Medical Law and Ethics
Handout 2.0
Patient Rights and Responsibilities

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In the previous handout (Handout 1.9) we looked at the rights and responsibilities that physicians and other healthcare professionals had for their patients. As we had read, physicians and other healthcare professionals handle a variety of issues such as treating indigent patients and those who have HIV/AIDS. However, in all cases physicians must provide a professional standard level of care to all of the patients whom they are treating.

To finish up this chapter we will look at the different rights and responsibilities that patients have during the course of their medical care and treatment. We covered many of these points earlier on:

- Patients have the right to provide their approval and give consent for any medical treatment or procedure
- Patients have the right to be fully informed on the advantages and risks of treatment; as a result, they have the right to move forward or decline the proposed treatment
- Patients have the right to privacy (only authorized individuals have access to their protected health information and be present during medical procedures)

Another point that we will discuss in this handout (and thus, expand on point #2 above) is that patients have the right to express their wishes to withhold life-sustaining treatments.

Physicians and healthcare professionals should also understand the background of certain patients in regards to medical treatment. Individuals who come from certain cultural or religious groups may decline certain treatments or procedures (e.g. blood transfusions). In these cases, physicians may not coerce or treat them without their consent.

In this handout we will examine how patients play a key part in managing the affairs of their medical care. A couple of topics in this handout will include organ donation,

medical care as it relates to minors, and the elements of advance directives (legal documentation such as living wills) as it pertains to healthcare.

Confidentiality

As we had discussed in previous handouts, it is important for physicians and other healthcare professionals to maintain the confidentiality of their patients' records.

Privileged communication is confidential information that patients disclose to professionals such as physicians or attorneys during their established, protected relationship. If the patient discusses this information with a third party, the privilege is invalidated (i.e. the right is waived).

The physician-patient relationship and attorney-client privilege are important foundations as patients/clients disclose sensitive information keeping in mind that these professionals whom they entrusted with this information won't be coerced into disclosing this protected information in court.

In addition, many states provide patients with a bill of rights which have detailed explanations on the legal rights afforded to them in regards to their medical care. I have included an example that you can read. [**Please see New York State's Patients' Bill of Rights**: New York Public Health Law (PHL) 2803 (1)(g) Patient's Rights, 10NYCRR, 405.7,405.7(a)(1),405.7(c)]

Advance Directives

The United States Congress passed the **Patient Self-Determination Act (PSDA)** in 1990. This act is an amendment to the Omnibus Budget Reconciliation Act of 1990 (**Section 4206:** Medicare Provider Agreements Assuring the Implementation of a Patient's Right to Participate in and Direct Health Care Decisions Affecting the Patient and **Section 4751:** Requirements for Advanced Directives under State Plans for Medical Assistance).

PSDA mandates that healthcare facilities inform, discuss, and educate patients regarding their rights with respect to making healthcare related decisions. The healthcare facility will provide the patient with written information regarding his/her medical decision making rights, discuss the healthcare facility's policies on these rights (as well as rights on advance directives), and provide guidance on advance directives.

When healthcare facilities provide guidance on advance directives, healthcare professionals cover points such as the following:

- Checking whether the individual has an advance directive or not
- Explaining the healthcare facility's policies on advance directives to the patient
- Requesting that the patient provide the advance directive to the healthcare facility (if he or she has one)
- Ensuring that the wishes listed in the advance directives are implemented
- Providing education to the facility's staff and the community on issues pertaining to advance directives

The points listed above are discussed in the PSDA.

Advance directives are written documentation such as living wills, durable powers of attorney, and organ donation, in which patients apply their right to self-determination for their care prior to a medical necessity. These documents play a key role to protect the patients and their healthcare providers in the healthcare decision making process. By setting out the terms of their care, patients can maintain their autonomy and be guaranteed that their wishes will be followed in the event that they may not be able to express their intent. Physicians can also be assured that they are providing medical care within the guidelines established in the advance directives of their patients.

In certain cases, an individual can choose someone to act on his/her behalf when making healthcare decisions. The chosen person is referred to as a **proxy**. We will cover this in more detail when we discuss durable power of attorney. A **healthcare proxy** is the legal document in which the individual (in this case, the patient) gives written authorization for another person (e.g. family member, friend, or other close confidant) to manage their healthcare decisions on their behalf should the patient be unable or incapable of making them.

Let's examine these different types of advance directives in more depth.

1. Living Will

A **living will** is a legal document containing information in which patients explicitly write out and express their wishes and intentions in advance regarding their medical care and treatment.

Intentions commonly discussed in a will include:

- **Withholding nutrition and hydration**: Patients may wish to refuse any artificial nutrition and hydration and allow their condition to proceed naturally. This is <u>different</u> from actively trying to seek death and end one's life since the patient does not request to be euthanized. (Ackermann, R. J., 2000)

  [For more details, please see Dr. Ackermann's article "Withholding and Withdrawing Life-Sustaining Treatment," in American Family

Physician. 2000 Oct 1; 62(7): 1555-1560]

- **Do Not Resuscitate (DNR) order:** A patient may request that clinical interventions (such as cardiopulmonary resuscitation or use of a ventilator) be withheld in the event that his/her heart stops beating or his/her respiration stops. The physician then writes a DNR order and puts it in the patient's medical chart.

In every case, the physician should thoroughly discuss these issues with the patient and his or her family. During this discussion, the patient should be conscious and capable of making a decision regarding any of these cases. The family members and other pertinent parties can also participate in the discussion and decision making process. When the patient signs the living will, a witness (or witnesses) should also be present.

The **American Medical Association's Education for Physicians on End-of-life Care (EPEC)** provided informative guidelines when discussing end-of-life care with patients and their families. These guidelines cover issues such as considering a patient and his or her family's ethnic and cultural background, social support and relationships, what physical symptoms are currently affecting the patient's state, and how palliative care can play a key role with improving the patient's quality of life.

I've included the full document separately so that you can refer to the specific details:

(**Please see EPEC Participant's Handbook, Plenary 3 Elements and Models of End-of-Life Care**)

2. Durable Power of Attorney For Healthcare

The **durable power of attorney for healthcare** is a legal agreement that allows a patient to designate an **agent/proxy** (an individual chosen to represent the patient on his or her behalf) as an authorized representative when making decisions. The agent/proxy is authorized to make decisions when the patient becomes unable to make healthcare decisions on their own volition/free will.

In the case of medical care, (when given authorization by the patient) the **agent/proxy** will be able to perform duties such as

- having access to the patient's medical records and be the gatekeeper on which entities can review or be privileged to the patient's information
- making decisions on behalf of the patient's care (i.e. determining instructions for personal care, hospitalization, liaising with medical staff, and treatment plans)
- managing patient's instructions after death (i.e. [if specified] handling the organ donation process or process for donating the body for medical research and education; authorization of postmortem testing and evaluation)

In the durable power of attorney, the patient can also state any restrictions or limitations as to what the agent/proxy **may not be able to do**. Examples of these restrictions or limitations may include refusal to certain procedures (e.g. blood transfusions or psychosurgery) and denoting the specifics with regards to what decisions the agent/proxy can make (e.g. requirements for when life-sustaining measures are to be discontinued).

Additionally, the patient can also designate the start date and end date when the power of attorney will be in effect as well as choose any successors who can take the agent/proxy's place should he or she be unable to perform their duties for the patient. Instances when this is the case are when the original agent/proxy dies or becomes incompetent and thus, cannot fulfill their duties.

3. Uniform Anatomical Gift Act

The **Uniform Anatomical Gift Act (UAGA)** was initially passed in the United States in 1968 (with subsequent revisions in 1987 and 2006). This act helped provide a more uniform standard for the entire country regarding organ and tissue donation. Prior to this act, individual states set their own laws with respect to how the bodies of the deceased patients would be handled. The most recent revision in 2006 clarified and addressed many important points in the organ donation process.

Under UAGA, a physician who is not participating in the transplant should determine the time of death of the patient. In addition, the 2006 revision stated that coroners and medical examiners are not allowed to make donations of organs except when they are the ones in charge of the body's disposal. There must be no financial exchange for organ transplants (i.e. organs should not be bought and donors should not be paid).

Organ donations are voluntary and individuals may refuse to be a donor. In addition, an individual can formally specify in writing that others may not override his or her decision regarding organ donation (i.e. the individual forbids others to act on his or her behalf and allow the use of his or her organs upon death). However, if an individual does not specify their desire to be a donor, the organs may be donated by a close person (e.g. a family member).

As we had discussed in point 2 above (durable power of attorney), the designated agent/proxy can make an organ donor decision in the event that the individual is unable to make healthcare decisions.

Prioritization is also discussed in the 2006 revision. In the event that the individual does not specify how his or her organs will be used after death (i.e. medical/therapeutic purposes versus education and research), transplant or therapeutic purposes will be the **priority**.

A final important point highlights the falsification of documentation related to organ donation and financial gain. It is considered a felony to falsify documents stating that

an individual agrees to be a donor or changing the individual's refusal to be an organ donor in order to sell the organs for research purposes.

In the United States, some states allow individuals to indicate their wish of being an organ donor through their driver's license. For example, in states such as New York or Texas, a heart symbol and/or the words donor or organ donor are put on an individual's driver's license to indicate this wish.

Here is a sample driver's license indicating a donor courtesy of the New York Department of Motor Vehicles:

Although states may vary in the design or how they indicate that a person is a donor, the heart or word "donor" are generally used on the licenses. In the previous New York State license, you can see the red heart and organ donor designation in the top right.

Advanced directives play a significant part in a patient's right to self-determination regarding their health and well-being. When working on advanced directives, patients should maintain a checklist of the process:

- **Providing copies to important parties involved in the patient's care** (e.g. the physician, family members, close friends, or the healthcare facility)
- **Storage and access to advance directives:** make it easily accessible in case of emergencies or situations when the advance directive may be needed
- **Revisions to the advanced directive:** if the patient decides to make changes to the advance directive, he or she should include the updated date and provide their signature; in addition, the updated copies should be given to the important parties listed in the first point above
- **Revoking the advance directive:** if the patient wishes to cancel their advance directive, he or she should do so in writing and notify all involved parties of his or her decision

There are a few restrictions on a patient's right to self-determination. An example that we discussed in a previous handout (Handout 1.7) was physician-assisted suicide. In

many states, this will not be honored if requested by the patient since the state laws classify the act as illegal. As of 2016, only five states have passed legislation or allow physician-assisted suicide. They are California, Montana, Oregon, Vermont, and Washington. In New Mexico, physician-assisted suicide is legal in one county (Bernalillo County).

(To see an example of an advance directive, please see the external resource Advance Health Care Directive Form from California's Office of the Attorney General)

Minors: Classification and Rights in the American Healthcare System

In the United States, an individual is a minor until he or she reaches the age of majority (usually 18 or 19 years of age). The individual states in the US set the age of majority.

Here are the classifications of minors in the United States:

1. Minor- (also referred to legally as "infant") refers to a person who has not reached the age of majority

2. Mature minor- A few states have passed a statute on mature minors (those who are unemancipated). They are judged mature enough to give their consent to proposed medical treatment and procedures.

Regarding the rights of a mature minor, the 2010 Arkansas Code (Title 20, Subtitle 2, Chapter 9, Subchapter 6, §20-9-602) states

"*…Any unemancipated minor of sufficient intelligence to understand and appreciate the consequences of the proposed surgical or medical treatment or procedures, for himself or herself…*"

3. Emancipated minor- refers to a minor who is independent from the care of their parents and handles adult responsibilities before reaching the age of majority. Emancipated minors usually have the financial means to support themselves, submit a petition for emancipation to the judiciary, are in the military, or are married. Regarding healthcare decision making, they are able to provide their consent to medical treatment and procedures without needing prior approval (parental consent) from their parents or guardians. Documentation that a minor is emancipated (such as a court order or marriage certificate) should be placed in the patient's medical record.

For minors who are not considered mature minors or emancipated minors, they are unable to provide their consent for procedures in many states. However, there are a few cases for treatment where they may provide consent such as assistance with substance

abuse, mental health services, or sexual health services (e.g. testing for sexually transmitted infections or assistance with pregnancy issues).

A physician must first receive a parent or guardian's consent before providing medical treatment or performing any other procedures on the minor patient. Failure to do so can open up the physician to litigation. In the event that a parent is not available to give his or her consent, another individual can stand in place of the parent. This is referred to as ***in loco parentis***. *In loco parentis* is Latin for "in the place of a parent" and is the person assigned by the court to stand in place of the parents and assumes the legal rights and responsibilities towards the child.

In the event that the child is removed from the parent or guardian's care as a result of negligence or abuse, the state will assume responsibility for the care of the minor. This doctrine is referred to as ***parens patriae*** and is Latin for "parent of the country" or "father of his country." Under this doctrine, the state also assumes the parental responsibilities (i.e. providing protection and safeguarding the rights) for individuals who do not have parents or guardians and cannot adequately care for themselves. In addition to minors, the state can also assume responsibility for individuals with disabilities or who are mentally incompetent.

In cases where children are removed from their parents, the court must protect the rights of both parties (the children's rights and the parents' rights) through due process. Since it is a serious matter to take children away from their parents, the state **must prove** to the court that the parents were neglectful or do not have the capacity to properly ensure the well-being and care of the children. When the state has sufficient proof, the matter proceeds to juvenile and family court.

Patient Responsibilities and Obligations

Although physicians and other healthcare professionals play a significant role managing a patient's health and well-being, patients are also expected to play their part in the process. Patients should keep track of their personal care (e.g. following the physician's orders, monitoring any changes to their condition and then informing their physician of these changes, maintaining their regular medication schedule) and should be honest during medical history assessments. By being honest in their assessments, the physician can provide more accurate care and services when treating the patient. Patients are also responsible for paying the physician, other healthcare professional, or facility for any services rendered.

A major topic that we will cover in this section is consent. **Consent** is the voluntary agreement given by the patient to permit a healthcare professional to touch, examine, and perform medical procedures on him or her.

Expressed consent is consent that is clearly granted by a patient through writing (e.g. signing the consent form), verbal cues (e.g. responding with a yes or stating that they

give their consent to treatment), or behavioral gestures (e.g. shaking hands or nodding). An example of expressed consent would be a nurse asking a patient if she can take the patient's vital signs and the patient nods or replies with a yes.

We will take a look at two types of consent: **informed consent** and **implied consent**.

Informed consent has elements of expressed consent, but goes into more detail. **Informed consent** is consent given by the patient after he or she is provided a detailed explanation by the physician regarding the facts and potential consequences (risks and benefits) of a procedure. This provides the patient with the autonomy to make reasonable healthcare decisions with respect to their treatment. Informed consent is exhibited in instances where a patient will need to undergo a surgical procedure.

According to the Doctrine of Informed Consent, the physician must provide the following information in a language that the patient understands (whether it is non-technical, simple language or their native language translated by the doctor or interpreter):

- The details of the patient's diagnosis
- What the proposed treatment or procedure consists of (what will be performed, how it will be performed, what is its purpose and application to the diagnosis)
- The benefits and risks to the proposed treatment or procedure
- Any alternative treatments that may be chosen by the patient and the financial responsibilities that come with it (i.e. the costs for the alternative treatments and if they will be covered by the patient's insurance plan)
- The potential outcomes of the treatment or procedure [how successful it may be, follow-up care, what the patient may expect posttreatment (e.g. scarring, temporary hair loss)]
- Potential benefits and risks if the patient decides to refuse the treatment or procedure

Providing this information gives the patient the right to self-determination and allows him or her to make an informed decision based on the details given by the physician. There are standards used to determine whether the patient has understood the facts and details of the proposed treatment or procedure (i.e. patient is "fully informed").

The first is the **reasonable physician standard**. If you remember from our previous discussions about standard of care, the "standard of care" is the ordinary skill and care used by medical professionals that would be considered appropriate care used in similar situations by medical practitioners in a similar specialty. For example, two pediatric nurses from different states who are treating children with a similar diagnosis and treatment plan would apply similar standards of skill and care when caring for these children.

We can now extend this to the reasonable physician standard. When courts or other legal entities determine whether a patient is fully informed, they will use the "reasonable

physician standard" which states that a physician should tell the patient all of the details and information that a reasonable physician practicing the same specialty would tell the patient under similar circumstances. This allows the informed consent form to have "standardized" language and information applicable to the treatment or procedure used by other physicians of that similar specialty. In addition to explaining the details of the procedure, the physician should also discuss any known risks as well as alternative forms of treatment available to the patient. Although it is impossible for a physician to know everything that may happen during treatment (i.e. unforeseen circumstances), the physician should make a reasonable attempt to explain as much as he or she can to the patient.

The second is the **reasonable patient standard**. Similarly, the reasonable patient standard states that a patient should receive the same information that other patients with similar circumstances receive from his or her physician who have a similar specialty. The patient should also be able to ask the physician questions as well as discuss any concerns or issues that he or she may have after being informed.

For procedures that are investigational/experimental, have slight risks associated with them, or are categorized below*, patients should be provided an informed consent form to sign.

*Procedures which can fall in the categories stated in the previous sentence include:

- Chemotherapy
- Procedures with a small risk of harming the patient
- Organ donation
- Radiation therapy (Radiotherapy)
- Minimally invasive surgery
- Investigational/Experimental medical treatments

The purpose of the informed consent form is to have a legal, signed document outlining how the benefits, risks, and alternative treatments were thoroughly explained to the patient, and the informed patient has then decided to accept the treatment on their own volition/free will without any influence or coercion. **Once the consent form is signed, the patient's informed consent is only limited to the procedures that he or she consented to.** For example, if the patient consented to have surgery for appendicitis, but the surgeon notices an issue with another organ, he or she can only perform the planned surgery on the appendix. The surgeon must get informed consent from the patient again if he or she would need to perform another procedure.

Before any procedure (e.g. surgery), the patient and all of the healthcare professionals who will be involved with the procedure should be completely informed regarding every detail of the process. This includes ensuring that the correct procedure is performed at the correct site. In the Joint Commission Resources' ***Issues in Provision of Care, Treatment, and Services for Hospitals*** published in 2004, the JCR (a not-for-

profit affiliate of the Joint Commission on Accreditation of Healthcare Organizations) discusses "signing the site" in which a hospital implemented a change in the operative marking policy where surgeons signed the operative site with an unambiguous mark (i.e. the surgeon's initials). The patients are conscious and competent during the marking process and will work together with the surgeon to agree on (1) where the operative site will be and (2) what procedure will be performed. As we had discussed earlier, giving the patient the autonomy to play a part in the healthcare decision making process gives the patient a better sense of control of their health and can ease any anxiety.

Implied consent, on the other hand, is consent made through inference by signs, inaction, or silence. An example of implied consent would be a patient lifting his or her sleeve or offering his or her arm for a vaccination or to give blood. Implied consent shows the physician or healthcare professional that the patient's nonverbal communication denotes agreement to the procedure (e.g. opening mouth to have throat examined).

In the event of an emergency, implied consent is assumed when the patient is unable to provide verbal consent. For example, if the patient had a car accident or a heart attack, paramedics would assume that if the patient could provide consent, he or she would provide it in the emergency situation so that they [the paramedics] can stabilize him or her.

Exceptions to Consent

Although states may have variations on what is considered an exception to informed consent, there are a few general situations when informed consent may not be required:

- the patient does not want the physician to disclose the risks and thus, the physician has to respect his or her wishes
- the physician may not need to discuss risks that are common knowledge (e.g. there may be a chance of choking from swallowing a pill)
- the physician cannot guarantee the success of every treatment, cure every single patient, or restore the patient to his or her original state of health; in many cases, patients and physicians understand that there may be factors that cannot be predicted beforehand. A physician cannot guarantee 100% that a procedure will work or be successful during informed consent.

Refusal to Consent

Individuals who are of sound mind and body (mentally capable and conscious) are free to refuse any medical treatment or procedure. Regardless of the patient's reason (e.g. unsure whether to proceed, religion, or he or she may not be comfortable with the physician), his or her refusal must be respected. The physician, healthcare professional,

or facility may be liable in court for assault and/or battery if they do not consider the patient's right to refuse.

In the matter of *Erickson v. Dilgard*, 252 2d 705, N.Y.S. 1962, the patient, Jacob Dilgard Sr. agreed to have surgery for his upper gastrointestinal bleeding, but refused to have a blood transfusion for the blood loss accompanying the surgical procedure. Mr. Dilgard was deemed competent and fully aware of his choice even after he was informed of the risks. The county hospital (Meadowbrook Hospital of Nassau County) took the matter to court to have the blood transfusion authorized. However, the court ruled that Mr. Dilgard was completely competent when he made his decision (as opposed to someone who may not be able to such as a minor), and declined the order for the blood transfusion.

The implication of this case is that a patient who is completely competent should have their rights and wishes respected. Failure to use reasonable care when handling patients when consent has not yet been granted can result in liability of assault and/or battery.

Responsible Decision Making for the Health Consumer

With easier accessibility to healthcare related resources, people are more informed about their health. Individuals also have greater access to cover the counter (OTC) medication and dietary supplements. Patients should be honest when the healthcare professional (e.g. physician, nurse, or pharmacist) takes down information during the medication (drug) interview. When the patient provides this information to the physician or other healthcare professional, they can help notice and prevent any medical errors or harmful drug interactions. In addition, patients should also alert the medical professionals of any allergies or adverse reactions to medications that they may have.