Examining a Challenging Case to a Patient's Right to Autonomy

Alanna Cronk

Georgetown University Department of Philosophy

PHIL 427 Topics in Moral Philosophy

Dr. Sherry Kao

December 10, 2021

Introduction

The doctor's office is political. Many moral theorists who reason about the importance of autonomy or the utility of paternalism in the doctor's office neglect this fact. Rather than focus on made-up scenarios with fake people or incorporating data divorced from the historical and relational realities, I will posit what I believe to be the proper doctor-patient decisional relationship in the context of the medical establishment's political realities. It is my belief that doctors have a duty to respect patient autonomy fully because patients are best located to protect their own wellbeing. To put this theory to the test, I will examine a particularly challenging case: Judith, a woman who decided to have a "freebirth" against all medical advice which most likely caused the death of her unborn child, which consequently led her to feel regretful of her decision.

To illustrate the non-negotiable nature of doctors respecting patient autonomy, I will first bring up the historical, carceral origins of the creation of hospitals in the United States and its legacy in the US's preventable maternal mortality rates. I will then explain how patents are, when one considers the practical realities, the best available option to protect their own interests in comparison to doctors who represent a complicated, untangleable web of conflicting interests. Judith's is the kind of case that those in support of libertarian paternalism would cite as the prime example of a time when doctor's nudge would be useful because it lessens the possibility of outcomes harmful to patient wellbeing (i.e. the loss of Judith's child, her regret, and the loss all those implicated in the situation feel). Consequently, I will raise objections from libertarian paternalism in favor of nudging. Finally, I will explain how the imposition of libertarian paternalism as a rule in the case of doctors perceiving irrational decision-making ignores the realities of power dynamics in the Place that is is hospitals.

Before I begin, however, I would like to make a few things clear about the scope of this paper. First, given the nature of medical decisions, I take it as a rule that there is no medical decision in question that can be made by one agent that is played out on another. Therefore, one's worries about safety and negative impacts of complete patient autonomy should be comparatively lower (as opposed to someone having complete control over something that could directly harm others). I realize, though, that this "rule" is not without a few key exceptions: those who are not legally in possession of medical autonomy. This vulnerable population lies beyond my scope since this paper's focus will be on Judith and her decision to have a freebirth, but I will say for now I am personally in support of broadening the list of people who have medical autonomy to include many minors and many cases of conservatorships. It is not the aim of this paper to find the distinct line that makes up the difference between comatose people, small children, and cognitively disabled people with regards to adequate decision-making capacity.

Additionally, the paradigm that I am proposing is not a complete theory of well-being. It is not even a complete theory of health. There are several other kinds of relationships and decisions that need to be made beyond medical ones that contribute to a person's physical, mental, emotional, and spiritual health. I believe that autonomy is a necessary condition for *protecting* people's well-being though it is not sufficient as threats to well-being come from several other places.

Case Study

One pertinent study of seemingly irrational medical decisions gone-wrong is the case of Judith, a 28-year-old formerly pregnant woman who refused medical intervention which likely led to her miscarriage. Whether this tragic outcome was a direct result of her decision to refuse

medical aid or caused by something else, the article written in the NBC News titled “She wanted a 'freebirth' with no doctors. Online groups convinced her it would be OK” certainly begs the question if doctors should respect seemingly irrational decisions from patients.

Judith planned to have a freebirth, an “unassisted” birth without the use of doctors, midwives, or other medical personnel (Zadrozny, 2020). In regards to doctors, Judith notes: “I never felt heard. I never felt listened to” (Zadrozny, 2020). Judith immersed herself in the freebirth community and partook in related Facebook groups, Instagram pages, podcasts, and online classes (Zadrozny, 2020). Doctors (who Judith had to visit for insurance reasons) and friends both expressed their concern over her plan, but Judith preferred the advice of the people she met in these freebirthing online communities (Zadrozny, 2020).

One month *after* the expected due date, Judith went into labor (Zadrozny, 2020). She posted in her Facebook groups that contractions had begun, her mucus plug broke, and that she noticed the fetus was moving less than usual—the groups told her that she just needed to listen to her body (Zadrozny, 2020). Ten hours later, Judith began vomiting, was unable to measure the fetal heartbeat, and her water broke and contained fecal matter (Zadrozny, 2020). After this, Judith decided to seek medical help and rode to an emergency room where she discovered the child she was carrying was no longer alive (Zadrozny, 2020).

Nine months on, Judith feels overwhelming guilt and regrets her choice to plan for a freebirth (Zadrozny, 2020). In retrospect, Judith notes that the origins of her former desire to have a freebirth come from her past negative interactions with doctors and her idealization of a Free Birth Society podcast series where she listened to around seventy women tell their story of successful freebirths.

My View

Many theorizations about wellbeing and autonomy in the medical establishment do not take into account how harmful, dangerous, and hostile it historically has been and continues to be for marginalized groups. The conversation around patient autonomy within the medical establishment cannot be divorced from the relational power dynamics and historical-political influences. When one enters the Place of the doctor's office, it is a location of energies relating to one another where the doctor has a certain power over the patient.[1]

Liat Ben Moshe, Chris Chapman, and Allison Carey write in their book *Disability Incarcerated* about the relationship between the modern medical establishment and containment of marginalized populations. In the United States, poorhouses were a Place where "poor, disabled, widowed, orphaned, and sick people, in a relatively undifferentiated manner" were confined from more privileged members of society (Ben Moshe Et al, pp.3-4). Hospitals became an offshoot of these poorhouses in the mid-1800s, only this time differentiated to only house those who are sick or disabled in some way (Ben Moshe Et al, p.5). The idea that hospitals were actually helpful for those who are confined within them was introduced during the 1800s to aid the growth of "incarcerative and institutional solutions" in the United States (Ben Moshe Et al p. 5). Prior to this, Ben-Moshe notes, "Wealthy people who were sick would never stay in a hospital, which was understood as a place of contagion rather than cure" (Ben Moshe Et al, p.4).

Doctors are not solely bringers of medical knoweldge and expertise, they also represent the interests of several other individials, in addition to the legacy of confinement and oppression they inheret. For one, hospital administrators impose policies onto doctors which "divert time and focus" from patients and reduces the quality of care they receive (Erickson et al, 2017, p.

[1] I capitalize "Place" to indicate that I am intentionally bringing to attention energies relating to eachother in a specific space rather than solely to connote a specific location.

659). Additionally, insurance companies have direct influence over the care doctors provide to patients with a practice known as prior authorization. Prior authorization requires that doctors get the permission of a patient's insurances company before they are able to proceed with medical treatment (Miller et al, 2018). This process puts the determination of what treatments are "medically necessary" into the hands of the company providing the insurance. Often, desired tests, prescriptions, and procedures are denied and time with patients is reduced as a result (Miller et al, 2018).

There are also several ways in which doctors change their general practices to avoid lawsuits. For example, there is a rise of doctors refusing to allow patients to film the birth of their children (Seele, 2013). This decision is motivated by their fear that if something were to go wrong, there would be evidence available for the patient to sue for malpractice (Seele, 2013). Obstetrician Dr. Eric Tracy remarks, "I want to be 100 percent focused on the medical care, and in this litigious atmosphere, where ads are on TV every 30 seconds about suing, it makes physicians gun-shy" in reference to his choice to not allow his patients to film their child birthing experience (Seele, 2013). Given all these factors, it would be incorrect to assume that doctors solely represent impartial facilitators of medical knowledge and practice— they have their own conflicting interests and represent the conflicting interest of numerous others.

Given the legacy of the medical institution as not a Place of community care but rather directly about maintaining power and oppression, the United States' comparatively high maternal mortality rate makes a lot of sense. Vishwani Persaud-Sharma writes in her paper, "Rethinking Maternal Healthcare for the 21st Century in the United States" about the "abominable" statistics about maternal mortality:

> Yearly, 50,000 American women endure life-threatening maternal complications, where 700 women die from childbirth; greater than half of such deaths are preventable [4]. American women state the least optimistic experiences compared to high-income countries like Canada, the UK, Netherlands, France, Germany, Norway, Switzerland, Sweden, Australia, and New Zealand; they demonstrate the highest burden of chronic disease, greatest rates of opting out of needed healthcare due to cost, exhibit difficulty affording health care, and are the least satisfied with their quality of care (Persaud-Sharma, 2020, p. 294, 297).

While Judith's decision to have a freebirth is certainly risky and dangerous, it is not monolithically irrational. This is important. Judith's doctors are not in Judith's head. Her decision to have a freebirth is extremely multifaceted. She liked the community. She did not like her past experiences with doctors which made her feel disempowered. The causes of *those* circumstances are exponential. Doctors represent all these different forces, many of which are not for Judith's benefit, and her desire to keep away was justifiable on some level. Not all of them. But in the way that mattered to Judith at the time. I posit that seemingly irrational decisions have some empathetic aspects. Judith did not form her strong convictions for *no* reason at all.

While several other forces such as historical oppression, insurance company executives, hospital administrators all influence the political reality of a patient entering a hospital wanting to give birth, it is the doctor who is the interface between these forces and the patient. This is why the fierce defense of patient autonomy is non-negotiable. Patients do not have these conflicting interests. Agents are invested in their own well-being because they are the ones who will have to experience pain as a result of poor decision-making and stand to gain from good decision-making. Patients like Judith do not arrive to the Place of hospitals to make insurance

companies or hospitals or doctors money—they come in hopes of protecting their future well-being. Hospitals are Places where the interests of many are incredibly entangled and the patient themself is the only one who can reliably be said to be singularly invested in their obtaining optimal outcomes. Given the domain of medical decisions, more specifically planning the birth of a child, is Judith's own body absolute preservation of autonomy is practically necessary for protecting her well-being.

For a doctor to detangle their fear of lawsuits, ignore the expectations of administrators, and run interference on insurance companies trying to turn a profit from their medical advice *entirely* is a difficult task. What is in it for the doctors to wholly align their interests consistently with a patient? Knowing they are a good person? Would a doctor ever break hospital or insurance protocol or depart from "cover your ass medicine" if there was a possibility that a care plan could benefit the patient? Probably not. Or perhaps occasionally. But certainly not every doctor, every time. The same conflict does not exist in patients, which is why doctors need to recognize the complicated and entangled nature of their own bias and always respect patient autonomy. In this Place where so many interests are represented and conflict with one another, the agent themself is the only one who can be trusted to more reliably be truly investing in their own wellbeing.

The question of this then becomes, what *should* a doctor have done in this situation and how do we confront the harm to wellbeing that occurred? Judith did visit a doctor while she was pregnant and mentioned her plan to avoid the medical establishment. Since we already know the tragic outcome of Judith's circumstances, it is tempting to desire a more aggressive approach from the doctor. But we need to remember that the outcome of this tragic scenario was not always apparent.

Judith herself regrets her decision deeply, but denying Judith of her autonomy is not a means to avoid her unborn child's tragic death. Let us consider for a moment that Judith's freebirth could have gone well. Because of her investment in the ideology, there would be a strong level of satisfaction with buying into the ideology. There would also be no reason to question whether she ought to have the right to make this kind of decision at all. It was not inevitable that Judith's case would turn out the way it did. Each of the 70 people interviewed for the Free Birth Society podcast that Judith listened to represented a positive and successful freebirthing experience. Yet, things went wrong with Judith and she has come to regret her decision. So what does this mean? Would it have been preferable for the medical establishment to practice clinical paternalism and force her into a medical birth? Let us consider for a moment a stark alternative.

Forced imposition of another's will can be more harmful than the undesirable outcome this other desires to prevent. Daniel Groll writes about this in "Medicine and Well-Being" saying, "even if it is true that it would be best for the patient to choose the treatment, it certainly doesn't follow that it would be best for the patient for us to force the treatment on him. The cure (forced intervention) might be worse than the disease when we tally up the psychological and physical costs to the patient" (Groll p. 506). In regards to Judith's case, I would agree completely with Groll.

What if Judith had been forced to induce labor in a hospital. The means of the "force" can vary. She could have been threatened with a psychiatric hold, she could have been physically restrained, the doctor could have declared her incompetent of making he own decisions, or something else. The point is, imagine Judith went for her insurance-mandated checkup, communicated her desire to have a freebirth, and sensing irrational decision-making and fearing

poor patient outcomes, the doctor forced her to induce. This would undoubtedly be a traumatic and undesirable violation of Judith's autonomy. Judith would most likely not be thankful afterward, even if her child were saved. In other words, the extreme opposite of respecting her autonomy also sees Judith not satisfied with the decision made regarding her birth.

Objection From Nudging

However, if the goal is to protect well-being, then it seems to follow that doctors ought to be able to do something when patients are set out to make irrational decisions. Judith's birth plan carries unique dangers and is most likely a result of misinformation. Freebirthing precludes access to medical intervention should a complication arise. Judith would also not have access to the same kinds of efficient and continuous monitoring available in a hospital to detect the early signs of problems and prevent a complication arising in the first place. This is an inherent risk to freebirth and in Judith's case, unfortunately, something did go wrong. As a consequence, Judith and her family experienced extreme loss. One seemingly reasonable objection to my prescription that her original birth plan be completely respected is that Judith represents exactly the kind of tragedy that could be reduced or prevented by the employment of nudging by doctors.

In her book *Good Ethics Bad Choices*, Blumenthal-Barby defines nudging as "any aspect of the choice architecture that alters people's behavior in a predictable way without forbidding any options or significantly changing their economic incentives" that is also "easy and cheap to avoid" (Blumenthal-Barby, 2021, p. 85). Blumenthal also identified a specific kind of nudging inspired by libertarian paternalism which aims to improve people's wellbeing while preserving people's liberty and ability to choose something other than the nudger is suggesting (Blumenthal-Barby, 2021). Since the suggestion of the doctor an objector is suggesting by

definition is cheap and easy to avoid, this does not seemingly represent a significant threat to Judith's autonomy.

Furthermore, Blumenthal-Barby describes the principle of easy rescue saying if something only takes a "small to moderate sacrifice" to prevent significant harm to someone's well-being, then " it would be wrong not to do so" (Blummenthal-Barby, 2021, p. 88). Even if a doctor's nudge represents a moderate "sacrifice" to Judith's autonomy, it would be outweighed by the fact it would be attempting to prevent the loss of her child.

Given the stakes of this decision, it is even harder to put aside the fact that Judith is most likely acting on misinformation. Judith has seemingly surrounded herself in an internet echo chamber parroting extreme, non-scientific viewpoints. Blumenthal-Barby points out that a doctor's nudge to patients to reconsider their decision could actually make patients like Judith "feel more informed, better appreciate the consequences of her choices, feel more clear about her values, and engage in more considered and intentional decision-making" (Blummenthal-Barby, 2021, p. 91).

The objector may be insistent that as a rule, doctors should nudge patients towards what is best for them in the doctor's opinion (given a doctor's superior medical knowledge, education, and training). Doctors would frame the information they provide the patient in a way they know will be rhetorically more likely to succeed at persuading their patients.

For example: At the doctor's appointment Judith attended while pregnant, Judith's pregnancy arises at the beginning of screening questions, and Judith then informs the doctors about her decision to have a freebirth. The doctor then uses particularly gruesome details from past patients with childbirth complications to communicate the potential risks of her decision. The doctor frames all the information they give to Judith in a way they hope increases Judith's

appreciation of the danger of her free birth plan. Judith would still be completely free to keep her original choice. The benefit to this strategy is that the possibility that Judith makes a choice more likely to protect her future wellbeing, and the wellbeing of the child she is carrying. An objector may even go farther and point out this is not only a desirable option but a positive duty because of the principle of easy rescue. She might also have a greater appreciation for the danger of her decision and overcome some of the misinformation she has been fed in the online spaces she frequents.

My response

Nudging at first glance, given that patients technically still make the final decision, may seem compatible with my assertion that patients' autonomy is to be completely and wholly respected by a doctor, it is not.

My first response to an objection from nudging would be that Judith seems to be particularly strong in her convictions, and I do not think anything short of coercion or force would have made her change her mind. What is noteworthy about this observation is that nudging is not guaranteed to actually change the patient's decision because definitionally it needs to be easy to resist. It is entirely possible that the "sacrifice" to a person's autonomy in the name of the principle of easy rescue is made entirely in vain.

Additionally, given the place of esteem that doctors hold in American society, resisting physician any kind of recommendation is difficult. Resisting an especially colorful or vigorous case for why Judith ought to change her mind would be difficult, and I am not sure avoiding compliance would really be all that easy. Judith would need to carry the guilt of knowing that she is also rejecting the ethos of science doctors also carry with them and she unpopularly asserts her knowledge as superior.

I would agree that at the doctor's visit that the doctor should provide Judith with the relevant information about the possible dangers and complications that accompany her birth plan. Though, I think this information should not have an underlying intention to alter her choice and be based in the scientific literature. Though, it is worth noting that there has been no conclusive, empirical American study published on freebirthing maternal mortality or stillbirth rates or dangers as of yet (McKenzie, 2020). So for Judith, this would not actually include statistics about dangerous outcomes. All a doctor could do while complying with my framework is explain the complications possible in childbirth as they would with any other patient decision they personally agree with and also answer Judith's resulting questions.

Blumenthal-Barby works from an assumption that doctors can have an adequate understanding of a patient's unique worldview and are qualified to reliably detect irrational decision-making. To understand how people arrive at (seemingly) irrational decisions, there is a complicated network of life experiences, personal political realities, historical influences, among several other factors. Even if the doctor does not take away Judtih's option to have a freebirth, they still would have been guiding her towards an interest that comes from a Place that is not guaranteed to be only inspired by what is best for Judith.

To assume that the physician has the ability to *always* understand the patient's reasoning and have the best interest in mind to such a degree that nudging should be the protocol between is impractical, given the several compromised viewpoints that doctors carry into an exam room. This relates to my original assertion that hospitals are Places with a messy, untangleable interplay of forces, many of which do not serve Judith's interest. Judith even cites previous negative experiences with doctors as a reason for making her decision to not involve the medical establishment in her birth plan. When doctors, with all the power they possess over patients, are

not completely respectful of patient desires and viewpoints, that can be a real cause for avoidance as a necessary means of protecting patient well-being. The desire to avoid paternal intrusion of patient autonomy then deters people who could benefit from medical assistance from seeking it. At worst, if one opens the door to nudging in current medical practice anytime a doctor senses irrationality, the power doctors have over patients increases far more than it is in the present day and only worsens the problem of protecting patient well-being. Paternalism assumes that the decision-making of doctors is suited to optimize results for patients when it is not.

Humans make decisions with incorrect knowledge and imperfect contemplation. Humans make decisions that result in tragedy. This is an unavoidable reality. Doctors can protect patient well-being by offering relevant medical knowledge in a non-judgemental manner, but it is no guarantee that the patient will appreciate it. There is no paradigm for perfect decision-making. Decisions necessarily take place before the consequences of said decisions play out. The endorsement of a doctor-patient relationship needs to be able to withstand such negative outcomes.

The desire to reduce the rate of occurrences of said tragedies is understandable. Nudging, though, is not an appropriate path to this end. Nudging compromising patients' right to protect their wellbeing using *their own* means. I realized there is not a single paradigm for the doctor-patient relationship that will erase the existence of unfavorable and harmful outcomes. Therefore, my goal is to make sure patients are well-positioned to be safe and in their interactions with the medical establishment.

Conclusion

At the end of the day, I want people to be safe. Doctor's offices are Places where people go when they are particularly vulnerable. It would be nice to assume that doctors are in fact nothing but stewards of care, but at the end of the day, they are people. Even a doctor with the noblest of intentions will not be able to appreciate the complex nature of well-being for each person they come across. This is why patients need to have their right to exercise choice over their own body respected completely—they are the only ones in the exam room who are completely invested in a positive outcome. Situations like Judith's are incredibly heartbreaking. But, ultimately, it was her choice to make and no one else's.

Reference

Ben-Moshe, L., Chapman, C., Carey, A., & Davis, A. Y. (2014). *Disability Incarcerated: Imprisonment and Disability in the United States and Canada* (2014th ed.). Palgrave Macmillan.

Blumenthal-Barby, J. S. (2021). *Good Ethics and Bad Choices: The Relevance of Behavioral Economics for Medical Ethics (Basic Bioethics)*. The MIT Press.

Erickson, S. M., Rockwern, B., Koltov, M., & McLean, R. M. (2017). Putting Patients First by Reducing Administrative Tasks in Health Care: A Position Paper of the American College of Physicians. *Annals of Internal Medicine*, *166*(9), 659. https://doi.org/10.7326/m16-2697

Groll, D. (2017). *The Routledge Handbook of Philosophy of Well-Being (Routledge Handbooks in Philosophy)* (1st ed.). Routledge.

Miller, A. P., Shor, R., Waites, T., & Wilson, B. H. (2018). Authorization Reform for Better Patient Care. *Journal of the American College of Cardiology*, *71*(17), 1937–1939. https://doi.org/10.1016/j.jacc.2018.03.465

Persaud-Sharma, V. (2020). Rethinking maternal healthcare for the 21st century in the United States. *Journal of Health and Social Sciences*, *5*(3). https://doi.org/10.19204/2020/rthn1

Seelye, K. Q. (2013, February 5). *Hospitals Weigh Bans on Videos of Birth*. The New York Times. https://www.nytimes.com/2011/02/03/us/03birth.html

Zadrozny, B. (2020, February 22). *She wanted a "freebirth" with no doctors. Online groups convinced her it would be OK.* NBC News. https://www.nbcnews.com/news/us-news/she-wanted-freebirth-no-doctors-online-groups-convinced-her-it-n1140096

McKenzie, G. (2020, December 1). *Exploring the conceptualisation and study of freebirthing as a historical and social phenomenon: a meta-narrative review of diverse research traditions*. Medical Humanities. p. 520 https://mh.bmj.com/lookup/doi/10.1136/medhum-2019-011786

thesis∃respect pateint autonomy full stop

1. a person is more invested with their own well being than other people

that is why we need to respect their autonomy

besides they also have a right to do so

2. we shouldnt assume that from themedical establishment that they always act from a caring and beneficent position
    a. cite high mortality rate for pregnant women
    b. history of medicine
    c. medical institution is really complicated intertwine of difference forces such as medicine, insurance compmany and acting out of best interest for patient a dubious idea
3. bc medical instituion is such a cokmplicated place where forces fight against eachtoehr, sometimes the physcians might have good intention but their hands are tied or bureaucracy, not unreasonable to cast doubt about how much they really act in best interest of the patient

judiths example, she shuld be allowed to make her free brith decision, no matter how irrational and crazy it looked like, she deserved to exercise her rights

objection

judith received misinformation, thats why she decided the way she did, should a physician nudge, they would be acting with judith wellbeing in mind

a critic says , i see your point, respecting patient autonomy its really important, and its a pillar of medical ethics, howeever, your view is really extreme, respect patient autonomy full stop, is that the poisiton we sohuld hold, we know she is acting from misinformation, she made an irrational decision, it is doctors duty bc do no hoarm hypocratic oath, doctors havea duty to provide adequate information, doctor might even need to nduge,

two layers,

1. provide adequate information to judith

2. is it okay for doctor to nudge judith around

at the moment of the meeting, we dont know the outcome, it could have gone well still

need to consider the following, the opponent might say that nudging is just using peoples biases to counteract their misinformation, doctor would be providing adequate information about birth in such a way that is not just dry statistics but rather using some iind of nudging technique, its ousnds like at the end of the day that ulitiately its up to the patient to decide, compatible to use nudging

response

<u>libertarian paternalism</u>

judith probaly wouldnt actually answeer to the mndge, her mind is mad eit, it would need to be coercive or forceful

as a rule, because hospital is apsace of power, docotrs arent well suited

yes give information but not nudging

while nduging seems compatiable with my view, patients make final decision any way, nudging can be seen as efficient method to help patient to make good decisoin, but to assume thtat the physcian has the ability to always understand the patients backround and have best interest in mind to such a degree that nduging should be the protaocal is impractical in our current medical practice, which ties to previous point about medical instiution is a messy interplay of forces,

authority figure of physcian, she distrusts physciians based on past experineces and those experiences come from authoritative voice of physicians int he past

blummenthal assumed that doctor really care and deliberate and thats a little naive in our current medical practice

š

power dynamic itself just invalidates patients opinoin immediately

if we open to nudging in current medical practice, we open the door to more abuse from doctors, even leess likely to prevent harm, could harm us to a more dangers path than we are now

align decisoin making with their own

also address in judiths case, it was a tragedy, but it doesnt mean thats always the case, and we shouldnt compromise pateint autonomy because it doensnot 100% end up well

what is the framework in teh wake of knowing we are not birds eye view, doesnt mean others can make decision for us