Decision Making for Unrepresented and Incapacitated Patients

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The Challenge
- How should medical decisions be made ETHICALLY for incapacitated patients without surrogate decision-makers and/or advance directives?

Who are these Patients?
- Those who are decisionally incapacitated and alone and lack valid advance directives:
  - Some who have never had capacity
  - No family, lost contact with friends, outlived or abandoned by family
  - “Loners” who have never been connected
  - Those whose family/friends refuse to act as surrogates
  - Not publicly or privately conserved
  - The mentally ill
  - The elderly who are alone

The problem population is likely to increase
- Aging population increasing –
  - Aging alone, in SNFs, &/or losing capacity
- Mobile population – no family
- Mentally ill – increasing
  - Only 1/3 treated
  - 23% of homeless are severely mentally ill

Samples of Health Care Decisions for Unbefriended Patients
- Routine (non invasive, eg x-rays)
- Major Medical (invasive, pain eg amputation)
- Emergency
- To SNF?
  - From home, From acute care hospital
- End of life decisions
  - DNAR
  - Feeding tube
  - Dialysis
  - Withhold/withdraw (medically ineffective intervention)

Evolving Medical context
- Increased ability to treat acute illness
- Increased ability to prolong “life” without restoring health or quality
- No effective intervention for cognitive decline
- Increased awareness of importance of cultural issues vs. autonomy
- Has intervention become the “default” for all patients without AHCD or POLST?
THE PROBLEMS – decisions for unbefriended
- Decisions are made “ad hoc”
- Decisions are inconsistent
- Decisions may not be “in best interests”
- Some informal studies estimate 4% of SNF patients are unbefriended
- Hastings Center estimates up to 30% of facility residents are isolated and unbefriended

SARA
- 88 yr old woman presents by ambulance from nursing home to ER with pneumonia requiring mechanical ventilation.
- She had been released from another hospital 4 weeks ago for septic shock 2°to recurrent UTI.

Past Medical & Social History
- Diabetes
- Dementia
- Recurrent aspiration pneumonia and UTIs
- 6 year resident of a nursing home
- Completely dependent for all her care
- No known family
- No visitors for over 3 years
- No conservator

ICU Course
- Over the next 3 days, the patient’s pneumonia and oxygenation improve.
- The ICU team would like to extubate, but they prefer a DNR/DNI status as her chance of re-intubation is significant.

Decisions?
- Who is the decision-maker for Sara?
- What is in Sara’s best interest?
- What is the ethically appropriate course of action?

Possible Solutions
- Santa Clara County Medical Association Model Policy
- Other Policies to consider
  - CHA
  - CCRMC
  - Ohio: University Hospital & Case Western views
- Other approaches:
  - Physician decision without institutional or judicial review
  - Single person with statutory authority
- Other alternatives?
Early 2000 at SCCMA BEC

- Several cases reported – key ethical issue
  - Who SHOULD make health care decisions for unbefriended, incapacitated patients?
- New HC decisions law - but
  - Omitted section on decisions for this group

Alternatives reviewed by Santa Clara County

- Conservatorship by the Public Guardian
  - Time-consuming – six weeks?
  - Cumbersome
  - Under-funded and under-staffed
- Court Order (PC 3200)
  - Seek order authorizing particular treatment
  - Can be used for DNR, withhold & withdraw treatment
  - Can be used to appoint surrogate decision-maker
- Find something better?

Santa Clara County process

- Consult with drafter of new HC Decisions law
- Discuss “bottom up” vs “top down”
- Assemble a task force which
  - Recruited stake-holders
- GOAL: Develop a model protocol for Health Care Decisions for “Unbefriended” / Incapacitated Patients Without Surrogates
- Nearly two years of discussions, meeting, research, writing – model policy

SCCMA Model Protocol

- GOAL: treatment decisions by a method which serves to:
  - Avoid conservatorship or court order;
  - Allow decisions to be made more quickly;
  - Avoid “ad hoc” and inconsistent decisions.

Policy Goals

1. “To make and effect health care decisions in accordance with a patient’s best interest, taking into consideration the patient’s personal values and wishes to the extent that these are known.
2. To establish uniform procedures to make and implement appropriate health care decisions for unrepresented patients . . . [including] both the provision of needed and wanted medical treatment and the avoidance of medically ineffective interventions or excessively burdensome treatment.”

(SMC Draft based on SCCMA Model Policy)

Policy only affects . . .

- patients who:
  - Lack health care decision making capacity as determined by primary physician
  - AND
  - Lack an available, appropriate, and willing surrogate decision-maker and/or lack a written health care instruction
- Despite the lack of decisional capacity, such patients are entitled to have appropriate medical decisions made on their behalf.
Definition of Capacity

- Health care decision making capacity = “. . . a person’s ability to understand the nature and consequences of a decision and to make and communicate a decision and includes in the case of proposed health care, the ability to understand its significant benefits, risks, and alternatives” (CA Probate Code §4609)

Decisions for those who lack capacity . . .

- are made in their best interest,
- respecting their wishes and values as best as they can be determined.

Lacking a Surrogate

- No agent, conservator, or guardian has been assigned
- No dispositive health care directive is available
- No appropriate surrogate decision maker is available or identifiable
  - Extensive efforts must be made by a social worker to identify, locate, and contact appropriate potential surrogates

Policy does not apply . . .

- in emergency medical situations;
- when a physician makes a bedside decision to cease attempts at resuscitation;
- to patients less than 18 years old.

Other Limits

- Legal counsel must be consulted if:
  - injury appears to be result of a criminal act;
  - condition was aggravated or caused by medical error;
  - the patient is pregnant; or,
  - the patient is a parent with sole custody or responsibility for the support of a minor child
- If the Public Guardian has been appointed, he/she must be involved in medical decision making.

Procedure

- Begin with an ethics consult to ensure there is an ethical dilemma and to provide advice re medical decision-making
  - Members w/ conflict of interest excused
  - Ethics committee => advisory
- Medical team obtains a second opinion about the decision from a physician with relevant qualifications
Procedure

- For medical decisions re withholding or withdrawing life-sustaining interventions:
  - Medical team must get a second opinion
- For all: the Chair of the ethics committee will appoint a subcommittee (of the ethics committee)
- **to act as the surrogate decision maker**

The Subcommittee as surrogate

- Multidisciplinary team, including one “non-medical” member of the ethics committee
  - Physician, social worker, chaplain, (ethics consultant), community member
- Will act as patient advocate
- Will consider patient values and cultural, ethnic, or religious perspectives, if known
- Will take the patient’s perspective
- Will decide based on patient’s best interest

Subcommittee Action

- Interview medical team and anyone else closely involved with the patient
- Inquire re
  - Medical evaluation(s)
  - The process to determine lack of decisional capacity
  - Attempts to learn medical preferences of the patient
  - Attempts to discern patient values
  - Attempts to find a surrogate
- Discuss basis for recommended procedure (including withhold/withdraw)

Decision making

- If the subcommittee agrees re the proposed decision, then that decision can be implemented by the primary treating physician.
- If the subcommittee cannot reach a decision or if it disagrees with the action proposed by the medical team, the Chief of Staff will assist in resolving any disagreements.
- Irresolvable conflicts can be referred to the court.
- Implementation of a decision to withhold or withdraw life-sustaining intervention is the responsibility of the primary treating physician.

Record Keeping & procedures

- Medical progress notes include references to all of the steps followed
- Emphasis on attempts to locate surrogate decision-maker –
  - **VALIDATES the important role of social workers to search for a potential surrogate**

ADVANTAGES

- Treat patients with dignity and respect
- Makes decisions based on patient best interests
- Avoids ad-hoc decisions
- Empowers staff to search for informal surrogate
- Avoids over/undertreatment
Points of concern

- Ethics Committees are only “advisory”
- Conflicts of interest –
- Liability?
  - Negated because this is “POLICY”
- Education of staff

FIRST USE – “GEORGE” - 2003

- Dx: Aortic aneurysm – non-emergent surgery proposed
- Schizophrenic & non-compliant
- Sister refused to act as surrogate; no AHCD or other document
- Psychiatric review found he had insufficient capacity to decide
- “Policy” recommended by BEC but approval pending for adoption by hospital

Court ordered medical tx for Adult without capacity or requires:

1. Describe condition.
2. Rx. Medically appropriate tx.
3. Threat to health of patient if denied
4. Probable outcome
5. Medically available alternatives
6. Efforts made to obtain pt. consent
7. Name of person at hospital who will give consent
8. Patient’s mental function deficits PLUS link to pt’s inability to respond.
7. Names of those who must get notice.

Use Probate Code Section 3204

- Petition [Request to court] to appoint a surrogate to decide
- Petition attached copy of Policy to describe surrogate selection
- Court’s Order approved policy as method to select the surrogate for use in this case….

Court Order -

- Petition granted in Santa Clara County Superior Court
- Subcommittee assembled per policy
- Subcommittee acted as surrogate

Decision for George?

- History of non-compliance and failure to follow medical advice
- He vigorously declined surgery
- Sister still refused to participate
- Decision?
  - No surgery
  - Result: 1 year later George still living
SCCMA Decision to recommend policy

- Approved by SCCMA BEC
- Referred to Executive Committee which approved recommendation to all member acute care facilities
  - "Preamble" and model protocol/policy sent to all
- Adopted by seven hospitals
- 1 year later – discussion of results led to determination by BEC:
  - This protocol is “standard of care” in SCC

Other California proposals

- CHA Model Policy for Acute Care hospitals:
  - Assembles multi-disciplinary team to evaluate
  - If all agree re treatment, it is provided
  - If all agree to w/h or w/d – implementation by primary MD
  - If disagree, use ethics procedure to facilitate resolution
  - If agreement, decision is final
  - If disagreement, current interventions continued
- CCRMC: Clinical guidelines not protocol
  - Similar pattern to SCCMA – use of subcommittee
  - Provides support for primary physician decision
  - Includes someone from PGO on subcommittee