Ch. 5: Autonomy and Informed Consent

Brendan's Big Book of Bioethics | Brendan Shea, Ph.D. (Brendan.Shea@rctc.edu)

1 CONTENTS

2 WHAT IS AUTONOMY? WHAT DOES IT MEAN TO RESPECT IT?

In this lesson, you'll learn to:

1. Explain what "autonomy" is, and how it relates to liberty and agency.
2. Compare and contrast differing philosophical theories of autonomy.
3. Apply philosophical theories of autonomy to real-world cases.

2.1 AUTONOMY, LIBERTY, AND AGENCY

One of the four main principles of the common morality most relevant to biomedical ethics is **respect for autonomy. Autonomy** can roughly defined as the ability to "govern oneself" or to "make important choices about one's life." Autonomy requires both **liberty** ("independence from controlling interference") and **agency** ("capacity for intentional action"). So, normal adults are, in most circumstances, capable of making autonomous choices. They can choose where to go to dinner, who to associate with, which doctor to see, whether to buy a gun, and whether to drink alcohol. They do not have *unlimited* autonomy, though—they cannot buy heroin, chase people with axes, or go to the restaurant naked.[1]

By contrast, a person who is in prison (as punishment for a crime) lacks *liberty* and thus do not have full autonomy. They are not allowed to do many of the things that normal adults can do, though they do still have *some* room for autonomous choice (they can, for example, choose which books to read from the prison library, whether to work out, etc.). On the other hand, elderly persons with severe dementia lack *agency,* and thus do not have autonomy for a very different reason. Their diminished cognitive abilities mean that they cannot do many of the things that normal adults can do. Again, however, this does not mean that they have *no* capacity for autonomous choice. Among other things, they generally have the capacity to participate in choices regarding their diet, choice of entertainment, and so on.

Other beings that have diminished autonomy include children and adolescents, and possibly some animals (chimps, apes, etc.). By definition, beings without sentience (that cannot feel pleasure or pain) can't have autonomy, since there is nothing "good" or "bad" that can happen to them. So, a rock doesn't have any autonomy. In this lecture, we will talking about the importance of respecting patients' **autonomous choices.** While not everyone has the exact same "level" of autonomy, most patients are capable of making *some* important choices about their medical care.

2.2 IS AUTONOMY A SECOND-ORDER CAPACITY?

"To give another example, a person might desire to learn to ski. He might believe there is no further motivation or he might believe that what causes the desire is the wish to test his courage in a mildly dangerous sport. Suppose he is now led to see (correctly) that he desires to ski because he is envious of his brother who has always excelled in sports. Having recognized the

[1] Both the Stanford Encyclopedia of Philosophy and the Internet Encyclopedia of Philosophy have good entries on philosophical debates concerning autonomy. John Christman, "Autonomy in Moral and Political Philosophy," in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, Spring 2018, 2018, https://plato.stanford.edu/archives/spr2018/entries/autonomy-moral/; Jane Dryden, "Autonomy," in *Internet Encyclopedia of Philosophy*, May 2019, https://www.iep.utm.edu/autonomy/.

source of his desire he can now either wish he were not motivated in this way or reaffirm the desire. If the latter, then he is acting authentically in that he identifies himself as the kind of person who wants to be motivated by his envy." -- G. Dworkin[2]

Dworkin's Split-Level Theory. According to the **split-level (or hierarchal) theory of autonomy,** autonomy can be defined as a "second-order capacity of persons to reflect critically upon their first-order preferences, desires, wished, and so forth and the capacity to accept or attempt to change them in the light of higher-order preferences and values" (G. Dworkin, *Theory and Practice of Autonomy*). The basic idea is that (1) an autonomous being has first-order desires for things such as food, sex, and shelter. However, (2) an autonomous is capable of *reflecting* on these desires and constraining them if need be. So, for example, both adults and toddlers occasionally look at other people's plates and think "That food looks really good. I wish I had some." The toddlers (who are NOT fully autonomous) may simply try to take the food. By contrast, the adults (who ARE autonomous) have control over their desire. In the skiing example above, Dworkin argues that the person is acting "authentically" (and with more autonomy) if he self-consciously "endorses" the desire in question. By contrast, if the person thinks "I wish I wasn't so envious" and feels regret/embarrassment over having this desire, the person is NOT behaving autonomously, since it looks like they are being "ruled" by a desire that they think of as being "outside themselves." (A more serious, and realistic, version of this problem occurs when the desire in question is the result of addiction, mental illness, severe trauma, etc.).

Figure 1 Physician with an elderly male patient (Brendan Shea x Dall-E).

The Problem. Beauchamp and Childress's *Principles of Biomedical Ethics* argues that this definition is INCORRECT because it would entail that many obviously autonomous choices are NOT autonomous. For example, alcoholics often lack the second-order capacity to "stop" themselves from drinking (in part because addiction can "skew" our second-order desires along with our first-order desires), and adulterers lack the capacity to "stop" themselves from cheating. Nevertheless, we think that alcoholics and adulterers are at least partially *responsible* for these actions, in a way that a toddler or a patient with severe dementia would not be. A less dramatic example: many of us "know" we should eat healthier, but have our willpower "break down" when we are presented with our favorite foods. This does NOT mean that we are not autonomous, or that our physician, the government, etc. needs to step in to control our diets.

2.3 INTENTIONALITY, UNDERSTANDING, AND NONCONTROL

In contrast to the split-level theory of autonomy, B&C propose a **three-condition theory of autonomous choice.** The three conditions are as follows:

[2] Gerald Dworkin, "The Concept of Autonomy," *Grazer Philosophische Studien* 12 (1981): 203–13.

- **Intentionality.** Autonomous choice "requires plans in the form of representations of the series of events proposed for the execution of an action." For example, if a patient chooses to have a surgery, they (at the very least) need to have in mind something like the *process* they will be going through, and the likely *end results* of this process). There is no guarantee that the action will turn out as intended, of course; autonomous choice merely requires that you *chose* to do this action for some *reason.* Another way of putting this: intentionality requires that you can "imagine" what will happen in the future.
- **Understanding.** Autonomous choice requires a "substantial degree" of understanding. In a medical context, some factors that inhibit understanding include poor communication (by the medical professional), illness, and immaturity. In some cases, a person might make an autonomous choice *not* to be told some information (e.g., you can ask your physician *not* to tell you the chance that your cancer will be terminal).
- **Noncontrol.** Autonomous choice requires that a person "be free of controls exerted by external sources [e.g., family, medical staff, insurance companies] or by internal states [e.g., mental illness, severe anxiety] that rob the person of self-directedness." There is nothing wrong with a person *voluntarily* accepting an authority, of course (e.g., choosing to follow the rules of a certain religion, or agreeing to do whatever the doctor recommends).

Intentionality is "all-or-nothing", in the sense that an action is either intentional or it is not. Understanding and noncontrol, by contrast, are matters of degree. So, you can partially understand something, or be partially influenced in your choice by external threats or mental illness. An *autonomous choice* requires that you (1) acted intentionally and (2) did so with an *adequate level* of understanding and control.

How to Respect Autonomy: Negative and Positive Obligations. The principle of respect for autonomy includes both NEGATIVE obligations (don't lie to people; don't threaten them to make them do the things you want them to do) and POSITIVE obligations (try to help them understand what is at stake; help them make their *own* choice). The principle of autonomy can sometimes conflict with the other three principles (nonmaleficence, beneficence, or justice). For example, we might restrict a person's right to autonomous choice if doing so allowed us to prevent a significant harm (nonmaleficence), provide important benefits (beneficence), or distribute resources fairly (justice).

Example: Is a 10-year old autonomous? While 10-year olds often can usually use language well enough to communicate with medical staff, we usually think that they are NOT autonomous and thus, should not make their own medical decisions. BC's theory can explain why this is. They often lack full intentionality (they can't really picture the intended long-term "result" of the treatment with great precisions) and understanding (of major benefits and risks). Finally, their emotions make it difficult for them to meet the "noncontrol" criterion. Dworkin would agree, but for different reasons: he would point out that young children have many of the same desires (for food, safety, etc.) that adults do. However, they lack the adults' second-order ability to reflect on and overrule these desires. According to both theories, moreover, children will (usually) become increasingly autonomous as they age. So, for example, the typical 15-year-old will do better by both B-C's theory and by Dworkin's theory. Correspondingly, we think that medical professionals ought to pay more attention to their wishes.

2.4 REVIEW QUESTIONS

1. Which theory of autonomy do you find more persuasive—Dworkin's theory or B&C's theory? Why?
2. Judgements about the extent to which patients are "autonomous" are especially important when these patients either refuse treatment that the medical team recommends, or wants additional treatment that the medical team would NOT recommend. To what extent would the following patients count as autonomous? Consider the potential role of intentionality, understanding, and noncontrol. How might

you respond in each case? (For example, what sort of information might you try to find out? How might you go about trying to increase the patient's autonomy, if this is possible?)

a. A patient who requests an unneeded prescription because of (false) information that he has read on the internet.
b. A patient who refuses surgery because she has an overwhelming fear of needles.
c. A patient who has recently by diagnosed with a terminal, painful illness, who requests aid in dying.
d. A 13-year-old patient who requests cosmetic surgery, and who reveals that they are motivated primarily by the desire to avoid teasing and bullying.
e. A patient with a history of drug addiction who tells you they have been in chronic pain, but doesn't have any obvious physical symptoms.

3 WHAT IS INFORMED CONSENT? WHO IS COMPETENT TO GIVE IT?

Over the course of this lecture, you'll be learning to:

1. Distinguish between express, tacit, and implied consent.
2. Explain what "competence" is, and how it is assessed.
3. Describe different standards governing the disclosure of information to patients.
4. Explain when a choice counts as "voluntary."
5. Reflect on the importance of informed consent in medicine.

3.1 VARIETIES OF INFORMED CONSENT

The principle of respect for autonomy requires that medical staff get **informed consent** to carry out treatments or research on **competent** patients[3]**.** Because of this, it is important to know what we mean by these terms:

- **Express consent** occurs when a person gives explicit verbal or written indication that they agree. This is the "paradigm" of consent both in medicine and the law, and it should be obtained whenever possible.
- **Tacit consent** occurs when a patient effectively "consents" to some action by *failing to object* in certain circumstances where they clearly understood that they could stop the action by objecting (and in which no one is pressuring them to agree).
- **Implied consent** occurs when the person's past choices provide strong evidence that they *would* agree, were they capable of doing so. (For example, suppose that Jones is unconscious and cannot give explicit consent to a blood transfusion. If he has agreed to blood transfusions in the past, this would be grounds for assuming implied consent).
- All of these are different from **presumed consent** (what any "rational" person *should* agree to).
    - A number of bioethicists and legal scholars have argued that that this isn't really a form of consent at all. So, for example, suppose a car accident victim comes in to the ER unconscious, and needs life-saving treatment. However, we have no idea who this person is. Should we treat? Almost everyone would say "Yes!". Some would argue that this shows respect for presumed

[3] For more on informed consent, see Nir Eyal, "Informed Consent," in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, Spring 2019 (Metaphysics Research Lab, Stanford University, 2019), https://plato.stanford.edu/archives/spr2019/entries/informed-consent/; Christine Grady, "Enduring and Emerging Challenges of Informed Consent," *New England Journal of Medicine* 372, no. 9 (February 26, 2015): 855–62, https://doi.org/10.1056/NEJMra1411250.

consent ("Who wouldn't want their life to be saved?"). The critics of presumed consent argue that we don't really need to appeal to consent at all in this case—we can just appeal to principles like nonmaleficence or beneficence.

Consent can be either **specific** (for a certain procedure) or **general (**for "any treatment needed"). In general, patient autonomy is best respected by *explicit, specific consent to the treatment proposed*. By contrast, presumed, general consent has often been abused ("I *presume* these children would agree to participate in this risky experiment…").

What does it mean to be "competent" to provide informed consent? Competence can be generally be defined as "the ability to perform a task"; different people may be more or less competent to do different tasks, or to make different sorts of decisions. It is closely related to autonomy, and is required for informed consent. In each case, we need to establish **standards** that allow us to say "A person with condition C is/is not competent to complete task T." We then to establish **tests** that allow us to determine whether or not a given person meets this standard.

Some factors that are relevant to determining incompetence include the inability to (a) rationally explain or defend one's choice, (b) understand relevant information about risks or benefits, or (c) behave as a minimally rational person would behave. Different people have argued for different (and incompatible) standards. In general, it is reasonable to require *more* or *stronger* evidence for a patient's competence as the seriousness of the procedure increases. For example, we might be satisfied with a 10-year-old's competence for choosing his or her own cough medicine; by contrast, we would not allow the child to decide on serious surgery.

3.2 TWO CONCEPTS OF CONSENT

B-C argue that there two *types* of consent that often get confused by medical professionals, by patients, and even by lawyers and administrators), sometimes with bad results.

- **Informed consent as autonomous authorization:** "An informed consent is an individual's *autonomous authorization* of a medical intervention or participation in research." This requires careful consideration of the *individual patient*.
- **Informed consent as (legally or institutionally) effective consent:** "*conformity to the social rules* that require professionals to obtain legally or institutionally valid consent from patients before proceeding with diagnostic, therapeutic, or research procedures."

These two things are related, but they are importantly different. For example, a person may fully consent in the first sense even if the rules governing the second sense prohibit her from doing so. An example: a 19-year old might give fully informed consent to donate organs to save a sibling, even if state laws or hospital policies say she has to be 21. Conversely, there are MANY cases of medical staff who get patients to sign all the correct paperwork (sense 2), even though these patients don't really understand or agree to the medical procedures they describe.

While the first sense of consent is something like the "primary" sense of consent (and it's the idea that the laws and policies in sense 2 are all "about"), this doesn't mean we should simply ignore the second sense. In general, medical professionals need to be concerned with BOTH versions of consent, since they mutually reinforce each other. The first sense has to do with making sure the particular patient with whom one is working really knows what is going on; the second sense is about maintaining a rule-following culture where patients and staff have clear idea about how things "ought" to work.

3.3 INFORMED CONSENT IN THE LAW

Most state/federal laws (and most hospital policies) require that patients be told at least the following FOUR things:

1. The **nature of the procedure** that they are being asked to consent to. (For example, they should understand the basic differences between chemotherapy, radiation, surgery, hormone therapy, etc.). The patient should also be told the (likely) time frame.

2. The magnitude and probability of various **risks.** Basically, they should be aware of both what kinds of *harms* this procedure might cause, and how *likely* these harms are.
3. The **alternatives** to the proposed procedure, together with information about benefits/risks.
4. The expected **benefits** of this procedure. The patient should not be given unrealistic ideas of what the procedure can accomplish.

While it is undeniably important to write up informed consents documents that technically meet these requirements (and to present these to patients in an appropriate manner), its often much more difficult to determine (1) whether a patient is actually **competent** to give consent, and (2) whether they actually understand all of the above. This is because patients are generally NOT medical professionals with detailed knowledge of medical procedures. In the rest of this lesson, we'll be thinking about what this means for medical professionals.

3.4 WHAT INFORMATION SHOULD I DISCLOSE? WHAT COUNTS AS "RELEVANT"?

In order to obtain informed consent from a competent patient (or from a surrogate for an incompetent patient), medical staff must **disclose** all relevant information. But how do we determine what's relevant? Again, there are competing standards:

- The **professional practice standard** holds that you are required to disclose only the sort of information that other people in your profession normally disclose. The problem: What if the majority of professionals "agree" to give patients inadequate information (historically, this has certainly been the case)? This is the current law in many states.
- The **reasonable person standard** holds that you should disclose information that would be relevant to a (hypothetical) purely rational person. The problem: While this is better than the professional practice standard, it risks ignoring the differences between patients. In recent years, some states have adopted this standard.
- The **subjective standard** judges disclosure by "the specific informational needs of the specific person." Problem: While this is an ideal *moral* standard for judging disclosure, it probably won't work as a *law* or *guideline*. It can serve as a valuable supplement to the professional practice or reasonable person standards, however.

Withholding Information. In *some* circumstances, it is both legally and morally OK to withhold information. These cases include instances of the **therapeutic privilege** (when giving the person the information would cause them severe and unnecessary pain, or would undermine their ability to behave rationally) or **research** (when telling the patients all of the info would ruin the study). In these cases, the patients' "right to know" must be balanced carefully against other moral principles, and all alternatives must be carefully considered. For example, it is almost never OK to withhold info simply because you think it might make a patient refuse a treatment. In the long term, failing to disclose relevant information will undermine patients' trust in their medical staff, which can lead to bad outcomes.

3.5 HOW MUCH UNDERSTANDING IS REQUIRED FOR INFORMED CONSENT?

Almost no one can understand *everything* relevant to making to particular choice. In the context of informed consent, **understanding** requires that people have "acquired pertinent information and have relevant beliefs about the nature and consequences of their actions." Some common barriers to understanding often include:

- **Assessing risks and benefits.** Both patients and medical staff are often confused by statistical data such as mortality, morbidity, and survival rates; specificity and sensitivity; and so on. In these cases, information should be presented in multiple ways.
- **Failures of imagination.** Patients often fail to predict how much they will dislike negative outcomes (such as postsurgical recovery), or enjoy positive ones (such as long-term health).
- **The "therapeutic misconception.**" Many patients believe that their participation in experimental research is likely to improve their *own* chances for recovery, even though research is primarily directed at helping *future* patients.

3.6 WHEN IS A CHOICE VOLUNTARY?

A person acts **voluntarily** if "he or she wills the action without being under the control of another person or condition." A person can be controlled (in whole or part) by three different sorts of **influences:**

- **Coercion** occurs if and only if "one person intentionally used a credible and severe threat of harm or force to control another." Actions undertake because of coercion are not voluntary, and coercion is justified only in extreme cases (e.g., to prevent severe harm from coming to the patient).
- **Persuasion** involves appeal to reason, and need not undercut voluntariness.
- **Manipulation** involves types of influence (lying, withholding information, exaggerating, etc.) that are neither coercion (which threat-based) or persuasion (which is reason-based). It can undercut voluntariness, and should generally be avoided.

3.7 REVIEW QUESTIONS

1. Give an example of express, tacit, implied, and presumed consent.
2. In your own words, describe the difference between the three standards of disclosure discussed above.
3. Give an example of coercion, persuasion, and manipulation. How do these interfere with a person's ability to consent?
4. In the last few years, many colleges (as well as a few states) have adopted a "Yes means Yes" (or **affirmative)** policy of sexual consent[4]. This means that, *for the purposes of campus affairs* (such as student discipline), sexual activity requires something like express consent by both parties. Before this, campus policies often allowed for somewhat weaker forms of consent (closer to implied or tacit consent, as we have defined them here). Why do you think that campuses have adopted this policy? What are the potential benefits of doing so? The drawbacks?

4 BIOETHICS AND THE LAW: CANTERBURY V. SPENCE[5]

"The record we review tells a depressing tale. A youth [Jerry Canterbury] troubled only by back pain submitted to an operation without being informed of a risk of paralysis incidental thereto. A day after the operation he fell from his hospital bed after having been left without assistance while voiding. A few hours after the fall, the lower half of his body was paralyzed, and he had to be operated on again. Despite extensive medical care, he has never been what he was before. Instead of the back pain, even years later, he hobbled about on crutches, a victim of paralysis of the bowels and urinary incontinence. In a very real sense this lawsuit is an understandable search for reasons.

The context in which the duty of risk-disclosure arises is invariably the occasion for decision as to whether a particular treatment procedure is to be undertaken. To the physician, whose training enables a self-satisfying evaluation, the answer may seem clear, but it is the prerogative of the patient, not the physician, to determine for himself the direction in which his interests seem to lie. To enable the patient to chart his course understandably, some familiarity with the therapeutic alternatives and their hazards becomes essential…A reasonable revelation in these respects is not only a necessity but, as we see it, is as much a matter of the physician's duty. It is a duty to warn of the dangers lurking in the proposed treatment, and that is surely a

[4] Janet Napolitano, "Only Yes Means Yes: An Essay on University Policies Regarding Sexual Violence and Sexual Assult," *Yale L. & Pol'y Rev.* 33 (2014): 387.
[5] Canterbury v. Spence, 464 F. 2d 772 (Court of Appeals, Dist. of Columbia Circuit 1972).

facet of due care. It is, too, a duty to impart information which the patient has every right to expect. The patient's reliance upon the physician is a trust of the kind which traditionally has exacted obligations beyond those associated with armslength transactions. His dependence upon the physician for information affecting his well-being, in terms of contemplated treatment, is well-nigh abject…

In our view, the patient's right of self-decision shapes the boundaries of the duty to reveal. That right can be effectively exercised only if the patient possesses enough information to enable an intelligent choice. The scope of the physician's communications to the patient, then, must be measured by the patient's need, and that need is the information material to the decision. Thus the test for determining whether a particular peril must be divulged is its materiality to the patient's decision: all risks potentially affecting the decision must be unmasked. And to safeguard the patient's interest in achieving his own determination on treatment, the law must itself set the standard for adequate disclosure.

…

Of necessity, the content of the disclosure rests in the first instance with the physician. Ordinarily it is only he who is in position to identify particular dangers; always he must make a judgment, in terms of materiality, as to whether and to what extent revelation to the patient is called for. He cannot know with complete exactitude what the patient would consider important to his decision, but on the basis of his medical training and experience he can sense how the average, reasonable patient expectably would react. Indeed, with knowledge of, or ability to learn, his patient's background and current condition, he is in a position superior to that of most others -- attorneys, for example -- who are called upon to make judgments on pain of liability in damages for unreasonable miscalculation."

Brendan's Questions. In this important court case, the state adopted a "reasonable person" standard of informed consent (i.e., that the physician should tell patients those facts a reasonable person would want to know). They held that this standard was *objective* (it did not vary between patients), and they held that it was NOT determined by "medical practice" (that is, it was not determined by what most medical staff believed was right).

1. Do you agree with the court?
2. Do you think that the patient [Canterbury] deserved to win the case?

5 READING: NO PATIENT IS AN ISLAND (BY ANITA HO)[6]

How a concern to protect the autonomy of patients leads to the exclusion of families just when they are needed the most.

I wouldn't show them the note,' a retired nurse told my mother. It was a request to meet with my father's physicians. He had undergone a cardiac surgery, and soon after became lethargic and difficult to rouse. The nurses thought he was simply fatigued from his procedure, and my mother didn't want to question their professional judgment. Two days later, my father suffered an acute respiratory failure and was rushed to the intensive care unit (ICU). He was intubated and remained dependent on a respirator for days. The nurses told my mother that the doctors were considering a tracheostomy, but up to that point no ICU physician (called an 'intensivist') had so much as talked to my family.

[6] Anita Ho, "Why Doctors Should Involve a Patient's Family in Decisions," Aeon, March 19, 2020, https://aeon.co/essays/why-doctors-should-involve-a-patients-family-in-decisions.

Intensivists were not at the bedside during the limited visiting hours and, as they rotated, a series of different intensivists attended to my father. So my mother was left to wait outside the ICU in the remote chance that she would run into my father's doctor, but nobody told her the name of the attending physician *du jour*, and the doctors' faces were often hidden behind surgical masks as they walked the halls. So, with my help, she had drawn up the note, requesting a meeting. But it was to no avail. 'The doctors might think your family is difficult,' the nurse said.

Figure 2 Patient alone in their room (Brendan Shea x Dall-E).

I wondered why the doctors didn't hold a family meeting to discuss my father's prognosis and clinical options. While my mother wanted to speak to at least one of the intensivists, attempts to make appointments were met with reluctance. The nurses said the doctors were busy, that they had to uphold patient privacy and confidentiality. My mother started to blame herself for not insisting on further investigation regarding my father's lethargy, and she was anxious about the lack of information. Worse, the insinuation that she would be bothering the busy clinicians for wanting a meeting with them intimidated her. She was sternly warned by a nurse not to overstay the visiting hours.

I am a bioethicist who has worked alongside clinicians in supporting patients and families making complex and rending care decisions. I have seen how physicians are bombarded with demands. Meeting with families requires not only coordination but energy: it is emotionally draining for clinicians to share grim prognoses with patients and families. But patients have a fundamental right to pertinent information regarding their illness. The doctrine of informed consent and related legislations in various jurisdictions require that adult patients be given relevant information about their conditions, and the risks and benefits of their care options, so that they can make decisions according to their values and goals. In situations where patients – like my father – might not have the mental capacity to make healthcare decisions for themselves, substitute decision-makers take that role on the patient's behalf.

[Brendan's Question: Have you ever had experience with elderly relatives in the hospital? How does the author's experience compare with yours]

In many jurisdictions in the US and elsewhere, patients can legally appoint a healthcare agent or power of attorney who can make decisions for them if they lose such capacity. When no such person has been appointed, physicians themselves are expected to identify a surrogate decision-maker. It is generally assumed that family members or intimate associates are aware of a patient's wishes and that most are concerned with their loved ones' best interests. Getting family involved early on can clarify any misinformation as well as the goals of care. Most of all, involvement reassures everyone. It provides comfort at a tragic time.

My father was frail and delirious in the ICU. Being intubated and connected to monitors, he was unable to see, hear or speak. He had no glasses or hearing aid, perhaps because the care team worried that putting them on for him would interfere with his equipment. Or maybe they thought he wouldn't need to see or hear, given that they weren't going to directly communicate with him any time soon, so he was incapable of making or communicating his wishes.

My parents had been married for more than 45 years. Throughout all his illnesses, my mother was the informal caregiver for my father, tirelessly accompanying him to all medical appointments and helping him with medication, mobility – any and all personal care. Their lives and identities were intertwined. But now, for 22 hours a day, my mother was separated from her life partner by the walls of the ICU, wondering whether he was improving or declining, and lamenting that she could not be at the bedside to comfort him, especially when he appeared confused and agitated. With the ICU's very limited visiting hours and no concrete information, she was isolated from my father, and he from her. Still, my father's physicians had made no effort to meet with my family.

By this point, I was supporting my mother from afar. Having worked with many patients and families in end-of-life care, I was not afraid of a grim prognosis. I was more concerned about how my mother felt abandoned by a care team that was likely trying to provide what they considered to be the best clinical treatment for my father. I tried to comfort her, but she needed answers that only my father's doctors could provide. My colleagues gave me general information about tracheostomy and associated risks. But despite my extensive bedside and research experience on navigating care decisions, I was unable to walk my mother through prospective treatment options for my father. Not only did we lack direct information from the care team, we weren't even confident that the doctors would ask us to help make the treatment decisions. I could do little except urge my mother to continue nudging the nurses for as much information as possible, carefully observe my father's presentation during her visits, and ask for a meeting with the doctors while I planned a trip to be with my family.

Having worked alongside clinicians for many years, I trusted the care team's integrity and commitment to do what they believed would be in any patient's – including my father's – clinical interests. What I doubted was whether they would be able to accurately determine his overall best interests without involving our family in discussions about who my father was, his hopes and fears, and our understanding or concerns about various care options. After a couple more days of no response, my mother summoned the courage once again to give the nurses the note requesting a meeting with my father's physicians. Eventually it worked. After I arrived, we met with an intensivist by my father's bedside.

The first thing I did was assure the intensivist that we trusted the care team's competence and that we knew they were doing their best for my father. I recognised that concerns about family involvement in Western medicine are partly due to the development of the concepts of individual self and autonomy in moral philosophy. From René Descartes to contemporary theorists, many Western philosophers consider the self as individualistic, independent and in control. This view of rugged individualism contrasts with – and, to some extent, refutes – the inherent significance of family relationships, which can include biological and adopted families as well as other domestic partnerships and intimate relationships. These relationships are characterised by collectivity, non-consensuality, sensibility and favouritism: much messier than the view of individuals being steadfastly in control of their own destiny.

According to rugged individualism, rational adults are separate from others by boundaries that can be justifiably breached only by the explicit and voluntary consent of self-determining subjects. Such individual boundaries support the patients' moral and legal rights to give informed consent (or refusal) to various treatments without undue influence from others. In liberal societies, it is now generally accepted that patients are most invested in their own interests, such that they should be the ones to make voluntary decisions

regarding their care. If my father were capable of making decisions, he would be solely authorised to receive information from his doctors regarding a tracheostomy or other care options, and to make his choices accordingly. If, however, he foresaw that he might lose his decisional capacity, he would have had to explicitly designate my mother, my brother or me, in advance, to be a substitute decision-maker.

[Brendan's Question: What do you think of the 'rugged individualism' view of patient autonomy an decision-making? How does the author think it causes problems for families?]

'They're too emotional,' one physician said. 'They don't understand what's going on'

But for a couple who had been together for almost half a century, and with my brother also residing with them and taking on some of the caregiving duties, was such formal delegation really necessary to involve my family in the discussions and decision-making process? Certainly, for those who are fortunate enough to have family support at times of illness, many clinicians welcome varying levels of family involvement in patient care, especially when family members can provide emotional support to the patient, relay valuable patient information to clinicians, provide personal care while the patient is in hospital, or assist with discharge planning by assuming long-term care once the patient returns home. Nonetheless, family members are seen mostly as a means to the patient's clinical ends, and are sometimes considered an intrusion in the professional caregiving space.

Our family was welcomed at the bedside when we could help soothe my flustered and bewildered father, but less so when we had questions about his fluctuating heart rates, even as my mother was the one who first noticed and reported my father's lethargy a couple of days before his respiratory failure. While professionals usually recognise that building rapport with family members is essential for good patient care, many clinicians still experience uneasiness in dealing with families. ('They're too emotional,' one physician said when asked about including families in decision-making. 'They don't understand what's going on.') Subtle doubts about family members' qualification and motives for getting involved further strain relations between caregivers and families. This all makes some family members – such as my mother – very cautious in asking for information or being involved in the decision-making process.

In our case, the doctor seemed to think that since the team was contemplating a tracheostomy only if they couldn't wean my father off the respirator, there was no need yet for a family meeting. After all, no urgent decision was required, and my father might regain decisional capacity during that time. My mother experienced herself as being strongly intertwined with my father, and I was confident that my father would want her to be informed and involved throughout, even if he were fully capable of making his own decisions. It probably never occurred to him that he would need to explicitly sign a legal document for his family to support him through the tough times. Nonetheless, contemporary healthcare continues to centre on individuals' boundaries and to treat family involvement as non-ideal or even suspicious. In the autonomistic climate that thinks of patients' identity in isolation from their social context, many clinicians worry that the voices and considerations of intimate others would 'taint' the care decisions.

While respect for patients' self-determination is undeniably important, my experience accompanying many patients and families in making agonising healthcare decisions – and my own journey with my parents – has led me to believe that autonomy or individual agency is experienced, paradoxically, with others. Vulnerability is the reality at times of illness. My father couldn't verbalise his concerns, but tears would flow as soon as we entered the room. Seeing him, I couldn't help but wonder if the atomistic view of individuals as separate social units is false and impoverished. My father's identities and values were rooted in his social and familial affinities with us, and such relational identity was central to his medical decision-making.

In an ageing US population with an increasing prevalence of chronic conditions, illness in contemporary medicine is often not an isolated or time-limited event. Healthcare decisions are shaped by one's intimate

others, and patients' interests are rarely ever purely self-interested. My father had lived with his cardiac and respiratory illnesses for years and was cared for by my mother, such that his illness and care experiences evolved from their history and contributed dynamically towards its future. The same was evident in many patients and families I had worked with. Patients in tight-knit families often discuss their conditions and care with family members long before seeking professional help.

As my father's hospitalisation prolonged, his identity shifted and disintegrated. Despite the rhetoric of patient-centred care, the structure, incentives and culture of the health system are often poorly aligned to respond to patients' needs. My father was objectified in sterile settings governed by 'foreign' customs and rules. He was studied, tested and prodded by unfamiliar instruments in mechanical ways. He was not identified by his personal stories, histories or relationships, but primarily or even solely through bed or room numbers in the name of protecting patient anonymity, symptom-focused medical charts, and clinical jargons regarding diseased body parts. Visiting hours, diets, diagnostic schedules and discharge plans were determined not by his or our family's preferences but by bureaucratic matters, lab or bed availability, cost-efficiency, professionals' convenience, insurance coverage, and so on. While my father's care team initially hesitated to meet with my family, presumably due to privacy and confidentiality concerns, the institutional care setting was anything but private. The hospital beds were separated by thin curtains. Patients and visitors could hear every moan and conversation from the other beds.

My mother is a reminder that patients such as my father are not mere collections of dysfunctional body parts

My father's experience was not unique. With healthcare teams and division of labour, patients often have minimal contact with any particular provider and little continuity of care. As specialised medicine results in patients being attended by more clinicians than ever before, 'care' has ironically become increasingly impersonal and fragmented. Healthcare team members, especially in intensive care, are what the medical historian David Rothman has called 'strangers at the bedside' who usually focus only on their own specialised area. Well-meaning professionals are often overworked and attend to the patients only according to a very specific set of clinical and institutional circumstances. With the emergence of electronic health technologies, contemporary medicine has inadvertently exacerbated the isolation by reducing many patients with full histories and relational identities to quantified entities on dashboards.

Against this backdrop, family involvement helps to preserve or restore patients' autonomous agency. Patients today are faced with complex data and choices, some of which are expensive and/or existentially tragic, such that those who are already burdened by illness and an unfamiliar medical culture might feel even more overwhelmed when they are expected to remember and analyse intricate medical information and make decisions on their own. Ironically, autonomous decision-making can lead some to feel *more* helpless and isolated. Even when patients are cognitively capable of participating in decision-making, such deliberation is often physically and emotionally exhausting rather than empowering.

[Brendan's question: What do you think of the claim that "family involvement helps to preserve or restore patients' autonomous agency"? This seems to be something like the author's tehsis]

So the patients' priority might not be taking charge of their desires when they weave through the medical maze. Perhaps more important to some patients is the preservation of an overall sense of identity, agency and selfhood through connections with familiar others. Family members such as my mother – the constants in a changing plethora of health professionals – are reminders that patients such as my father are not mere collections of dysfunctional body parts or numbers on the digital dashboards that require professional interpretation and intervention. They are moral agents with full histories and deep relationships. Family involvement can preserve patients' integrity and worth, rather than violate privacy or autonomous agency. Patients might prefer to entrust and defer decision-making to their family members or consider their interests extensively in the planning process. Since intimates generally care deeply about the patient's interests and

wellbeing, and likely have knowledge of the patient's overall goals, family involvement enhances the patient's agency.

For ethnic-minority patients in contemporary medicine, the concern over isolation is heightened. Some patients face language and cultural barriers, and might not be familiar with the specific healthcare system or Western medicine in general. They might also worry about breaking hierarchy and confronting their professional carers, who likely have little knowledge of the patients' cultural and familial history. Ethnic minorities in the US might also lack adequate insurance coverage and depend on family members for medical care and advice. As family involvement is often integral to patients' recovery and continued wellbeing, and as that familial caring relationship is in stark contrast to the service-for-hire model in institutional medicine, many patients might be inclined to trust their family's judgment and seek their support in decision-making. These patients have been marginalised as 'the other' in clinical settings. Family involvement is helpful in preventing alienation and radical shifts in patients' sense of identity and agency.

The rugged individualist framework ignores how a patient's experience of illness has a tremendous impact on their friends and family. Indeed, the concerns and wellbeing of families is morally relevant in healthcare decision-making. My father's illness and recovery experience were my mother's life experience – they were intertwined and could not be separated. It was no surprise that soon after my father regained some cognitive function and was extubated from the respirator, he told my mother that he was terribly concerned about how his illness was burdening her emotionally and physically. Healthcare experiences highlight how our self is constituted by relations with others, and the responsibilities we have towards them. Even self-determining patients exist fundamentally in relation to others, such that patients' interests might involve a dynamic balance among interdependent people who have overlapping concerns. Illnesses have very disruptive effects on family members, particularly on women, who are expected to provide various forms of care. Healthcare decisions are not simply individual affairs. My parents' relationship should partly determine how my father's medical needs would be met, as well as how our respective family members' lives have to change to accommodate his care. Even as my father entered the professional care setting, our family remained an inextricable part of the processes.

Illness is a family matter. Familial care can be substantial in scope, intensity and duration. The family's understanding, expectation and capacity to care for the patient are thus relevant to the treatment decision, both for its own sake and for the patient's care pathway. As increasing institutional and systemic constraints can leave family members with no option but to take on an expanding range of care responsibilities, justice demands due attention to the impact that treatment decisions can have on family members. Inviting family members to be part of the decision process early on, and exploring their respective expectations and concerns, can help clinicians understand the patient's overall context and to suggest the most appropriate care plan. In a society where women such as my mother are the primary carers, consideration of the impact that healthcare decisions have on intimates not only promotes patients' overall agency, but also women's wellbeing and moral status.

Certainly, a recognition of patients' relational identity does not mean that all patients would want their family members involved in care decisions. Rather, a respect for patients' relational identity and the family's concerns requires that all parties keep the decisional space open. Such effort can clarify expectations and misconceptions. When we reframe familial involvement as one of a relational response to promote the patient's identity and best interests, we can facilitate further strategies for collaboration, and promote patients' and families' wellbeing.

As my family's struggle with my father's final months showed me, after the farewell, the families are the ones who will live with the memories of their loved ones for their remaining days. How they cared for the patient in the process, and how the care team responded, would be part of their memories and narratives. How

patients involve, connect with and protect their loved ones is also a crucial part of the patient's wellbeing in their final journey. True respect for patients requires that we also honour the family's involvement in decision-making: family-centred care *is* patient-centred care.

[Brendan's Question: What did you think of this essay? Do the author's observations/experiences fit with what you have experienced?]

6 CASE STUDY: WHAT SHOULD PHYSICIANS AND CHAPLAINS DO WHEN A PATIENT BELIEVES GOD WANTS HIM TO SUFFER?[7] (BY FRUSH ET AL)

Abstract. When physicians encounter a patient who gives religious reasons for wanting to suffer, physicians should maintain their commitment to the patient's health while making room for religiously informed understandings of suffering and respecting the patient's authority to refuse medically indicated interventions. Respecting the patient can include challenging the patient's reasoning, and physicians can decline to participate in interventions that they believe contradict their professional commitments. Chaplains likewise should both support and possibly respectfully challenge a patient in instances that involve desire to suffer for religious reasons, and physicians should draw on chaplains' expertise in these situations to attend to the patient's spiritual concerns. Finally, conversations involving spiritual and existential suffering might include members of the patient's religious community when the patient is open to this option.

[Brendan's Question: If you're not familiar with the idea of a "hospital chaplain," I'd encourage you to quickly Google it. Why do you think that most hospitals employ chaplains?]

6.1 CASE

Mr. L is a 47-year-old father of 2 who has a history of alcohol abuse but has been sober for over a year. He was admitted from the emergency department, where he presented earlier this morning with acute abdominal pain. He was diagnosed with pancreatitis and biliary colic, indicating the need for a cholecystectomy (a laparoscopic procedure to remove the gallbladder to prevent gall stones, pain, and infection). However, before the procedure could take place, Mr. L stated that he did not want pain medication after the surgery because, as he said, "God wants me to be in pain." The medical team, unsure how to proceed, delayed the surgery.

Dr. J, a fourth-year surgery resident, met with Mr. L to discuss his request and quickly reach a resolution, as the medical team did not want to delay the procedure for more than 24 hours. After Mr. L explained why he did not want pain medication, Dr. J stated, "You are going to feel a lot of pain after this surgery. Sometimes the pain is so extreme that patients have difficulty breathing. So the pain medication helps you be able to take full breaths, which reduces the likelihood of getting pneumonia." Dr. J then asked Mr. L if he would be willing to speak with a chaplain about his ideas of what God wants for him, and Mr. L agreed.

Dr. J consulted with the chaplain on call, Mr. K, and explained Mr. L's case. "We can't, in good conscience, not give him pain medication," she said. "It's just bad care. I respect his beliefs, but I can't be forced to give

[7] Benjamin W. Frush, John Brewer Eberly Jr, and Farr A. Curlin, "What Should Physicians and Chaplains Do When a Patient Believes God Wants Him to Suffer?," *AMA Journal of Ethics* 20, no. 7 (July 1, 2018): E613-620, https://doi.org/10.1001/amajethics.2018.613.

him what I know to be bad care because of his beliefs. We need to manage the pain to help him heal, if not to be compassionate." Mr. K suggested, "I'll speak with him to get a better understanding of his spiritual concerns. Why don't we talk after I meet with him?"

Mr. K visited Mr. L. They spent some time getting to know each other and, eventually, Mr. K asked, "So would you tell me more about why you think God wants you to be in pain after your surgery?" Mr. L nodded his head and lifted his hand. "I've done a lot of wrong in my life and hurt a lot of people. I haven't been a good father to my kids. And from the way I see it, God wants me to be in pain—God wants me to suffer through this so I can atone for some of my sins. And God's right—I don't deserve the pain meds and I don't want the pain meds."

Dr. J and Mr. K now meet and consider how to proceed.

6.2 COMMENTARY

Recent research has indicated that religious identity and practice can impact health outcomes at the population level as well as individual clinical decisions of patients.[1, 2] This research has spurred discussion over how to properly attend to the religious concerns of patients, particularly when such concerns influence clinical decision making.[2] Although physicians often engage with patients' religious beliefs to support clinical recommendations and to help patients cope with illness and the burdens of medical treatment, sometimes patients give religious reasons for resisting or refusing medical recommendations.[3] Conflicts about medical decision making that involve religion and spirituality can be particularly fraught due to the seriousness and the deeply personal nature of religious belief and practice. The vignette involving a patient (Mr. L), his physician (Dr. J), and his chaplain (Chaplain K), offers such an instance.

Specifically, this scenario pits the patient's desire to forego postoperative pain medication against the physician's judgment that not treating postoperative pain constitutes bad medical care. For Dr. J, the proper course of action must conform to "good care," which, in her judgment, entails administering effective pain medication after a major surgery. For Mr. L, the patient, the proper course of action requires refusing this pain medication under the religiously informed conviction that the pain to be suffered might "atone" for past sins. This commentary explores the conflict between the patient's and physician's views—first, through a reflection on the purpose of medicine, then through an analysis of the particularities of accommodating religious belief in a clinical context, and finally by addressing the role of a chaplain and the wisdom of a community.

6.3 SUFFERING, HEALTH, AND MEDICINE'S PURPOSE

First, this case raises a critical moral question: namely, what does good care entail for those who practice medicine? ***The traditional understanding of medicine holds that its telos ("purpose" or "end") is health, which Leon Kass famously defined as "the 'well-working' of the organism as a whole."***[4] This traditional delineation of medicine's purpose differs starkly from a contemporary vision that does not promote an objective definition of health as the end of medicine but rather champions the relief of suffering as medicine's purpose, an evolution whose roots lie in the philosophy of Francis Bacon.[5] These two rival accounts of what medicine is for lead to different approaches with respect to the present vignette specifically and medical praxis and decision making more generally.

[Brendan's Question: Which of the two accounts of medicine's "purpose" do you agree with? Why?]

As the third author (F.A.C.) has argued elsewhere, preserving and restoring the health of the patient has been understood for centuries as the constitutive purpose of medicine.[6] Under this traditional approach, physicians seek to relieve suffering, not as an end in itself, but insofar as the relief of suffering is part of attending to the

patient's health. For example, the physician might readily prescribe narcotics for a patient whose health is diminished by wracking pain from metastatic cancer, but the same physician might refuse such narcotics for a patient suffering chronic pain when short-term relief of suffering is not proportionate to the long-term health-diminishing effects of dependence on narcotics. In the latter situation, the physician adhering to the traditional approach to medicine might prescribe an alternative regimen that is more conducive to the patient's health, even though doing so brings about less relief from suffering, at least in the short term. In contrast, a contemporary approach that champions the relief of suffering as the proper goal of medicine might struggle to distinguish between different types of patient suffering, potentially compromising the patient's health as a consequence. The authors contend that in order to discern when and how to relieve patient suffering, physicians need to maintain the profession's traditional orientation toward the patient's health.

Importantly, with respect to our analysis of the case, the traditional approach allows room for accommodating a spiritual or theological understanding of suffering as long as doing so does not contradict the physician's commitment to the patient's health, whereas the alternative approach leaves little room for such an understanding as it views suffering strictly as something to be eliminated.

6.4 PHYSICIAN-PATIENT ACCOMMODATION IN ENGAGING WITH PATIENTS WHO INVOKE RELIGIOUS BELIEFS

On the traditional understanding of medicine as oriented toward the patient's health, the question is not, "How should Dr. J reconcile Mr. L's religious beliefs with her professional beliefs?," but rather, "Does accommodating Mr. L's desire to forego pain medication compromise Dr. J's commitment to the patient's health?" Concern for Mr. L's health circumscribes which decisions are acceptable from Dr. J's point of view; it defines what can and cannot be done. Within the boundaries set by this professional commitment, Dr. J can search out with Mr. L a course of action that respects his religious concerns. What Dr. J is looking for is what Mark Siegler has described as **"a physician-patient accommodation**," a way forward in which both the physician and the patient are acting with integrity.[7]

In the current scenario, if evidence suggests that withholding pain medicine would unduly reduce the chances of a successful operation, compromise the patient's recovery, or otherwise threaten Mr. L's health, then Dr. J should refuse to offer this course of action, regardless of the religious rationale for such a request. Clearly, there are circumstances in which such refusals are warranted; Dr. J would have clear reason to refuse, for example, if the patient wanted surgery but would not consent to anesthesia.

Conversely, if Dr. J concludes that foregoing postoperative pain medication in this case would not otherwise unduly threaten the health of the patient, then she should feel free to accommodate Mr. L's religiously informed wishes, even if she disagrees with them. Once again, it does not matter so much whether Mr. L's refusal is religiously informed or not, although it is worth noting that physicians tend to be more accommodating of religiously informed requests, perhaps out of respect for the seriousness of religious convictions.[8]

[Brendan's Question: Do you agree with the claims of the last two paragraphs? Why or why not?]
Whatever Dr. J decides, she should explain her reasoning to Mr. L candidly and make clear that her rationale is based upon her professional judgment, not scorn for his religious ideas. If possible, Dr. J should take time to listen to Mr. L in order to better understand his reasoning and how his religious beliefs inform his desired course of action. Such listening opens up the possibility that Dr. J and Mr. L will find an accommodation that will allow Dr. J to do what she thinks is medically necessary. Instead of treating conversation about religious matters as out of bounds, Dr. J should freely inquire about how Mr. L understands the decisions he faces in

light of his religious (or other) beliefs. This approach conveys respect, builds trust, and opens up the possibility of finding an accommodation that both patient and physician can pursue with integrity.

In the context of such **respectful listening**, Dr. J should also feel empowered to respectfully challenge Mr. L's beliefs about suffering. Indeed, as part of their professional commitment to the patient's health, physicians have some obligation to respectfully challenge patients' refusals of medical care that the physician believes is needed. A sincere discussion—even a respectful debate—in no way denigrates Mr. L's religious beliefs. Rather it treats religious concerns with the seriousness that Mr. L ascribes to them and so treats Mr. L with the respect he deserves. Such conversations do not require physicians to get into theological arguments with patients. Simply asking patients whether there are alternative understandings within their faith tradition regarding the issue at hand might circumvent an impasse.

6.5 THE ROLE OF THE CHAPLAIN

We now turn to the role of Chaplain K in this dilemma. While chaplains are not health care practitioners per se, they are generally considered members of the health care team.[9] Within that team, chaplains focus on the religious and spiritual care of patients, even when they are employed by secular institutions.[10, 11]

Ideally, Dr. J would involve Chaplain K early in this scenario—when it first becomes apparent that Mr. L's faith is important to him. In the course of these conversations, the chaplain, like Dr. J, may also seek to understand and potentially to challenge Mr. L's religious reasoning. He might, for example, encourage Mr. L to consider whether there are alternative understandings of suffering, guilt, or grief found within his religious tradition.

The chaplain should not, however, seek to bring about a predetermined outcome on behalf of the medical institution (such as changing the patient's mind about pain medication). The chaplain is not an instrument subordinated to the health care enterprise but rather a co-contributor to the flourishing of the patient. The commitment of the physician to the patient's health and of the chaplain to the patient's spiritual care are distinct commitments, but both should ultimately be expressed in a caring and respectful stance toward Mr. L throughout his treatment process. For Dr. J, this commitment means providing the best medical care possible within the constraints posed by what Mr. L is willing to consent to, all while exploring and even challenging his refusals. For Chaplain K, this commitment means continuing to attend to Mr. L's spiritual good and observing whether and how Mr. L's religious reasoning about his own suffering changes in the course of his treatment.

[Brendan's Question: How does the chaplain's "purpose" in medical care differ from that of physicians or nurses?]

It is entirely possible that, in the current situation, no accommodation can be found. Dr. J might conclude that she cannot operate safely without knowing she can give adequate postoperative pain medication. Meanwhile, Chaplain K's presence, prayer, and conversation with Mr. L could result in Mr. L becoming more entrenched in his refusal of such pain medication. Such conflicts are sometimes inevitable, and respect for patients' authority means allowing them to refuse medical care that we believe they desperately need. However things turn out, the chaplain is there to provide spiritual care, not simply to persuade the patient to go along with medical recommendations.

6.6 THE WISDOM OF A COMMUNITY

In the case of Mr. L, and in other related cases, it can be helpful to broaden the conversation beyond the confines of the hospital and the medical team. Toward this end, Dr. J or Chaplain K might encourage Mr. L to invite his family, friends, and members of his faith community into further clinical discussions. Mr. L may

decline to do so, of course, but, in our experience, many patients have more confidence in their own clergy or other religious counselors than they do in hospital chaplains, and inviting faith communities into these conversations can allow for more meaningful and effective spiritual care in such cases.

Inviting members of an outside religious community into clinical discussions is not without risk; in the present case, the faith community might fortify Mr. L's refusal of pain medication. However, the faith community might instead qualify or alter his understanding of suffering and atonement for sin while affirming the theological truths important to Mr. L's religious framework. For example, Mr. L's faith leaders might suggest that his refusal to accept pain medication will further burden his loved ones who will watch him suffer. They might help him explore the difference between pursuing suffering and patiently enduring suffering or how the work of reconciliation, repentance, and forgiveness can offer more peace than his current understanding allows.

[Brendan's Question: Under what conditions can bringing in members of a patient's religious community help? Under what conditions might it hurt?]

6.7 CONCLUSION

Ultimately, when religious reasoning leads patients to disagree with or refuse their physicians' recommendations, physicians must seek to understand patients' reasoning and respectfully try to find an accommodation that neither undermines patients' authority to refuse medical interventions nor contradicts their professional commitment to patients' health.

In such encounters, the virtues of humility and patience are essential for physicians. They must have the humility to acknowledge the limits of their knowledge, expertise, and authority, and to ask for help from chaplains or religious leaders from the patient's community who have much more experience with spiritual concerns. They must have the patience to respectfully seek an accommodation with a patient whom they might be tempted to dismiss as simply irrational, and, even when it might not bring about the outcome they desire, they must give chaplains and clergy the freedom to do their work.

Such health care can be arduous and time consuming. However, if we are truly to respect and respond appropriately to patients' religious and spiritual beliefs, it is health care we must practice.

7 CASE STUDY: 23 & MEMAW

From: National High School Ethics Bowl Regional Case 2022. Parr Center For Ethics. CONTRIBUTORS Tylor Cunningham, Ramona Ilea, Audra Jenson, Joanna Lawson, Marko Mavrovic, John Miller, Sally Moore, Z Quanbeck, Alex Richardson, Alyse Spiehler, Meredith Sheeks, Ehsan, Sheikholharam, Delaney Thull, Dustin Webster

Nancy, who is in her late 50s, and two of her maternal cousins gave each other gene testing kits for Christmas this year, so that they could discover their ancestral genetic profiles. They fully expected to learn the same information about their maternal family members, as their three mothers are sisters. They were interested to learn how their three different fathers impacted their genetic profiles. However, when they received their results, they uncovered something surprising. Nancy's maternal information is slightly different from her two cousins'.

It turns out that Nancy's mother and her aunts most likely have different fathers. So, this means that Nancy's grandmother Barbara most likely committed infidelity in her marriage with Nancy's grandfather. Nancy and her cousins are faced with the question of whether or not to tell Nancy's mother, who is in her late 80s. Her

cousins' mothers, Nancy's aunts, have already passed away, as have both of her grandparents. She has asked her cousins not to say anything to her mother or to anyone else in their family, while she decides what to do.

Nancy never met her grandfather, as he died just before she was born. But Nancy knows that her grandmother Barbara and her grandfather had a very fraught marriage. Her grandfather was an alcoholic and was known to be verbally abusive and financially controlling to her grandmother Barbara. Nancy has always avoided alcohol, assuming that she might have inherited a genetic predisposition to alcoholism from her grandfather, as several of her cousins have struggled with excessive drinking as well. She feels drawn to the idea that her grandmother Barbara found some happiness outside of an abusive marriage, and she doesn't mind thinking of her mother and herself as the results of her grandmother Barbara finding some independence. She is curious to talk with her mother about the possibility that they aren't descended from the man they have always assumed was their father and grandfather. She would be interested in learning more information about her grandparents' close friends, community and church members, or colleagues, on the off chance that she might be able to discover information that would lead her to her biological grandfather and potentially to other biological family members.

However, Nancy's family is religious and they have strong beliefs about the importance of marriage and of being faithful to a spouse. Nancy feels like her mother has a right to know this information about her own parents and ancestry. And, her mother has only ever talked bitterly about her relationship with her father. Yet, she knows that this information might be deeply distressing to her mother. Though Nancy's mother never seemed to express love for her father, she always talked with deep love and respect for her mother Barbara and held her up to Nancy as a role model of virtue and of religious faith. Nancy worries that revealing this information to her mother might cause her to question her relationship with her mother Barbara and to endure pain and sadness upon realizing that her mother Barbara kept secrets from her. Also, Nancy's mother suffers from health problems and receives a twice-weekly home visit from a nurse. The nurse has advised Nancy that protecting her mother from stress is important for keeping her health stable.

7.1 DISCUSSION QUESTIONS

1. Should Nancy tell her mother about her suspicions? Is it at all significant that there is some degree of uncertainty about the conclusion she is drawing?
2. How do her mother's health concerns factor into this decision?
3. Do we owe others, especially those near and dear, the hard truth? What if they would be "better off" not knowing?
4. How, if at all, do the facts about Nancy's grandmother Barbara's fraught relationship with her grandfather change the moral dimensions of Nancy's decision

8 CASE STUDY: THE SOCIAL (EXPERIMENT) NETWORK

From: National High School Ethics Bowl Regional Case 2022. Parr Center For Ethics. CONTRIBUTORS Tylor Cunningham, Ramona Ilea, Audra Jenson, Joanna Lawson, Marko Mavrovic, John Miller, Sally Moore, Z Quanbeck, Alex Richardson, Alyse Spiehler, Meredith Sheeks, Ehsan, Sheikholharam, Delaney Thull, Dustin Webster

Across the globe, Facebook users utilize the platform in a variety of ways, and more than a third of adults report regular use of Facebook as a news source.[8] Behind each user's news feed is an algorithm that controls what that user will or will not see. The algorithm is based on a collection of factors—including which types of posts a user interacts with and what their Facebook friends are posting about. At one level, this process is

[8] https://www.pewresearch.org/fact-tank/2021/06/01/facts-about-americans-and-facebook/

practical. When a given user opens their news feed, there are thousands of posts that Facebook could show them. Processing through such a large number of posts would be overwhelming to the user. So, the algorithm streamlines a mere hundred posts to the user and selects posts that will presumably keep them coming back for more.[9]

However, some types of algorithm tinkering seem different. In 2012, Facebook intentionally altered the news feed algorithm of hundreds of thousands of users in order to conduct a psychological experiment.[10] The experiment was designed to measure whether or not emotional states are contagious via social media networks, as they can be with in-person interactions. By changing the number of positive or negative posts that users would see, researchers concluded that, indeed, emotional states are contagious via a social media network.[4] The experiment's findings are informative, but many have questioned whether Facebook was morally justified in conducting such an experiment in the way it did.

Facebook withheld experimental information from hundreds of thousands of users about how the emotional tone of their news feeds was being directly and intentionally altered. Moreover, Facebook users were unaware that they were the subjects of a psychological experiment designed to impact their moods. However, Facebook users consent to the intentional alteration of their news feeds when they agree to the terms of service. So, defenders argue that Facebook had the requisite permission of its users to use them in the psychological experiment, regardless of whether or not the users were explicitly aware of their participation in the experiment or their consent to it.

8.1 DISCUSSION QUESTIONS

1. Are social media companies like Facebook ever morally permitted to conduct psychological research on their users without the direct knowledge of those users?
2. To what extent, if any, does the tacit consent of social media users—i.e., their agreement to the terms and conditions of utilizing a social media platform—grant social media companies the moral permission to conduct psychological experiments on them?
3. Under what circumstances, if any, might social media companies have a moral obligation to intentionally alter their algorithms or to modify what certain users see on their news feed?

[9] https://www.facebook.com/business/news/News-Feed-FYI-A-Window-Into-News-Feed
[10] https://www.nytimes.com/2014/06/30/technology/facebook-tinkers-with-users-emotions-in-news-feed-experiment-stirring-outcry.html [4] https://www.pnas.org/content/pnas/111/24/8788.full.pdf