

THE RIGHT TO BE ILL: REFUSAL OF MEDICAL TREATMENT V. PUBLIC HEALTH IN A DEMOCRACY

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Abstract Debates regarding health and health care generally involve questions regarding whether there is a right to -either. But in a democracy do individuals have a right to refuse medical treatment? The 2019 Covid pandemic raised this question as democracies sought to balance individuals with medical mandates such as the wearing of masks or vaccines. This article examines that question asking whether there is a right to be ill and to refuse force medical treatment in the case of infectious diseases that are life threatening. The article will conclude that in most cases competent adults have a right to refuse medical treatment and be ill, yet such a right has to be balanced against a host of factors supporting the preservation of the life of others.

Keywords

right to be ill,
right to refuse,
informed consent,
democracy,
pandemics



1 Introduction

Samuel Butler's 1872 *Erewhon* (2002) describes a world where criminals are labeled as sick and illness is criminalized. It is a dystopia where one is punished for being sick, holding one responsible for diseases and maladies, where generally most would argue culpability is not an issue and the ill person is a victim if anything.

But what if a person chooses to be ill. Or perhaps decides to take steps not protect one's health and thereby place the health or lives or others at risk. Could a person be punished for a failure to act? Even more, what if a person who is presently healthy but decides not to take preventive measures to protect oneself and others from illness, should such an action be prohibited or regulated?

The Covid-19 pandemic brought this question back to light. While at the beginning of the twentieth century many countries, including the USA, had quarantine laws seeking to regulate those with typhoid or tuberculosis, many had forgotten the impact of the 1919 pandemic, Polio, or even HIV/AIDs. Across the world Covid ravaged populations. Public health measures including closed businesses, masks, and vaccines were instigated, forcing individuals to act—often against their will. These state measures denying liberty, raise troubling questions for a democracy. Under what conditions, as John Stuart Mill once asked in *On Liberty* (2011), is society justified in intervening in the life of an individual?

This article explores the issue of whether there is a human right to be ill? By that, may a competent adult who is ill refuse to take steps to prevent others from becoming infected? Similarly, may healthy individuals be required to take steps to take prevent oneself from becoming ill and thereby risk others to becoming infected or ill?

2 The Values of a Democratic Society

Two of the most important values in a democratic society are liberty and equality (Pennock, 1979; Sartori, 1987). Both terms are intertwined and have various meanings.

Political theorist Robert Dahl argues that one of the first values of a democratic society is the notion of individual moral autonomy (1986). For many democratic theorists, democracy begins with the idea of individuals liberty or freedom (Pennock, 1979; Sartori, 1987). For John Locke, the idea that government derives its justification from a social contract and consent of the people (1996). Consent thus is a powerful metaphor enabling a theory about limited government and personal freedom. The government derives its just ends from the people, and there are boundaries across which the government may not transcend.

Other theorists, such as Jean-Jacques Rousseau (1977) and Immanuel Kant (1978), echo similar thoughts. For Rousseau the concept of freedom resides in conforming to the general will is an important one. It is here where the people get to make the laws that will govern them that one gets a sense of Rousseauian democracy. For Kant (1978), the very notion of autonomy—living according to rules that one has legislated for herself—is the purist notion of what a democracy is. It is self-rule. It is where the people, as French political theorist Jean Bodin stated, are sovereign (2003) Democracies are where the people hold political power, either directly or indirectly, and generally, at least in the United States, are viewed as the ultimate source of authority.

But embedded within the notion of liberty is another distinction—positive versus negative freedom. Isaiah Berlin (1969) famously distinguished the two, with the former meaning a positive right to do something whereas the latter a right to not do something. Positive rights are claims to a right to an education, health care, or other basic necessities in life. Negative freedom is classically liberal freedom. For Thomas Hobbes the absence of external restraints or impediments (2017). Negative freedom may be associated with what former US Supreme Court Justice Louis Brandeis called a right to privacy or a right to be left alone (Warren & Brandeis, 1890). Rousseau's famous phrase in *Du Contract Social* "L'homme est né libre, & partout il est dans les fers" captures the sense in which the state or civil society is the source of oppression. Negative liberty includes the right to free speech or bodily autonomy. It is, in the case of the latter, the right to be free to use one's body in ways one wishes. In many ways, negative liberty is a libertarian perspective or position.

Thus, for a democracy, personal autonomy or liberty of some fashion is required. That autonomy is also one that is shared equally. As Jeremy Bentham (1948) and other nineteenth century philosophers would declare, each person should count as one and no more than one (Halévy, 1955). For Kant, the concept of dignity and the idea that no person should be treated as a means but only as an end is central to the idea that the life of one person is not more valuable than another.

Democracies mean that each person has an equal voice, and the equal freedom to act upon that voice. Thus Rawls (1971, p. 60) may be correct in describing the first principle of justice as perhaps also the first rule of a democracy that each person is entitled to “the most extensive basic liberty compatible with similar liberty for others.” Later, in his 2005 book *Political Liberalism*, he refines this statement to declare that “each person has an equal claim to a fully adequate scheme of equal basic rights and liberties” (Rawls, 1993, p. 5). In reformulating the way he does in his latter book, Rawls makes it clear that democracy embraces both concepts of equality or equal voice and the personal liberty to act on that voice.

Political theorist Robert Dahl (1986) himself argues for both a procedural and formal sense of equality before the law as well as some kind of substantive equality in terms of economic resources. Others, too, have described various meanings of equality as essential to democracy (Dahl, 1986; Dworkin, 1978). Theorists such as John Rawls (1971) have rendered similar claims, contending that a liberal democracy adhering to his two principles of justice—equal liberty for all consistent with like liberty for others, and the structuring of economic inequalities, so that they are of benefit to the least advantaged representative person in society, demand something approaching an equality both in terms of economic conditions and equality before the law (Rawls, 1971; Rawls, 1993; Rawls & Freeman, 2007).

But exactly what the liberty and equality extend to is a matter of contention. Moreover, in a democracy, the depth of that equal voice also is a matter of dispute. Does it include a voice to dissent or disagree, or perhaps take positions that are contrary to the interests of society? Rousseau’s famous assertion in *Du Contract Social* that a society may “ce qui ne signifie autre chose sinon qu’on le forcera d’être libre.” It may force a person’s will to conform to the general will of society, and only then will that person be free.

Contrary to Rousseau, John Stuart Mill's *On Liberty* offers a classic defense of liberal freedom which is essentially negative. It draws a public and private distinction, demarking zones of interest between when a society can interfere with the life of a person versus when it may not. For Mill, he asks: "*What, then, is the rightful limit to the sovereignty of the individual over himself? Where does the authority of society begin? How much of human life should be assigned to individuality, and how much to society?*" He responds with a classic distinction.

Society has jurisdiction over it as soon as any part of a person's conduct affects prejudicially the interests of others, and when the question whether the general welfare will or will not be promoted by interfering with it becomes open to discussion. But there is no room for entertaining any such question when a person's conduct affects the interests of no persons besides himself or needs not affect them unless they like (all the persons concerned being of full age, and the ordinary amount of understanding). In all such cases there should be perfect freedom, legal and social, to do the action and stand the consequences. (Mill, 2011, p. 141).

For rational adults, the only time society may legitimately interfere with the personal rights or freedom of an individual is when the conduct of that person harms another. Intervening to protect against self-harm—paternalistic actions—are not justified. Rational adults should be free to make choices, even if they hurt themselves in the process.

But what constitutes harm? Clearly, active physical assault upon another would constitute harm. As the expression goes, "my right to extend my arm or fist ends when it reaches your face." I have the right to extend my arm or swing my limbs wildly, so long as they do not hit another or violate their rights (Turner, 2014). This is the concept of assault and battery in US and UK common law. Additionally, I have a right to say or believe whatever I want, or to advocate my beliefs, but when those thoughts translate in to "true threats" they have crossed the line into actions that may be regulated, at least in the US (Rothman, 2001).

But defining harm is problematic, as we shall see. Being intoxicated at home or in public may not appear to hurt anyone, but what if my intoxication means my family goes without food or my actions mean I may become injured and therefore a ward

of the state that will have to support me? My decision not to wear a helmet while riding a motorcycle, or deciding to consume tobacco products may be an individual choice, but what if such a choice means I may eventually become a financial burden to a society that has to pay the costs for my choices (Dworkin, 1972)? May society interfere? Mill's public versus private distinction based on what is harmful or the legitimate business of the self-versus society, while perhaps good in theory, might break down in practice. It assumes each person is almost an autonomous entity operating in a bubble and able to disconnect from others. It potentially ignores the social or wholistic aspect of society. It also ignores, as Hart et al. (1994) once asserted, that society is not a suicide pact and that some rules of governance and sociality are needed if we are to live together. Social rules, as Freud (2010) would eventually note, are a source of civilization and discontent—they enable freedom at the cost of some personal freedom.

3 Human Rights: Health and Sickness

Generally, concerning discussions of health care treatment and rights, the issue is about a right to either.

In the United States there is no right to health or to health care. Health care treatment is mostly allocated based on market principles guided by a fee for services and distributed on the basis of the ability to pay. While public and private insurance do exist, there is no explicit right to health or health care and individuals could be denied service if they show up to a hospital. While the 2010 Patient Protection and Affordable Health Care act expanded insurance coverage in the United States, not even that law amounted to any right to health care treatment.

The Universal Declaration for Human Rights indirectly creates a right to health care. Article 25 stated:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

While health care is not a specifically enumerated right, it is still listed as something that someone should be able to secure with adequate income.

The European Convention on Human Rights (ECHR) does not recognize a right to health or health care. On the other hand, the 1947 World Health Organization Constitution does, declaring “*The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.*” The Office of the United Nations High Commissioner for Human Rights (2008) also recognizes a right to health. The American Medical Association, the American Bar Association, the US National Institute of Health, and Amnesty International declare health to be a human right.

Across the world, according to one study of 191 UN member countries, 72 countries provide universal health care (Wisevoter, n.d.).

In 2011, a minority of the countries guaranteed the rights to public health (14 percent), medical care (38 percent), and overall health (36 percent) in their constitutions. Free medical care was constitutionally protected in nine percent of the countries. Thirteen per cent of the constitutions guaranteed children's right to health or medical care, six percent did so for persons with disabilities and five percent for each of the elderly and the socio-economically disadvantaged (Heymann et. al., 2013).

In Germany, the Constitutional Court has created a quasi or semi constitutional right to health care (Pestalozza, 2007). The UK's National Health Service effectively provides universal, if not a constitutional right, to health care, and in Spain everyone paying into social security get health care and that in turn provides health care for others (Wisevoter, n.d.). Outside of Europe, various states provide some guarantee to health or health care (Wisevoter, n.d.), and thus the focus is on access to, or availability to secure either.

Overall, the general focus when it comes to discussions regarding health care is that there is or ought to be a right to treatment regardless of income, race, or any other demographic reasons.

4 A Right to be Ill

But conversely, is there a right to refuse medical treatment? Kielanowski (1972) first proposed a right of those with mental illness not to be punished for their illness. He contended:

Soyons vigilants enfinet ce point est bien délicat — quand ce voudraient nous donner la puissance de priver tels ou tels humains de droit de procréer. Aujourd'hui nous nous limitons à in communiquer aux ressés les inquiétudes que leur santé nous donne. Mais que sera-ce de.

(Right now, we must fight against the tendency of the world that let us build, which we plan, to be a world of healthy people and worship as gods the winners of the two Olympics. Beware that the right to health does not engender contempt for weakness, the setting up by the healthy of all those who are not healthy.)

Kielanowski's argument was not a wholesale right to refuse medical treatment. Instead, it was a more limited plea on behalf of those who were mentally ill to afford them the respect they deserved. Even with their mental illnesses they deserved passion and respect for the dignity as humans and not to be forced into treatment or degrading conditions.

But is there a right to be ill, or at the very least a right to refuse medical treatment? There are two models that address this issue: The medical model and the civil rights model.

The medical model declares that there is a right to health and therefore a right to be treated. In fact, the medical model is somewhat paternalistic, contending, perhaps ala Rousseau, that individuals can be compelled to be treated, if not for their own good then for the good of society. Treatment can be mandated as promoting the best interests of the patient.

The civil rights model emphasizes respect for equality and autonomy in a Kantian sense, and also a Hobbesian or liberal sense, of a right to be free from external constraints. Here, one may refuse forced treatment under some circumstances. Yet,

even under this model, competent adults may refuse forced treatment under some circumstances. Mentally incompetent persons may be forced to be treated or detained if they constitute a threat to self or others. John Dawson (2006), Fischer (2006), Wicks (2001), Fox (2023).

Terminally ill patients, for example, are often given the right to refuse medical treatment. In the United States, for example, the US Supreme Court ruled in *Cruzan v. Missouri* (1989), that medical treatment may be refused in some cases. In the case of *In re Quinlian* (1975), among others in the US, established the point that the family of terminally ill individuals may refuse treatment under limited circumstances. The concept of living wills in the US also respects the right of competent adults to refuse treatment. Other countries across the world also recognize a right of individuals to withhold or refuse medical treatment in some cases (Nafziger, 2022).

These cases or instances implicate the issue or practice of euthanasia (Emanuel, 1994). Generally, two distinctions are made when thinking about this practice. First, there is the distinction between what is called active versus passive euthanasia. Active is when affirmative steps are taken to end someone's life—such as administering some drug to cause death. Passive is when medical treatment, food, water, or other procedures are withheld which eventually lead to death. The second distinction is voluntary versus involuntary euthanasia. Voluntary is generally a first-person choice to end a life or hasten death. Involuntary involves decisions by a second party to act to end a person's life of hasten death by withholding medical treatment, food, or water. Thus, what we get is a fourfold distinction.

Table I: Euthanasia Classification

	Passive	Active
Involuntary	Withhold treatment	Homicide
Voluntary	Refuse treatment	Suicide

Table I provides a four-way classification to think about euthanasia. For many, passive involuntary, where one makes a choice to refuse treatment, food, or water, is the most acceptable (or least problematic) of the choices. This is especially the case where it involves an adult of sound mind and perhaps facing a terminal illness.

This could be a situation where the person is conscious to make the decision or has pre-determined the choice through some legal instrument such as a living will.

Second would be where a second or third party, such as a close family member, makes a decision not to administer life-saving aid for an adult, again often terminally ill. This could include withholding food or hydration. Or it could involve decisions not to resuscitate if the heart stops. Often the law requires that the person making the choice to have good evidence of the ill person's wishes.

Third, there is the situation where competent adults who are terminally ill decide to take active steps to end their life. Traditionally this would be considered suicide, but some jurisdictions have altered their laws to allow for this. In some cases, physician-assisted suicide is permitted, such as in ten US states such as New Jersey, Oregon, and Washington, (Pappas, 1996; Compassion & Choices, 2022) and countries including Belgium, Luxembourg, the Netherlands, and Spain.

The most problematic of the four is when an adult is terminally ill, and another person makes a decision to end the former's life. Normally this is classified as some form of homicide or murder. In general, actively ending the life of another is not permitted, especially absent some evidence or clear indication by the ill person that this would have been their wish or choice.

The basis or rationale for this distinction is that it advances a couple of objectives. First, it respects the autonomy or choice of rational adults to make decisions regarding their own body or life. At the same time, it also respects the concept of human dignity because it aims to prevent individuals from having their lives ended without their choice, or simply it means that society values life and it should be preserved or protected much in the same way that the criminal law seeks to prevent homicide or serious bodily harm.

5 Illness in a Democratic Society

How do we take the distinctions made with euthanasia and apply them to illness in a democratic society?

First, as a matter of common courtesy, manners, or etiquette, individuals should take actions to prevent the spread of disease or prevent themselves from infecting others (Buss, 1999). Human decency simply dictates that we should cover our mouths when we cough, stay home when sick, or wash one's hands after using the toilet. Few would object to these actions, but the question might be different if such measures were compulsory and enforced by law. The question thus is about coercive or mandatory actions undertaken by the government to compel individuals to act in certain ways to promote public health.

In general, the concepts of autonomy, liberty, equality, and human dignity translate into two basic concepts or values of importance regarding medical care or treatment in a democratic society. The first is a respect for self-determination of individuals, while the second is the sanctity or protection of life. The two concepts must be balanced against one another (Wicks, 2001, p. 18). As applied to medical treatment, competent adults generally should be given the right to refuse it. However, this right might be balanced alongside the need to protect society or others from harm.

The Article 2 of the ECHR guarantees a right to life and Article 3 contains a provision against degrading treatment. In interpreting this provision, the ECtHR has ruled in *Herzegfalvy* (1992) Series A, No. 244, and *N.H.S. Trust A v. M, N.H.S (Trust B v. H.2, The Times* 29 November 2000), that forced medical treatment for incompetent individuals or those in a vegetative state is permitted. Experimental treatment is non-consensual and illegal (Wicks, 2001, p. 22). Forcible treatment is only permitted for mentally ill when necessary (Wicks, 2001, p. 23). In some cases, a compelled C-section to give birth has been permitted (Wicks, 2001, p. 28). Under British law, forced treatment for competent persons is considered battery (Wicks, 2001, p. 25).

In the US, its Supreme Court has long ruled that minors may be compelled to receive medical care even if they or their parents object. Additionally, in *Jacobson v. Massachusetts*, the Court declared that states may compel even competent adults to be vaccinated. According to the Court:

There is, of course, a sphere within which the individual may assert the supremacy of his own will and rightfully dispute the authority of any human

government, especially of any free government existing under a written constitution, to interfere with the exercise of that will. But it is equally true that, in every well-ordered society charged with the duty of conserving the safety of its members the rights of the individual in respect of his liberty may at times, under the pressure of great dangers, be subjected to such restraint, to be enforced by reasonable regulations, as the safety of the general public may demand.

US Courts have also upheld laws that do not grant exceptions or objections for religious reasons (*Employment Division, Department of Human Resources of Oregon v. Smith*, 494 U.S. 872 (1990)).

6 Current Line of Debate

Covid-19 will not be the last pandemic (National Academy of Sciences, 2023, p. 10). Future medical emergencies will occur testing the relationship between respect for self-determination or autonomy and protection of society. How should a balance be struck?

The most difficult issue is mostly for competent adults. There are several distinctions. Table II describes those distinctions.

Table II: Classification of Diseases

	Ill and non-life threatening	Ill and life-threatening
Non-Infectious	No	No for an adult
Infectious	No	?

First, consider those who are ill with a non-life-threatening ailment that is non-infectious. Consider a person with only a headache, minor cuts and bruises, arthritis, and eczema (Cirino, 2018). In this case the public is not in danger and the person with these ailments is not facing a life-threatening loss. Here, the respect for self-determination is at its strongest. The second scenario is where someone has a non-infectious but life-threatening ailment, such as cancer or appendicitis. Assuming one is a competent adult, the cases for paternalistic action to protect that person similarly should weigh against forced medical treatment.

But now consider a scenario where a person is ill with an infectious medical condition that is either non-life-threatening or life-threatening. The former might be the common cold or some viruses. While respect for self-determination is power, so is, especially in the case of a life-threatening malady, the societal imperative of preserving life. A host of factors must be considered when making decisions to force competent adults to receive medical treatment. These factors include the degree of intrusion, such as whether it is a vaccine, oral or injection or encouraging people to wash hands; the seriousness and probability of illness; the rapidity and ease of the spread of the disease along with its severity; the social costs of forced compliance; the fatigue in prolonged action; and whether isolation is a possibility and for how long (Georgieva et al., 2012; Mental Health America, 2023; Lin, 2021). All of these factors must be weighed not only against individual autonomy and a right to refuse treatment but also whether there are less restrictive alternatives to address the spread of a disease. In all cases, there must be some due process or review of decisions to force medical treatment when it is before or after treatment has been administered.

Finally, there is another scenario or concern, the problem of the slippery slope. What if individuals simply choose not to take care of themselves. They drink, smoke, overeat or expose themselves to activities where, while not presently ill, they could well become so in the future because they voluntarily make unhealthy choices. Is a democratic society warranted in taking preventive action to protect itself? Would this not be the specter of *Erewhon*? This is a concern that must be considered and anticipated if there is any decision to force medical treatment upon individuals.

7 Conclusion: A Right to be Ill?

Illness is unfortunately a part of life. Social interaction facilitates the spread of infectious if not fatal diseases. Clearly, mitigating the spread of disease and the loss of life is a primary goal of public health. At the same time, respect for individual freedom or autonomy is equally a compelling goal in a free society. The question thus becomes at what point is the government entitled to take action to compel individuals against their will to act to prevent them from becoming ill and infecting others? This article argues that in a democratic society there is a tradeoff between autonomy and the preservation of life, and only in the most extreme measures should the government tip the balance in favor of coercive or mandatory measures.

Short of that, the government may encourage voluntary measures or encourage rules of etiquette or good manners to prod individuals to act in healthy or socially responsible ways, but in general there are limits regarding how far individuals can be forced to be healthy.

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Povzetek v slovenskem jeziku

Razprave o zdravju in zdravstveni oskrbi običajno vključujejo vprašanja o tem, ali imamo pravico do enega ali drugega. Toda ali imajo posamezniki v demokraciji pravico do zavrnitve medicinske obravnave? Vprašanje se je postavilo med pandemijo COVID-19 leta 2019, ko so demokracije iskale

ravnovesje med pravicami posameznikov in medicinskimi ukrepi, kot so nošenje mask ali cepljenje. Ta članek preučuje to vprašanje in sprašuje, ali imamo pravico do bolezni in zavrnitve prisilne medicinske obravnave v primeru nalezljivih bolezni, ki ogrožajo življenje. Članek bo zaključil, da imajo v večini primerov kompetentni odrasli posamezniki pravico do zavrnitve medicinske obravnave in pravico do bolezni, vendar se mora takšna pravica uravnotežiti z različnimi dejavniki, ki podpirajo ohranjanje življenja drugih.

Ključne besede: pravica do bolezni, pravica do zavrnitve, informirano soglasje, demokracija, pandemije