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Anna Rath

"Determination of Competence for Informed Consent"

Beginning in the 1950s, there was a shift in the paradigm of the doctor-patient relationship. The model lost some of its paternalistic leanings, and replaced them with a new notion of informed consent founded in patient autonomy. Faden and Beauchamp present the hypothesis that

Law and ethics, as well as medicine itself, were all affected by issues and concerns in the wider society about individual liberties and social equality, made all the more dramatic by increasingly technological, powerful, and impersonal medical care (Faden and Beauchamp, 87).

Thus, due to increased concern that physicians were not always putting their patients' interests first, and that they might not even have a full understanding of what those interests would be, the practice of requiring physicians to educate their patients concerning potential treatments, and to obtain the patients' permission before beginning a treatment, came into being.

As an expression of the ideal of shared decision-making, the doctrine of informed consent recognizes that while the physician commonly brings to the physician-patient encounter medical knowledge, training, and experience that the patient lacks, the patient brings knowledge that the physician lacks: knowledge of his or her particular subjective aims and values that are likely to be affected by whatever decision is made (Buchanan and Brock, 29).

For this to be an effective model for allowing patient participation in decision-making, certain criteria must be met. "The informed consent doctrine requires the free and informed consent of a competent patient to medical procedures that are to be performed" (Buchanan and Brock, 26). Thus, if a patient does not truly have understanding of the situation, or the options available, he is not truly informed; if the decision resulting from the information given is in any way coerced, that decision is not free; and if despite the attempts of the physician to facilitate the decision-making process, a patient is still unable to reach a rational conclusion regarding treatment, then the patient is not competent to be making decisions of that type. The remainder of this paper will focus on how this determination of decision-making capacity should be made.

Although the courts are always available to make such determinations, it is customary practice in the medical profession for a patient's attending physician to do so. In any event clinicians, of necessity, must provide the first level of screening

for incompetency, since the initial decision as to whether or not to accept a patient's decision rests with them (Applebaum *et al.* 1987, 83).

Because this responsibility often rests with the physician--a single individual, and the result of her decision will have tremendous repercussions for the fate of the patient--careful attention must be paid so that the determination is made in as fair and just a manner as possible.

If the label "incompetent" is placed on a patient or subject, a train of coercive events is potentially set in motion. The label "competence" commonly functions to denote persons whose consents, refusals, and statements of preference will be accepted as binding, while "incompetence" denotes those who are to be placed under the guidance and control of another (Faden and Beauchamp, 290).

My examination of the criteria for determining competence will proceed by using the model set forth by Bernard Lo as an example of widely held beliefs concerning important considerations in this determination. I chose the standards set forth by Lo as the basis for this critique because they were clearly articulated in the form of specific principles, which enables them to be specifically addressed. Some of these beliefs will be supported by the arguments which I will set forth, and others will be challenged with suggestions included as to possible alternatives.

In his article Assessing Decision-Making Capacity, Bernard Lo presents a series of three abilities to be used as clinical standards for decision-making capacity. These include the patient's recognition of the fact that he has the power to choose between various alternatives and his willingness to exercise that choice, the patient's appreciation of the medical situation, prognosis, and various alternatives presented, and finally the compatibility of the patient's decision with his values and goals and its consistency over time. The extent to which a patient must exhibit these-the proof of competency--is determined by a sliding scale based on the inherent risk associated with the treatment decision (Lo, 196-7).

The first two of Lo's criteria are principally objective, and are important for the determination of a patient's competence for making a decision. The third criteria, however, contains a highly subjective determinant—that a patient's decision is compatible with her values and goals. Because in many cases the physician is given license to determine a patient's competency, I will argue that this third standard results in an inherently unequal physician—patient relationship when discussing treatment options, and further that when used as a determination of competency, it can actually lead to a patient's values and goals not being represented by the final treatment decision. If a patient faces the possibility of being declared incompetent for making a decision which is atypical of the standard rational agent, this could result in coercion of the patient; if it is the doctor who has the power to declare the patient incompetent, then the patient is not truly free to discuss her views with the physician without fear of repercussions, and thus an inherent inequality exists.

Therefore, the Lo model should be altered to remove this portion of the third criteria. In addition, I will argue for a different basis for the sliding scale. A model should be adopted which reflects the risks involved with the proposed treatments, rather than those involved with the decisions regarding those treatments.

Before reaching a decision on how competency for decision-making should be determined, the importance of this capacity must be determined. Why is it essential that a patient be competent to make decisions concerning his treatment? After all, a physician will always attempt to provide treatment that is in a patient's best interests, and it seems that the physician, given her expertise in the medical field, is probably more well-qualified to make this determination. The problem with this assumption is not only that it ignores a patient's intimate self-knowledge as a qualification, but also that it ignores a patient's right to autonomy.

There is a long tradition in medicine that the physician's first and most important commitment should be to serve the well-being of the patient. The more recent doctrine of informed consent is consistent with that tradition, if it is assumed that, at least in general, competent individuals are better judges of their own good than are others (Buchanan and Brock, 29).

The reason that competence and informed consent are essential is that they ensure respect for a patient's decisions regarding her own treatment, and the interest that the patient has in making significant decisions about her life.

The concept of competence in decision-making has close ties to the concept of autonomy.... Although autonomy and competence are different in meaning (autonomy meaning self-governance; competence, the ability to perform a task), the criteria of the autonomous person and of the competent person are strikingly similar. Two plausible hypotheses are that an autonomous person is (necessarily) a competent person (for making decisions), and that judgments of whether a person is competent to authorize or refuse an intervention should be based on whether the person is autonomous (Beauchamp and Childress, 135).

Thus, in order to respect a person's right to autonomy, we must ensure that he is competent to make a decision regarding the issue in question.

To respect an autonomous agent is, at a minimum, to acknowledge that person's right to hold views, to make choices, and to take actions based on personal values and beliefs. Such respect involves respectful action, not merely a respectful attitude. It also requires more than obligations of nonintervention in the affairs of persons, because it includes obligations to maintain capacities of autonomous choice in others while allaying fears and other

conditions that destroy or disrupt their autonomous actions (Beauchamp and Childress, 125).

The portion of this which is not provided for by the Lo model is the "obligation to maintain capacities of autonomous choice." Because he allows for determination of competence in retrospect, once a decision has already been made, there is less assurance that autonomy is being respected during the decision-making process.

Competency should be determined by the patient's ability to make a rational decision, not the particular decision she chooses to make. Whether a person is competent must be ascertained prior to the actual treatment decision being made. The level of proof of competency required for consent or refusal of a medical treatment should then be dependent upon the severity of the treatment and the decision which must be made.

Let us begin by examining each of Lo's three proposed standards.

1) The patient appreciates that he has a choice. That is, the patient must realize that he has decision-making power, not the physician or family members. (Of course, one way for the patient to exercise that decision-making power is to ask the physician or relatives to decide.) Unless the patient appreciates his power to make decisions, he may not play an active role when plans of care are discussed. In addition, the patient must be willing to exercise his decision-making power and to make a choice among alternative courses of care (Lo, 196).

This is seemingly very simple; but it is truly an extremely important criterion, and should be regarded as such. If the patient does not think that she is controlling the outcome of treatment, it is unlikely that she will consider all options as seriously, or spend as much time in deliberation of consequences. For instance, a patient may assume that the physician will do what he sees fit regardless of the decision of the patient, or that other family members will have a say in what will happen. A significant component of informed consent is the knowledge that the consent one is giving is actual and will result in action being taken.

2) The patient appreciates the medical situation and prognosis, the nature of the recommended care, the alternatives, the risks and benefits of each, and the likely consequences. In decisions about life-sustaining treatment, the patient should realize that declining treatment is an option and that such refusal may hasten his death. Philosophers have stressed that it is not enough to understand the issues in an intellectual way--for example, that angioplasty or bypass surgery will probably relieve chest pain, but that there is considerable perioperative mortality. In addition, the patient needs to apply this information to her own situation (Lo, 196).

Embedded in this standard is what is generally regarded as informed consent. It is important to note, as Lo does, that informed consent requires more than a surface understanding of the situation and options; it requires that a person is able to take these abstract ideas of pain, death, etc. and realize what they would mean for her. Especially when the decision involves issues such as potential death, loss of limbs or extreme pain, it is often very difficult for a patient to truly understand these possibilities, as they are so distant from her present reality. For instance, saying that there is a twenty percent chance of death involved in a particular treatment may

not be sufficient to make the person understand that she should be certain that her affairs are in order before undergoing the treatment.

Another example of this would be knowing that the country is going to war, but not understanding the personal implication that a close friend who is a member of the reserves will be called on to fight and could potentially die. This, however, is a realization that could be achieved, given enough information; if someone were to sit down and explain this implication, it would not be difficult to conceive. However, this is not necessarily the case with issues surrounding medical treatment. It is often argued that states of being cannot be fully understood unless one has experienced them firsthand; this means that as a person, I cannot truly conceive of what it would be like to be a plant. More relevant to the present discussion would be the assertion that as a person with four fully-functioning limbs, I could not possibly fathom what it would be like to be paraplegic. Following from this would be the argument that it is illogical to expect patients to be able to make rational decisions regarding treatment options because they can not really be informed of the potential outcomes: they cannot conceive them.

As the response to this could alone provide the material for a separate paper, I will sidestep the issue for the purposes of this paper by pointing out that because these choices present themselves, someone must make the decisions. Also, even if it would not be possible for the patient to acquire a complete and full understanding of the possibilities of conditions such as paraplegia, it would be possible for him to conduct research by reviewing literature or by questioning a physician, which would lead to an adequate understanding. Because the patient is the person with the most intimate knowledge of his own values and goals, and thus the most likely to be able to determine how these possibilities would affect him, even if his understanding of some of the outcomes is limited to some extent, he is still the best qualified to make the decision.

Ascertaining this type of competency can be executed by asking a patient to paraphrase information that has been disclosed to her, and asking what she thinks is likely to happen if a treatment is accepted or declined. Ensuring that a patient understands probable outcomes of particular treatments would be an effective way of making sure that the patient understands the repercussions of the treatments for herself, rather than just in general. The physician must be confident that the patient is not only receiving the information, but is also able to use it to help her reach a decision concerning treatment.

3) The patient's decision should be stable over time and consistent with his values and goals. Some indecision is natural and understandable and does not call into question the ability to make decisions. Some persons, however, change their minds back and forth repeatedly without any changes in external circumstances, so that it is impossible to carry out plans for medical care. It is sensible to agree that such profound vacillation demonstrates that a person is incapable of making a decision, let alone an informed one. In addition, people may change their minds, particularly as their situation changes, as they receive more information or advice, or as they deliberate. Such changes, of course, should be respected (Lo, 197).

Requiring that a decision is stable over time helps to ensure that it is truly an autonomous decision which will not be easily overturned or affected by the

introduction of new information. This criterion is important for two reasons. First, if a patient is not able to stick to a particular decision, this is good reason to call her competence into question. The patient may be so overwhelmed by the situation and scared at the repercussions of whatever the decision may be that she can not commit herself to actually making the decision. In this case, she may require simply that the physician sit and discuss further probable treatment outcomes with her, or possibly that a proxy be appointed. Whichever the case, this is surely a relevant concern regarding capacity. The second reason that this criterion is important is that if new information is sufficient to easily overturn the patient's decision, then that decision is most likely not completely autonomous. Hopefully, the patient has received enough information regarding the potential treatment to reach a decision which would not be affected by any new information. If this is not the case, then the decision can not be regarded as a truly informed decision.

However, requiring that it be consistent with a person's values or goals is simply too subjective to serve as a standard for competence. Lo does not elaborate on this idea of a decision being in a patient's best interests here, but he addresses it further later in the article.

Patients may refuse treatments even though physicians believe the benefits far outweigh the risks. When this occurs, physicians should keep in mind their duty of beneficence, to act in the best interests of their patients. Further efforts are appropriate to assess whether the patient is truly informed and has the capacity to make decisions. The amount of effort by physicians should be proportional to the likely consequences of the patient's refusal. The greater the potential harm to the patient resulting from the refusal, the greater the duty on physicians to probe for misunderstanding or lack of capacity (Lo, 200).

In other words, a physician is supposed to call into question the capacity of the patient, his ability to make a decision, simply because he has made a decision which the physician does not consider to be consistent with his values. This seems very problematic; it implies that the physician is more capable of assessing whether a decision is in accord with the patient's goals and values than that patient is of making a decision which reflects those goals and values. Each person is an individual with a lifetime of distinct experiences which contribute to the formation of his own personal attitudes and perceptions. Because of this, it would seem impossible for a physician to have knowledge of all of the various inclinations of a patient, or even all of those that could affect a particular treatment decision.

People are project pursuers; the particular projects toward which a person works are a defining characteristic of that person, and have a significant effect on her values and goals. For instance, if a person's project is acceptance to a particular, very competitive graduate school, that person will value studying for the GREs much more than a person who plans to attend a less competitive graduate school or no graduate school at all. Because these projects can be viewed as defining a theme and/or a direction in a person's life, it is considered to be in the best interests of people that

they be allowed to pursue them, and an infringement on their right to autonomy for someone to impede their pursuit of these projects.

Thus, if a patient makes a treatment decision which does not coincide with his values and goals, then that decision is not in his best interests. As discussed earlier, it is not practical to think that a physician would have a full understanding of all of a patient's values and goals. For this reason, the criterion for determination of competency, that a treatment decision not conflict with the values and goals of a patient, is often reduced to the idea that the decision must be in the best interests of the patient. Physicians may then consciously or unconsciously utilize a more general notion of what things are in the interests of a rational being as a substitute for probing to find out what exactly is in the best interests of a specific patient. Either way, the intention of the criterion as a method for determining competency is perverted; and instead the physician is given license to label incompetent anyone who makes a treatment decision which the physician does not regard as being in their best interests. This does not allow for patients making decisions for highly personal reasons, or reasons that are not accepted as rational by the physician determining competency. Do we really want to question a patient's competence just because he has made an atypical decision concerning treatment?

It could be claimed that this would be merely a case of bad practice, and does not represent a significant counter-example to the Lo model. However, it seems impractical to place on the physician the burden of probing the patient's entire life history in order to discover all of the influences which may have shaped her values and goals and to come to a complete understanding of the same. Also, I would argue that nothing short of this would give a sufficient picture of the influences which may pertain to a certain case. It is naive to think that a physician could, in the context of a typical physician-patient relationship, garner an adequate knowledge of a patient's values and goals to be able to assess her competency based on the agreement or disagreement of her treatment decisions with these values and goals.

When the physician's idea of what is in the patient's best interests, and the patient's decision regarding treatment conflict,

It may be difficult or even impossible to determine whether this conflict is simply the result of a difference in values between this individual [patient] and most reasonable persons (for example, a difference in the weights assigned to various benefits or risks), or whether it results from some failure of the patient to assess correctly what will best serve his or her own interests or good (Buchanan and Brock, 40).

For this reason, consistency with a patient's values and goals must be removed as a standard for a competent decision except as it can be determined by the consistency of that decision over time and by the ability of the patient to provide justification based on an understanding of consequences (as provided for by the second standard) for the decision reached.

Giving the physician license to question a patient's autonomy on subjective criteria results in an inherent inequality in the physician-patient relationship, which

fosters coercion rather than true informed consent. The fact that the physician has the role of determining competency at all means that there is necessarily a small amount of inequality. However, if the assessment is based on reasonably objective criteria, this inequality does not have to foster coercion. When, on the other hand, a patient knows that making an atypical decision, one which the physician would not agree is in the patient's best interests, could result in being declared incompetent, and in the loss of power and autonomy that would accompany this, it is evident that the physician's power is out of proportion in this decision-making process. Rather than educating the patient, and allowing the patient to reach his own decision after it has already been determined that he is competent and capable of doing so, the physician starts with the decision of the patient, and calls his competency into question whenever that decision seems atypical or not in the patient's best interests.

The ability of a patient to make a rational decision should not be determined after the decision has already been made, based on what that decision is. It should be determined long before this point, according to the other criteria that Lo has presented. If the physician is able to determine that the patient knows that she is making a choice, can understand all of the information relevant to that choice and is capable of making a decision that will remain consistent over time, then that patient should be allowed to make that decision, and should not have her competence called into question as a result of it.

The basic view is that if a patient is able to make a decision, but unable to make it in the preferred manner, then the decision is somewhat less of a decision and deserves less to be honored.... The most fundamental problem with this approach is that a standard by which the nature of the decision determines whether the patient is incompetent seriously undermines individual autonomy (Applebaum *et al.*, 86).

A much better scenario would be for the physician to question the decision with which she is in disagreement, and to ask the patient about his reasons for making the decision. The physician is still free to attempt to persuade the patient, and offer additional information which may be helpful, but now the physician and patient are discussing the treatment as equally competent and rational beings, rather than the physician having the power to label the patient incompetent for refusing to concede that the physician is correct. Thus, by eliminating the criterion that a patient's decision coincide with her values, the ability of the physician to practice beneficent medicine is in no way hindered. She may still call into question any decision which does not appear to coincide with the best interests of the patient. However, the result of this decision being called into question could only be that the decision is overturned after the physician has presented more information, or that the patient is able to convince the physician that the reasoning behind the decision is truly in agreement with his values and goals. The patient's capacity for rational decision-making would not be questioned.

Allowing a patient's decision to be a possible basis for labeling them as incompetent produces an inherent inequality in the doctor-patient relationship which can result in coercion.

If the decision is not voluntary, but instead coerced or manipulated, it will likely serve another's ends or another's view of the patient's good, not the patient's own view, and will in a significant sense originate with another and not with the patient (Buchanan and Brock, 26).

Bernard Lo's model for determining the capacity for decision-making is based on a sliding-scale theory for the determination of competence. The reason for this is that competence is specific to the particular issue in question rather than being a blanket statement about a person's state of being. In other words, because a patient may be incompetent to feed herself or to walk unaided, this does not mean that the patient can not make autonomous decisions regarding treatment. Because competence is generally regarded as the ability to perform a certain task, it follows that the criteria for determining competence should be specific to that task.

Competence is always competence for some task--competence to do something. The concern here is with competence to perform the task of making a decision. Hence competence is to be understood as decision-making capacity (Buchanan and Brock, 18).

However, when we are discussing only one task, that of rational decision-making, it seems problematic to think that simply because the risks involved in a decision are greater, it is somehow more difficult to make the decision. Rather, it seems that decision-making ability is a constant for a particular person, more of a threshold value. This does not mean that we should abandon the sliding scale. Although the ability may not change based on the particular decision to be made, our need to ascertain that the decision is being made truly autonomously does. We are much more concerned that the patient is making an autonomous decision when that decision could include death than we are when the decision is simply whether to take painkillers for relief of suffering (provided there are no serious side-effects of either taking or not taking them). Thus it is reasonable to require a higher level of competence, or perhaps a higher assurance of competence, in a case where the decision to be made entails greater risk to the patient.

But there are potential problems with such a sliding scale. Determinations of incapacity may be made inconsistently on different patients or by different physicians. A sliding scale might give too much weight to the views of physicians regarding the harms and benefits of medical treatment, rather than the views of patients. It might allow physicians to exercise control over patients who disagree with them (Lo, 195).

The first of these worries, that too much weight would be given to the views of physicians concerning harms and benefits of medical treatment, can be overcome by establishing guidelines which would require certain levels of competency for certain risks involved. This ranking of potential harms could be carried out by a panel of experts, or alternatively by surveying a cross-section of the population concerned in order to determine what risks they considered to be more or less severe. Either of these methods could be used to make a reasonably objective standard by which a given treatment could be measured. Then, based on the seriousness of the risks involved with this treatment, the physician could be more or less stringent in determining the competency of the patient based on the aforementioned criteria, not on the decision made by the patient.

Lo's current third standard, which allows the decision itself to be a measure of the patient's competence, is open to the second critique offered by the above quote: that physicians would be given license to exercise control over patients who disagree with them. By allowing a patient's decision to be reflective on their competence to make that decision, the physician is empowered to question the competence of any patient who makes a decision which the physician does not agree with. This allows for considerable abuse on the part of physicians who may not agree with the personal convictions which lead to a particular decision, or who do not wish to take the time to attempt to persuade patients that their decisions may not be in their best interests. Also, this results in a physician not questioning the competence, or more importantly the decision, of any patient who makes a decision with which the physician is in agreement. What if the patient has made a preliminary decision which is not in his best interests based on limited information?

Lo contends:

Determining whether a patient is incapacitated is clinically significant only if medical decisions would change.... There is little practical purpose in challenging the decision-making capacity of a patient when the physician believes that her decision is in her best interests (Lo, 195).

This is problematic because it assumes that the physician will always know what is in a patient's best interests. In order for this to be true, the physician would require a knowledge of all of the patient's values and goals, which most physicians do not have. Consider a situation in which a physician discloses only certain information to a patient. The physician does this not to intentionally manipulate the patient, but rather because he or she considers it to be the only relevant information needed to make the decision. Based on this limited information, the patient makes a treatment decision which the physician agrees is in her best interests, and the physician proceeds to procure this treatment. However, had the physician probed further, he would have discovered that the decision made did not actually agree with the patient's values because the information necessary for the patient to realize this conflict had not been disclosed. Therefore, the patient was not sufficiently informed, and the decision was not autonomous. The physician allowed the decision anyway, without

questioning the patient's competence, because it was considered to be in the patient's best interests as the physician had interpreted them.

A similar problem could arise using the proposed revised model for determining patient competence as well. However, because the revised model assumes that a patient must be determined to be competent before the actual decision is made, it would be necessary to rely more heavily on alternate criteria, especially the second of the aforementioned criteria. By placing more emphasis on the patient's understanding of treatment alternatives and their outcomes for determination of decision-making capacity, the physician should be better situated to garner information about the patient's ideas and concerns regarding treatment outcomes than if the question of capacity did not come up until after the decision had already been made

Lo does address the possibility of using a model without this sliding scale; he contends that "Overlooking the decision itself, however, ignores the harm that it might cause the patient" (Lo, 197). What needs to happen is not the complete elimination of the sliding scale, but rather a revision of it. By basing the sliding scale on potential risks involved with a particular treatment, a greater level of objectivity can be obtained, while still taking into account potential harm to the patient. One worry that comes with preventing a physician from questioning competency based on a patient's decision is that it could potentially inhibit the ability of the physician to ensure that a patient receives treatment which is "truly" in his best interests. This is actually not the case. Simply because a physician would not be allowed to question the competency of a patient at the time the decision is reached does not mean that she could not attempt to persuade the patient that the decision reached was impractical. However, in this situation the patient and physician would be operating as equals, negotiating and giving rational reasons for why a particular decision should be made. The patient's competency would have already been established. This is a much more appealing alternative than a physician assuming that a patient is incompetent because of an atypical decision.

In his model for assessing decision-making capacity, Bernard Lo presents some extremely valuable criteria for making this assessment. He recognizes that in order to make an autonomous decision, a patient must realize that he is actually making that decision, must be able to understand all of the alternatives and their implications, and must be able to make a decision which is consistent over time. All of these are very necessary and insightful criteria. However, the portion of the third criteria which suggests the actual decision as a basis for determining competence should be stricken, as it is too subjective and places too much power in the hands of physicians. With this criterion eliminated, in order to ensure that potential harm to the patient is still taken into consideration when determining the level of proof which is required to determine competency, the sliding scale on which this model is based should be altered slightly. It should have as its basis a more objectively determined ranking of potential treatments based on their possible risks and benefits; those involving greater risks should necessitate a higher level of proof of competence. With these changes, the Lo model for determining competence could be put to use without fear that physicians would abuse their power in determining a

patient's capacity for rational decision-making, and with the assurance that competent patients would be making free and informed decisions.

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