SUPPORT researchers similarly found that the timing and use of DNAR orders varied significantly between hospital sites.¹²² These and other data which have demonstrated how widely practice patterns vary from institution to institution, have led many to believe that medical care is determined far more by pre-existing institutional routines than by patient preference or prognostic indices.

How might hospital routines influence individual courses of care? As Kaufman described in her ethnography of ICU patients and care in a community hospital, critical illness is often a singular experience for many patients and families. Thus, unfamiliar with physiologic processes and hospital policies and protocols, and overwhelmed by the critical illness of a loved one (or self), patients and families may be woefully unprepared and ultimately unable to make the kind of informed medical decisions requested of them. Physicians may present information and choices, but patients and families may not know how to interpret the information provided, and may not understand the implications of their choices.¹²⁵ Not knowing what they should want (beyond the cure of their loved one), or how to decide, many families will thus simply go along with the hospital's default routines. Thus, patients and surrogates may consent to emergency surgery, but fail to realize that post-operative full-code status will then be in effect, in accordance with hospital protocol. Indeed, code status discussions may not explicitly occur with surgical patients because surgical candidates are, by

definition, expected to recover, or be "healed". Surgeons may thus feel such discussions to be almost inappropriate.

Appropriate Discussions

Perhaps the single most intractable barrier to more rational, judicious use of CPR and other life-sustaining interventions has to do with our societal discomfort with the consideration of death. For the notion that improved communication would minimize unwanted or unbeneficial CPR inaccurately assumes that most patients *want* to talk about and plan for death. In fact, those who do are in the minority. A 1997 Robert Wood Johnson Foundation-funded survey of Americans' values, opinions, and attitudes about end-of-life care documented widespread discomfort with the topics of death and dying. Participants spoke of it as "depressing," "bad luck," and "too far in the future."¹⁰⁴ And despite the fact that other surveys indicate that Americans have a strong interest in preparing advance directives or designating health care proxies,⁵² few actually take the steps to make these a reality. In one study, Yamada, et al conducted an elaborate educational effort to teach veterans about advance directives. The intervention improved short-term knowledge about CPR and advance directives, but totally failed to stimulate any actual advance care planning.¹²⁶ As investigators for the 1997 Robert Wood Johnson survey wrote, "These Americans seemed to believe that vague comments about not wanting to be hooked up to machines are enough that they do not need to have more explicit conversations to guide their loved ones...until

Americans are more comfortable talking about their deaths, they are unlikely to take the most preliminary steps to plan for their end-of-life-care.¹⁰⁴

A Revolution

As Callahan has suggested, changing the way our medical culture responds to death, which certainly includes taking a hard look at our current uses of CPR, will take not merely reform, but a revolution.¹²⁷ For as must now be clear, indiscriminate use of CPR (and other life-sustaining measures) results from the convergence of a number of factors, and not solely from the dynamics arising between individual physicians and patients. For in addition to patient/provider communication, provider behaviors and practice patterns, institutional culture, and societal attitudes vis-à-vis death and dying *all* impact the choices we make for those at the end of their lives. To effect real change, then, not one, but all these factors must be addressed and changed.

First, patient/provider communication must continue to improve. Medical students need to receive better, more extensive training in discussing code status, advance care planning, and other end-of-life issues.^{70, 128} We must also continue to press patients to think about and prepare advance directives. Though advance directives have failed to effectively guide medical care,¹²⁹ some believe that their failure lies with *physicians*, not with the directives themselves. As one observer noted, "advance directives are going to be only as good as our efforts to obtain them"¹³⁰ Thus, medical providers and other patient advocates must

continue working to develop more creative means to elicit and document patient values through them.

Next, changing physician behaviors/practice patterns will be a vitally important component to improving patient selection for CPR. As the American Heart Association wrote in its International Guidelines for CPR and Emergency Cardiac Care, "All decision making begins with the physician making a recommendation based on sound medical judgment to the patient."¹³¹ Thus, physicians must continually avail themselves of available outcomes and prognostic data, and of their patients' values and goals for the end of their lives, and make clear recommendations accordingly. Physicians are admonished never simply to ask, "Do you want us to do everything?"¹³² - a hopelessly vague, easily misinterpreted question. Indeed, some have argued that physicians should not even raise the possibility of CPR with patients with irreversible conditions.^{21, 133} For in their eyes, to do so is to feed unrealistic hopes for recovery. Others have argued further that physicians can ethically *refuse* to provide CPR if asked, when the patient has no hope of recovery.¹³⁴ Faber-Langedoen suggests that even *transient* benefit fails to justify its use because the ultimate goal of medicine should be to heal disease -- not to delay death indefinitely.²¹ Instead, physicians are urged to "recognize the patient's impassioned plea for CPR for what it is - a cry for help, an acute expression of the dying patient's distress," which could be addressed in more constructive ways.¹³³

How might physicians be co-opted to make such changes in their behaviors? Recruiting respected physician mentors to educate physicians, and providing data for doctors to compare themselves with others have been advanced as possible means to promote these kinds of behavioral changes.¹³⁵

Finally, we must change institutional patterns of care if we are to improve patient selection for CPR and other life-extending measures. As SUPPORT researchers observed: "The 'default option,' or what is 'usually done,' is very powerful. If the default option at a particular hospital is a certain pattern of aggressive care, then the salience and timing of various 'decisions' will reflect that milieu."¹¹² Thus, changing the default options in hospitals will be key to improving CPR selection. As alluded to above, some reformers have suggested that CPR be reclaimed as a *medical* procedure to be applied in appropriate cases only, rather than an emergency one to be attempted on everyone.^{10, 136, 137} Other reformers have admonished hospitals and physicians to take real responsibility for offering patients meaningful alternatives to CPR: detailed treatment plans for palliative and/or hospice care. Physicians must *explicitly* assure patients that having a DNAR order does not mean that they will be abandoned, or receive inferior quality of care or attention. Accordingly, physicians must make the necessary institutional and *internal* adjustments to ensure that these are more than empty promises.

IN-HOSPITAL CPR STUDY OF ALTA BATES MEDICAL CENTER

Introduction

In the context of all that is known and has been said about this very complex issue, where are we now? Is there any evidence of progress, of movement? In part, yes, there has been evidence that DNAR policies have improved the process by which decisions to withhold CPR are made.¹⁰ As Prendergast et al's national survey of ICU care has demonstrated, fewer patients who die now undergo CPR.¹²⁴ While this trend is encouraging, there still exists a very marked variability in care across the United States.

I was curious, then, to learn about the in-hospital CPR experience in my local community of Berkeley, California. What kinds of patients undergo CPR in this community? Where do we fall in terms of success and failure rates, and in terms of the timing of code status decisions? How and when do physicians speak with their patients about code-status? Do they feel that in-hospital CPR is performed judiciously, or over-applied? If over-applied, what are the reasons for that? Are there any elements of their experience which can be improved upon?

It was with these questions in mind that I set out to explore in-hospital CPR experiences at Alta Bates Medical Center (ABMC), a 555-bed not-for-profit hospital in Berkeley, California.

Methods

To learn the particulars of in-hospital CPR occurrences, I conducted a retrospective chart review of all adult ABMC inpatients who underwent the procedure between the years of 1997 and 2000, as identified by their having been assigned a 99.60 CPR ICD 9 code.^N I used the attached coding form (Appendix B) to capture patients' demographic information, medical diagnoses, decision-making processes, and CPR outcomes, and then examined the data using the Statistical Program for Social Scientists (SPSS).

To gain insight into the nature of decision-making processes that occur between providers and patients (notoriously absent from medical records), I then conducted semi-structured interviews with 12 ABMC-affiliated physicians: three inpatient care/hospitalists (AIS physicians), four intensive care/pulmonologists (intensivists), one cardiologist, two family practitioners, and two primary care internists. The years of practice as attendings ranged from 1 to 32, with a mean of 12.9 years.

In unstructured, audiotaped interviews lasting 30 minutes to an hour, I asked physicians to tell me about their practice patterns, experiences, and perspectives caring for patients who ultimately received CPR in the hospital. I uniformly asked only three questions of the physicians: "Do you think that too many

^N *Cardiopulmonary resuscitation may involve chest compressions, intubation, defibrillation, and pharmacotherapy, or any one of these procedures in isolation, depending on the clinical circumstances.*

patients receive CPR in the hospital? How good are you at predicting who will and won't do well?" and "Could we do this any better?" From these initial questions, I simply allowed physicians to tell me what they wanted. I asked for clarification of their remarks, and pursued responses that were interesting to me. Physicians very readily shared their opinions as to how circumstances should be handled. But whenever they did so, I pursued their statements by asking them to recall the last patient with whom they had had such a conversation or interaction, in order to ascertain how and why their actual practices might diverge from their theoretical responses. I believe I gathered the richest sources of insight from those who *could* recall specific details of situations in which they had been involved.

Results: Chart Review

Between 1997 and 2000, 104 hospitalized adults at ABMC received cardiopulmonary resuscitation ("a code"). I identified these patients by searching through the inpatient database for all adults who had been assigned a 99.60 ICD-9 code, which denotes cardiopulmonary resuscitation. Alta Bates' inpatient database also revealed that 412 adult inpatients died at Alta Bates in 1998, 365 in 1999, and 422 in 2000. ^Ω

Demographic Profile of Patients

^Ω number unavailable for 1997.

Fifty-two patients (50%) were men and 52 (50%) were women. The mean age at the time of the code was 68 years \pm 15 (range 24-96). Fifty-three (51%) were non-Hispanic whites, 37 (35.6%) were African-American, 10 (9.6%) were Asian, two (1.9%) were Hispanic, and two (1.9%) were of mixed or unknown heritage.

tables 1-3

Patient Code-Status Decision-Making

Seventy patients (67.3%) were admitted to the hospital with no evidence of having either elected to undergo or decline CPR if they were to suffer a cardiopulmonary arrest. In medical parlance, these patients were of unknown "code status." Thirty patients (28.8%) had elected for full or limited CPR measures at time of admission, and four (3.8%) patients had actively declined it (in other words, chose to be DNAR). *table 4*

Twenty-seven patients (26%) indicated that they had completed Advance Directives or Durable Powers of Attorney, though only a handful of the forms were present in the medical chart. Nineteen of these patients were white (70.4%), seven (25.9%) were African-American, and one was Asian (3.7%).

tables 5 & 6

Overall, ten patients (9.6%) were stable and alert enough to make decisions regarding their care throughout their hospitalization. Fifty-eight patients (55.8%) gradually lost that capacity, and 36 patients (35%) were at no point well enough to make health care decisions.

Code status for 32 patients (30.8%) was revised during their hospitalization. Of these, 26 (81%) shifted from full CPR measures ("full-code") to DNAR, and six (18.8%) shifted from full-code to limited measures ("partial-code"): four opted for pharmacologic measures only, one for pharmacologic and intubation only, and one for pharmacologic and chest compressions only. Only two of the 32 patients were directly involved in revising their status; code status changes were negotiated solely between care providers and family and partners for the other 30. *table 7*

Medical Conditions

According to patients' discharge diagnoses, the most common medical condition among these patients was coronary artery disease (31.7%). Twenty patients (19.2%) suffered from congestive heart failure and 13 (12.5%) from end stage renal disease. Eighteen patients (17%) had suffered strokes previously, 10 patients (9.6%) carried CA diagnoses, and two (1.9%) suffered from AIDS-defining illnesses. Six (5.8%) suffered from chronic obstructive pulmonary disease, and four (3.8%) from dementia. Discharge diagnoses also indicated that eight (7.6%) became septic during the hospitalization, and eight (7.6%) developed pneumonia. *table 8*

Code Data

Eighty-five patients (81.7%) experienced a single resuscitation attempt. Four of these patients had previously declined CPR, but were coded nonetheless. Do-Not-Attempt-Resuscitation (DNAR) status had been recorded in the medical charts for two of these patients.

The mean length of the first code was 23.59 minutes \pm 21.03 minutes (range 2 - 135 minutes). Thirty-three patients (31.7%) received the full CPR algorithm, 46 (44.2%) received three of the four procedures, 20 (19.2%) received two of the four, and five (4.8%) received one of the four.

Fifty of the 104 patients (48%) did not survive the CPR attempt. Of the 54 (52%) who were successfully resuscitated, 18 (33%) re-arrested and were re-coded. Fifteen of these patients (83.3%) underwent two resuscitation attempts, two patients (11.1%) underwent three attempts, and one (5.5%) underwent six attempts. All 18 patients of these patients died. Twenty-four others who were resuscitated initially but did not undergo a second attempt, also died. Of the 104 patients, then, 11(10.6%) ultimately survived to discharge. *tables 9 & 10*

Post-Code Outcomes

Of the 54 patients who survived the first code, 100% were moved to the intensive care unit if they were not already there at the time of the code. Of the 43 patients

who subsequently died before discharge, 27 (63%) died within 24 hours of the code, and another 11 (88% cumulative) died within the week. *graph 1*

For the patients who eventually died prior to discharge, 37 of the 43 patients (86%) remained unconscious in the hours and days following their code. Four (9.3%) were somewhat arousable, two (4.7%) were completely alert.

Neurologically, 28 (65.1%) suffered severe impairment, one (2.3%) suffered mild impairment, and three (6.9%) suffered no impairment. Neurologic status was unobtainable for the remaining 11 patients (25.6), though nine of these 11 were completely unconscious post-code. *tables 11 & 12*

Finally, of the eleven patients who survived to discharge, five (45.5%) were alert, five (45.5%) were somewhat alert and arousable, and only 1 (9.1%) was unarousable. Eight (72.7%) were found to be free of neurologic deficits, two (18.2%) found to have sustained slight deficits, and one (9.1%) found to have sustained severe deficits. *tables 13 & 14*

Results: Interviews

Too many patients with end-stage disease undergo CPR

Virtually all in-hospital physicians felt that too many patients for whom CPR is futile continue to undergo it.

"Are there too many terminal oncology patients and [others] with endstage diseases [being coded]? Yes. Are too many old people with Alzheimer's

and other chronic diseases you can't cure [being coded]? Perhaps. Fifty percent of the people I code here are inappropriate [CPR recipients]."

*"We put people who are critically ill through CPR when we know fairly well ahead of time that the ultimate outcome is going to be poor **at best** because their starting point was so bad. And you're never going to get them better than their starting point after they go through that."*

"There's an old guy up in the ICU right now...who I think is going to do quite poorly. And whom I'm expecting will get pneumonia in the next few days and probably end up on a ventilator...The patient is 88, on coumadin, and fell and bled into his head and had a subdural hematoma, and [is] not quite comatose, but close to it. And just being 88 is a bad prognostic sign. But 88 with blood in your brain is a terrible prognostic sign, and it's unlikely that he's going to pull out of this and certainly not in any kind of functional state... His family...wants everything done. And when I spoke to the patient's son last evening, it was clear from his comments that they're trying to be 'very positive' and 'only tell mom that things are getting better' which is a very unrealistic expectation."

"A 96 year old woman...[was] in the ICU, she had a swann [catheter] in, and was intubated, and her swann eroded thru one of her pulmonary vessels. Ninety-five year-olds shouldn't have swanns in, in the first place. But she was a full code. It was Christmas Eve night, there we are, this lady's bleeding to death, I mean, blood coming out of her trach tube... and there we are doing CPR and compressions on a woman we shouldn't have been doing any of these interventions on. She was demented, had a PEG tube in, chronic foley, decubitis ulcers, bed bound, it was ridiculous to code on somebody like this. I mean, what kind of status are you bringing [her] back to?"

Primary care physicians voiced a somewhat different perspective; they acknowledged that inappropriate CPR *did* occur from time to time, but did not feel that it was a major problem.

"Most people getting CPR aren't 89 yrs old with sepsis. Most people are more likely to [have been a victim of] a car accident than any of that stuff...I don't think CPR happens all that often."

"My impression is that things have improved... maybe more patients are receiving counseling about their options and making decisions and not being inappropriately maintained on life-support."

"CPR is pretty infrequent. I suspect that most people have the same understanding about CPR that you and I do. That it often doesn't work and is usually done on people who are really sick, and occasionally you can bring back a healthy person who collapses. But I think most people are aware that it's no great shakes. I don't think that we have information that they don't understand."

Patient's Preferences Are Rarely Known To Physicians Who Run Codes

Although Alta Bates requires patients to be asked about advance directives and durable powers of attorney upon admission, inpatient physicians reported that such information is rarely available to them: few patients complete them, those who have them rarely think to bring them to the hospital with them, and admitting physicians do not routinely record their preferences in their admitting note.

"99.9% of the time, there is no code status written in the chart. There just isn't. So I don't know if that means resuscitate or don't or if the patient thought about it or the [admitting] doctor thought about it. I don't know. So if I'm here in the hospital and I'm the code physician, my hands are tied. And ... I can't tell you how many times I've resuscitated [a patient], only to call the family and have them say that they didn't want to be resuscitated. Just happened last week. A gentleman was in the hospital who'd had a cath, and was found down in his room with a super slow heart rate, and coded, we were in there, did CPR, got him on a ventilator, brought him to the ICU, went to the chart, and called the family and they said 'oh, he didn't want that.' If [the code sheet] was even in 50% of the charts, it would be such an enormous improvement over what we have now."

"What would help us? People don't know their spouses' wishes or medications. People don't know their own medications. These things should be established before they get to the hospital... if you look through the charts in this hospital, not even close to half have the form in them, and of those, maybe not even a half are filled in."

"It should be part of the admitting History & Physical taking that's done, and it's not."

Primary care physicians echoed the concern that information transfer between outpatient and inpatient settings is poor.

"yeah, ideally, the primary care doctor should have those discussions with patients and it should get decided before someone winds up in the hospital. But... even if I have that discussion, my record is not in the hospital, so unless I admit that patient, no one is going to know I had that conversation... now hopefully the patient will know, but the patient may not be in the position to say, or the family may not know that we had that conversation."

"Doctors in the outpatient setting are taking care of inpatients [less and less], and especially those in the [ICU]. So #1, do I find out about [my patient being admitted] in any timely way? Does anyone call me? That may or may not happen... 10-20% of the time [I] won't know until maybe lab slips from the hospital start coming in, or they call you after a few days. So... does that [code status information] ever even get to the inpatient setting? And if it were there, how much of the time would it be acted upon?"

It is difficult to raise the issue of code status during a hospitalization

Most AIS physicians and specialists felt that code-status discussions were difficult to initiate with hospitalized patients, who are, by the fact of their hospitalization, ill and unstable. All believed that the issue should be initiated in the outpatient setting, when patients are well enough to reflect on their wishes and share their desires with their loved ones. Nevertheless, these physicians stated that they were typically the first physicians to broach the issue with patients and their families.

"The primary care doctor almost never has that conversation before the patient comes to the hospital... it's quite awkward for me, when I meet the person in the ER, even though I know, from my experience, looking at them, this is gonna go bad; this person is probably gonna die... The problem is that in the vast majority of cases, I've never met the people before, and I have no history with them, nor do I, other than the fact that I

have a white coat on, have any reason to think they should want to have that conversation with me...I have no credibility with them, or at least not enough to make a life and death decision with them."

"I'm shocked at some of the patients we get in [the hospital] where it's like, no one's ever discussed code status with this person? What are we waiting for? And we're the hospitalist, and this may be the 1st time you're meeting the family or patient, and you have no rapport...and that's hard. And that's hard for families, too, and patients. You're a stranger, and you're talking about end of life with them."

"[Patients are] almost always receptive [to code status discussions]. That's why I think the opportunity is missed a lot of times. Then the job is 10 times harder when the patient is in crisis, in the ICU...even logical thinking people become irrational when death is upon them... They become desperate and clear thinking is difficult to come by... it's a lot easier when things are stable, and they can reflect on their lives... they don't have that kind of autonomy when they're impaired, on a vent, sedated. Their dignity kind of washes away in that environment."

"This should be an outpatient thing. And it should be part of the admission history. Because chances are, if [a patient] comes into the hospital and you're thinking about code status, [they're not] in a position to give a clear answer. Making a [code status] decision in a hospital is never a good thing...when it's relevant, it's way too late."

Primary Care Physicians Say They Don't Have Time

For their part, three of four of the primary care physicians cited a lack of time as a major barrier to discussing advance directives and end-of-life care issues.

"I wish I could say that it was a routine thing. It's on our adult physical forms for the 60-65 and older age group. But I rarely do it, I'm sorry to say. Because we just aren't budgeted the amount of time. ...You know, people come in visit after visit with all this stuff they throw at you...15 minute visits supposedly to follow-up on their diabetes and you find out that they're seriously depressed and they have like 3 other diseases and you're following them for 6 things anyway I get a lot of negative feedback here for how slow and behind I often am, and it's because I try to talk about things that are important, and yet I'm lax on this issue of end-of-life decisions."

"[the amount of time] depends on [the patients'] educational background, their culture, their personality, religious beliefs, their family, how much their family grants them autonomy vs. wants to make the decision [themselves]. Yeah, if you're talking to my mom and dad, educated white

people whose daughter is a physician, they could make that decision fairly quickly. That's not the people I take care of. And based on someone's personality, family or culture, even with educated white people, I'm sure, there'd be families for which that would be tremendously difficult."

"one woman in particular... she's probably late 70s... She has hypertension, a bad heart, diabetes, and chronic renal failure and she has been in the hospital probably every other month; she goes into flash pulmonary edema and comes in... she has not had a heart attack ...but ...she probably has a 30 or 40% chance in the next 5 years.... but ... she barely comes into my office. And when she comes in...I'm trying to lay out 15 drugs, and find out if she's taking them...and there are so many issues to talk about, that it's been a while since I've talked to her about death and CPR."

Notably, however, time was not an issue for everyone.

"Getting to know each other happens with every encounter. Then to say I want to talk about this, usually doesn't take long. Usually only a couple of minutes of my saying to them, 'You would not do well intubated and I advise against it.' And that would be the end of it ... it's not a long discussion unless they have questions about it, and usually those questions are easily answered."

"[These conversations are] not hard. The hardest thing is taking the time to do it. Maybe we're just a newer breed but I do not have a problem discussing life and death issues with patients at any time...it only takes like 2 minutes; it's easy."

Patients lack the medical sophistication to fully engage with physicians about what CPR entails or what they are consenting to.

Physicians in this study also found patients generally to be medically unsophisticated, which hindered their ability to make timely and necessary medical decisions, or truly understand the ramifications of their decisions.

"One of the huge problems is that most people don't have ...any clue what you're talking about when you talk about resuscitation... It happened to me on Sunday night. I was on call, and admitted a 91 yr old woman, bedbound, lots of medical problems. Probably should be a no-code. If she got to a point where her heart stopped or breathing stopped, she would probably do very poorly. I attempted to have this conversation with this woman who was a little bit demented and probably was in no way capable of making this decision. And her daughter was at the

bedside, and the daughter deferred the issue to her mother. "Mom, do you want to be coded?" and I tried to explain what that meant and the daughter still kept referring it to her mother who said, "oh yes, I want everything done." And the daughter came out to talk to me after I left the room... she didn't really understand what I meant by beating on the chest, and life support. I think she had some better grasp of it by the time we were done, but then she didn't want to make a decision. So she was going to think about it, which is often what happens..."

"Let's just say you try to get consent for...CPR, [with] no countershock, but intubation and drugs [are] ok. Then you have to go through all the advanced cardiac life support (ACLS) algorithms with the patient and say, 'if in fact you have a respiratory arrest and we do this, it's possible that we'll be able to bring you back by putting a breathing tube in for you. However, if you've developed a bradycardia because your PCO₂ is 90, you're still going to die, because we're going to give you atropine but it's not going to circulate. If you develop atrial fibrillation, we'll probably be able to bring you back by giving you a drug, if you develop ventricular tachycardia, there's a small chance we can fix that because maybe with ventricular tachycardia a little blood will circulate.' ...Just imagine how you'd obtain that consent...That kind of conversation never happens...So people are consenting for the ultimate procedure without having been informed appropriately about it. And I think that's just horrible."

"Most people haven't been in an ICU and don't really have any idea what it means to be intubated and what it means to be on life support, and know what it means that once you are resuscitated, to have lines in and have all the ICU care going on and how uncomfortable that can be, and how that can drag on and how there's an enormously small possibility that they're going to get better."

"I have talked to patients who experienced [CPR] and survived, and the majority of those people would not do it again. They've told me, 'That was awful,' and in some cases was worse than what they perceived death to be...And some of them may not remember the exact code, but they remember suffering after, and being hooked up to the machines, and it wasn't a good quality time for them."

Patients don't trust physicians or the medical system at large

Physicians also cited patient mistrust of the medical system as a barrier to negotiating the limitation of medical interventions towards the end of life – a mistrust they found somewhat justified.

"There's this paranoid ... opinion that we like to see people die so that we don't have to take care of them...this whole mood, richly deserved, of HMOs trying to screw people and not provide care. Some of it is true. It's too bad that it totally interferes with my relationship with my patients because there's this whole idea that if I ever refuse anything to a patient, they immediately feel like [I'm] just doing this because [I'm] trying to save money for [my] HMO. I've had patients leave my practice ... I'm sure because I refused to give them an authorization. Some people will go see other doctors because they don't trust me. They just think I'm trying to deny them care."

"usually what [patients are] saying when they want everything done is that they're afraid somebody will call the on-call doctor at night and say, well this person has a temp of 103 and the lab just came back and he has a hematocrit of 8, and this person's a no-code. Which changes the way on-call MDs react to an unknown person. And for fear of that, a lot of people will say, you just do what's appropriate, and I will not sign that kind of paper. I think justifiably. I think there are occasions when the on-call MD gets told by a nursing home, 'oh this person's a no-code. The person's got this,' and he'll say, 'well just give him tylenol,' and the issue gets lost. So there is a risk."

"[people are] afraid that they won't get treated as aggressively or promptly as someone who's a full code, and to be honest, I don't know if that's true or not. I've seen a lot of nursing staff and other ancillary staff say..."oh, this person's a no-code" and you have to prioritize..."

Emotions, culturally and socially-based experiences and beliefs drive code status decisions

In the experience of these physicians, many patients' and families' code status decisions ultimately rested on emotional ties and culturally and socially-derived values and experiences rather than purely rational, medically-based considerations. Unfortunately, these priorities too rarely permitted them to choose DNAR status for loved-ones, regardless of the person's prognosis.

"They don't want to hear it. People don't want to make decisions about mom or dad's death..."

"Basically what every kid wants for their parent is to get up out of the bed ... they want their parents to wake up and act like parents again. Even if they're 80 years old, and the kid's 60 years old."

I think [the hardest thing is] objectively talking to patients who aren't open about talking about it. The fundamentalist Christians who see the doctor as doing God's will, to keep him alive, that God invented the breathing machine to keep grandpa alive. I mean, I had a horrible experience with a family where there was a guy who was 94 or 104, and he was an emaciated little old ... man, and he was dying. There was no getting around it. And he was a minister, a bishop in his church. And the family basically said 'you will ...do everything' and I said 'if I press on his chest, I will break every rib in his body with the first compression.' ... They heard what I said, and said 'do it anyway.' And I said, 'it won't matter, he'll die. He'll never leave the hospital'...[and they said] 'Jesus will save him. You're doing the Lord's work and you need to do all that.' And that's hard because I think I'm doing battery on that guy because medically I see no way he can survive.

"There are people that don't want to talk about [end of life care] because it wasn't the way they were brought up. You're talking about 70, 80, 90 year old people who were born in the 20s and teens and it was a completely different environment...and if they're not prepared to discuss it, or don't want to face it, [that's] a group that you don't get anywhere with because they don't want to talk about death and dying."

"Whether [patients] overtly knew about things like the Tuskegee Incident or [not]... it seemed like a pretty common phenomenon that [African Americans] were anxious that medical practitioners were not treating them totally with their best interests and with respect and full candor. Even if they seemed to like me and identify me as their doctor, if I asked them to sign something, I might get that reaction... there was a really interesting recurrence of that."

Questionable Utility of Advance Directives

Although all physicians certainly agreed that advance health care planning is a good idea, and should be pursued actively, several physicians complained that the language of their patients' advance directives has been too restrictive to make them of use. Furthermore, one physician's experience was that the nature of a person's wishes regarding his/her death are inherently too variable to be accommodated by a legal document - that people say they want one thing but, in the moment of truth, want another.

"The advance directives [patients] tend to have tend to be the standard form and frequently they will have checked the box that says, "if I'm ever in a persistent vegetative state, you can stop." But they're almost never in a persistent vegetative state. What they are, are critically ill with multiple organ dysfunction, or even in a coma, but they don't meet the specific words in the box. What I tell families is that it would be much more helpful...I don't even care if they have the damn piece of paper...is if the patient has had a conversation with their decision-makers about their general philosophy. And if the patient says, yeah, go ahead and resuscitate me and if it looks like I'm gonna get better, great, but if not, after a couple of days, throw in the towel. That's a much more useful piece of information than checking a little box on a state-mandated form that says if I'm in a persistent vegetative state, you can risk and weigh the benefits and blahblahblah... because I've had numerous families come to me with that form and say, we have no idea what this means. What does **this** mean? Is he **this** yet? Where they've got the damn medical dictionary out, and [are asking] does he meet this specific word yet. So I don't find that form to be particularly useful at all..."

"A lot of people have advance directives but a lot of advance directive sheets are incredibly vague, so you might as well not have them. They are for long-term ICU care. They're useless... I think you have to make a decision. Intubate or not. CPR or not. Pressors or not. Defib, don't. That's it. But people have to know what that means, and that's going to require education."

"a DPOA ... doesn't address the issue. it would be nice if it would. it names an agent and asks if you want to be on life support, but it doesn't address do you want to be coded.... A lot of people have [filled out the DPOA]. They've done what they [think they] need to do. And then I have to say, no no, there's another issue we have to bring up. So that's a problem."

"...in some ways, ... non-American born cultures ... seem more accepting of the fact of death than the majority culture. But when it comes down to saying, "I'm going to sign this paper so that you won't do this procedure on me" -- that's harder for them to grasp what that means."

"I don't think we should treat all people alike, and require something [like a code status form or AD]... it might be offensive to the patients.... And my thing is, once a DNAR form is signed, what about if they change their mind, and they want it? Does anybody take that off the chart? CPR status probably follows people around better than allergies... And I think what we [really] mean when [we] sign it is that we want the treating doctor to use his judgment... somebody who is knowledgeable, and who knows us and knows the medical circumstance there at the time... The form is binding and I think it gets misinterpreted. Is it the fault of the language? No. It's the fault of the complexity of life that we like to imagine that we can put it in words, and it actually takes more back and forth."

"A long-term patient of mine...a brilliant woman...was a long-term smoker and a long-term diabetic...she had opted to be DNAR probably a year or two before when she was first hospitalized for her heart disease. The cardiologist said she needs [a] CABG, and with [that her] 5 yr survival [would be] 90% and with maximal medical treatment only, it [would be] 70%. And she said I don't want the surgery. I don't want 5 years. I'm having memory troubles...and my family gets Alzheimer's and CA, and I don't want the bypass. [But] she [would] come into the hospital repeatedly with CHF, every 2 or 3 weeks or a month for the lasts 4-6 months... she would get SOB ...and in the ER they would give her O₂ and lasix, and she would be hospitalized and the cardiologist would look things over and she would get stabilized and go home and would be ok until it happened again...why did she come? Because she got short of breath. Why didn't she just ask for morphine? She didn't. She never said don't take me to the ER. She said, "I can't breathe." ... Well that's the same as saying, "I don't want a code, but I want a code." ...What would it take for her to say just give me morphine? Who has ever said that? Who says that? [In her final hospitalization], she was in the ICU, she was talking to her husband when the cardiologist came over and as he was there she developed an arrhythmia and he felt obliged to make it go away. It wasn't full CPR, but it was enough to say ok put her in trendelenberg, give her some atropine, and this and that...She ended up getting more treatment than she wanted, but ...would she have been glad? Yeah. She apparently was the last time...she wouldn't have minded...we're just like that."

Early end-of-life care planning simply is not possible for some patients

Physicians shared that even when time, trust, and communication were optimal, some patients simply could not tolerate thinking about or planning for their death until their illness was quite advanced.

"I've been this one woman's doctor for years and have seen her monthly for the last number of years, and so we have a very strong, positive relationship, and I think a good level of trust and even then...she has very terminal heart failure and complications of DM [and] for years and years I would attempt to approach this topic and she would have a clinically diagnosable panic attack...she would start hyperventilating and have her baseline tachycardia go from 95 to the 120s, or start crying."

"I've had numerous code conversations with this one particular patient, both out and in house. He can't handle that conversation very well. This is a class 4 CHF patient with extremely poor quality of life: wheelchair bound, just getting dressed is fatiguing. He lives with his wife. He's had numerous admissions and I've had three discussions with him, and although he recognizes that his quality of life is terrible and his life span is pretty short, no matter how gently I bring it up, he hears, 'oh, I'm dying, and she's saying

I'm dying.' and he'll call his daughter and say 'Dr. X says I'm dying and you should start selling my things,' and I find myself backtracking. I like to have an upfront honest conversation, but some patients can't hear it that well, and for some patients maybe that much information isn't all that helpful... The next time he came [in to the hospital], I just said, 'now if your heart starts going out of rhythm and the defibrillator has to shock you many times, do you want me to turn it off?' And he said 'yes.' 'And we are going to do everything but if we couldn't improve your breathing enough and you had to be on a ventilator, would you want to do that?' And he said, 'no, I don't want to be on life support.' so to directed questions he [did] well. But a discussion about, here's where you are, this is how your heart's doing, and this is what I think your prognosis is, didn't work for him."

Physicians alternately coerce, accept, and slow-code patients when they can't obtain a DNAR

Ultimately, all physicians reported trying to convince terminally ill patients and their families to forego CPR, but they differed in how they dealt with patients and families who insisted on coding. Some felt it their place to be quite forceful, while others simply acquiesced. Almost all reported having engaged in limited codes.

"I explain to someone with a chronic terminal illness that if something like [cardiac arrest] happens to them in a hospital, unwitnessed, on the floor, their chance of getting out of the hospital is less than 2%. Their chance of making it through [the CPR] is very poor, maybe 10%, and [the chance that] their quality of life will be improved after ... is nonexistent. And I don't think that's being unnecessarily bleak...when... you've got rational people who can understand what you're talking about, those kinds of stats and info about their disease and disease process, stated bluntly, not wishy-washy. You have to say, "thing ARE going to go badly at some point." Not "MAYbe they'll go badly"...that makes a difference.

*"Do I ever spell it out? Heck, yeah. [For] the people who don't really ... get it... we're saying that it **won't** work, and that it will be painful, not that 'we can bring you back to life, but we're not gonna.' That is really important to clarify. 'We're going to shock your heart, and ...break ribs and all that to just give you an extra day if that, and you're not gonna be awake,....and you're going to be brain-damaged' and I don't feel bad about that. I don't feel bad about coercing a patient to be a no-code. I think that's sometimes our job. Most of us, when we want them to be a no-code, we're not giving them the fair talk. Why? I think the doctor needs to come in and paint the ugly picture...The one thing I can do as a doctor is help them die, and not do a futile, yucky intervention that's not gonna help. Part of being a doctor*

is helping someone die, which is probably really different from the way it was in the past, when you were trying to make them live all the time. That's a whole different way of medicine."

"What I do do is what I think is medically justifiable. For instance, if somebody is in the ICU, on a ventilator, on epinephrine and neosenephrin drips wide open, and their blood pressure continues to drift down.. in my personal opinion, that person is already being resuscitated and if their heart can't pump pharmacologic doses of epi around, CPR is not gonna pump it around. So in that instance, even when a family says, "you must absolutely do everything," I haven't done a code. I haven't pushed the button on the wall because there's nothing else medically I can do that's even remotely likely to be successful.

Have I ever engaged in a slow code? Yeah. Absolutely. Not meaning that I didn't run to the code, but I wouldn't exhaust the whole arrhythmia algorithm. I would stop sooner. The nurses are a major part of the team, and they have very strong opinions about the codes and appropriateness and stuff, and they're really good at knowing what's going to work, and what's not -- better than a lot of us physicians are, and so it's a feel of the group. I will always ask, "is everybody comfortable stopping?" and if anybody has reservations about it, we continue until we can sort that out. I've never had anybody say no. Most of the time, they say, "can we stop now?"

"I certainly have had patients who wanted to be resuscitated for whom it seemed medically futile...[where] their prognosis is going nowhere. And I'll give you an honest approach to that patient... I usually just resort to my backup, which is that I do a very limited resuscitation. They could have a life threatening arrhythmia. In which case I could try shocking him... but I sure as heck wouldn't keep doing it for any length of time. I'd be pretty quick to stop. I don't know if that's ok to say, but that's what we do."

"You're either running [a code] or you're not. Doesn't matter how futile it is. It's not your place [to run a limited code]... it's kind of like a business these days. As a salesman, I'm comfortable letting people choose. It's ok to let them go, or I think it's fine to keep people alive."

The frustration of running futile codes can engender anger and resentment in physicians

"There's times I feel [angry]. Especially when I feel it's a futile situation when I feel like I'm just going to hurt this person, and make them suffer more as opposed to letting them die with peace and dignity...On whatever level that they may be experiencing discomfort, they're going to experience a LOT of it. You know, chest compressions, especially on these elderly people, very frequently crack ribs, and that hurts".

"It takes a piece of your soul to run a code on somebody you know isn't going to make it. Really. It's like assault and battery. The staff is uncomfortable, the family, the victim..."

Anything other than a 0% chance of survival and I won't do [a slow code], because I don't want to get sued. If I have to pick between breaking grandpa's ribs because the family demands it, or getting sued, I'll break grandpa's ribs. It's his family's decision, and if I'm involved, I feel comfortable that they've made an informed decision...I think I've evolved over the last couple years, thinking that these people are getting what they deserve..."

"Is it gonna affect me as a person? No. Because I could code a million people for fewer reasons. And you know why? Hardly any of 'em are gonna survive anyway. (laughs) so it's really not gonna bother me...But the farther away from residency I get, the more compassionate I get. Which is nice."

On the other hand, physicians themselves have acted against their better medical judgment when *they* have been emotionally attached to patients – placing their *best-loved* patients at risk for precisely the kinds of poor outcomes they most want to prevent in all their patients.

"there's a lot of emotional stuff that goes on in a code. If it is a patient [I've] been following for years in a clinic, I might press on for a little bit longer than perhaps the statistics would suggest [I] should."

"[with] patients I'm really attached to...people I've known for years...who are slowly sliding down.. I had a patient like that in the hospital a month ago...it was clear that he was dying...and I knew I needed to talk to him about [code status], and I just couldn't bring myself to do it...I ended up actually going about it through his wife and son."

"I have a very distinct memory of one of these low blood pressure sort of codes. Young woman with young family, 5 children. Had this terrible sudden disease...And I remember having an irrational discussion with a pharmacist because they were running out of pressors that she needed because she was using such enormous quantities that we had to borrow it from other hospitals. More epi or dopamine. And I remember them calling me and saying do you really want us to continue at this rate? and I remember sort of irrationally saying, "Yes, yes, get more!" And I distinctly remember this picture of her family that was taped to the ventilator so that

she could see it if she potentially opened her eyes. And that just killed me; I couldn't, I couldn't let go."

Society is not ready to ration care or deny patient autonomy

Finally, both in and outpatient physicians shared feelings of frustration as well as resignation over the fact that code status decisions in the United States ultimately rest on patient wishes over all other considerations.

*"Society in general could do a better job...We don't have the resources to keep people alive on ventilators for 2 or 3 weeks as they're dying of their cancer. Therefore, when their heart stops, [we shouldn't] try and restart it and put them on a machine and keep them alive for 3 more weeks. And that is a fact of what medical care in this country has to be limited to...And that means ethics committees biting the bullet, which they refuse to do, ...saying I can't tell somebody what the quality of life is... Well I'm sorry, I see people suffering all the time, and you can't tell me because you're a lawyer and you're protecting that person's rights, that that person should suffer that particular way because they want to, or you **think** they want to... they gotta spend some time watching people die...being around people who are dying and chronically ill... there's no other society in the world that lets this happen like it does in this country. England, Sweden, I don't care where it is. They just don't let it happen. But ours does."*

"It wouldn't be justified to bring me back, nor would I do it for any of my relatives, but like the cute little old lady I have up [in the ICU right now] who says, "I don't care, I want every extra day, I don't care what my condition is." I say, ok. I mean, society certainly isn't ready to ration that kind of care. And I can think of a lot better ways to spend the money, but we're nowhere ready, as a society, to have that discussion. so if that's what people want...I mean, who am I to say what a good quality of existence is? I mean, there are people alive over at Herrick, at the subacute [hospital], for 10 years. 10 years! Somebody thinks that's ok. Some people find it morally unacceptable to do anything less than keeping people alive under any condition."

"I think 90% of the families who say "you gotta keep grandpa alive; he's in a persistent vegetative state, but you gotta put that tracheostomy tube in," ... if they had to spend the \$13,000 a day for the support, they would think differently about it. I am absolutely convinced about that. You've got insurance companies and Medicare and 3rd party payers in between, so that the families... don't have the cost part of the equation ...we might find out that in the future economy of this country is threatened by war or other considerations, it would change quickly but as long as we have the kind society we have, I think we're ultimately stuck with this problem."

"Medically we can do almost everything, to our detriment, I think. We had a patient here a few months ago who was 90 yrs old and had a coronary artery bypass graft. I was sick about it. She had complications...was in the ICU for months.... How many years does she have? I'm sure her hospital bill was approaching a million dollars. And this was for somebody who was 90. I mean, it just doesn't make any sense."

Discussion: Chart Reviews

The outcomes data and provider perspectives from this study reveal a mixed picture regarding the frequency and nature of CPR occurrences at ABMC.

Similar to patient profiles seen in studies at other community hospitals, patients at ABMC were older (mean age 68), carried illnesses associated with poor CPR outcomes (e.g. CHF, CAD, renal failure, sepsis, pneumonia, AIDS), and experienced an ultimate survival-to-discharge rate of 10.5%.

The prevalence of co-morbid conditions in these patients highlights one element of what remains so difficult about determining the kinds of patients appropriate for CPR. For while it seems clear that patients with end-stage HIV disease and metastasized cancer will not benefit, it is less clear that patients with diseases such as CAD or CHF won't. Such conditions, though life-threatening, follow notoriously variable trajectories in which patients may benefit from life-sustaining measures even very late in the course of illness, thus confounding physicians' attempts at accurate prognostication.

Even diseases with seemingly linear and predictable courses, such as non-metastasized cancer or end-stage renal disease, pose prognostic challenges:

toxic chemotherapeutic agents and dialysis treatments can themselves cause patients to appear (and indeed, *be*) more end-stage than they would be without treatment. And yet, for all the prognostic uncertainties associated with these diseases, their life-threatening nature should prompt early end-of-life care discussions.

The fact, then, that the majority of patients (67%) had no known code status preference upon admission is disappointing. And while it is encouraging that 26% *had* completed advance directives or DPOA's, the fact that the vast majority of these documents (or the information contained therein) were unavailable to clinicians, is not. Further, the striking ethnic differences between those with ADs/DPOAs: 70.4% white, 25.9% African American, 3.7% Asian, and 0% Hispanics, points to a particular need to make such documents known and acceptable to non-majority cultures.

Furthermore, only ten of 104 patients were well enough to make their own health care decisions throughout their hospitalization, and only two of 32 patients were directly involved in changing their code status. These number dramatically demonstrate how vulnerable and lacking in autonomy hospitalized patients can be when they have not engaged in advance-care planning: in the vast majority of

instances, major medical decisions were made without the patient's guidance, knowledge, or approval.[Ⓢ]

Also of note, all 18 patients who underwent multiple CPR attempts died. An extensive literature on outcomes for multiple codes does not yet exist, in part because international guidelines have only recently been established for distinguishing single, prolonged episodes of in-hospital CPR from discrete episodes for reporting and research purposes.¹³⁸ ABMC intensivists were, however, of the mind that outcomes following second codes were, in the words of one, "abysmal." As we know, however, such impressions are of limited relevance if patients continue to desire coding. Unfortunately, too, 11 of the 18 patients experienced their second arrest less than seven hours after the first, giving families relatively little time to regroup and revisit the issue of code status - in this study, only two of the 18 changed status between codes.

[Ⓢ] *Notably, families of six of 26 patients who changed their loved ones' code status moved to accept partial measures, as opposed to no measures: four opted to accept pharmacologic interventions only, one opted for pharmacologic intervention and intubation only, and the last to pharmacologic intervention and chest compressions only. All decided to forego defibrillation.*

Controversy exists as to the efficacy of these partial codes, though Alta Bates' DNAR policy specifically recognizes them as "modified DNAR" designations. However, as noted in the literature, and pointed out by one physician in this study, partial measures are "not associated with survival." For example, a bradycardic patient who receives a bolus of medicine without chest compressions will likely die because the medicine will not circulate. Similarly, a patient in ventricular tachycardia or ventricular fibrillation nearly always requires cardioversion to restore normal cardiac rhythm.

Moreover, physicians in this study found it hard to believe that any physician would review ACLS algorithms with patients in sufficient detail to gain truly informed consent for such codes. The occurrence of these changes, then, raises the serious question of whether or not these families understood the ramifications of their decisions. For such reasons, critics have condemned partial codes as not only ineffective, but also ethically suspect, and little more than a means of allowing physicians and families to avoid having to directly acknowledge that a patient is dying and should be made DNAR.

On the other hand, partial codes have been effective in select clinical circumstances, and in this study, were defended by as many physicians as decried them. Clearly, there is a need for further research into the efficacy of limited codes, until which time (and probably even after) partial codes will continue to be ordered.

Other problematic areas regarding in-hospital CPR manifested themselves through the occurrence of four *unwanted* CPR attempts. One of these events exemplifies the ongoing difficulty of assessing appropriate code status for peri-operative patients. This patient arrested immediately following an angioplasty, while she was still in the catheterization lab. According to her chart, she specifically stated that if she were to experience complications after her procedure, that they should just 'let her go.' At this point, one can only speculate as to whether clinicians were ignorant of her wishes, deliberately overrode them, or considered her arrest an *intra*-operative complication (during which DNAR status is suspended) which they attempted to correct as a matter of course.

Two other unwanted CPR attempts were performed because DNAR orders were unavailable to the inpatient medical staff - an inevitable consequence of the lack of an established mechanism to share patient information between outpatient and inpatient settings. Who should be responsible for this information transfer? Should it be the patient's family, when families often have less information than

the primary care doctor? Should it be the hospitals, since it has assumed responsibility for the patient's care? Naturally it would be ideal for a patient's outpatient records to be fully available to hospitalists, but what would it cost to effect that kind of integration? Who should pay for that? How would we ensure confidentiality of patient records? These questions have yet to be answered to anyone's satisfaction.

One case of unwanted CPR in particular exemplifies perhaps *the* most fundamental barrier to the limitation of CPR. This patient arrested while sitting in her hospital bed, eating breakfast and visiting with her family. The code team rushed into the room, instituted the full ACLS algorithm on the patient, in full view of her family, and successfully resuscitated her, though she was left unconscious and intubated. *After* her resuscitation, her family informed the staff that in fact, she had an advance directive through which she indicated that she did not wish to be coded. At their request, then, she was extubated and died shortly thereafter. While it may initially seem nonsensical that her family members would simply look on as the resuscitation attempt proceeded, their "failure" to intervene far more likely reflects the most basic human desire to reverse a catastrophic event befalling a loved one. Particularly when the collapse is as sudden, one wonders how anyone would behave otherwise.

Finally, despite all the problematic consequences which can result from poorly-considered CPR attempts, few would deny the value of attempting to extend

one's life even a short time if that time would allow the patient to actively engage in meaningful activities and personal interactions. The fact that the majority of initial survivors who died prior to discharge fared so poorly in the hours and days after their code, then, was particularly disappointing. Overall, only two patients were completely alert and interactive, post-code.⁷ Sadly, the occurrence of such outcomes, foreseeable as they may be, have had exceedingly little ability to aid us in preventing their continued occurrence.

Discussion: Interviews

ABMC physicians, particularly those practicing in the hospital, had serious concerns about the nature of patients receiving CPR. Consistent with findings from the chart reviews, most in-hospital physicians reported performing codes on patients with endstage disease, having little knowledge of patients' wishes beforehand, and being placed in the awkward position of initiating DNAR discussions with patients with whom they had had minimal prior contact. These physicians stated that such scenarios occurred with regularity. Not surprisingly, it was from them that I elicited the strongest expressions of frustration over this issue, and for whom lasting emotional consequences, at least by their tone and outlook, appeared the most pronounced.

⁷ *An important caveat here is that, according to one physician I interviewed, in the 48 hours following a code, most patients will be unconscious and appear neurologically "brain dead," but may later recover. The fact that 86% of study patients died within five days of the code, however, suggests that these people sustained more permanent injury.*

By contrast, primary care physicians had little everyday experience with these situations in their current practice, and so, not surprisingly, high-risk codes were of less immediate concern. This perspective, combined with unremitting time constraints, low levels of patient medical sophistication, and varying degrees of patient mistrust fueled by the managed care environment, all help explain why none of these physicians regularly engaged in end-of-life care discussions with their patients.

Significantly, too, many primary care physicians felt that the subject of end-of-life care was only relevant for those with serious medical conditions, thus they would not routinely engage in such discussions even if time and communication were optimal. For example, several shared that they wouldn't think to initiate such a discussion until *after* a patient had been hospitalized for the first time. While discussions following a hospitalization presumably better contextualize end-of-life care issues for patients, they clearly require that patients *survive* their first hospitalizations.

These physicians revealed still other reasons for delaying such conversations. One felt that truly ill patients care less about self-determination, but instead, prefer that others make decisions for them. This particular physician felt comfortable making major medical decisions for his patients, and from his narratives of typical conversations with patients, clearly evinced a more paternal style of practice in general than others with whom I spoke. In addition, this

physician also felt that the public at large is aware that CPR is rarely successful, and thus have low expectations of it at the outset. In addition, he feared that some patients might choose to be DNAR, later change their minds, but forget to void their prior paperwork, thus binding them to their prior directives. Clearly, physicians with such perspectives and styles of practice will not be the strongest advocates for formal advance care directives.

Several other physicians were similarly concerned that patients with DNAR designations were at risk for receiving inadequate medical attention by virtue of their DNAR status. These fears were born of personal experiences during residency when, as harried and overworked house staff, many triaged DNAR patients to the bottom of their priority lists. Though no physician could quantify the extent to which they had witnessed (or participated in) this kind of triaging at ABMC, their past experiences with such practices persisted in their minds, and made them somewhat reluctant to advocate too aggressively for early DNAR status for some of their patients.

Clearly, the determinants of whether or when a physician will discuss code status are complex and involve far more than time limitations or communication difficulties: for at least some of the physicians in this study, the implications of DNAR status are problematic for reasons having as much to do with the practice and culture of medicine as they do with patients' concerns. Such implications clearly need to be addressed if primary care physicians – universally

acknowledged as *the* caregivers in the best position to address advance health care planning with patients – are to find the proper motivation to act in that regard.

Conclusions

Though this study revealed the occurrence of the kinds of problematic issues seen vis-à-vis CPR in other hospital settings: a dearth of early decision-making, high-risk CPR attempts, and poor-outcomes, the data from ABMC also provide reasons for optimism -- such occurrences are not rampant. Over the four years of this study, 104 patients underwent CPR – roughly two patients per month. These patients made up 28 of 412 (6.8%) patients dying in the hospital in 1998, 21 of 365 (5.8%) in 1999, and 25 of 422 (5.9%) in 2000. Contrasting such percentages against those of other facilities in which up to 75% of dying patients have been coded, these numbers are impressively low. More tellingly, these numbers are considerably lower than those found in an internal Alta Bates CPR study conducted in 1979-1981, in which 182 patients underwent CPR – roughly twice the patients in half the number of years.

If this dramatic decrease in CPR occurrences is not due to reporting artifact, to what factors might we attribute the decrease, and how might such a trend towards ever-more judicious use of CPR continue? We may attribute the decline in part to improved patient education. If so, it seems clear that it will continue to

be crucial that physicians inform patients as to the realities of CPR's limitations: that at best, CPR can reverse a sudden collapse, but can never restore health, and that therefore, CPR vs. DNAR in a patient with serious co-morbid conditions is rarely a choice between life and death, but more often, a choice between a short or prolonged death. Defining CPR in such terms, and urging the patient to consider how she wishes to spend the remainder of her life (i.e., in the hospital, with intensive medical interventions, or elsewhere, in pursuit of final goals in life) remains the cornerstone of judicious application of CPR, as well as good doctoring overall.

How else might we improve our practices? ABMC might consider training persons in each unit to code its own patients. Currently, one code team performs CPR for cardiac arrests occurring anywhere in the hospital (except in the intensive care units), thus exposing patients to being coded by physicians entirely unfamiliar with their clinical condition. These occurrences could be minimized by the presence of code teams on each ward, responsible for the care of their own patients.

Another means by which to limit futile CPR attempts would come with the development of a palliative care team for the hospital, composed of providers with expertise in medical management and spiritual support for the dying and their families. The presence of such a team, dedicated to providing services to patients who wish to die in the hospital, would provide a material alternative to

pursuing futile, life-sustaining measures in the face of certain death, and demonstrate to both patients *and* primary care providers, that DNAR will not place patients at risk for abandonment or a substandard level of care.

ABMC and its primary care physician affiliates should also explore the development of a formal mechanism for patient information sharing between in and outpatient settings, though the financial burden may be considerable. Clearly, though, better information sharing would benefit patients in many ways, not the least of which would be to prevent DNAR patients from being coded inadvertently.

Next, health maintenance organizations (HMOs) should consider requiring primary care physicians to raise the issue of advance care directives with certain populations of patients (e.g., over age 55), in the same manner that some require physicians to discuss the presence of smoke alarms in the home, and car seatbelt use. One physician acknowledged that he had readily incorporated such requirements, and would ask about advance directives if required to do so. To introduce the issue in the context of it being a routine inquiry may make the topic less awkward for physicians to raise, and may help patients feel less threatened by the question. Though the initial conversation may be brief, its introduction could facilitate future discussion.

Finally, American society at large would benefit from increased public discussion about death and dying – topics seldom explored in any but the most sensational manner in the media. As a consequence, most individuals make medical care decisions for themselves or loved ones only when death is upon them, and from positions of fear, denial, or combativeness. As a consequence, many then seek futile medical interventions they may not have chosen for themselves had they known the realities of such interventions, or had they invested more time pondering their mortality before illness struck. Clergymen, legislators, journalists and other public figures could all assist in encouraging public and private discussions as Bill Moyers did last year, through in his television documentary series on death and dying, *On Our Own Terms*.

In addition to encouraging public discussions about personal behavior and decision-making, we need also raise consciousness and discussion regarding the role of CPR and associated high-tech medical interventions near the end-of-life. Where do we draw limits? And until such time as everyone has contributed to the conversation, how can we do so ethically? As one writer has observed, most Americans are simultaneously egalitarians and capitalists.¹³⁹ As capitalists, we want unlimited access to whatever medical care we can afford, regardless of effectiveness, and as egalitarians, we are uncomfortable seeing others die because they cannot afford care, thus we attempt to provide universal coverage through insurance. Because our resources are limited, this dualism places us in a precarious and ultimately untenable situation. Whether we will ever develop

the political will or desire to change the status quo remains one of the greatest challenges facing medicine and society.

Limitations & Future Directions for Research

This research had several limitations. First, I relied solely on ICD-9 codes to identify patients who had received CPR, which may not have been sufficient to capture all episodes the procedure during the years of the study. In-hospital physicians gave me the strong impression that high-risk codes occurred far more often than the numbers in this study reflect, and clinicians may very well have failed to complete the hospital CPR form in all cases – particularly if codes were very brief. In hindsight, I should have cast a wider net by investigating, for example, discrete episodes of in-hospital cardioversion, or perhaps even intubations. In addition, I might also have searched physician Current Procedural Terminology (CPT) codes for evidence of CPR activity. By extending my search to these areas, I may have uncovered further cases.

A second, significant limitation was the fact that I relied on physician notations to assess post-code mental and neurologic status. Very few uniform notations of these physical states were recorded in the charts, and real-time documentation of changing physical and mental states was sparse. Thus, some patients may have experienced moments of lucidity following their codes which, though short,

may have been meaningful (and indeed, priceless). I was not able to capture such information, and my data are the poorer for that.

In addition, because DNAR orders are, by definition, orders to *desist* from action, no methods were available (short of reviewing the charts of all inpatients) to identify these patients. A comparison of DNAR patients with the patients in this study may have revealed important dissimilarities between the groups from which we may have learned.

Finally, I interviewed only twelve physicians, and only those who agreed to speak with me. Thus the range and generalizability of their comments and perspectives is limited. The comments and insights that emerged were also undoubtedly influenced and/or limited by what I chose to ask, and by my limited interviewing skills. Furthermore, I interviewed no patients or families, whose perspectives are certainly necessary for a full exploration of the physician-patient dynamic in end-of-life-care negotiations. Future research should incorporate their thoughts and perspectives more directly.

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Appendix A

Tables 1-3: Demographic Characteristics of Patients Undergoing CPR

Table 1: Gender

<u>Gender</u>	<u>Frequency</u>	<u>Percent</u>	<u>Valid Percent</u>
Men	52	50.0	50.0
Women	52	50.0	50.0
Total	104	100.0	100.0

Table 2: Age Distribution

<u>Age Distribution</u>	<u>Min</u>	<u>Max</u>	<u>Mean</u>	<u>Std. Deviation</u>
104	24	96	68.80	15.347

Table 3: Ethnicity

<u>Ethnicity</u>	<u>Frequency</u>	<u>Valid Percent</u>
White	53	51
African American	37	35.6
Asian, PI	10	9.6
Hispanic/Latino	2	1.9
Mixed/unknown	2	1.9
Total	104	100.0

Tables 4-7: Patient Decision-Making

Table 4: Initial Code Status

<u>Initial Code Status</u>	<u>Frequency</u>	<u>Valid Percent</u>
No Designation	70	67.3
full code, specified	28	26.9
DNAR	4	3.8
Partial Code	2	1.9
Total	104	100.0

Table 5: AD or DPOA

<u>AD or DPOA</u>	<u>Frequency</u>	<u>Valid Percent</u>
No	77	74.0
Yes	27	26.0
Total	104	100.0

Table 6: Advance Directive/DPOA by ethnicity

<u>AD/DPOA by ethnicity</u>	<u>Frequency</u>	<u>Valid Percent</u>
White	19	70.4
African American	7	25.9
Asian/P Islander	1	3.7
Hispanic	0	0
Total	27	100.0

Table 7: What was code status changed to?

<u>Code Status</u>	<u>Frequency</u>	<u>Percent</u>	<u>Cumulative Percent</u>
DNR	26	81.3	81.3
Partial Code	6	18.8	100.0
Pharmacologic only	4		
Pharmacologic & chest compressions/bag ventilation	1		
Pharmacologic & intubation	1		
defibrillation	0		
Total	32	100.0	100.0

Table 8: Frequency of Co-morbidities

Diagnosis	Frequency	Percent
Coronary Artery Disease	33	31.7
Congestive Heart Failure	20	19.2
Cerebral Vascular Disease	18	17
Myocardial Infarction	14	
End Stage Renal Disease	13	12.5
CA	10	9.6
Sepsis	8	7.6
Pneumonia	8	7.6
COPD	6	5.8
Dementia	4	3.8
AIDS	2	1.9

Tables 9-14: CPR Outcomes

Table 9: Number of Codes

<u>Number of codes</u>	<u>Frequency</u>	<u>Percent</u>	<u>Valid Percent</u>	<u>Cumulative Percent</u>
1	86	82.7	82.7	82.7
2	15	14.4	15.4	97.1
3	2	1.9	1.9	99.0
6	1	1.0	1.0	100.0
Total	104	100.0	100.0	

Table 10: Outcome of first code

<u>Outcome</u>	<u>Frequency</u>	<u>Percent</u>	<u>Valid Percent</u>	<u>Cumulative Percent</u>
Immediate death	50	48.1	48.1	48.1
Survived < 24 hrs	27	26.0	26.0	74.0
Survived > 24hrs, but died before discharge	16	15.4	15.4	89.4
Survived to discharge	11	10.6	10.6	100.0
Total	104	100.0	100.0	

Graph 1: Percentage of patient alive by days after code

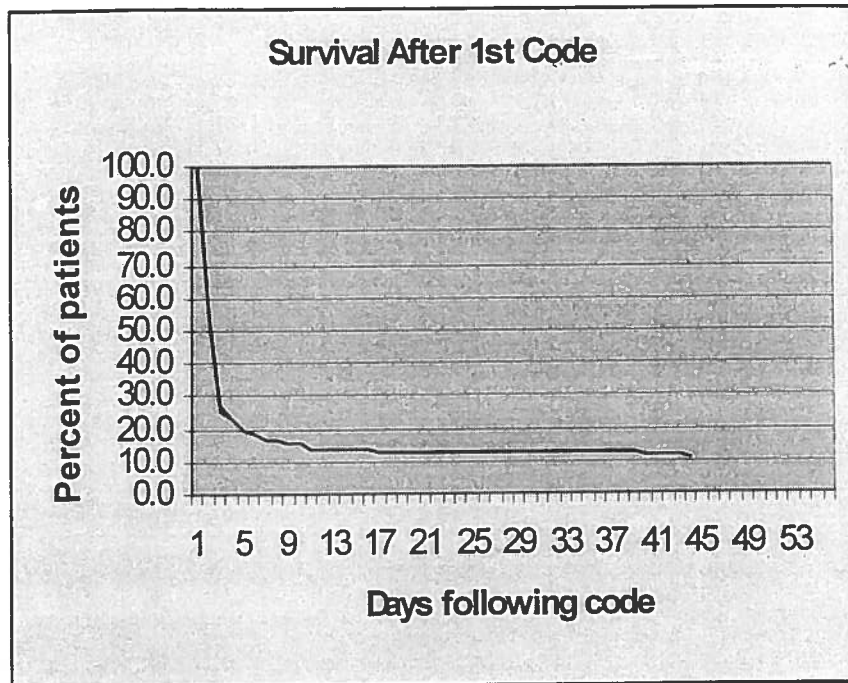


Table 11: Mental status of patients who survived code, but died before discharge

Status	Frequency	Percent	Cumulative Percent
not at all alert	37	86.0	86.0
somewhat alert	4	9.3	95.3
alert	2	4.7	100.0
Total	43	100.0	

Table 12: Neurological status of patients who survived code, but died before discharge

Status	Frequency	Valid Percent	Cumulative Percent
No impairment	3	7.0	7.0
some impairment	1	2.3	9.3
severe impairment	28	65.1	74.4
unable to infer	11	25.6	100.0
Total	43	100.0	

Table 13: Mental status of patients who survived to discharge, post-code

Status	Frequency	Percent	Valid Percent	Cumulative Percent
not alert	1	9.1	9.1	9.1
somewhat alert	5	45.5	45.5	54.5
Alert	5	45.5	45.5	100.0
Total	11	100.0	100.0	

Table 14: Neurological status of patients who survived to discharge, postcode

Status	Frequency	Percent	Valid Percent	Cumulative Percent
no impairment	8	72.7	72.7	72.7
slight impairment	2	18.2	18.2	90.9
severe impairment	1	9.1	9.1	100.0
Total	11	100.0	100.0	

Appendix B

CODE/CPR INFORMATION SHEET 9/12/00 v.7

Patient ID #: _____

Date of Admission: ____ / ____ / ____
Mo da yr

A. BACKGROUND INFORMATION

1. Age: ____

2. Gender
- 1. male
 - 2. female

3. Ethnicity
- 1. white, non-Hispanic
 - 2. Hispanic/Latino
 - 3. African American/Black
 - 4. Asian American/Asian, Pacific Islander
 - 5. mixed

4. Primary insurance
- 1. Medicare
 - 2. MediCal
 - 3. Medicare/MediCal
 - 4. Medicare HMO
 - 5. HMO
 - 6. private
 - 7. other
 - 8. none

- 4a. Which type of physician was in charge of the case?
- 1. AIS
 - 2. MD referral

5. Top three discharge/death diagnoses:

6. Hospital unit where patient was admitted
 1. CCE
 2. CCW
 3. oncology (4NE)
 4. SNF (4NW)
 5. any medical or surgical unit (4W, 4E, 6NW, 6NE, 6SW)
 6. ITC
 7. TRU

7. Did patient have decision-making capacity during the hospitalization?
 0. no
 1. yes, during part of hospitalization
 2. yes, during entire hospitalization

8. How was informed consent obtained?
 1. from the patient
 2. from a relative
 3. other (SPECIFY:) _____
 4. not designated in the chart at all

B. CODE STATUS

INITIAL CODE STATUS

9. What was the initial code status of the patient? (circle one)
 1. full code specified
 2. DNR
 3. partial code
 4. no designation (full code by default) (skip to #14)

If the code status was partial code, circle all that apply:

- 10a. pharm code
- 10b. CPR – chest compression, bag/mask ventilation
- 10c. defibrillation
- 10d. intubation

11. Date of original code status designation: ___/___/___
Mo da yr

12. Was the patient's code status discussed in the physician's H&P or progress notes?
 0. no
 1. yes (describe:)

13. If other than full code, was there any documentation of an informed consent process regarding CPR?
- 0. no
 - 1. yes

(FIRST) CHANGED CODE STATUS

14. Was code status changed during this hospitalization?
- 0. no (skip to #26)
 - 1. yes
15. If yes, what was code status changed to?
- 1. full code
 - 2. DNR
 - 3. partial code

If the (first) changed code status was partial code, circle all that apply:

- 16a. pharm code
- 16b. CPR – chest compression, bag/mask ventilation
- 16c. defibrillation
- 16d. intubation

Who made the decision to change code status? (circle all that apply)

- 17a. patient
- 17b. family
- 17c. medical staff

18. Was the patient's change in code status discussed in the physician's progress notes?
- 0. no
 - 1. yes (describe:)
-

19. Date of (first) changed code status: ___ / ___ / ___
Mo da yr

(SECOND) CHANGED CODE STATUS

20. Was code status changed a second time during this hospitalization?
- 0. no (skip to #26)
 - 1. yes
21. If yes, what was code status changed to?
- 1. full code
 - 2. DNR
 - 3. partial code

If the second change to code status was partial code, circle all that apply:

- 22a. pharm code
- 22b. CPR – chest compression, bag/mask ventilation
- 22c. defibrillation
- 22d. intubation

Who made the decision to change code status? (circle all that apply)

- 23a. patient
- 23b. family
- 23c. medical staff

24. Was the patient's change in code status discussed in the physician's progress notes?

- 0. no
- 1. yes (describe:)

25. Date of second changed code status: ___ / ___ / ___
Mo da yr

C. THE CODE EXPERIENCE

FIRST CODE

26. Date of first code: ___ / ___ / ___
Mo da yr

27. Hospital unit where first code was done

- 1. CCE
- 2. CCW
- 3. oncology (4NE)
- 4. SNF (4NW)
- 5. any medical or surgical unit (4W, 4E, 6NW, 6NE, 6SW)
- 6. ITC
- 7. TRU
- 8. ER
- 9. OR
- 10. radiology/procedure lab
- 11. other

27a. Was the code done post-surgery?

- 1. no: there was no surgery
- 2. no: code was done during surgery
- 3. yes

- 27b. If code was done post-surgery, how soon after surgery was it done?
1. 48 hours or less after surgery (exact number of hours if available: ____)
 2. more than 48 hours after surgery

Type of code (circle all that apply):

- 28a. pharm code
28b. CPR – chest compression, bag/mask ventilation
28c. defibrillation
28d. intubation

29. Length of first code in minutes: ____

30. Outcome of first code:

1. immediate death (code unsuccessful) (skip to #58)
2. survived less than 24 hours
3. survived > 24 hrs, but not until discharge: number of days survived: ____
(#30a)
4. lived to discharge

31. Mental status of patient in hours/days post-code (describe:)

0. not at all alert
1. somewhat alert
2. alert
3. not able to infer

32. Neurological status of patient in hrs/days post-code (describe:)

0. no neurological impairment
1. some neurological impairment
2. severe neurological impairment
3. not able to infer

SECOND CODE (skip to #47 if there was no second code)

33. Date of second code: ____ / ____ / ____
Mo da yr

34. Hospital unit where second code was done

1. CCE
4. CCW
5. oncology (4NE)
6. SNF (4NW)

7. any medical or surgical unit (4W, 4E, 6NW, 6NE, 6SW)
8. ITC
9. TRU
10. ER
11. OR
12. radiology/procedure lab
13. other

34a. Was the code done post-surgery?

1. no: there was no surgery
2. no: code was done during surgery
3. yes

34b. If code was done post-surgery, how soon after surgery was it done?

1. 48 hours or less after surgery (exact number of hours if available: ____)
2. more than 48 hours after surgery

Type of code (circle all that apply):

- 35a. pharm code
- 35b. CPR – chest compression, bag/mask ventilation
- 35c. defibrillation
- 35d. intubation

36. Length of second code in minutes: ____

37. Outcome of second code:

1. immediate death (code unsuccessful) (skip to #58)
2. survived less than 24 hours
3. survived > 24 hrs, but not until discharge: number of days survived: ____
(#37a)
4. lived to discharge

38. Mental status of patient in hours/days post-code (describe:)

0. not at all alert
1. somewhat alert
2. alert
3. not able to infer

39. Neurological status of patient in hrs/days post-code (describe:)

0. no neurological impairment
1. some neurological impairment
2. severe neurological impairment

3. not able to infer

THIRD CODE (skip to #47 if there was no third code)

40. Date of third code: ___ / ___ / ___
Mo da yr

41. Hospital unit where third code was done
1. CCE
 2. CCW
 4. oncology (4NE)
 5. SNF (4NW)
 6. any medical or surgical unit (4W, 4E, 6NW, 6NE, 6SW)
 7. ITC
 8. TRU
 9. ER
 10. OR
 11. radiology/procedure lab
 12. other

- 41a. Was the code done post-surgery?
1. no: there was no surgery
 2. no: code was done during surgery
 3. yes

- 41b. If code was done post-surgery, how soon after surgery was it done?
1. 48 hours or less after surgery (exact number of hours if available: ___)
 2. more than 48 hours after surgery

Type of code (circle all that apply):

- 42a. pharm code
- 42b. CPR – chest compression, bag/mask ventilation
- 42c. defibrillation
- 42d. intubation

43. Length of third code in minutes: ___

44. Outcome of third code:
1. immediate death (code unsuccessful) (skip to #58)
 2. survived less than 24 hours
 3. survived > 24 hrs, but not until discharge: number of days survived: ___
(#44a)
 4. lived to discharge

45. Mental status of patient in hours/days post-code (describe:)

- 0. not at all alert
- 1. somewhat alert
- 2. alert
- 3. not able to infer

46. Neurological status of patient in hrs/days post-code
 (describe:)_____

- 0. no neurological impairment
- 1. some neurological impairment
- 2. severe neurological impairment
- 3. not able to infer

D. DISCHARGE AND READMISSION

47. (Skip to #58 if patient did not live to discharge)

If lived to discharge, date of discharge: / /
 Mo da yr

48. If patient lived to discharge, was he/she readmitted to the hospital within one year?

- 0. no
- 1. yes

49. Date of readmission: / /
 Mo da yr

50. Did patient die during this new hospital stay?

- 0. no
- 1. yes

51. Was patient coded during this new hospitalization?

- 0. no
- 1. yes

52. Hospital unit where code was done

- 1. CCE
- 2. CCW
- 3. oncology (4NE)
- 4. SNF (4NW)
- 5. any medical or surgical unit (4W, 4E, 6NW, 6NE, 6SW)
- 6. ITC
- 7. TRU
- 8. ER
- 9. OR

10. radiology/procedure lab
11. other

- 52a. Was the code done post-surgery?
1. no: there was no surgery
 2. no: code was done during surgery
 3. yes

- 52b. If code was done post-surgery, how soon after surgery was it done?
1. 48 hours or less after surgery (exact number of hours if available: ____)
 2. more than 48 hours after surgery

Type of code (circle all that apply):

- 53a. pharm code
- 53b. CPR – chest compression, bag/mask ventilation
- 53c. defibrillation
- 53d. intubation

54. Length of code in minutes: ____

55. Outcome of code:
1. immediate death (code unsuccessful) (skip to #58)
 2. survived less than 24 hours
 3. survived > 24 hrs, but not until discharge: number of days survived: ____ (#54a)
 4. lived to discharge

56. Mental status of patient in hours/days post-code (describe:)
- _____

0. not at all alert
1. somewhat alert
2. alert
3. not able to infer

57. Neurological status of patient in hrs/days post-code (describe:)
- _____

0. no neurological impairment
1. some neurological impairment
2. severe neurological impairment
3. not able to infer

E. DEATH: COMPLETE THIS SECTION IF PATIENT DIED IN HOSPITAL
(whether during the hospital stay when the first code was done or during a new hospital
stay):

58. Date of death: ___ / ___ / ___
Mo da yr

59. Hospital unit where patient died
1. CCE
 2. CCW
 4. oncology (4NE)
 5. SNF (4NW)
 6. any medical or surgical unit (4W, 4E, 6NW, 6NE, 6SW)
 7. ITC
 8. TRU
 9. ER
 10. OR
 11. radiology/procedure lab
 12. other

F. COMMENTS: