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Medical Expertise, Patient Expertise, and Surrogate Decision Making:
The Importance of Co-deliberation in Medical Decision-Making

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A Thesis Submitted to The Graduate School at the University of Missouri-St. Louis
in partial fulfillment of the requirements for the degree
Master of Arts in Philosophy

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Suppose a patient by the name of John Smith has been admitted to the ICU (intensive care unit) at a local hospital. Mr. Smith has never had any serious health conditions before now. He has never felt a need to authorize a surrogate decision maker or construct a living will. However, Mr. Smith has unexpectedly developed a severe respiratory infection from a circulating virus. He is intubated. Then, he is put on a ventilator due to a respiratory crisis. Due to the comatose state induced for intubation, Mr. Smith is incapacitated and unable to make his medical decisions. Dr. A, Mr. Smith's hospitalist, has a treatment she believes would be beneficial for Mr. Smith. Mrs. Smith has extensive knowledge of Mr. Smith; Dr. A has an abundance of knowledge regarding necessary/desired medical care. The two individuals disagree which course of treatment should be administered. It is pertinent to understand the rules are not clearly defined since surrogate decision making laws are made on a state-by-state basis. The construction of a universal law on this would prove beneficial. Which person should be given the authority to make decisions on Mr. Smith's behalf?

There are a few potential solutions I would like to consider. In the first solution, Dr. A (hospitalist) is given the surrogate role and complete authority to make Mr. Smith's medical decisions. I argue without any requirement of deliberation, there exists a substantial risk for a violation of the principles of bioethics. In the second solution, I demonstrate the risk of family members being given full authority. Mrs. Smith is the surrogate decision maker and is given authority over Mr. Smith's medical decisions. I argue having Mrs. Smith as an unauthorized decision-maker does not maximize the achievement of the guiding principles of biomedical ethics either. I then offer my solution

for these two cases: a requirement for deliberation. In the last case, I apply the requirement for deliberation between Mrs. Smith and Dr. A. I then will explain how a requirement for co-deliberation between the two individuals would protect the incapacitated patient from undue harm. Certain qualities must be present in the family member that the doctor deliberates with, namely, patient expertise.¹

It is important to outline the kind of medical cases I am discussing. I am interested in decision-making cases meeting the following criteria: (a) That it involves a doctor with no pre-established rapport with an adult patient. Criterion (a) establishes that primary care physicians, who sometimes possess a certain level of patient expertise, are not being included in the role of medical expert and that pediatric situations are not addressed in this paper and are outside the scope of this thesis. (b) That it involves a family member/loved one as an unauthorized alternate decision-maker. Criterion (b) establishes that a family member is present, although not an officially recognized decision-maker. An unauthorized decision-maker is one the patient did not explicitly state is their alternate decision maker. Law which dictates hierarchies for surrogate decision-making are set aside in this thesis to better understand the role a medical professional and family member can play together in the decision-making process.² Finally, (c) involves both parties individually holding the kind of expertise specific to their role in the decision-

¹ I also argue that the doctor must demonstrate medical expertise, but I will not spend much time expanding on this, as it is not the crux of this thesis.

² I am aware that legally, physicians are not allowed to be decision-makers in 35 of the fifty states. However, this thesis only sets forth one idea: that the physician officially authorizes the treatment that is jointly discussed between medical expert and patient expert. This is not saying anything of the physician being declared the surrogate decision-maker, but in having the authority to move forward with treatment after co-deliberation.

making process.³ This ensures the foundations of this proposed solution are present in the case it is being applied to.

I argue the doctor needs to authorize treatment before any treatment can take place. However, this is not an outlandish claim. As is standard practice now, a doctor would not perform a procedure they saw as being detrimental to the patient, especially in the circumstances I have outlined: the patient has no authorized decision maker and we have set aside all legal definitions and hierarchies of alternate decision-making to better understand the role expertise and co-deliberation can play in the decision-making process. Furthermore, it is necessary that a doctor authorizes care. This stipulation does not undercut a patient's autonomy.⁴ If Mrs. Smith were to request a procedure be done to Mr. Smith which would cause harm to him, Dr. A would not perform the procedure. Dr. A does not have a moral obligation to follow what Mrs. Smith requests to be done on behalf of her husband just because of her knowledge of him. Mrs. Smith is not an authorized decision maker for Mr. Smith; he never established her as such in any official capacity. It (the doctor having the final say) encourages a protection of the patient's rights given the circumstances of the case I have set forth.

Authority refers to an individual or a group who has control (and power) to make decisions for themselves or for other people. Authority for the kinds of expertise I talk about is extremely limited. Ideally, the patient has authority. The surrogate decision

³ In biomedicine, many patients do not have an authorized surrogate decision maker. Many people do not have a living will or legal document established for medical care decision-making or have these explicitly spoken to their surrogate decision maker. Many relationships have become strained due to limited visitors (or no visitors to reduce spread of infection) and it is vital for the surrogate-medical provider relationship to be maintained in whatever capacity is possible.

⁴ A patient's ability for autonomy to be reached in an incapacitated state is already limited.

maker acting as an extension of the patient uses their authority (which is the ability to make medical decisions for the incapacitated patient) to do what the patient would want as if they were still awake.⁵ Within this thesis, the authority a doctor has is specific to medical care and the authorization of that medical care.⁶

Expertise is a certain elevated level of skill or knowledge held by an individual which is garnered from study and/or from experience in a specific area. I have no arguments proving the existence of expertise; the focus of this thesis is to support the value of co-deliberation between two individuals for a patient in a alternate decision-making situation.⁷

Medical expertise, for this paper, is someone with extensive knowledge in a particular subject matter, such as a cardiothoracic surgeon. This surgeon has (a) spent years dedicated to studying the anatomy and physiology of the heart and the best and newest surgical procedures; (b) continues to stay abreast of the newest techniques to improve patient outcomes; (c) builds experiential knowledge the more time he/she practices the technique and applies the knowledge he/she has learned. Also, one must hold either certifications/licenses and/or degrees pertaining to the medical subject they practice. An audiologist does not have medical expertise regarding neurophysiology; a physician who serves in the ICU will not have the same level of expertise in the surgical unit as an cardiothoracic surgeon would. Additionally, a medical expert has knowledge of

⁵ However, I acknowledge that in many cases, it may not be outlined to the surrogate decision maker what the patient would want. When a patient does not have a living will or forms filled out in the hospital (outlining what kind of treatment the patient would want.) But I think we can all agree that ideally this is always the case.

⁶ I expand on this later on when discussing co-deliberation.

⁷ In expertise, I do not place an expectation of perfection.

“people in general”.⁸ This is to say a medical expert has a wealth of knowledge about the human body as a collective: it’s anatomy and physiology, how it functions well, what can lead it to functioning poorly, potential fixes/solutions, etc. This general knowledge allows for medical professionals to treat many individuals based on disease and how it affects the body.

To describe the problems which arise in the solutions I present, we need to define some important concepts. These concepts are foundational beliefs in bioethics. Ideally, these concepts are upheld whenever possible by all those involved in medical-decision making. The principles of bioethics form the foundation of why problems arise when either Dr. A or Mrs. Smith is given authority without a requirement for co-deliberation.

There are four important principles to define in bioethics relevant to this paper. I will attempt to clarify their definitions.⁹ Thomas Beauchamp and James Childress defined, developed, and refined these four principles: (1) respect for autonomy, (2) non-maleficence, (3), beneficence and (4) justice. These four principles underlie the most important things to provide for patients- respect for their decisions, doing no harm, benefiting the patient whenever possible, and giving care that is just.¹⁰

⁸ I feel safe making the claim medical experts are required to have certain certifications, licenses and degrees, but this is not a general claim for all areas regarding experts.

⁹ R. Gillon states “I think the four principles should also be thought of as four moral nucleotides that constitute the moral DNA - capable alone or in combination, of explaining and justifying all the substantive and moral norms of health care ethics and I suspect of ethics in general.” I agree with this sentiment completely. The four principles should be, as much as possible, a guide to medical workers’ behavior.

¹⁰ Beauchamp and Childress’ account of the four principles are what I define here and apply to my cases.

Respect for autonomy is the exercise of a patient's right to their own medical decision making.¹¹ Respect for autonomy is not a more important principle than the other three I mention and therefore does not take priority over fulfilling other bioethical principles we discuss. In order that a decision be considered fully autonomous, the agent must intentionally act with understanding and in a state of "non-control".¹² For example, if a patient refuses treatment altogether or elects to have a certain kind of procedure done, the patient is exercising their right to their own autonomous decision-making concerning their healthcare.¹³ In the case of an incapacitated patient, respect for autonomy becomes a difficult value to uphold, since the patient acts with diminished autonomy. In the case of Mr. Smith, having Mrs. Smith or Dr. A decide for the patient would be to have the individuals act as an extension of Mr. Smith. Ideally, their decision-making would match the decision Mr. Smith would make if he had the ability to make sound autonomous decisions; often, this is not the case.¹⁴ If Mrs. Smith were an authorized decision maker for Mr. Smith, then his autonomy would be respected by following what Mrs. Smith asks of the medical team.¹⁵

¹¹ Beauchamp and Childress (2019, 101) also explicitly state that they believe respect for autonomy is not excessively individualistic, not excessively focused on reason, and not unduly legalistic. I support these claims as well.

¹² Beauchamp and Childress (2019, 104) There are several degrees of autonomous decision-making. It is a huge undertaking in biomedicine for every patient to act completely autonomously, as it would require complete understanding of the procedure and other medical jargon, which is not a patient's expertise area like it is the medical professional's.

¹³ I am not concerned with any other definition of autonomy. When I refer to the word autonomy in this paper, I will be exclusively referring to a patient's decision-making concerning healthcare; I am not making a claim about the nature of determinism, free will, etc.

¹⁴ Shalowitz DI, Garrett-Mayer E, Wendler D. (2006, 493–497)

¹⁵ This is a demonstration of how respect for autonomy might be shown in a surrogate decision-making scenario; however, this thesis is not concerned with pre-authorized decision makers and it is outside the scope of this thesis.

Non-maleficence is a principle that rests on not causing harming to others.¹⁶ Non-maleficence addresses directly and indirectly harmful acts. In biomedicine, harm can be physical, psychological, emotional, or spiritual.¹⁷ A directly harmful act would be purposefully harming a patient without reason. An example of a direct act violating the principle of non-maleficence is performing unnecessary surgery on a patient. An indirectly harmful act would be accidentally causing harm to a patient, like administering the wrong medication to a patient who is allergic to that medicine. Indirect acts which violate the principle of non-maleficence manifest themselves often in situations of decision-making. When a patient is incapacitated and unable to participate in the decision-making process, the opportunity for maleficent care increases. I will explore this point further in the solution with Dr. A having full authority.

Beneficence is providing care which is *not* innocuous but beneficial to the patient in one way or another. The principle of beneficence would be violated when a patient must undergo a blood draw that is not necessary.¹⁸ Beneficence is also the prevention of harm to the patient, removing the opportunity for harm and promoting good and beneficial care to the patient.¹⁹ Beneficence and non-maleficence can be easily confused; beneficence is promoting the good of the patient while non-maleficence is a claim one

¹⁶ Beauchamp and Childress (2019, 154) illustrate five rules specifying the principle of non-maleficence: (1) Do not kill; (2) Do not cause pain or suffering; (3) Do not incapacitate; (4) Do not cause offense; (5) Do not deprive others of the goods of life.

¹⁷ In a case where a patient is physically harmed unnecessarily; in a case where psychological harm from a physical event has taken place; and where a patient's religious convictions have been violated.

¹⁸ Blood draws are not always necessary, but many times they are put in automatically, or in the emergency room to cover all the bases.

¹⁹ Beauchamp and Childress, (2019, 152)

ought not to inflict harm upon a patient.²⁰ Beneficent care for an incapacitated patient in certain cases (like the one this paper is concerned with) will look different than in cases where a patient is (a) awake and has capacity or (b) has an authorized decision maker. An authorized surrogate decision maker is someone, perhaps a family member, who was elected by the patient to make their medical decisions if the patient should be incapacitated and unable to make their own decisions. An unauthorized decision maker is someone whom the patient did not elect to make their medical decisions.

Lastly, the fourth principle is justice. Justice in the healthcare setting is fairness in access to medical care and involves active attempts to address concerns of disparities in an individual's ability to pay for the rising cost of healthcare.²¹ It is a difficult principle to define. Justice, while it is an important principle and has a role in alternate decision making, is a principle I set aside to address beneficence and a respect for autonomy.

Briefly, I would like to outline the kind of surrogate I am referring to- surrogate decision makers can be different individuals.²² When a patient has no authorized or elected surrogate, a default is chosen. The most common default surrogate is a family member or loved one.²³ A surrogate decision maker is an individual who, in the case of a patient becoming incapacitated, makes decisions concerning the patient's health. If Mrs.

²⁰ Beauchamp and Childress (2019, 151-153)

²¹ Beauchamp and Childress (2019, 250)

²² When I state this, I am referring to moral strangers, legal individuals, DPAHC, living will, etc. This thesis is not concerned with the legal side of surrogate decision making- laws vary by state, and that would make it much more difficult to put forth a solution. PLUS, I am concerned with cases where an unauthorized family member is called into the decision-making spotlight.

²³ DeMartino, E. S., Dudzinski, D. M., Doyle, C. K., Sperry, B. P., Gregory, S. E., Siegler, M., Sulmasy, D. P., Mueller, P. S., & Kramer, D. B. (2017, 1478-1482)

Smith or Dr. A are to make decisions for Mr. Smith, they are taking on the role of a surrogate decision maker.²⁴

Solution 1: Mr. Smith's hospitalist (Dr. A) should step in to make the patient's medical decisions.

Let's say that Mr. Smith's hospitalist, Dr. A, steps in to make all the patient's medical decisions. There seems to be a unique benefit to the wealth of medical knowledge a doctor has, and to have them as your decision maker seems to be a wise choice. For example, Dr. A knew Mr. Smith was more susceptible to severe symptoms of this respiratory virus because he is asthmatic. Dr. A was able to quickly prescribe bronchodilator medications and get Mr. Smith placed on CPAP to increase blood oxygen levels. In more complicated decisions, like the removal of the ventilator, Dr. A knows, physiologically and statistically, when the ventilator is prolonging what is inevitable (Mr. Smith's death). Dr. A can independently research, understand and practice different techniques, tests and clinical trials that would potentially help Mr. Smith's health. Dr. A's medical expertise encompasses having a variety of treatment options and knowing which one is best based on physical data, patient history, and research. She also has years of experience gained through her training that gives her the intuition needed to know when treatments are going to be effective. She has an idea of multiple courses of treatments, like a certain kind of medicine known to clear up other respiratory infections; a course of antibiotics available to be given intravenously; or a clinical trial that was recently

²⁴ In this paper I use terms such as alternate decision maker, surrogate decision maker, surrogate, or decision maker: these are all synonymous.

approved for human experimentation with promising results for Mr. Smith's virus. There are certain specificities helpful to the case that Dr. A can deduct from Mr. Smith's medical chart- like that he is allergic to penicillin.

Yet, this knowledge, when isolated, is not convincing enough for Dr. A to be given *complete* authority in Mr. Smith's medical decision making. I will proceed to highlight a few examples where Dr. A can potentially violate the principles of biomedical ethics.

Remember that in this case, full authority means the doctor has no requirement to discuss treatment with family or to go through other mediating channels. The doctor can do what they see as best. This full authority to a doctor results in a substantial increased probability of a violation of beneficent care and a lacking effort to provide the most respect for autonomy to the incapacitated individual.²⁵ I believe that when no individual with patient expertise is involved in the decision-making process, the non-involvement results in increased likelihood of (a) a violation of the principle of beneficence and (b) lacking respect for autonomy.

Medical expertise would be necessary in medical decision-making situations, but it does not seem sufficient for making the best decisions for the patient. In biomedicine, no other individual has the amount of medical knowledge the doctor does. Yet, giving Dr. A complete authority over Mr. Smith's health does not feel quite right. Dr. A lacks awareness of potential fears, beliefs and/or values the patient holds which would affect the decision being made, and without any requirement for pause or conversation, these

²⁵ I do confess that respecting autonomy is difficult to navigate; however, I am arguing that co-deliberation helps to encourage a patient's autonomy even when incapacitated.

variables probably would not come to light.²⁶ A hospitalist has access to a patient's medical chart, which contains a wealth of information pertaining to medical history, DNR/DNI orders, allergies, past prescriptions and past hospital visits.²⁷ However, a hospitalist has limited time with each of their patients.²⁸ It cannot be expected with US hospitals' expectations of doctors for them to know much about the individual in front of them.²⁹

Mr. Smith's right to beneficent care can be violated when an individual lacks the relevant knowledge of the patient. Thomas Beauchamp's definition of beneficent care encompasses three rules to satisfy providing such care: (1) one ought to prevent evil or harm; (2) one ought to remove evil or harm; and (3) one ought to do or promote good.³⁰

In (1), Dr. A can prevent many obvious direct harms to the patient. However, indirect harms like not advocating for the best treatment based on the individual are potential harms the doctor would be unable to completely avoid.³¹ This is not to say every doctor would choose a clinical trial for an incapacitated patient, but Mr. Smith is a

²⁶ In a healthcare team, (generally but especially for a patient who is incapacitated for whatever reason) there are many individuals involved- a nurse, patient care technician, a hospitalist who may consult the patient's primary care physician (if the patient has one), and ideally, family may be involved. However, the hospital setting is fast-paced, and many a time all these people are not involved in the decision-making process. In my own medical experiences working in the field, patients' family members' opinion were often looked down upon for not being medical in nature. This poses another problem which isn't explicitly address in this paper, but should be researched.

²⁷ DNR is a do not resuscitate order; DNI is a do not intubate order.

²⁸ This is one of many differences in the hospital setting. (1), not everyone has access to a PCP; (2), a hospitalist is in charge of many patients and therefore has limited time to spend with each patient and (3) while a hospitalist may consult someone's PCP if the patient has one, it's not a guarantee and the PCP will not be present for medical decisions, especially in the case we have outlined.

²⁹ On average, hospitalists see between 15-20 patients per day. They are also expected to do extensive research, get published, stay abreast in the newest treatments, consult where necessary, etc. The multiple jobs expected to be completed by doctors is lengthy.

³⁰ Beauchamp and Childress (2019, 154)

³¹ Due to their lack of necessary knowledge of the patient.

member of a vulnerable population at an increased risk for advantage-taking behavior. Furthermore, Mr. Smith is an individual with certain beliefs, values and principles, ones that potentially conflict with courses of treatment available for Mr. Smith. I believe that even when the doctor is doing *medically* what is best, he/she can still be violating the principle of beneficent care.³² If Mr. Smith had recently become a Jehovah's Witness, it may not have been updated in his medical chart, and it would affect Mr. Smith's healthcare options.

In (2) and (3), harm can be avoided and the good can be promoted by a requirement for extensive co-deliberation with a family member. In co-deliberation, Dr. A can voice different treatment options and involve Mrs. Smith in the discussion. She might voice her husband's fear of clinical trials and his recent conversion to be a Jehovah's Witness. Now that is not to say the chance is completely avoided; the doctor still has the authority for the decision to be made. However, the risk of a patient's right to beneficent care being violated is severely decreased. Information outside of Mr. Smith's medical chart that otherwise would not have been made known to the doctor is shared in co-deliberation.

The same idea can be said of Mr. Smith's right to a respect for his autonomy. A patient has the most knowledge of what he/she would want regarding healthcare. If he/she were awake, he/she would make his or her own medical decisions. When a patient lacks capacity, the ability to respect autonomy becomes more complex. However, a

³² When family is available and uninvolved.

patient's autonomy can be respected through family members being involved in the decision-making process to some extent.

Generally, in biomedicine an emphasis is placed on protecting life in abnormal circumstances.³³ While there are many works on euthanasia and the right to die, an incapacitated patient with no legal document or authorized decision maker is an individual who should be protected. In the case I have outlined above, it is more reason Dr. A should have technical authority for Mr. Smith's decision-making. So, it seems that without any additional requirements, giving a doctor unfettered authority does not seem *quite* right. Let's move to the next potential solution and see where that takes us.

Solution 2: Mr. Smith's spouse should step into the decision maker role.

Let us proceed to the solution that Mrs. Smith should be given full decision-making power over Mr. Smith. Mrs. Smith has patient expertise of her husband. That is to say that she has evidence which implies what he might want in medical situations.

While it is easy to think patient expertise is the most important expertise to have in each situation, it is complex to integrate into medical decision-making. Let's say Mrs. Smith lied about her husband's dislike of clinical trials. It would be difficult to uncover the truth if Mrs. Smith put forth this idea without any other credible sources available to either verify or challenge it.³⁴ However, a doctor would not perform a procedure that

³³ Where a patient requires resuscitation and is later found to be a DNR, things like this.

³⁴ There are several *possible* conflicts of interest when a spouse or family member makes decisions in situations that satisfy the conditions I set forth in this paper. If there is money coming to a family member in a will, or there has since been a falling out between the family member and the incapacitated patient, etc. These are both occurrences in cases I have heard.

would cause harm just because a patient's surrogate authoritatively said to do so; especially because this surrogate is not officially authorized. The act of treating the patient is ultimately left to the doctor.³⁵

One might also argue that patient expertise takes precedence over medical expertise because the patient's rights come first. However, this is a misplaced concern for this thesis. My concern is maximizing an incapacitated patient's ability to get the healthcare they would have chosen. In all alternate decision-making cases, the patient is declared incompetent due to mental disease or defect or due to an altered mental status. Therefore, in these special cases, the patient is unable to make their own decisions. The waters start to become murky in surrogate cases because a totally separate being makes decisions on someone's behalf. The distinct kinds of expertise I proposed to take part in co-deliberation are an attempt to clear the waters.

The principles of biomedical ethics apply to family members involved in medical decision-making as well. A family member with the authority I describe is subject to violating these principles, too. Let's say Mrs. Smith wanted Mr. Smith to be removed from life support as soon as possible. Mrs. Smith wants to receive her inheritance from Mr. Smith's will. This would be a maleficent action. If we also state that someone was aware of Mr. Smith's desire to stay on life support as long as possible, Mrs. Smith's action would violate Mr. Smith's right to a respect for autonomy and beneficence.

³⁵ One might say another family member could be utilized to discern what is factually true about the patient and Mrs. Smith's opinion- which is true. However, the parameters of the case set forth state Mrs. Smith has all the decision-making power.

This knowledge is necessary in making the best healthcare decisions for Mr. Smith, but not sufficient. If Mrs. Smith were to be given full authority, her lack of medical knowledge raises the odds of maleficent and non-beneficial care being given to Mr. Smith. However, this is not a situation the doctor would allow.³⁶ In walking through this case, it does seem like the requirement for someone else to be involved in the decision-making process would be beneficial and prevent direct or indirect maleficent acts to the patient from taking place.

What if my decision maker is also a medical professional?

I argue that there are important benefits from the co-deliberation of two individuals which are missed when one individual, like a doctor, holds both expertises. One individual cannot sufficiently hold medical expertise for a patient *and* *simultaneously* hold patient expertise. I believe that the expectation for one human to adequately hold, consider, and deliberate within each kind of expertise is difficult to meet. The point of co-deliberation is two individuals contributing important kinds of expertise.

If Mrs. Smith (yes, Mr. Smith's wife) also happened to be a doctor, having both kinds of expertise would also *not benefit* the decision-making process. My response to this is that one person cannot sufficiently make decisions and give proper credence to

³⁶ Many obvious cases of maleficence and non-beneficence would quickly be stopped; cases where it is not as clear require more analysis and on a case-by-case basis. Unfortunately, this one part I do not have room to discuss in this thesis due to each case being different. One family's request for the removal of life support may be done knowing the incapacitated patient would want it done; another family's request for the removal of life support may be so they can receive money from a will. This is something to be addressed.

each kind of expertise. If one person were to hold each kind of expertise, there would be additional benefits to having more than one person involved in the decision-making process which would be missed. This is one of the supporting reasons why teaching hospitals provide better care: there are more individuals which can catch others' mistakes. While the literature I cite suggests I am saying two medical experts should be involved, this is not the case. It illustrates the importance of more than one individual, which disrupts this line of thought (of Mrs. Smith also being a medical professional, and this somehow being extra beneficial.)³⁷ Medical expertise does not make the patient expert a better candidate to be decision maker. The co-deliberation would not take place; this is a disservice to the incapacitated patient. The co-deliberation is what allows for the patient's wants and needs (to the extent they can be made available for us) to be actively advocated for as decision-making comes about.

A Conflict Between Beneficence and Autonomy with Mrs. Smith as sole decision-maker

The patient has not specifically outlined a decision maker. Patient expertise, while valuable, does not warrant Mrs. Smith to be an unauthorized decision-maker. However, this does not mean the doctor can do whatever they please. The doctor still must co-deliberate with the person who knows the patient best. One comes to a point where one realizes the limitations of adequately meeting the expectation of a respect for

³⁷ Glickman (January 2020)

autonomy given the situation that Mr. Smith is in. There seems to be a conflict between reaching beneficence and reaching the expectation of a respect for Mr. Smith's autonomy. However, we can achieve a higher amount of beneficence by acknowledging the limitations on reaching autonomy for Mr. Smith. The co-deliberation requirement is supposed to preserve a patient's autonomy (to the extent it is possible) while achieving beneficence. Mr. Smith has no specific decision-maker and forfeits having his autonomy respected to the greatest extent. However, patient expertise encourages beneficence and a respect for Mr. Smith's autonomy at the cost of permitting Dr. A to authorize treatment post- co-deliberation. This is done by involving Mrs. Smith in any important medical decision.

What sort of qualities are necessary in a person for appropriate co-deliberation and what would this co-deliberation look like?

I argue that a certain amount of knowledge about the patient is required. Patient expertise is knowledge pertaining to a specific person, such as a husband (whom is the surrogate decision maker for his wife, who is on life support.) One comes to possess patient expertise when they have "knowledge of the individual." This includes understanding that person's values, beliefs, different struggles, personality traits, desires, needs, etc. Within biomedicine, it is important for those with patient expertise to be individuals with knowledge of how the patient believes a life is well lived for himself; how they feel about certain kinds of treatments, resuscitation, intubation, etc. For example, perhaps Mrs. Smith knows that her husband hates the idea of being intubated and had said over the years that "it prolongs the inevitable." Mrs. Smith knows Mr. Smith

holds strong opinions on intubation and can volunteer this information to those who need to be aware that her husband wishes not to be intubated.

There are three necessary qualities I put forth for someone to hold patient expertise: Having either (A) explicit knowledge of a patient's wanted medical care or (B) implicit knowledge of a patient's wanted medical care; partnered with (C) an evidential current personal relationship to the patient. A spouse is not the only individual who can hold patient expertise; however, the spouse is the individual we pose in this thesis. Group decision-making outside of two people is a subject which is not addressed in this thesis.

So, patient expertise looks like having either *explicit evidence* of how the patient felt about specific care (intubation, cardiopulmonary resuscitation, being put on a ventilator) or *implicit evidence* of what the patient's medical decisions would be based off the person's beliefs, goals, and values.³⁸ This knowledge being useful is contingent on having a current personal relationship with the patient. The patient's beliefs very quickly tie in to how the patient would want to be treated. Beliefs encompass religious affiliations. Goals, while not as strongly as beliefs, play a role in understanding one's medical decisions. Understanding one's goals may play a supporting role in other decisions.

The requirement of co-deliberation would look like a conversation and vary in length, depending on the subject of the conversation. Each expert would bring the value of their expertise to the table. Co-deliberation is a required meeting between the patient

³⁸ If a patient cannot present a valid DNR/DNI order, then medical professionals are mandated to perform life-saving measures. Demonstrating explicit knowledge is a lot more difficult as an unauthorized decision maker, but still potentially useful to the discussion.

expert and medical expert to discern the best course of treatment for the patient. It allows for the patient's wants to be present in the absence of an authorized surrogate decision-maker while protecting the patient as much as possible.³⁹

(1) It is a required meeting before the doctor can act on serious treatments which satisfy at least one of the following criteria:

(A) non-emergent care, where there is adequate time for a conversation to be held.(B) care involving the withdrawal of life support

(C) care involving a change of medication

(D) any change in course of treatment

(E) all care involving a substantial or probable impact on the patient.

Co-deliberation allows for a positive learning environment from doctor to family member and vice versa. Not every medical decision will go through the process of co-deliberation.⁴⁰ Co-deliberation would allow for a mutually beneficial conversation: the doctor benefits from learning more about the patient in a directly helpful way and the patient expert learns about the medical care in a directly beneficial way (and allows for the patient expert to directly apply their expertise to that specific medical care.)

Under (A), any non-emergent care which allows for adequate time for a conversation to be held should be co-deliberated on. This also includes explaining different options for treatment (if applicable.) For (B), any care where an individual will

³⁹ I understand authorized/unauthorized are traditionally legal terms; I use them to make it clear whether an individual was a declared or undeclared decision maker. I say nother of these being legal words.

⁴⁰ Where they're moving an IV, implementing care that was deliberated on, etc.

most likely die as a direct result of the care being withdrawn. (B) includes care that sustains life (feeding tube, delivers oxygen, keeps the heart beating, etc.) (C) includes any medication change- this entails a conversation about dosages, changing route of medication (intravenously, etc.) (D) encompasses any changes which alter the goal of the course of treatment (whether the goal is to sustain life for a period of time, to prolong life, to fulfill an explicit request through the family member's disclosure of the knowledge, etc.) (E) involves a catch-all for potential changes which would impact the patient, like a shift change of doctors, nurse, or technicians; potential new tests to be run, any new knowledge discovered from research, discovery or realization of new information surrounding the patient, patient's history and/or home life, etc.⁴¹

In biomedicine today, there are a variety of different ways a doctor approaches a family member when surrogate decision making is necessary. One study identifies six different approaches. “(1) building trust, (2) educating and informing, (3) providing surrogates more time, (4) adjusting surrogate and physician roles, and (5) highlighting specific values.”⁴² In the concept of co-deliberation I present, all these approaches are important from doctor to patient expert, and from patient expert to doctor. To promote the incapacitated patient's rights, the doctor should be involving the patient expert in as many decisions as possible.⁴³ Trust-building between the hospitalist and family member promotes better discussion; educating and informing is a necessity for *full understanding*

⁴¹ Co-deliberation can be called for by the doctor or patient expert (family member with necessary knowledge for the role in co-deliberation)

⁴²Brush, D. R., Brown, C. E., & Alexander, G. C. (April 2012, 1080–1087)

⁴³ This also promotes the concept of informed consent to the extent it is possible for an incapacitated individual.

of what care is being done, the implications of such care, and the proper understanding of the patient's values as it relates to such treatment.

There can also be a variety of roles played by the physician and patient expert. The theory I put forth answers this based upon (a) promoting the safety and life of the patient as an individual with no authorized decision maker and no capacity to make their own decisions and (b) promoting, to the extent it is possible, the patient's rights to a respect for their autonomy, beneficence, non-maleficence, and justice. The physician will have the authority to make the decision, as their medical expertise promotes the safety and life of the patient when possible. The family member must advocate for the patient through co-deliberation, sharing their relevant knowledge of the patient to aid the doctor's decision in what care is best. The family member doing this promotes the patient's rights to the principles of biomedical ethics. Without co-deliberation between the two individuals with respective expertise taking place, the doctor cannot make medical decisions outside of what is emergent.⁴⁴

Co-deliberation: What is it and how does it work?

Co-deliberation is a joint decision-making process between two individuals: a medical expert and a patient expert. This does not mean that the two individuals have equal roles or equal power. Each individual brings expertise which is an asset to promoting the best healthcare for the incapacitated patient. Co-deliberation is a conversation about a decision for the patient's care, regarding any changes which may

⁴⁴ Emergent care encompasses life-preserving measures that there isn't time to deliberate on- CPR, intubation, etc.

substantially impact the patient (any decision which meets one of the criteria I described above.) The conversation may take place over the phone, a video call or in person, depending on the gravity of the decision and the availability of the individuals. A conversation regarding switching the brand of antibiotics is better suited to over the phone than a conversation regarding the removal of life support.⁴⁵ It would involve a source and a receiver and would follow the subsequent guidelines:

- (1) two individuals are present in an agreed-upon capacity.
- (2) The problem is articulated and explained so that both individuals are fully aware of the situation. Any questions for clarification occur in this step.
- (3) Any concerns from either individual are voiced. Some examples might be: if the patient expert believes the care proposed would conflict with what the patient would have desired for themselves; if the medical expert believes the treatment may not be the best option, but it is an option requiring discussion.
- (4) Disagreements with the concerns are voiced and a resolution is attempted. Two examples of this might be: If the medical expert believes the treatment is still beneficial even with possible conflict with the stated desires of the patient; if the patient expert believes an alternate treatment should be discussed. This may involve extensive explanation, an articulation of potential effects from accepting/rejecting the change in treatment.

⁴⁵ Also, the COVID-19 Pandemic has made restrictions on visitors, which exacerbates the problem of a requirement like co-deliberation being easily implemented. However, mediums such as Zoom and Facetime make it possible in some capacity. The importance of patient expertise should not be understated- it is vital that an incapacitated patient's autonomy be respected to the extent it is possible (even though it is greatly limited in a situation with no authorized decision-maker.)

(5) If the two individuals continue to disagree and the results of a doctor authorizing treatment would potentially deprive the incapacitated individual of their rights, a third party may be consulted where is necessary. However, in disagreements where this potential is not present, the doctor may authorize the treatment.

Solution 3: Mrs. Smith and Dr. A co-deliberate.

So now, let us proceed with installing our now-defined requirement of co-deliberation. I will run through an example of each of the criteria I put forth (A-E) and explain the benefits of co-deliberation here.

(A) non-emergent care, where there is adequate time for a conversation to be held.

Mr. Smith needs a simple but necessary procedure. It needs to happen soon but does not have to happen immediately. There is time for Dr. A to call or have Mrs. Smith come to the hospital. Mrs. Smith agrees with the doctor's decision to proceed with the procedure, but states her husband was a minimalist when it came to medicine and would prefer for few of those sorts of procedures to take place. Dr. A authorizes the procedure. Co-deliberation helped Dr. A learn the patient was not fond of being on multiple medications and this helps promote future care, which respects Mr. Smith's autonomy.

(B) care involving the withdrawal/placement of life support

Mr. Smith has been on a ventilator for a couple of weeks with no signs of improvement. Dr. A is aware the probability of Mr. Smith recovering is extremely low and sees it as prolonging death. Dr. A approaches Mrs. Smith to co-deliberate on the

removal of the ventilator. Mrs. Smith becomes emotional during the conversation (understandably so.) Mrs. Smith states that Mr. Smith always said he would not want to be on life support past a month, although she will have a difficult time letting go at any point. Dr. A decides to wait another week after hearing Mrs. Smith's explicit knowledge of what the patient would have wanted. Co-deliberation aids the process by providing Dr. A relevant information about what the patient would have wanted. Dr. A knows waiting another week poses no harm to the patient and does not violate the patient's autonomy (he said maximum a month) and beneficence.

(C) care involving a change in medication

A nurse talks to Dr. A about a new medication which is less likely to cause redness around the IV location. The new medication is another antibiotic. Dr. A calls Mrs. Smith to deliberate the medication change and Mrs. Smith agrees with Dr. A's decision. Co-deliberation was simple and promoted an open space for the two experts to talk further on the subject if it had been necessary.

(D) any change in a course of treatment

Dr. A learns of a new treatment that may prove beneficial for Mr. Smith. Thus far, this new treatment has shown promising results in helping clear the infection Mr. Smith is suffering from (and is the reason he had to be placed on a ventilator.) Dr. A meets with Mrs. Smith to deliberate. Mrs. Smith voices her dissent because she believes trying this treatment is "as good as quitting." Dr. A explains the physiological state of Mr. Smith and how the treatment may prove beneficial. Mrs. Smith counters, stating Mr. Smith hated the idea of enrolling his parents any sort of non-traditional treatment and that

caused them to be less present in their final moments. Dr. A decides to proceed with the treatment for Mr. Smith. (since not trying this newer treatment would result in the eventual removal of life support and most likely Mr. Smith's death.

I assume this is the example which does not sit well with many people. However, this is where the requirement of co-deliberation proves its' worth. The co-deliberation allows for relevant information to be passed between family and the medical professional. Since Mr. Smith has not authorized anyone to be his designated decision-maker, Mrs. Smith and Dr. A are jointly involved in Mr. Smith's health decisions and Dr. A authorizes the treatment after co-deliberation. Mrs. Smith's information does not go unheard or unheeded. Dr. A has fulfilled the requirement for deliberation, weighed out the implications of the information she heard and decided to proceed with the treatment. It still benefits Mr. Smith for Dr. A to be aware of what the patient may have wanted. However, Mrs. Smith is not authorized to make Mr. Smith's decisions. Additionally, the new treatment is likely Mr. Smith's last chance of recovery.⁴⁶ Medical expertise takes precedence over the patient expertise due to the nature of the case being set forth. Dr. A believes the treatment will likely be beneficial, and so we adhere to the medical expertise.

(E) all care involving a substantial or probable impact on the patient.

It comes time for Dr. A's shift change to the next ICU hospitalist. Dr. A meets with the doctor taking over and Mrs. Smith to pass along all relevant information (that is outside the medical chart.) After listening to the knowledge garnered from both individuals' experiences with Mr. Smith, the new doctor receives the authority Dr. A had

⁴⁶This thesis makes no claims on anything involving research ethics or potential benefits from research regardless of Mr. Smith's success/failure.

and the requirement for deliberation with Mrs. Smith before any non-emergent medical decisions can be made. As the need for co-deliberation arises, the new doctor does so. There is not much up for debate in a situation like this. Dr. A's shift is over at the hospital and a different hospitalist comes in to relieve her. In this example, the three people sitting down, and deliberating is an opportunity for goals to be set for Mr. Smith's treatment. Dr. A contributes her experiences treating Mr. Smith, Dr. B contributes her medical expertise and a fresh set of eyes, and Mrs. Smith contributes her patient expertise. Fulfilling (E) protects the valuable lessons learned by each medical professional caring for Mr. Smith. This helps preserve the integrity of co-deliberation as care continues.

Most of these examples involve a brief conversation between the two experts. There is no required length of time for the conversation, just that one must occur. The deliberation potentially prevents any one person from being "tyrannical" in the decision-making process. Mr. Smith has no declared decision maker. The doctor's expertise does not necessarily rank higher than Mrs. Smith's expertise; but given the parameters of the case, the doctor's expertise protects the patient's health more than Mrs. Smith's does. However, the deliberation process keeps the patient expert involved in the decision-making.

Co-deliberation addresses the concerns raised earlier regarding the principles of biomedical ethics. When each individual has decision-making authority without my proposed requirement for deliberation, problems quickly become apparent. For Dr. A, issues arise when lack of information regarding the patient causes potential harm and not the best form of care for the patient.

The Concern of Beneficence

The ability for quality beneficent care increases when a requirement for deliberation between the two experts is implemented.⁴⁷ In the first solution, our biggest concern is with (2) one ought to remove evil or harm and (3) one ought to do or promote good. With (2), co-deliberation can relieve many opportunities for unnecessary harm. If Dr. A has a duty remove evil or harm, then Dr. A has a duty to find treatment plans best suited for Mr. Smith. Communicating with Mrs. Smith would maximize Dr. A's ability to act beneficently. To satisfy (3), Dr. A must promote what is good for Mr. Smith. In biomedicine, the good can vary patient to patient. For any specific patient, what is good will vary in each situation. In Mr. Smith's case, the patient expertise Mrs. Smith can offer gives insight into what Mr. Smith might have wanted. In requiring deliberation between Dr. A and Mrs. Smith, the potential for beneficent care increases and helps to satisfy (2)-(3). Dr. A will authorize care for Mr. Smith with insight into his character provided by Mrs. Smith. When dissenting takes place, the medical expertise will be the "final say" which protects the patient from unnecessary harm.⁴⁸

⁴⁷ I believe that within the principle of beneficent care, that this notion includes not just a universal approach, but also a patient-centered approach- which factors in all necessary information about the patient (beliefs, religion, personality, etc.)

⁴⁸ The expertise kicks in to protect the patient because he has no authorized decision maker and is incapacitated. In this situation, erring on the side of medicine is best *when complimented by a requirement for co-deliberation between patient expert and the medical expert.*

The Concern for Autonomy

When Dr. A has authority over Mr. Smith's medical decisions, respect for his autonomy can be in jeopardy. However, this is not to say Dr. A's decision power necessarily produces Mr. Smith's autonomy being violated. Respect for autonomy is a hard concept to achieve in alternate decision making. The requirement for co-deliberation promotes the incapacitated patient's (in this case, Mr. Smith's) autonomy. Mrs. Smith presents a wealth of knowledge about Mr. Smith: a lifetime of memories, an intimate relationship with the patient and a multitude of conversations which collectively give Mrs. Smith *explicit or implicit* insight into what Mr. Smith would want in his critical medical care.

Limitations

This thesis does not address group decision-making outside of two individuals. In biomedicine, there is often a medical team and/or ethics committee available or present. The medical team may consist of patient care technicians, nurses, phlebotomists, doctors and nurse practitioners. All these people are involved in caring for the patient. This is for a couple of reasons: (a) I focus on the important dynamic between medical expert and a single patient expert to explore the relationship between the two; (b) group-decision-making involving more than two people additionally involves addressing other dynamics between multiple individuals which is outside the scope of this thesis. However, group settings where more than one individual has the specified expertise and what co-

deliberation might look like for them are important and should be discussed at length in the philosophical community.

This solution is also limited to a certain kind of surrogate decision making- albeit necessary, it still limits the application of the theory. There are other kinds of alternate decision makers, including legally appointed ones, such as moral strangers, Durable Power of Attorney for Healthcare, and ethics committees. Many states have laws dictating the hierarchy of alternate decision makers.⁴⁹ Furthermore, many states do not allow a patient's physician to be involved as an alternate decision-maker. The ethical implications of surrogate decision makers are a subject which requires more study and debate.

Conclusion

Much work needs to be done in the philosophy of surrogate decision-making. As each person is unique, each case with a decision maker is as well. This thesis focuses on one specific kind of alternate decision-maker case: one which a) involves a doctor with no pre-established rapport with the patient; b) involves a family member/loved one as a potential unauthorized surrogate decision-maker; and c) involves both parties holding, individually, the kind of expertise specific to their role in the decision-making process. I offer one such case study example, explain the unacceptable consequences of either patient expert or medical expert having authority with no requirement for deliberation,

⁴⁹ Alternate decision makers are people who step in to make medical decisions for those with no legally recognized and authorized surrogate decision maker. This normally looks like their parents/spouse, then children, etc. The concern of legally declaring a hierarchy for decision makers is something not addressed in this paper but should be studied from a philosophical perspective.

and set forth criteria which requires for the two people to co-deliberate. I argue while both patient expert and medical expert bring important information to the decision-making process, in order to (1) promote the safety and life of the patient as an incapacitated individual and (2) promote, to the extent it is possible, the patient's rights to a respect for their autonomy, beneficence, non-maleficence, and justice, the doctor, after fulfilling the requirement for co-deliberation, has authority to execute the desired to decision. I apply each criterion to the case of Mr. Smith and demonstrate how a requirement for co-deliberation has the potential to avoid consequences of any one individual making decisions solo.

In an era where the healthcare system is relied on heavily, protecting patients' rights is more important than ever before. Surrogate decision-making cases have always been difficult. The additional layer of the COVID-19 pandemic has restricted visitors; the number of patients on ventilators and/or other life support has exponentially increased. There should be an increasing concern for an incapacitated patient's rights. While the solution I establish requires additional time commitments on behalf of family members and doctors, I believe co-deliberation is necessary to improve the quality of care given to patients who are incapacitated and without an authorized decision-maker. Surrogate ethics requires much more attention and rigorous debate within the philosophical community in order to produce ideal and non-ideal theories. These theories will prove useful for medical professionals to potentially implement and massively reduce the stress our current system of addressing surrogate cases has on patients, patients' families and the entire healthcare system.

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