

Paternalism, Truth-Telling, and Informed Consent

Here, we will consider the question of paternalism in the context of telling the truth to patients. Is it permissible to deceive patients “for their own good”?

1. Informed Consent: Though it was once standard practice for doctors to withhold information from their patients (by not telling them when they had cancer, not disclosing the nature of treatments, or their risks and benefits, and so on), it has become standard practice in the past few decades to require physicians to get “informed consent” from their patients whenever possible before carrying out any procedure:

Informed Consent: Consent which has the following features:

- (a) The patient is **competent** enough to make a decision.
- (b) The patient receives adequate **disclosure** of relevant information.
- (c) The patient **understands** the information.
- (d) The patient makes a decision **voluntarily**.

(a) Competence: Clear examples of incompetent patients (those who are incapable of making informed decisions) are those who are severely psychotic, or mentally disabled or very young. But, what about these less clear cases: Those who are not thinking clearly because they are crippled by fear or pain, or even stupidity?

(b) Disclosure: The relevant information to be disclosed is generally thought to at least include (i) the nature of the proposed procedure, (ii) alternatives to the proposed procedure, (iii) their potential risks, and (iv) their potential benefits.

This is the important one for the question of truth-telling. Exceptions are made in medical emergencies, when there is no time to obtain informed consent. But, what about cases where full disclosure is thought to likely result in harm (e.g., because it terrifies or depresses the patient, makes them give up hope, or even have suicidal tendencies)? Legally, sometimes informed consent is not required if there is some kind of “**therapeutic privilege**”. But, this is just shorthand for “when therapeutic benefits outweigh the need for truth.” We will mostly be debating this claim. Do they EVER?

(c) Understanding: Obviously, one can only consent to something if they understand what they are agreeing to. But, some have argued that many patients will NEVER truly understand what they are agreeing to, unless they themselves have been to medical school, since most treatments and medical issues are incredibly complex. So, is understanding really possible?

(d) Voluntary: Obviously consent is only valid if it is voluntary. This is, for instance, why we consider contracts to be rendered invalid if signed at gunpoint. But, there are much subtler forms of coercion than being held at gunpoint. For instance, is subtle manipulation a violation of freedom? Or, failing to disclose ALL of the relevant alternatives, and their potential harms and benefits?

2. Against Truth-Telling and Informed Consent: Mack Lipkin argues that informed consent is impossible, and advises against full disclosure. He cites several reasons:

- (1) Understanding is Impossible: Medicine is so complex, and patients are so ill-informed about the nature of the human body, and sickness, that they are incapable of true understanding, or assessing information accurately. For instance, when they hear the word "cancer", some will assume this means they are going to die in a few weeks, while others will think it is nothing serious. Similarly, "arthritis" may make one patient think of their completely incapacitated grandmother, and make another patient think of their grandfather who complained just a little. These broad labels are not very informative, but the narrower labels or any in-depth explanation would be too confusing for them.
- (2) People Don't Want to Know: Lipkin claims that, while people may SAY they want to know the truth, they really don't. For instance, someone might ask, "Do I look fat?" and SAY they want the truth—but when you tell them they DO, you quickly learn that they did not really want the truth. What they WANTED was a "No", whether it is true or not. Doctors face similar questions. "Am I dying?" or "Is it bad?" What they WANT is a "No", whether or not this is true (even if they claim otherwise).
- (3) Placebos: Placebos are obviously permissible. These are treatments where the physician CLAIMS to be giving the patient something to treat their illness, when in fact it has no medicinal effects at all (e.g., sugar water). The goal is to improve the PSYCHOLOGICAL state of the patient, which often leads to a visible improvement in their actual physical health.

There is an interesting argument here. It might go something like this:

1. Placebos are clearly morally permissible.
2. Placebos are instances of deceiving patients in order to benefit their health.
3. Therefore, some instances of deceiving patients in order to benefit their health are morally permissible.

Thomasma cites a number of other cases where deceit might be the right thing to do:

- Telling someone in an ambulance about to die, who asks, "Am I going to be ok?" that they ARE going to be ok.
- A father in critical condition has just been in a terrible car accident in which his entire family died, and asks, "Is my family ok?" The doctor replies that they are.
- Withholding the truth that someone has cancer because his entire family claims that "he will go off the deep end", and perhaps even become suicidal.
- Telling a young woman who does not know that she is a hermaphrodite that she has a "gonadal mass" that needs to be removed in order to get "her" to agree to a procedure which will in fact make her fully female.
- Failing to tell someone with Huntington's Disease (a disease that may not set in for another 15-20 years) that they are sick and will probably die in 20 years.

What do you think of cases like these? If withholding the truth in these cases is permissible, then it is at least SOMETIMES permissible to deceive patients for the greater good. But, then, how easily can beneficence trump autonomy in this way?

3. Health: The Greatest Value? When we are asking whether beneficence ever trumps (i.e., takes greater moral importance than) the patient's autonomy, we mean beneficence TOWARD THAT PATIENT. Doctors might want to violate a patient's autonomy in order to be beneficent to THEMSELVES (e.g., by telling a patient to pay for all sorts of treatments that they don't need in order to make more money), but this is clearly wrong. Similarly, a doctor might want to violate a patient's rights in order to be beneficent to OTHER PATIENTS (e.g., by harvesting their organs and saving 4 other people's lives), but this is clearly impermissible too.

The idea behind paternalistic deception is, then, as follows:

1. Telling patients the truth may sometimes negatively affect their health, well-being, or life expectancy (depression, fear, and worsening of their physical state).
2. Health and prolonged life have priority over all of the patient's other interests.
3. Therefore, it is permissible to deceive a patient, in cases where doing so is in THAT PATIENT'S best interests.

Is this argument correct? Goldman challenges premise 2. He asks, are health and prolonged life REALLY of the greatest value, or priority? It seems that we often do things that trade in health or longevity in the interest of doing things we prefer NOW, and when we do so, it is not generally viewed as irrational. For instance, we:

- Eat delicious food that we know is bad for us.
- Fail to exercise even though it would make us exercise.
- Smoke cigarettes or drink alcohol.
- A person with a heart condition may still work hard to pursue unfinished business or projects, even though they know this will worsen their condition.

These things do not seem to be irrational. It is natural to trade in quantity for quality, and this might just be what we are doing here: Trading in quantity of life or health for other things that are more important to us now (like quality of life).

Health and Life Not Intrinsically Valuable: When something of value is said to “trump” all other things, it is generally thought that it must be INTRINSICALLY valuable in order to do so. But, Goldman suggests that health and life are not intrinsically valuable. Rather, they are only of INSTRUMENTAL value. They are valuable only because we need to have these things in order to accomplish the things that are truly valuable to us (e.g., life projects, building relationships).

For instance, if life were intrinsically valuable, then it would be valuable to just keep people alive in persistent comas. But, that doesn’t seem right. Even pleasure may not be intrinsically valuable (he references the experience machine to support this). He writes,

“Many people are willing to endure frustration, suffering, and even depression in pursuit of accomplishment, or in order to complete projects once begun.” (97)

People are not pleasure-seekers. For, they often forego pleasure for things that they think are more important, just as they also sometimes forego life or health for this same reason.

Autonomy Intrinsically Valuable: The underlying thing of value behind all of our decisions to forego life, health, or happiness to pursue life projects and relationships is AUTONOMY—the freedom to direct our own actions. This is why the experience machine is so unattractive, or why slavery seems so awful. They remove our freedom of self-determination.

Imagine: If there were an algorithm for determining the best fit for marriage, or career, or school, we would still prefer to make our own choices than to have the government force us to live by that algorithm—even if we could pretty much guarantee that our own choices would not make us as happy as the algorithm’s choices.

[Objection: Is this correct? I think we would agree with Goldman only if we were not properly imagining the proposed scenario. Imagine that the algorithm was 100% accurate, such that it was GUARANTEED that you would be immensely happy for the rest of your life? Would we really reject such a resource?]

Autonomy Fundamental: Autonomy seems, even, to be the most basic of all values. Self-determination is what makes us US. **It is what makes us who we are.** It is what makes us human beings, or “persons”.

Conclusion: Deceiving a patient because you believe you know better than they do “what is best for them” fails to respect the fact that autonomy is valuable—perhaps of the UTMOST value.

Why, then, are there any lingering doubts? Well, Goldman says, when your job is to secure the health or lives of persons, this may come to seem like the MOST important thing. Letting a patient’s condition worsen, or letting them die might seem like defeat, or the worst thing ever. But, this might just be the result of the skewed perspective of those in the medical field. However, these are not the worst thing ever, so long as they are traded in for other things of greater value. Patients can only assess this, though, if they are fully informed (otherwise, the doctor violates their autonomy).

4. Respect For Persons: Susan Cullen and Margaret Klein concur with Goldman here. Deceiving a patient, they say, fails to treat them with the proper respect as a HUMAN BEING. They write,

“If we are each special because of our ability to make choices, then others should not destroy this ability or interfere with our exercise of it.” (149)

Cullen and Klein focus on the importance of autonomy, citing the decisions that we WOULD make are very different than those that we DO make when we are deceived—thus the physician fails to respect our right to self-determination when s/he deceives us. For instance, consider these cases:

- A doctor deceives a single mother by telling her that she will be ok, when in fact she will die in one month. If she had known the truth, she might have reached out to people who were important to her (to say goodbye), finished her uncompleted projects, or made arrangements for her son.

- A doctor fails to tell a man that he has Huntington's Disease (a degenerative disease that is eventually completely debilitating, and then fatal, but takes a long time to onset) because it is nothing to worry about for 15-20 years. If he had known the truth, he might have made different life decisions. Especially, regarding children, since the disease is 50% likely to be passed on to children.

The "Whole Truth" vs. "Wholly True": In response to the objection that patients could never know or understand the whole truth: There is a difference between conveying the **whole truth** and giving them information that is **wholly true**. Clearly, patients could not understand (and it would not even be useful for them to be given) the WHOLE truth. But, this is not a problem peculiar to the medical field. Auto mechanics, electricians, auto mechanics, and computer I.T. workers all face it too. But, it does not follow from the fact that the whole truth cannot be conveyed that physicians are then permitted to say things that are not wholly true (i.e., it does not follow that deception is permissible).

Deception Does Not Promote Beneficence: In response to the claim that it is often in the patient's health's best interest to deceive them, they claim: (1) The idea that patients who know that they are sick will suffer from anxiety and depression that makes their condition worse is unsupported by data. So, an unverified, hypothetical speculation is no justification of deception. (2) Patients who know how serious their condition is are generally more receptive to treatment (i.e., will be more cooperative, work harder toward recovery, etc.). So, knowing the truth might actually help to IMPROVE their health.

Patient Does Not Want to Know?: In general, if a patient does not WANT to know their condition, or the nature of their treatment, etc., then it is obviously permissible to withhold information. But are there exceptions? For instance, if someone receiving an HIV test does not want to know, does the physician have a duty to violate their wishes and tell them anyway? (Not doing so could result in the person passing on this virus to someone else). Cullen and Klein say that this IS an exception, since respecting the patient's autonomy could result in someone else's death.

Against Absolutism: They are not suggesting that autonomy is ABSOLUTE. For instance, as we have seen, it might be permissible to deny someone's wishes to remain ignorant in cases where doing so might harm OTHERS (e.g., if someone has a communicable disease). But, are there any exceptions to their claim that it is wrong to violate a patient's autonomy in order to prevent harm to THAT PATIENT?

Clearly, it is permissible to restrict autonomy to some extent in order to promote the greater good (e.g., taxation, driver's licenses and laws, laws against killing, etc.). So, this sort of trade-off is not ABSOLUTELY wrong. It is only prima facie wrong. These are cases of MINOR restrictions in the interest of MAJOR benefits. Cullen and Klein conclude that, while restricting patient autonomy in order to promote other goods is generally impermissible, it is permissible to deceive them for a short while if doing so will save their life. (However, such cases are actually quite rare)