End of life in the ICU in NYC
A clinician’s perspective

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Faculty Disclosures
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Maquet Cardiovascular
   Research support
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I am dying from the treatment of too many physicians.

-Alexander the Great
I am dying from the treatment of too many physicians.

-New York State Legislature
End of life care in the ICU in NYC

NY State Legislature vs. physicians
(& surrogate decision makers)
Balancing physician input (paternalism) with patient autonomy has a distinct role

But it’s the balance that’s key
Origins of Do Not Resuscitate in New York
When end of life care was nearly criminalized
March 27th, 1981

78 year-old woman in the ICU at La Guardia Hospital in Queens
Was “mysteriously disconnected from her respirator and went into cardiac... arrest.... No effort was made to sound the Code 33 alarm.”

The woman had previously disconnected herself from the ventilator on several occasions

1982

Deputy state attorney general initiates a grand jury investigation

Considering criminal charges

1982

Backdrop

Los Angeles, California

Patient disconnected from life-support

By her physicians: “out of compassion”

Homicide charges filed

The reaction
La Guardia Hospital administrators:

The criminal investigation forces hospitals & physicians to adopt “exceedingly conservative policies involving emergency life-prolonging measures for terminally ill patients.”

La Guardia Hospital’s President:

“Some patients [will] needlessly suffer’ because the hospital adopted a policy of resuscitation in virtually every terminal case ‘until the issue... is officially resolved’”

“Cruel and inhumane”

President of the Greater NY Hospital Association

“We are floundering in a morass of legal uncertainty”

Urged the NY Department of Health to issue regulations

The practices at the time (some dubious)
No guidelines at that time

DNR orders rarely written in the chart

When written:
“Patient has no chance of recovery – just keep comfortable”

Not “DNR”

Known as “no code” cases

In some instances,
Written in pencil or on blackboards
So they can be erased later
Out of fear the orders could be used against doctors in malpractice lawsuits

In light of this... 

Special grand jury in Queens reported uncovering “shocking procedural abuses” in the way La Guardia hospital kept secret its withholding of emergency resuscitation

The hospital “tried to escape legal consequences of withholding the emergency measures by making sure there would be no record of ‘do not resuscitate’ orders”.

A “purple decal” was attached to a patient’s nursing record & discarded when the patient died.
“We found that the ‘purple dot’ system virtually eliminated professional accountability, invited clerical error and discouraged physicians from obtaining informed consent. . .”

Seeing both sides of the issue
The grand jury did not indict anyone

They recommended that the NY State legislature & Dept of Health establish strict procedures

“Responsible physicians should not have to ignore their own best medical judgments, or the wishes of their suffering. . . patients, out of an unjustified fear of legal consequences.”

“At the same time, the enormous significance of such life & death decisions cannot be minimized, and appropriate procedures must be established to assure that they are not made carelessly, unilaterally, or anonymously.”

Addressing the issue
Medical Society of the State of NY issues guidelines for withholding emergency resuscitation from a terminally ill patient

Advisory only
No legal authority

1982

NY became the 4th state in the US to have such medical society guidelines

“Do not resuscitate” orders, according to the guidelines, required

- Attending physician determines it is appropriate
- The patient is involved in decision making
  - Otherwise the physician consults family members
  - If there is disagreement, no order is given
- May be rescinded at any time

Evolution

• 1985: Formation of The New York State Task Force on Life and the Law

• 1986: Task Force proposed legislation on DNR

• 1987: Proposal became law (amended in 1991)

• 1990: Health care proxy law enacted
1987 NYS DNR Law

The decision over DNR is given to the patient

If no capacity,
Surrogates have power to decide DNR

Criticism:

CPR became the default position

Every patient must undergo resuscitative attempts before dying unless they or their surrogates actively decline
“It has become increasingly difficult to die in a New York Hospital without first being subjected to CPR, due to a state law that went into effect. . . . Under the banner of patients’ rights and combating physician ‘paternalism’, the State Dept of Health dealt a blow to good medical care by dictating the manner in which physicians may withhold CPR. . . . Although at first the law sounded reasonable, experience with it . . . has shown it to have negative effects on the very patients it was meant to help.”

The perception

Powerless doctors
1987 NYS DNR Law

Not simply a paternalistic approach

“Resuscitation. . . the path of least resistance”

A questioning of informed consent

“Critically ill patients... often have no idea of what the procedure involves and of the possible state to which they might be restored in the event of a ‘successful’ resuscitation.”

Is that true?
“Shared decision making on the part of physicians & patients about the potential use of... CPR requires patients who are educated about the... risks & benefits. TV is an important source of information about CPR for patients.”
• All episodes of ER & Chicago Hope 1994-1995 season + 50 episodes “Rescue 911”

• Identified all occurrences of CPR: Cause, demographics, underlying illness & outcomes
Results

• 60 CPR events in 97 episodes (31 ER, 11 Chicago Hope, 18 Rescue 911)
  • Etiology mostly trauma (only 28% cardiac causes)
  • 73% men
  • 65% children, teenagers, young adults
  • 60% out of hospital arrest
  • 75% survival after arrest
  • 67% survival to hospital discharge
Do those sound like your patients?
Unclear survival from cardiac arrest
In 1980s television
Clearly TV still misrepresents the reality today
1987 NYS DNR Law

“What was originally a great advance in medical care in 1960, when...used to resuscitate otherwise healthy victims of acute heart attacks or trauma, came to be used inappropriately for many of those dying in a hospital. The new law aggravates this lamentable process.”

1987 NYS DNR Law

“Those who drafted the legislation seem to have ignored entirely a number of reputable studies... that show that CPR is utterly futile in... certain classes of patients, such as those with metastatic cancer... Mandating CPR in such cases amounts to a... desecration of the human body.”

At odds with the good work done by living wills

End of life care in New York
Key point

Who’s making the decisions?
At least

DNR could be decided by surrogates
Where NY stood virtually alone (until 2010)
Otherwise powerless surrogates
• DNR became the only health care decision that a surrogate had the right to make
  – For a patient without capacity
  – No other health care decisions could be made by a surrogate
Case law on surrogate decision making (1988)

- “There can be no surrogate decision making to decline life-sustaining care in New York.”
- To remove life support, we need “clear and convincing evidence” of the patient’s prior wishes (written or verbal)
- No substituted judgment
In the incapacitated patient

The physicians hands were tied

Surrogates hands were tied

Except for DNR

Or where there was “clear & convincing evidence” of the patient’s known wishes
What about cases where resuscitation is deemed futile?
• According to the law, resuscitation attempts must be carried out
  – Even if deemed medically futile where family declines the DNR
  – However
    • The law does not prescribe the duration or aggressiveness of the resuscitative effort
      – Based on physician judgment (the only instance)
    • Rare exceptions
      – Exception when there is no surrogate
        » 2 physician DNR for medical futility
      – Exception by court order “in patient’s best interests”
      – Exception for “therapeutic exception” i.e. too big a burden on the patient to involve them in the discussion
        » Requires 2 physicians AND a health care agent or surrogate
Family Health Care Decisions Act
2010
FHCDA

• Sets out, in priority order, the surrogate decision makers who can make *any health care decision* for an incapacitated patient

• Surrogate must decide based on patient’s known wishes or best interests

• Surrogates may withhold or withdraw life support
  – May withhold resuscitative efforts

• NY = the 49th of 50 states in the US to give this power to surrogates (without “clear & convincing evidence” of what the patient wanted)
FHCDA

Advance for surrogates

Not for the clinical team
Deference to patients (& families)

Brain death
• NY & New Jersey only states in US that, by law, require appropriate “accommodations” to the religious & ethical beliefs of families before removing ventilator support in brain dead patients
  – Each hospital must make its own policy
  – NYP
    • Continue vent support, IV fluids, feeding in brain dead patients if family insists
    • We are seeing increasing refusals to allow apnea testing to declare brain death

Futility
• Medical futility is, for all practical purposes, non-existent in NY
EOL in ICU in NY

Positive

NY State law prizes patient autonomy

Now allows greater substituted judgment by surrogates

Minimizes paternalism

Negative

At the expense of physician input

Almost no recognition of futility