

2012 SAEM Ethics Curriculum

Module 2: Issues Related to Patient Autonomy

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ACGME EM Milestones:

- Prof1 (professional values)
- ICS1 (Patient centered communication)

Review 5.4.12

- 2.1 Informed consent and Refusal**
 - 2.2 Patient decision making capacity
 - 2.3 Treatment of Minors
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2.1 Informed Consent and Informed Refusal

Objectives

1. Define Autonomy
 2. Explain why informed consent is obtained for treatment.
 3. Define the emergency rule. (Do we want to call this the emergency rule or emergency exception)?
 4. Define express and implied consent
 5. Describe the circumstances under which a physician may treat a patient against his or her will.
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Case Study 2.1a: Consent for LP in HIV Patient

A 39-year-old male with HIV presents with a severe headache. The patient has a history of headaches, but this episode is worse than usual. He is afebrile and has a normal, nonfocal neurological exam. The physician feels that a lumbar puncture is indicated.

Case 2.1a: Questions

1. In this case, what must be discussed with the patient in order to obtain his consent?
2. How would this change if the patient was encephalopathic and refusing the lumbar puncture?
3. Why must a physician obtain informed consent for treatment?

4. How do the principles of beneficence and autonomy relate to consent issues?
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Background Information

Autonomy

Autonomy is defined as self-determination and refers to a person's ability to make his or her own decisions, including those affecting medical care. Respect for autonomy requires the recognition of a person's right to make independent choices, and take action based on personal values and beliefs. Informed consent –the process of communication between a patient and physician that results in the patient's authorization to undergo a specific medical intervention --takes into account patient autonomy. Furthermore, informed consent and is a moral and legal obligation of physicians, enumerated in case law in all 50 states. The key elements of informed consent include adequate patient decision making capability, disclosure of information about the proposed treatment and its risks, patient comprehension of the information and the patient's voluntary consent without coercion. In the emergency setting issues of consent frequently arise for procedures, informed refusal of care, treatment of minors, and consent for research protocols.

Obtaining informed consent in the emergency department is challenging for a plethora of reasons. Many ED patients may not be capable of making decisions secondary to their acute life threatening condition, intoxication, language barriers, cognitive limitations, or other impairments. Yet, it is the emergency clinician's responsibility to assure that the patient can meaningfully participate in decision-making. Shared decision making requires that the patient possess correct and complete information, and that the decision promote the patient's goals and life values. When it is not possible to obtain informed consent, implied consent, surrogate consent and emergency treatment may be invoked.

Legal support for informed consent

While informed consent is an ethical imperative, United States' law also requires that a patient provide informed consent for medical treatment, except under unusual circumstances. This legal principle was recognized in 1914 when the New York State Supreme Court held that, "Every person of adult years and sound mind has the right to determine what shall be done with his own body and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages." This landmark case cites the fundamental premise upon which our understanding is based. Any time a health care provider touches a patient; the patient must authorize such action. In the absence of such authorization, the intervention can be actionable in tort as a battery. The imminent threat of such a violation constitutes

assault. This principle gives the patient with decision-making capacity the legal right to refuse medical care.

In addition, lack of informed consent may result in an action for negligence against the health care provider. A failure to disclose potential complications or alternative treatments may constitute negligence if such information would influence the patient to alter his or her decision. This distinction was made in 1972, when the court (unclear from the previous author which court made this distinction) affirmed that performing an unauthorized procedure is battery, but performing an authorized procedure without appropriately disclosing the risks constitutes negligence.

The Emergency Exception

The court has stated that an emergency exception applies when a patient is incapable of providing consent (due to physical or psychological extremis (unconsciousness, sepsis, intubation, traumatic brain injury, etc.) and when harm from a delay to treat is imminent and outweighs any threatened harm by the proposed treatment. When time does not permit informed consent, emergency practitioners operate under the moral imperative of beneficence, acting in the best interests of the patient. Under the "emergency exception," immediate intervention can proceed without informed consent in order to prevent death or serious disability. The emergency exception is based on the presumption that a reasonable person would consent to treatment to preserve life and health if he or she were able.

Courts also have held that in time of life threatening crisis, it is the physician's duty to do that which the occasion demands, even without the consent of the patient. However, it is imperative that the condition of the patient be so severe that definitive care could not be delayed until consent is obtained. Thus, the emergency exception depends upon the patient's inability to provide consent as well as the medical urgency of their circumstances. The urgency of a situation depends primarily upon the consequences to the patient of a delay in rendering treatment, or indeed, the consequences of a failure to render any treatment at all.

Surrogate Consent

When the patient is unable to consent due to physical or psychological distress, the nearest relative or designated surrogate may provide consent. It is assumed that the surrogate decision maker will make decisions based either on the patient's best interests or the patient's previously expressed wishes. . At times, the patient's own surrogate consent may appear in the form of a DNR/DNI form, POLST form, or Living Will.

Implied Consent

"Implied consent" is defined as a logical inference from the conduct of the patient. The individual patient's actions indicate to the health care provider that the

treatment was requested. This is described in the case of O'Brien v. Cunard Steamship Co. (1891). A passenger sued the steamship company for administering an immunization without her consent. The court held that by the plaintiff's act of standing in the line where vaccines were being administered, rolling up her sleeve and submitting to the injection, she provided a consent implied by her actions. The typical prehospital or ED encounter may parallel this situation. The patient or a designee requests help, and care is administered. The patient implies consent as he or she participates in the care, and actively submits to treatment (ex: extending an arm for IV placement). While implied consent may refer to treatments such as the physical exam, blood draw, and most parenteral medications, express consent must be obtained for any intervention with more than remote risks. For express consent, risks and benefits of the intervention must be shared with the patient, and their approval must be obtained.

Refusal of Care

Informed consent requires decision-making capacity. It follows that patients with decision-making capacity have a right *not* to consent to care. The elements of a valid, informed refusal are the same as consent: the patient must have decision making capacity, information including significant risks and magnitude of harm must be provided, the patient must comprehend the information and the refusal must be voluntary without coercion or duress. Because refusal of care may conflict with the judgment and recommendation of the physician, it is prudent for the physician to emphasize the risks presented by refusing care and outline specific consequences to be expected.

2.2 Patient decision making capacity

Objectives

1. Define decision-making capacity
 2. Contrast medical interpretations of decision-making capacity with the legal definition of competence.
 3. List the elements of decision-making capacity.
 4. List the ways decisions can be made when a patient lacks decision-making capacity.
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2.2.a: Case Study: A Homeless Intoxicated Patient Refusing Care:

A 54 year old homeless male is brought to the ED by ambulance. EMS personnel state that he was found down on the sidewalk. The patient is obviously intoxicated and has a hematoma overlying his left temple and forehead. He becomes belligerent and demands to leave the emergency department immediately.

2.2.a: Case Questions:

1. In the case does the patient have adequate decision-making capacity?
 2. What are the key elements to determining decision-making capacity?
 3. How would you assess whether the patient possessed adequate decision-making capacity?
 4. What are alternatives when a patient lacks decision-making capacity?
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Background Information:

When a patient arrives in an emergency department and an evaluation by a physician begins, the physician-patient relationship is established. This relationship carries certain legal and ethical obligations for both parties. The physician assesses the patient and proposes a plan of evaluation or a course of care. Patients have the ultimate authority to accept or refuse this proposal.

The patient's authority is founded on 1) the ethical principle of respect for autonomy, 2) the legal right of self-determination, and is based on the pivotal assumption that the patient is acting in his or her own best interests. The obligation of physicians to protect patients from harm can conflict with the obligation to respect patient autonomy when the patient makes decisions that seem unwise or self-injurious. When this conflict occurs, physicians must assess the patient's ability to make a reasonable decision.

Competence and decision-making capacity are two descriptors commonly utilized to characterize this ability. Though competence and decision-making capacity are often used interchangeably, they are distinct terms. Competence is a legal term that can only be determined by a court. Decision-making capacity is a medical concept that is determined by a health care provider.

The Medical Concept of Decision Making Capacity

All adult patients are assumed to have appropriate decision-making capacity to accept or refuse a plan of evaluation or course of therapy unless there is evidence obtained by history, behavior, or physical examination that would lead the physician to believe that the patient's decision-making capacity has been significantly compromised. Decision-making capacity can be altered or obscured by pathophysiological conditions, such as acute physical or mental illness, traumatic brain injury, severe pain, pain medications, substance use (withdrawal or overdose), and emotional factors, including stress, denial, and suicidal ideation. Decision-making capacity is decision-relative; a patient may have the capacity to make a simple medical decision but not a more complex one. The determination of decision-making capacity requires that the patient:

1. Be able to receive information
2. Be able to process and understand information
3. Have the capacity to deliberate
4. Have ability to articulate and defend choices.

The concept of decision-making is a dynamic one that changes throughout a patient's illness. Decision-making capacity exists along a continuum, referring to the ability of a patient to make a specific decision at a specific time; it is not a global determination. The degree or level of decision-making capacity a patient must exhibit varies with the degree and probability of risk, the degree and probability of benefit, and the patient's decision to consent or refuse.

In a "sliding scale" model of decision-making capacity, as the risks and consequences increase, patients may need to demonstrate higher levels of decisional capacity than under less critical circumstances. This model is calibrated to reflect the risks associated with the patient's choice by increasing the stringency of the capacity standard required. To use it, physicians must navigate between respecting patient autonomy and protecting patients from the possibly mortal consequences of a bad decision. Thus, a patient might need only a low level of decision making capacity to *consent* to a procedure with substantial, highly probable benefits and minimal, low probable risks, but a high level of decision making capacity to *refuse* the same treatment.

Determining Decision-Making Capacity

Determining capacity begins when a physician walks into a room and begins taking a history. Most patients are able to receive and process information in order to cooperate with a history, exam, and treatment plan. If patients cannot, then questions arise about their decision-making capacity. Patients who are intoxicated, delirious or unconscious clearly are not able to make life or death medical decisions. Standard mental status exams may be helpful in determining decision making capacity, but only when patients clearly fail such tests. If a physician believes that a patient does not have sufficient decision-making capacity for a particular decision the physician may need to call upon a third party such as a family member, health-care proxy or psychiatric consultant for assistance. However, when faced with medical emergencies requiring urgent action and decision making, the emergency practitioner does not have the luxury of time to consult psychiatric professionals, an ethics committee, or hospital legal counsel.

The Concept of Legal Competence

In legal terms, “competence” requires mental capacities sufficient to appreciate the nature and consequences of such legal rights or responsibilities as making a will or contract, standing trial, or rearing a child. The degree of understanding required by the law will vary in relation to the task to be performed. The law assumes that adults are competent until proven otherwise in a formal legal decree. Once the person is formally judged incompetent, a guardian, conservator, or Durable Power of Attorney (DPOA) is appointed by the court to make decisions. Depending on the degree of incompetence, a person may be judged incompetent relative to business or financial affairs, yet competent to consent to or refuse medical evaluation or treatment. If a conservator is appointed to make medical decisions on behalf of the patient, then the conservator is the individual who must give consent, not the patient or family members

When a Patient Lacks Decision-Making Capacity

If the physician perceives that a patient does not have medical decision-making capacity to give an informed consent, how should medical decisions be made? The answer to this question depends on the speed with which the decision must be made, and what information about patient preferences is available.

If a decision needs to be made immediately to save a person's life or limb, then legally and ethically, the emergency physician is obligated to provide appropriate care under the Emergency Exception (that is, when the patient's consent is unobtainable). If time permits and there is a legal decree that the patient is incompetent, then the emergency physician should contact the conservator of the patient who would have legal responsibility for medical decision-making. In addition, patients may have a durable power of attorney for health care, living will or previously expressed wishes to family or others, which should be honored (see section on advance directives). When patients previously expressed wishes are known, based on the principle of respect for autonomy, those wishes should generally be honored.

Historically, there was substantial ethical and legal consensus supporting the concept of surrogate decision-making by family members. Surrogate decision-makers may be acceptable in the emergency setting, but the time required to confirm surrogate identity, explain the medical circumstances and prognosis, and assure sound reasoning, may be prohibitive when there is a medical imperative to intervene. When doubt exists, a conservative course (resuscitation/stabilization) is warranted. Consequently, emergency physicians typically “err on the side of life”.

2.3 Treatment of Minors

Objectives:

1. Explain how consent for minors is obtained.
 2. Explain how EMTALA affects care for minors.
 3. Explain how state laws regarding minors and pregnancy, sexually transmitted diseases, substance abuse, and child abuse relate to consent and confidentiality.
 4. Explain the concepts of emancipated minors and mature minors.
 5. Describe situations when a minor can refuse care.
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Case 2.3a: Parent requesting drug testing of a teen:

A sixteen year old is brought to the emergency department by his parents who insist on a drug screen to confirm their suspicions that the teenager is using marijuana. The patient refuses to submit to any exam or provide a urine sample.

Case 2.3a: Questions

1. How should you resolve the above case? Can you treat this teenager against his will?
 2. Describe treatments for which a mature minor may give consent, and treatments for which the mature minor may not give consent.
 3. Can an emancipated minor refuse a life saving blood transfusion on religious grounds?
 4. Do you need to obtain parental consent to treat a 10-year-old trauma patient?
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Background Information:

Respect for autonomy presumes that a person with decision-making capacity has a right to make choices about health care. However, minors are generally presumed not to have decision-making capacity. In general, consent for treatment of minors is obtained from the parent or legal guardian. Ideally, parents will make decisions based on the best interests of their child. Thus, with minors we are more likely to base our actions on the principle of beneficence than on the principle of respect for autonomy. However, as children become old enough to express their wishes and reason for themselves, they are entitled to respect for their preferences. In recent policy statement the American Academy of Pediatrics recommends a three-way interaction in which the physician has a responsibility to address the parent who provides informed permission, but the minor

gives informed assent (as appropriate for their level of maturity). The ethical task is to weigh the preferences of parents and children and solve the conflicts, which may arise.

In the emergency department it is not uncommon for minors to arrive without a parent. Under the federal law Emergency Medical Treatment and Active Labor Act (EMTALA) a medical screening exam must be performed and if an emergency medical condition is found it must be treated. This takes precedent over obtaining parental consent for treatment. Therefore, in most cases, beginning treatment without the consent of parents is legally mandated. Once an emergency medical condition is ruled out, however, consent needs to be obtained.

In many states, laws permit minors to function as adults when they seek health care regarding substance use, pregnancy, sexually transmitted diseases (including HIV), and abortion, as well as child abuse/neglect. Physicians must know the requirements of the law in the state in which they practice. In addition, many states by statute or common law allow emancipated minors or mature minors to consent for their own medical care.

Emancipated minors are usually defined as minors who live independently of parents or guardians, minors who are married, are or have been pregnant, or who are in the armed forces. The mature minor is a young person who the physician believes possesses the requisite decision-making capacity and demonstrates understanding of the nature of treatment. Under most circumstances the mature minor can consent to or refuse treatment that is of low risk and to the minor's benefit. A mature minor is generally 14-15 years or older and is mature enough to understand the risks and benefits of the proposed treatment plan.

Like adult patients, minors have a right to privacy and respect for confidentiality. Ethical dilemmas may arise when a minor is accompanied by a parent who demands to know the nature of the condition or treatment which involves one of the exceptions for which a minor can give consent (pregnancy, child abuse, etc.) and the minor refuses to provide that information to the parent. The physician may feel conflicted when she or he believes that involving the parent is in the child's best interests. However, in general, the wishes of the minor patient should be respected when the minor is allowed by law or ethics to consent. In addition, older minors have a right to privacy and sensitive information should generally not be shared with parents or others without first discussing disclosure with the minor.

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