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Short Communication

Ethical Challenges to Respecting and Meeting Patients' Requests: Lessons from Providing Palliative Care for Coronavirus Disease 2019 Patients

John Weru, MB CHB, MPC*

Pain and Palliative Medicine and Chair-Hospital Ethics Committee, Aga Khan University, P. O. Box 4614-00200, Nairobi, Kenya

Corresponding author
John Weru, MB CHB, MPC
Assistant Professor, Pain and Palliative Medicine and Chair-Hospital Ethics Committee, Aga Khan University, P. O. Box 4614-00200, Nairobi, Kenya;
E-mail: drweru@gmail.com

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INTRODUCTION

The World Health Organization (WHO) defines palliative care as: "*an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*"[1] Thus, palliative care is associated with chronic, serious illnesses. However, coronavirus disease 2019 (COVID-19) is a novel disease presenting acutely with acute symptoms but requiring the level of care, even in an urgent manner that patients with chronic serious illnesses that are normally associated with palliative care require. Palliative care clinicians are uniquely equipped to address the suffering of COVID-19, especially where the health system is significantly strained. This is accomplished through high-level communication and symptom management skills and a transdisciplinary approach to address physical, emotional, and existential suffering.[2] It is within the ability and the ethical duty of palliative care to relieve suffering, physical pain and other symptoms.[3]

However, as the world accepts the role of palliative care in managing COVID-19, it is important to assess the ethical challenges that the palliative care provision system as we know it today is facing given the new context.[4] Patients, caregivers, healthcare providers, and health systems can benefit from the extensive knowledge of the palliative care community by urgently considering to improve access to essential medicines, particularly opioids for the relief of breathlessness and pain the two key symptoms that patients with COVID-19 faces and the palliative care fraternity are well-versed in managing.[5]

COVID-19 has ravaged many parts of the world sparing no country or any sphere of life including economic, political and social arenas.[6] The most significant challenge has been in the medical field. Clinical care is guided by the principles of medical practice; respect for autonomy, beneficence, non-maleficence and justice as popularized by Beauchamp and Childress.[7] Some of the values that underpin the principles of respect for autonomy and justice that have been seriously challenged by the situation COVID-19 has placed the world and the interrelationship between these two principles will also be outlined.I will discuss some values that underpinthe principles of respect for autonomy and justice that have been seriously challenged by the situation COVID-19 has placed the world in.[8] The interrelationship between these two principles will also be outlined.

DOCTOR- PATIENT RELATIONSHIP

Healthcare is provided within the doctor-patient relationship of trust. To maintain this value of trust, the healthcare provider is obligated to respect the patient's autonomy and the inherent choices that they make. The principle of respect for autonomy is well-documented in the Universal Declaration of Human rights and many national constitutions.[9] The Universal Declaration of Human Rights, National Constitutions and Rights Charters across the world detail the rights to access of highest quality of care, right to confidentiality, right to informed consent and the right to select the healthcare provider of choice.[10] However, COVID-19 has brought questions on how feasible these guidelines, policies and internationally accepted laws are.[11]

In respecting autonomy, there are directives for the recognition of choices made by competent patients so as to honor

their liberty, privacy and integrity as independent beings. In case of informed consent, the patient is given information regarding their diagnosis, the available treatment options, the side-effects of these treatment and what the outcome of non-treatment may be. This entails clear and detailed communication which might be in multiple sittings thus providing full disclosure on the elements mentioned above. However, in the context of a pandemic like COVID-19 these values and ethos are not assured or even practical.

CAPACITY TO MAKE DECISION ON HEALTHCARE PROVISION

Capacity is important as it enables the patient to use their right to decide what happens to their own body.[12] But the consenting person must be able to fully comprehend the information being given in form of a full disclosure, understand the options they have and eventually make voluntary decisions to receive or refuse treatment. In the context of COVID-19, where a lot is not yet known of the disease, where treatment is on trial bases and there is no standard treatment, it is questionable what full disclosure would mean. Further, is such a disease with severe negative outcomes (social and medical), presenting with sudden severe symptoms, capacity to make any well-informed treatment decision may be significantly limited. There is a likelihood of clouded judgment when making decisions for or against treatment or when giving consent for any recommended medical intervention. This is significantly complicated by the fact that access to the treatments being recommended is also curtailed by multiple other factors.

PRIVACY AND CONFIDENTIALITY

These values are key to respecting autonomy and form the core of this principle in regards to patients controlling information about and regarding themselves. However, an infectious pandemic demands that others are warned of the likelihood of contamination emanating from their interaction with the infected person. As such, personal medical information is collected and collated to be used in controlling the spread of an infection. The infected person cannot refuse to provide this information in this context. Nor can the treating health care providers withhold this information from the authorities by invoking protection by the clauses of confidentiality and privacy. It would be argued that authorities are justified in doing so in order to avoid massive loss of lives from the spread of infections. Further, the freedom and liberty of the infected person is limited and they cannot be free to be treated in the institutions of their choices as there are usually designated treating centers. Nor can they move or interact as they usually do. Thus, the right to privacy and confidentiality conflicts with the right to health begging the question of the obligation that we have to society *vis a vis* their obligation to respect our individual liberties. Considering the concept of triage, it's composition by clinicians and non-clinicians, the limited resources that guide towards its use, confidential information is thus shared with other health care workers and non-health care personnel who are not immediately involved in the patient's care.

HUMAN DIGNITY

As Kant would say, autonomy belongs to moral agents who are able to reason and rationalize. Human dignity is a fundamental characteristic of these rational agents and need to be fully respected. At the foundation of dignity, is the respect of personal choices irrespective of the consequences. However, in a pandemic, the right to personal freedom may be limited by public health measures such as lock downs, curfews and social distancing. We therefore find that personal dignity is tramped on in favour of common good.

Right, timely and quality information leads a patient to reason, rationalize and make a decision. However, in the context of COVID-19, with overstretched and overworked health care personnel, it is difficult to assure the access of all information that the patient may need to make a decision. This, it would be argued, further limits dignity and thus challenges the fronting of respect for autonomy as the key to care provision.[13] With this and the fact that only those who can afford are able to access even treatments on compassionate use, the concept of global distributive justice is negatively negated and significantly challenged as a guide to global access to health care. Further, these factors are likely sources of moral distress for health care providers because of the way they limit the care they can offer for their patients.

RESOURCES

The concepts of equity and equality form the ethos of the principle of justice in medical practice. The world is racing to develop effective treatment and therapies towards COVID-19.[14] But the question arises on modalities to be used in ensuring the equitable worldwide distribution of vaccines and therapeutics resulting from the current ongoing biomedical innovations. Absent broad agreement and buy-in on those plans, governments may prioritize their own populations, resulting in inequitable distribution of medical products both within and among countries. Those in dire need for this consideration are those who are moderately or severely sick with COVID-19.

It might be difficult to conceptualize how resources relate to the principle of respect for autonomy. The limited resources demands an allocation that will consider the welfare of the majority even if a particular patient demands the said resource. This personalized need and demand may be overlooked and curtailed. At the peak of the pandemic, scarce resources such as ventilators, ICU beds, dialysis machines and the human capacity are not available for all patients who may be in need. Thus, the patient's choices are limited by the virtue of the unavailability and inaccessibility of the resources. In this way, despite the choices and preferences that the patients make, their autonomous decisions and demands may not be respected. The access to the highest available or attainable quality of health care enshrined in the International Declaration of Human Rights, many constitution and other human rights documents are challenged.

The concept of first come first served has been the key guide in ensuring that equity in access is assured in health care. But in a pandemic, this might not be feasible thus requiring the health care providers to utilize other modalities of decision making. COVID-19 has taught the medical fraternity that the concept of triage is the best guide on who is to access limited resources when de-

manded by many patients. The triage system uses multiple factors and considerations to arrive at a decision. The presence of other diseases or health conditions, the physiological status and laboratory findings of the patient at the given time are some of the factors considered in the triage system by a multi disciplinary team made up of clinicians and non-clinicians. This eventually avoids biases that might arise if only 1 factor is considered and is considered in many Guidelines to Ethical Decision Making during COVID-19. With a triage system, there is rationing of available resources that a patient has at their disposal and that they can access even if they demand the same. These patients, who are unable to access these services are then recommended to receive comfort care only. How then can we fully apply the principles of respect for autonomy and just access to resources in such situations?

CONCLUSION

In conclusion, it is evident that there are specific challenges in attempting to respect and implement a patient's demands in the context of COVID-19. These challenge are not only faced by the health care providers but also by the patients themselves, their families and policy makers. Of note is the fact that in the normal health care systems, the default application of the principles of respect for autonomy and distributive justice has the presupposition that health care resources and infrastructure are available and need just to be contextualized to the given patient's needs and demands. COVID-19 has taught us that health care resources and infrastructures are limited all over the world. As such, we are called upon to interrogate the principles of medical practice further on their applicability not only based on the various diverse global contexts but also the presentation of the diseases that mankind is bound to continue facing.

This commentary would further be enriched if we look at the other principles of medical practice; beneficence and non-maleficence. Encompassing these other 2 principles might have a broader view and thus a deeper understanding on the confounding factors and challenges faced by clinicians in their practice.

ETHICAL CONSIDERATION

This is a commentary article and did not therefore require ethics review

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