Simon’s Law: Unleashing Surrogate Authority to Demand Potentially Inappropriate Treatment

University of Kansas Medical Center
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Thaddeus Mason Pope, JD, PhD
Mitchell Hamline School of Law

Nothing to disclose

Roadmap

4 parts

1 Background & Context

Simon Crosier
S.B. 85
Kansas is not alone

2 Assessment
Consult mandate
No consent mandate

Parents may veto
So what?

No unilateral anyway
Consensus anyway
Can replace SDM

Odd defects

Simon Crosier
Simon Crosier 09/07/10
DNR
Died 12/03/10
3mo old

Without
parents’
consent

Without
parents’
knowledge

Trisomy 18
“incompatible with life”
“uniformly lethal”

John Lantos
“inaccurate”

Trisomy 18
13% live 10 years

2015
Mo. H.B. 113

2016
Mo. H.B. 1915
Kan. S.B. 437

Parents became advocates
2017
Kan. S.B. 85
Kan. H.B. 2307

S.B. 85

Senate 3/16

2 main parts

Part 1
Share LST policies

Effective
July 1, 2017
“Upon the request . . . shall disclose in writing any policies . . . involving resuscitation or life-sustaining measures, including any policies related to treatments deemed non-beneficial, ineffective, futile or inappropriate”

Applies to **all** patients & LTC residents

**Not** a big deal

**Already** required by PSDA

**Part 2**

**Narrower Scope**

1 unemancipated minors

2
“do-not-resuscitate order or similar physician’s order”

Original bill:
“withhold, withdraw or . . . restrictions on life-sustaining measures”

3 Mandates

Re:
DNR
For minor

Consult

Mandate 1
“shall not be instituted . . . unless at least one parent . . . has first been informed”

“reasonable attempt has been made to inform the other parent”

Must try both
Must tell one

“information must be provided both orally and in writing unless . . . urgency . . .”
No consult

Mandate 2

Document how you satisfied the consult mandate

No DNR

“[who, when, how informed parent] contemporaneously . . . medical record”

“When only one parent . . . informed, . . . reasonable attempts . . . in . . . medical record.”

Accept veto

Mandate 3

“Either parent . . . may refuse consent . . . either in writing or orally.”

“Any such refusal . . . must be contemporaneously recorded . . . medical record.”
“No [DNR] shall be instituted either orally or in writing if there has been such a refusal of consent”

Refuse consent

No DNR

Kansas is not alone

Simon’s Laws

There is a need for Simon’s Law nationwide. In many hospitals across America it is legal for a child to be denied life-sustaining care and for a ‘do not resuscitate’ order (DNR) to be placed on a child’s medical chart without parental knowledge or consent.

http://www.ipetitions.com/petition/simons-law
Simon’s Law spreading

More Red Light Laws

Your own neighbors

Nondiscrimination in Treatment Act
Nov. 2013

“shall not deny . . . life-preserving health care . . . directed by . . . [surrogate]”

Medical Treatment Laws Information Act
Nov. 2014
"If surrogate directs [LST] . . . provider . . . not wish to provide . . . shall nonetheless comply . . ."

“Health care . . . may not be . . . denied if . . . directed by . . . surrogate”
Those are legislative red lights
Also judicial red lights

Brett Shively
2yo “drown”
Wichita, 2006

Feb. 1, 2006
TRO forbid brain viability exam
Discharged home March 17

Enough background & context

Assessment

Consult mandate
“shall not be instituted . . . unless . . . one parent . . . has first been informed”

Be overt & open

Already required

Janet Tracey

Jay Wawrzyniak

Successful lawsuits

IIED

NIED

Secretive

Insensitive

Outrageous
Consultation expected
Distress foreseeable

Secret DNR unacceptable
Similarly dishonest
Slow code
Show code

Contrast:
Short code

SB 85 impacts
whether CPR
Not how CPR

There is no consent mandate

Original bill
“No withhold, withdraw . . . without the written permission . . . .”
Prohibits unilateral DNR
No written permission
No DNR
As enacted
“No [DNR] shall be instituted . . . if . . . refusal”

Does not prohibit unilateral DNR
No written permission
DNR okay
No oral permission
DNR okay

“No [DNR] shall be instituted . . . if . . . refusal”

“institute [after] parent informed”
Seek assent Not consent
Open ended question

Announce plan: “We are going to...”
Silence = assent

DNR is default
Parents must affirmatively object

Parents veto
Honor veto

Parents can veto, so what

No unilateral anyway
Consensus anyway
Can replace SDM

No unilateral anyway

Opponent testimony
Karin Porter-Williamson

“It isn’t a problem in Kansas”

Kathleen Davis

“DNAR would not be implemented without parental consent.”

Cave-in

“follow the . . . SDMs instead of doing what they feel is appropriate . . .”

BUT

Some unilateral LST limiting in Kansas

In what circumstances will a neonatologist decide a patient is not a resuscitation candidate?

Peter Daniel Murray,1 Denise Esserman,1 Mark Randolph Mancur2,3


500 / 3000 members
American Academy of Pediatrics Section of Neonatal Perinatal Medicine

Targeted conduct probably **does** really happen

**Usually get consent anyway**

High consensus rate in futility disputes

Surrogate will **not** consent when you think they should

**Appropriate**

**Inappropriate**

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Figure 1. Percentage who answered ‘yes’ to question 2.
1. Is a unilateral Do Not Attempt Resuscitation (DNAR) permissible when survival is unlikely?
2. Is a unilateral DNAR permissible when survival is impossible?
3. Would you actually enter the order in this case?

Figure 2. Percentage who answered ‘yes’ to any of the 8 questions:
1. Is a unilateral Do Not Attempt Resuscitation (DNAR) permissible in cases associated with a poor quality of life?
2. Is a unilateral DNAR permissible in cases where the diagnosis is unknown?
3. Would you enter a unilateral DNAR in this case?
<table>
<thead>
<tr>
<th>Advisable</th>
<th>Inadvisable</th>
<th>Proportionate</th>
<th>Disproportionate</th>
<th>Beneficial</th>
<th>Non-beneficial</th>
</tr>
</thead>
</table>

| Inside the standard of care | Outside the standard of care | Therapeutic obstinacy | Surrogate driven overtreatment |

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Surrogate</th>
<th>Surrogate will not consent to CMO recommendation</th>
<th>95%</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMO</td>
<td>LSMT</td>
<td></td>
<td></td>
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</tbody>
</table>
Prendergast (1998)
57% agree immediately
90% agree within 5 days
96% agree after more meetings


Garros et al. (2003)

Hooser (2006)

5% PLUS Can do even better
Robust evidence shows PDAs are highly effective.

> 130 RCTs

Accurate
Complete
Understandable

Informed surrogates request less aggressive treatment.
Shared Decision Making in ICUs: An American College of Critical Care Medicine and American Thoracic Society Policy Statement

Alexander A. Kuo, MD, FCCM; John F. Davidson, MD, BS, FCCM;
Wynne Marvinon, MD, MBE, FCCM; Adrian Davis, MD

PDA $\rightarrow$ more likely consent

5% $\rightarrow$ 3%

BUT

“Promise remains elusive”

§ 3056

AFFORDABLE CARE ACT

Link liability & reimbursement incentives to certification

CMS

CENTERS FOR MEDICARE & MEDICAID SERVICES

NATIONAL QUALITY FORUM

National Standards for the Certification of Patient Decision Aids

DRAFT REPORT FOR COMMENT

September 22, 2006
Limit on consensus rate

New veto power relevant for only 5% conflicts

BATNA

Best Alternative To a Negotiated Agreement

5% → 8%

Still no consent

Annie Janvier

Recommend CMO to 100%

25% elect LST

Replace Surrogate

Clinician

CMO

Surrogate

LSMT
Get consent from **new** surrogate

"surrogate’s decision . . . almost always accepted"

Parents *presumed* act in best interest

Too **little** medicine

Not best interest

Too **much** medicine

Not best interest

You’re Fired!

More aggressive treatment
COI

Jada Ruiz

Not BI

Tuesday 4/11

Charlie Gard
mitochondrial disease that causes progressive muscle weakness
1. Find parents “unfit”
2. May **new** SDM authorize DNR

Too aggressive

Unfit

Aiden Stein
Guardian cannot w/h w/d until parental rights terminated

New SDM may authorize DNR

Permanent custodian

Even without termination parental rights

Kan. Stat. 38-2272(d)(6)

“all rights”

“court may impose limitation . . . life-pronging treatment”

Temporary custodian

“When a child in the custody of the Secretary . . . requires a Do Not Resuscitate Order . . . and parental rights are not terminated, the parent(s) consent shall be sought.”
“If, after diligent efforts, it is not possible to obtain parental permission, Court consent shall be sought, unless an emergency exists . . .”

SB 85 overbroad

An Official ATS/ACCN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units

Gabriel T. Breese, Theodore M. Piper, Cooch D. Robertson, Bernard L. Robert C. Trang, Cynthia A. Rahn, O

Futile
Legally Proscribed
Legally Discretionary
Potentially inappropriate
Futile interventions cannot accomplish physiological goals.

Scientific impossibility

Example 1

Example 2

Antifungals as treatment for myocardial infarction.
Example 3

CPR when show rigor mortis or dependent lividity

Example 4

“Futile”

Value free objective

May & should refuse

Even EMS protocols for “futility”
BUT not excepted by SB 85

Potentially Inappropriate

Some chance of accomplishing the effect sought by the patient or surrogate

Not “futile” because might “work”

E.g. dialysis for permanently unconscious patient

E.g. vent for patient w/ widely metastatic cancer

We call them “futility disputes”

Disputed treatment might keep patient alive.

But . . . is that chance or that outcome worthwhile
Not a medical judgment

Value judgment

SB 85 rightly targets PIT

But wrongly also targets “futile”

Original bill

“No shall not apply” if “futile because . . . withholding not cause or hasten death”

No such exception in as enacted

Parents veto CPR even if “futile”

Thank you
Since July 2007, I have been blogging, almost daily, to medicalfutility.blogspot.com.

This blog reports and discusses legislative, judicial, regulatory, medical, and other developments concerning end-of-life medical treatment conflicts. The blog has received over two million direct visits. Plus, it is distributed through RSS, email, Twitter, and re-publishers like Westlaw, Bioethics.net, Wellsphere, and Medpedia.

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