

Autonomy and Informed Consent in the Context of a Pandemic

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Abstract: *In this article we discuss respect for autonomy as a bioethical principle correlated with the idea of informed consent. We situate this in the context of challenges related to emergencies such as the coronavirus pandemic we are currently experiencing, which has affected all of humanity. It is important to emphasize that autonomy is a key to modernity, a perspective on the world that is in fact one of the constitutive values of modern society. Autonomy is given by the fact that we are human beings, but not all human beings have the same degree of autonomy.*

Keywords: *autonomy; informed consent; pandemic; bioethics.*

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Introduction

Respect for autonomy, as it appears in the Kantian tradition (Kant, 2007; 2010), is based on our confidence that the individual can decide for themselves in a political, ethical, and cognitive sense. Of course, in this context we are talking about situations of autonomy in which the individual manifests him or herself as autonomous.

From a bioethical perspective, we can speak of decisional autonomy (Sandu, 2011) or the individual's ability to make decisions regarding their state of health and their general existence. Of course, there are people who have limited autonomy. However, this decisional autonomy, based on reason, informed consent, and the presumption of the capacity to consent, can also be thought of as expressive autonomy. This refers to the individual's ability to express himself (Caras & Sandu, 2014). We do not have the inner capacity to express our will in every situation – it depends on our psychological frame of mind, various anxieties, inner states, fears, and so on - and the ability to express our ideas. For example, in medical situations, patients may prefer a certain treatment or, conversely, wish to give it up, but in expressing autonomy the patient takes into account the opinions of others, especially those close to them. When making a health-related decision, patients often say, "My decision will affect my family's situation." For instance, the decision to undergo a particularly expensive treatment will place the family in a situation of financial risk. Thus, when manifesting decision-making autonomy, the patient takes into account not only their rational understanding of the situation, but also the emotional situation, in which their level of emotional load limits their ability to express their consent or opinion regarding desirable or undesirable situations. Furthermore, not all categories of people have a high level of awareness on their condition. People affected by certain mental pathologies and those who are elderly may have a limited level of autonomy due to their reduced ability to understand their situation. Children also have a limited ability in this regard and, as such, decisions concerning them should be made by close relatives or legal guardians, who express delegated consent.

Autonomy is a concrete and practical expression of the idea of freedom. As long as I am a free being who can decide for oneself, I must express this freedom through my ability to make my own choices. If freedom is a philosophical, legal, and metaphysical foundation, autonomy is the concrete expression of the idea of freedom, of the idea of a decision, because having freedom is a potential situation; it signifies my potential to decide. Autonomy is precisely the effective expression of this freedom to

decide with respect to my own situation or, in the case of delegated consent, to decide on behalf of those I care for, be they children, elderly, or people unable to decide due to certain mental limitations (Funză, & Sandu, 2017).

Autonomy must be concretely expressed and this raises the issue of what we in bioethics call *informed consent*. An autonomous decision must be correctly communicated to the decision makers, the therapist, the doctor, the one who performs an experiment etc., because a decision left unexpressed does not always have consequences, or has consequences related to following or not following a treatment, that are direct expressions of autonomy.

In order for consent to be informed and for the autonomy of the consenting person to be respected, therapists must ensure that they have provided that person with the information necessary to be able to make the decision, and have done so in a language that the person understands. It is fruitless for the therapist to express himself very briefly or at length if this is couched in terms the patient does not understand and is thus unable to make an informed decision. Indeed, one limitation of consent concerns the patient's ability to understand, hence the importance of educating the person whose consent is required. It is important for the therapist to give explanations about the patient's condition and treatment on a level they can comprehend. The therapist must ensure, through dialogue with the patient, that they have understood the situation they are in, and that the decision they have taken is a result of conscious and rational deliberation regarding their health condition, the risks to which they are subjected, and potential developments in their health.

There are two ways in which informed consent is generally understood. The first, the correct one from a bioethical point of view, starts with Beauchamp and Childress's (2001) understanding that obtaining informed consent is a process that continues from the moment a person is consulted and a diagnosis is made, when he/she is presented with an analysis of his/her condition, to the point when they agree with the therapeutic act. We are talking about informed consent not only in the medical field, but also in areas such as psychology, social work, nutrition or physical therapy. In each of these cases, the therapist must ensure that communication is real and effective, not superficial and vitiated by various forms of incorrect communication. Careful attention must be paid to doctor-patient communication in the process of obtaining informed consent (Gavrilovici & Oprea 2013).

1. Informed consent as a process

The trust we have in the therapist fundamentally influences our autonomy because, if we trust that the person who provides us with information does so in good faith and with a high degree of professionalism, then we are able to make an easier decision or a more informed one, one that is closer to what we really want. Of equal importance in the process of obtaining informed consent is the stage in which the patient reflects on their situation in accordance with their level of knowledge and understanding.

The decision-making process regarding health is complex because rational factors intervene. However, informed consent is an act that also involves emotional, or affective, spiritual factors. All the considerations made by the individual when deciding on their own state of health that influence them constitute, in the end, the limits of their own freedom and expressive autonomy.

Expressive autonomy often refers to relational elements, which lead on to another form of autonomy, *relational autonomy*. In this respect we are referring to trust in the doctor-patient relationship and how this trust influences decisions. A social entourage exists that is important to us. There is a scale of social distances, important in terms of the trust we have in people and, accordingly, the importance they have for us and for our decision-making process. There are situations when we have more trust in people who have demonstrated competence, hence the different levels of trust in doctors, teachers or other professional categories.

Returning to bioethics in the scenario of a pandemic, we emphasize the special role of family doctors during this period, of the medical staff who have direct connections with the patient. Direct and trusting relationships between physician and patient can be of particular importance in combating the impact of rumors that affect trust in public institutions.

The Church and the messages it sends to the believers can play an extremely important role in these times. If the Church acts responsibly and sends messages of respect for security measures, of trust in state institutions, then believers will tend to place greater emphasis on those messages.

In my opinion, it is important that in these situations we bring into discussion the idea of bioethics in extreme situations in order to understand how we can make decisions and what are the best decisions to make; to understand the ethical, social, and medical reasons that led to a series of decisions and how we can react to them. Thus, ethics is both a science and a philosophy. Accordingly, there are philosophical and scientific models that

allow us to live ethically and morally, and there are ethical values such as respect, solidarity, responsibility, and autonomy that must be learned, primarily in bioethics and medical ethics courses along with notions of patients' rights and associated health legislation.

It is important to talk about the ethics of emergencies from several perspectives. The first of these is related to respect for autonomy and the practice of obtaining informed consent (Frunză & Sandu, 2017), specifically regarding alteration of the limits of autonomy (Gavrilovici & Oprea, 2013) in such situations.

2. Autonomy in stressful contexts

Stress can be as destructive, or sometimes more destructive, than the virus, without minimizing the risks that such diseases can pose to human health given that thousands of people have already lost their lives. It is a serious mistake to minimize the risks and not follow the instructions on hygiene, travel, limiting unnecessary travel, and restricting one's autonomy. The approach proposed by the WHO and accepted by most governments was the drastic limitation of contact between infected people, including potentially infected people, and the rest of the population. This reduces the risk of transmitting the disease by asymptomatic infected people.

Because there are people who have contracted the virus but do not show symptoms, social distancing measures should be as broad as possible, addressing first people who enter the country from places where there have been outbreaks and then, ideally, the entire population. A complete cessation of all activities is, however, impossible; public order, health services, the supply of food, medicine, and other products of strict necessity must be ensured. Therefore, blocking the transmission of the virus through complete isolation is simply not possible. Transmission of the virus can only be slowed, not annihilated.

Another perspective on stopping the pandemic is that most people will develop immunity. This happens when they have been infected with or are vaccinated against the virus. In the absence of a vaccine, health policies in some states have been based on what is called *herd immunity* (Regalado, 2020; Iftikhar, 2020) which, until recently, has formed the basis for health policies in the UK and the Netherlands. Given the virulence rate, it has been calculated that between 60% and 70% of the population need to be infected (O'Grady, 2020; Boseley, 2020) to stop the epidemic. Infected people, once recovered, are assumed to develop immunity. It has also been found that most people who contract the virus either manifest symptoms that are not

very severe or develop no symptoms at all (INSP, 2020, April 3; Rothe et al., 2020).

If a large number of people who have been infected and subsequently developed immunity is reached, transmission becomes impossible and the pandemic practically stops. Of course, there will be isolated cases, even the return of symptoms when immunity is still low, but we can no longer speak of a pandemic. However, such an approach is risky as it involves allowing a high number of deaths. As a compensatory measure, states that apply the concept of herd immunity should also ensure the complete isolation of people at increased risk of developing an aggressive form of this disease. Those most at risk of death from Coronavirus infection are generally the elderly and people with associated comorbidities - diabetes, neoplasm, high blood pressure, cardiovascular disease, and so on (***, 2020, April, 4; Guan et al., 2020). Some models of the pandemic response focus on the idea of isolating such high-risk people very carefully, while leaving other people free to develop immunity by subjecting them more aggressively to the risk of illness so that they acquire herd immunity as soon as possible. This would eventually allow even people at higher risk to return to a normal life (Kluge, 2020).

However, using quarantine to prevent infection cannot be the only measure employed, it must be accompanied by large-scale testing to identify as many people as possible who carry the virus, albeit within existing health resources. This involves conducting epidemiological surveys that identify who has had contact with those infected, and who then should be more drastically isolated than the rest of the population. This policy consists of taking specific measures of isolation and self-isolation at home, i.e., limiting contacts and socially isolating people. This is termed social distancing and aims to avoid peaks of the epidemic that will exceed the capacity of health care systems to provide care to people with more severe forms of the illness who need mechanical ventilation or other forms of support. Such people are also problematic because they put medical staff working directly with patients at risk of infection.

This health policy, which Romania also applies, aims to extend the period in which people will develop natural immunity and contract the virus, and thus enables the health system to theoretically deal with serious illnesses that require hospital care, as opposed to people who develop a mild form of the disease and can be cared for and isolated at home, which will prevent further transmission of the virus and enable them to recover.

The stressful situation this pandemic invokes is caused not only by the fear of illness but by the alarmist news (Schulman & Siman-Tov, 2020; Tasnim, Hossain & Mazumder, 2020) that are circulating which create uncertainty and confusion in terms of knowing what to think about infection, what the mortality rate is, what risks we all face, and what the real dangers are. Stress is inevitable because. Suddenly we became aware of the imminence of death, the fact that there is an immediate and conscious risk.

The imminence of death therefore exists but it becomes increasingly salient in pandemic situations and then, inevitably, the perception of fatality, that we are in immediate danger, affects us, it concerns those close to us and, in the opinion of many, it is somewhat inevitable that we will become sick, even though this can be avoided by applying very strict self-isolation measures. Sudden awareness of the risks makes us vulnerable and thus puts us in a stressful situation.

Beyond the stress generated by this threat, this anguish of death – which philosophers have spoken about at least since Heidegger (2002), but also before, as philosophy was thought, among other things, to be a preparation for death - has been an object of study, of philosophizing, that has been important for a multitude of thinkers. We are also experiencing a lifestyle anxiety. We are accustomed to having an active, social lifestyle in which we meet each other, and suddenly we have to distance ourselves, to remain (self)isolated as much as possible at home. The stress of limiting daily activities, of limiting social relations, to occasional short meetings or virtual meetings, is accentuated by an awareness of the lack of meetings with others, especially in the current context where most public meeting places are visibly closed. On top of these concerns people are having to face the specter of unemployment, sometimes immediate, because many companies are in a perilous financial situation and even entire industries, such as the book industry and cultural institutions, are at risk of immediate bankruptcy. Inevitably, people are asking about their jobs and their income, and each of us feels at risk concerning the lifestyles we have become accustomed to and the changes we will have to deal with.

There is also stress regarding the future, the security of tomorrow, because we live in a society where we are used to having a certain level of social security and comfort. Suddenly this is being threatened and therefore it is very important for the state to take immediate action to reduce these risks. An example might be a measure that Greece has taken, which is to support the salaries of employees who are laid off or are technically unemployed, or to subsidize the salaries of employees that companies do not

dismiss. Similar measures have been taken in Germany and in the Netherlands.

We are also used to living in a globalized society, accustomed to the fact that we can travel, we are used to the freedom of movement yet we are suddenly faced with the fact that a large number of people have been unable to return to their country because the vast majority of European countries have closed their borders to foreign nationals and limited the possibilities of movement. This has happened in a Europe in which freedom of movement is a fundamental right that European citizens have acquired through the supranational construction called the European Union. Freedom of movement is one of the founding values of this Union. Limiting freedom of movement at an individual and group level therefore creates additional stressors.

3. Long-term side-effects of the pandemic on personal autonomy

The long-term effects will be increased risks of mental illness, of more or less severe forms of asthenia, and also of neuroses. Most important in overcoming stress is solidarity and a sense of belonging, the feeling that you are not alone even if you are restricted, that you are with others, even if this is more or less virtual. In my opinion this is one of the most important things that can lead to a decrease in psychological risks, because in difficult situations psychological stress can lead to the development of psychopathologies.

Psychologists, psychiatrists, counselors in general, and social workers, must strive to find ways to eliminate stress, to eliminate its negative effects and, of course, take precautionary measures.

For medical staff especially, who are in the front line in the fight against this virus, this can be a very difficult situation because they are aware they are taking huge risks. In countries with high levels of infection, large numbers of members of the medical staff have been positively diagnosed, including doctors - and some, for example in China, have died, such as the first doctor to publicize the epidemic (Li, 2020; Yu, 2020).

The risk factor to which medical staff are subjected is increasing and they need to be supported, first with sanitary material so that they have what they need to carry out their duties, such as masks and protective equipment. In the case outlined above, stress is also increased by the worries for one's own family, by the risk they have to face, by the fact that medical staff should remain isolated from their own family so as to avoid putting them at risk of infection, all these elements serve as additional stressors. In such

circumstances, of course, psychological support is absolutely necessary, and this can come primarily from psychologists, social workers, and doctors. However, it is important that this also comes from society, and we have seen manifestations of this in various cities; for example, from balconies in Italy, doctors and medical staff have been applauded at certain hours and various songs of encouragement have been sung.

4. Criteria for making deliberate ethical choices during crisis situations

It is important to understand the ethical dilemmas we all face in the current pandemic situation: *herd immunity* versus almost total isolation; who is entitled to life-saving therapies or medical equipment in situations where supplies are insufficient; building trust in the medical act and in health policies; the conflict between the principles of charity and autonomy; the possibility of violating the principle of social justice; derogation from quality standards in order to obtain the best possible care for as many people as possible, and so on.

Assuming that more people will need to be infected to obtain herd immunity and that this risk is real is an ethical decision, that should not be neglected. On the other hand, extending the duration of the pandemic generates other risks. We have been talking about stress at an extreme level, which can lead to a wave of suicides among various categories of vulnerable populations. There must be coherent social policies aimed at avoiding and limiting stress risks - not only those caused by health inequities arising as a result of the pandemic but also the economic and social risks to which various categories of vulnerable populations will be subjected. These public policies must be obvious and immediate (Ministry of Internal Affairs, 2020). However, no policy can limit the suffering a family feels when it loses one or more members, nor the situations of vulnerability in which such a family is placed (Ministry of Internal Affairs, 2020).

Basically, in terms of bioethics, in pandemic situations the issue arises of establishing criteria on which to make a deliberate choice as to who is more entitled to live and who is not, a choice that is dramatic in any situation whatever the criteria. Any criteria ultimately leads to a public health policy that emphasizes the strict isolation of all people, with long-term risks to the economy and thus the quality of life of the entire population. Conversely, strict isolation for vulnerable groups with more relaxed mobility than other population categories diminishes the economic risks, but increases the immediate risks of suffering and death. The risks associated with a period of

economic depression – as indicated in the dramatic fall of stock markets and the bankruptcy of many companies – can be expected to generate a traumatic situation after the end of the pandemic that will probably last for years and bring with it a wave of suicides or at least severe depression, along with an increase in the incidence of mental illness due to post-traumatic shock caused by the trauma experienced during this period.

Furthermore, from a bioethical point of view, we must also talk about the risks associated with the dramatic change in people's way of life as a result of the severe limitations imposed by the pandemic, such as those on freedom of movement which were previously discussed. Confidence in medical institutions, and also in state institutions, is also deeply impaired when measures to restrict individual freedoms are taken, especially when it seems that some states – Spain and Italy for example – have been abandoned by the rest of the European Union. Although measures taken at the level of the European Union – such as risk compensation policies and the allocation of increasing funds for social protection – are absolutely necessary, they must also be clearly expressed and communicated (EURACTIV.com & EURACTIV network, 2020; FRA European Union Agency for Fundamental Rights FRA, 2020; European Commission, 2020).

Social communication is also fundamentally important, especially when we talk about social distancing. Physical social distancing must be compensated for by eliminating distances in communication. It is also of great importance, from an ethical point of view, to communicate the real situation, so that public institutions – such as the National Committee for Special Emergency Situations - communicate correctly and credibly the number of people infected, the number of deaths, the number of people in quarantine, and also the number of people who have recovered.

There are countries in which suspicions have arisen that the real situation regarding the evolution of the pandemic has not been correctly and completely communicated (Putz, 2020). For example, China has been accused of not communicating the risk of a pandemic during the first few days in which initial cases were identified (Wadhams, Jacobs, & BLOOMBERG, 2020). When the first cases occurred in Wuhan, the idea that circulated was that the virus was transmitted from animals to humans and that human-to-human transmission was not possible. China also accuses the United States in claiming that carrier 0 was not Chinese but an American, an athlete who was present at the Wuhan military Olympics in November 2019, and that the pandemic started in November and not in December (Digi Sport, 2020; Vacaru, 2020). Whether or not this is the case, there may be considerable justification for the fact that the first few cases

were not communicated in advance – the nature of the virus was unknown and it could not be imagined that we were dealing with a dangerous pandemic. This explains the reluctance of local communist authorities to communicate the situation before obtaining the consent of the central authorities – although if it had been communicated in advance and the measures had been applied earlier, the situation could have been kept under control in the same way that the SARS epidemic in 2001-2002 was kept under control. Public communications from Russia (Rettman, 2020; De Haldevang, 2020) or Iran are also accused of limiting the declared number of deaths. Other accusations even relate to the situation in Romania (INSP, April 15), as the relatively small number of infected may have been greatly underestimated by the fact that not all people who have symptoms, or who are at risk of being infected, have actually been tested. Furthermore, the triaging of people who are tested is not very strict and most people who are carriers but do not show symptoms remain untested for the virus.

5. Crisis situations as tests of personal autonomy

Every situation that humanity goes through teaches us something. We cannot live our lives without learning any lessons. There can be two perspectives of a believer in God on the origin of the pandemic: the first is to consider the idea that such a misfortune is the result of a divine punishment, that the sins accumulated by humanity, a kind of collective karma, are those that generate such a situation and make it necessary. We are talking about a karma of humanity that makes necessary, from time to time, the appearance of suffering, or, if we speak in European terms, a destiny that accumulates such negative elements at the level of all humanity and that ultimately makes such a divine correction necessary. Another religious spiritual thought is that in the end, such a manifestation has come to bring on and demonstrate divine power and, as such, must be rather understood in the positive sense that a divine intervention will be the one that will end such situations.

There is an extremely important topic of study in bioethics - *the bioethics of the end of life* - and research we have undertaken in this field shows that, for those people who are in terminal situations where they have a few months left to live, if they show confidence in the Divinity, they live much more serenely in these terminal stages (Damian et al., 2013; Necula, Damian, Caras, Sandu, & Vicol, 2013). After all, when the end is imminent, the quality of life of patients in terminal stages, in what is called palliation, matters a great deal. It is one thing to go through the terminal stages

accompanied by pain and anguish, with a fear that generates even more suffering, and another to trust God to limit your suffering, at least psychologically if not physically. It is important to be aware of our condition as temporary beings, that we are subject to the effects of time, aging, death - a limited condition that can be understood by giving it meaning through an experience of religiosity.

I do not think we should go too far in interpreting such a situation as a kind of punishment that humanity receives, rather we should consider it a step in the development of society. For example, we can see that the level of pollution of the environment, of the air in the big cities, has decreased on a global level. It is a lesson in how we can work more from home and pollute the planet less, because I think that will maybe change our lives the most after the end of the pandemic. I think this is because, once companies have moved most of their business to telework, many will continue to do so because it involves low costs, for example in terms of space rents, and because it is easier to manage from certain points of view. This will lead in the long run to a greater social distance - not just the one imposed in the current period - and we will have a situation where social distancing is a habitus. In this quarantine period we will get used to the idea that social distance is a good thing and we will tend to practice social distancing even when these measures are no longer mandatory. However, if they are not accompanied by clear elements of social solidarity and individual and social responsibility, there will be a tendency to slide towards an increasingly distant society and the social distance will be an emotional distance first of all, then a decrease in social cohesion, which, from an ethical point of view, can mean a state of risk for society and the profound transformation or even disappearance of society as we know it today.

Conclusions

Social distancing will leave traces that will irrevocably change our way of life and the way we understand communication with others. One of my theories, expressed from a sociological and philosophical perspective, is related to the virtualization of social space (Sandu, 2003; Sandu, Cojocaru, & Ponea, 2010; Sandu 2019a, 2019b). This refers to the fact that for a long time humanity has transferred many of its social interactions to the virtual environment. Long before this pandemic, we were talking about virtual ubiquity (Sandu & Vlad, 2018), about the fact that distances have become spiritualized along with borders. Now physical boundaries have reappeared while virtual ones have not. Basically, this virtualization of the social space will be accentuated, we will have a social space that will become another

dimension of our communication space. Consequently, we will interact even more in the virtual world, we will distance ourselves socially, we will reduce our face-to-face interactions and, possibly, a new form of solidarity will appear. It appears thus far that virtualization of the social space seems to have led to a series of inconveniences related to the superficialization of social interactions. Increased virtualization, which we are now witnessing, may also intensify virtual interactions although previous experience suggests that the more intense these interactions are from an emotional point of view, the more superficial real relationships or even reality becomes.

A research study I conducted many years ago regarding erotic interaction at a distance through video chat (Sandu, 2003) shows that there is a significant relational mutation towards the other person, namely a transformation of the other's body into an object of amplification and satisfaction of certain desires. This superficiality is accentuated by moving to a virtual corporeality, a kind of phantom game, because the sensation of "the other" and the corporeality of the other disappears, which usually leads to the annihilation or at least limiting of emotions felt toward the other as a real person. The "other" acquires an avatar body and even an avatar identity. Through the virtual relationship with the other, the individual builds their own avatar reality, transferring their fantasies to this new identity-surrogate and identifying with it.

Nevertheless, the transfer of many interactions from the physical environment to the online environment means that, for many young people, especially digital natives, virtual space is considered a fourth dimension, is considered real, is reified and we live without realizing it in a universe (Sandu, 2018; 2019c) that did not exist when we were children, a universe dominated by the virtual world. This merits further investigation - sociologically, philosophically, economically, politically and bioethically - because such virtualization will eventually lead to lives increasingly lived in the virtual world, where to have a *second life* means to have an avatar life that surpasses real life.

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