

REPORT

ON TRANSMISSIBLE INFECTIOUS DISEASES: PUBLIC INTEREST AND AUTONOMY

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I. Introduction

In current medical practice, patients are free to agree or decline therapeutic interventions suggested to them by physicians through informed consent. But when their individual decisions can directly affect the health of other people, their personal autonomy as the only factor in making such decisions is put in question. The present report discusses the limits of personal autonomy when a conflict with public interest arises, particularly with the protection of public health.

Such conflict of interests becomes an issue mainly with regard to infectious (transmissible) diseases, which can spread from one person to another. Decisions on the prevention and treatment of such diseases put at stake the health and lives of not only the patients themselves but also of healthy individuals in their immediate or wider vicinity. Thus, if a person affected by a contagious disease or belonging to a high risk group decide against a diagnostic test or treatment, they automatically become a certain or likely “source” of transmission of the disease.

1. Infectious diseases

Infectious or transmissible diseases are caused by pathogen agents invading the organism (viruses, bacteria, fungi, parasites – monocellular or multicellular – or

infectious proteins (e.g. prions in case of spongiform encephalitis)). Pathogens are transmitted in specific ways e.g. by saliva droplets (*path of transmission*), take hold and proliferate more or less successfully in young subjects (*infectivity*), provoking symptoms of varying severity or no symptoms at all (*virulence*), in which case they remain latent and the host becomes a carrier, but not actually sick.

Usually, the disease can be transmitted by carriers as well as patients. The path of transmission, infectivity and virulence are critical factors when developing public health protection programmes or evaluating arguments for or against personal autonomy where an evaluation is required. By way of indication, a common cold – highly transmissible through droplets but causing mild symptoms and posing little risk for life - is different from influenza – also highly infective but causing more severe symptoms as compared with common cold - or hepatitis B, which is harder to contract (by blood transfusion or exchange of bodily fluids containing blood), but has higher mortality rates or likelihood of permanent damage.

2. *Epidemiology*

Infectious diseases can cause *epidemics*, i.e. a significant increase in the number of infected people within a given population in a given time period, beyond what might be normally expected, based on the epidemiological statistics for the particular disease (Encyclopedia of Public Health, on line).

The geographical area, in which the rise in the number of infected people is observed, will determine whether it is a mere outbreak – when the rise concerns a relatively small area, e.g. a town -, an epidemic – when the rise in the number of infected people spreads over a wider area, e.g. a whole country or district – or a pandemic – when a disease spreads significantly world-wide. The 1919 influenza and HIV/AIDS from the 1980s are examples of pandemics (Encyclopedia of Public Health, epidemics). After the manifestation of an epidemic the disease may

disappear or persist in the population in latent form causing occasional outbreaks or remain endemic with a steady number of patients.

Nowadays, the term “epidemic” is not only used for contagious diseases. It can be used for other pathologies, currently on the rise, like cancer or cardiac disease, even for conditions that are not a proper disease, like obesity. This report, however, focuses only on transmissible diseases, since they give rise to the particularities of the implementation of personal autonomy in medical practice, when a conflict with public interest arises, i.e. the protection of the healthy population from the transmission of pathogens from patients or carriers.

Measures of protection against infectious disease are taken by responsible health authorities irrespective of outbreaks. Restrictions to personal autonomy can be applied even without an increased risk of epidemics. However, once a disease is qualified as epidemic or pandemic, emergency measures shall be taken. Accordingly, the legitimacy or illegitimacy of restrictive measures will obviously be influenced by the level of risk or the manifestation of an epidemic.

It must be noted that a disease can amount to an epidemic based on the relative, not absolute, numbers of infected people. Thus, a relatively small number of patients or carriers can give rise to an epidemic. This is to say that the terms “epidemic” or “pandemic” do not necessarily involve an emergency situation. The risks posed by a disease depend on its specific characteristics, like the severity of symptoms, mortality rates and infectivity.

3. Preventive measures

One of the most effective tools of contemporary medicine in the prevention of transmissible diseases is vaccination. To mention a typical example, smallpox was eliminated thanks to successful immunization against the disease. Vaccines reinforce the defenses of recipients against the specific pathogens for which they are designed, preparing the immune system to immediately recognize and

effectively resist any future attacks by these pathogens. Vaccines do not ensure absolute protection and people may still be infected with a disease against which they were vaccinated. Vaccines, however, significantly reduce the probability of infection as well as the severity of symptoms in the event of infection.

The success of a vaccination programme, however, depends not only on the efficacy of the vaccine but also on the rate of the population participating in the programme. Vaccination does not reduce only the likelihood of infection in case of contact with the pathogen but also the likelihood of such contact itself, if sufficient numbers of the population are vaccinated. This is known as “indirect immunity” or “herd immunity”. Therefore, the decision to be vaccinated or to have one’s children vaccinated has implications for society as a whole because the vaccine protects not only recipients but also the rest of the population. Therefore, the decision to participate or not in a vaccination programme can produce a dilemma between autonomy and public interest.

II. Ethical issues

In case of contagious diseases the scope of personal autonomy is defined by the legitimate interests of others or of society as a whole. Limits to autonomy are of two natures: those imposed by the necessity of medical intervention (diagnosis, prevention or treatment) and those imposed by the autonomy of others.

Transmissible diseases, like other risks to public health, affect the latter category.

The following questions arise in this respect:

- To what extent are limits to personal autonomy justified on public health grounds (1)?
- What is the effect of informed consent when public health is at risk (2)?

To these questions, we must add the implications of the “doing good, not harm” principle, that is the scope of medical duty in case of health-threatening (perhaps

also life-threatening) situations for entire populations since, in this event, the exercise of autonomy by patients is *de facto* affected (3).

Finally, two related issues call for special consideration: clinical trials and respective patents for vaccines and medicines, for they also raise important ethical questions. On one hand, these are associated with the provision of accurate information to patients, and on the other hand with access of patients to treatments in the context of exercising autonomy,(4).

1. General autonomy and public health: restrictions and the risk of stigmatization

The legitimate objective of protection of the health of others sets the grounds for imposing restrictions on the general autonomy of those infected, especially in regard to movement and social contact.

This calls for a number of qualifications. Indeed, not all transmissible diseases justify the same restrictions. Distinctions are necessary between easily and less easily transmitted diseases as well as between mild and serious diseases (influenza *versus* HIV, for example).

Mild diseases, even when easily transmitted, do not justify such restrictions to general autonomy; the same is true of serious diseases that are hard to contract. Of course, there are many variations of these combinations, which prevent the formulation of more specific rules of universal effect.

Restrictions to general autonomy can lead to unfair discrimination arising from a kind of “stigmatization” which isolates patients – even if temporarily – from social life. Above all, this raises a wider ethical problem. Historically, the stigma against population groups on public health grounds has been a recurring phenomenon, from the persecutions and massacres of Jews during the times of “Black Death” in the Dark Ages (the plague pandemic), to the persecution of beggars on the same grounds in the XIX century or of prostitutes for spreading syphilis in World War I,

to contemporary practices of discrimination against AIDS patients. In our country, stigmatization phenomena occurred in the past in the cases of leprosy and tuberculosis.

These facts demonstrate that public health is not to be considered only as a medical problem, but involves a serious social and political dimension. The latter must be taken into account when adopting restrictions to general autonomy. Such restrictions are not justified unless accompanied by social measures aimed at minimizing the likelihood of transmission (e.g. housing, food, etc. for the poor or disadvantaged groups of the population) and by steps ensuring fair treatment (not distinguishing, for example, between prostitutes and their clients regarding the risk of transmission of venereal diseases).

The current wave of immigration carries great potential of stigma on public health grounds. The fact that the country of origin – particularly of illegal immigrants – is often afflicted by a high prevalence of infectious diseases (especially sub-Saharan Africa and southern Asia), while local health services remain rudimentary, represents a real cause of concern for the spreading of these diseases in the hosting countries. However, stigmatization practices – unfair treatment, “ghettos” etc. – stem rather from the idea of “miasma” due to lack of information or misinformation about the medical-biological particulars of disease, especially infectivity. Hansen’s disease (leprosy) and, more recently, HIV/AIDS confirm this observation since these population groups are stigmatized, although the disease is relatively difficult to contract.

In case of Hansen’s disease, the exact path of transmission is still unknown, but it is accepted that although it can be contracted through prolonged social contact, approximately 95% of the population are immune to it, though the mechanisms of immunity have not been identified. Perhaps it was this last parameter in combination with the deformity caused by the disease that has led to social stigma against these patients in the past.

In case of HIV/AIDS, the path of transmission is known and involves exposure to body fluids through sexual intercourse or the transfusion of contaminated blood or use of a contaminated needle. The virus can also be transmitted to the foetus by the mother. Mere social contact with patients or seropositives does not constitute a risk of transmission. Despite this, especially in the early years since the appearance of the disease, but even today, seropositives are treated with far greater caution, even prejudice, than is justified by medical fact. Apart from the severity of the disease, which meant near certainty of death in the beginning, whereas now there are available treatments, prejudice emanates from the fact that, initially, the disease had a higher incidence among male homosexuals in western countries. The pre-existing stigma against homosexuals exacerbated the stigma against HIV/AIDS patients and carriers.

On a practical level, the difficulty here lies in the justification of restrictions on grounds of public health protection. Public authorities can be motivated by non-medical parameters (e.g. systematic deprecation or exclusion of specific groups) when considering such restrictions, in particular to the freedom of movement and residency. Hence, the importance of having an official entity of indisputable independence, providing accurate and understandable medical information on the disease to the wider public, becomes crucial.

2. Autonomy and forced treatment

The second serious ethical issue arises with respect to the freedom of individuals to take care of health matters regarding themselves.

Here, the principle of “informed consent” may be restricted, especially with regard to “refusal of treatment”. The health of others being directly at stake, the freedom to deny treatment does not enjoy the ethical justification acknowledged in different circumstances.

Hence, forced treatment or prevention (e.g. mandatory vaccination) may be considered as option, especially if this is the only way to restore the general autonomy of the affected person (the subject of restrictions).

The same can be argued about the extent of (personal) information and the availability of alternative treatments which are also limited by the emergency and time constraints of an epidemic.

One may object that forced treatment is not the only option when a patient denies therapy. Besides, insofar as it involves a direct intervention on the latter's body, its compatibility with the respect for human value is questionable, given that the affected person is used as a common "means" to protect society. The alternative – should this objection be sustained – would be to impose other restrictions to protect others, e.g. limits to the freedom of circulation and installation, not involving forced treatment. A solution more compatible with autonomy in view of the above would be to leave the choice of preferred option to the one concerned.

At any rate, with the exception of emergencies which leave no time for government intervention – in which case it is ethically justified to leave the initiative to physicians – autonomy does not evaporate before public interest. Particularly in case of mild diseases or hard to transmit diseases, the obligation to respect autonomy remains fully effective.

3. Scope of medical duty

When public health is at risk from a contagious disease, objective parameters – time, in particular – often prevent the unhindered practice of medicine. In such cases, physicians must set health care priorities, which may result in depriving certain people from care. The availability of physicians is obviously an external *sine qua non* for exercising patient autonomy.

The necessities of war can offer a precedent for such prioritization. Since World War I, a three-fold division of the population in terms of priority ("triage"), based

on the probability of cure is generally accepted: those in immediate need of help come first; next follow those who can be transported to a hospital even if more seriously hurt, and last are those with minor injuries or few chances of survival. But one may think of other considerations (e.g. priority to those who will treat others, to the young or the elderly, even a “first come first served” approach). Although “triage” is mostly associated with war (and natural disasters or train derailments) its core concept can be of use also in case of epidemics.

At all events, health care priorities must be set by public authorities in advance on the basis of fixed rules in order to prevent physicians from having to make so many ethically questionable judgments.

4. Special issues: clinical trials, patents

The urgent need for prevention and treatment in times of epidemics painfully illustrates the question of the adverse effects of trials of new treatments (medicines, vaccines) to contain the risk.

Given that clinical trials are now subjected to a specific control procedure, ensuring the safety of volunteering participants and of the end-product before it becomes available to the public, at issue is whether this procedure should be relativized in case of an urgent need to supply new cures. Since the pursuit of absolute safety, even in normal circumstances, obviously undermines the effort to find new cures (as being too time- and resource-consuming) the debate on the “maximization of risk” is not without cause. The criteria of socially acceptable risks from a new medicine or vaccine are ultimately a matter for bioethics, and must be considered as such.

Similar arguments can be made on the scope of patents – and, with that, on the scope of trade prerogative – on new treatments in case of emergency. Here too, limiting the duration of privilege of the patent holder for the sake of providing

easier (and cheaper) access to a highly needed drug or vaccine is a matter for bioethics.

III. The legal dimension

1. International law

Public health is considered as a remit of national sovereignty. As a result, there are no international policies underpinned by international rules for the moment on the protection from epidemics except from trade in foodstuffs and animal feed. To this, we must add the reluctance of developed countries to effectively combat serious transmissible diseases, which are endemic in developing countries (e.g. malaria, tuberculosis, HIV).

Nevertheless, provisions on international protection from epidemics exist in the form of guidelines (IHRs) issued by WHO. These guidelines are not legally binding, of course, but non-compliance can lead to other types of sanctions (e.g. WHO travel alerts). Considering that international movements, immigration flows and trade have become easier with globalization and with the recent experiences of wide-spreading transmissible diseases in mind, proposals are under discussion with a view to developing international instruments in this field.

2. Greek law

The protection of the population from the transmission of contagious diseases is governed by arts. 21 (3) and 5 (4) of the Constitution and art. 5(1)(e) of the European Convention of Human Rights (ECHR)¹.

¹*Article 5 (4) of the Constitution*: “Individual administrative measures restricting the free movement or residency in the national territory or the free entry into or exit from it to any Greek citizen shall be prohibited. Such restrictive measures may be imposed only as ancillary sanctions by criminal court ruling in exceptional emergency circumstances exclusively for the prevention of indictable offences as specified by Law”.

Under art. 21 (3), the Constitution recognizes health as a social right in addition to its recognition as an individual right². Thus, a distinction is drawn between the right of the individual citizen to take care of matters pertaining to personal health and public health care for all. In this sense, the social entitlement to health can be taken as a basis for adopting health protection measures (organizing vaccination programmes, blood donations, etc.).

However, both the Constitution and the ECHR acknowledge the need of restrictive measures to protect public health.

Thus, the art. 5(4) of the Constitution (interpretation statement) exceptionally accepts individual administrative measures “*on grounds of public health protection or the protection of patients as specified by Law*”. It is important to stress that such measures amount to extensive inroads into individual freedom – prohibiting “*the free movement and residency in the national territory or the entry into and exit from it*” - and can be decided by any public authority (health authorities, police, local government, etc.), but always under specific legal provisions.

Along the same lines, the ECHR (convention with overriding formal effect *versus* ordinary legislation) accepts the deprivation of individual freedom such as, among other things, “... *the lawful detention of a person for the prevention of the spreading of infectious diseases, ...*” (art. 5(1)(e)), but always “*in accordance with a procedure prescribed by law*”.

The above provisions seem to grant broad discretionary powers to the common legislator when adopting restrictions to the individual freedoms of persons affected by transmissible diseases but, in any case, the legislator’s powers are delineated by the Constitution. However, there are limits:

Interpretation clause:

Paragraph 4 does not preclude the prohibition to leave the country by order of public prosecutor due to criminal proceedings or measures imposed on grounds of public health protection or the protection of patients as specified by Law”.

Article 21 (3) of the Constitution: “The State shall care for the health of citizens and shall adopt specific measures to protect youth, old age, disability and health care for indigents”.

² *Article 5 (5) of the Constitution:* “Everyone is entitled to the protection of their health and genetic identity...”

a) In principle, the above restrictions pertain to personal freedom, not to other fundamental rights. That is, they are meant to protect others from contracting the disease, and not to treat the affected subject. Therefore, they cannot amount to forced treatment bypassing the patient's will.

b) Restrictions are subject to the principle of proportionality (art. 25 (1) of the Constitution). That is, they are justified only in the extent which is necessary to protect others.

c) Furthermore, they cannot go as far as totally eliminating personal freedom. The "core" of the right must remain intact in all cases.

IV. Concluding remarks

Based on the above discussion a number of conclusions can be drawn to assist the Commission in issuing an opinion.

1. Personal decisions on health matters may have critical implications for the health of others, as the example of transmissible infectious diseases typically demonstrates. Therefore, the exercise of autonomy in this area must take public interest into account – i.e., the protection of public health – and, in all terms, is determined by such interest.
2. The above statement does not imply that personal autonomy may be "brought to tatters" – or virtually eliminated – by policy choices to protect public health. Autonomy is still the rule, even in case of epidemics or pandemics, which means that any encroaching measures are always exceptional and can be justified only to the extent that they are demonstrably appropriate for the objective they serve (principle of proportionality). It is, therefore, indispensable to distinguish between infectious diseases depending on the level of risk and their transmissibility.
3. The adoption of general rules in advance – if possible in periods of "normality" – both in terms of restrictions as well as of access to sanitary

authorities in times of epidemics or pandemics not only safeguards the efficacy of prevention or treatment, but also strengthens the feeling of fair distribution of resources and means in emergency situations as imposed by the respect for human value.

4. The potential of social stigma against persons or groups under the pretext of public health protection is very potent in situations calling for measures. This risk can be addressed only with constant vigilance based on valid and accurate information, a task pertaining mostly to public authorities and institutions. Public health cannot be allowed to inspire phobic reflexes in a modern democratic society.

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