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COVID -19: Looking Through Patient's Perspective And Experiences.

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ABSTRACT

The 4 important ethical issues in medical practice include Patient Autonomy, Beneficence, Nonmaleficence and Justice. But with the onset of the global pandemic Covid-19 following the protocol for the greater benefit of the mass has been on emphasis and the key doctrines of medical practice stands at a stake. In this case series we would like to highlight the patients perspective and experience with respect to the disease and related ethical concern. We have discussed about the mediocre of the situation for an ethical medical practice. To study the Covid-19 patient's perspective and experience about the disease and, also to assess the conformity of the Covid-19 patient's treatment with medical and social ethics. This is a cross sectional case series study where in case histories of three COVID-19 patients are described. The case histories were obtained from news articles available online. The case series illustrates the ordeals and experiences of the COVID-19 patients during the disease. The COVID-19 patients as discussed in the cases were not given the Autonomy of choosing their hospitalization or their treatment. In case 2 the principle of beneficence which is prima facie has been over ruled by the principle of utility. The principle of justice to provide treatment to the patients and equal opportunity for best treatment has been at odds. With the limited knowledge of the disease, its spread, its changing pathogenesis, nonmaleficence is also at stake. From the case narrations it is clear that COVID-19, not only affects the physical health, it also takes a toll on the mental health of the patients and their attendees. At the same time following the key components of the ethical medical practice i.e. autonomy, beneficence, non-maleficence and justice has been a mirage for the health care providers.

Keywords: COVID-19, patients, autonomy.

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INTRODUCTION

With the onset of the global pandemic Coronavirus disease (COVID-19) social life of the general population stands at a stake. The four key doctrines of ethical medical practice includes beneficence, non-maleficence, autonomy, and justice which remains a mirage for the health professionals.

Also with the growing public interest with regards to the ethical handling of health-care professionals there has been an increasing incidence of litigations against the health professional's about the poor ethical conduct [(1)].

One of the important plausible factor for the hindrance of practicing autonomy and non-maleficence during Covid 19 situation could be the scarcity of manpower and resources as well.

Explaining the care givers about the application of Triage and categorizing the patient by the health professionals without affecting the patients autonomy, is again a challenge to ethical practice. With the available limited resources should the health professionals decide whom to be given ventilator support and when to withdraw or should they consider the patient's autonomy. Providing life support for a patient who's condition has a more favorable outcome with the treatment or allowing to fulfill the autonomous rights of the patient who demands for a ventilator but whose outcome is less favorable even with the life support cannot justify maleficence.

Corona viruses are known from a long time to cause respiratory illness. It is popular in causing various serious respiratory illness like Middle East Respiratory Syndrome and Severe Acute Respiratory Syndrome. But the novel Corona virus which is responsible for the disease COVID-19 is new to the mankind and now it has become a global pandemic. The symptoms of COVID-19 ranges from mild fever, Upper respiratory tract infection or just myalgia and headache to severe respiratory difficulty compromising the lung function. It may present with certain nonspecific symptoms like, conjunctivitis, diarrhea, or a rash on skin or discoloration of fingers or toes. Loss of taste or smell is one of the common symptom experienced by all. The most susceptible population include Older people, and those with co-morbidities like hypertension, cardiovascular and respiratory problems, diabetes, or cancer, for developing serious illness. Some studies have shown that more than the physical well-being, the mental well-being of the patient plays a very important role in recovery of the patient. In fact the reality of unmet needs of healthcare during COVID-19 pandemic could be much worse and the scale of the impact could be many times greater in the areas where there is already the vast pre-existing need for healthcare[(2)]. Let us look through at some of the experiences shared by the COVID patients and their outlook on the disease.

Objectives

a. To study the Covid-19 patient's or their attendants perspective about the disease.
b. To illustrate the Covid-19 patients and their attendants experience of the disease.
c. To assess the conformity of the Covid-19 patient's treatment with medical and social ethics.

MATERIALS AND METHODS

This is a case series report, where in case histories of three COVID-19 patients are described. The case histories were taken from the individuals by Telephone contact and email correspondence.

Approval and clearance from the Institutional Ethics Committee was obtained before starting the study

Case Description

Case 1

"On 14th August 2020, I started my journey to my hometown after learning my father was moved to ICU. It was frustrating, as this was the first time since February I was outside my house for more than 20

minutes. As my father was tested negative for Covid-19, I was relatively less worried. Reaching hometown, I went straight to the hospital only to be informed of what seemed like common cold a week ago has turned itself to a severe case of pneumonia in my father's lungs.

My brother who was taking care of my father started developing fever, cold and other symptoms of Covid-19. I decided to not go to my home and rather stay at hospital. Following days were heart wrenching as I had to witness my father's health deteriorate. My father was tested negative for Covid-19 twice before he was shifted to a normal ICU. With treatment failing, he was tested again for Covid-19 and this time the result came out as positive. To make things worse, my brother, mother and sister were tested positive too and were immediately quarantined at a government facility.

On 17th August 2020, Doctors gave me the devastating news that my father passed away. It took me next 30 minutes to console myself and comprehend the event. That was the loneliest day of my life. I was scared to death breaking the news to my family, that was the toughest phone call I ever had to make. I started attending to the hospital and insurance formalities. It was already dark and I was told of the only option I have to bury my father. The government official in charge showed no shame or remorse when he put forth his expected number to do the needful. I obliged. My brother was granted permission to see my father for the last time – again for a reasonable bribe. We buried our father at an unearthly hour of 1 AM, and I like to think we did what we could.

Following day, I went into a hospital to get myself checked. I wore 2 masks (N95 and a normal mask) every minute I spent in the hospital, used at least one 100ml hand sanitizer a day and still somehow, I had contracted Covid-19. I was asked to get admitted into the hospital. I showed no symptoms, no sore throat, cold or fever. I was kept in observation for 5 days and was later let go to be quarantined at home. I came back to what was left of my family. My brother was recovered and so was my mother and sister.

Looking back, it is evident that we wasted few precious days, where my father direly needed medical attention. What we thought was a simple cold due to weather change was secretly turning in to pneumonia in my father's lungs. The frightening things that we exposed ourselves though media ensured that we did not step out of the house even for medical reasons. My father was afraid that he would contract Covid-19 if we step into a hospital. Ironically, all of us did.

In the whole process we were not given any option but to follow the suggestions of the doctors. Doctors were though emphatic and tried best to answer our queries. They always seemed visibly tired and drained of energy. It's hard to understand their problems and easy to turn a blind eye to what they are going through. In fact, doctors were the only set of kind people I got to speak in this ordeal, and others just meant business.

I honestly wish people would come out and get the medical assistance as soon as they encounter any health-related problems. I wish Vaccine (when it comes) to be effective and be available to everyone in need. And I wish no one to go through the things me and my family did".

Case 2

"Being a photojournalist, I was keen on documenting the COVID-19 outbreak, but a phone call changed my life altogether".

"I had undergone swab test after a few of my colleagues had tested positive". Soon, I received the dreaded phone call from Municipal Corporation and was asked about my whereabouts, and was informed that my report is positive." "My first instinct was to safeguard my family. I rushed home, while maintaining safe distance, broke the news to my family and waited outside for the ambulance to arrive".

"I was informed by another friend who had tested positive that asymptomatic patients will be quarantined at a hotel for the next 14 days. As it seemed like it would take some time for the ambulance to arrive, I decided to head to the hotel in my car".

"Once I reached there, ground reality of this horrid pandemic hit me. It was clear that people were treating us differently and we had become 'untouchable'. Even the hotel staff maintained a six-feet distance while providing us essential items. The next day we were informed that we would have to collect food from near the elevator".

"I got the information that some of my neighbors have also become COVID-19 positive and the society would be sealed for the next 14 days. I felt guilty that other residents were forced to stay indoors because of me and my friends and was worried for my family's health. Soon we were informed by a doctor that patients suffering from co-morbid conditions such as hypertension and diabetes will be shifted to another hospital. I was among four media persons who were shifted".

"At the hospital entrance gate, all of us were sanitized, including our bags and, the ambulance we had traveled in. I was admitted in a ward reserved for COVID-19 patients.

"On the third day a second swab test was done, followed by an ECG and a basic parameter check. I was worried about by family, they had undergone the swab test too, thankfully they did not show any symptoms".

"To distract myself, I started interacting with the hospital staff, who were involved in the COVID-19 fight despite the risks involved. During my stay I interviewed a very modest cleaner, who said "I do my job wholeheartedly; I don't know if it is great work. I only hope that if I get infected and die, I will be called a shahid (martyr). I am glad my family supports the work I do for patients and my country,".

I also got the chance to interview an auto driver who worked at the hospital premises. He said "Once the lockdown was imposed, my daughter asked me if I would be interested in working at the hospital, where she is employed. I immediately said yes. It is better to do something good for others than sit and whine about the situation."

"On the fifth day, my third swab test was done and the doctor informed me that my second swab test had come out negative but my third test results will decide if I will be discharged. On the sixth day I received the good news that my parents had tested negative".

I also interviewed a government staff nurse, who was working at the hospital's covid care unit. "Whenever I returned home after my duty, my neighbors would stare at me as if I was a terrorist. I was sad and applied for a transfer," said the staff nurse, she was later accommodated at a hotel. "At the end of that day, Dr Y, told me that I had tested negative in my third test. My joy was unparalleled. As I packed my bags, many of the hospital staff took selfies with me. I was also given an enthusiastic welcome by members of my housing society and it truly humbled me. Even as I was under home quarantine and can only catch passing glimpses of my princess (my daughter), I feel fortunate to have come out of this nightmare, to wake up in the safe confines of my home"[(4)].

Case 3

A fully recovered, male COVID-19 patient, from Bengaluru, Mr Z said, "I am doing perfectly well now. I came in contact with many travelers due to my travel to a foreign country, I might have contracted the infection there." He also added, "When I returned back to Bengaluru, I had temperature, I isolated myself and went to a hospital where my travel history was noted down and I was tested positive for COVID-19. Next day, I was admitted to the isolation centre. Fortunately my entire family was tested negative." "COVID-19 is similar to any other viral fever, nothing to be scared of. Unlike hospitals where doctors and nurses takes care of the patients, at the isolation centre patients have to take care of themselves, ", said Mr Z [(5)].

RESULTS

The case series illustrates the ordeals and experiences of COVID-19 patients during the course of the disease. The Covid-19 patients as discussed in the cases were not given the Autonomy of choosing their hospitalization or their treatment[(6)]. In case 2 the principle of beneficence which is a prima facie has been over

ruled by the principle of utility[7]. The principle of justice to provide treatment to the patients and equal opportunity for best treatment has been at odds. With the limited knowledge of the disease, its spread, its changing pathogenesis, nonmaleficence is also at stake[9].

DISCUSSION

The above case series illustrates the ordeals and experiences of the patients affected by COVID-19 during the course of the illness. With the onset of global pandemic COVID-19 affecting most of the countries, ethical medical practice is at a stake. Patient's Autonomy being a key concern in biomedical ethics is widely hampered. Patient 's Autonomy emphasizes on the rights of the patient and freedom of the patients to decide upon the health care interventions[6]. The covid19 patients as discussed in the above mentioned cases were not given the autonomy of choosing their hospitalization or their treatment. This global pandemic situation has inevitably withdrawn the autonomy of the patients in most situations. It is clear that a COVID -19 patient has to face many hurdles and obstacles to not only get treatment for COVID-19, but also to even get tested for the disease. In such a scenario maintaining the patient's beneficence and the principle of utility is yet another challenge. In case 2 the principle of beneficence which is a prima facie has been over ruled by the principle of utility as seen in other similar studies[7]. It has been stated that "The principle of utility under the general principle of beneficence implies that the interests of the society as a whole should override the individual interests and rights" [8]. India being a developing country with its large population, it is difficult to prevent or control the spread of a pandemic, in such a situation beneficence of the patient stands as a conflict.

Whereas few articles state that certain situations wherein critical decisions has to be made by the patients' attendants or the patient themselves has put them into untold stress[9].

Though the health care system is trying its best to provide quality affordable health care which is accessible to everyone, however due to the disproportionate increase in number of positive cases, and deficiency of infrastructure, man power and medical equipment with respect to health care facilities, the principle of justice to provide treatment to the patients and equal opportunity for best treatment has been at odds.

Nonmaleficence which states that "A medical practitioner has a duty to do no harm or allow harm to be caused to a patient through neglect". In this situation where the benefits of intervention has to be weighed against the risks and consequences and that occasionally no treatment would be the best treatment, [10] and with the limited knowledge of the disease, its spread, its changing pathogenesis, Non maleficence is still at stake.

Our study emphasizes that in this covid-19 pandemic era apart from medical ethics, the social ethics also remains at a stake. COVID-19 patients in all the above cases are stigmatized by the society and made to undergo a lot of mental harassment besides fighting for their life. Similar situations may arise in future with unforeseen situations for which ethical medical practice may become a challenge to the health care practitioners.

Limitations of our study is that all the above illustrations were taken from the patient perspective but opinion from the health care professionals were not considered. One can further extend the study from both the ends which can justify the situation.

CONCLUSION

From the above case narrations it is clear that COVID-19, not only affects the physical health, it also takes a toll on the mental health of the patients and their attendees. At the same time following the key components of the ethical medical practice i.e. autonomy, beneficence, non-maleficence and justice has been a mirage for the health care providers. The increasing no of cases, lack of knowledge and ignorance from the general population has added to the burning problem. During these hard times, the society also should empathize with the patient and their family members and also with the health care system and support them during these trying times. The regressive mind set of the society can be changed by proper education and awareness about the illness.

REFERENCES

[1] Subramanian T, Mathai AK, Kumar N. Knowledge and practice of clinical ethics among healthcare providers in a government hospital, Chennai. Indian J Med Ethics. 2013;10:96-100.

[2] Feroz Ahmad Wani, Rouf Hussain Rather, Mudasir Ahmad. Self-reported unmet healthcare needs during coronavirus disease-19 pandemic lockdown Int J Med Sci Public Health. 2020; 9(9): 503-507

[3] Available from https://weather.com/en-IN/india/coronavirus /news/2020-04-22- delhi-first-covid-19-survivor-shares-harrowing-experience.

[4] Available from https://www.indiatvnews.com/news/india/mumbai-journalist-defeated-coronavirus-recalls-quarantine-experience-612558.

[5] Available from https://economictimes.indiatimes.com/news/politics-and-nation/bengaluru-man-shares-experience-of-recovering-from-covid-19/videoshow/74918318.cms?from=mdr.

[6] Schneider CE. The practice of autonomy. New York: Oxford University Press; 1998.

[7] Mawere Munyaradzi[1,&] Pan Afr Critical reflections on the principle of beneficence in biomedicine Med J. 2012; 11: 29.

[8] Tom L. Beauchamp, Laurence B. McCullough, Book Occupational ethics series : Medical ethics : the moral responsibilities of physicians; 1984: p. 27.

[9] Vikki A. Entwistle et al Supporting Patient Autonomy: The Importance of Clinician-patient Relationships. J Gen Intern Med. 2010 Jul: 25(7):741–5.

[10] Steven J Girdler et al , Nonmaleficence in medical training: Balancing patient care and efficient education, Published online: December 12, 2018 DOI: https://doi.org/10.20529/IJME.2018.100