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Slow Codes, Show Codes and No-Codes

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With support from the Claire Giannini Trust

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- Recent publications:
  - **Categorizing neonatal deaths: a cross-cultural study in the United States, Canada, and The Netherlands.** *J Pediatr 2010*
  - **Ethics ain't easy: do we need simple rules for complicated ethical decisions?** *Acta Paediatr 2008*
  - **Nobody likes preemies: the relative value of patients' lives** *J Perinatol 2008*

William Meadow

- Professor of Pediatrics.
  Section Chief and Fellowship Director in Neonatology, University of Chicago
- Recent Publications:
  - **The mathematics of morality for neonatal resuscitation.** Clin Perinatol. 2012
  - **End-of-life: death and dying in neonatal intensive care units - a North American perspective.** Acta Paediatrica 2012
  - **The prediction and cost of futility in the NICU**. Acta Paediatr. 2012
  - **Should the "slow code" be resuscitated?** Am J Bioethics, 2012

Futility Controversies

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Futility Controversies
or
All Codes are Slow Codes

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Department of Pediatrics
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I have, sadly, no relevant financial relationships to disclose.

I have no conflict of interests to resolve.

I will not be discussing off-label use of meds.

Futility Controversies

1. Predictions
2. Goals
3. Endings

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2. Goals
3. Endings

Consider this case:

- 2 y.o. microcephaly, MR; G-tube; trache;
- Admit for respiratory failure (RSV);
- HFOV; pneumos; CPR x 1 already;
- Now hypoxic, hypotensive, bradycardic

Consider different cases:

- 24 wk premie, Gr IV IVH; septic hypotensive despite pressors;

- 94 year old demented adult with metastatic ca and renal failure;

What should we do?

What should we do?

What do the parents want?

What should we do?

What do the parents want?

What do the docs/nurses want?

What might be a ‘good’ death?

What might be a ‘good’ death?

1. Peaceful – comfort and palliation

What might be a ‘good’ death?

1. Peaceful – comfort and palliation

2. Not giving up –

- ‘my baby’s a fighter’;
- ‘she deserves a piece of the pie’

How will this baby die?

1. Comfort Care

How will this baby die?

1. **Comfort Care**

    docs and nurses happy;

    parents may be happy

How will this baby die?

1.Comfort Care

docs and nurses happy;

parents may be happy … but some parents may not accept complicity in their child's death

How will this baby die?

1. Comfort Care
2. Unilateral DNR

How will this baby die?

2. Unilateral DNR

docs and nurses profession respected;

parents disrespected?

How will this baby die?

1. Comfort Care
2. Unilateral DNR
3. Full CPR

How will this baby die?

3. Full CPR

docs and nurses frustrated;

parents respected;

baby subjected to pain/suffering

How will this baby die?

1. Comfort Care
2. Unilateral DNR
3. Full CPR

How will this baby die?

1. Comfort Care
2. Unilateral DNR
3. Full CPR
4. ‘Slow’ Code

What is a slow code?

1. Not epinephrine in the mattress
2. Less than full CPR (dose, duration)
3. Responsibility/ambiguity ‘shared’

Advantages of a Slow Code?

a. best of bad choices

b. docs and nurses less frustrated

c. parents still respected

d. baby less subjected

e. ambiguity in decision-making

What do others think of ‘slow codes’?

What do others think of ‘slow codes’?

“Because it is deceptive, physicians or nurses should not perform half-hearted resuscitation efforts ("slow codes").”

American College of Physicians Ethics Manual.

What do others think of ‘slow codes’?

“Dishonest, crass dissimulation, and unethical.”

Jonsen A, Siegler M, Winslade W. *Clinical Ethics*, p38.

“Deplorable, dishonest and inconsistent with established ethical principles.”

Muller JH. Shades of blue: the negotiation of limited codes by medical residents. Soc Sci Med 1992; 34:885-98.

What do others think of ‘slow codes’?

“Patients, families, and health care professionals all need to rely on the good-faith assumption that when CPR is attempted it will be done with vigor and genuine hope for success….If you are going to do something, do it right. Charades are not acceptable when it comes to life-and-death matters.”

Kodish E. Ethics rounds: symbolic resuscitation, medical futility, and parental rights. Pediatrics 2010;126;769-72.

Problems with a ‘slow’ code?

1. Failure of communication

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2. Deception (lying?)

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3. Not professional
   a. not ‘best practice’ technically
   b. baby is your patient, not parents

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Problems with a ‘slow’ code?

1. Failure of communication

   sometimes it is;

Problems with a ‘slow’ code?

1. Failure of communication

   sometimes it is;

   and sometimes people have different values

Problems with a ‘slow’ code?

1. Failure of communication
2. Deception (lying?)

Problems with a ‘slow’ code?

1. Failure of communication
2. Deception (lying?)

- a very ‘thin’ view of ‘truth’
- ambiguity is not dishonesty
- ‘do everything we can that we think will help’

Problems with a 'slow' code?

1. Failure of communication
2. Deception (lying?)
3. Not professional
   a. not 'best practice' technically
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Problems with a ‘slow’ code?

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2. Deception (lying?)
3. Not professional
    a. not ‘best practice’ technically
    b. baby is your patient, not parents

I DON’T BELIEVE THAT FOR A MINUTE!

Problems with a ‘slow’ code?

1. Failure of communication
2. Deception (lying?)
3. Not professional
   a. not ‘best practice’ technically
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Problems with a ‘slow’ code?

1. Failure of communication
2. Deception (lying?)
3. Not professional
   a. not ‘best practice’ technically
   b. baby is your patient, not parents
4. Linguistic

Linguistic Alternatives to ‘Slow’ Code

Linguistic Alternatives to ‘Slow’ Code

1. ‘Abbreviated’ code
2. ‘Short’ code
3. ‘Low-dose’ code
4. ‘Tailored’ code
5. ‘Appropriate’ code
6. ‘Symbolic’ code
7. ‘Family-centered’ code

Practical alternatives to ‘slow’ code?

1. Work harder to get consent

Practical alternatives to ‘slow’ code?

1. Work harder to get consent
2. Assent – Informed non-dissent

Practical alternatives to ‘slow’ code?

1. Work harder to get consent
2. Assent – Informed non-dissent
3. Full CPR

Practical alternatives to ‘slow’ code?

1. Work harder to get consent
2. Assent – Informed non-dissent
3. Full CPR
4. ‘Tailor’ code as medically appropriate

What others say about tailored codes

Kon: “Include various limits – e.g. one dose epinephrine; 5 minutes; bag/mask only

Janvier/Barrington: “Appropriately perform 3 minute codes”

Morrison/Feudtner: “5 minutes, or even less, might be appropriate if not expected to survive”

Weinaker: “Clinical circumstances dictate extent of resuscitation; decision by MD at bedside”

Lantos J, Meadow W, Should the “slow code” be resuscitated? Responses; Am J Bioethics, 2011

They get it:

They get it: half right

Final two questions

1. How many of you ‘tailor’ your codes now?

Final two questions

1. How many of you ‘tailor’ your codes now?

2. How many of you tell the parents that you’re ‘tailoring’ their baby’s code?

Hello?

Final comments

- We rarely offer all of the medical options that might be possible (LVAD, ECMO, drugs, duration)

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- We rarely tell parents that we aren’t offering them all these options

- Almost all codes are slow codes

- **As they should be**

Final ethical exhortation

- Process matters
- Don’t abandon your patients
- That's what ‘attending’ means

Thanks to my colleagues at the University of Chicago

Kwang Lee
Jaideep Singh
Mike Schreiber
Bree Andrews
Leslie Caldarelli
Jessica Fry
Naomi Laventhal
Bridget Spelke
Susan Plesha-Troyke
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John Lantos

Thank you

Slow codes = failure to adapt to the changing face of death in modern intensive care

Annie Janvier, MD, PhD

Disclosures

- Dr Meadow was my PhD director
- Dr Meadow and Lantos are my two mentors
  - I love them
  - They are generally right
  - But not this time!

CPR works on television

- Bill; … John did this study!
  - Diem SJ, Lantos JD, Tulsky JA, NEJM
- On American television…

CPR DOES NOT WORK IN THE NICU

- Bill; … John published this study!!
  - Lantos et al, N Eng J Medicine
- Life is not an American movie
- CPR in the NICU is more like a French movie: the baby dies at the end

How many babies die with CPR in the NICU?

- In my unit: 5% (2010)
- In Dr Meadow's unit: 31%

- Why this difference: because of the parents?
- I DON'T BUY IT!

- IT TAKES TWO TO TANGO
  - 2 stories to illustrate this

When do slow codes occur?

- To avoid CPR that is physiologically futile: slow codes for actively dying babies, CPR that would not work
  - BAIL OUT
- To avoid CPR that is "not worth it": slow codes for babies with uncertain futures or life-limiting diagnoses
  - CPR that may work, but prolonging a life that some judge is "not worth it"
  - REVOLTING

When do babies die in the NICU?

- End of life decision-making has changed, babies die much later now
  - Dr Meadow's NICU = 57 d median; our NICU = 23 d
- Joanne Lynn: [in the past] « people usually experienced life-threatening illness the way they experienced bad weather—as something that struck with little warning—and you either got through it or you didn't. »
- It is not this way anymore, for many babies, dying is a medical struggle

Story 1: The Vietnam effect
(Leuthner, Janvier)

- "We can fix this", "we can cure this", "we can make this baby survive"
- The baby survives a surgery and an infection
- The baby fights many battles; the war is not over
  - ("some babies survive, let's try to extubate again")
- The more battles there are, the less likely it is that the war will be won
- But let's just fight one last battle… in case
  - Baby: fighter or exhausted collapsed wounded soldier?
- We have forgotten to speak about death, we now speak about battle strategies and numbers

Bailing out

It is easier for some physicians to provide a slow code than to talk about death, how babies die and the meaning of a short life

Can my baby die?
Is my baby dying?
If she dies, how will she die?
Is there still a risk of death?

- Answer the question!
- Later death = more time to know the parents
- Often, we speak about death much too late
  - "Fighter fantasy"

Do we even need a DNR order when CPR in the NICU does not work?

- We do not need: DND, DNPHT, etc…
- When DNR order absent: CPR is generally started
- DNR order is very useful: for the attending staff to go home
  - BAILING OUT
- In my unit, 65% of babies die without a DNR order (and without CPR)
  - Attending staff are physically present

Quality control

- CPR is rare and it is a complex team effort
- CPR needs to be CPR all the time: excellent

A short code is not a slow code… and you don't have to lie to parents

- The only time I did a short code (after a caesarean section): I did not lie to the parents "I normally do not do this because it does not work. I will do it for you for a short time, just in case…"

CPR IN THE DELIVERY ROOM IS DIFFERENT

- Many babies survive with adequate resuscitation (including cardiac massage) and can have good outcomes

CPR in the delivery room
“Futile patients”

- Neonatology is the only field where categories of patients are declared futile
- Resuscitation ‘not indicated’ for
  - Extremely preterm babies: 22, 23 or 24 weeks
    - Depending on policy statements
  - Trisomy 13 and 18
    - According to the NRP (AAP) and ILCOR statements
- <u>Not physiologic futility</u>
  - Some babies survive
  - Physicians decided they were futile

What about parents in all this? Why do they demand futile CPR?

- MISTRUST
  - Why?
- Medical health-care system?
- Social inequalities?
- What is it like to be the parent of a baby considered futile?

An example: how parents of "futile" babies lose trust

- Trisomy 13 and 18: Resuscitation and life prolonging interventions are not indicated because of "Unacceptable outcomes"
  - Survival at 1y = 10% and severe disabilities

- Policy statements were written without parental input

Parents report being told that their child (n=332; Janvier et al, Pediatrics)

- Was incompatible with life (87%)
- Had a lethal or futile condition (87%)
- Would be in constant pain (57%)
- Would be a vegetable (50%)
- Would have a life of suffering (57%)
- Would live a meaningless life (50%)
- Would ruin their family (23%)
- Would ruin their marriage (23%)
- “There is nothing we can do” (65%)

Parents of children who live(d)
(160 children lived more than 3 months)

- 53% state that their child experiences (ed) more pain than other children
- 48% recognize that caring for a special needs child is (was) more difficult than they thought it would be

Not futile conditions for parents

Yet, all parents report that the overall effect of their child's life is (was) positive, that their child was (is) a happy child, that their child enriches (ed) their life, the other siblings' life (83%) or their marriage (75%) independently of longevity

- Only 3% separated…

"Futile conditions": Medical View vs. Parents' View

Parents felt their children had no value to healthcare providers

- "Why were physicians is such a hurry to see my daughter die?"
- "He was not incompatible with life. He was compatible with our life. He lived inside me. He lived 102 days. He was my son. He was a brother. He was a nephew. He was compatible with our family."

Story 2: A story of broken trust

- Shattered dreams
- What should we do?
- They are uncertain about interventions, the life of their child, their families

After meeting providers:

- They feel their child has no value
- They feel lied to, they lose trust
  - Physicians believe their child is better off dead?
  - They may hear about slow codes,
- They may become “difficult” and suspicious

- Parents usually get one shot at end of life decisions
  - We get many
- They are doing their best
- A slow code may be the best option some physicians have: this may be a win-win-win
- BUT ONLY FOR A SHORT TIME
  - Short codes brings more mistrust = vicious downward spiral
- Next thing you know, you have 31% deaths with CPR in your NICU!

Conclusion
Slow codes = bail out

- In cases of physiologic futility
  - Indicate a need to speak better about “modern” death
- For babies are judged to be not “worth it”
  - Mistrust from parents
  - Slow codes brings more mistrust

Conclusions

- I DON’T BELIEVE A THIRD OF PARENTS IN THE NICU WANT CPR TO BE THE LAST MOMENTS OF THEIR CHILDREN
- … OUR MEDICAL SYSTEM IS SICK AND WE NEED TO MAKE IT BETTER

Parents do not have a voice in the medical literature!

WHERE IS THE PARENTAL / FAMILY VOICE?

What happens to families and patients?

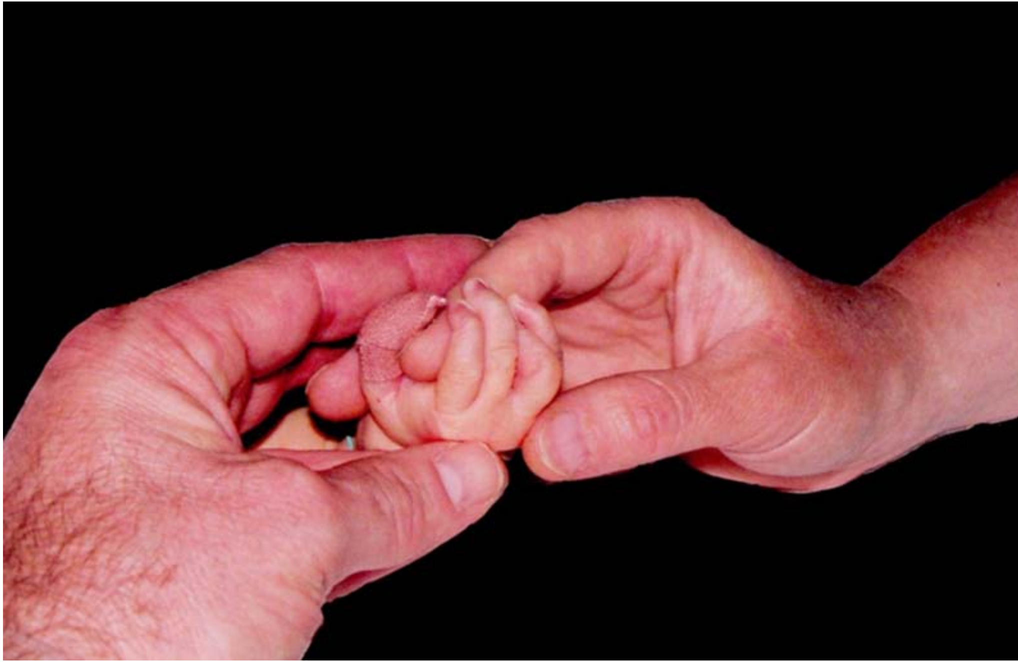
-Unilateral DNR

-”Futile” CPR

-Slow code

Will my baby die?
Is my baby dying?
How will my child die?

- When neonates die, they do in the NICU
- New discussions: not about curing and fixing
- Discussions /research / investigations about healing, the meaning and value of a short life, how to survive the death of your child, what kind of life you want for your child, and rewriting your story
- <u>These inquiries need to involve parents-families</u>



Life is not a matter
of holding good cards,
but of playing
a poor hand well

Robert Louis Stevenson (1850-1894)

Questions?

Please type your questions in the Q & A Panel.

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Does the Concept of 'Medical Futility' Help Clinicians?

Robert D. Truog, MD
Robert L. Fine, MD, FACP, FAAHPM
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