



COVID 19 and the Aspect of Autonomy and Its Limitation or Not? - a Case for Kenya

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COVID 19 and the aspect of autonomy and its limitation or not? - A case for Kenya

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Abstract

Coronavirus disease (COVID-19), an infectious disease caused by a virus that started in china late 2019 and has caused a worldwide pandemic. The world has been affected one way or the other from the outbreak of COVID-19. So far 357,736 have died from it with more than 5,704,736 confirmed infections across the world as at May 29, 2020². Kenya has not been spared either, with numbers steadily increasing day by day. Apart from causing a health crisis, it has created a human, economic and social crisis. There are currently no specific vaccines or treatments for COVID-19, however, there are many ongoing clinical trials evaluating potential treatments. Pandemics of this scale raise pressing medical, ethical, bioethical and organizational challenges. These include global governance, priority setting, allocation of scarce resources and restricting individual liberty – autonomy in the interests of public health. Are there instances where the promotion of autonomy of patients as a means of upholding their respect and dignity impossible?

Key words: *autonomy; beneficence; preparedness; bioethics; patient rights; pandemic*

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² WHO Coronavirus Disease (COVID-19) Dashboard. Data last updated: 2020/5/29, 7:02pm CEST.

https://covid19.who.int/?gclid=CjwKCAjw5cL2BRASEiwAENqAPhBAKxYVE5PxYQN1-Qvt_3sFs-KUbJLLWyyAu5nwoCdPAY-B9odWnRoCR4IQAvD_BwE

1. Introduction

This paper seeks to analyze how the aspect of autonomy is accessed during health emergencies using the Kenyan scenario. The word *autonomy* comes from the Greek *autos-nomos* meaning “self-rule” or “autonomy”. According to Kantian ethics, autonomy is based on the human capacity to direct one’s life according to rational principles (Meglino 2004; Korsgaard 2004). Rationality, in Kant’s view, is the means to autonomy. Autonomous people are considered as being ends in themselves in that they have the capacity to determine their own destiny, and as such must be respected.

Health emergencies pose a challenge to public health care for health practitioners, the nation and population³. With the current pandemic, physicians face a number of competing duties like duty to patients; duty to protect oneself from undue risk of harm; duty to one's family; a duty to colleagues whose workloads and risk of harm will increase in one's absence; and a duty to society. One of the bioethical challenges facing millions of healthcare workers who provide medical care to patients, millions of patients, and the rest of the population is the aspect of autonomy.

Kenya had the first reported positive case of COVID 19 patient on 13th March, 2020. Almost immediately afterwards an executive order from the president was made. The executive order provided directives, policies and laws that touch on public health, fiscal policies, social status (behavioral) and the administration of justice that have been passed, cited and used by the Government⁴. They are intended to help the control and mitigate the spread of the COVID 19 virus, since the state of exception and suspension of individual guarantees are not adequate measures to control epidemics.

2. Background

What happens if the government is taking the necessary action, but the populace is not doing its share by staying home and washing their hands and all that it takes to protect themselves from infection. This is where the challenge begins. Looking at the case for Kenya, her President, Uhuru Kenyatta, gave a directive that “anyone who does not follow the directives should be taken

³ General Health Act, Chapter I, Article 5

⁴ <http://kenyalaw.org/kenyalawblog/kenyas-response-to-covid-19/>

to a quarantine facility” (Yusuf, 2020). Interim Guidelines on Management of COVID-19 in Kenya, Infection Prevention and Control (IPC)⁵ and Case Management describes quarantine and social distancing as the separation and restricted movement of well persons presumed exposed often at home or may be in designated residential facility or hospital. It can be applied at the individual, family or community level. The Ministry of Health confirms all COVID-19 cases identified to be monitored closely at a health facility isolation room. Contacts of cases are then quarantined either at home or in designated facilities. Once sustained community transmission has been established, home management of mild cases is encouraged.

These consolidated guidelines provide recommendations for comprehensive prevention and case management strategies in Kenya. However, adhering to these restrictions has proven challenging to most Kenyans who deem it as unwarranted, unnecessary, an infringement on their rights and most importantly interfering with their ability for self-determination. People have not been turning up for the nationwide mass testing campaign launched by the country’s Health Ministry being conducted across the country. During the daily televised briefings from the Ministry of Health on Sunday May 3, 2020, Kenya’s chief administrative secretary for health, warned that “COVID-19 testing has so far been a failure in the country”, yet the free mass testing was to help the country to flatten the infections curve. The willingness of people to be tested is low, and there was an urgent appeal to Kenyans to willingly come forward to be tested, indicating that experience has shown that countries that have managed to flatten their infection curve quickly have heavily relied on targeted testing.

3. Social responsibility

This brings in the roles and responsibilities, preparedness and response of a state, a nation, a government. While all sectors of society are involved in pandemic preparedness and response, the national government is the natural leader for overall coordination and communication efforts. Kenya’s president has been on the forefront in the battle against the pandemic through the adoption of different measures taken to control the spread. He has delegated different state machineries to

⁵ Interim Infection Prevention and Control Recommendations for Coronavirus Disease 2019 (COVID-19) in Health Care Settings. Ministry of Health - Kenya. https://www.health.go.ke/wp-content/uploads/2020/04/Kenya-IPC_Considerations_For-Health-Care-Settings-1.pdf

enforce this. Whilst the ministry of Health has been providing daily briefs on the numbers, fatalities and recoveries from COVID-19.

National preparedness and response is a whole-of-society responsibility. This approach to the COVID-19 pandemic emphasizes the significant roles played not only by the health ministry, but also by all other sectors, individuals, families, and communities, in mitigating the effects of a pandemic. Developing capacities for mitigating the effects of COVID 19 infection is pivotal in dealing with and overcoming such a pandemic.

Despite the appeal, the general populace seems to have varied reasons for their unwillingness for not availing themselves for the COVID 19 tests. One of the reasons resonates with the aspect of autonomy – autonomy. Many do not really understand what is COVID 19 and how it is relevant in their lives. After all, the disease cannot be seen. The people who are “claimed” to test positive are not known to everyone, therefore making it difficult to back up facts. Others associate it with having caused chaos in their lives. There is also a fear of imagined pain in the testing process, while they are afraid of the pain as those who were tested told them it is painful, and they are afraid of getting the virus since they could be exposed to the ones who are getting tested. “They should test us in our homes like how they did it with census”; “I will not join the crowd there, where the chance of getting the virus is so high”. “I am 59 years old, and I might die from coronavirus if I get it” – these are some of the remarks made by people who do not wish to be tested. Hospitals also reported low hospital visitation for health services, citing fear of contracting the virus, or being assumed to be infected. The Ministry of Health has assured Kenyans that all hospitals have taken measures to ensure that other services are delivered without putting anyone at risk (Wasike 2020).

4. Principle of autonomy

A standard approach to biomedical ethics, developed by Beauchamp and Childress (2001) in Principles of Biomedical Ethics, resolves ethical issues in terms of four ethical principles: Autonomy, Beneficence & non-maleficence and Justice. Each of which need to be weighed and balanced in determining an optimal course of action. All of these principles require a conversation about the needs and desires of the patient or, in the case of justice, members of community. The principles are intended to guide. In the case of autonomy, the wishes of the patient need to be determined in order to protect his or her autonomy. This is a question healthcare professionals

have to answer almost every day. As they work with patients and families who are making healthcare decisions. COVID 19 has brought this aspect to the fore, querying just how much control should patients have over their healthcare decisions. For a bioethicist, the outright answer would be to give as much control as is feasible. *However, when do we know that a patient may not be able to fully control their care decisions? In the face of such a pandemic, where can we find moral action guides when there is confusion and or resistance about what ought to be done?*

The very nature of being a physician entails a duty of beneficence to patients. Hence, morally, Physicians have greater obligations to help patients than non-physicians. Beauchamp and Childress (2001) spoke of Beneficence as the principle of acting with the best interest of the other in mind and Non-maleficence as the principle that “above all, do no harm,” as stated in the Hippocratic Oath. Therefore, in the healthcare settings we are required to determine the patient’s views of what does and does not count as goods to be pursued or harms to be avoided. The medical fraternity as a whole also has an implicit contract with society to provide medical help in times of crisis.

4.1 Competency and Authenticity

Two criteria preconditions often considered to be for autonomous actions: competency and authenticity (Freer, 2017). Liberal thinkers have theorized the autonomous individual as necessarily rational and self-controlling, with Mill conceiving of “human beings in the maturity of their faculties,”⁶ and John Rawls describing an individual capable of “deliberative rationality.”⁷ Diana Meyers (1989), sought to describe a vision of individual autonomy as social that retains an understanding of individuals as being capable of calculating rationality. She explains how close emotional human relationships and autonomy are compatible, since “memory, Ethics & Medicine imagination, and instrumental reason, are usually enhanced through conversation with others and enable people to envisage options—to conceive of combinations of traits they could embody and aims they could pursue.” Further she posits that people “who never exercise autonomy competency can be presumed not to have it”—and they cannot be considered autonomous if they “never ask

⁶ Mill, JS. On Liberty. Broadview Press, 1999.

⁷ Rawls, J. A Theory of Justice. Harvard University Press. Revised edition; 1999.

the question ‘What do I really want?’” Meyers’ criteria of competency are stricter than those given by Beauchamp and Childress in their *Principles of Biomedical Ethics*. Essentially this means that an individual lacking autonomy is compared to someone who is in some respect controlled by others or incapable of deliberating or acting on the basis of his or her desires of plans.”⁸

4.2 Autonomy and Human rights

Human rights have increasingly been put forward as an important framework for bioethics. The basic concept of human rights is that people have certain moral rights by virtue of being human. But it does not follow from this concept that international instruments of human rights and the national constitutions protect all rights agreed or shared within international or national communities.⁹ The Universal Declaration on Bioethics and Human Rights of UNESCO 2005, echo this under Human dignity and human rights and fundamental freedoms which are to be fully respected. An individual person is a rational moral agent who has the ability to evaluate choices and take decisions based on all factors considered through understanding situations, and evaluating consequences.

When it comes to Respect for Persons specifically, this principle is developed in terms of five distinct core concerns (autonomy, dignity, integrity, privacy, and vulnerability). In this case, one human right is conflicting with another, or with some other moral consideration. The right to personal freedom and the right to health. Griffin (2008), considers trying to resolve this conflict by weighing the conflicting items. To weigh them, we have to decide what gives them their weight in the first place. If we favour the personhood account, for example, then we are forced to decide between a deontological and a teleological understanding of the value of personhood. Griffin further follows Kant, by contrasting ‘persons’ with mere ‘things’. ‘Things’ have ‘price’, and so have equivalents. ‘Persons’, however, have ‘dignity’; they are of unique value; they have no equivalents. One might want to endow human rights, therefore, with something akin to that which surpasses all other moral considerations. He explains that the ground for my liberty is a ground for your equal liberty; the ground cannot justify my being more at liberty than you are. That identifies

⁸ Meyers, DT. *Self, Society, and Personal Choice*. Columbia University Press; 1989.

⁹ Sándor, J. (2012). Bioethics and basic rights: persons, humans, and boundaries of life. In *The Oxford Handbook of Comparative Constitutional Law*.

a formal constraint on the content of the right: each person's liberty must be compatible with the same liberty for all. If that is so, then instead of conflict, a degree of harmony is built into people's liberties¹⁰. What Kant calls 'The Universal Principle of Right' can be stated as a principle for distribution of freedom: 'Any action is right', the Principle says, 'if it can coexist with everyone's freedom in accordance with a universal law, or if on its maxim the freedom of choice of each can coexist with everyone's freedom in accordance with a universal law¹¹.' one person's liberty must be compatible with equal liberty for all¹². It is widely, perhaps nearly universally, accepted that if a threat to the survival of the nation is great enough, if its ability to protect the life and liberty of its citizens is in sufficient peril — in short, in a grave emergency — a government may set aside certain human rights (Griffin, 2008). In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect of the rights of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

4.3 Patient Autonomy and Informed Consent

All around the world, people have different reasons for fearing to get tested. In Kenya, apart from being infected with the virus, there is the fear of being locked up in a Kenyan quarantine centre. Its currently equated to a prison cell by many, since also those who have been found contravening the provisional laws related to the pandemic have been taken to quarantine. If you are a suspected COVID 19 carrier, you and your family are taken to these government-assigned facilities that for some, it's considered as a less than honorable place to live. Once one is taken to the quarantine facility, they are expected to spend at least 14 days. However, the quarantine period can be extended twice for everyone at centers where someone has shown symptoms of the virus - and they have had to keep paying the bills, with many lamenting of it being impossible to social distance in some of the facilities because of overcrowding. Others spoke of their psychological and mental anguish after the government extended their stay beyond 14 days. In the words of

¹⁰ Griffin, J. (2008). On human rights. Retrieved from <http://ebookcentral.proquest.com>

¹¹ Rauscher, Frederick, "Kant's Social and Political Philosophy", The Stanford Encyclopedia of Philosophy (Spring 2017 Edition), Edward N. Zalta (ed.), URL = <<https://plato.stanford.edu/archives/spr2017/entries/kant-social-political/>>.

¹² Griffin, J. (2008). On human rights. Retrieved from <http://ebookcentral.proquest.com> Created from anahuac-ebooks on 2019-08-16 14:27:33.

another quarantine complainant: “It’s like you are condemned... it’s like you are at the mercy of the government” (Mutahi 2020).

From the above, it can be deduced that there is a semblance of a lack of autonomy. There are individuals who may feel they are not being given the opportunity to choose what happens to them and how. The ethical principle of autonomy, is highly valued in personal healthcare decision-making. While it is quite correct to say that in some circumstances, other considerations take precedence over the wishes of a person like in instances where their decisions may cause avoidable harm to others – autonomy should be thought of more broadly. Autonomy could be limited when its exercise causes harm to someone else or may harm the patient and or person or if its exercise violates the physician’s/healthcare team’s medical conscience. Patient wellbeing and autonomy go hand-in-hand. Autonomy should not necessarily be seen as ‘patient control of decision-making,’ but as a clinical reality which consists of education, conversation and concern for patient wellbeing¹³.

Healthcare professionals could think of autonomy, not as an immaterial principle or as something that is entirely lost if a right to choose is denied, but rather as a matter of the degree to which it is honored, aimed at providing respectful patient care. The implication is that once information relevant to treatment is made available and the patient is deemed capable of making treatment decisions, then the healthcare professionals proposing treatment should not prevent the patient’s decision unless respecting the wishes would cause harm to others, or seriously undermine the patient’s wellbeing¹⁴. Consideration for patient autonomy must always be the starting point for interventions that seek to enhance patients’ dignity. Beyond this, the issues must be resolved using appropriate moral reasoning, clear communication, comprehensive assessment of the situation, respect empathy and personal judgement¹⁵.

John Stuart Mill, expressed that the concept of respect for autonomy involves the capacity to think, decide and act on the basis of such thought and decision freely and independently. Further advocating the principle of autonomy (or the principle of liberty as he called it) provided that it did not cause harm to others (Mill 1968). The principle of not causing harm to others (known as

¹³ Hospital News, Are there limits to a patient’s autonomy in making health care decisions? <https://hospitalnews.com/are-there-limits-to-a-patients-autonomy-in-making-health-care-decisions/>

¹⁴ *ibid*

¹⁵ *ibid*

Mill's "harm principle") provides the grounds for the moral right of a patient to refuse medical treatment and for a Physician to refrain from intervening against the patient's wishes. Nevertheless, Mill believed that it was acceptable to prevent people from harming themselves provided that their action was not fully informed.

Nowadays, an autonomous decision might be described as one that is made freely/without undue influence, by a competent person, in full knowledge and understanding of the relevant information necessary to make such a decision (Ungerleider et al, 2018). It should also be applicable to the current situation or circumstances. Autonomy in health care, is gradually moving away from a paternalistic approach towards a more individualistic, client-centred approach where the patient plays a more active role in his/her own health and well-being. Such an approach requires that patients take responsibility for making their own decisions and bear the consequences of those decisions.

How does autonomy role play into the current situation whereby the government forces people to go for quarantine, is it for public good or there is infringement of one's fundamental rights and the principle of autonomy and beneficence. Autonomy and individual responsibility shows that the autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests. While, Article 6 in the Universal Declaration on Bioethics and Human Rights¹⁶ on Consent states that any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. The consent should, where appropriate, be expressed and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice. It is important for a patient to be well informed in order to make an informed decision. Informed consent is a process whereby information is shared with a patient to enable an informed decision. Full disclosure to a patient will empower a patient to make a true informed decision.

¹⁶ Universal Declaration on Bioethics and Human Rights.http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html

Autonomy is a central value in medical ethics. It is plausible that autonomous persons are often in the best position to determine what would be good and bad for them (Sumner 1996) and, consequently, it is arguable that there is good reason to consider patients' autonomy to have instrumental value in their healthcare decisions. Where does public good come in, when should we consider to override this principle. The principle of autonomy acknowledges the positive duty on a health care practitioner to respect the decisions of a patient. The common notion is to protect a person's liberty, privacy and integrity. The relationship between the healthcare practitioner and the patient is based on trust and communication.

5. Lack of information

The concept of autonomy in the practice of health care has to find a balance between the good of an individual and the good of the community (Engelbrecht, 2014). This tension presents challenges to health care practitioners in Kenya, especially those in the public sector. In essence, autonomy is a manifestation of "one's legal and mental capacity to understand and make an informed decision" (O'Neill 2002). Therefore, to exercise personal autonomy one needs the capacity to understand what is available and whether it is appropriate for one's purpose. Providing information and assistance is the key ethical responsibility of health care representatives. Providing the legal framework supporting autonomy is the role of legislators. First, to be autonomous (literally a self-lawmaker), an individual must have adequate knowledge to explore and examine all options relevant to the healthcare decision that needs to be made. This specialized knowledge is beyond the scope of most patients, so they must rely on healthcare professionals to present them with the information they lack (often in a simplified version). Furthermore, although a patient may fully understand the medical treatments and consent to it, it can seldom be said the consent and autonomy are truly manifested. A patient will almost never fully grasp all the medical procedures and consequences. In this regard, Caplan (2014) argues that consent is "inherently limited". A patient is not in the position to fully predict, let alone comprehend or appreciate all the risks associated with the medical treatments and or procedures.

Patients may be quite knowledgeable about their illness, but they usually do not know the whole story. With COVID 19, there is a lot of information and misinformation making it difficult for a person to make an informed analysis that could be considered rational. As we have seen currently,

even a physician who becomes a patient may lose objectivity about specific details of treatment. It is the obligation of the healthcare professional who is proposing treatment to provide the relevant information needed to enable the patient to make an informed decision towards the facilitation of their medical treatment, and consequently enhancing their dignity.

The Ministry of Health in this case, or designated health institution should be tasked with the responsibility of dissemination of information to the public. Using social media and televised advertisement help but only for a few people. This would be mainly people who have access to it and or are already have an idea of what the pandemic entails. An additional effective approach would be to find a mechanism that would relay information directly to the common “*mwananchi*”. This refers to the general public, the common person, children, the vulnerable, the minorities, people living in low income settings and rural areas. Using a person or medium knowledgeable to them would build trust that would give them confidence to make informed decisions on their health. This will also make it possible for everyone to understand the importance of social distancing, safety measures, wearing of masks, lockdown, and others - and that it will require for them to bear with a difficult period economically too albeit only for a period of time. This would definitely work towards eliminating the problem of the unwillingness of people getting tested, or abiding with the safety measures put in place. Providing reliable information on the risk, severity, and progression of a pandemic and the effectiveness of interventions used during this pandemic; prioritize and continue the provision of health-care; enact steps to reduce the spread of the virus in the community and in health-care facilities; and protect and support health-care workers during a pandemic.

6. Collective right to health

An absence of early and effective preparedness, societies may experience social and economic disruption, threats to the continuity of essential services, reduced production, distribution difficulties, and shortages of essential commodities. Disruption of organizations may also have an impact on other businesses and services. For example, if electrical or water services are disrupted or fail, the health sector will be unable to maintain normal care.

To protect our collective right to health in the current pandemic situation, we need to balance our individual rights with collective responsibilities. In order to fully implement human rights, we need to place more emphasis on the responsibility of all actors, and not just the government and its machinery, to take action together to make sure rights are enjoyed. The health sector (including public health and both public and private health-care services), has a natural leadership and advocacy role in such a pandemic preparedness and response efforts.

While every patient deserves medical care as Article 43(2) of the Kenyan constitution guarantees every person the right to the highest attainable standard of health¹⁷, not all of them should receive the same type of care, for some the treatment will be for healing purposes and for others it will be palliative care. That is why, regarding the issue of the patients to whom resources should be assigned, at all times human dignity should prevail as a fundamental value of medical care and ethical behavior.

Seedhouse (2009), notes that even autonomous people with self-governing capacities sometimes fail to govern themselves in the making of particular decisions because of temporary constraints caused by illness or depression or because of ignorance, coercion, or other conditions that restrict their options. Hence, autonomy may in itself benefit the patient, but it may disadvantage him or her as well. For example, a person who refuses to go for quarantine when they are exhibiting symptoms of COVID 19 may not just be putting their health and those their loved ones at risk, but it may also be difficult for health professionals to carry out their moral duties of doing goods (concept of beneficence), that is to adequately treat any severe symptoms and avoid increased cases of fatalities. Furthermore, Rogers (2002) posits that, when provided with information and the opportunity for greater involvement in making decisions, consumers generally become warier of the treatments offered and make more conservative decisions.

Epstein (2009), asserts that having the freedom to self-govern does not necessarily mean that the agent will simultaneously have the capacity and the opportunity to exercise the right of self-rule. However, the limitation in human, medical and technical resources does not justify abandoning the ethical and legal obligation of providing care to a patient and ease their suffering, always observing the informed consent and the patient's human rights. Medical intervention should be permitted in a situation where there is evidence of dangerous behaviour. This intervention is

¹⁷ Article 43 (1) of the Constitution of Kenya, 2010

permissible in order to prevent any harm to others or self-harm. Society confers professional autonomy and it is limited in comparison to the protection of a patient's autonomy and human rights. The respect for autonomy has only prima facie standing and competing moral considerations can sometimes override it. For example, if our decisions jeopardize public health, potentially harm others, or require a scarce resource for which no funds are available, others can justifiably curb our exercising of autonomy.

Zolkefli (2017), further postulates that, to be genuinely autonomous, we are required to take seriously the social implications of our autonomous decisions. Placing too much emphasis on the promotion of individual patient autonomy, particularly when such decisions are actually made alone, carries the risk that we might forget either the interests of others or the wider public interest (Zolkefli 2017). In this case it would greatly benefit the society if people would cooperate with the medical practitioners and by extension the state. Beginning with the populace willingly accepting to undertake COVID 19 tests.

7. Conclusion

The Bill of Rights provides protection for individual rights including that of autonomy, but all the rights and liberties listed can be limited if the reason is legally justified. One may therefore conclude that autonomy, whilst strongly protected, can be limited in our context under strict rules to enable justice for society and without terminating the rights of the individual patients. The aspect of autonomy remains a good thing in health care, however when faced by calamities, state emergencies or pandemics of the COVID 19 magnitude, we should query if limited autonomy can be justified if it saves a human life or a community. The principles of beneficence, non-maleficence and justice would still come into play. It is important for a patient or would be patient in such extraneous circumstances as now, be given specific and clear information regarding the pandemic. Since most express a sense of fear, it would be the responsibility of the state through medical personnel to help allay their fears and give them the confidence of making right autonomous decisions. Therefore, although there is a compelling argument for promoting autonomy of patients as a means of upholding respect and dignity for patient autonomy, there is strong evidence that it is not always possible, particularly when the quality of decision and its impact on others are, to an extent, disputed.

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