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Because every encounter between a doctor and a patient has a moral dimension, competency in ethics is essential to being a good doctor.

“Everyday ethics in internal medicine resident clinic: an opportunity to teach”
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RIGHT TO REFUSE TREATMENT/ DUTY TO TREAT/ PROFESSIONAL RESPONSIBILITY/ EXTREMECONDITIONS-Clinicalforum8Ethics

C 10 Decision- Making Capacity

Physicians must respect the informed, autonomous choices of their adult patients regarding their medical care unless the patient lacks decision making capacity. When a patient lacks a ‘surrogate’ should be appointed to assume the decision making power.

Sometimes the principle of patient autonomy, patient’s right to make personal medical decisions conflicts with the principle of beneficence, the physician’s duty to act in their patients’ best interest. It makes sense to raise more questions about a patient’s capacity when his/ her choices are against best medical interest/ or he/ she refuses a beneficial intervention. If the patient has decision making capacity then these choices should be respected.

Capacity to make medical decisions is not a global determination of legal competence/ incompetence which must be determined by a court. Capacity to make medical decisions is specific. Some patients have capacity to make medical decisions but not to make financial decisions.

The author suggests clinical standards to determine patient’s capacity to make medical decisions as: 1- Communication-patient appreciates his/ her ultimate authority to decide, is willing to choose among alternatives and communicates the choice – either verbally, in writing , by blinking or nodding as the medical condition may dictate. 2- Understanding –patient understands pertinent information: the diagnosis and prognosis, the nature of the proposed tests/ treatments and the alternatives, the risks and benefits of those proposed and the alternatives and appreciates the probable consequences of each. 3- Decisions are consistent with the patient’s values and goals. 4- Decisions are not the result of delusions. 5- Patient uses reasoning to make the choice

Mental tests for determining capacity: evaluating orientation (name, place & date) attention span, short term memory, and ability to perform calculations -may be helpful to assess patient’s capacity but direct assessment: understands nature of illness, risks & benefits, alternatives & consequences, is the choice reasonable, does it make sense - is more important.

Consulting psychiatrists to assess medical decision making capacity can be helpful. Some decision making impairments are reversible by treating underlying medical or psychiatric disorders, by adding or discontinuing certain medications.

While many patients with mental conditions can make medical decisions, mental illness ‘may’ impair this capacity. Patients with major depression may fail to appreciate benefits, and patients with schizophrenia may fail to appreciate the relevant information. When mental patients do not

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have the capacity to make medical decisions, an appropriate surrogate should be appointed or court ordered to make these decisions.

Ultimately the attending physician is responsible to judge the patient's health care decision making capacity.

Patient may refuse medical treatment based on religious beliefs. Rational arguments and empirical evidence have little impact on religious beliefs. Unwise medical decisions based on religious beliefs do not render patient legally incompetent or incapacitated to make medical decisions.

During medical emergencies when patient lacks capacity and there is no available surrogate decision maker, physicians should provide emergency care unless it is known that the patient or surrogate would refuse such care. (In LA two physicians must examine patient and agree that patient will suffer serious injury or death without certain emergency medical care.)

For patients lacking decision making capacity- preference is given to the patients preferences if known. It is generally morally unacceptable to force care unwanted by the incapacitated patient. Physicians should make every effort to gain the patient's assent/ cooperation even if the patient cannot give informed consent. Family members/ surrogates might be enlisted to obtain patient's assent/ cooperation.

C 11 Refusal of Treatment by Competent, Informed Patients

A competent, informed adult has the legal right to refuse medical treatment recommended by their physicians including highly beneficial care with few side effects, life support care such as mechanical ventilation, cardio pulmonary resuscitation and Medically administered nutrition & hydration even when the refusal will end life or cause death.

Physicians should attempt to persuade their patients to consent to recommended, beneficial care but must ultimately respect a competent adult patient's informed refusal. While respecting the refusal, physicians need to clarify what exactly a patient is refusing.

The strongest refusals of care are informed, voluntary, clearly articulated, consistent with the patient's values & goals and steadfast over time.

Physicians must respect a patient's informed decision to refuse care even when the decision such as refusal of a blood transfusion during surgery may compromise care or make the patient's care more difficult for the physicians.

For all refusals of recommended care - but especially relating to refusals based on religious beliefs (such as refusal of blood transfusions)- the physician should assure that the refusal is voluntary & not coerced by other members of the religious group by 1- talking with the patient alone when no religious advisors, family or friends are present; 2- asking whether or not the patient would accept court ordered treatment (transfusions); 3-clarifying refusal (whether of all blood products, or only red blood cells), etc ; 4- clarifying that the reason for refusal is religious as stated and not for another reason / fear which physician could address or remove.

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When parents refuse necessary medical care for minor children for any reason including religious beliefs the physician should seek review of these refusals including seeking a court order to provide a child with the necessary medical care.

(In LA, when parents refuse necessary medical care for their minor child based on their religious beliefs, physicians should refer the case to child protection. The courts have independent jurisdiction under child welfare laws to intervene and order necessary medical care for minors. In states that have statutes that allow parents to make medical choices based on religious beliefs that are against best medical interest of their child – these statutes are limited – do not allow child to suffer serious bodily injury or death.)

When patients refuse necessary care such as dialysis or request deactivation of a pacemaker, that may result in their death, the physician needs to assure that such refusals are informed and voluntary.

The right to refuse medical treatment may be restricted in certain circumstances when a patient's refusal of treatment harms other people, such as when a patient has a communicable disease. In some cases such as TB, patients are required to accept treatment or can be quarantined until they no longer pose a risk to others. (LA law provides for direct observation treatment [DOT] of tuberculosis.)

In cases of pregnancy, attempts to force medical treatment upon a pregnant woman for the best interest of the fetus have been generally rejected by the courts as a violation of the woman's bodily integrity and right of self determination.

Physicians should not override the informed decision of a competent adult patient for the benefit of the patient.

C 12 Standards for Decisions When Patients Lack Decision- Making Capacity

Advance Directives are written or oral statements made by competent adults that: 1-direct which interventions they would accept or refuse and/ or 2-appoint proxy decision makers should they lose their capacity to make their own health care decisions.

Author suggests hierarchy of respect for decision making: 1- Advance Directive, objective statements made by patient – what the patient wants. 2- Substituted judgments- proxy decision makers chosen by the patient or surrogates, usually family members, by default when patients have not appointed proxies – who know patient's preferences and are able to interpret the patient's previous statements in light of the patient's present medical situation. 3- Best interest Standard– when patient's preferences are unknown, surrogates/ physicians act in best medical interest of patient.

Advanced directives may be

1- Oral statements

a- .Oral statements to family & friends. Limitations: these statements may relate to care of others but are not intended to direct their own care, statements may be casual & not well thought

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out, a listener may not accurately recall the statement. The author comments on the legal standard, *clear & convincing evidence*, for accepting oral statements to direct care. Trustworthiness of patient's oral statements can be evaluated based on whether preferences were informed, related to specific treatments, and repeated over time. [Also review C 11, supra, ...clearly articulated, consistent with the patient's values & goals and steadfast over time.... as guideposts]

b-Oral statements/ discussions with physicians- Physicians can review patient's directives, explore alternatives and assure these directives are informed.

- 2- Written documents- patient completes a formal written document which directs future care and/ or appoints a health care proxy to direct the care that must be either witnessed or notarized. Courts consider written documents more reliable than oral statements. Courts presume people give more forethought to executing formal documents.
- 3- Living wills- patient directs physicians to withhold/ withdraw life sustaining treatments. Forms are directive specific: ventilators, medically administered food & hydration, etc. DNR- do not resuscitate is usually a separate document for refusing CPR -cardiac pulmonary resuscitation upon cardiac arrest.
- 4- Health Care Proxy/ durable power of attorney- patient appoints another adult person to make health care decisions should become comatose, incompetent or otherwise physically or mentally incapable of communication. (LA- With respect to end of life withdraw/ withhold decisions patient must be a qualified patient- diagnosed by two physicians as having terminal irreversible condition/ profound coma with no reasonable chance of recovery for which life sustaining procedures would only prolong death)

Limitations Advance Directives- Patients are not fully informed. Patients might change their minds. Vague terms such as heroic & extraordinary are difficult to interpret/ carry out. Directives relating to one medical condition are not easily applied to another. Directive does not apply/ cannot be applied to the existing condition. Directive may conflict with patient's best interest. New therapies may have become available. The patient's life situation may have changed enough that past directives seem irrelevant. Author suggests ADs are helpful to encourage beginning of 'end of life care' discussions.

Federal Patient Self Determination Act requires hospitals, nursing homes and HMOs (that participate in Medicare/ Medicaid) to inform patients about rights to ADs at admission/ enrollment and to carry out executed directives. Patients are not required to execute ADs.

Author suggests problems with physician/ patient discussions include vague unexplained language (CPR –DNR- poor quality of life) and they rarely elicit patient's values and goals or reasons for choices.

Author suggests these discussions should begin when patients have serious chronic medical conditions before patients are terminal or in downhill spiral. (Why not encourage conversations with all patients? Life threatening illness or trauma can occur at any time.)

Proxy decision makers should be someone whom patient trusts to exercise good judgment regarding what the patient would want and who would act in patient's best medical interests.

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Physicians (and proxies) need to discuss patient's goals & values, and patient's preferences in specific clinical situations, and interpret vague terms and how patient wants to be treated at end of life.

Physicians (and surrogates) should continue discussions over time, recommend written directives and physicians should document discussions in the medical record.

Substituted judgments are less trustworthy than patient's \written advance directive because: Patients often at best have a general discussion with the surrogate leaving the surrogate to make the decision.

Judgments can be inconsistent- reasonable persons may disagree about what patient would want

Judgments can be inaccurate- proxies confuse what they want with what patient would have wanted

Some considerations are questionable- What importance, if any, should burden on family finances or stress on caregivers play.

Judgments are unavoidably speculative- substitute judgment is inherently less certain than written directives

They may conflict with best interest of patient- (What is physician's role when this occurs- independent fiduciary duty to patient best interest)

Best Interest- When what the patient would have wanted is unknown or at best speculative physicians (and substitute decision makers) should make judgments based on the principle of the objective best interest of the patient (not what the physician or surrogate would want but what is objectively in the best interest of the patient).

The most difficult medical decisions are for patients with no written directive and no substitute decision maker (the homeless without family who are unable to make their own medical decisions. Physicians should consider patient's best interest in consultation with resources including other physicians and the institution's ethics committee.

Overall, physicians (and surrogates) should: 1-encourage patients to think thru, discuss and write down preferences, and 2- guard against withholding beneficial treatments or continuing treatments that patient would not want or which burdens outweigh benefits.

C 13 Surrogate Decision Making

When a patient lacks the capacity to make medical care decisions, physicians turn to surrogates to make decisions on the patient's behalf. The author uses the term health care proxy to denote a person whom patient has formally designated as the decision maker and uses the term surrogate for anyone who makes the decision. The patient can designate a health care proxy while still competent. Written designations are best and avoid any confusion about whom the patient wants to make decisions.

Courts have the legal authority to declare a patient incompetent and to appoint a guardian to make legal decisions. The author suggests the court is not the best place for making health care decisions. A court's formal adversarial approach may polarize parties rather than foster mutually acceptable decisions, delay the process and should be used only as a last resort.

Family members can be good surrogates because they often know what the patient would want

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and are generally presumed to act in the patient's best interest. Sometimes decisions by family members as a group work best. One designated member may be uncomfortable contradicting other members' perspectives. Family members survive the patient and have continuing relationships. Respecting each family member's opinion may facilitate future family harmony. When no family member is available physicians should consult other physicians, the hospital ethics committee and, as a last resort, the courts.

Most states specify which relatives have priority to act.

[LA RS 40:1299.58.5 in part: (a) Any person or persons previously designated by the patient....(b) The judicially appointed tutor or curator of the patient if one has been appointed....(c) The patient's spouse not judicially separated.... (d) An adult child of the patient.... (e) The parents of the patient.... (f) The patient's sibling.... (g) The patient's other ascendants or descendants. If there is more than one person within the above named classes...then the declaration shall be made by all of that class available for consultation upon good faith efforts to secure participation of all of that class.]

When the surrogate's decision conflicts with either the patient's previous known decisions or the patient's best interest- the physician must always serve as the patient's advocate. Surrogates commonly have difficulty making decisions because of emotional stress arising from sadness, denial, and/or guilt. Some surrogates may impose their own values and/or religious views rather than the patient's. And in some cases surrogates have a conflict of interest and promote their own interests such as continuing a pension or welfare check and propose non beneficial care to keep the patient alive. The physician should attempt to resolve family/ surrogate disagreements but is responsible ultimately to act in the best interest of the patient.

To facilitate the surrogate decision making process the physician should discuss with and help the surrogates/ family to understand the patient's medical situation. Physicians should remind surrogates/ family that decisions should be made based on patient's preferences and best interest and should make recommendations based on these preferences and best interests. When conflicts arise, physicians should consult other health care workers and the ethics committee to facilitate these discussions and sort out the best interest