



Bioethical and Human Right Considerations during COVID-19 Pandemic Period: Reflections of Integrated Oncology Clinical Services from India

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Abstract

Ever since the outbreak of COVID-19, the global health care systems are overwhelmed to cope up with the rapidly evolving disease paradigm through implementation of action plans at societal and medical domains. As per the directives from the World Health Organization and learned professional organizations, the international governments and states have formulated different protocols to prevent disease spread, for diagnosis and treatment of the disease and associated comorbidities, and to educate citizens during this crisis phase. Health care services across the world followed a “prioritizing strategy” for hospital population wherein the non-COVID cases were given less focus. Many hospitals opted for a conscious staff-sparing strategy to minimize exposure and protection of clinically valuable staff. Oncology services across the world reported a decline in the provision of clinical services to patients. There were medical concerns such as missed diagnosis, delayed diagnosis, delayed treatment, stoppage of screening programs, and differed follow-ups during the last 2 years of pandemic. The multidisciplinary oncology teams aim to ensure that cancer patients in the continuum of integrated cancer care pathway get globally accepted standards of optimum care. However, Beauchamp’s ethical principles of autonomy, beneficence, nonmaleficence, and distributive justice were arguably compromised during the pandemic period. The

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articles of UNESCO Universal Declaration on Bioethics and Human Rights (UDBHR) declaration were possibly violated in cancer patients as a vulnerable population. This article analyses the bioethical and human right concerns with respect to medical and societal domains in oncology during the COVID-19 pandemic period.

Introduction

Bertrand Russell's quote in *History of Western Philosophy* (1945) "To teach how to live without certainty, and yet without being paralysed[sic] by hesitation, is perhaps the chief thing that philosophy, in our age, can still do for those who study it" reflects the global uncertainty the humanity is facing for the past 2 years.¹ In December 2019, cases of pneumonia with unknown etiology were discovered in Wuhan City, Hubei Province of China,² and this quickly spread across the world to trigger a global pandemic and caused grave misery and deaths worldwide including in India.³⁻⁵

COVID-19 brought in a plethora of events that impacted health care not only as a disease on its own but also other diseases. Cancer patients were left stranded mid-therapy, thus worsening their prognosis. The COVID-19 pandemic caused significant fatalities and highlighted both the advantages and drawbacks of global health care systems.⁶ Even after 3 years since the initial report, the virus continues to mutate, and in spite of global vaccination initiatives, it still infects and spreads, thus challenging the health care providers and health care systems globally.⁷⁻¹¹ This uncertainty about future and unpredictability of this disease have led to multiple medical and ethical dilemmas in oncology¹¹ reflecting its impact in a clinical service model.

Impact on Oncology

Patients with cancer are obliged to attend health care institutions more frequently than patients with other diseases because of the nature of the disease and its many treatment techniques. Multidisciplinary teams must be fully involved in the treatment of cancer patients at all stages of the disease, from diagnosis through survivorship or end-of-life care.^{12,13} In addition to various therapeutic interventions, cancer patients need multiple hospital visits for assessment, diagnosis, staging, or monitoring the effects of treatment. As any unjustified divergence from the well-established norms may result in fragmented and subpar care and affect patient outcomes, these clinical services should operate in harmony and on schedule with strong dedication and compliance from both patients and health care workers.¹⁴

When compared with the general population, cancer patients are known to be vulnerable and susceptible toward airborne microbial infections and are at increased risk of hospitalizations and mortality due to the ensuing pathogenesis.¹⁵ Regarding COVID-19, research from China has indicated that there was no rise in the prevalence of COVID-19

infection in cancer patients compared with the general population. However, cancer patients showed a higher incidence of serious events such as hospitalization, respiratory complications, and need for care in intensive care units.^{16,17} Health services were overburdened during the epidemic principally because COVID-19 care was given priority over other illnesses.^{14,18,19} The health care sector was stalled by the fear of COVID-19 transmission in both the public and health care practitioners. In these uncertain times, oncology and health care settings concentrated on four key areas: (1) to protect patients from contracting SARS-CoV-2 and reduce the risk factors for COVID-19-related mortality in the case of infection; (2) to stop COVID-19 from spreading throughout health care facilities and the general public; (3) to reduce the danger of COVID-19 transmission to health care personnel; and (4) to properly distribute resources among all patients during a period of resource shortage.²⁰

Global Data from Oncology Service Sector

In the course of the pandemic, the number of cancer patients receiving diagnoses and treatments decreased significantly, according to several cancer centers and societies around the world. According to studies, the pandemic had a significant impact on all facets of cancer care, including screening, diagnosis, treatment, palliative care, and follow-up. For at least a fraction of the individuals who would have received a cancer diagnosis during this time, it is likely that these decreases led to delayed diagnosis and inadequate treatment. Thus, the negative consequences of COVID-19 significantly affected the cancer patients across the globe. To substantiate this, seminal studies by Jazieh et al¹⁴ and Ranganath et al²¹ reported that a big majority of cancer patients were exposed to varying degrees of harm in the pandemic, including individual, societal, medical, and ethical problems.^{14,21}

Doctor–Patient Paradigm and the Principlist Approach

The unanticipated interruptions in cancer care pathway had detrimental impact on the timely diagnosis and treatment of cancer. The above studies clearly show that cancer care was suboptimal and ethical concerns were evident during this period. In cancer care, a stronger trust and bond form between patients, families, treating physicians, and the support staff because the condition is serious in nature and treatment lasts over longer periods of time. For the patient's physical and mental health, as well as their

compliance with treatment modalities, the development of positive trust and a strong understanding between the oncologist and the patient is crucial, which was affected during the pandemic.^{22,23} Unfortunately, the recommendations and measures put forward during the COVID-19 pandemic period failed to take the feelings of cancer patients and their morale into consideration, jeopardizing the desired trust-based physician–patient relationship.²⁴

When the situation is analyzed according to Beauchamp and Childress' four ethical principles of beneficence, non-maleficence, autonomy, and justice, the oncology services during the pandemic faced immense challenges. Deviation from the standard treatment plan, reduced number of treatment sessions, and delayed follow-ups would upset cancer patients, make them feel neglected, and pose risk to their lives.²⁵ This shows denial of beneficence and imminent harm or maleficence, which was compounded by uncertainty and suboptimal standard of care during the pandemic.²⁰

Autonomy of cancer patients during the pandemic was infringed upon as a sequela to this. The decision-making to proceed with cancer treatment was not in the hands of patients or their families although potentially fatal risk is theoretically more associated with cancer than with the pandemic itself. The uncertainty, fear, and anxiety associated with possible SARS-CoV-2 infection influenced the patients' decision regarding their treatment. The situation was worse in people who developed recurrence or metastasis as immediate therapeutic interventions were not easily available. Due to the lockdown, there was acute shortage of anticancer and supportive drugs, and break in supply chain. This shows how nonmedical social contexts that are vital, can interfere with the ethical principles embedded in health care delivery.

Social justice and equity were skewed unfavorably, thus vitiating the fourth principle, which states that all patients should be treated equally.²⁶ However, an equal treatment does not mean the same treatment for all. The COVID-19 pandemic was an eye opener detailing the imbalance between medical needs and the available resources in health care systems across all nations. This resulted in clinical decisions that affected patient access to necessary care, quality-of-life, or end-of-life situations violating a patient's rights as an individual.¹⁷ In terminally ill cancer patients, the futility of the treatment and choosing less aggressive life-saving interventions would have been the observed protocol, which is generally substantiated even in non-COVID periods in the past.^{27,28} From the clinicians' perspective, dilemma occurred when patients with a high chance of cure and a long life expectancy, like early breast cancer, get neglected due to circumstances, which jeopardized all four ethical principles negatively in clinical oncological services.

Universal Declaration of Bioethics and Human Rights Perspectives

When the pandemic health care services are analyzed within the scope of the Universal Declaration of Bioethics and Human Rights,²⁹ the national and international guidelines and restrictions imposed on the general population were

infringed upon. These aspects said in the articles and guiding principles are described in subsequent paragraphs.

Article 3: Human Dignity and Human Rights

Imposing travel restrictions lead to inconveniences to access of patient care. The right to health care and patient's expectation to be treated in illness in a dignified manner were not always met within global contexts as reflected in studies.

Article 4: Benefit and Harm

This reflects Beauchamp and Childress's³⁰ principles of beneficence and nonmaleficence. Studies show many clinical trials and research activities faced setbacks²¹ delayed treatment. This hampered the expected health benefits and possibly caused harm to patients. These aspects need to be revealed in future studies. The risk-benefit ratio in COVID plays a great role in imparting effective health care despite the lack of evidence was followed Social distancing and other clampdown measures require rethinking based on the benefit and harm principles.

Article 5: Autonomy and Individual Responsibility

For those who have had access to care, oncology services followed this as the standard operating procedures. However, prioritization of care in resource-limited settings affected the autonomy of the patient, as explained earlier. Mandatory vaccination, emergency use, and reuse of drugs should be with the choice of the individual patient and not just for the common good.

Article 6: Consent

Most nations experienced deficits of manpower of health care workers and infrastructure, access to care, and availability of medicines. During the COVID period, the additional comorbidities associated with the pandemic made the situation worse. There were reports wherein the patient's right to consent for a given intervention would have been affected as many were alone at critical stages of the disease and the health care team or the institutional guidelines decided on triage, treatment, and end-of life decisions without respecting this important principle.

Although many clinical trials were halted during the pandemic,²¹ there were global efforts in vaccine development and clinical trials. Participants at multinational centers underwent explicit consent protocols in accordance with article 6. Policy decisions notwithstanding, informed consent forms an integral part even in such a dire situation of COVID.

Article 7: Persons without the Capacity to Consent

It is evident that the pandemic caused panic and chaos within the health care sector. There were instances wherein

the general conditions of many cancer patients during their course of treatment suddenly deteriorated, and isolation protocols and a large number of incoming patients burdened the daily functioning of cancer centers. It is expected that in the absence of family members in attendance and in poor general conditions, the provision of special protection available to the cancer patients was suboptimal or compromised.

The pandemic outbreak witnessed many therapeutic interventions that were not evidence based such as post-convalescent plasma infusions, antimalarial drugs, and certain antiviral agents, to name a few. The medical fraternity utilized them without scientific evidence and many patients suffered complications of such research interventions as COVID-19-related complications.

Article 8: Respect for Human Vulnerability and Personal Integrity

Cancer patients are vulnerable and depending upon their stages in continuum of care, the ability to provide consent varies. When there is a shift from Kantian utilitarian principle at early stages of treatment to a patient-centered deontological approach at later stages, the ethical framework changes from a health care provider's perspective. In advanced end-of-life situations, a family-centered approach sets in wherein family takes decisions on behalf of a vulnerable relative. These ethical paradigms in cancer care were affected due to COVID-19 protocols and affected the human rights of such patients as well. Vulnerability is universal in these COVID times, leading to the crossing of barriers that would otherwise not have been reported.

Article 9: Privacy and Confidentiality

In many countries, the initial panic reaction after disease outbreak led to disclosure of patient identities and family whereabouts in the media. In an attempt to "keep safe," many digital platforms were launched and the societal impact of those initiatives is yet to be analyzed with regard to data protection and patient confidentiality. Another issue was how the patient's privacy and confidentiality were protected in crowded hospital wards, hospital corridors, and in do-or-die situations. The nature of the disease and associated comorbidities played a huge role in cancer care settings competing for access to care in compromised infrastructural conditions.

Article 10: Equality, Justice, and Equity

Beauchamp and Childress's³⁰ principle of social justice echoes here. Duration of cancer treatment is lengthy and requires multiple visits to the health care facility. When the provisions of cancer services were affected due to the pandemic protocols and allocation of resources, patients did not receive the aspect of equality grounded in article 10 as non-COVID patients belonged to a lesser priority category from the service providers' point of view. As they were a medically compromised vulnerable population, priority for vaccination was ensured in

the majority of nations for cancer patients. Enforced lockdown, quarantine, and restricted movement of persons across district/state borders could also trespass the lines of justice in access to care.

Article 11: Nondiscrimination and Nonstigmatization

In many communities, stigma still exists for cancer patients; however, cancer awareness programs work in a positive manner to eradicate such fears at the societal level. Unfortunately, during the initial phase of the pandemic, panic and chaos among the general population created unrest and fear in the realm of social psyche. This resulted in inadvertent isolation strategies wherein COVID-positive patients were discriminated and stigmatized in many communities. Denial of access to cancer care resulted as sequelae to this. Declaration of the names of COVID-afflicted patients could lead to positive discrimination. Surprisingly stigmatization did not rally as the infectious period of the disease was short and a multitude of people were affected by the disease in a short period.²⁷

Article 12: Respect for Cultural Diversity and Pluralism

The observable trends in general hospital population influenced the paradigm of cancer care services also. Many cancer patients in end-of-life situations were forced to spend their last days in isolation away from family and friends. There was lack of access to perform their religious rituals from a spiritual perspective. Further, many COVID-positive dead bodies were cremated in mass graves in the absence of family members. Due to the fear of spread of the disease, the utilitarian approach enforced by the governments violated article 12 in many instances. Being a pandemic, indigenous traditions were acceptable at times, helpful to some extent, but many required diametrically opposing changes.

Article 13: Solidarity and Cooperation

The pandemic was an example of human beings raising their collective conscience as a species through solidarity and transglobal cooperation. International efforts in preventing the disease, vaccine development, and vaccination drives illustrate this aspect. Although there was a palpable decrease in cancer services across nations, communities of different cancer support groups, NGOs, and professional associations gave advice and support to patients mainly through digital platforms and social media. This pandemic witnessed the coming together of people voluntarily to dispel the afflictions in myriad avenues.

Article 14: Social Responsibility and Health

Under the supervision of WHO and opinions from the international panel of experts, governments worked for the good of all—a utilitarian approach. Professional organizations gave updates on treatment protocols through public health

initiatives. The benefits aimed at the general populations to which cancer patients form an integral part.

The highest attainable standards of care were not achievable in the first year of the pandemic as humanity was not prepared for such a large-scale global catastrophe. The disease affected both developed and developing nations, and different income categories of countries alike. There was shortage of cancer medicines and other lifesaving or supportive care essentials, and supply chain worked hard to keep up with the demands. This was due to logistical hardships in procurement of pharmaceutical agents, infrastructural issues, and suboptimal productivity of drug manufacturers during that time. Loss of jobs and income affected many cancer patients and there were many cases of skipping the treatment due to financial constraints.

The pandemic was a testing time in terms of personal responsibility that fell upon the shoulder of every individual. In addition to maintaining social distancing, quarantine, and other security measures, the spread of false information and news regarding the disease was a challenge to achieve. Isolation for prolonged periods and uncertainty in job prospects coupled with fear and anxiety took a toll on the mental health of a lot of individuals. This was not adequately addressed during the time.

Article 15: Sharing of Benefits

The pandemic witnessed a well-focused and accelerated research program in an attempt to contain, treat, and prevent COVID-19 infection. The changes that led to a paradigm shift in medical developments were shared at international platforms, and efforts to share those benefits were evident transnationally. An example would be vaccine development and provision of its availability in nonmanufacturing countries through sharing of technological assistance and international treaties. This also included capacity building, clinical trials, and training workforce in the fight against the disease. Sustained efforts in this domain halted many routine cancer-related research and screening programs, which could have a detrimental effect in upcoming years. In the wake of the pandemic, the focus of the scientific community and the public was the international sharing of information on a variety of topics regarding the viral genome, mode of transmission, incubation period, vulnerable groups, signs, and symptoms. Information on all these was valuable.

Article 16: Protecting Future Generations

The true biologic impact of the disease on the future generations is still unknown. The virus by virtue of multiple cycles of significant mutations illustrated unpredictability of human disease development and its impact on medical science and social well-being of individuals. Vaccinations could prevent or reduce the seriousness of the disease as of omicron variant of COVID-19. The manner in which vulnerable cancer patients may be affected with subsequent significant mutations of the virus is unknown, which adds to the uncertainty to the future.

Article 17: Protection of the Environment, Biosphere, and Biodiversity

There are debates on the initiation and mode of spread of COVID-19 virus to the first human host. Investigations on the developmental biology of the virus, its viral signature, may shed light on the mystery of whether it was transmitted from across species (putatively from bats) or was artificially created under laboratory conditions. In either case, article 17 details the need for respect while dealing with environment and preserving our biosphere. Adaptive laws and policies are required to integrate new environmental and health knowledge in specific socio-ecosystems. Respecting and nurturing the biodiversity of the planet also means holistic interactions within sociocultural contexts and preserving and protecting animal and human health along with environmental health.

Article 18: Decision-Making and Addressing Bioethical Issues

Promotion of professionalism, honesty, integrity, and transparency in decision-making reflects here. The brunt of the disease bore heavily upon the health care workers during the pandemic. However, the professionalism and true workmanship of many supporting systems were put to test during the pandemic. Intergovernmental and interdepartmental consensus on strategic planning and care delivery resulted in issues on triaging patients, resource allocation, and prioritization. Bioethical and human right issues were identified and addressed in vast majority of situations. But the unprepared and overwhelmed systems were coerced into making decisions on ethically debatable scenarios that violated patients' human rights. The most important example was, waiting for ventilators or oxygen supplements to be made available for the needy. Cancer patients in continuum of care were harmed in these compromising scenarios.

Health professionals engaged globally through open dialogues and debates since the disease was declared internationally. Along with other specialists, professional organizations and researchers in oncology took part in those professional discourses and expert consultations while addressing specialty-wise health concerns. Setting up telemedicine services with inputs from treating centers proved helpful in addressing patient concerns during these times.

Positive Outcomes

Ranganathan et al²¹ pointed out some positive outcomes from the COVID-19 pandemic. This includes (1) global realization of the need for a strong public health care system; (2) prioritization of oncology treatments based on value and outcomes, both from a monetary and a patient-benefit viewpoint, emphasizing the importance of value-based care³¹; (3) accessibility of cancer care closer to home that encourages a distributed model of care; (4) adoption of digital platforms such as teleconsultations and video consultations in health care systems, which increases the

efficiency of cancer centers; and (5) research demonstrated that large-scale practice-defining trials can be both pragmatic and reliable, and modification of cancer trial protocols led to more efficient and practical ways of doing clinical research, for example, follow-up evaluations nearer to patients' homes and less frequent imaging in oncological services.^{32,33}

What Is Next?

In many countries such as India, patients choose their cancer treatment center based on the personal preference of a named consultant of repute, goodwill, specific skill, or facilities available there. Travel restrictions during these times forced many patients to seek treatment at a nearby facility due to logistical reasons. This trend changed once free travel was possible. In future, telemedicine and video conferencing may be practiced routinely for regular follow-up of distant patients. It is expected that the cessation of different screening programs and reduction in diagnostic services would lead to missed diagnosis, delayed diagnosis, and delay in treatment, which can lead to overall increase in cancer mortality and public health burden in the next 5 years.²¹ As Indian yogic teacher Sadhgurujji said, "*every uncertainty is a tremendous possibility. What needs to be fixed is not uncertainty, but one's interiority to handle it.*" The medical profession will come up with solutions for these anticipated challenges that we face today, and the learned optimism and faith in our fraternity are the way forward for our uncertain future.

Conclusion

Myriad ethical issues plague the oncologists in delivering their integrative clinical services in the pandemic era. Certain issues that came to the forefront were unprecedented. Problems like moral distress and looking on at inevitable grim endings need to be actively countered by willful inclusion of proactive measures. Solidarity, dignified respect, and concern for future generations and the environment are the way forward. The indisputable faith invested in the health care systems should never be compromised, and this will be facilitated by affirming to uphold the principles of UDBHR adopted in 2003 at the UNESCO General Assembly, Paris. COVID has propelled the citizens of the world into unprecedented uncertainty and suspended animation. Despite grappling with the unknown disease entity of SARS COVID2, the health care community needs to use and deliver. The HCW were the need of the hour and yet resisted due to the stigma of infectiousness. The general public need to come to terms with battling the new disease with unfamiliar tactics. The present illness pales in comparison with the potential to be infected with an unknown disease. We further realize the scope and applicability of UDBHR in those global medical emergencies from the bioethical and human rights perspective.

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Conflict of Interest

None declared.

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