

Chapter 11

The Right to Refuse Treatment for Infectious Disease



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Abstract One of the central tenets of contemporary bioethics is that mentally competent persons have a right to refuse medical treatment, even if the refusal might lead to the individual's death. Despite this principle, laws in some jurisdictions authorize the nonconsensual treatment of persons with tuberculosis (TB) or other serious infectious diseases, on the grounds that doing so is necessary to protect the safety of others. This chapter argues that, in the vast majority of situations, overriding a refusal of treatment for infectious disease is not justifiable, as the risk to third parties can be avoided by the less restrictive alternative of isolating the patient. At the same time, it rejects the extreme position that the nonconsensual treatment of infectious disease is never appropriate. Instead, it concludes that compelling an individual to undergo treatment for infectious diseases may be ethically justifiable in exceptional situations if a refusal of treatment poses a grave risk to third parties, the treatment is not overly burdensome and has been established to be safe and effective, and less restrictive alternatives, including humanely isolating the patient, are not feasible under the circumstances. The burden should be on those seeking to compel unwanted treatment to demonstrate that these requirements have been met.

Keywords Bioethics · Public Health · Infectious Diseases · Medical Law · Human Rights

11.1 The Right to Refuse Medical Treatment

If there is one unifying concept that runs through the field of bioethics, it is the doctrine of informed consent — i.e., the principle that individuals have the right to make their own decisions about medical treatment after having been informed of the risks, potential benefits, and reasonably available alternatives (Beauchamp and Childress 2013). The principle of informed consent is grounded in two interrelated

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justifications. First, by conditioning the imposition of medical treatment on the individual's authorization, informed consent protects persons' right to bodily integrity. Second, by requiring the provision of information needed to evaluate the desirability of proposed treatments, informed consent shows respect for individuals as autonomous decision-makers. The right to refuse medical treatment is "the logical corollary" of the informed consent doctrine: if there were no right to refuse proposed treatments, the process of soliciting consent would be a hollow charade (*Cruzan v. Director* 1990).

In addition to its ethical foundations, the right to refuse medical treatment is supported by internationally-recognized human rights principles. These principles include the right to security of the person (*International Covenant on Civil and Political Rights* 1976), the right not to be subjected to torture or to inhuman or degrading treatment (*International Covenant on Civil and Political Rights* 1976; *European Convention on Human Rights* 2010), and the right to health (*International Covenant on Economic, Social and Cultural Rights* 1976). The United Nations Committee on Economic, Social, and Cultural Rights has specifically recognized that the right to health includes the "right to be free from ... non-consensual treatment" (*United Nations Committee on Economic, Social and Cultural Rights* 2000).

Courts have upheld mentally competent individuals' right to refuse medical treatment in a variety of situations, including those in which the refusal of treatment might strike some observers as irrational or unwise. For example, in the case of *Fosmire v. Nicoleau*, the New York Court of Appeals found that an adult Jehovah's Witness had the right to refuse blood transfusions prior to and immediately after the delivery of her baby, despite her physicians' belief that without the transfusions she was likely to die (*Matter of Fosmire v. Nicoleau* 1990). While some older judicial decisions in the United States suggested that the right to refuse treatment must be balanced against the state's interests in the preservation of life, the prevention of suicide, and "the maintenance of the ethical integrity of the medical profession" (*Annas* 1992), there are no recent cases in which any of these state interests has been deemed sufficient to override the refusal of treatment by a mentally competent adult.

However, like most individual rights, the right to refuse treatment is not absolute. First, refusals of treatment may be overridden when the patient lacks the mental capacity to provide informed consent and the imposition of treatment would be in his or her medical best interests (*Steele v. Hamilton Cty. Community Mental Health Bd.* 2000). This justification for compelled treatment typically arises in the psychiatric context, where a refusal of treatment may be the result of an underlying mental illness rather than the manifestation of a genuinely voluntary choice. The main issues in these situations involve the standards and procedures for determining the patient's mental incapacity (*Klein* 2012), as well as the appropriate role of family members and other surrogates in making decisions on the patient's behalf (*Vars* 2008).

Second, the nonconsensual treatment of mentally competent persons may be authorized when doing so is necessary to protect the safety of others. For example, courts have upheld the forcible medication of violent patients in emergency

situations “when there is an imminent danger to a patient or others in the immediate vicinity” (Rivers v. Katz 1986). Courts have interpreted the danger-to-others rationale particularly broadly in the context of prisoners. For example, some courts have authorized the forcible feeding of prison inmates on hunger strikes on the theory that a hunger strike can threaten “institutional order and security” (Matter of Bezio v. Dorsey 2013).

Finally, competent individuals may sometimes be compelled to submit to medical interventions as part of the process of investigating or adjudicating criminal responsibility. For example, criminal suspects may be required to undergo physical examinations, which may include the collection of bodily fluids such as saliva or blood (Maryland v. King 2013; Missouri v. McNeely 2013). In addition, courts in the United States have authorized the government to administer medications to render mentally ill criminal defendants competent to stand trial, citing the governmental interest “in bringing to trial an individual accused of a serious crime.” However, the forcible medication of criminal defendants is permissible only “if the treatment is medically appropriate, is substantially unlikely to have side effects that may undermine the trial’s fairness, and, taking account of less intrusive alternatives, is necessary significantly to further important governmental trial-related interests” (Sell v. United States 2003).

11.2 Existing Approaches to Compelled Treatment for Infectious Diseases

Several jurisdictions have laws that authorize the nonconsensual treatment of persons with serious communicable diseases. For example, in the early 1990s, in response to a dramatic increase in TB cases, New York City amended its health code to authorize the Commissioner of Health to compel TB patients to complete treatment and, if necessary, to detain them during the process (Gasner et al. 1999). Under the law, detention can be authorized for persons with active TB “where there is a substantial likelihood, based on such person’s past or present behavior, that he or she can not be relied upon to participate in and/or to complete an appropriate prescribed course of medication for tuberculosis” (N.Y.C. Health Code §11.21(d)(5)). In most cases, treatment under detention is sought only after other less restrictive alternatives, including directly-observed therapy, have already been attempted (Gasner et al. 1999). However, the Department of Health has the discretion to order treatment under detention as a first resort if it concludes attempting outpatient treatment would be futile in light of the patient’s history of nonadherence.

Similar laws exist in other jurisdictions. For example, South Africa’s National Health Act provides for an exception to the requirement to obtain informed consent to medical treatment in cases where “failure to treat the user . . . will result in a serious risk to the public health” (Republic of South Africa National Health Act § 7(1)(d)). Relying in part on this provision, the High Court of South Africa has upheld the

involuntary isolation and treatment of patients with multi-drug resistant (MDR) TB (Minister of Health v. Goliath 2008). Similarly, Canadian courts have upheld orders requiring patients with TB to submit to mandatory detention and treatment (Ries 2007), relying on provincial legislation authorizing the board of health to issue orders requiring the “care and treatment” of persons with “virulent” communicable diseases (Ontario Health Protection and Promotion Act § 22(4)(g); Silva 2011). The state of Alabama also has a law authorizing the “compulsory treatment and quarantine” of TB patients, but with an unusual exception: Confined patients are permitted to refuse treatment if they “desire treatment by prayer or spiritual means” (Ala. Code § 22-11A-10). The Alabama law does not permit patients to refuse treatment for reasons unrelated to religion.

In contrast, laws in some jurisdictions provide that patients with infectious diseases can be subject to mandatory detention but not forcible treatment. For example, the state of Minnesota authorizes the involuntary isolation of persons with diseases “that can be transmitted person to person and for which isolation or quarantine is an effective control strategy,” but it specifically provides that isolated patients have “a fundamental right to refuse medical treatment” (Minn. Statutes 144.419). Similarly, Israeli law permits the involuntary isolation of persons with TB or other serious infectious diseases, but isolated patients may not be forced to undergo unwanted medical treatment (Weiler-Ravell et al. 2004). The law in Iceland appears to follow a similar approach (Eggertsson 2004).

The Model State Emergency Health Powers Act, a proposed law developed by the Center for Law and the Public’s Health, initially included provisions authorizing forcible treatment of patients during an infectious disease outbreak, but after extensive criticism, those provisions were eliminated from the proposal (Annas et al. 2008). The proposed law now provides that “persons who are unable or unwilling for reasons of health, religion, or conscience to undergo treatment” may be subject to isolation (Center for Law and the Public’s Health 2001). The implication is that, once isolated, infectious persons may not be subjected to treatment involuntarily.

It is unclear whether compelled treatment for infectious disease would be permitted under international human rights law. On the one hand, some human rights documents cite “the prevention and control of communicable diseases” as a situation in which “coercive medical treatments” could be justified on an “exceptional basis” (United Nations Committee on Economic, Social and Cultural Rights 2000). In addition, the European Court of Human Rights (ECHR) has found that requiring individuals to undergo TB screening by means of a tuberculin skin-reaction test or chest X-ray “can be considered necessary in a democratic society for the protection of health” (Acmanne and others v. Belgium 1984). On the other hand, no human rights tribunal has directly addressed the permissibility of compelling individuals to undergo treatment (as opposed to testing) for infectious diseases. Moreover, citing ECHR decisions condemning the force-feeding of prisoners, a World Health Organization (WHO) mission to the Ukraine concluded that “administering a TB treatment without the consent of the patient is an intrusive major intervention that constitutes a prohibited interference with a person’s rights under the ECHR” (Dagron 2016).

Finally, it is worth noting that, although “compulsory vaccination” laws are sometimes cited as support for overriding the right to refuse treatment for patients with infectious diseases (Valenti 2012), those laws do not actually support the forcible imposition of medical interventions over a patient’s objection. For example, in the United States, unvaccinated children who have not received an exemption from a state’s vaccination requirements may be denied enrollment in the public schools (Barraza et al. 2017), but they will not be forcibly given vaccines to which their parents have objected. In a few other countries, parents can be fined for refusing to vaccinate their children (Reuters 2017), but, again, forcible vaccination does not appear to be authorized. Similarly, in the frequently-cited U.S. Supreme Court case of *Jacobson v. Massachusetts*, which upheld a Massachusetts law requiring individuals to be vaccinated for smallpox, the plaintiff was never actually required to undergo vaccination. Instead, the consequence of his refusal of the vaccine was a fine of five dollars (Jacobson v. Massachusetts 1905).

11.3 Ethical Analysis

As discussed in the preceding section, there are two dominant legal approaches to protecting third parties from the risk of serious infectious diseases: compelling such persons to undergo medical treatment, or isolating them without forcing them to accept treatments to which they object. While the latter approach does not technically override the individual’s right to refuse treatment, an offer of treatment that can be refused only by submitting to isolation is inherently coercive. Because “[v]oluntary consent is usually thought incompatible with coercion” (Eyal 2012), both approaches can be seen as exceptions to the general principle that medical treatment requires the patient’s voluntary informed consent.

Recognizing an exception to informed consent for patients with infectious diseases can be compared to cases authorizing nonconsensual medical treatment when necessary to protect third parties from violence. As an ethical matter, both situations implicate John Stuart Mill’s “harm principle,” which provides that individual liberty does not include the right to cause harm to third parties (Brink 2014). As Marcel Verweij explains, “[i]f patients with infectious diseases neglect the treatment they need, this could have harmful implications for others, and that may be reason to overrule the requirements of informed consent” (Verweij 2011).

However, even if the harm principle can justify an exception to informed consent in some situations, the mere possibility of harm, standing alone, is an insufficient basis to justify compulsion. Instead, a full analysis must consider factors such as the likelihood and magnitude of the potential harm, the burdens of compulsion on the individuals affected, the likely effectiveness of the proposed interventions, and the alternatives that are realistically available under the circumstances. This kind of fact-sensitive inquiry is an implicit requirement of consequentialist ethical theories, which require assessing the aggregate balance of potential benefits and harms of any proposed course of action (Sinnott-Armstrong 2015). It is also supported by the

human rights principle of proportionality, which requires a “fair balance between the demands of the general interest of the community and the requirements of the protection of the individual’s fundamental rights” (Soering v. UK 1989).

Coercive action is most justifiable in cases of highly contagious, life-threatening illnesses, such as MDR-TB. As the likelihood of transmission and/or the consequences of infection lessen, the justification for coercion diminishes as well. The precise point at which a refusal of treatment becomes sufficiently dangerous to justify coercion can be difficult to determine. For example, as Richard Coker asks, “given that the risk of relapse is higher if compliance with [TB] treatment ceases after two months of treatment compared with, say, five months (where, in most cases it is probably very small indeed), should those who fail to comply after two months face the prospect of detention if they fail to comply, whereas those who do so only after five months remain at liberty?” In answering these questions, “one is forced to question issues relating to utility, about how one measures the burden of risk, and utility gains and losses. Objective evidence to support decisions is largely lacking” (Coker 2000).

For many diseases, both the likelihood and magnitude of potential harm exist on a lengthy continuum. With respect to the likelihood of transmission, consider the case of sexually-transmitted infections (STIs). Many persons with STIs pose little or no risk to others because they are either sexually inactive or consistently use barrier protection. However, the level of risk increases if they engage in unprotected sexual encounters with multiple partners. The likelihood of transmission is particularly high for persons whose sexual partners do not recognize the need to take precautions against transmission, such as spouses who may mistakenly assume that their relationships are exclusive. In light of these uncertainties, is the likelihood of harm to unknowing third parties sufficient to justify the use of compulsion? While public health authorities generally favor a voluntary approach to STI testing and treatment (WHO Statement 2012), efforts to use compulsion sometimes occur. For example, under 2017 guidelines from the British Columbia Centre for Disease Control, public health authorities may issue orders compelling HIV-positive individuals to initiate and continue HIV treatment if they engage in high-risk sexual behavior or share needles and/or other drug paraphernalia with other persons and do not disclose their HIV status (British Columbia Centre for Disease Control 2017). Violation of such orders can result in court-ordered detention under the British Columbia Public Health Act, which allows medical health officers “to do anything that the ... officer reasonably believes is necessary ... to prevent the transmission of an infectious agent” (British Columbia Public Health Act). In 2018, a man from Vancouver was charged under these provisions for allegedly refusing to comply with a medical officer’s order to submit to HIV treatment (Proctor). Similarly, a man in Fayetteville, Arkansas was charged in 2016 for a misdemeanor public health violation for refusing to undergo treatment for syphilis (Vendituoli 2016).

Similar uncertainties relate to the magnitude of harm resulting from an individual’s refusal of treatment. For example, seasonal influenza typically resolves itself without any long-term consequences, but it can be life threatening for elderly patients or those with compromised immune systems. If a treatment were developed

that quickly made patients with seasonal influenza incapable of transmitting the illness, would the magnitude of avoidable harm justify imposing this treatment over a patient's objection? Even seemingly innocuous infectious diseases, such as athlete's foot, can cause severe consequences in some subgroups of patients (e.g., persons with diabetes). So far, no one has seriously proposed compelling individuals with athlete's foot to use anti-fungal medications, or to threaten infected persons with detention if they visit a public swimming pool with bare feet during an outbreak. Yet, the idea of invoking the harm principle in this situation might seem perfectly reasonable to a diabetic patient who is forced to undergo a foot amputation after being exposed to an untreated fungal infection.

In determining whether the likelihood and magnitude of harm are sufficient to justify compulsion, some commentators have suggested that the risks posed by an individual's refusal of treatment should be compared to the other risks that individuals typically confront on a day-to-day basis. For example, Mark Cherry argues that compelled treatment for infectious disease can be justified when necessary to prevent "significant and unusual risk" to "non-consenting others." He gives the example of legally-mandated treatment for patients with extensively drug-resistant TB, explaining that "[t]he risks associated with such diseases are significantly greater than the background risks that one generally assumes in daily life" (Cherry 2010).

Yet, while a comparison to the risks of daily life provides a useful framework for analysis, it does not follow that, as long as the risks of refusal are greater than the risks of daily life, the use of compulsion is necessarily warranted. Instead, the existence of a "significant and unusual risk" should be considered a necessary but insufficient criterion for justifying compulsion. In other words, if the risks of treatment refusal are less than the risks of daily life, the use of compulsion should not even be considered; if the risks are greater, compulsion *might* be justifiable, but additional considerations must also be factored into the analysis.

One of these additional considerations is the burden of compulsion on the individuals affected. For example, in upholding Belgium's policy of mandatory skin-tests and chest X-rays for TB, the ECHR pointed to the absence of evidence suggesting that those interventions involved "disadvantages comparable to the former ravages of tuberculosis" (*Acmanne and others v. Belgium* 1984). The implication was that more burdensome interventions would require a more compelling justification.

Some interventions might be too burdensome to be justifiable under any circumstances. By way of analogy, in refusing to authorize a Caesarean section on a dying woman who had refused the procedure, the District of Columbia Court of Appeals noted that, to perform the procedure, the patient "would have to be fastened with restraints to the operating table, or perhaps involuntarily rendered unconscious by forcibly injecting her with an anesthetic, and then subjected to unwanted major surgery." It concluded that "[s]uch actions would surely give one pause in a civilized society, especially when [the patient] had done no wrong" (*In re A.C.* 1990). For similar reasons, it is difficult to imagine a scenario in which it would be acceptable to force a patient with an infectious disease to submit to a major surgical procedure, even if doing so were the only way to render the patient non-infectious.

Another consideration is the likelihood that the proposed intervention will be effective in reducing the risk that the disease will be transmitted to third parties. At a minimum, as the World Health Organization emphasizes, overriding an individual's refusal of a medical intervention for the treatment of an infectious disease should not be considered unless the proposed intervention "has proven to be safe and effective and is part of the accepted medical standard of care" (World Health Organization 2016). Likewise, requiring individuals who refuse treatment to undergo isolation would not be justifiable if the disease is already so prevalent in a population that isolating untreated patients is unlikely to make a significant difference in reducing transmission.

Finally, even if an individual's refusal of treatment creates a sufficient risk of harm to others to justify the use of compulsion, the type of compulsion used should be the least restrictive option reasonably available under the circumstances. The "least restrictive alternative" requirement is a well-established principle of human rights jurisprudence. For example, the Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights provides that any restrictions on human rights must be "strictly necessary" and that "there must be no other, less intrusive means available to reach the same objective" (American Association for the International Commission of Jurists 1985). The United States Supreme Court applies a similar standard in analyzing restrictions on fundamental constitutional rights (Chemerinsky 2015), as does the European Court of Human Rights (Brems and Lavrysen 2015).

In light of this principle, if it is possible to protect the public from harm by isolating the patient, there would be no justification for insisting that the patient, once isolated, submit to medical treatments to which he continues to object. The WHO Ethics Guidance for the Implementation of the End TB Strategy makes this point forcefully:

While contagious persons with TB who do not adhere to treatment or who are unable or unwilling to comply with infection prevention and control measures pose significant risks to the public, those risks can be addressed by isolating the patient. Patients who are isolated should still be offered the opportunity to receive treatment, but if they do not accept it, their informed refusal should be respected. Forcing these patients to undergo treatment over their objection would require an unacceptable invasion of bodily integrity, and also could put health care providers at risk. Moreover, as a practical matter, it would likely be impossible to provide effective treatment without the patient's cooperation. Nevertheless efforts to convince the patient and re-examine his or her refusal should not be abandoned (World Health Organization 2017).

The Belgian Advisory Committee on Bioethics takes a similar position, finding that "if an MDR patient who does not have any psychiatric problems rendering him incapable of giving his consent refuses a treatment, the health authorities can hold him in isolation to avoid the spread of the disease but cannot force him to receive treatment" (Belgian Advisory Committee on Bioethics 2013).

This position is consistent with the logic of the danger-to-others exception to the informed consent requirement. In particular, cases involving the forcible medication of violent patients emphasize that the use of force is justified only as a temporary

measure, “continuing only as long as the emergency persists” (Rivers v. Katz 1986). Once a violent patient has been medicated to a point that he can safely be isolated, there would be no justification for further medication unless another basis for overriding consent, such as mental incapacity, also exists.

Taken together, the considerations discussed above suggest that nonconsensual treatment for infectious disease will rarely be justifiable. Even if the magnitude and severity of harm resulting from a treatment refusal are significant, and even if the proposed treatment is not especially burdensome and is likely to work, the less restrictive alternative of isolating the patient will usually be sufficient to protect the public from harm. While involuntary isolation still involves an element of coercion, in most cases it should be up to the patient to decide whether this option is preferable to submitting to an unwanted medical intervention.

Yet, it would be a mistake to think that the option of isolation will always eliminate the need to consider the appropriateness of nonconsensual treatment. One situation in which isolation may be impractical is when individuals are already living in confined settings, such as in prisons or the military. While isolating a small number of individuals in these settings may be possible, the available space for isolation is likely to be limited. In addition, there may be other persons with a stronger case for access to these limited facilities — for example, prisoners who need to be separated from the general population because they are at heightened risk of violent attack.

Another situation in which isolation may not be a practical alternative is during an epidemic outbreak involving substantial numbers of persons with contagious infections, particularly in low-resource settings with a limited capacity to provide humane isolation facilities. In some cases, voluntary isolation at home may be a reasonable alternative, but this will work only if the patient is willing and able to follow infection control precautions (World Health Organization 2017). Otherwise, if isolation facilities are limited, protecting the public may sometimes require consideration of nonconsensual treatment. Yet, even in these scenarios, compelled treatment would be justified only if a safe and effective treatment exists that would not be unduly burdensome to the patient. If there is such a treatment, it seems unlikely that the number of people refusing it would be high enough to overwhelm available isolation facilities, particularly if public health authorities have engaged in an adequate process of community engagement (World Health Organization 2016). Thus, as a practical matter, the need to invoke this exception may be more theoretical than real.

In all cases, the burden should be on those seeking to compel unwanted treatment to demonstrate that no less restrictive alternatives, including isolation, are realistically available under the circumstances. As the World Health Organization recommends, “objections to diagnostic, therapeutic, or preventive measures should not be overridden without giving the individual notice and an opportunity to raise his or her objections before an impartial decision-maker, such as a court, interdisciplinary review panel, or other entity not involved in the initial decision” (World Health Organization 2016). Such a process provides an important check against abuse and can avoid undermining public trust in the integrity of the public health system.

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