



Ethical Dilemma: Patient Autonomy and Public Health Considerations in Infectious Diseases

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Abstract

Introduction: Independence or autonomy is one of the fundamental rights of patients that must be respected by health professionals in all medical interventions and diagnostic and therapeutic measures. In conditions of infectious disease, the health system, in order to fulfill its moral and legal duty to protect the health of the community, is sometimes forced to violate this principle and limit the autonomy and right to choose of patients. This ethical dilemma is the subject of discussion in this article.

Material and Methods: The present study is a review of articles, books, and ethical charters in the field of patient and community rights. To achieve the goal, articles and books published between 2000 and 2024 were reviewed.

Conclusion: It seems that although violating the principle of respecting the patient's right to autonomy in conditions of widespread disease is morally justified, complete disregard for this right and arbitrary restriction of it without sufficient evidence, in addition to violating the patient's fundamental rights, will also damage public trust and the social capital of the health system, and will make it difficult for this institution to achieve its major goals and attract public participation.

Keywords: Patient autonomy, Patient's Charter of Rights, Ethical dilemma, Public health, Widespread diseases

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INTRODUCTION

Patient-centeredness is one of the new health strategies in countries that have a modern and successful health system. Adopting this strategy in all preventive and therapeutic policies and methods by increasing public trust and social capital makes the health system successful in involving society in advancing its goals in promoting public health. Among the important principles of this strategy is attention to patient rights and efforts to protect these rights by policymakers and health activists in all medical and health centers. One of the fundamental rights

of patients, which is stipulated in the Charter of Patients' Rights and is also recommended to be protected in the Code of Medical Ethics, is the right to independence or autonomy of the patient. Health activists and medical staff must consider the patient's freedom and discretion at all stages of diagnosis and treatment and must refrain from taking any action without the patient's knowledge and consent. However, in epidemic conditions where the health system feels the heavy responsibility of protecting public health and the lives of individuals in society, sometimes medical staff and the health system are

forced to violate the individual rights of patients in order to advance their macro-level actions and policies for public health and the health of the community and to combat widespread diseases. This article examines this ethical dilemma and suggests ways to overcome it that can help the health system and medical staff fulfill their professional responsibility and ethics.

MATERIAL AND METHODS

The present study is a review of articles, books, and ethical charters in the field of patient and community rights. To achieve the goal, articles and books published between 2000 and 2024 were reviewed.

DISCUSSION

The patient's legal charter is one of the most important issues in medical ethics. The five pillars of this charter are: 1) Receiving the desired health services, 2) Receiving the desired and sufficient information, 3) The right to choose and make decisions freely, 4) Respect for privacy and adherence to the principle of confidentiality, 5) An efficient system for handling complaints. In the third pillar of this charter, which is dedicated to the patient's right to choose and make decisions freely, it is emphasized that the patient's choice and decision-making must be free, informed, and based on receiving sufficient and comprehensive information. Examples of this principle are mentioned, including: choosing a treating physician and a health service provider within the framework of the criteria; participating or not participating in any research; accepting or rejecting proposed treatments after being aware of the possible complications resulting from accepting or rejecting them; giving the patient the necessary and sufficient time to make decisions and choices after providing information [1].

In addition to the patient's rights charter, another charter regulates the health system's interventions in society within an ethical

framework, which is public health ethics. Public health ethics includes the requirements that the health system must comply with in ensuring public health and respecting social rights. In fact, it should be said that in medical ethics, importance is given to the patient and his independence and freedom in choosing and maintaining the privacy of individuals are of particular importance, but in public health ethics, more attention is paid to society, citizenship, and participation. Ethics in public health focuses on the areas of health policymaking, health service provision, health system interventions, and health research [2]. Therefore, for example, creating restrictions on individuals' freedom and determining its limits in order to prevent harm to the health of society are among the important issues in public health ethics [3].

Autonomy and the right to choose

Among the fundamental human rights is the right to freedom, choice, and choice between different options. Every human being has this right by virtue of being human, and no one can oppressively deprive any human being of this right and force him to do something.

The right to freedom has also been recognized in important international documents such as Articles 3 and 9 of the Declaration of Human Rights, Article 9 of the International Covenant on Civil and Political Rights, and Article 37 of the Convention on the Rights of the Child [4].

A review of the definitions of freedom presented in political and sociological literature focuses more on the meaning of this word in human relations and social relationships. For example, Montesquieu, the French political philosophy theorist, in his book *The Spirit of Laws*, limited freedom in two areas: relations with people and relations with the state. He considers freedom in relation to the state to mean that a person has the right to do whatever the law permits and not be forced to do whatever the law does not prohibit. In relation to people, he considers freedom to

mean security or a feeling of security [5]. However, since bioethical discussions concern the protection of fundamental human rights, definitions that refer to the natural nature of this right should be considered, not definitions that refer to its legal and contractual origin. Freedom in the philosophical approach is the same option or right of choice that everyone finds intuitively within themselves. Humans have the will and power to choose and make decisions in their actions, meaning that in the process of deciding to do something, they first imagine it and then weigh its benefits and then acknowledge its benefits. After these stages are completed, another emotional quality is realized, which is desire and passion. Sometimes this desire is uncontested and sometimes it conflicts with the desire to do something else. In the event of a conflict, a person chooses whichever one he prefers. This is the same option and freedom that is opposed to philosophical determinism [6]. In contrast to this a priori approach, Kant believed that the only way to prove freedom in man is through the posterior way, through morality and practical reason. In his opinion, the existence of moral principles leads us to consider man as a free and autonomous being, because without this assumption, the existence of any moral obligation would be fruitless and futile. The assumption of every moral instruction and advice is that man is free and has the power to do or not do an act [7]. In medical ethics, the right to freedom as a natural right plays an important role in decision-making regarding therapeutic and diagnostic methods, and the need to respect it sometimes limits the methods used in treating patients. In this area, freedom means that “every sane and mature person has the right to determine what is to be done with his or her body, and a surgeon who performs an operation without the patient’s informed consent has committed an injustice against him or her” [8]. In this article, by developing the concept of autonomy, the use of

opportunities and facilities that the patient is free to use under normal circumstances is considered an example of autonomy, and the conflict of this principle with the principle of striving to ensure public health is examined. Some of these opportunities include: meeting with family and relatives, especially in the final stages of life, knowing the exact state of health and the progress of the disease, hospitalization in medical and quarantine centers, and conducting non-conclusive tests.

Ethical dilemmas between medical ethics and public health

1. Visiting family and relatives

One of the patient's rights is the possibility of meeting with his family and relatives, and the medical staff is responsible for providing this opportunity for him. This issue becomes more urgent in the case of patients who are at the end of their lives.

During the outbreak of infectious diseases such as Covid-19, we witness the hospitalization of a large number of patients, especially in special hospital wards, and due to the lack of definitive treatment, the hope of their return to life is very low. In these conditions, on the one hand, adherence to the above requirement makes it necessary to allow the patient's family to be with him, but on the other hand, the presence of people in the hospital is dangerous and is considered a serious threat to the lives of their companions. In such conditions, medical ethics and public health ethics conflict with each other in practice and pose an ethical challenge. Although the presence of a family member of a patient with an infectious disease in the hospital is associated with risks, there are several reasons why it is necessary to find safe and supervised ways for the patient to meet with his family, two of which are mentioned below.

- Allowing the patient to meet with relatives can be considered in line with the new

patient-centered care policy. In the new approach to health care, treatment is carried out in a way that is meaningful and valuable to the patient. This method follows eight principles, the sixth of which is to involve family and friends in the treatment process. For this purpose, the following measures have been recommended: providing a suitable place in the treatment center for the patient's family and friends; involving the patient's family and close friends in treatment decision-making; supporting the family as health activists; and recognizing the needs of family and friends [9]. Although it can be said that this recommendation is related to normal conditions, it is not applicable in the conditions of the spread of the disease, but if this visit can be provided in safe conditions, this action is preferable to pure inattention. The patient-centered care strategy pursues goals that the health system also needs in epidemic conditions.

- New scientific research indicates that the presence of the patient's family in special hospital departments such as the ICU plays a significant role in reducing stress and psychological pressure on the patient and his family. For example, a study based on clinical evidence found that the presence of the patient's family in the intensive care unit is one of the principles of patient-centered health care and, contrary to popular belief, stated that if the patient's visit is made with the consent and desire of both parties, it will make the patient's family more involved in the health of the member, increase the satisfaction of the patient and the family, and also reduce stress in the patient and his family [10]. Considering the above, it can be said that although in conditions of widespread disease, the principle of maintaining public health can limit the patient's right to visit, especially in the final hours of life,

considering measures for safe visits can not only provide satisfaction to individuals and make patients and their relatives more confident that the medical staff is concerned about the individual rights of patients, but it will also be effective in terms of the health and recovery process of patients. For this purpose, isolated and controlled places can be considered in the hospital so that the patient's relatives can visit their patient while observing all safety and hygiene points, even behind glass and at specified times.

2. Knowing the exact state of health and the method of treatment

Another action that seems necessary in the context of the spread of a dangerous and fatal disease and challenges one of the patient's basic rights is the refusal to accurately communicate the health status to the patient. Since knowing the extent of the disease's progression, especially fatal diseases, may cause severe stress to the patient and reduce the body's resistance to the disease, medical staff sometimes prefer to choose the treatment method and act without the patient's knowledge and consent and based on the extent of the disease's progression. In these cases, limiting the patient's right to know about the disease and choose the treatment process is also ethically challenging.

In 1997, Ruth Chadwick, a philosopher of applied ethics, along with two others, presented a new definition of the principle of informed consent in genetic testing in a book titled *The Right to Know and the Right Not to Know in Defense of Privacy in Genetic Research*, which could also be useful in the above challenge. Considering both positive and negative dimensions, he defined informed consent in the positive dimension as meaning that patients should be fully informed about the process and possible harms in the implementation of treatment methods and health tests and participate in these tests with complete

satisfaction, but consent in the negative sense means that volunteers have the right to be unaware of some of their own and others' genetic information [11]. This division is important because the patient's right to free access to health information and treatment methods in all circumstances should not be viewed only in a positive sense, but rather the patient has the right not to know things; information that is harmful to him and that he will blame others if he learns about it.

Considering what has been said, it seems that a general ruling cannot be issued in the face of the above challenge, and it is better to examine the conditions in each case and make a decision.

Some conditions can be suggested for informing the patient about his health status and treatment method:

- If the patient requests it, accurate and correct information should be provided to him, especially if he is in the final stages of life.
- Accurate and correct information about the disease should be given in accordance with the patient's level of culture, education, and awareness.
- An appropriate time should be chosen to provide information about the disease and only as much as is necessary for the patient to know.
- If providing information based on the doctor's diagnosis causes stress and acute psychological problems, this should be avoided.
- If the patient does not request it or there is a strong possibility of harming him, the patient's family and companions should be informed.

3. Hospitalization and mandatory quarantine

Another measure that seems absolutely necessary and justified in epidemic conditions is the hospitalization of patients with infectious

diseases and individual and group quarantine during the outbreak in order to prevent the development of the disease cycle. Regarding the latter issue, it can also be said that public health ethics require the health system to take any action that it deems useful to save the lives of individuals. However, this principal conflicts with another principle of the medical profession's code of ethics regarding obtaining patient consent for any medical intervention.

At first glance, in times of conflict between public health and the wishes of individuals, public health will take precedence over the wishes and desires of individuals and the action of quarantine or mandatory hospitalization will have the necessary moral justification. As stated in the Guide to Managing Ethical Issues in Outbreaks of Communicable Diseases published by the World Health Organization in 2016, in the section on restrictions on freedom and movement as a result of quarantine.

Restrictions on freedom of choice and movement include measures such as isolation, quarantine, travel advisories, school closures, and the cancellation of gatherings to reduce public contact. These measures can play an important role in controlling the spread of infectious diseases and, in such circumstances, are justified by the moral principle of caring for the health and well-being of the community [12].

The above view is justified on the basis of the principles of ethical schools that consider public benefit and benefit as the criterion of moral value, but some liberal tendencies in ethics reject any moral argument based on the norm of social happiness and consider what others recognize as collective happiness and well-being to be a function of individual will and will. From the perspective of those who defend this tendency, the use of coercive power of the state to limit individual freedoms during a pandemic, although it may ensure the health of the community, undermines the foundation of public trust and

participation [13]. Therefore, some health institutions in some countries advise doctors that although measures such as isolation and quarantine of individuals are inevitable in epidemic conditions, the independence and autonomy of patients must also be respected. For example, in 2006, the American Medical Association (AMA) prepared comprehensive guidelines and recommended the following to doctors for cooperation with health authorities in epidemic conditions:

- Use scientifically sound methods to identify public health risks;
- Avoid arbitrary and arbitrary isolation and quarantine of local, ethnic, and social groups;
- Educate patients on the importance of adhering to public health measures;
- Support mandatory quarantine of patients who do not adhere to public health measures [14].

The above guidelines suggest a soft and cautious approach to mandatory quarantine in order to minimize violations of patient autonomy and potential harm to public trust. Quarantine should be based on a thorough scientific assessment of the risks and harms involved, and quarantine should not be imposed on small social groups such as ethnic and local communities without a scientific assessment, as this would lead to misunderstandings and damage to the trust of these groups in the government and the health system.

It seems that the above method is a suitable way for the health system to fulfill its mission in the field of public health and for the medical staff to act within the boundaries of professional ethics. The important point is to avoid any arbitrary action that lacks scientific support and is based on personal estimates in imposing quarantine or compulsory hospitalization, which will damage public trust and cause problems for the health system in another dimension.

Therefore, it is essential to educate the public about the necessity of these measures to combat the spread and epidemic of a disease before imposing compulsory hospitalization or quarantine, and any action should be based on scientific and confirmed research on the effectiveness of these measures.

4. Inconclusive tests on patients

Another important and necessary measure during the outbreak of widespread diseases is the comprehensive effort of the health system to find ways to prevent and treat. Under normal circumstances, obtaining treatment methods, including the discovery of drugs and vaccines, must go through certain stages before they can be used on a large and public level. Given the dangerous nature of these tests and the possible risks, obtaining the consent of the test subjects has always been an important ethical requirement in the course of these tests. However, in epidemic conditions of the disease and in conditions where accelerating the access to vaccines and drugs becomes a public demand, researchers are looking for ways to shorten the path, which may harm the informed consent of the test subjects, which gives rise to another ethical challenge.

To overcome the above challenge, two ways have been proposed so that while obtaining the consent of the test subjects, researchers can proceed with research projects more quickly; one is testing on volunteer cases and the other is testing on patients who are in the final stages of life.

A) Testing on volunteer patients

In a 2020 article on the ethics of accepting volunteers for research trials on Covid-19, renowned ethical philosopher Peter Singer argued, citing the principle of “balance of risk,” that it is morally permissible in circumstances that imposing a potential risk on a group of individuals (those who are willing to participate in trials to find a cure for Covid-19 with full knowledge of the potential risks) can prevent

widespread harm to the entire population [15]. Citing this principle, he argues that it is morally permissible to ignore the steps that medical trials must take to test on human samples in pandemic conditions, such as testing treatments on animal samples before testing on humans. This article states that while in the current situation, according to the statistics provided, more than 14,000 people from 100 countries are volunteering to receive the Covid-19 vaccine, if these people are fully aware of the possible risks of injecting this vaccine and, despite this, are willing to help defeat the coronavirus by participating in these studies, there are strong ethical reasons that their request can be openly accepted [15].

The people on whom Peter Singer considers conducting therapeutic trials on pandemic diseases and Covid-19 despite the possible ethical risks are volunteers who have fully informed and consented to these trials, including receiving the vaccine. However, in the absence of these people or in the impossibility or time-consuming of obtaining informed consent, can these trials be conducted on other human samples? In response to another group of patients, it has been suggested that conducting trials even without obtaining their detailed consent can be ethically permissible, and these are patients who are in the final stages of life.

B) Testing on patients near death

The issue of conducting non-conclusive medical tests on patients who are in the final stages of life is one of the most challenging issues in the ethics of the medical profession. Even when the patient consents to these tests and tests of treatments and drugs, some believe that the element of informed consent is still not obtained. In their opinion, the concomitant disease places great psychological pressure on the patient, and when an individual sees his life in danger and threatened by a disease, he sees little choice regarding treatment [16]. The use of these individuals in studies known as

randomized controlled trials (RCTs) has also been criticized for misinterpreting their autonomy and informed consent, and rejecting the argument that ensuring the autonomy of patients nearing death in such studies has been stated:

Such studies do not leave the least effective choice for patients who are about to die, because these trials prevent patients from being able to choose the experimental treatment method that is applied to them with their own will and discretion [17].

In response to this view, some critics have tried to analyze the concept of informed consent and not consider the limitation of choice options due to being in an emergency situation to be inconsistent with informed consent. If a person was forced to choose a method and procedure without any external pressure or coercion and only due to external requirements and conditions, it cannot be said that he lacked the freedom to choose that method [18]. In fact, a distinction should be made between coercion and urgency. A patient who sees no other way than to submit to a drug test, vaccine, or any other uncertain test for his possible salvation cannot be considered a forced person and lacking informed consent. This person has also in fact made a choice, although his choice was made under difficult circumstances.

The analysis of informed consent of patients close to death in the above articles does not refer to the epidemic conditions of the disease. In these conditions, another principle also prescribes the non-profit performance of inconclusive tests on patients, and that is to save the lives of the people in the community. As Peter Singer points out, the more we delay in understanding the coronavirus disease and how to deal with it, the more lives this disease will take. Therefore, the principle of public benefit, which in previous cases was also a determining principle for determining ethical

behavior when a challenge arises, can be used here as well.

Finally, it can be said that in order to advance research projects in order to find preventive and therapeutic methods while respecting the fundamental right of the patient to voluntarily participate in research experiments, volunteers as well as patients who are in the final stages of life can be used.

5. Informing the family about a member's illness

Due to the contagious nature of widespread diseases and the severity of transmission of the disease to relatives, it is essential that people who have been in contact with the patient also refer to medical centers for testing and other necessary measures, in order to protect their own lives and prevent the development of the disease cycle. This issue prompts the medical staff and the health system to inform their relatives and family if a person is definitely diagnosed with the disease and ask them to refer to medical centers for testing. However, given the society's misconception about such diseases and the limitations and problems that may arise in family and social relationships for the patient even after recovery, some patients are not willing or willing to provide information. Here, another challenge facing the health system becomes apparent, and finding a solution requires evaluation.

The above challenge was also visible during the spread of HIV/AIDS in 2018. According to statistics provided by the United Nations, nearly 38 million people were infected with this disease and 770,000 people lost their lives [19, 20]. Given the negative perception and perception of society towards people with AIDS, one of the important ethical challenges facing the health system at that time was the principle of confidentiality. Given the traditional and common perception of people about AIDS, patients were reluctant to disclose their disease. On the other hand, due to the important role of information about individuals'

diseases in preventing and stopping the spread of this disease, the need to clearly explain the exceptions to the principle of confidentiality regarding the disclosure of patient information gained more support [21]. It can be said that the challenge of confidentiality will manifest itself in a less subtle way in the situation of the spread of other widespread diseases such as COVID-19; because the negative perception of society towards COVID-19 patients is far less than that of HIV patients, and therefore Corona patients are less inclined to keep information about their disease secret and not disclose it, and this will lighten the responsibility of health activists; However, the essence of this challenge still exists. To overcome the above challenge, perhaps the first and most important step that can be taken is to talk to the patient and inform him/her about the consequences of keeping his/her health status confidential.

Of course, in epidemic conditions, health officials can, in order to expedite the process, assess the conditions and prepare and compile a single regulation regarding the disclosure of information about the patient's illness and informing the family and those who have been in contact with him/her for testing and other diagnostic and treatment steps, and notify hospitals and medical staff to expedite the process of controlling the disease.

CONCLUSION

Being in a situation where a disease is widespread places the health system in a dilemma between fulfilling its professional responsibility to protect public health and committing to professional ethics and upholding the patient's charter of rights. Among the fundamental rights of patients is freedom and autonomy in choosing the method of treatment and, in general, the right to choose in all interventions of the health system, which in a way relate to the patient. Although violating this principle and crossing the

boundaries of professional ethics to protect public health in a situation where a disease is widespread seems morally justified, such measures should be taken with full caution, specifying restrictions, weighing the conditions, and evaluating their effectiveness based on the results of scientific research. Ignoring this issue and violating the principle of patient autonomy without the necessary scientific support, apart from being an action that goes against the ethical commitments of health activists, will seriously damage public trust and the social capital of the health institution and will seriously endanger the overall policy of patient-centered care, which plays an important role in attracting public participation in achieving health goals.

ETHICAL CONSIDERATIONS

Ethical issues (such as plagiarism, conscious satisfaction, misleading, making and or forging data, publishing or sending to two places, redundancy and etc.) have been fully considered by the writers.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interests.

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