Ethics Course for Pediatric Residents

Instructions to "Teachers"

Powerpoint Presentations (includes all the below)

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Instructions to "Teachers"

I developed this course for teaching ethics to pediatric housestaff in response to the ABP requirement that training programs have a formal course in ethics. I am a Professor of Pediatrics and the Residency Director at the University of Florida. I am not an expert and I have no formal training in ethics. This course has been taught over a period of three years to our pediatric housestaff, and their feedback has been very positive.

The course is designed to present to them a limited amount of didactic material and to engage them in a discussion about an ethical dilemma. Most of the topics have a "workshop" that aids in focusing the discussion. The topics that do not include a workshop have questions and discussion points included in the powerpoint presentation.

The "handouts" are quite limited in scope, and are designed only to be reminders of the points made during the presentation. I generally hold the handouts until the end of the session and add a copy of the slides used that day. The "teachers" will need to do preparation beyond simply reading the material provided here to be able to lead a rich discussion of these topics.

It is my hope that this material will be practical and useful as you develop or modify the ethics instruction for your housestaff. Where I have borrowed material, I have tried to give full credit. Most of the teaching material herein is original, and I bear the blame for its inadequacies. It is not copyrighted and is presented for you to use in whatever way you find useful. I would be grateful for your feedback, both positive and critical. I hope to add further topics, and will modify the material based on feedback, experience, and further learning.

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Éthiques théoriques

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ÉTHICAL THEORIES

Éthiques théoriques sont des énoncés larges qui couvrent ou incluent plusieurs règles éthiques et/ou principes, généralement systématiquement liés. Une théorie fournit un cadre dans lequel quelqu'un peut déterminer les principes qui pourraient déterminer une action éthiquement appropriée.

Il y a plusieurs "tests" d'une éthique potentielle. Une bonne théorie éthique sera claire et facile à comprendre et à appliquer. Elle doit être cohérente internement. Cela signifie que les différentes parties d'une théorie devraient être en concordance et que différentes personnes appliquant la théorie à des situations similaires devraient arriver à des conclusions similaires.

Une théorie doit être aussi complète que possible, sans grandes lacunes ou omissions. Une théorie doit être aussi simple que possible, sans plus de règles et de principes que ce qui est nécessaire pour être rappelé et appliqué. Une théorie doit tenir compte de l'expérience morale et générale du jugement individuel et de la meilleure décision générale et la meilleure évaluation et jugement. Bien que les théories éthiques puissent être utiles en nous aidant à résoudre des dilemmes moraux, elles peuvent aussi nous pousser à changer notre jugement à propos d'un problème, une théorie qui est incohérente avec la plupart ou l'ensemble de nos jugements ordinaires devra être modifiée.

L'utilitarisme est une théorie éthique qui mesure la valeur d'une action par son "effet" ou son "conséquence". Il estime que "utilité" est le principe fondamental de l'éthique et que dans toutes les circonstances, nous devons produire le bien le plus grand (ou le moins mauvais) pour toutes les personnes concernées. Cette théorie peut être exprimée de plusieurs manières, mais elle justifiera toute décision si elle produit plus "bien" que "mauvais".

Dans l'utilitarisme, il y a controverse sur la question de savoir si la théorie est appliquée aux actes particuliers dans des circonstances particulières, ou si elle est appliquée à des règles de conduite qui déterminent si un acte est juste ou mauvais. Considérons la vérité. L'utilitarisme considère que la vérité est utile comme une règle, mais ne l'est pas. Si la conséquence de dire une "blague" est positive, alors elle le justifie. Le "utilitarisme" serait d'accord avec le fait que la société est bénéficiée par l'utilité générale de la vérité, et que le dano qui est engendré par l'utilité générale d'une "blague" ne peut être justifié. Mais le "utilitarisme" en tant que tel ne peut pas être supposé par lui-même: sa valeur réside dans sa positivité générale. En situation de changement social drastique, les règles seraient adoucies.

Les théories déontologiques sont telles que les actes ont des caractéristiques intrinsèques qui les rendent justes ou mauvais, pas simplement leurs conséquences. Ces propriétés intrinsèques peuvent être basées sur des croyances religieuses, "droit naturel" (ce que l'on comprend comme raison humaine), ou "morale courante". "Act" déontologie est une position inutile qui dit que l'individu peut percevoir immédiatement par révélation ou intuition ce qui est juste ou mauvais. "Rule" déontologie indique que il y a un ensemble d'âges et de règles qui classifient les actes comme droit ou mauvais. Ces règles comprennent la Honneté, la Fidélité, la Gratitude, la Justice, la Bienfaisance, la Non-Malefiquence, l'autonomie, et la Précision. Les débats entre les déontologistes se concrétisent sur un de ces...
principles or rules are primary in any particular situation. As we go on through these exercises, you will be presented with many situations that require you to apply and balance these principles as you try to determine how to act.

Rule utilitarians and rule deontologists reject "situational ethics" espoused by act utilitarians, and find that ethical decision making requires a set of rules. Although act utilitarians may recognize rules, they are treated as "rules of thumb", easily discarded when the ultimate "good" demands it. Rules may be considered otherwise as "binding" or as "absolute". A binding rule is one, which should almost always be followed. It should be broken only in unusual circumstances. An absolute rule should never be broken. Although absolute rules seem to undermine our freedom and discretion, there are circumstances when they may seem appropriate. For instance, if murder is defined as "unjustified killing", then a prohibition of murder would seem absolute.

Although all societies do not recognize personal "rights", in the United States with its history of individualism, the rights of groups and individuals are recognized. "Rights" are best understood in terms of "claims" that can be made upon others or upon society. Legal rights are those justified by law, moral rights are those justified by moral principle. For instance, a patient's right to self determination is justified by the moral principle of "autonomy". Like rules, rights may not be absolute. My right to do as I please with my property may not allow me to drive my car on your vegetable garden! Again, the conflict between different people's rights is the basis of many moral dilemmas.

Rights may also be "positive" (those requiring someone to do something) or "negative" (those requiring someone to refrain from doing something. A person reporting to the ED for care has a positive right to care from that facility. They also have the negative right to not be taken to the OR without their express consent.

The following situations are designed to illustrate some of the concepts of ethical theories, rules, and rights covered in this section. (See slides # 8-11)
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Ethical Principles

Ethical principles can be defined as "fundamental truths (laws, doctrines, motivating forces) upon which decisions can be based". These are the "rules" discussed in the section on Ethical Theory, and the rules that "rule utilitarianism" or "rule deontology" are based. They are rights that society generally believes are due to individuals in the society. Ethical dilemmas often involve conflicts in ethical principles as they apply to a particular situation.

Autonomy is derived from Greek words meaning self rule, and describes the principle that each competent adult has the right to make decisions for themselves as long as those decisions produce no serious harm to others. In the physician-patient relationship this principle leads to the necessity of fully disclosing information to patients. Without it, patients cannot make fully informed choices. Autonomy leads to confidentiality issues; patients have the right to determine to whom they want to disclose personal information. Autonomy leads directly to "consent" requirements; patients make their own decisions about surgery, involvement in research, hospital admission, etc. Physicians certainly have a role in helping patients with difficult decisions, but autonomy holds that patients reserve for themselves the final authority. Autonomy applies to those who are deemed "competent" to exercise it and has some limitations for children and for adults who are totally or partially "incompetent".

One of the first formal written declarations of a person’s autonomy was as a result of the Nuremberg War Crimes trial. The Nuremberg Code is 10 rules about the conduct of human experimentation. Rule 1 states that potential subjects must have the legal capacity to give consent, they must have free power of choice, and must have sufficient information for them to determine the nature and duration of the experiment, its methods, its hazards, and its long term consequences. All these have their basis in a subject’s right to "autonomy".

Nonmaleficence is a principle associated with the maxim: primum non nocere, "above all, do no harm". It is implied in the Hippocratic Oath, "...I will never use it (treatment) to injure or wrong them." The duty not to injure others is stronger that our duty to take positive steps to prevent injury or harm. For instance, our duty not to push someone in front of an oncoming train is stronger than our duty to jump in front of the train to rescue someone who fell. "Harm" in the context of nonmaleficence may have a broad application. Most would agree that it encompasses a duty not to murder, not to cause suffering, and not to incapacitate. Under most circumstances it also includes not causing offense and not depriving others of the "goods of life". Some harm may be considered trivial. For instance, starting an IV causes damage to the skin, is painful, and has potential complications and yet this harm is considered trivial compared to the benefits. In medicine, nonmaleficence is usually considered in the context of intending, causing, or permitting death or serious injury or the risk of either.
**Beneficence:** Beneficence describes the ethical duty to help others further their legitimate and important interests. It includes both conferring benefit and actively acting to prevent and remove potential harms. It also entails the necessity of balancing the potential benefits and harms of any action. In the broadest sense, beneficence is limited in its imperative. For instance, most of society would regard it as foolish to send all their income to relieve poverty in Appalachia or to build flood control systems in China. In medicine, beneficence is usually directed to our efforts on behalf of our patients, but public health measures, research projects, and CME programs can all be viewed as influenced in part by the principle of beneficence.

**Justice:** The ethical principle of justice involves giving to each individual in society that which they can legitimately claim. Most societies proclaim the equal worth of all citizens and pass laws to support that claim. Yet those same societies have clear disparities in wealth, education, and possessions. The distribution of various resources in society often is governed by different philosophies: to each according to their need, or their merit, or their "worth" to society. Or to each an equal share, or according to their contribution. Health care in the US is a limited resource and is distributed to its citizens in a complicated manner governed by competing philosophies of justice. This topic will be covered in detail in the section on "Use of Limited Resources". As it applies to individual patients, the principle of justice suggests that each of our patients have a right to expect an equal effort on their behalf. A child in our care from a welfare family should get care that is of the same quality as the child from a wealthy family.
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Ethical Principles Workshop

This case is modified slightly from Case #2 in Beauchamp, Childress. *Principles of Biomedical Ethics*, 2nd ed.

Instructions: Choose participants to play the role of Dad and Nephrologist. Have them act out the described encounter, not using too much time in the medical details. You can choose two people in front of a group, or you may choose to divide the group into many "twosomes". Give them enough time to complete the role-playing, and then reassemble the group to discuss the issues that come up. Answer the questions and lead them in a discussion of the issues in terms of the ethical principles just presented.

Patient data: You have a patient, a 5 year old girl with progressive renal failure, who is not doing well on chronic dialysis. Renal transplantation is somewhat questionable, but it is generally felt that the primary disease process will not recur in a transplanted kidney. The parents concur with the plan to try transplantation. The tissue typing indicates that it will be very difficult to find a match for the girl. The staff excludes her two siblings, ages two and four, as too young. The mother is not histocompatible, but the father is a good match. You, the nephrologist, meet alone with the father and give him the result of the match, indicating that the prognosis is uncertain for the child, even with the possibility of a transplant. After thinking about it for several minutes, the father decides he does not want to donate his kidney. He has several reasons, including his fear of surgery, his lack of courage, the uncertain prognosis, the slight chance that a cadaver kidney might be found, and the suffering his daughter is incurring. He asks you to tell the family that he was not a good match. He is afraid that his family, if they knew the truth, would accuse him of allowing his daughter to die, and telling the truth would "wreck the family".

Nephrologist: You are a caring physician who wants to treat your patient to the best medical science has to offer. However, you know this family well, and know that it is dysfunctional. Dad, who loves his daughter, is a weak person. You agree that it will divide the family if they know Dad refuses to donate a histocompatible kidney, yet you do not want to lie to them.

1. How do you feel about Dad's decision not to have surgery?
2. How do you feel about his asking you to lie to the rest of the family?
3. How are you going to respond to his request?

Dad: You love your daughter, and don't want her to die. Yet you also don't want her to suffer any more, and these doctors can't give you a certainty that this procedure will help her. Also you are afraid to have surgery and why should you be the one in the family that has to risk his life for an uncertain chance? If the family finds out that you are a possible donor and you refuse to donate your kidney, they will think you are selfish and a coward, and are letting your daughter die.

1. How do you feel about being asked to donate a kidney?
2. How do you feel about asking the doctor to lie?
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Informed Consent

The roots of the rules concerning informed consent are in the Nuremberg Code and then subsequently in the Declaration of Helsinki. These primarily involve protection of subjects of experimentation. Many further modifications have evolved from case law involving malpractice cases. There are two positions about the justification of informed consent. The less common holds that informed consent must protect patients from harm (whether or not it is the patient's choice that leads to an "unwise" decision). Such a position might lead to a decision by a physician to give a blood transfusion to an adult who refuses one. A more common justification of informed consent is that it protects a patient's autonomy. This position would allow a patient to make an "unwise" choice.

The "informed" part of informed choice demands that patients be given all the pertinent information ("full disclosure"). The "choice" part demands that their decision be completely "voluntary", and that the patient be "competent" to make the decision. The competence thus required need not be more than that required for the decision at hand. Patients, for instance, may have been found incompetent to manage their finances, but still retain the power to make their own medical decisions. When there is a question of competence, courts usually will make a ruling based on whether the patient's decision seems based on rational reasons, leads to a reasonable result, and whether the patient seems to have the capacity to make such a decision. Competence decisions are sometimes easy (a comatose patient is clearly not competent to make decisions, thus the value of a durable power of attorney), but when not straightforward are usually value laden. What is "rational", what is "reasonable", and how to measure "capacity" are entirely subjective. Children are generally not considered competent to make their own decisions, and unless the courts have already ruled otherwise, their parents are considered to operate in the child's best interest and have the legal authority to make decisions for them. This leads to some interesting situations. Minors who have children can consent to a procedure for their children but not for themselves (unless they are considered an "emancipated minor")!

"Full disclosure" can mean different things. In some malpractice cases, physicians have argued that they needed to disclose only that information usually disclosed by other similar practitioners, the "professional practice standard". Courts, however, have generally held physicians to a "reasonable person" standard. This requires disclosure of all information felt to be necessary for a decision as judged by a jury of the patient's peers. It would include disclosure of all significant risks (anything the patient might consider significant, not just those risks considered by the doctor to be "significantly likely"). The "reasonable person" is a composite, not any particular person. Physicians have not been allowed to claim that they should be held to different standards than other professionals by virtue of their general regard for their patient's welfare.

The "comprehension" involved in informed consent can also be problematic.
Comprehension includes understanding the information given, but can also involve acceptance, believing that the information applies to them. Patients may hear and understand that there is a small chance of death as a result of a procedure without really accepting that it might happen. Finally, patients may understand that a procedure will produce pain, accept that they will feel it, and still not "appreciate" how much distress they will be in. Giving information to patients in such a way as to maximize their understanding, acceptance and appreciation is all part of the comprehension of informed consent, and failure to do so is at the root of much litigation.

Informed consent decisions must be voluntary. Information about alternative choices must be given with the same full disclosure and attention to comprehension as the therapy being offered. All patients will have external "influences" that affect their decisions. The voluntariness of informed consent requires avoidance of "controlling inducements" (those that force patients into decisions), but may allow patients to be influenced by persons, including their physicians and their family, operating out of beneficence. Consider this list: coercion; indoctrination; manipulation; seduction; emotion-laden appeal; rational persuasion. This list runs the gamut from clearly wrong to permissible to perhaps even desirable influences.

Informed consent issues have moved beyond ethical decision making into legality. When there is conflict involving informed consent, it may be prudent to obtain legal counsel.
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Informed Consent Workshop

Instructor: Print out each of the scenarios that follow on separate pages. If your group is large enough, distribute the different scenarios equally, one to a participant. Have them read them and respond on the paper. Then ask the group to report their responses for each scenario. Usually the responses will support donation of bone marrow from both the 6 and 15 year-old children, but a kidney donation only from the 15 year-old. Explore with the group why they responded in the way they did. What are the pertinent differences in donating a kidney vs. a bone marrow? What are the differences in acceptable informed consent from a 6 and a 15 year-old child? Can either child be considered to have a fully "voluntary" choice? How do "comprehension" and "fully informed" apply to these cases?

Case 1: A woman brings in her child, requesting your help. You have previously seen this child for intermittent sick visits, but have little relationship with the family. The mother is a single parent; Dad has no custody and is nowhere to be found. The mother is in chronic renal failure and needs transplantation. She wants the child to donate a kidney for her but her nephrologist is reluctant unless the child’s pediatrician agrees. The child is 6 years old and has been in good health. When you meet with her privately, she states she has thought about it and she wants to be a donor for her mother. She says she understands the risk of surgery, that something could happen to her other kidney, and that there could be other donors found for her mother. She seems appropriately mature for her age, intelligent, and emotionally stable.

We will talk through this case and the issues involved, but please answer this question first. Would you, in general, be in agreement with allowing the child to donate to her mother?

Yes No

Case 2: A woman brings in her child, requesting your help. You have previously seen this child for intermittent sick visits, but have little relationship with the family. The mother is a single parent; Dad has no custody and is nowhere to be found. The mother is in chronic renal failure and needs transplantation. She wants the child to donate a kidney for her but her nephrologist is reluctant unless the child’s pediatrician agrees. The child is 15 years old and has been in good health. When you meet with her privately, she states she has thought about it and she wants to be a donor for her mother. She says she understands the risk of surgery, that something could happen to her other kidney, and that there could be other donors found for her mother. She seems appropriately mature for her age, intelligent, and emotionally stable.

We will talk through this case and the issues involved, but please answer this question first. Would you, in general, be in agreement with allowing the child to donate to her mother?

Yes No

Case 3: A woman brings in her child, requesting your help. You have previously seen this child for intermittent sick visits, but have little relationship with the family. The mother is a single parent; Dad has no custody and is nowhere to be found. The mother has aplastic anemia and needs bone marrow
transplantation. There are no other relatives and no better matches in the BM registry. She wants the child to donate bone marrow to her, but her hematologist is reluctant unless the child’s pediatrician agrees. The child is 6 years old and has been in good health. When you meet with her privately, she states she has thought about it and she wants to be a donor for her mother. She says she understands the risks and the procedure. She seems appropriately mature for her age, intelligent, and emotionally stable.

We will talk through this case and the issues involved, but please answer this question first. Would you, in general, be in agreement with allowing the child to donate to her mother?

Yes No

Case 4: A woman brings in her child, requesting your help. You have previously seen this child for intermittent sick visits, but have little relationship with the family. The mother is a single parent; Dad has no custody and is nowhere to be found. The mother has aplastic anemia and needs bone marrow transplantation. There are no other relatives and no better matches in the BM registry. She wants the child to donate bone marrow to her, but her hematologist is reluctant unless the child’s pediatrician agrees. The child is 15 years old and has been in good health. When you meet with her privately, she states she has thought about it and she wants to be a donor for her mother. She says she understands the risks and the procedure. She seems appropriately mature for her age, intelligent, and emotionally stable.

We will talk through this case and the issues involved, but please answer this question first. Would you, in general, be in agreement with allowing the child to donate to her mother?

Yes No
CONFIDENTIALITY

Information that is confidential is "imparted in secret". The term "confidentiality" is used in medicine to describe the "secret" nature of information shared between patients and their physicians, and the information that results from their interactions (i.e. laboratory results, surgery, etc.). Confidentiality has much to do with the rights to privacy and autonomy. These rights would suggest that patients have the right to determine what information about themselves can be shared with others, and how wide this audience might be. In each society, some information is considered to be very private, shared with no one or a very select group. Such information might be described as our "innermost thoughts" and kept private except in an interaction with a psychologist. Other information would be available to anyone in a group granted access through relationships such as love, friendship or trust. Some information may be considered to be so public that it can be made available to many or even anyone. Our societal beliefs, personal beliefs, personal relationships, and professional relationships all impact on our decisions about the confidentiality of our personal information.

There is widespread agreement that confidentiality is necessary in patient-physician relationships. The Hippocratic Oath, the AMA Principles of Medical Ethics, and World Medical Association International Code of Ethics all agree on the need for confidentiality. Confidentiality can be supported by utilitarian (if there is no confidentiality patients will lose trust in their physicians and withhold information necessary to their treatment) or by deontological arguments (a patient’s right to autonomy clearly leads to their right to privacy and to confidentiality). Patients have the right to direct that otherwise confidential information be given to others (family, insurance companies, employers, lawyers, etc.).

Confidentiality is not generally viewed as an "absolute rule", but as an ideal that should not be overridden except for justifiable reasons. There is, therefore, a "burden of proof" on anyone who decides that disclosure of confidential information is morally or legally necessary. Some legal responsibilities to do so are the reporting of communicable disease, gunshot wounds, and child abuse. There is perhaps a moral issue in the case of a psychiatric patient who discloses to the psychiatrist that they are planning to assault someone. Physicians have a moral responsibility (but no legal requirement in Florida) and legal protection to breech confidentiality in the case of patients who are HIV positive and who continue to have unprotected sex with partners who are uninformed about their HIV status.

Infringing confidentiality where there is no legal duty to do so is easier to justify if there is potential harm to others rather than potential benefit to the patient. The probability of harm is also important. A remote chance of trivial harm is probably not sufficient, whereas a high likelihood of death to many (a patient who has already constructed a bomb) would morally mandate a breech of confidentiality. Whenever possible, alternatives to a breech of confidentiality should be sought. Dilemmas in confidentiality cases often involve
uncertainty about diagnosis, prognosis, and likelihood of an untoward event.
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**Ethics OSCE: Confidentiality**

This OSCE was produced by Dr. Peter Singer and Anja Robb from the University of Toronto. It is not copyrighted and can be reproduced for educational purposes. The ethics website from which this was downloaded is: [http://wings.buffalo.edu/faculty/research/bioethics/bcp.html](http://wings.buffalo.edu/faculty/research/bioethics/bcp.html)

The OSCE was modified for this exercise.

**Preceptor:**

Divide the learners into groups of two or three (if three, one acts as an observer). Allow them a brief time to read their roles and about ten minutes to role-play. At the end of the exercise, discuss these questions:

1. Should the father receive the information about his daughter? Why or why not?
2. What are the conflicting ethical principles or "rights" involved here?
3. Who is best able to act in Susan’s "best interest", she or her father? Would your answer be different if she were 13...or 11...or 19?
4. "Susan’s confidentiality must be protected, because to do otherwise would eventually compromise a minor’s access to birth control, and that would be bad for society." What ethical theory is operational in this statement? (Rule utilitarianism)
5. "Parents always have the right to information about their minor children. They are the ones who have the responsibility and the right to make decisions for them." What ethical theory is operational in this statement? (Deontology)

**Physician Instructions:**

You started doing a locum for Dr. Hardy a few weeks ago. He will be gone for about 6 months.

You are about to see Jim Sherman, the father of one of Dr. Hardy’s patients, a 16 year old named Susan. A few months ago, Dr Hardy prescribed birth control pills for Susan because she was sexually active. Susan asked several informed questions and was fully aware of the risks and benefits of taking the pill. Dr. Hardy wrote in his notes that he felt she was fully competent to make that decision. Susan told Dr. Hardy in no uncertain terms that she did not want her parents to know she was on the pill or why she was being prescribed the pill. Last week you saw Susan to renew her prescription for the pill. You agree with Dr. Hardy’s assessment of her competence.

The father, Jim, has subsequently become suspicious about Susan's visits to the doctor’s office and has made this appointment to discuss the issue. You have a very busy office today, and have only 10 minutes to see him.
**Father's instructions:**

Your name is Jim Sherman. You are a Deacon in your church, a leader in the community, and a very concerned father. Your daughter has begun to rebel against the values you have tried to teach her and against her parents' authority. You and your wife have spent hours discussing Susan and how best to get her back on "the right path". You are concerned about her friends, her failing schoolwork, the possibility that she may be experimenting with drugs, and the possibility that she is sexually active. You have tried restricting her privileges, but she has not cooperated, and you are afraid she may "run away". You are considering enrolling her in a residential program for "wayward youth" but are not sure it is necessary. Your wife found two appointment cards for Susan to see Dr. Hardy, and you want to know why. That might be the information you need to make your decision.

Dr. Hardy has had a long-term relationship with you and your children. He has been very supportive and tolerant of your belief system. You do not anticipate any trouble with getting the information you want. After all, you are her parent; you have the right to information about your minor daughter. You are surprised and upset when you get resistance to your request for information. You think you have every right to the information, and that Dr. Hardy would have given it to you.
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Do Not Resuscitate

Resuscitation can be defined as a series of steps directed to sustaining adequate circulation of oxygenated blood to vital organs while an effective heartbeat is restored. Many patients who require resuscitation are very ill and may have underlying conditions that will inevitably lead to death. For this reason, overall statistics show a limited short and even worse long-term outcome for patients undergoing resuscitation. For adult patients, immediate response to resuscitation is seen in 10% to 30% of patients, and survival to hospital discharge is only 5% to 10%.

Despite these poor outcomes, resuscitation is considered the standard of care for patients. In general, in an emergency a patient is presumed to give consent to medical standard care unless they have previously stated an objection. Therefore resuscitation is unique in that it is a therapy applied to patients without their consent, and withheld only upon their consent (or direction).

To be precise, resuscitation is the successful outcome of an attempt to resuscitate. A request to forgo resuscitation maneuvers is therefor properly termed Do Not Attempt Resuscitation (DNAR), although the DNR shorthand is commonly understood to be equivalent. The right of a patient or their proxy (see advance directives) to request a DNAR status is based on the patient’s right to autonomy, or self-determination (assuming patient competence). This right takes precedence over other considerations such as the likelihood of success, other family member’s desires, or physician preference. Many hospitals have policies that patients are asked about their preferences on admission. It can be held that physicians have an obligation to discuss DNAR issues with patients based on the principles of beneficence and justice. Beneficence would hold that it is in the patient’s best interest to have the opportunity to make their wishes known, and justice would hold that since some patients have the opportunity, all should. Justice and beneficence also would support a patient’s right to refuse a DNAR status and thus have access to a therapy that might be ineffective and costly regardless of their ability to pay the costs.

When patients are not competent, decisions about resuscitation are made by others. A proxy decision-maker, designated by the patient in an advance directive, is legally empowered to be the decision-maker in every state in the US. If none has been designated, the courts may appoint a surrogate. For children, the parents are usually considered to be acting in the best interest of the child. (For a more complete description of these issues, see the discussion under "Refusal of Therapy"). Decisions are directed by previously expressed desires of the patient either formally (instructive advance directive), or informally in discussions with their proxy. If there is no such prior information, the proxy or surrogate decision-maker may make a decision based on what a reasonable person would do in similar circumstances, or make a decision in the "best interest" of the patient. Again, parents are usually considered to be acting in the best interest of their children.
Physicians are not required to perform treatments that are futile. For instance, there is no necessity of continuing to ventilate a patient once they are brain dead, and no need to continue to resuscitate a patient once it is clearly futile to do so. On the other hand, if a patient has an ultimately, but probably not immediately, fatal condition, resuscitation for a temporary exacerbation might be successful even if for only a brief period. Patients or their surrogates sometimes want resuscitation even when the health care providers may feel it inappropriate. If there is some chance of success, even temporary, resuscitation cannot be termed "futile" and refused on that basis. It is not necessary that the patient have some reasonable chance of surviving the hospitalization or of having the underlying condition reversed.
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DO NOT RESUSCITATE WORKSHOP

Presenting Situation:

Ms Smith has a 3-month-old child with Trisomy 18. The child is in the ER with pneumonia and Mother wants admission and aggressive therapy. You need to discuss a possible DNR order with her.

Activity:

Interview

Time allotted:

10 minutes

Instructions:

You are about to interview Ms Smith, a 25-year-old mother of a child with Trisomy 18. This child was born at Shands and is known to have severe hypotonia, poor feeding, a large VSD and PDA, and has the typical phenotype. Chromosomes confirmed the diagnosis in the NICU, and a decision was made not to intervene. Mother is paranoid schizophrenic, on medications that she does not always take, and was at odds with the medical team in the NICU. In the past she has insisted that her child is fine and will grow up normally. The ER team tells you that the child is very ill and may not survive the hospitalization. For now ignore the issue of whether antibiotics and fluids are the appropriate thing to give, and focus on the possible need for resuscitation and how you will have that discussion.
Instructions to "Ms Smith":

Your name is Elizabeth Smith. You are 25 years old and have carried the diagnosis of paranoid schizophrenia for many years. You have not been institutionalized for a long time and have managed to remain marginally functional, but frequently do not take your medication or show up for your psychiatric appointments. Your father is not available, your mother is accessible only in an emergency and is an alcoholic, and you have no siblings. The father of the child is in prison for raping you while you were living in a homeless shelter.

Your interactions with the pediatricians at Shands have not been easy. You don’t really believe there is anything wrong with your baby, Alicia, and you wonder why they try to convince you there is. It makes you very suspicious of their motives, and you think they are trying to trick you into giving her up to them. You wonder if they are going to use her "organs" for someone they like better or who has paid them more. You don’t like the necessity of bringing Alicia to Shands, but you have no other option. Allowing a DNR order on Alicia is absolutely out of the question. The harder they push the idea, the more adamant you become.

During the interview you should not become so upset or irrational that the doctor must break off the interview. Give the doctor the chance to ask the questions he needs to ask. Answer the questions, but do not volunteer information you are not asked.

In response to the interview you may say things like,

"You’re just like the other doctors, you don’t want to help me or Alicia"

"What are you saying, that you think Alicia is going to die? What are you going to do to her?"

"Alicia is a perfectly normal baby, just a little sick right now"

When the doctor comes in, begin the conversation with, "So when do you think I can take her home?"
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REFUSAL OF THERAPY

Patients have a right to accept or refuse medical intervention. This right is explicit in the Patient’s Bill of Rights: "...the patient has the right to refuse treatment to the extent permitted by law and to be informed of the medical consequences of his action." The first expression of this right was apparently in a statement by the AMA in 1973 that affirmed the right of the patient and the family to decide about "the cessation of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent."

At least part of the impetus for this statement was a need of Roman Catholics to be able to refuse some kinds of therapy without being guilty of suicide, thus the differentiation of ordinary from extraordinary. "Extraordinary" however is poorly defined and "unusual" or "not customary" might be considered synonyms. In an ICU setting, intubation and mechanical ventilation may be common. Does that mean they are not "extraordinary" means of prolonging life? "Obligatory" and "optional" have been suggested as better ways to define levels of care. If a treatment offers a reasonable prospect of benefit to the patient and is available without excessive pain, expense, or inconvenience, it would be considered "obligatory." Food, water, and air would clearly be obligatory by this definition and a patient who refused to eat and therefore died would be considered to have committed suicide. Treatments that offer little chance of benefit and are painful, expensive and/or inconvenient are "optional". Thus, a patient with metastatic cancer who refused surgery would not be committing suicide, but exercising their opportunity to decide whether or not to undergo an optional therapy.

The "right" of patients to refuse therapy is based on their right to self determination, the principle of autonomy (see previous discussion in Ethical Principles). Secondarily, beneficence and non-maleficence impact this right. There may be conflict between these principles. A therapy may clearly be of potential benefit to a patient but have an associated cost in terms of pain or expense or inconvenience. For the healthcare provider and perhaps the patient's family, the benefit to the patient (beneficence) may seem to outweigh the cost. For the patient, the cost may exceed the benefit and the patient may refuse the therapy. The principle of autonomy, assuming the competency of the patient, takes precedence and the patient has the right to refuse.

In Pediatrics, our patients are frequently, because of their age, considered "incompetent". In general for incompetent patients, we have the obligation to provide therapy. An exception is made if the patient is dead (i.e. brain dead), or death is imminent and irreversible, or if the burden of therapy outweighs the benefit. In a consideration of "burden of therapy" it is the burden vs. benefit to the patient that is the primary or only consideration. Considering the cost to the family, healthcare provider, or insurance company in an ethical dilemma is at least controversial.

Surrogate decision makers for children are almost always their parents or legal guardians. These decision makers are usually considered to have the best interests of the child at heart, and to be in the best position to weigh the potential costs and benefits. In adult patients who require surrogate decision making and who have no "living will" in which they have recorded a prior decision, there are two means of coming to a decision. The most acceptable is the "best interest" standard. This makes a decision based on what is, in the opinion of the decision maker, in the best interest of the patient. A second, generally less accepted standard is "substituted judgment". This requires that the decision maker put themselves in the "shoes" of the patient and make the decision the patient would have made if they were still able to do so. This is a less accepted standard because of the difficulty of knowing with any degree of certainty what a patient would have done. The "substituted judgment" standard is particularly difficult to apply in pediatric cases, and the "best
interest" standard is usually used.

Challenging ethical dilemmas arise because people weigh costs, benefits, autonomy, and beneficence differently. Parents are usually considered to have the best interests of their children as the basis of their decision making, but parents will often consider decisions in view of costs not only to the patient, but also to themselves and the rest of their family. Parents may have value systems so different from those of their caregivers, that significant differences of opinion arise as to the "correct" course of action. The following brief cases offer an opportunity to discuss a variety of issues that will arise in the course of a pediatric practice. Read them, commit to one of the answers, and then work through them with your group. You will find almost unanimous consensus on some of them, and great diversity of opinion in others. For most, there is no "right" answer.
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Instructions to Teachers (Refusal of Therapy)

Incorporated into the PowerPoint presentation are a series of brief case scenarios. They should lead to a brief discussion by the residents. The following are the points the cases are designed to illustrate:

Case 1. Because she is an "emancipated minor" most will agree the principle of autonomy gives her the right to outpatient therapy without further testing. States have differing laws about treating minors who have not been designated as emancipated. I have a handout for the residents about the laws in my state. You can get a summary of your state law from the hospital or institutional attorney.

Case 2. The key here is the right to refuse therapy "...to the extent allowed by law." Because of the public health implications of patients with untreated or partially treated cavitary TB, most if not all states would direct this patient to be institutionalized if that was the only way to assure his cure.

Case 3. Because of the 40% success rate, there will usually be a split in the respondents. Some will regard that as good enough to petition the court, others will feel that is a low enough rate to allow the parents to make a decision they would not make for their own children. Point out that most parents will choose to put their children through a procedure with a low chance of success, but would not make that choice for themselves. It may also be worth discussing the impact of the parent's decision to pursue an "alternative" therapy.

Case 4. There is no obligation to continue a therapy after "death". Many would give the family a brief period (up to 24 hrs) to "come to grips" with the situation. Point out that there is no legal problem with the possible charge of murder in this case. Lawyers cannot successfully argue that the death was caused by the discontinuation of "life support". Because of the need to clearly declare someone as "dead" before organ donation, "brain death" is equivalent to "dead" for death certificates and in every other legal sense.

Case 5. This case is also likely to cause a difference of opinion and may bring up the "quality of life" issue. There is some discussion in the ethics literature that QOL is not an appropriate consideration in these cases. While I may consider such a QOL unacceptable for myself, this patient may never have had any other QOL and in a "substituted judgment" sense might well find it acceptable. Another issue is the issue of the "cost" of care in this child. While it is clearly a burden for the family to continue to care for the child, it is the "cost" of a procedure to the patient not the family that is of primary ethical importance. A g-tube may be considered a "low-cost" procedure, but an article in Pediatrics in 1999 suggests the cost may be higher and the benefit lower than we might think. Even if the patient had both a Nissen and a g-tube for all feedings, the aspiration of oral secretions would likely continue and the recurrent pneumonias might continue unabated. Finally, the motive for the family's refusal of therapy might be to "allow" the patient to more rapidly die. That is euthanasia: involuntary (the patient did not agree to the decision), passive (the patient had no part in the decision), and indirect (death is the consequence of inaction, the patient was not given something to induce death).

Case 6. Discharging the patient and leaving him without access to medical care is unethical. Going to court to force good care would likely be the choice in a 5 year old (for many), but not in a 15 yr old who has the ability to participate in the decision making. It is also much less likely to be beneficial. A suggestion from one resident was to continue to provide albuterol but only a month's supply at a time, giving opportunity on a monthly basis to build a relationship and perhaps influence the patient and family.
Case 7-10. At what point does a child develop competence in your opinion?

Case 11. The care here is "obligatory", simply food, water, and an airway. The burden of care is large to the family, but not to the patient. There is no benefit to the patient of either choice. In a PVS there is no suffering and no pleasure. Life or death is neither a burden nor a benefit. If there is no benefit to the patient, and no cost to the patient, then the cost/benefit analysis to the family becomes of primary importance, and it is their decision to make; UNLESS there is something beneficial in life itself. Audience members who have a deontological perspective that life is sacred will have difficulty in withdrawing "obligatory" treatment. Audience members who have a utilitarian view will more easily accept withdrawal of therapy.
Advance directives is the generic term for instructions a competent patient gives regarding their health care in the event they are no longer competent or able to make decisions. The right of patients to direct their health care is rooted in the principle of "autonomy" (respecting the decision-making capacities of autonomous persons).

Advance directives come in two forms, instructional and proxy. Instructional directives provide details about preferences for anticipated treatment decisions. Another common term for instructional advance directives is a "living will". Proxy advance directives identify an individual who has the patient's permission to make treatment decisions on their behalf. This is also referred to as a "durable power of attorney".

These advance directives may be done as a single or as two documents. They are legal in every state and the District of Colombia. Different states have varying legal criteria involving notaries, witnesses, and forms to be used, but even documents that do not meet the legal criteria carry a moral weight in medical decision making.

The proxy advance directive is probably the more important of the two advance directives because it has the most flexibility. No matter how carefully a patient may consider the future and write an instructional advance directive, circumstances may be altered enough that it may not be clear how the patient's directions apply. A proxy agent can use the instructions from the patient, consider the new circumstances and make a decision for the patient when an instructional directive would not have applied.

Advance directives are appropriate for any competent patient, not just for terminally ill or elderly patients. Advance directives never take away decision making from a competent patient. While physicians and hospitals are not legally bound to honor the advance directives, they are ethically required to uphold them when they can, and to try to find another health care facility that will honor them when they cannot. For instance, a Catholic hospital might feel ethically unable to withhold food and water from a patient in a persistent vegetative state. If that were the advance directive of the patient, the hospital would be obligated to transfer the patient to another facility that could honor the request.

Advance directives do not usually cause ethical dilemmas. Physicians need to make sure patients are "competent" to make decisions. Competency has both legal and medical components. Patients must be old enough, have the mental capacity to understand the decision they are making and the consequences of that decision, the decision should be based on "rational" reasons, and lead to a "reasonable result". Decisions to declare a patient "incompetent" because of a disagreement with their decision tend to be very "value laden" and should be made very carefully.
Prompt 1 (immediately)

"I had a cardiac arrest a couple of hours ago. I know what was happening, and was really disappointed when I woke up being resuscitated. I don’t want that to happen again!"

Prompt 2 (by two minutes)

"I really don’t want CPR again. I want to make sure you won’t let that happen to me again"

Prompt 3 (by 5 minutes)

"If I have another cardiac arrest, are you going to let me go?"

Prompt 4 (by 7-8 minutes)

"How will you make sure my wishes are respected"
Instructions to Teachers

It usually works best to have covered the didactic material before this workshop. Divide your learners into pairs and have them choose a role. Allow each pair 15 minutes to work through this exercise. When they have finished, call the whole group together and have a discussion. Ask them what were the important issues they discussed or addressed with the patient. These should include the following:

a) is the patient competent to make this decision

b) is the patient depressed

c) does the patient understand the disease, the prognosis, and his options

d) are there others who need to be part of this decision

e) the physician should agree with the patient's right to make this decision

f) describe the option of an advanced directive

g) state the patient can change his mind

h) offer to help mediate a discussion between the patient and his family
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f) describe the option of an advanced directive
g) state the patient can change his mind
h) offer to help mediate a discussion between the patient and his family
Abortion Ethics

Abortion is probably the most divisive, in today's society, of the ethical issues we will consider. It is divisive because each side in the debate is firmly convinced of the strength of their arguments, and because there is no current way to prove or disprove the central issue, the "personhood" of the unborn. Both sides have important moral insights. In considering the issues of abortion it is important to consider the valid concerns both sides have.

In the debate over abortion, two "rights" come into conflict, the "right" of the fetus to live and develop, and the "right" of a pregnant woman to have an abortion. The right of the fetus is tied into the issue of the "personhood" or "humanity" of the fetus. No one would argue that a woman had the right to kill a three-year-old child because caring for the child was inconvenient. The right of the child to life outweighs the right of the mother to "manage" that part of her life. If the fetus is not a human being and has no rights, then the benefit, no matter how trivial, to the mother of an abortion takes moral precedent. If the fetus is a person, the right of the fetus to life might outweigh any or almost any right of the mother to an abortion.

What are the criteria for "personhood"? There are many possible criteria, but how to choose amongst them is the problem. Which of the many possibilities is a sufficient condition or a necessary condition? Different authors have stated quite different criteria. The presence of life has been suggested. But a beating heart is evidence of life and we accept the definition of brain death as "not-life" despite the "life" of the heart. The presence of a soul might suggest "personhood", but when does that occur? Proponents of immediate animation suggest the soul is present from conception. Opponents wonder what this implies for homozygous twins since the zygote splits after conception. Do twins share the same soul? Delayed animation postulates the soul becomes present sometime later, perhaps in the second trimester. With this approach, abortion during earlier gestation is fine, later abortion would not be allowable. Finally, some have suggested that the ability to reason is necessary for "personhood". Thinking, reasoning, emotions all are part of personhood, but probably not sufficient conditions, since animals can certainly do all these. If they are necessary conditions then patients who are severely retarded or in a persistent vegetative state cannot be "persons".

Some philosophers have suggested that even if a fetus is defined as a person, abortion may be justified on the premise that the benefit to a mother outweighs the limited issue of non-maleficence to the fetus. What are these rights of the mother? They are the rights to privacy, the right to determine what happens to her body, the right to equal treatment, and the right to self-determination. In fact, the original Roe vs. Wade Supreme Court decision was really about privacy, the right of a woman and her physician to make a decision during the first trimester, without the interference of the State.
Most would now agree that a woman should have those rights, particularly if they do not impact on another person’s equally valid rights. But that has not always been the case. Women have, through many periods in history, not been viewed as having any rights, and feminists in particular may view the abortion debate in the context of the historical oppression of women. When abortion was illegal, many women underwent dangerous illegal abortions. Many people are concerned that history not be allowed to repeat itself!

Other groups may have a very different perspective. Many of the abortions done in this country are in African-American women, and some have seen abortion as a racist, genocidal threat. Some have even argued that abortion could be used as a means of sex selection, probably resulting in fewer female infants!

Father’s rights have not been given much weight in the debate. Because fathers do not carry or bear the child, and because our society places most of the child-rearing responsibility on the mother, a father’s right to have a voice in the decision to abort his child is seldom a deciding factor ethically or legally. Paternity issues may further complicate the issue.

Some situations seem to require an abortion even for someone who generally opposes it. For instance, a woman may have a tubal pregnancy, or may have an intrauterine pregnancy but require a hysterectomy because of cancer. To address these kinds of situations, the "Principle of Double Effect" has been proposed. For this principle to be operand, four conditions must be met. The action itself must be either morally good or at least morally neutral (an abortion is "morally bad", but a hysterectomy is not morally bad in itself). The bad consequences must not be intended (the intent of the hysterectomy is to save the mother, not to kill the fetus). The good consequences cannot be the direct causal result of the bad consequences (the mother was not saved by killing the fetus, but by removing the cancer). And the good consequences must be proportionate to the bad consequences (a life saved, a life lost). Thus, proponents of the principle of double effect would allow abortion in certain cases.

Because of these different beliefs, there are positions on abortion that vary widely. Some argue that the personhood of a fetus begins at conception and that abortion is murder and never justifiable. The other end of the spectrum is the position that an unwanted pregnancy is a venereal disease and it is immoral not to allow the mother to terminate it. We have examined some of the beliefs that lead others to take a position somewhere between these two extremes.

There are some points of common ground for goodwill proponents and opponents of abortion. Both would agree that unwanted pregnancies should be reduced although they might disagree on the means of accomplishing this. Both would agree that pregnant women considering abortion should have genuinely free and informed choice (both would agree that this is seldom the case currently although they might disagree about which side is most at fault!). Both would agree that all children should have a loving home where they are wanted
and valued.

The web resources listed here include literature from both extremes and from more centrist positions. Although your own position is likely firm, reading about the positions of those with different opinions offers an opportunity to learn something. Persons whose opinions differ widely from your own are likely to have very legitimate concerns. Demonizing an opponent will rarely lead to reconciliation or constructive movement toward a solution. Read what they have to say!
Scarce Resources

Justice is defined as giving to all persons their "rights" or "desserts". What people deserve or can claim as rightfully theirs may be based on their productivity in society, their need, or on the basis of some other morally relevant property. Society uses various rules and principles (moral, legal, and ethical) to decide how to distribute in a just manner its benefits and burdens. This process is called "distributive justice". Distributive justice becomes an important discussion only when a resource is limited and when there is competition for it. Protection of the environment became an issue when the availability of clean air and water was seen as threatened by those who used it to dispose of their unwanted byproducts. When clean air and water became viewed as scarce and threatened, society had an issue of distributive justice, balancing a citizen’s right to a clean environment against a citizen’s right to dispose of pollutants in the least expensive way.

Most societies proclaim the equal worth of all persons and give legal guarantees of equal justice and rights. Yet these societies still have obvious and ubiquitous disparities. There are economic, political, financial, and health care disparities between individuals, social groups, cultural groups, nations, and races. There are less obvious disparities in this country in certain other areas, such as legal status and primary and secondary education.

A "material principle of justice" identifies a relevant characteristic on which burdens and benefits should be distributed:

A. to each person an equal share
B. to each person according to individual need
C. to each person according to individual effort
D. to each person according to societal contribution
E. to each person according to merit

Some theories of justice hold more than one to be valid. Most societies use all these material principles, applying them in different contexts. In our country, unemployment benefits use B, jobs and promotions use C and D, high incomes C,D, and E, and elementary and secondary education use A. Use of different material principles will lead to conflicts in distributive justice. Two patients need a transplant and only one organ is available. One child has been listed for 1½ years but is stable. Another child is much more ill but listed for 6 months. Currently, if the transplant in question is a liver, the second child will receive it based on need. If the transplant is lungs, the first will receive it based on equal share and fairness.

Justice theories select and emphasize one or more of the material principles. Egalitarian theories emphasize equal access, Marxist theories emphasize need, Libertarian theories emphasize a persons rights to social and economic liberty on the basis of contribution and
merit. Utilitarian theories use a mix of criteria to maximize public and private utility.

Public policies involving distributive justice are frequently built on material principles i.e. that of need. Such a policy might suggest that persons of equal need would be treated equally but would allow people of unequal need to be treated differently. Three people need treatment for pneumonia. One has private insurance. The two without other means would receive treatment at public cost (equal treatment for equal need). The patient with insurance would receive treatment but not at public expense (unequal need, allows unequal treatment). Some things are not fundamental needs. In the above example, perhaps only the patient with private insurance would get a private room. The others would be in semiprivate rooms because a private room is not a "fundamental need". Society needs to determine what these are. Nutrition, education, and basic health care have been suggested as fundamental needs. If you used a justice theory other than need, you would develop a very different system of distribution.

Public and institutional policies of distributive justice devolve from one or more material principle. Health care in the U.S. is a combination of libertarian (marketplace driven by the ability to pay), Marxist (Medicaid), and egalitarian (hospitals cannot turn away anyone who comes for care).

Material principles specify relevant properties that must be possessed in order to qualify under that principle. Other properties are regarded as irrelevant. Thus under a "need" based theory, income and social standing are irrelevant, only need is relevant. Sometimes the "relevant properties" are not obvious and must be established. An example is the setting of "criteria" for allocation of transplantation. In general, we consider it "unfair" or "immoral" to treat people differently based on differences for which they have no responsibility. Therefore, age, sex, race, national origin, and IQ are not usually considered relevant properties, but may be in special circumstances (it would not be immoral to exclude men from routine mammogram screening).

"Fair opportunity" may require unequal distribution of resources. More intensive instruction for slow learners, and more expenditures for health care for those with birth defects will mean more expense for them.

Society frequently makes allocation decisions concerning scarce resources based on justice theories, fair opportunity, and prevailing feelings about fundamental needs. In the late 60s, the patients on chronic renal dialysis and receiving renal transplantation were predominately white, male, married, high school graduates, and between 25 and 45. The controversy over this apparently "unethical" distribution of resources led in 1972 to the end-stage-renal-disease (ESRD) program. By the late 70s, the patients in the ESRD program closely reflected the incidence of renal failure in the various groups. Equal access (egalitarian theory) was nearly achieved. However the cost to society of this program has prevented its being duplicated for any other organ failure.
Should government be involved in health care allocation? If the government is involved, how much of its budget should be spent for health care compared to other societal needs such as housing and transportation? How should the health care funds be allocated, i.e. prevention vs. treatment? What categories of disease should have priority, HIV or cancer? Within each disease category, which technology or procedure should be funded? In general, physicians are asked to be advocates for their patients and ignore the public and societal implications of their decisions. The answers to these issues in macroallocation will shape the medical environment in the future just as they shape it now.

Microallocation decisions are those that decide which patient receives a scarce resource. This should not be an arbitrary decision, but one made through some standard procedure. A preliminary pool of candidates may be determined by standards such as citizenship, payor class, and prospect of success. If further decisions about allocation are necessary, the most ethical is something random such as a "first come, first served" or the "sickest first". Allocation based on the value of the recipient to society, age, number of dependents, are less defensible because they do not incorporate equality, fair opportunity, and equal access as well as random allocation.

Triage is another example of microallocation, but based on injury severity. Patients are rapidly assessed and divided into those who will die without immediate help, those whose therapy can be delayed without immediate danger, those with minor injury, and those in whom no therapy will be efficacious. This system to allocate care is justified because it maximizes success without considering "irrelevant properties" such as societal worth. However, if those with minor injury are physicians and treating them early on would serve the societal good by allowing them to help other injured, they might justly be given treatment priority they would not otherwise get. Their "societal worth" is valued for what it can do for the community.
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Patient-Physician Relationship

The nature of the patient physician relationship is determined by the society in which it functions. In the United States, medicine has been primarily focused on the good of the individual and therefore the physician has had that as their highest goal. In a communist society, the goal might well be different. The Hippocratic tradition of medicine suggested that the physician was dominant in the relationship, making decisions in the best interest of the patient without much input from the patient or their family. In 1980 the American Medical society mentioned "patient rights" for the first time in their Principles of Medical Ethics. Since then patient rights have evolved and been further defined in the Patient's Bill of Rights and many other documents supporting patient autonomy. The nature of the physician-patient relationship, then, is an evolving one.

Ethically, the relationship between a patient and a physician is a contract entered into by autonomous persons. Either party is free not to enter it. Patients are not generally obliged to see particular physicians if they choose not to do so, and physicians are generally not obligated to enter into this contract if they choose not to do so. Physicians may refuse to accept a patient into their practice for a variety of reasons, although not for reasons prohibited by laws concerning discrimination. Physicians and patients may choose to terminate a relationship, although physicians have an obligation not to "abandon" patients once they have entered into a relationship (contract) with them.

This freedom to choose patients with whom to have a "contract" is not absolute, but may be limited by other considerations. Physicians working in an ER must provide care to the patients seen in the facility. Physicians working under a contract with an employer such as an HMO or the US Government have obligations to patients in those provider groups. If a physician contracts with a payor they may need to see all patients covered by that payor. "On call" physicians have similar patient care obligations.

There are a number of "models" that have been proposed to describe aspects of the patient-physician relationship. Most patient-physician relationships have elements of more than one of these models. One utility of understanding these models is that they may illuminate some of the tensions and misunderstandings that arise when patients and physicians feel most comfortable in different models and haven’t worked out the differences.

The Engineering Model treats physicians as applied scientists. Physicians know the scientific basis of therapy, know the evidence behind their treatments, use tests to arrive at a diagnosis, and coldly apply science to treat the patient. Here physicians treat diseases, not patients, and are interested in facts not values. The current emphasis on Evidence-Based-Medicine fits well with this model, but few physicians and fewer patients would be comfortable with the absence of human values.
The Priestly Model suggests that since physicians are expert in medicine, they are expert in all other areas of life. It puts the physician in a position of moral dominance over the patient to the extent that the physician has the ultimate say in all decisions. The physician’s determination of beneficence takes precedence over the patient’s right to autonomy. This is really a reiteration of the paternalistic "Hippocratic" tradition mentioned previously.

In the Collegial Model, physicians and patients are equal partners cooperating in pursuit of a common goal. That goal may be the treatment of a disease, the prevention of death, or a death free of pain and suffering. The physician makes the treatment decisions without much ongoing consultation with the patient, but does so having considered all the patient’s life goals, desires, values, and history. This model requires great communication between the parties, often more than is reasonable to expect. It also requires great trust and confidence. This model of relationship is sometimes seen between patients and a "family doc" but not often between patients and subspecialists.

The Contractual Model compares the relationship to a business contract with a service rendered for an agreed upon payment. As in other contracts, there is no obligation other than that covered in the contract. The patient pays for the office visit but is under no obligation to follow the treatment plan or follow up with the physician. The physician renders the care at that visit but has no future obligation to the patient. In some ways this models the care given at walk-in care centers. Many aspects of our current care system have elements of the contractual model in them. Physicians expect payment for their services; patients expect to get something in return for their payment. But most patients and providers find the contractual model unsatisfactory to explain other aspects of their relationship.

The Covenantal Model’s name comes from religious terminology wherein there is an agreement that a relationship will be established as a result of two parties agreeing on their obligations. Some of the obligations to the physician are those imposed by society, that they act "ethically", are available to patients, and render scientifically acceptable care in a humanistic manner. The relationship is assumed to be permanent or at least open-ended and must be formally broken or it is assumed to still exist. There is assumed to be an understanding about each party’s role. The physician respects the patient’s values; the patient follows the treatment plan.
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Patient-Physician Relationship Workshop

Issue:

To try to bring some clarity to your relationship with a patient.

Activity:

Patient encounter

Instructions to "Physician"

You are meeting today with a 17 year old patient with longstanding asthma. You have followed this patient for about 5 years. The asthma is moderate to severe and persistent with daily symptoms. The patient uses 2 to 3 albuterol MDIs a month for symptom control. In the past the asthma was better controlled on inhaled corticosteroids, but over the past two years, the patient has refused any and all preventative drugs, saying, "they don’t work for me". The patient has had only one hospitalization in the past three years. The patient doesn’t like to take oral steroids, objecting to the acne they cause. Pulmonary function tests show an element of non-reversibility probably due to chronic inflammation. The local asthma specialists have all tried and failed to convince your patient to "take better care of their asthma".

The patient is here today because you refused to call in a refill for the albuterol without an appointment. No parent is present.

Please begin the discussion by saying, "I’m very worried about the risks you are taking by not taking better care of your asthma"
Instructions to the Patient:

You are a 17 year old with chronic moderate to severe asthma. Although you have abnormal pulmonary function tests, you feel fairly good. While it is true you cannot exercise to the same extent as some others, you do as well as many of your friends and exercise isn’t very important to you. Your family life is very dysfunctional. You have left home on a number of occasions and are now living in a shelter. A state program pays for your health care for children with chronic health problems. You actually see your nurse more often than your mother. While you frequently feel tight, your albuterol inhaler takes care of that. You are convinced that the other medicines are not useful to you and are no longer interested in even discussing their use. You want an albuterol inhaler, you want it as often as you decide you need it, and you resent the physician making you come in today in order to get it. As far as you are concerned, you are doing fine.

Your attitude is that the state pays your doctor for your care, and they should just take their money, give you what you want, and leave you alone. You are not in school, you get money by petty larceny and selling drugs, you have been arrested, you see no reason you cannot continue on this way indefinitely. Make up the rest if asked.

During the discussion that follows, you frequently state "Hey, Doc, just give me my prescription and let me get out of here!"

Answer the physicians questions, although as briefly as possible. Please do not "role-play" to the extent you walk out or refuse to communicate. Do not concede to "try one more time" or make any other commitment to be "more reasonable". You are difficult. Stay that way. Your response to your doctor’s statement that they are worried about your failure to take care of your asthma is, "Don’t worry, Doc, I’m doing fine. Just give me my prescription and I’ll get out of here"
Instructions to preceptor:

Divide the participants into teams of two or three. If you use two person teams, leave out the role of observer. Give the teams ten minutes to work through the exercise and warn them with two minutes left. Tell them to come to some kind of resolution by then.

Gather the group at the end of the exercise to debrief them. An important area for them to have explored was the patient's expectations from the relationship. Also ask, "what patient-physician model did the patient prefer". "What model did the physician in your group try to use? Was there a conflict between them?" Discuss what resolution was reached. If the conflict between the relationship models was too strong to allow an ongoing relationship, the physician may have discharged the patient. Did they offer to help find another physician? Did they make the discharge explicit and arrange to provide emergency care until the patient made other arrangements? Make sure they understand that they cannot "abandon" the patient.

Another acceptable outcome is that the physician was able to agree with the patient to limit their interaction to the "contractual" relationship for the present. A physician might agree to provide the albuterol to the patient but to give only a one month prescription. To get more, the patient would need to return for another visit, giving the physician additional opportunity to convince them of the desirability of a different treatment decision.

An important goal for this exercise is for the students to understand how differing expectations of the patient physician relationship can lead to conflict, and to help them to address these expectations and conflicts in a difficult situation. Another goal is that they understand their obligations to a patient even when there is conflict, and know what they have to do if they choose to terminate the relationship. Finally, they need to recognize that sometimes continuing an unsatisfactory relationship is the best option.
Morality

Our discussions of ethics have so far focused on ethical theories, principles and rules. We have discussed actions that are right and obligatory (truth-telling, informed consent), and actions that are wrong and prohibited (murder, unauthorized disclosure of medical information). In a broader context, ethics also encompasses morality, virtues, ideals, and character. These might be characterized as actions that are optional, but, when present, are praiseworthy and meritorious. In this section we will discuss these broader concepts. It would be possible to identify some of these as "professionalism", one of the "competencies" now being emphasized by the Accreditation Council for Graduate Medical Education.

We might describe someone as having high "ideals". That would suggest they had actions and attitudes that were in some way "better" than one would expect from the "average" person. Such actions might include volunteerism, mercy, forgiveness, and generosity. Such attitudes might include kindness, gentleness, sympathy, and patience. Sometimes the examples of such high ideals go so far outside the normal human experience that we describe the persons as "saints" (Mother Theresa, Albert Schweitzer), or "heroes" (a soldier who throws himself on a hand grenade to save others). We recently read of a young man who donated a lobe of his liver to a stranger after reading in a newspaper of her need. Living unrelated donors are more common but still unusual for renal transplantation. Less remarkable is a living unrelated donor for bone marrow. Blood donation to a stranger is so common as not to be noticed, but is still an action motivated by high ideals.

Some people have a habit or disposition to do what is morally right and praiseworthy. It might be described as a character trait. It leads the person to always or usually act in accord with moral principles, rules, and ideals. When we get to know such a person, we find that we can count on them to act in ways we view as "virtuous". We can "trust" them to act appropriately in many different situations. Trust is the opposite of "control"; it implies vulnerability. A person is "worthy" of trust if they display several of the actions and attitudes we defined above as "high ideals" along with honesty and integrity. A patient's relationship with a physician is dependent upon trust. Patients who hold their physicians in high regard will assume that poor outcomes are the result of "honest mistakes" or uncontrollable circumstances. Patients who do not trust their physicians often assume poor outcomes to be the result of poor physician judgement, carelessness, and negligence.

The degree of trust we have for others often is based on their jobs and positions. It is also dependent on our past experiences and on our general approach to life. Do you always carefully count your change at a toll booth or do you just drive away? Did you have a lawyer review the last contract you signed? Do you carefully go over the grocery receipt when you get home? How carefully do you research the physicians who care for family members? Do you have the same degree of trust in your physician, your auto mechanic, your local politician, and your pastor? The public clearly has high expectations about the moral
character of physicians. It expects that they will have high ideals, integrity and honesty.

Every parent knows that children are not born with high ideals. In fact, children are extremely egocentric and must be taught to share, to be honest, to think about others, etc. In the best of all worlds, these qualities would be consistently taught in homes, schools, the media, and in society in general. In such an ideal world, it could be assumed that every citizen had these qualities. In our less than ideal society, medical schools try to screen applicants for desirable qualities. Applicants rapidly learn what "actions" make them acceptable to admission committees and "actions" lose their ability to define "attitudes". While most of the physicians I know are "worthy" of trust, some are not. The issue of how to "train" them, how to "objectively" assess them, and the issue of how to deal with them is, has been, and will continue to be subject to debate.

The people who are most likely to be able to identify physicians-in-training who are not "worthy of trust" are other physicians-in-training. While none of us are comfortable with judging others, no one else is as qualified to do it. On a state-wide basis, this has led to the creation of Boards of Medicine with the power to remove a physician's license to practice. Similar peer panels exist in military academies. While peer review is less than perfect, can you think of a better way? Is there a need within your residency program to model, teach and assess professionalism? The ACGME thinks so.
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Divide yourselves into groups of 4 to 5 residents. Discuss the following scenario and try hard to come up with answers that you would be comfortable seeing in your own program.

"Morality/Ideals" Workshop

A second year resident is often late showing up for work, particularly on weekends and in the ED. He is frequently unavailable when he is called for "back-up". He seems to "forget" his weekend coverage more often than most. When his peers suggest he should be on time, he grins, shrugs, and seems unconcerned. His behavior doesn’t change. He is bright, has good clinical judgement, and is a lot of fun at a party. You are a resident in the program.

Is there a problem?

How should it be handled?