Death and Dying in the times of Covid

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The Corona pandemic has brought out many fundamental questions from a wide landscape into the public arena. Ranging from the preparedness of our health care system, inequities in society, the limits of science to even existential questions about the future of the planet.

One disturbing and yet profound discussion it has raised is about death, its mode and the circumstances. This is inevitable. Humans are dying in large numbers all around us often in a sudden manner and sometimes in very tragic surroundings and circumstances. Death is affecting everyone, the rich and the poor, the developed and the developing world. Of course, in countries like India, death has also been undignified and inhumane. In a city like Mumbai which is glorified for its so-called spirit and modernity, the stories of desperate patients moving around from hospital to hospital looking for a bed and dying for want of oxygen are some examples.

This pandemic has touched all of us. Most of us will know someone who has succumbed to the disease. It has halted us in our tracks. It has given us time. This has forced many of us to reflect on our own fragility and impermanence. I have no illusions that to reflect on a difficult area like death in a small piece of few words is impossible, if not simplistic. And that my perspective is necessarily biased by my role as a health provider.

There is no doubt that people in India are living longer with the average life expectancy shifting from around 40 years at independence to around 70 now. Of course, this is still lower than that for many developed countries. The cause of death has changed from predominantly infectious disease to heart disease, cancers and neurodegenerative disorders. Also advanced health care has developed though in a skewed manner. But this also means that the elderly population has increased and our ability to prolong life has improved. Though part of this is due to advances in health care, it has much to do with prevention and treatment of infectious disease including effective vaccines.

We must also note that the system of recording cause of death in India including death certificates is fraught with a lot of inaccuracies. In any case there are a lot of deaths in rural India in which the cause of death is not even recorded and hence not known. The work of Prabhat Jha & associates in the well-known Million Death Study in several underdeveloped districts of India through verbal autopsy showed this in a very stark fashion. We still don't know the precise reason why many of our poor citizens in rural India die as they pass away at home and never get a death certificate.

Death is said to be a great leveller but that is only partly true in divided societies. Perhaps, only in the physical sense. In fact, if there is anything remarkable about the feature of the process of dying in India, it is the difference in the way the poor and the rich die. Even Covid is bringing out this dichotomy.

What's happened in India in the last few years that has impacted the process of dying? How has the growth of large hospitals and ICUs affected this process? There are certain relevant developments worth looking at.

The first is the legislation and acceptance of the idea of 'brain death' as opposed to 'cardiac death' Does everyone die in the same way or are there different ways of dying? Things were rather easy when death was equal to stoppage of the heart. But inevitably, the world of medicine with its sense of observation and yearning for scientific reasoning, recognised, somewhere in the middle of the last century, that the brains of some individuals hooked onto support in ICUs were dying first, inevitably followed by the heart after some time. The huge progress

in the science of resuscitation, organ support and intensive care while saving many lives resulted in an increasing number of such individuals, who were soon termed “brain dead” but whose hearts were still beating. The damage to the brain was irreversible, complete and inevitably, the heart had to follow within hours, or sometimes days. More than fifty years after it was recognised and then legalised, the concept of “brain” death as distinct from traditional “cardiac” death remains enigmatic, complicated and still lends itself to doubts. From questions around its scientific validity, to the accuracy of the diagnosis, to its application in the context of organ donation, brain death has been subjected to intense technical, ethical and philosophical analysis.

By now, in many countries across the globe, brain death is legally accepted as death, though the criteria for declaring it differ marginally from country to country. Donation of organs in the state of brain death, when the organs are perfused with blood, contributes to a larger proportion of organs available for transplants. In addition, once brain death is declared, if organ donation is not possible, either for medical reasons or lack of consent from the family, the medical supports which include a ventilator are actively withdrawn. It is intuitive that it is futile to keep a dead person hooked indefinitely onto multiple supports including a ventilator.

India formally recognized brain death through the Human Organs Transplant Act of 1994. Following this deceased donation is now being performed regularly in some states, which means brain dead individuals in a way are being disconnected from the ventilator. There is an interesting and disturbing situation in India right now. If the family of a brain dead individual agrees for donation, the organs are removed for transplant. However, if the family refuses to donate, the same ‘dead’ individual is kept in the ICU on a ventilator till the heart stops. This has led to ambiguity around the idea of brain death. It is perhaps a reflection of our hesitancy to withdraw treatment in a futile situation.

Amongst the myriad ethical challenges that Corona has thrown up is the question of how the elderly with a host of comorbidities should be treated. How far should the treatment go? Is it a good idea for them to die in ICUs alone and hooked up to machines and monitors? Also given the relative shortage of beds, issues of rationing of limited beds have also been thrown up globally, though in India the

rich anyway get their way if they want a hospital bed.

We live in a country and a culture where there is a fairly strong religious and spiritual discourse around death. But strangely issues like terminal illness, withdrawal of care and even euthanasia have not received the attention they should. Though ideas of 'futile' care of the terminally ill and euthanasia in some form has not only been intensely debated globally but even legislated. Simultaneously, the palliative care movement has grown in strength and spread across the globe.

Historically, one could say that in Indian culture (if indeed there is a monolith like that) there have been concepts like Samadhi. The Jain community continues with practices like 'Santhara' & 'Sallekhana'. These seem to be some sort of a voluntary renouncing of life as distinct from suicide.

A recent big push to the discourse in India about terminal illness, end of life care and withdrawal of care came with the national interest around the tragic story of Aruna Shanbaug. Aruna had been in a permanent vegetative state since 1973 after she was raped by a hospital employee Sohanlal Bhartha Walmiki. He asphyxiated her with a dog chain, and the lack of oxygen damaged her brain. Shanbaug, who was 25 years old at the time of the assault, was admitted and looked after by the state government-run hospital till her demise in 2015. Anyone else would have died but the nurses, kept her alive for over four decades—bathing her, turning her to ensure that she wouldn't get bedsores, and feeding her through a tube.

In 2009, journalist Pinki Virani who had written a book on Shanbaug moved the Supreme Court through a Public Interest Litigation (PIL) seeking to become her 'next friend', as Shanbaug's kin had either died, or were unable to look after her. A next friend is appointed to take essential decisions for a person if they are unable to do so themselves and in the absence of a legal guardian. She asked the court to allow passive euthanasia be allowed for Shanbaug. The 2011 judgment, an outcome of this litigation, declared the KEM hospital staff, instead of Virani, as next friend. The nurses, in turn, chose not to stop her treatment.

In 2011, a 110-page judgment delivered by Supreme Court Justices Katju and Gyan Misra heard the case and ruled that in cases of irreversible illness, and after a

thorough medical evaluation, passive euthanasia should be permitted. The judgment provided strict guidelines for it, which involved clearance by a high court. This was never implemented.

Simultaneously an NGO called Common Cause had filed a plea in the Supreme Court asking for citizens to have a right to formulate a 'living will' about what they would like to be done in case they are terminally ill. A living will is a concept where a patient can give consent that allows withdrawal of life support systems if the individual is reduced to a state with no real chance of survival. It is a type of advance directive that may be used by a person before incapacitation to outline a full range of treatment preferences or, most often, to reject treatment. A living will provides a person's preferences for tube-feeding, artificial hydration, and pain medication when an individual cannot communicate his/her choices.

In another landmark judgment in 2018, the Supreme Court recognised passive euthanasia and "living will". However, they proposed a rather complicated mechanism to do so. Passive euthanasia will apply only to a terminally ill person with no hope of recovery, the panel of five judges said. Active euthanasia, by administering a lethal injection, will continue to be illegal. They have suggested to the parliament to enact a law.

Death is inevitable. Every human being is aware of that though the awareness may vary. However, the tragedy of India is that not everyone gets peace in death. On one hand it can be cruel, undignified and preventable. This is the case for a lot of India's poor. Many of them succumb to delay or lack of treatment. The large number of accidental deaths on India's roads is an example of this where effective treatment in the first 'golden' hour is almost non-existent or; the continuing large number of deaths due to tuberculosis. And now Covid.

On the other hand, the rich now have a high chance of dying in hospital ICUs hooked onto machines, comatose. By a system that has vested interest in keeping the terminally ill alive. The way people die is a good indicator of the evolution of any country's sense of solidarity for its citizens and maturity as a nation. In a sense, it's a development index.

In spite of centuries of a rich philosophical heritage modern India's approach to death is nebulous and of course dichotomous. In some sense it had to be. Covid has just brought it out into the public domain.