

MAXIMIZING PATIENT AUTONOMY BY UNDERSTANDING INFORMED
CONSENT IN CLINICAL PRACTICE

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ABSTRACT

Medical decision making is complicated and requires a full understanding of the options being presented. It is easy as a practitioner to assume that a patient has capacity, when in fact they might not. Evidence indicates that frequently with the best intentions, health care practitioners allow people to make medical decisions when they do not understand the implications of that choice. I believe that this happens when practitioners feel that the patient is autonomously making a choice that promotes beneficence. This too creates an ethical dilemma, as it does not fully promote autonomy if the patient does not have capacity to make the decision. I believe that further reflection can help physicians understand what motivates their patient's, and their own, decision making.

This thesis is dedicated to:
The professors and leaders of the
Lewis Katz School of Medicine Urban Bioethics Department
and to the hundreds of patient's
who's lives and expriences have shaped my own.

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CHAPTER 1: INTRODUCTION

Autonomy

Autonomy is one's ability to make decisions for themselves. In the context of medicine, this is understood as a person's ability to choose what actions are taken in their medical care, including engaging in medical interventions, undergoing procedures, and the option to reject said interventions. Throughout history, the medical community has not always viewed individuals as necessary participants in their treatment which drove the medical community to strive to engage patients in their care and the decision making process (Varelius, 2006).

Beneficence

Beneficence as applied to medicine, is most easily understood at the principle of doing what is best for the patient. This means that a physician should consider what is in the patient's best interest before acting. The concept sounds simple, but is more complicated when considered with the previously stated principle of respecting patient autonomy. What is the correct course of action when the physician and the patient want different things? It is easy for physicians to feel that we know what is best for a patient, based on years of training and studying medical literature about how diseases "should" be treated. It is equally easy for individuals to feel that they know what is best for them,

based on years of life experience, and the unique perspective that comes with having to live ones own life and suffer the consequences of choices.

The idea of doing what is “best” for a patient necessitates understanding what that person wants, and prioritizing their desires for exactly the reason that individuals are the only people in the world who can truly understand their experience and their own life. It would be presumptuous for a physician to assume that they know what the best outcome for a patient is, even if they might know the best steps that medicine can offer towards various outcomes. For example, it is not clear that everyone wants to live as long as possible no matter what. For that reason we as a community have decided that people should have the option to request that no extraordinary resuscitation measures be taken if their heart should stop under medical care. As another example, not every person wants to donate their organs for medical use, even if said donation would be feasible upon their death. If the medical community were to prioritize the value of beneficence, doing what is best, then this principle would align with not allowing for choice after death, and would necessitate that organs that could save another patient’s life be donated to that person. This is not how medicine is practiced however. The American medical community places an enormous amount of weight on the principle of autonomy. For that reason, individuals are given the ability to choose while they are alive whether or not they would like to become organ donors after death.

Capacity

The two principles of autonomy and beneficence are potentially conflicting, but easily balanced when the patient is able to fully understand and communicate their views. A problem arises when there is a question of whether or not the patient understands the question that is posed to them. If they do not understand, then ethical guidelines indicate that a physician or third party should make a choice for the patient. This idea allows room for subjective judgment, and is delicate and contentious in practice.

It is dangerous to allow subjective decision-making about which individuals cannot make important decisions for themselves, and also dangerous to ask people to make serious choices about their healthcare if they are not well enough to understand the options. The Medical Treatment Planning and Decisions Act of 2016, published in Australia, specifies that “a person has decision-making capacity to make a decision to which the Act applies if the person is able to: a) understand the information relevant to the decision and the effect of the decision; b) retain that information to the extent necessary to make the decision; c) use or weight that information as part of the process of making the decision; d) communicate the decision and the person’s views and needs as to the decision in some way, including by speech, gestures, or other means,” (Hempton and Bhatia, 2019).

The outlined the guidelines of “capacity”, meaning that a patient must be presented with all information, and be able to clearly understand the decision that they are making in order to be deemed capable of making said decision. The patient must be presented with all information so that they are making an “informed decision”. In certain instances a person would not be capable of informed decision-making.

The threshold for who has capacity sounds clear-cut, but as with most things in medicine, it is not. A low threshold for having capacity is the idea that a person has a certain level of cognitive ability, often assessed by asking “orientation questions.” A patient has to be able to state their name, where they are, and the date in order to be considered oriented to “person, place, and time”. For example, a patient who is unconscious or heavily sedated would not be alert or oriented. Patients who are not oriented are not considered to have a high enough level of cognitive ability to manage more complicated tasks such as decision making.

A higher threshold for capacity to make decisions mandates that the patient be able to describe the information that was presented to them, and that they are able to understand it. They must be able to show understanding by being able to describe or state the consequences of making or not making the decision. If they have been given all relevant information in a clear and appropriate way, and they are not able to understand the outcomes, then they are deemed not to have capacity.

Capacity Assessment In Practice

This line is significantly harder to draw. A few challenges arise with this standard. The requirement that someone understand the consequences of accepting or denying treatment hinges on the concept of understanding. While it might seem simple enough, it is actually fairly difficult in practice to determine what constitutes true understanding. Understanding can be complicated by cognitive impairment, low health literacy, intoxication, anxiety and fear, etc. Some physicians feel that the ability to repeat outlined

consequences indicates understanding. Others feel that true understanding requires being able to discuss those consequences and offer reasoning as to why one outcome is better than another. Unfortunately, evidence indicates that physicians often overestimate patient's capacity for decision making, in both medical and mental health settings.

A 2001 study published in the *Journal of Aging and Mental Health* found that 48% of patients lacked capacity to consent to voluntary admission to a geriatric psychiatry facility, but that the concordance between this retrospective assessment and their admission records was 0.6. The majority of the patients were admitted voluntarily to psychiatric inpatient care informally despite lacking capacity to consent to the admission because they did not dissent (Mukherjee and Shah, 2001).

This problem is not unique to psychiatric settings, and is pervasive on medical floors as well. A systemic review published in the journal *Clinical Medicine* aimed to estimate the prevalence of incapacity to consent to treatment or admission in different medical and psychiatric settings, and to compare the two. The authors reviewed 58 studies, 35 of which were in psychiatric settings, and 23 of which were in medical settings, and conducted a meta-analysis of the 70 data sets that they included in order to compare rates of capacity between the two settings. Weighted average for incapacity of patients in psychiatric settings was 45%. Weighted average of incapacity for patients in medical settings was 34%. The two groups were not significantly different from one another in terms of proportion of incapacity ($p=0.92$). This analysis highlights how few patients in clinical settings actually have capacity to consent to treatment (Lepping, Stanly, Turner, 2015).

A study conducted in Greece in 2017 aimed to assess decision making capacity of patients admitted to psychiatric hospitals with schizophrenia, and to medical floors with various medical illnesses using the MacArthur Competence Assessment Tool for Treatment (MacCAT-T). The authors found that while medical patients scored better than psychiatric patients overall, there were still cases of patients who lacked decision-making capacity in the first days of hospitalization, with higher age being associated with lack of decision making capacity. Both populations included patients who did and did not meet standards for capacity. The authors concluded that the ability of patients to consent to treatment should be re-assessed during hospitalization, and when restored, informed consent should be obtained by physicians. (Bilanakis, Peritongiannis, and Vrasista, 2017).

A study 1981 study of 50 psychiatric patients who were admitted to inpatient units voluntarily determined that the majority of patients who were interviewed as new inpatients did not meet the legal standard of competency to offer informed consent to hospitalization (Applebaum, et.al, 1981). Unfortunately, this scenario, while common in a psychiatric population, is not unique to this population as outlined by the example above.

In a short paper published in JAMA, Drs. Sessums, Zembrzuska, and Jackson outline a clinical scenario where an elderly patient is being admitted for a total hip replacement, and has known Alzheimer disease with a low score on her Mini Mental Status Exam. The physician in the scenario consents the patient for surgery, and questions at the start if the patient has capacity to offer her consent. They note that patients are frequently assumed to have capacity to make medical decisions unless proven otherwise (Sessums, Zambrzuska, Jackson, 2011).

As a young physician, I have seen this example play out time and time again in a clinical setting. I remember many patients who presented voluntarily for treatment because they felt that they were not quite themselves, and needed help. These people were asked to sign into the hospital, and they frequently did so. If people have brought themselves to a hospital asking for help, then we as the medical team assumed that they understood that they were in a place to be medically treated, and that they were safe there and wanting to be there. The evidence presented above indicates how wrong this assumption might be.

CHAPTER 2: CONFLICT BETWEEN AUTONOMY AND BENEFICENCE

A patient can have a full understanding of a decision, and come to a different conclusion that the physician thinks is best. This is a difficult position for all to be in. It is easy in this case for the physician to feel that they patient must not really have understood the choices, or they would have made the “right” choice, which would be the choice that the physician has made.

Lepping and Raveesh address this conflict in an editorial published in the British Journal of Psychiatry in 2014. They write, “All serious ethical frameworks consider a numver of competing ethical principles, of which autonomy is only one. Most famously, Beauchamp and Childress postulated beneficence (‘do good’), non-maleficence (‘do no harm’) autonomy and justice. These principles were always meant ot be taken into account together when solving ethical problems.” Here they address the conflict between the principles, but imply that they should not be considered as one versus the other, but should be weighted. The question lies in how you weight them against each other and in what settings should one be valued over the other.

How can this problem be addressed? I believe that the answer is in careful self-reflection.

When The Patient Disagrees With You --

Tackling this situation requires that the physician first investigate our own understanding of the choice. Why do we as the physician think that one choice is better? Is there information that we have, that perhaps we did not offer or explain clearly to the patient? Or are we biased to a certain choice based on our own values and perspective? Is

there something about our perspective that is rooted in scientific fact that the patient may not know.

Is our choice different than the patient's based on a personal value system? Is the decision to choose the other path uncomfortable for the physician or healthcare team because we are emotionally pulled another way? I saw repeated examples of this conflict while working with palliative care patients and their long time doctors. It was frequently quite difficult for physicians who felt that "more could be done" to accept a patient or their family's decision that more should not be done to prolong that person's life. In many cases, the decision was medically sound either way. I remember meeting a 75yr old man who was originally from Haiti, and was diagnosed in the hospital with a large, but not yet metastatic stomach cancer. The man had a 14 year old son for whom he was the sole caretaker. Oncology was consulted and they came to meet the patient. They explained what the CT scans he'd had showed, and what his biopsy results were. The doctors were confident that with chemo, surgery, and radiation this patient could have a fairly optimistic prognosis, despite his weak state. All of this was explained to him by the oncologists and by his primary medical team. It was made clear to him that he had an aggressive cancer that would certainly kill him, but that it appeared to have been caught in a stage where intervention may be able to significantly prolong his life.

The man called his brother and made arrangements for the brother to come to the hospital with legal paperwork to become the guardian of his child. He filled this paperwork out with his brother. He explained to his son from his hospital bed that his cancer would kill him and that the boy's uncle would take care of him. He told the medical team that he was not interested in treatment, and that God had chosen this path

for him. He did these things not because he didn't understand that there were options to prolong his life, but because his value system prioritized full faith in a higher power's ability to heal and to choose his path.

The medical team tried repeatedly to change this man's mind. We as a team went to explain to him multiple times what kind of cancer he had, what his options were, and that he could live longer than a year with treatment. I remember the man staring into the distance over my shoulder. I remember his bright blue eyes and his tears as he talked about his child. He certainly cared about his son. He also clearly understood that he would die without medical treatment for his cancer. He also understood that I did not understand. I did not understand his perspective and his faith. I knew that it was present, but I did not understand it in a way that allowed me to empathize with his decision. I learned from that man how both physician and patient must sit with discomfort. It was uncomfortable for the medical team to accept that someone's life could be longer if he were to choose treatment. In this case, the man did have the capacity to reject treatment, and was fully aware of the consequences of this choice.

When The Patient Agrees With You --

In cases where the patient does make the choice that the medical team hopes they will make, it can be easy to accept this choice without question, and to assume that they made the choice for the same reasons that we, the medical team, would have. This is not always the case. It is critical that as a second step, physicians make an effort to understand from the patient why it is that they have decided to engage or not engage in a certain treatment or option regarding their care. This again requires critical self-

reflection regarding what values, information, and beliefs have driven us to believe that a certain decision is best. It then requires asking a patient what it is that has led them to make a choice. People can arrive at the same destination via different paths. As previously stated, making assumptions about what has motivated a patient's choices can lead us to misunderstand what is important to them, and to draw the wrong conclusions down the road when additional choices need to be made, as in the example of the patient who presents for detox, but then declines to go to rehab services once they are sober.

When The Patient Cannot Consent –

If a patient cannot offer informed consent, then best practice requires that the physician makes the choice that maximizes good outcomes and does the least harm to that person. This is frequently interpreted by standards and values that the medical world has created over time. For example, if a person cannot say that they do not want to be resuscitated in the event that their heart stops, then they are made “full code” on admission to the hospital. This is not inherently a bad thing, or harmful to patients, but it is a reflection of the imposed medical value system in the absence of one's ability to advocate differently for their self.

Regularly in clinical settings there are decisions that need to be made in which a patient makes the choice that the medical team thinks is best. If the patient has capacity, then this is an easy moment in which the patient autonomously chooses to do what the team thinks maximizes beneficence. An ethical conflict arises in the moments in which the patient “might” have capacity? What should be done in moments of uncertainty? If

the patient is making the “right” decision, but it is not clear why they are making it, or that they understand the consequences, should the physician be willing to accept that choice? What should the physician do if the ability to make an autonomous choice holds significant beneficial consequences to the patient?

A common example can be seen in admissions to psychiatric care. Involuntary admission to a psychiatric hospital remains on a person’s record and can carry with it significant consequences. In the state of Pennsylvania, a person who has been involuntarily committed might have to report this to certain employers, for example in medical fields or education, and cannot hold a gun license. They also might suffer from trauma of being hospitalized against their will. This is a loss of certain privileges that are afforded to most citizens, such as the freedom to conceal health records from ones employer, and the right to bear arms. Due to the long-term consequences of this decision, many physicians prefer to let people sign into the hospital voluntarily if they are willing and sober.

The question remains, is this ethical? The choice to sign in to the hospital does maximize patient autonomy. It also might maximize good for them and minimizes harm by avoiding the long-term consequences of involuntary admission. This is an example of the patient making the choice that the physician hopes they will make, but not necessarily for the same reasons. In this moment, it is imperative to consider why the patient made the choice, and why the physician wanted them to make that choice. It is critical that the physician try not to assume they understand the patient’s motivation, and that they ask the patient about their understanding of the decision. In asking these questions, it is possible that it will become clear that the patient does not have a clear understanding of

the options. For example, if a patient is experiencing a psychiatric illness that impedes their cognitive functioning, they may present to the hospital voluntarily with family. They may consent to voluntary admission because they know that a person who they trust wants them to. This does not mean that they understand the full extent of this decision and the implications. Once admitted, a person would be required to comply with treatment, meaning take medications, and to stay until the medical team feels they are safe to leave the hospital, and must give 72hrs notice in writing of their intent to leave ****. This is a significant amount of time, especially if someone regrets having made the decision to be admitted once they are away from the safety of their trusted caretaker, or once they become aware that they must engage in treatment by meeting with the treatment team and taking medication.

The SAMHSA writes; *“Involuntary commitment, whether associated with hospitalization of a community treatment program, involves a significant limitation of liberty – the kind of limitation that is rare outside of the criminal justice system. For this reason, among others, commitment remains controversial, especially among recovery-oriented mental health stakeholders who place a high value on personal autonomy and self-determination. Ethical critiques of commitment invoke the dubious moral legacy of psychiatric paternalism from a previous century, when long-term institutionalization of persons with mental disabilities was commonplace, and, in some cases, used as a form of social control.”* (SAMHSA, pg. 23)

This argument reflects the side of preserving autonomy, and of placing control in the hands of the patient. It aligns with the idea that a physician could allow the patient to make the choice that one feels is in their best interest if there is a true question of whether or not they have capacity in the moment, because the beneficent thing to do would be to preserve the patient's autonomy.

It is likely that in the majority of cases, when the beneficent choice can be made autonomously, it will be in the patient's best interest for the physician to allow them to make this choice. They argue that, "benign medical paternalism implicitly privileges beneficence over respect for autonomy when these principles appear to conflict, based on the assumption that an expert clinician knows best in decisions about mental health treatment," (SAMHSA, pg. 27). They go on to elaborate that this is the ethical groundwork for legal justification of commitment when a patient's conflicting judgment is clouded by symptoms of an illness.

The difficulty of this choice is well embodied by a patient whom I met while working on an inpatient psychiatric floor at a hospital in Massachusetts. The patient was a young man in his early twenties. He had a history of severe clinical depression, and had been admitted many times previously to the same hospital as well as others in the area following suicide attempts. He presented to the hospital on an involuntary petition by his mother for severe depressive symptoms and suicidal comments. Upon presentation to the hospital, he endorsed suicidal ideation and was admitted involuntarily for the limit of three days. After being admitted, the patient continually denied suicidal ideation, and reported that he would be able to safely care for himself outside of the hospital. Unfortunately, he displayed no behaviors of self-care in the few days he was inpatient.

On the third day of admission, the patient was asked if he would like to sign into the hospital voluntarily, per protocol. There was a debate amongst the team about if this was in his best interest as physicians who knew him well suspected that he would not want to stay or engage in treatment.

Once voluntarily committed, the patient stopped taking his medications and filed notice that he would like to be discharged within 72 hours. He continued to deny suicidal ideation to his treatment team, but his mother reported that he was calling her and saying he was suicidal and had a plan to kill himself. The treatment team ended up trying to appeal the patient's request to leave by taking him to mental health court to have his voluntary admission status revoked. In court, the patient was assertive about his safety and vehemently denied suicidal ideation. It was determined that he did have the capacity to remain on voluntary commitment status and that his request for discharge must be requested. Upon discharge the patient did attempt suicide again.

This situation highlights the difficulty of the decision of weighing autonomy and beneficence, and of understanding capacity. This patient did have the capacity to make a choice that the team did not agree with. Those who knew him understood that his motivations in advocating for himself were rooted in intent to harm himself. However, he it was deemed that he did have the capacity to make this choice. The medical system tried to prevent people from being harmed, and uses beneficence as a way to override autonomy when we feel that someone does not know what is in their best interest. It is difficult to argue that if a person understands the choice, then it can still be wrong for them, even if it feels wrong. This case presents an example of a moment when

understanding what “felt wrong” about the patient’s choice may have allowed the physicians to engage in dialogue with the patient about their choice.

This is also an example of a moment to reflect on capacity. If a thought process is clear, but is a manifestation of disease, is it ethical to assign that person full capacity. That is the exact question posed by SAMHSA regarding the paternalism of beneficence. Sabine Muller writes, “respect for autonomy involves respecting existing autonomy, and additionally saving or restoring the biological and social prerequisites of autonomy if they are endangered,” (Muller, 2017). This understanding of autonomy addresses directly the question of what change from baseline function. It does not alleviate the potential paternalism involved in assuming that a patient does not know what is best in a state of illness, but it does lend credence to the argument that autonomy and capacity are so closely tied that you cannot weigh autonomy as a driving ethical force in the absence of capacity.

CONCLUSION –

I believe that when capacity is clouded by disease, it is not ethically appropriate to weigh patient autonomy over beneficence. It is necessary for physicians to consider what a patient feels is in their best interest, and to comply with these wishes when the patient clearly understands the decision. It is not ethical to allow someone to make a decision that we as the physician feel is best when their capacity for consent has not been assessed. It is not ethical to allow them to make a decision that is we as the physician might feel is best when there is an obvious question of capacity in the moment.

I believe that physicians can work to reduce the potential harm by making an effort to understand where our own views and our patients stem from, and by making a more concerted effort in hospital settings to assess what a patient's understanding of their condition is.

BIBLIOGRAPHY

1. Hempton and Bhatia, *Deciding for when you cant decide: The Medical Treatment Planning and Decisions Act 2016 (vic)*. Journal of Bioethical Inquiry, 1-12. 13 Feb, (2020)
2. S. Mukherjee, A. Shah, *The prevalence and correlates of capacity to consent to a geriatric psychiatry admission*, Aging and Mental Health; 5(4): 335-339 (2001).
3. Sabine Muller, *Respect for Autonomy in Light of Neuropsychiatry*, Bioethics. 31 (5): 360-367 (2017).
4. N. Bilanakis, V.K. Peritogiannis, Aik Vratsista, *Treatment decision-making capacity in hospitalized patients with schizophrenia*. Psychiatriki. 28(1), (2017).
5. P. Lepping, and B.N. Raveesh, *Overvaluing autonomous decision-making*, The British Journal of Psychiatry. 204:1-2 (2014).
6. L.L Sessums, H. Zambrzuska, J.L. Jackson, *Does this Patient have Medical Decision-Making Capacity?* JAMA. 306(4): 420-427 (2011).
7. P. Lepping, T. Stanly, J. Turner *Systematic review on the prevalence of lack of capacity in medical and psychiatric settings*. Clinical Medicine, 15(4): 337-343 (2015).
8. P.S. Applebaum, S.A. Mirkin, A.L. Bateman, *Empirical Assessment of Competency to Consent to Psychiatric Hospitalization*. Am J Psychiatry, 138:9. 1170-1175 (1981).
9. (2019) Substance Abuse and Mental Health Services Administration, *Civil Commitment and the Mental Health Care Continuum: Historical Trends and Principles for Law and Practice*. www.samhsa.gov/ebp-resource-center.
10. J. Varelius, *The Value of Autonomy in Medical Ethics*. Med Health Care Philos, 9(3): 377-388 (2006).

