Ensuring Informed Consent:
Decisional Capacity and Surrogate Decision Making

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Objectives

- Describe the three tasks a patient must be able to do to be considered “decisional”
- Determine if an Advance Healthcare Directive is (AHCD) is valid
- Describe 1 instance when the agent can NOT be used
- Describe at least one way to determine the appropriate surrogate decision maker in the absence of an AHCD
- Identify the two signatures required for a POLST form to be valid
What is Informed Consent?

- It is a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention.
- It is NOT simply getting a patient to sign a written consent form.
Elements of Informed Consent

- The patient's diagnosis
- The nature and purpose of a proposed treatment or procedure (or service)
- The risks and benefits of a proposed treatment or procedure (or service)
- Alternatives including risks and benefits; regardless of their cost or the extent to which the treatment options are covered by health insurance
- The risks and benefits of not receiving or undergoing a treatment or procedure
Informed Consent in Hospice Care

- Diagnosis
- Prognosis for eligibility
- Palliative versus aggressive
- Discuss alternatives with physician?
- In light of your (disease) hospice would....
Why Get Informed Consent?

- To honor patients rights
- To avoid criminal and civil charges of:
  - Battery
  - Professional negligence (malpractice)
Definition of Battery

- Intentional touching of a person in a harmful or offensive manner without consent

- A claim of battery can be made against a healthcare provider who performs a medical procedure on a patient without consent
A physician (or healthcare provider) who fails to adequately disclose the nature of the procedure and its risks and alternatives may be liable for negligence (malpractice)
A medical emergency exists when:

- Immediate diagnosis and treatment of unforeseeable medical conditions are required, if such conditions would lead to serious disability or death if not immediately diagnosed and treated.
- Immediate services are required for the alleviation of severe pain.
Who Gives Informed Consent?

- Adult with decisional capacity
- Legal decision maker
“Adult” Means:

- Reached age 18
- Minor who has entered into a valid marriage (whether or not the marriage has been terminated)
- On active duty in armed forces of the USA
- Minor who has been declared emancipated by a court
“Capacity” Requires Three Things: #1

The person has the ability to do the following:

- Receive and understand information including:
  - Nature and seriousness of their illness
  - Nature of the medical treatment being recommended
  - Nature and consequences of the decision
“Capacity” Requires Three Things: #2

The person has the ability to do the following:

- Participate in the treatment decision by means of rational thought process
- Weigh risks and benefits of the intervention and any alternatives
- Evaluate, deliberate, and mentally manipulate information
Case of Carrie versus Case of Ruth

Carrie
- 54 y.o. Caucasian female
- Educated
- Breast cancer
- Married w/ teen son
- Aggressive path

Ruth
- 86 y.o. Caucasian Female
- Minimally educated
- Colon cancer
- Widowed, deceased son
  living daughter
- Palliative path
“Capacity” Requires Three Things: #3

The person has the ability to do the following:

- Ability to communicate a treatment preference
Assumptions re: Capacity

- It may be assumed that a patient presenting themselves for treatment has the capacity to make healthcare decisions unless there is evidence to the contrary.
- An adult with capacity has the right to make his/her own decisions re: healthcare including the right to treatment or to forego treatment.
Look for 3 things:

- Understanding
- Logic
- Consistency
Understanding

Understand the information about:

- Risks
- Benefits
- Alternatives of what is being proposed
Logic

- Question: Is the logic the patient uses to arrive at the decision “not-irrational?"
- Goal: patient’s values are speaking, rather than an underlying mental or physical illness
- Severe depression or hopelessness will make it difficult to interpret decisionality; consult with Attending Physician or Clinical Director
If a reasonable amount of time passes and I fail to ask for at least one of the following:

- Bloody Mary
  - Margarita
- Scotch and Soda
  - Martini
  - Steak
  - Crab Legs
- The Remote Control
  - Bowl of Ice Cream
  - The Sports Page
  - Chocolate

then.....
...it should be presumed that I won’t ever get better.

When such a determination is reached, I hereby instruct my appointed person and attending physicians to pull the plug, reel in the tubes and call it a day.
Consistency

- Is the patient able to make a decision with some consistency?
- Is the decision consistent with the patient’s values?
- If there is a change in the patient values, can the patient explain the change?
38 year old Caucasian woman
In ER as victim of domestic violence
Refuses to cooperate with law enforcement
Refuses domestic violence shelter/counseling
Believes she must remain in her marriage:
  ◦ Covenant to remain married
  ◦ Role model to her children re: maintaining commitments
Case of Jim

- 76 year old African American male
- Cancer with mets to multiple locations
- Wants aggressive care despite oncologist recommendation of hospice care

- Stopping chemo = giving up/not trying
- Stopping Chemo = suicide
- Suicide/not using tools God has provided= sin
Decision Making Capacity is Contingent

- Task specific
- Time specific
Some Decisions are Easy...
Some Decisions Are Not So Easy...
Deciding if the patient has decisional capacity means weighing the degree to which the patient has decision making capacity against the objective risks and benefits to the patient.

This sliding scale view of decisional capacity holds that it is proper to require a higher level of certainty when the decision poses great harm.
Sliding Scale re: Capacity

**Elizabeth**
- 87 y.o. Asian female
- Dementia
- Marginal capacity
- UTI
- Antibiotics?

**Robert**
- 23 y.o. Hispanic male
- Treatable cancer
- Choosing hospice
Time Specific

- When encephalopathic, a patient may not be decisional; after treatment, decisionality may be regained.

- Being asleep at the moment does not imply lack of capacity.
Case of Bob

- 66 y.o. Caucasian male
- Lung Cancer
- Memory impairment
- Lives alone in senior apartment complex
- Smoking
- Oxygen in use
Legal Decision Makers

- Advance Healthcare Directive agent
- Surrogate decision maker
- Parent/Guardian
What an Advance Directive Does

- Communicates broad wishes in advance
- Names an agent/decision maker
- Gives post-death instruction and authority
Who Can Create One?

- Adult
- Decisional Capacity
Criteria for Legal AHCD

- Signed by patient
- Dated
- Names an agent
- Witnessed by notary or 2 people who are not:
  - The patient
  - The agent/alternate agent
  - Patient’s healthcare provider
- 1 witness not related by blood, marriage, adoption
- Ombudsman for Skilled Nursing Facilities
Role of Agent

- Make decisions according to patient’s known or expressed wishes
- Make decisions re: disposition of remains including organ donation
- Decisions re: restricting visitors can only be done:
  - If the patient did not want the person to visit
  - If the person’s visits cause significant (obvious) distress
Authority becomes effective only when patient can no longer make his/her own decisions unless form specifies otherwise.
Case of Chan

- 67 y.o. Cambodian woman
- Monolingual Cambodian speaking
- Son states he makes decisions for patient
  - Declines for hospice staff to talk with patient re: hospice
  - States patient would not want to know
  - States he will translate
Limitations to Agent’s Authority

- Agent has the authority to make all healthcare decisions for patient that he/she would, if patient was able except:
  - As stated in the Advance Directive
  - Sterilization
  - Abortion
  - Involuntary psychiatric hospitalization
  - Convulsive treatment
  - Psychosurgery
Healthcare Provider’s Role

Do:

- Honor AHCD you believe to be real
- Encourage all competent adult patients to complete an Advance Directive
- Keep a copy in their medical record
- Accept a verbal Advance Directive/change to Advance Directive
- Give agent the same rights as you would the patient
Healthcare Provider’s Role

Don’t:

- Be the agent
- Witness the Advance Directive
- Allow agent to transfer their authority
Assembly Bill 891, effective July 1, 2000

- Protects healthcare providers and institutions
- Creates penalty for a healthcare institution or provider that intentionally violates an Advance Directive
Declining to Comply With an AHCD

- Healthcare institution may decline to comply with a healthcare decision if instructions/wishes:
  - Contrary to generally accepted healthcare standards
  - Require medically ineffective healthcare
  - Contrary to the policy of the institution (based on reasons of conscience)
    - Provided this policy is communicated to the patient/decision maker timely
    - Make effort to transfer patient
    - Provide care until transfer
Additional Info

- Former spouse named as agent
- AHCD no longer expires unless specifically stated by patient
- Verbal statement to healthcare provider is an Advance Directive
- If more than one document, the most recent document is used
- A copy is as valid as the original
- Agent cannot transfer their authority
When the Agent is Not Available

- Lack of availability is relative to the urgency of the decision being made
- There are few situations when the hospice cannot wait for the agent to become available
Case of Betty

- 99 y.o. caucasian female
- Dx: CHF
- Lacks capacity
- AHCD in place:
  - Agent: daughter Betty Anne (local)
  - 1st Alternate: son Pete (4 hours away, serious illness)
  - 2nd Alternate: daughter’s husband John (present)
What if There is No AHCD

- Conservator
- Closest available relative. Person who:
  - Most familiar with patient values
  - Demonstrates concern for patient
  - Had regular contact before illness
  - Available to visit and make decisions
  - Ability to understand the information
- Agreement with physician recommendation is not proper criterion
What if There is No AHCD

- Closest available relative
  - Spouse/domestic partner
  - Adult child
  - Either parent
  - Adult sibling
  - Grandparent
  - Adult aunt/uncle
  - Adult niece/nephew
Case of Michael

- 54 y.o. Hispanic male
- Dx: End Stage Renal Disease
- Lacks capacity
- No AHCD
- 4 adult sons:
  - 1 son with whom patient lives
  - 2 live 1 hour away
  - 1 out of state, just arrived
Case of Elizabeth

- 66 y.o. African American female
- Dx: Breast cancer with brain mets
- Lacks decisional capacity
- No AHCD
- Two daughter share caregiving:
  - Patient lives ½ with Marta, ½ with Elizabeth
What is POLST?

- Physician Orders for Life Sustaining Treatment
- A physician order recognized throughout the medical system
- A portable document that transfers with the patient
- Brightly colored, standardized form for entire state of California
Assembly Bill No. 3000

CHAPTER 266

An act to amend Sections 4780, 4782, 4783, 4784, and 4785 of, to amend the heading of Part 4 (commencing with Section 4780) of Division 4.7 of, and to add Sections 4781.2, 4781.4, and 4781.5 to, the Probate Code, relating to health care decisions.

[Approved by Governor August 4, 2008. Filed with Secretary of State August 4, 2008.]

LEGISLATIVE COUNSEL’S DIGEST


Effective January 1, 2009
Who is POLST Intended For?

- Chronic, progressive illness
- Serious health condition
  - ICU stay
  - Age and/or diagnosis
  - Medically frail
- Tool for determination
  - “You wouldn’t be surprised if this patient died or needed ambulance within the next year”
Who Can Help Complete POLST?

- Healthcare providers – “licensed, certified, or otherwise authorized to provide healthcare in the normal course of business.”
  - Best practice suggests use of those trained in the POLST conversation:
    - Physicians
    - Nurses
    - Social Workers/Social Service Designees (SNFs)
    - Chaplains
Criteria for Actionable POLST

- Signed by patient/decision maker
- Signed by physician
  - Not RNP/PA
- Any area not check is automatically full treatment for that area
Can POLST be Changed?

- Individual with capacity can request alternative treatment or revoke a POLST at anytime
- Legally recognized decision maker may request change based on condition change or new information regarding patient wishes
Where Should We Keep POLST?

- Copy in the patient’s chart
- Original with the patient at home:
  - Post in easy-to-find location (with AHCD)
  - Give to EMS to transport with patient
POLST: Depth of the Process

- POLST is more than a form
- POLST:
  - Facilitates rich conversations with patients/families
  - Complements the AHCD
  - Incorporates the depth of comfort care
## POLST vs. AHCD

### POLST
- For seriously ill/frail, at any age
- Specific orders for *current* treatment
- Can be signed by decision maker

### AHCD
- For anyone 18 and older
- General instructions for *future* treatment
- Appoints decision maker
If The Patient is a Minor:

- It is the parent who must give informed consent.
- The parent may choose to not inform the child about the nature of their illness and terminality.
- While this should be discouraged, it is the parent’s right and the hospice should honor this.
Parents are married:

- If both parents want the service, only one needs to sign
- If there is disagreement between the parents, services should not begin until both parents agree
Children of Minor Parents

- Parent gives consent regardless of parental age
- Parent must demonstrate ability to give informed consent by understanding:
  - Nature of the treatment
  - Risks and benefits
  - Alternatives to treatment
- Best practice: have signature of a responsible adult on consent form for billing purposes
When Patient Is A Minor: Special Circumstances

- Parents are divorced
- Parents are domestic partners
- A step-parent wants to be the decision maker
- Minors without biological or adopted parents
- Minors who are wards or dependents of the court system
In Conclusion

- Informed consent is a communication process
- Ethical obligation and legal requirement in 50 states
- Patient autonomy is the overarching ethical consideration that forms the core of informed consent
- The full disclosure of relevant information to patients is intended to protect each patient’s right to:
  - self-determination
  - bodily integrity
  - to protect his or her voluntariness in the health care decision making process.

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Questions?
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