



Violation of the Ethical Principle of Patient Autonomy in Pandemics

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Abstract

Introduction: Independence or autonomy is one of the fundamental rights of patients, which must be observed by health activists in all medical interventions and diagnostic and treatment measures. Considering the importance of patient autonomy in the field of health, the present study examines the violation of this ethical principle during pandemics.

Material and Methods: The present study is a review study in which the researcher examined the articles related to the keywords of the present study that were published in Google Scholar, PubMed, Science Direct and Springer databases from 2015 to 2023.

Conclusion: In the conditions of spread of the disease, the health system is forced to violate the principle of patients' autonomy in order to fulfill its moral and legal duty in protecting the health of the society. Although it seems that violating the principle of respecting the patient's right to autonomy in the conditions of spreading the disease is morally justified. However, completely ignoring this right and arbitrarily restricting it without citing sufficient evidence, in addition to violating the basic rights of the patient, has also damaged the public trust and social capital of the health system. And this institution will face problems in achieving its big goals and attracting people's participation.

Keywords: *Ethics, Patient autonomy, Patients' bill of rights, Pandemic*

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INTRODUCTION

One of the important principles in the health system is paying attention to the rights of the patient and trying to protect these rights by policy makers and health activists in all medical and health centers. In the meantime, one of the basic rights of patients, which is specified in the charter of patients' rights and is recommended to be protected in the code of ethics of the medical profession, is the patient's right to independence or autonomy. In all phases of diagnosis and treatment, health activists and medical staff

should consider the patient's freedom and freedom and refrain from taking any action without the patient's knowledge and consent. Considering the importance of patient autonomy in the field of health, the present study examines the violation of this ethical principle during pandemics.

MATERIAL AND METHODS

The present study is a review study in which the researcher examined the articles related to the keywords of the present study that were

published in Google Scholar, PubMed, Science Direct and Springer databases from 2015 to 2023.

DISCUSSION

The patient's legal charter

Currently, the most important document and system of medical ethics in the health system of any country is the patient's legal charter. Different countries prepare patients' rights charters and provide them to the health staff in order to protect the principles of medical ethics. Examples of these charters are: the rights of the patient according to the American Civil Liberties Union (22 articles), the charter of the World Medical Association (30 articles), the patient's rights charter in South Africa (13 articles), the patient's rights charter in Japan (11 articles)), Patient's Rights Charter in Europe (19 articles), Patient's Rights Charter in Canada (14 articles), Patient's Rights Charter in England (21 articles), Patient's Rights Charter in the European Union (Netherlands, Germany, Sweden, England and Australia) (25 articles) and...

In all these charters, the following 10 principles are presented in various ways in the charters of patient rights:

1. Justice and the right to receive appropriate and high-quality care and treatment, without any discrimination;
2. The right to have health-treatment information related to his illness;
3. The right to confidentiality of patient's health-treatment information and the confidentiality of health and medical service providers;
4. The right to declare informed consent for any health-therapeutic intervention;
5. Autonomy
6. the right to vote independently and make decisions about the type of healthcare services;
7. The right to respect the private environment of the hospital
8. The right to peace;
9. The right to protest and complain;

10. The right to compensation.

Autonomy and the right to choose

One of the fundamental human rights is the right to freedom and choice between different options. Every human being has this right because of being human, and no one can take away this right from any human being by cruelty and force him to do something.

The right to freedom is 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 [1]. Examining the definitions of freedom presented in the political and sociological literature mostly refers to the concept of this word in human relations and social relations. For example, Montesquieu, the theorist of French political philosophy, has limited freedom in the two areas of relationship with the people and relationship with the government in the book "The Spirit of Laws". And he considers freedom in relation to the government to mean that a person has the right to do whatever the law allows and not to be forced to do whatever the law does not prohibit, and in relation to the people, he considers freedom to mean a sense of security [2]. However, since bioethical issues refer to the protection of basic 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.

In the philosophical approach, freedom is the same option or the right to choose that everyone intuitively finds within themselves. Humans have the will and the power to choose and make decisions in their actions. This is the same choice and freedom that is opposed to philosophical determinism. Contrary to this prior approach, Kant believed that the only way to prove freedom in humans is through the latter through ethics and practical reason. According to his opinion,

the existence of moral principles leads us to the direction that we should consider human beings as independent and free beings; Because without this presupposition, the existence of any moral obligation will be fruitless. The presupposition of every moral instruction and recommendation is that a person is free and has the authority to do or leave an action [3]. In medical ethics, the right to freedom as a natural right plays an important role in the decisions of treatment and diagnosis methods, and the need to respect it sometimes limits the methods used in the treatment of patients. In this field, freedom means that "every sane and mature person has the right to determine what is going to be done with his body, and surgery that is performed without the patient's informed consent has wronged him" [4].

Violation of the principle of patient autonomy in pandemics

During pandemics, sometimes the moral principle of autonomy is in conflict with the principle of trying to ensure public health. Some of these challenges are:

1) Meeting with family and relatives

One of the patient's rights is the possibility of meeting the patient with his family and relatives, and the medical staff is responsible for providing him with this opportunity. This issue becomes more necessary in the case of patients who are at the end of life. In the epidemic conditions of fatal diseases, such as Covid-19, we see a large number of patients hospitalized, especially in special departments of the hospital, and due to the lack of definitive treatment, the hope for them to 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 the companions. In addition, this presence will cause the development of the

disease cycle in the society. In such cases, medical ethics and public health ethics collide with each other in practice and pose a moral challenge.

Although the presence of the family of a patient with an infectious disease in the hospital is associated with risks, it is necessary to find safe and cared for ways to meet the patient with the family. Although the principle of maintaining public health can limit the patient's right to visit, especially in the last hours of life, in the conditions of spread of the disease, thinking of measures to make the visit safe can provide people's satisfaction and make the patients and their relatives more confident about the concern of the medical staff regarding the individual rights of the patients, it will also be effective from the perspective of the patients' health and recovery process. For this purpose, it is possible to consider isolated and controlled places in the hospital so that the relatives of the patient can meet the patient in accordance with all the safety and health measures and even behind the glass and during specified hours.

2) Information about the exact state of health and how to treat it

Another action that seems necessary in the conditions of spreading a dangerous and fatal disease and challenges one of the main rights of the patient is the refusal to accurately convey the health status to the patient. Since finding out about the progress of the disease, especially fatal diseases, may cause severe stress to the patient and reduce the body's resistance to the disease, the medical staff sometimes prefer to choose and act on the treatment method without the patient's knowledge and consent. In these cases, it is morally challenging to limit the patient's right to know about the disease and choose the treatment process.

In 1997, Ruth Chadwick, a philosopher of applied ethics, along with two others, in a book entitled *The Right to Know and the Right Not to Protect Privacy in Genetic Research*, presented a new

definition of the principle of informed consent that can also be useful in the above challenge. By considering two positive and negative dimensions, he considered conscious satisfaction in the positive dimension to mean that patients should be fully informed about the work process and possible injuries in the implementation of treatment methods and health tests. and participate in these tests with full satisfaction, but negative satisfaction means that the volunteers have the right to be unaware of some genetic information of themselves and others [5]. This division is important because the patient's right to freely access health information and how to treat in all conditions should not be seen only in a positive sense, but the patient has the right not to know things; Information that is harmful to him and if he is informed by others, he will blame him.

Based on what has been said, it seems that in the face of the above challenge, it is not possible to issue a general ruling, and it is better to examine the conditions in each case and make a decision. And it is possible to suggest conditions to inform the patient about his health condition and treatment method:

- In case of patient's request, accurate and correct information should be provided to him, especially if he is at the end of his life.
- Accurate and correct disease information should be given according to the level of culture, education and knowledge of the patients.
- Choose the right time to give the information about the disease and only as much as it is necessary for the patient to know.
- Avoid this work if, according to the doctor's diagnosis, giving information causes stress and acute psychological problems.
- If the patient does not request or there is a strong possibility of harming him, the patient's family and companions should be informed.

3) Compulsory hospitalization and quarantine

Another measure that seems absolutely necessary and justified in the epidemic conditions of the disease is hospitalization of patients with contagious diseases and individual and group quarantine during the outbreak of the disease in order to prevent the development of the disease cycle. In the case of the latter issue, it can be said that public health ethics requires the health system to take any action it deems useful to save people's lives. However, this principal conflicts with another principle of the ethical charter of the medical profession in obtaining the patient's consent in any medical intervention.

At first sight, in the time of conflict between public health and people's wishes, public health will take precedence over people's wishes and wishes, and the act of quarantine or compulsory hospitalization will have the necessary justification from the moral point of view. As stated in the guide for the management of ethical issues in the outbreak of infectious 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, closing schools and canceling gatherings to reduce people's contact. These measures can play an important role in controlling the spread of infectious diseases, and in such cases, these measures are justified by the moral principle of caring for the health and well-being of society [6].

The above point of view is justified based on the principles of ethical schools that consider profit and public benefit as a measure of moral value, but some liberal trends in ethics reject any moral argument based on the norm of society's happiness. And what others know as collective happiness and well-being, they consider as a function of individual will. From the point of

view of people who defend this trend, using the coercive power of the government to limit individual freedoms during the outbreak of widespread diseases, although it may ensure the health of the society, but it destroys the foundation of trust and public participation [7]. Therefore, some health institutions in some countries advise doctors that in epidemic conditions, although measures such as isolating and quarantining people are unavoidable, the independence and autonomy of patients should also be respected. For example, the American Medical Association (AMA) in 2006 [8] by preparing a comprehensive guide, recommended the following to doctors to cooperate with health officials in epidemic conditions:

- Use valid scientific methods to identify risks that threaten public health;
- Avoid arbitrary and arbitrary action in isolating and quarantining local, ethnic and social groups;
- Patients should be educated about the importance of following public health measures;
- Support mandatory quarantine of patients who do not comply with public health measures.

In the above recipe, a soft and cautious move to impose mandatory quarantine can be seen in order to minimize the violation of the principle of patient autonomy and reduce possible damage to public trust. Quarantine must first be applied on the basis of a detailed scientific assessment of existing risks and harms, and quarantine should not be applied to micro-social groups such as ethnic and local communities without a scientific assessment; Because such a thing will cause misunderstandings and damage the trust of these groups towards the government and the health system.

It seems that the above method is a suitable solution for the health system to fulfill its mission in the field of public health and the movement of

medical staff within the framework of professional ethics. The important point is to avoid any arbitrary action without scientific support and based on personal estimates in applying quarantine or compulsory hospitalization, which affects public trust and causes problems in the health system.

4) *Inconclusive tests on patients*

Another important and necessary action during the outbreak of widespread diseases is the all-out effort of the health system to find ways of prevention and treatment. In normal conditions, obtaining treatment methods, including the discovery of drugs and vaccines, must go through certain steps so that they can be used on a wide and general level. Due to the dangerous nature of these tests and the possible risks, obtaining the consent of the tested subjects has been one of the most important ethical requirements in the course of these tests. However, in the epidemic conditions of the disease and in the conditions where the acceleration of obtaining vaccines and drugs becomes a public demand, researchers are looking for ways that shorten the path, and this may harm the informed consent of the tested subjects. And this issue causes another ethical challenge.

In order to get out of the above challenge, two ways have been proposed so that while studying the satisfaction of the tested subjects, the researchers can advance the research projects more quickly; One test on volunteer cases and the other test on patients who are in the final stages of life:

- A. Experiments on patient volunteers: In a 2020 article, Peter Singer argued about the ethics of accepting volunteers' requests for research experiments on Covid-19, citing the principle of "balance of risk"; In cases where it is possible to impose a possible risk on a group of people (those who are willing to participate in tests for the treatment of Covid-19 with full knowledge of the possible risks), widespread

harm to all people can be prevented, this is morally permissible [9]. Referring to this principle, he considers it permissible to ignore the steps that medical experiments must go through to test on human samples in the conditions of a disease pandemic; Such as testing treatment methods on animal samples before testing them on humans. It is stated in this article; If these people are fully aware of the possible risks of injecting this vaccine, and despite this, they are willing to help defeat Corona by participating in these researches, there are strong moral arguments that can be openly requested [9]. The people whom Peter Singer considers conducting medical tests regarding widespread diseases and Covid-19 on them despite possible moral risks, are volunteers who have taken part in these tests with full knowledge and consent, including receiving the vaccine. But in the absence of these people or the impossibility or time-consuming of obtaining informed consent, can these experiments be performed on other human samples? In response to another group of patients, it has been suggested that conducting tests even without obtaining their detailed consent can be ethically permissible, and those are patients who are in the final stages of life.

- B. Experiments on patients close to death: the issue of conducting inconclusive medical experiments on patients who are at the end of life is one of the challenging issues in the ethics of the medical profession. Even when the patient consents to these tests and tests of treatment methods and pharmaceuticals, some believe that the element of informed consent is not studied. According to him, the accompanying disease puts a lot of psychological pressure on the patient, and when a person sees his life in danger and threat due to a disease, he sees little choice regarding the treatment in front of him [10].

The use of these people in studies known as Randomized Controlled Trials (RTC) has also been criticized due to the misinterpretation of the autonomy and conscious satisfaction of these people, and it has been said by rejecting the argument to ensure the autonomy of patients near death in such studies:

Such researches on patients that lead to death do not leave the least effective choice for him, because these tests prevent patients from being able to choose the experimental treatment method that is applied to them with their own free will [11]. In response to this view, some critics have tried to analyze the concept of conscious satisfaction, not to consider the limitation of choices due to being in an emergency situation as contrary to conscious satisfaction. If a person was forced to choose a method without any external pressure and external constraints and only due to external conditions, it cannot be said that he had no choice in choosing that method [12]. In fact, there should be a difference between predestination and emergency. A patient who sees no other way than to submit to a drug test, vaccine or any other inconclusive test for his possible salvation cannot be considered a forced person and lacks informed consent. This person has actually made a choice, although his choice was made under difficult conditions. The analysis made in the above articles regarding the informed satisfaction of patients near death does not refer to the epidemic conditions of the disease. In these conditions, another principle prescribes the non-profit making of inconclusive tests on the patient, and that is to save the lives of people in the society. As Peter Singer points out, the more we delay in recognizing the corona disease and how to deal with it, the more people will be killed by this disease [9]. Therefore, the principle of public benefit, which was a determining principle in the previous cases to determine moral 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 patient's basic right to voluntarily participate in research experiments, it is possible to use volunteers as well as patients who are at the end of life.

5) Notifying the family of a member's illness

Due to the contagious nature of widespread diseases and the severity of disease transmission to relatives, it is necessary for people who have been in contact with the patient to go to medical centers for testing in order to prevent the development of the disease cycle while saving their lives. This issue prompts the medical staff and the health system to inform their relatives and family and ask them to go to the medical center for testing. However, due to the society's misconceptions about such diseases and the limitations and problems that may arise in family and social relations for the patient even after recovery, some patients do not have the desire and satisfaction to inform. Here, another challenge facing the health system is revealed, and finding a solution requires evaluation.

The above challenge was visible when the spread of AIDS (HIV/AIDS) in 2018. According to the statistics provided by the United Nations, nearly 38 million people were infected with this disease and 770 thousand people lost their lives [13]. Due to the society's perception and negative perception towards AIDS patients, one of the important ethical challenges facing the health system at that time was the principle of confidentiality. According to the traditional and common perception of people about AIDS, patients did not want to disclose their disease. On the other hand, due to the important role of people's disease information in the prevention and prevention of the spread of this disease, the necessity of detailing the exceptions to the confidentiality principle against the disclosure of patient information attracted more support [14].

It can be said that the challenge of secrecy in the situation of the spread of other widespread diseases such as Covid-19 shows itself in a less colorful way; Because the negative perception of the society towards the patients of Covid-19 is far less than that of the HIV patients, and therefore, the corona patients have less desire to keep the information of the disease secret and not disclose it, and this issue will make the responsibility of the health activists lighter; Although the essence of this challenge still exists.

To overcome the above challenge, perhaps the first and most important action that can be taken is to talk with the patient and make him aware of the consequences of keeping his health condition confidential.

CONCLUSION

Being in the conditions of spreading a disease puts the health system in two ways of performing professional responsibility in protecting public health and committing to professional ethics and upholding the charter of patient's rights. Among the fundamental rights of patients is freedom and autonomy in choosing the treatment method and in general the right to choose in all the interventions of the health system, which is somehow related to the patient. Although violating this principle and crossing the boundaries of professional ethics in order to preserve public health in the conditions of widespread disease seems morally justified, but such actions should be done with full caution and evaluation of effectiveness based on the results of scientific research. Failure to pay attention to this issue and the maximum violation of the principle of patient autonomy without the necessary scientific support, apart from the fact that it is an action against the moral obligations of health activists, has caused serious damage to the public trust and social capital of the health institution and the general policy of patient-centered care, which plays an important role in attracting public

participation in the realization of health goals, will face a serious risk.

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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