COVID-19 and the silent suffering

Talking point
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Death happens everywhere, but except in about 1% of people where death comes suddenly, it happens with a going, progressing illness which allows for some healing of the survivors’ wounds. But in COVID-19, death comes in the cruellest fashion, a loved one snatched away from the family in an instant, no one to be seen again. From the beating that is associated with high blood pressure to the rituals to follow is defined here. Medical parlance talks about pathological grief where normal healing doesn’t happen and limbs are left in emotional stasis. A support system has to be effective right now — not only for the next-of-kin to embrace acceptance and closure but also for the dignity of the dead.

In our attempt to offer more empathy and technology and advanced care, we have forgotten the healing touch, the personal hand and the idea of care for a fellow human being in distress. We allowed the global health care system to deteriorate to an entity that cures many diseases but ignores human suffering completely and unfortunately adds to suffering spectacularly.

Health is defined as “complete physical, social and mental well-being” and not merely the absence of disease or infirmity. If the treatment offered for a disease does cure it, but leaves the person a nervous wreck unable to function, and if it leaves the family financially destroyed, even denying education to the next generation, is it improving health? On the other hand, is it not actually destroying health?

COVID-19 has brought many inequalities to the surface. It has forced us to see things including deaths that so many of us so far had successfully avoided looking at. For a generation or two, we successfully denied death as the inevitable consequence of life. Health care systems have consistently kept people away from discussing it with their children or even with each other. If the process, death has become a stranger to be feared by everyone and an anomaly to be fought by the medical system even when the fight is clearly futile.

The four fundamental principles of medical ethics are autonomy, beneficence (doing good), non-maleficence (not doing harm) and distributive justice. In the context of COVID-19, we have not had a lot of opportunities to discuss these much but even amidst all our daily activity, it would be good to take a look at them.

Some day when we are all, you are likely to be taken to a hospital. Biblical in no way, as it has a right to anything to your body without your expressed permission.

That is theory. As Stephen met in the book, “in theory, there is no difference between theory and practice, but in practice, there is”. In the real health care world, once you are on a trolley, you are likely to be wheeled into room after room, from lab to imaging room to hospital to specialist after specialist, and you become an insignificant entity in the whole exercise. If you have to have an operation, your consent may be sought but if you are a bit delayed at that time, as is very likely in current practice, then the system may proceed with consent from your next of kin.

So, some violation of autonomy happens routinely in health care in the most advanced systems. In one report from Britain, they discovered that elderly patients admitted for a short-term medical problem were routinely catheterised (to empty the urinary bladder into a bag, so that they do not go to the toilet in incontinence). This is because there is no one to accompany the seniors to the toilet. The result: independent patients were catheterised and usually never returned to the ‘pre-hospitalisation’ state. If those are rates of conversion, and India has more of the same.

This routine violation of your right to die is amplified many times in COVID-19. First, autonomy is restricted because understanding someone’s condition is essential for consenting. Second, communication from families seems to be seen again. The family is denied the right to a final wish, before cremation. This violation, in a large extent, is justified because mankind needs to be protected. But at least the health care systems need to be cautious that such a violation is happening and needs to minimise its impact. We can’t afford to be oblivious to such monumental errors.

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Resilience and new realisations are rather obvious principles of ‘doing good’ and ‘not doing harm’. While isolation would be ethically acceptable, it is vitally important to ensure that the medical system minimises harm. And in this context, we should not be thinking only about treating the disease; there is no cure for the disease anywhere. We should be thinking about the well-being of the person and for this, mental and social well-being are vitally important.

If health care is physical, social and mental well-being, doctors and nurses need to be educated in scientific management of pain, breathlessness, delirium and other manifestations of COVID-19. This would have happened automatically if medical and nursing education had included palliative care; but it is only from 2020 that at least a part of it was included in the medical curriculum. Apart from doctors and nurses, certainly, a category of health care workers are needed to look after the social and mental well-being. The least we can do is to find out how the patient feels and to connect the person over a smartphone with relatives periodically. And also identify anxiety and depression that may become so bad that it may have gone off as a state of secondary serious mental illness.

The principle of justice demands fair allocation of available resources including the government kitty and the time of healthcare professionals. But fortunately, giving attention to wellbeing is not expensive. Services of medical social workers or counsellors with some online training will cost a fraction of what it costs to engage doctors. And it will actually reduce healthcare costs by freeing up the time of doctors and nurses to a significant extent.

The one major difficulty would be the resistance to change. But such change has already started and we need only official acceptance and an action plan. Over 300 doctors and nurses have already had online palliative care training in COVID-19 management in a programme conducted by the WHO collaborating centres at Tiruvanamalai under Pallium India. The national health mission of Uttar Pradesh and Maharastra have already taken an initiative in the matter.

The World Health Assembly resolution 73 on 19 May 2020 asked all member countries to include palliative care in their COVID-19 treatment plans. We seem to have been too busy to give much thought to this. But for rescuing the suffering of those infected with the virus and for the mental health of the survivors, the need of the hour is for a policy decision is needed to follow the World Health Assembly resolution, to give basic online palliative care education to COVID-19 treating healthcare professionals and to make essential medicines available.

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