Surrogate Health Care Decision-Making for Unbefriended Patients: “Attention Must Be Paid”

Erica Wood
American Bar Association
Commission on Law and Aging
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Incapacitated and Alone:
Health Care Decision-Making for the Unbefriended Elderly
Naomi Kary and Erica Wood

American Bar Association
Commission on Law and Aging
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“He's a human being, and a terrible thing is happening to him. So attention must be paid. He's not to be allowed to fall in his grave like an old dog. Attention, attention must finally be paid to such a person.”

Arthur Miller

Death of a Salesman

Raising Legal Consciousness About Unbefriended Patients- Overview

- Surrogates
  - WHO: circles of decision-makers
  - Trends in decision-making
  - WHAT: kinds of decisions
  - HOW: Decision-making standards

- Patients with NO Surrogates
  - Define & describe unbefriended population
  - Clinician role in decision-making; what is “best interest”? 
  - Three narrowing questions
Surrogates

- Surrogate –
  - Designated to act for another
  - Step into the shoes of another

Circles of Decision-Makers

- Person
- Decision-making support
- Others chosen by person
- Families decide
- Courts decide
Kinds of Decision-Makers

- **WHO: Decision-makers**
  - Individual with capacity to give informed consent
  - Individual with support for capacity
  - Agent under advance directive
  - Surrogate under default consent laws in 44 states
    - Family
    - Close friend
  - Guardian

TRENDS: Where are We Headed with Surrogate Decision-Making

- Rising need for surrogates
  - Demographics
  - 2014 JAMA study – surrogates involved for nearly half of hospitalized older adults
- Emergence of “supported decision-making”
  - Growing recognition of concept
  - “What would it take” to enable a decision?
- Most people still don’t do advance care planning
  - Between 18 & 30% Americans
  - Majority of surrogate decisions made by family, friends
WHAT: Kinds of Health Care Decisions

- Emergency
- Routine
- Major Medical
- End of Life

How: Decision-Making Standards

- Decision by self or explicit directions by self or by self with support
- Substituted judgment
- Best interest
- “Substituted interests & “Best judgments”
“Unbefriended” Population

- No decisional capacity to give informed consent
- No advance directive
- No capacity to execute advance directive
- No guardian
- No family or friends
- Fall through societal cracks
Unbefriended Population

- Increasing numbers
  - JAGS 1989 = 45% incapacitated patients next of kin could not be reached.
  - 2003 ABA study = 3-4% nursing home population
  - 2006 study = 16% of those admitted to ICU.
  - 2007 JAGS = 5.5% deaths in ICU.
  - Your experience???
- Generally in hospitals & nursing homes
- Socially isolated. Societal loners
- Multiple chronic conditions
- In need of decisions about major medical or end of life treatment

Clinician Role in Decision-Making

- New York law sets out physician role in making decisions for unfriended
  - Physician as surrogate
  - Safeguards re conflicts & personal bias
  - Concurring opinions & consultation
  - Best interest standard – “attention paid”
Narrowing the Scope

- Is it an emergency?

- Is patient really incapacitated?
  - *Stretch* capacity with support
  - *Wait* while capacity fluctuates or reversible conditions clear

- Is the patient really alone?

- Is there really no evidence?

Part II – 12:15 pm

National Efforts to Protect Unbefriended Patients
What Solutions Exist Across the States?  
- Overview of Toolbox

- Default consent statutes (FHCDA in New York)
- Judicial authorization for treatment
- Temporary medical treatment guardian
- Public guardianship
- Surrogate decision-making committees (Article 80 in New York)
- Institutional practice; ethics committees
Of the 44 states with default surrogate consent laws, some 14 have provisions for unbefriended patients – generally following “close friend” provisions usually involve role for attending physician provisions often require consultation or concurring opinions as safeguard frequently role for ethics committee limitations on types of decisions NY law one of only with “tiered process” pros & cons of physicians deciding

States Using Default Surrogate Consent Statutes for Unbefriended Patients

(AL, AZ, AR, CT, FL, IN, MS, NH, NY, NC, OR, TN, TX, and WV)
Court Decides or Appoints

- Judicial authorization statutes
  - Judicial stamp of approval
  - For example, Virginia, Florida; Georgia for placement
  - Judges at bedside
- Temporary medical treatment guardians
  - Trained volunteers – Colorado; Indiana; VoA Minnesota
  - Temporary medical treatment guardian model act
- Public guardianship
  - All states – some provision for guardian of last resort
  - About 30 states explicit, funded statutory programs
  - Vastly understaffed, underfunded
  - Delay & cost obstacles for use re immediate treatment decisions

Institutional Practice; Ethics Committees

- Role of ethics committee as consultative vs decision-making
- Statutes calling for physician in consultation with ethics committee
- Santa Clara County CA Medical Association model policies for facilities
- Veterans Health Administration model
  - Attending physician + service chief for major medical
  - Multiple layers of recommendation & review for withholding/withdrawing life sustaining treatment – includes multidisciplinary committee appointed by facility director
New York, Texas & Iowa have statutory systems of external surrogate decision-making committees

**New York Article 80** of Mental Hygiene Law
- Surrogate Decision-Making Committees
- Trained volunteers (clinician, family/advocate, attorney, other with expertise). Sit in panels of four.
- Developmental disabilities population
- Major medical decisions – and certain life-sustaining treatment decisions with safeguards

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**Hallmarks of Well-Designed System**
- Focus on patient
- Independence & freedom from conflicts of interest
- Continuity of care
- Applicability to full range of decisions
- Emphasis on least restrictive alternative
- Promptness
- Cost-effectiveness
- Accountability
- Expertise
- Credibility