

[MUSIC PLAYING]

JENNIFER BLUMENTHAL-BARBY: Thank you. Well, it's my pleasure to be here today and talk about sort of calling into question the idea of patients as autonomous decision-makers and thinking a little bit about the ethics of shaping patient decision-making.

So the plan is that I'll start out by talking about some of the different findings from behavioral science that I think are really fascinating findings about the psychology behind decision-making that really call into question this idea. And then we'll talk about this idea of shaping patient's decisions or sort of nudging their decision-making. And then lastly, of course, because this is an ethics talk, we'll talk about some of the ethical considerations in using these nudges to shape patient's decisions.

So this is a nice quote by Carl Schneider, who is a law professor who's done a lot of work trying to understand the ideal of autonomy in medicine. He wrote a book on this topic where he interviewed dozens of patients. And what he found is that there's a sort of ideal, which he represents in this quote, where he says, "over the past 40 years, there has developed an assumption that the physician's principal task is to just remove impediments to the exercise of autonomy, and that once those impediments are gone, people will naturally gather evidence about the risks and the benefits of each medical choice. They will apply their values to that evidence. And they will reach a considered decision."

I think we all recognize this as sort of the idea of autonomy in bioethics. And just because we'll be talking a lot about autonomy, I'll put a little bit of a more concrete definition up on the screen. When we think about autonomy, we are thinking about personal self-governance, of patients being free from controlling interferences by other people, or from personal limitations that might prevent choice. And there are really these sort of three key components.

So autonomous decisions are ones that are intentional. They're not just things that are done as a result of impulse, or habit, or being forced to do them. And they also involve understanding. And we'll be talking about that quite a bit. And of course, there is absence from any sort of controlling influence like a coercion or something like that.

So that is just sort of the ideal of autonomy. But behavioral science has shown that there are actually lots of problems for this autonomy ideal. And here are some of the most popular books. Some of you may have read some of them. If not, this is a great place to start to learn about this field of behavioral economics.

But basically, this field is showing that there's a lot of evidence demonstrating that patients typically use intuition, impulse, and various so-called cognitive biases in heuristics-- and I'll be giving a lot of examples of these-- when they make their decisions not according to the ideal of really deliberative planning or intentionality that we think about when we think about patient autonomy. So this idea of intuition and impulse being a reality of decision-making that causes problems for our idea of autonomy, Carl Schneider writes-- what he found in all of his empirical work interviewing hundreds of patients is that, even patients who were sufficiently well-educated and reflective to write memoirs, frequently described no decisional process at all. Instead, they invoke intuition, instinct and impulse. This is his work or findings of his qualitative work.

And he has some empirical studies that demonstrate this, as well. So here's an interesting study that's studying the decision-making process of 130 people who decided to be living kidney donors. And they found that 62% of these people describe themselves as making an immediate choice to donate. Only 25% describe themselves as engaging in any sort of deliberation.

And in my own research-- so I've been doing research with people who are making decisions about whether to get one of these left ventricular assist devices. These are advanced heart failure patients. So we did a lot of qualitative work, 45 interviews, to understand their decision-making process.

And one of the most striking findings for us in this work was, again, in this population, 30 of these 45 people describe themselves as engaged in really quick and reflexive decision-making. 28 of them said that they didn't even really think of themselves as having a real choice. So it's really interesting.

Because we're going into this thinking, this is a really preferred sense of decision. We want to understand how you made this tough decision. And they're sort of saying, this wasn't a choice. This wasn't something we really gave a lot of thought to. And 22 deferred heavily to clinicians.

So this is the first problem is this idea of decision-making really being driven by intuition and impulse. So the second problem is decision-making driven by these, as I mentioned, these things called heuristics and biases. So one of the most famous heuristics and biases that's been studied in behavioral science is something called the loss aversion bias.

And the idea here is that losses weigh more heavily to people than gains of equal magnitude. So if you frame things in terms of loss, people are going to be more responsive. It's going to influence their decision-making more.

Here's an example of this. This was a study where they were framing angioplasty to patients. And for some patients, they framed the procedure as having a one in 100 chance of complications, so the loss frame.

And then the other group, they framed it in terms of having 99 in 100 have no complications. And they asked them, hypothetically, how many would get the angioplasty? 49% of patients who got the loss frame information said they would refuse compared to only 15% in the gain frame. So again, that's very, very significant impact on decision-making just by how things are framed.

Here's another example of loss aversion bias, again, framing things in two different ways. So this study looked at women who were due for their mammography screening. And they were sending out informational packets to remind them they were due for screening. They divided them to two groups. For one group of people, they gave them so-called loss frame information where it emphasized sort of the risks of neglecting mammography, the things you're going to lose if you neglect your mammography screening.

And then for the other group of people, they really emphasized the benefits of mammography, the chance to catch cancer early, and things like that. And then they followed these women for 12 months. And they saw that 66% of the people who had received the loss frame information actually got screened compared to 51% in the gain frame-- so again, this hypothesis that framing things in terms of loss is more influential in people's decision-making.

Here's another bias that behavioral scientists have taught us about, which is sometimes called the frequency bias. And the idea here is that risk information that's framed as frequency is more influential. And I like this study, because it shows that it's not just patients that are susceptible to these biases and heuristics. We are all susceptible to these biases and heuristics.

This was a study that was actually done with psychiatrists. And what they did in this study is they were asking psychiatrists whether they would discharge a hypothetical patient. So for one group of psychiatrists, they said, this patient's risk of violence is about 20 in 100, other group, 20%. Exact same thing, right?

But they found that the people that got the frequency frame, 41% of the psychiatrists said they would refuse to discharge a patient like this compared to 21% that got the percentage frame. And this is because we know, when we frame things in terms of frequency, people can picture, OK, 20 out of 100, I can really picture those 20 people, or I can picture myself being in that group of 20 people. So it's more influential.

This isn't really heuristic or biased. But I think it's fascinating, so I just threw this example in. But even if you frame things to patients as discounted, this can actually have an impact on their perceptions and their decision-making.

I think this was a JAMA study a few years ago that found that when patients were told they were getting a discounted placebo, they found that less reported having a reduction in their pain. And more actually even reported that they had some pain increase. So this is just really demonstrating the power of framing on people's psychology, and perceptions and decision-making.

There is another bias called the relative risk bias. And the idea here is that relative risk is more influential than absolute. We can think about relative risk in two ways. One is, it's a sort of traditional, oh, this makes you 20% more likely to have this thing. The other way we can think about it is giving them their relative information compared to other patients, sort of comparative relative risk information.

So this is was a study where they had 300 women who were at risk for developing breast cancer. For half of the women, they just gave them their risk score, their absolute, their Gail score, told them how at risk they were. For the other group, they gave them their score. But they also gave them their comparative risk score, compared to other women, showed them that they had an increased risk.

And they found that the women also got this comparative risk information reported themselves as being more worried about developing breast cancer, engaged in more screening. They were more interested in preventative drugs, such as tamoxifen. So this piece of relative risk framing had an impact on their decision-making.

Another example is something that's sometimes called the comparison contrast bias, sometimes also called the decoy effect. And the idea here is really represented by this picture that we tend to like things that are middle-of-the-road. So the small seems really small. The big seems way too extreme. So we're going to choose something in the middle.

Well, this also comes out when people are engaging in medical decision-making. So if you give people options, and you say, option A versus option B, and they don't really have that much of a preference between A and B, but then you introduce an option C, such that option B now looks like it's sort of middle of the road. Now, all of the sudden, you'll see people starting to have a preference for option B, because it feels like a middle-of-the-road treatment scenario. And people are going to gravitate towards that.

Another sort of bias related to ordering of information is something that's called the recency and primacy biases. And the idea here is that what people hear first and what they hear last is most influential in their decision-making. So a study that demonstrates this is a study, again, for women who are at risk for breast cancer and were being told about the preventive drug tamoxifen.

So they just changed the order that they gave the information about the drug to women. So they would tell some women, here are the benefits of tamoxifen. Here are the risks. And then they emphasized the benefits.

For the other group, they heard about the risks, the benefits, and the risks. And they found that this former group that had the benefits right at the beginning and right at the end were more interested in taking the drug. They reported they'd be more likely to talk to their doctor about it. They were interested in it. They were going to have conversations and really consider it more.

And I think this is really significant. Because in medicine, we're giving constantly lists of risks, and benefits, and side effects for drugs. So this sort of sandwiching technique can be potentially really powerful in shaping people's decision-making.

All right, then there is the omission bias. And the idea here is that people tend to think that bad outcomes are the result of non-action are better than ones that are caused directly, even if they're of equivalent magnitude, or even if the ones that are caused directly are worse or more harmful. So here's a study looking at people's tolerance for risk of death.

And they framed it in terms of, well, this risk of death would be basically because your child got a disease and you didn't vaccinate, versus, you vaccinated, and there was this rare side effect, and there was a risk of death. Now, the risk of death was exactly the same that was presented to both groups. It was like one in 10,000 or something like that, a very small risk.

And they asked people how tolerant they would be of that risk. So you'd think it would be the same, because it's the exact same risk information. But they found that people who were told that the risk would be from vaccination were less tolerant of it. Because that would be doing something harmful.

Interestingly, in some clinical contexts, like cancer care, for example, we see another sort of opposite bias, which is called the commission bias. And the idea here is that people will sometimes think that trying something is better than nothing, even if trying something is harmful. So this is a really fascinating study where the researchers gave patients a hypothetical cancer diagnosis.

And then they said, all right, you have these choices. You can choose treatment. Treatment has a 10% chance of death. Or you can do watchful waiting, which has a 5% chance of death. So you would think that people would choose watchful waiting, since that has a lesser chance of death.

But they found that 65% of these people say that they would actually choose treatment. And we see this, actually, if you just look at natural, more organic context of, say, treatment for a low-risk prostate cancer. When you look at the number of people who engage in surgery, which is 90-some percent or something-- or it was some kind of immediate treatment, versus watchful waiting. So there's this idea of, I've got to try something. It's better than just sitting here and doing nothing.

And then there is what's called the availability bias. And the idea here is that people tend to remember what is most vivid, most recent, sort of what they can access in their memories, and that those things will drive their decision making more than individual statistics, probabilities, et cetera. So if you think about what this means in the clinical context, this means people will remember cases.

So they will remember, oh, I remember my grandma had this surgery, and this horrible thing happened to her. And that's going to be what's at the forefront of their memory and driving their decision-making, regardless of what the statistics are. So a study that demonstrated this was a study. This was published in *BMJ* a few years ago.

And what the researchers did is they were trying to engage people in advanced care planning in the scenario of advanced dementia. So for one group of people, they just gave them a basic, textual description of what life would be like with advanced dementia. So you're not going to be able to eat. You're not going to be able to communicate. You're not going to be able to ambulate.

For the other group of people, they got that exact same information. But they also saw a two-minute video of somebody with advanced dementia not being able to do those things. And then they asked people to engage in advanced care planning.

And what they found was the people that also saw that video had a higher percentage of patients say that they would want comfort care only. It was something like 86% compared to 63% or something like that. So the video, having that kind of case in their mind, and available, and vivid, really had a significant impact on their decision-making.

And sticking with the end-of-life theme and how decisions can be shaped in that context, we can think about the default bias, which is a bias it's been very well-studied and demonstrated in behavioral science and behavioral economics. And the idea here is that people tend to go with the status quo or with whatever is presented to them as the default option. So you have a lot of power in kind of presenting to patients a default option. Because that'll be the thing that they tend to go with.

So one study that looked at this changed the default on advance directives. So there were one group of people where they made no life sustaining treatment as the default, sort of the thing that was checked on advance directive. Patients could override it if they wanted.

For the other group of people, they made provision of life-sustaining treatment as a default that was checked. Again, you could override it, change it, fill out the advance directive however you wanted. But they found that, when they did the default, no life-sustaining treatment on an advance directive, only 20% of people said that they would want treatment. Whereas when life-sustaining treatment was checked as the default, 38% of people ended up saying that they would want treatment.

So this is really significant. Because this is something that's very serious. It's what kind of care you would want at the end of life. And it's impressive to think that this can be sort of manipulated by what's pre-checked on advance directive.

And interestingly, in some of these studies, the researchers have told me that they've gone back during the debriefing-- because they have to do a debriefing with these patients-- and say, we were doing a study where we actually checked the box, and we were trying to see if it made a difference in your decision-making. Do you want to change your answer? And most of the people don't change their answer even when they're de-briefed. That's sort of how powerful this thrust of defaults is.

And another bias that gets a lot of attention in behavioral economics that I think is really relevant to medicine is something called the impact bias associated-- sometimes called forecasting errors or affect to forecasting errors. And the idea here is that we kind of overestimate the impact of really bad things that will have on our life. And as a result, we do a pretty poor job of anticipating our future well-being or our future quality of life.

So here's one study where the researchers went to dialysis patients in healthy controls. And they asked the healthy people to imagine their life on dialysis, to kind of project into the future. Imagine you're on dialysis. And on a scale-- so it's a pretty narrow scale-- but the scale of minus 2 to 2, kind of periodically tell us what you think your quality of life, your quality of experience would be in that scenario. And they found that the healthy people actually gave it a negative rating, about a minus 0.17.

They then went to actual dialysis patients and asked them to do the same thing. And the actual dialysis patients rated at about a 0.64. So big discrepancy in terms of, we're thinking things are going to be so horrible. We go to the actual population. They tell us it's not so horrible.

And if you're curious, the difference between the rating of the dialysis patients and the healthy controls, I think healthy controls were a 0.8 or something like that. So it wasn't even that far off. They basically had calibrated back to where the healthy people were about, in terms of their experience of their quality of life.

Things can go the other way, however, with forecasting errors, as well. So what we tend to see a lot of is where people are forecasting and they're underestimating their ability to adapt to a situation. Sometimes we see people forecast and they're a little bit too on the optimistic side.

And this is a study that demonstrates kind of things going the other way where the researchers asked people who were about to get a transplant to forecast or imagine their life after the transplant in these various dimensions. And so, you can see the numbers here. But for things like travel, they predicted they'd be able to travel 20 days per year. They were actually only able to travel 12.

Work is a big one. They predicted they'd be able to work about 32 hours a week after their transplant. They could only work 15. And these are people who had been educated through the process about transplant and life with transplant. But they still, when they forecast into the future, have these ideas and these inaccuracies that persist and project.

So those are a lot of examples. And the list goes on. There's actually quite a list. I worked with one of my students a few years ago to do a systematic review of all of these biases and heuristics that had been studied in medical decision-making. And we ended up finding a total of 213 studies that met the criteria.

And so this is a sort of nice inventory of these studies that have been done to date on bias and heuristics in medical decision-making. There were a total of 19 different biases that were studied. So I don't know how many I just named. I didn't name 19. So there are more, even, that we haven't talked about.

90% of the studies actually confirmed the presence of whatever bias they were looking for in the population or some sub-population. So testing a bias found, unfortunately, that it's present. Interestingly, 30% of the studies were testing biases and heuristics in clinicians' decision-making. And 66% were testing these things in patients' decision-making. So more work has been done to test these biases and heuristics in patients' decision-making than has been in clinicians' decision-making.

I think both are, obviously, very relevant. So for any of you who are sort of research-inclined, I think there is kind of a need to look at how these biases play out more in clinician decision-making, as well. Know Interestingly, if you look at conformation rates, at least from the studies, we found that 61% of the patient studies confirm the bias. Whereas, 80% of the clinician studies confirmed it.

So this is just to say, we are all susceptible to these biases and heuristics in decision-making. And the biases that have been studied the most are the loss aversion bias, which is the first one we talked about, the relative risk bias, and availability heuristic. Those are kind of the most popular ones that have been studied.

So that was sort of a whirlwind of behavioral science and some of the, I think, really interesting, fascinating studies that are coming out. And so then we have to ask, what sort of ethical issues does all of this raise? And I've already sort of nodded my hat at the very beginning. And by the title of this presentation, I think it raises some significant questions and concerns for the idea of patient autonomy.

So the first ethical question is, well, gosh, our patients making uninformed, non-autonomous decisions. So we just kind of go back to thinking concretely about the elements of informed and capacitated decision-making that we all appeal to established by Paul Appelbaum, who's done so much kind of foundational work in this area, of understanding, reasoning, appreciation, clear and consistent choice. Those are the criteria for capacitated decision-making that clinicians always apply to see if a patient even has decision-making capacity.

And then we looked at our basic definition of autonomy, which is this idea that patients can govern themselves and act according to their own preferences. So if we put those two things on the table, along with what I've just presented, which is a lot of errors in ability to forecast future preferences, the fact that people's preferences are so dependent on context and framing effects, and on biases in decision-making, and on making really gut decisions, you kind of put all of that together, and I think we get significant concerns for the idea of autonomous decision-making. And just in case you're not convinced I have this extra drive-it-home slide.

So just briefly, I think, it's actually even worse. I've been talking a lot about biases and heuristics. But if we expanded beyond that to just more general concerns about decision-making, we can add some other interesting phenomena and concerns into the mix.

We know people have a lot of numeracy issues. Less than half of people can convert proportions to percentages. So when we're throwing numbers at people, and asking them to process them, and really understand them, it's kind of questionable how much mileage we're getting out of that.

And then there's some really interesting research about how people respond to threatening information, or concerning information, or bad news, which we're giving people a lot in medicine, and then asking them to respond and make decisions. So in one really interesting study, they found-- this was a study where they were giving people their cholesterol test results. And then they went back and they asked them to recall their cholesterol test results.

And they found, basically, that the higher risk category people were, the worse scores they had, the more distortion they had about their results. They were about 11 points higher than they actually were in the high-risk group compared to the group that had desirable results. They still had some denial or unrealistic optimism going on. But it was only four points.

And then there's another thing that they've discovered patients tend to do in response to threatening information, which is-- and those of you who are clinicians may recognize this. But patients will have a tendency to sort of focus on the periphery details instead of really focus on the bad information that you're giving them. So you might say, you have this 80% risk for this really bad thing happening to you. And then they're like, well, how's my this level or my that level? And you're like, it's not really kind of the central concern.

But we know from psychology that that's a tendency that people have. So again, just to put another nail in the coffin and say, I think we have a lot of concerns about, at least the assumption that, unaided, patients are generally making autonomous decisions. So the number one ethics concern is about autonomy.

Number two ethics concern is, does all of this cause concern for patients and their well-being? Are patients actually making harmful decisions? So we could have concerns about autonomy. But we could also have more consequentialist-based concerns about harm.

So I think that it is quite possibly the case that we can think of a lot of examples where, when patients decisions are driven by impulse, or they're driven by biases, they make decisions that actually harm them. So for example, imagine the patient-- this might be a common scenario for some of you who are clinicians-- imagine a patient that decides not to undergo a needed surgery because someone she knows died during a similar surgery. This would be the availability bias operating causing them to make a harmful decision.

Imagine a patient who is refusing life-sustaining treatment because she miscalculates the impact of an illness. She thinks it's going to be really, really horrible. And so she refuses treatment. This would be an example of the impact biased or a forecasting error resulting in a patient making a harmful decision. Or another example might be a patient with low-risk prostate cancer who chooses an immediate treatment that has risk of, say, impotence or incontinence because of the commission bias, because of this tendency to just feel like, I have to do something, regardless of the harm.

So I think there are autonomy-based concerns. I also think that there are beneficence, non-maleficence based concerns. So then we have the question of, well, what do we do about all of this? What can we do to try to help patients make more informed, better decisions?

So when I first started giving this talk, one response people had was sort of just this like return to paternalism. OK, well, people are making really non-autonomous, bad decisions. That means that we can just override their decisions. And we can do whatever we want, because they're not autonomous as we once thought they were. I think that's a little bit too fast, a little bit too extreme.

Another response that people typically have, maybe the more sort of benevolent response-- and maybe you can kind of separate people's personalities based on how they tend to respond to all this. I don't know. But another response is, OK, well, we just need to kind of return people back to their rational decision-making state. We've got to work to try to de-bias them, to try to strip them of these biases and heuristics.

And we can talk about this more in discussion. But I think the problem with that response is that there have been a lot of studies that have been done-- I don't know if so much in medical decision-making, but just in behavioral economics, more generally, that have tried to educate people about their biases and then see if it makes a difference, in terms of them actually being susceptible to them. And it really doesn't. They're so ingrained.

There are also so many biases. Even if we focused, and we said, let's get rid of the availability heuristic, and we worked really hard on some kind of intervention to get rid of the availability heuristic, then there are five other biases that are at play that we've got to try to deal with and get rid of. So it gets really complicated.

And I think the final kind of challenge with this idea of returning people to a kind of neutral, rational decision-makers is the idea that all of you must frame things one way or another. And this is the philosophy of Thaler and Sunstein, who have promulgated a lot of this work. They have this idea of there being really no such thing as a neutral design, that you have to present the risks and benefits in some order. You have to present a frequency or a percentage. So that idea gets very challenging.

So the kind of middle-of-the-road response-- and this is where the idea of nudging comes in-- is that what we want to do is, instead, try to harness the power of these biases, and heuristics, and our knowledge of them, and re-channel them to lead the patient towards decisions that are actually in accord with their values and their goals or that make them better off-- so to use the biases to our advantage, to really try to improve patients' decision-making and get them to a point where they're making better decisions.

And this is this idea of nudging patients' decision-making or shaping patients' decision-making. Sometimes in the literature this is called choice architecture. So if you went and did a search on PubMed, you could do a search on nudging. You can do a search on choice architecture. And you're going to get this whole literature of basically using some of these insights to shape people's decisions.

And to this idea I was just mentioning of Thaler and Sunstein saying that the idea of neutrality is kind of not really possible-- a quote from Thaler and Sunstein is that they say, "A choice architect has the responsibility for organizing the context in which people make decisions. Many people turn out to be choice architects, most without realizing it." So I would say, as a clinician especially, you're all inevitably choice architects, that you're all sort of inevitably to some extent shaping patients' decision-making.

So then we're in the territory of thinking more critically, how can we make sure that this shaping is being done in an ethically-responsible manner? So we can talk more about this during discussion. But I think up here on this slide, I'm just going to put some of the recommendations or tips that can help us be assured that things are heading in a good direction, rather than a bad direction.

The first is just being reflective about all of this, so recognizing that you actually do have incredible power to shape patients' decision-making, being reflective, and aware of that power and using it responsibly. The second is using these techniques, nudging, shaping patients' decisions with the patients' interests in mind and not our own. So what I mean here is something like, it would be very tempting to say, I just want this patient to be discharged, because it's going to save us money.

Or it's going to make things easier if I can discharge this patient at 2:00 o'clock. I can go home early. You could probably find a way to shape the patients' decision-making so that happens. But that would really be your interests driving the shaping, as opposed to the patient interests.

And then I think we should think a little bit about cases where it's clear which treatment or decision would really be in the interests of the patient's values and goals, versus cases where it's not. So for example, a case of a patient needs hypertension medication that seems to be in line with their values and goals, versus something like abortion, where it's not clear. It's very patient preference sensitive.

And so, in that case, you might not have any idea of what the patient values and goals are. Maybe you haven't even talked to them. As opposed to a case where you've talked to the patient, you've taken time to figure out what their values and goals are. And then you can actually shape the decision-making to be in accord with those values and goals.

I think another important ethical consideration is differentiating cases where you might shape a patient's decision, and the patient's decision is being driven by something like some of these biases and heuristics, versus being driven by their existing moral framework or values. So for example, if you have a patient who is refusing a blood transfusion because they are Jehovah's Witness, you want to try to nudge them away from a blood transfusion. Because they're actually making a decision that is in accord with their values and goals. So that would be inappropriate.

If you have a patient who is refusing a blood transfusion because of something like the availability heuristic, where they had a neighbor that got a blood transfusion, and this horrible thing happened, that's not a decision that's in line with their values and goals. It's a decision that's infiltrated by some of these biases. So it would be more appropriate to use our knowledge of decision psychology to nudge or shape the patient's decision-making in the direction of transfusion.

And then finally, I think a final thing to be mindful of in thinking about implementing some of these techniques is to not use some of these strategies or nudge in a way that might alienate the patient or harm the physician patient relationship. So an interesting example of this is where I am in Houston, Texas at Texas Children's Hospital, which is our major children's hospital, they've developed a series of videos to demonstrate the potential horrific harms of not vaccinating children. And these are very, very vivid videos.

And I don't think they were working with a behavioral economist on these. But they were certainly employing things like the availability bias to really bring these cases to the forefront, and demonstrate the harms, and make it salient. But a lot of the responses that they've got, especially from parents who are vaccine-hesitant, is that these videos felt like bullying.

They went too far. They were too strong. It was too obvious what was going on. And they were too pushy.

So I think being mindful of-- there's kind of an art to this, as well as a science-- but being mindful and reflective about, how is this individual patient going to respond to a particular attempt to shape their decisions? And if it's going to really alienate them or offend them, that would be something to keep in mind. Because the importance of preserving that good relationship is very central.

And then finally, before we open things up to some questions and discussion, sometimes people ask, well, if I use some of these techniques or these nudges, would this be a violation of a patient's right to informed consent? So it's interesting if you look at the requirements for informed consent, which are disclosure of information, patient understanding, voluntariness, and then the patient authorizes or refuses. There are actually pretty straightforward guidelines about what has to be disclosed. You all get some pretty direct guidance on the importance of disclosing diagnosis, prognosis, et cetera, et cetera.

But the literature has been pretty silent on how exactly those things have to be disclosed. And that's what this talk is all about, and what this literature on behavioral economics is all about, is that the how of disclosing those things really matters and can really shape people's decisions. And there's a lot of ethical challenges to think about when we think about the how. So I think that that's really interesting.

What I want to do for-- we have about a 20 minute left. I want to open things up to questions and discussions. I'd like to save the final five minutes. I'll go back to my slides.

I just want to share with you briefly some more controversial examples of shaping patients' decision-making in psychiatry that we found. So I'll just save those five minutes and run through those examples. And you can go home and talk about them. But I'll open things up for questions and discussion now. Thank you.

AUDIENCE: Hi. Thank you. My name is Amber Barnardo. That was a great talk.

One of the questions I have is related to the observation in that one study regarding disclosure to the patients or participants about the way that they had been nudged, and asking whether they wanted to change, and sort of idea of this anchoring, this tendency to anchor towards whatever the choices that you've already made. And if we're going to be, essentially, trying to nudge people away from things that they might have started with-- thinking, for example, of the availability heuristic and the patient who's refusing transfusion-- and then they have an outcome which is consistent with their worst fears. There's a lot that's been written on regret avoidance, or recrimination, and also outcome bias. And I'm wondering kind of how we would manage those kinds of situations where there might be a particularly strong affective response to the low likelihood outcome actually happening when they've been nudged away?

JENNIFER BLUMENTHAL-BARBY: Yeah, so it's an interesting question. So the question is about, say, you nudge them in a direction. Something bad happens. How did they respond, and how do you manage that?

I think it raises a question of, do patients know they're being nudged? So it would have to be a situation where the patient really felt or knew that they were being nudged in a particular direction, which I think is maybe a smaller subset. A lot of this stuff is more subtle. And the patient wouldn't really know that that's your agenda and that's what's going on.

I don't know if there's a lot of empirical evidence showing how patients who are in that unique circumstance of being kind of directed towards an outcome, and then having a really bad thing happen, what that does, in terms of long-term consequences. But I think it's an important ethical consideration if the long-term consequences would be some kind of real harm to the physician patient relationship, where the patient feels like, I can't trust this physician anymore, or something like that. I think that that's an important consideration.

So it's tough. And it goes to this point of nudging in cases, like you said, where if somebody already has a decision and you're trying to get away, versus they're sort of neutral, and you're shaping their decision. I think it's maybe an ethically safer territory when they're coming in and you're engaging in just shaping when they don't already have a set decision, versus trying to change their decision. That, I think, is something we probably have to use a little bit more caution about for the reasons that you mentioned. Yeah?

AUDIENCE: A question regarding clinical trials, it's how, in most cases, when a decision involves a clinical treatment of patients, the majority of doctors, the majority of cases do the interest of the patient. But in clinical trials, I can really imagine how framing the trial, the side effects, in a certain way can really be major, particularly for those trials that have no expected direct benefit for the patients. Are there studies to look at this? Or are there ways to minimize the risk of really unethically nudging the patient, even sometimes without realizing, for the both doctors and research coordinators?

JENNIFER BLUMENTHAL-BARBY: Yeah, so I think one response in the ethics literature would be to try to separate the person who is the treating clinician, the person who's doing the enrolling, and the informed consent about the trial. It should potentially be different people, because of concerns about conflict of interest, and things like that. So I think that that's a relevant potential argument that somebody could make.

Empirically, I don't know if there have been studies done that have actually just observed consent processes for clinical trials and sort of coded which kinds of techniques are potentially being used to shape the decision-making. I don't know of a specific study. That's not to say it hasn't been done.

But I think you could definitely, potentially, use some of these techniques to shape enrollment. And then you get to this concern about conflict of interest of these dual hats of, well, is that what's best for the patient? If that's not what's best for the patient, then that's more concerning ethically.

AUDIENCE: In all of your discussions here, you talk about patients' decisions. But in reality, it's not just the patient the physician has to confront. This the whole family, parents, the children, children's parents, spouses, and so on.

And they, in fact, can be in great conflict. And the doctor there has to navigate through a bunch of different alternative decisions that are biased. And sometimes the biases are positive, sometimes not.

And so in this whole thing, you are trying to tell us that it's the patient patient that should be the focus and the person who makes a decision. In some cases, that is true. The patient is in a position to make a decision. And it is a good idea that he does.

But in other cases, it's not necessarily the case, that the patient is incapacitated, or has made nothing but bad decisions in the past. And others should be making the decision, not necessarily the physician-- but often, the physician, assuming a golf date is not interfering with the whole process and we are on the up-and-up. So why does the patient is the best person to make the decision? And what do you do when that is not the case?

JENNIFER BLUMENTHAL-BARBY: Yeah, so I don't think that the patient is always-- so in cases where the patient is incapacitated and you have a surrogate-- I've actually done some work with colleagues looking at the ethics of nudging surrogate's decision-making. Because there may be some different ethical issues. I think you might be able to argue that's more ethically justified.

Because let alone having all these biases, there's also just we know that people do a poor job of predicting what somebody else would want. So it gets even more complicated. So I think you could say, if you're dealing surrogate decision makers, and the patient's out of the picture, there's even more ethical justification to use some of these techniques.

To your other point of, imagine this is team decision-making, or you've got it's not just the patient, but it's the patient, and their spouse, and their kids, and they all kind of making this decision together. The psychology of that decision-making and trying to dissect-- I mean, you're right. Everyone's going to have, particularly, a different bias that's driving why they want to do what they want to do.

So you almost have to diagnose what's driving each person's decision-making and kind of use knowledge of some of this psychology to address each person on their own terms. So it gets enormously complicated. And I definitely-- I'm all about-- one of the things we discovered in the LVAD study is we went into this big trial and tried to develop this decision made for patients making the decision.

And patients weren't making the decision. It was that the patient and their spouse. And so we had to get comfortable with that. And we were totally comfortable with that. But I think that that's a good point. It's not always just the patient. It's often much more complex. Yeah?

AUDIENCE: I think I have the mic. I'm a palliative medicine physician. What I'm struck by is that most of what you've discussed are cognitive biases. And certainly, what we find is our major nudge is an empathic response in identifying the emotional states. And I'm wondering if your studies have looked at the impact of empathic communication styles in decision-making?

JENNIFER BLUMENTHAL-BARBY: Yeah. Yeah, absolutely. So sometimes researchers in the more cognitive biases and heuristics world will just call this the affect bias, like as if it's all subsumed under this one thing. It's obviously much more complex. But yes, there's a lot of emotion going on here.

And being attuned to what emotions are going on, knowing which emotions can match, and can sort of appropriately tweak what's going on is very, very central to shaping people's decisions and engaging and in decision-making, absolutely. So there is a huge literature about the role of affect in decision-making and different types of affect. And it's absolutely important.

I think the focuses on this may be because people can sort of easily think about, oh, I can show a video or not show a video, or I can frame in terms of percent mortality or percent survival, or, oh, I can give them a frequency number. It's a little bit easier than training somebody, here's how you become, like, empathic or something like that. So these are maybe like a quicker kind of nudges that people can use. But definitely, the affect is extremely important. Yeah, Doug?

AUDIENCE: It's been a great talk. Thank you. Can you help us think about how the nudges that you're talking about differ from sort of standard engaged physicians who, in the face of a patient making a decision or beginning to make a decision they think is not a good one, really saying to them, I'm concerned about this decision. Here's why. Tell me a little bit about why you're thinking what you're thinking, and then sort of continuing to really explicitly try to persuade in ways that seem to promote the patient's values and preferences.

JENNIFER BLUMENTHAL-BARBY: Yeah. So the question is sort of-- I think what people would say is why that's ethically the gold standard is because it's rational persuasion. It's you transparently saying, here are my thoughts and concerns. Tell me what your reasons are. Let's put your reasons out on the table and talk about your reasons.

And so the criticism about some of this stuff is that this is beyond rational persuasion. This isn't putting their reasons on the table, and talking about the reasons, and why you might be concerned about their reasons. It's really bypassing their reasoning to frame information in a certain way or show them certain stories in the way that you probably also trying to direct them through rational persuasion.

But it's much more subversive. It's bypassing their reasoning. They might not be aware that it's even going on. I think that's the response that people would give of what the difference is.

Now my responses is that I think that the idea of this pure form of reasoning is a little bit problematic. Because even if you're putting reasons on the table and talking about reasons, you're still engaging emotions, or you're still talking about stories. You're still doing things that are going to be shaping their decision-making.

It's not just pure logic or something that they're using to make decisions. I guess the argument would be that it's a little bit more transparent, what you're describing, the more traditional role. Even if it's as effective, in terms of shaping decisions, it's more transparent would be the standard kind of response.

AUDIENCE: This is sort of a question beyond nudging, but a very real phenomenon. It's been my experience that, when confronted with really difficult decisions--

JENNIFER BLUMENTHAL-BARBY: Difficult what?

AUDIENCE: Really difficult decisions.

JENNIFER BLUMENTHAL-BARBY: Oh, OK, yeah.

AUDIENCE: The physician is confronted with something that has reasonably high risks and marginal benefits, frequently, patients will engage in what I've called invited paternalism. This is so complex. It's so confusing. I can't handle it. Doctor, what would you do?

Now, we can do one of three things. We can just refuse, which might be the most ethical thing. Or we could tell them what we really would do, which I never do. Because I tell patients, I'm a human being, too, and what I might do in that situation may be fairly irrational. Or we can try to synthesize as best we can on a purely biomedical basis, what is the most rational decision for that patient in our mind?

I've always hated that question, passionately. But I usually try to deal with it, usually in a third fashion. What is the best ethical response, sort of beyond nudging, if the patient still can't decide and they say, just tell me what to do?

JENNIFER BLUMENTHAL-BARBY: Yeah, so I think-- I mean, what some ethicists might say is that you can't tell them what you would do. You have to force them to make an autonomous decision. No, I think that that's-- you're just abandoning them. They're asking you to help them. They have decisional burden. They're asking for guidance.

So I don't think that's the ethically right thing to do. I think, if you're going to tell them what you would do, just recognize it has an enormous power and influence on their decision-making. I mean, there's been tons of studies that have shown this.

Physician recommendation, I mean, one of the biggest nudges out there. What would you do? OK, that's what I'm going to do, then.

But I think that the twist that you add of-- if you would tell them what you would do, you would say, but I would do that because, blah, blah, blah, blah. Tell them why. Because these are my values, and yours might be very different, or because I tend to think like this, and this might be really different. Or even to admit to them, this is what I would do, but I might be really biased, too. So kind of just tempering that a little bit, so that they still can engage in some of their own reflection, rather than just saying, yeah, I would do X and leaving it at that I think is the most ethically-responsible way to handle it.

So I want to spend just last three minutes running through these examples. Because I think they're totally fascinating. So what we did is we spent some time just watching how psychiatrists were framing decisions for patients. Here's just some quick cases. And then you can discuss them over dinner and see whether you feel like it was ethically appropriate.

So discussing treatment options with a psychotic patient who was very focused on her physical appearance, the psychiatrist framed the risk of tardive dyskinesia-- which is a kind of spastic disorder-- as sandwiched between the benefits. So it's a total sandwiching approach.

Second, this was an elderly [INAUDIBLE] guy whose wife had just died. He was ambivalent about starting treatment for his depression. Psychiatrist knew he really, really valued his wife and his wife's opinion. So he told the guy, your wife would not want you to go on being depressed. It was effective. He started his antidepressant.

Three, a psychiatrist reminded a very suicidal, religious patient-- sorry, a suicidal patient who was very religious, sorry-- that God would not want him to commit suicide, and reminds him that, in his religion, hell could be a consequence, so really using knowledge of the importance of religion to drive decision-making. Four, a psychiatrist who was dealing with a woman who was depressed who really, really, really cared about her kids but was seriously impaired to the point that CPS might need to be called to her home, told her that starting treatment would protect her children and her interest in being able to continue to parent her children in their own home.

Five, psychiatrists were offering in-patients particular privileges, like being able to go outside, or earlier discharge, special food items contingent on cooperating with treatment recs, like taking meds, being good in group settings, practicing good hygiene, et cetera. Six, a patient who was living in a circumstance of self-neglect, when the psychiatrist was doing discharge and he was presenting the option, he just left the option of going back home off the table. It was like, you can either go to a personal care home A or B. It wasn't like, A or B, or go home.

Seven, a psychiatrist told a patient that her condition would certainly recur without compliance with medication, when that information was actually not really, in fact, known that it would certainly recur. Eight, a psychiatrist told a psychotic patient that the medicine would remove the spirit. And nine, a psychiatrist-- as psychiatrists have an in-tune sensitivity that the patient was taking issue with certain words, such as psychosis, or mania, or mental disorders-- started re-framing things in terms of this medication helping your symptoms, such as your difficulty sleeping or your mood.

So those, I think, are just interesting cases to show shaping of decisions and the nuances, and how each case really deserves its own discussion about whether it's ethically-appropriate. Because there's so much nuance and analysis with each case.