



Jeevodaya Hospice

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Sr. Lilly Maria F.C.C., Chairman and President

From the Editors Desk

The whole world is under siege, as a deadly virus has created a pandemic shutting down places of worship, schools, and most public places. In the city of Chennai, we have seen the disease spread rapidly, forcing the government to declare one lockdown after another. This in turn has caused widespread financial hardship, bankrupting many. We have all been horrified by the images of migrants walking home, trekking miles to their home in other states, sometimes dying on the way. In the middle of this, cases of abuse are rising and mental health is deteriorating. Most of us sit at home chafing under restrictions of movement. Others like doctors, nurses, sanitary workers, and volunteers are in daily contact with those who are infected, putting themselves in danger to serve those in need.

The silver lining is that the earth subjected for decades to our heedless ravages, appears to be healing. Nature is recovering, pollution is dropping,

God's creatures are thriving gaining back the spaces that was once rightfully theirs.

Reflecting on the Gospel passage where the frightened disciples are buffeted by a storm that threatens to overturn their small boat, Pope Francis said, "We have realized we are on the same boat, all of us fragile and frightened, but at the same time important and needed, all of us called to row together". This storm, he said, has uncovered the falseness of what we considered important, our possessions, our egos, our pride, uncovering once more that blessed common belonging, our belonging as brothers and sisters.

Today, as we live under the shadow of the pandemic, it is a time for all of us to reflect on the meaning of our lives. It is a time to help all those we can. It is a time to bond with our families. It is a time to turn to God and pray. It is time to set aside differences of caste and religion, to rise above hate and division, a time to see each other as humans, all the children of the same God.

- Sr. Lalitha Teresa



PALLIATIVE CARE IN TIMES OF COVID-19 AND AFTER

Dr. Manjula Krishnaswamy

*'Life isn't meant to be easy, it's meant to be lived;
Sometimes happy, other times rough...
But with every up and down
You learn lessons that make you strong...'*

The world is now facing the worst pandemic ever, which none living now would have thought possible. An invisible speck called 'Corona' has brought the world down to its knees. All countries are reeling under impact of the deadly viral disease named 'Covid- 19' marching relentlessly, sparing no one. The carnage it has caused is indescribable. But there

is always light at the end of the tunnel; except that this tunnel seems never ending as of now. In India, they say it is still peaking, and it's bound to get much worse before it becomes better. Our medical scientists all over the world are working overtime, not only to find a cure but to find a vaccine that will halt the spread of the disease. All we can do is to hold on to the one word 'HOPE', that their efforts will bear fruit and believe, 'This too shall pass.. as always'.

Meanwhile the scourge continues and the death toll is steadily rising...

Most PC workers will agree with me, that patients who are facing death, will often confide, that it is not death that they are scared of, but the manner in which they are going to die the common fear is pain and isolation. One of my current patients said to me ‘ I will consider myself fortunate if I die of my disease now (rather than getting infected with Corona), for at least I can be assured that my family will be around me’. We are being bombarded daily with visuals on TV and social media of the Corona wards and ICU Patients surrounded by the health care professionals in their protective gears. To the patient it must appear that he is on a different planet in the midst of aliens!

Strangely there is a consolation in death; family experience a sense of closure and eventually move on. But to be separated from their loved ones at a time when they need them most, tortured by the thought of what is going on behind closed doors, not being able to help physically or emotionally and not knowing whether they will be able to see them again alive or even dead, if there is anything more cruel than death..well, this is it!

Now, let us take a look at the other side of the coin. Whom do we see? The so-called frontline workers – doctors, nurses, paramedics, health workers, sanitary workers, the police.. they are all out there in the open, so that we can be safe inside! They have responded to the call of duty without batting an eyelid. I can still hear the voice of a young obstetrician as she prepared to attend an emergency call, leaving behind her two year old son. ‘I’m so scared’ she confessed over the phone to me, but go, she must but I know once she reaches the gates of the hospital, her patient will be her only concern, throwing into oblivion anything personal. She is going to deliver into this world a new life, at a time when the lives of everyone already here is a big question mark. It’s the same for all these workers who have gone into the field with eyes open, to help those who are stricken and to prevent others from being struck. Fully aware of the lurking dangers, not knowing if, when and from where the invisible enemy will strike; perhaps not even knowing that they have been struck till it’s too late Yes, they are not just workers, they are

“I can still hear the voice of a young obstetrician as she prepared to attend an emergency call, leaving behind her two year old son ‘I’m so scared’ she confessed over the phone to me, but go, she must but I know once she reaches the gates of the hospital, her patient will be her only concern, throwing into oblivion anything personal. She is going to deliver into this world a new life, at a time when the lives of everyone already here...

“warriors” this is not just war, it is a world war.. the likes of which the world has never witnessed before!

The visuals of two stories will be engraved in my heart forever. A nurse on Covid duty for three weeks, a three year old daughter crying incessantly. The father brings the child on a motorbike. Mother is standing on the steps of the hospital with tears flowing down her cheeks. The father is struggling to restrain the child who is wailing loudly with outstretched arms the distance between them a hundred metres but in reality it is an unfathomable Ocean which both cannot breach. So near, yet so far!

The second story is the one involving a four year old boy, who needed emergency complicated heart surgery who was separated from his mother because she had tested positive for Covid. The boy was all alone but the medical team went ahead with the surgery and the boy was looked after by the doctors, nurses and paramedical staff for four months till the boy was on his feet again. But luckily this story has a happy ending. How can I ever forget the kneeling, weeping mother as she clasps her son to her bosom as the teary eyed, smiling foster parents look on.. and the emotional waving of hands as the duo say goodbye to each one of the staff who have walked the extra mile beyond the call of their regular duty! This will definitely count as one of the best faces of humanity that I have ever seen!

Let us for the time being move away from Covid.. what is the plight of the non Covid patients? The governments have decreed that non emergency treatments can be put on hold and most hospitals now are handling only emergencies. The act of the Govt should not be seen as being insensitive but rather as a measure of damage control. Strict lockdowns are in place (it’s been 105 days) as I write this. People have been asked to stay indoors to halt the spread of the disease, which spreads from person to person through respiratory droplets expelled during coughing and sneezing, by wearing facial masks and frequent washing of hands. This directive is even more strict for the elderly and persons with co morbid conditions such as diabetes, hypertension, kidney disease and other immune compromised patients such those with Cancer

because they are considered as 'highly vulnerable'. Which in turn will translate into a major chunk of patients who will come under the ambit of Palliative Care. So, these people are stuck at home. What do we as physicians who feel responsible for the welfare of our patients do? Tight rope walking is what I would say! And unfortunately the rope is rather thin one wrong step and you are endangering both yourself and your patient.

They say 'Necessity is the mother of invention' in our case no new invention is necessary, but an open mind is a must to adapt to changing times. This we have done by embracing technology. Tele consultation is the answer, it helps that almost everyone in India have a phone, so consultations are over phone calls, and people with smartphones connect virtually through Whatsapp video calls and face time. It may not be the best, but we must aim to do what is best under the circumstances. The question is not between choosing right and wrong but choosing the lesser of the two evils. Either not seeing patients at all or by connecting to them through technology!

Because oral morphine cannot be given as tele prescription, patients are encouraged to pay a one time visit to our OPD and the follow up is done from their homes through telephone. They are encouraged to call any time if they have issues and we empower the family by giving guidance in handling their loved ones. We also believe that the best place for such a patient is to stay at home, to limit exposure to the virus... unless there are extraordinary circumstances to the contrary. The act of admission to the facility can be a two edged weapon for the patient himself and for the other inmates who have been classified as highly vulnerable because of their immuno - compromised status. We have to take a lesson from the western world where the new scourge has wiped out the lives of thousands of elderly and sick patients in the care facilities housing them. We have to take all precautions to ensure that the mistake is not repeated here. We expect the medical fraternity to come out with guidelines soon, but, for now we must obey the existing rules.

Out patients visit has not been restricted. They are being seen in a room away from the inpatient facility. Strict precautions are taken by every single person working in the hospice as per the Govt.advisory. Masks, gloves, protective gear, frequent washing of hands, sanitisers, social distancing, except when giving personal care to patients, a total disinfection of the premises several times a day are followed meticulously. Visitors entry are totally restricted.

Elderly clinicians, as with all elders, much to their disappointment have been advised to stay at home. not just for their own safety, but, being vulnerable they are likely to contract the disease much more easily and are in grave danger of passing it on to their families and the community at large. So stay at home, they must.. a few lines from an ancient poem wafts in the air to reach my ears. 'They also serve, who only stand and wait.' (Poem: 'On his blindness' by John Milton)

So, we now come to the critical question. What is the future of Palliative Care from now onwards? It was just three decades ago that Palliative Care was revived because it was becoming evident that the practice of medicine was becoming more mechanical and dehumanised, with the younger generation resorting to more and more investigations at the expense of clinical examination the doctor-patient rift was widening, to the extent that patients were losing trust. Once revered as demigods, doctors were now viewed with suspicion. Palliative Care was a means to inculcate human values in the medical profession. Urging them to look at patients as human beings and not as mere cases or diseased bodies. To see beyond the physical body as people with emotions as people with souls! Imperative to this practice was to shrink the distance between the patient and the doctor, to have a one to one contact, breaking down the physical and the imagined barriers between the two. Doctors were urged to shed their ego and their superiority complex and to communicate to the patient in a way that would earn the trust of the patient and family. This was classically demonstrated in the serial cartoon depiction of the doctor doing away with physical barriers such as removing the intervening table, shedding the doctor's coat and the traditional stethoscope around the neck, sitting on the same level as the the patient, making eye contact and listening intently to the patient, who now, breathes easy and opens up his



internal fears to the doctor without inhibition. This is the mantra of the Palliative Care physician, who becomes a friend, philosopher and guide in addition to being someone medically equipped to treat the bodily ailments. Palliative care workers are ever ready not only to give a sympathetic ear, but also to hold a hand to lend a shoulder to lean on and cry! It is this basic tenet of physical and emotional proximity of Palliative Care that has come to a grinding halt in times of COVID-19!

So now, we are facing an uneasy situation where the barriers have increased many fold. Both the doctors and patients have to wear masks, the doctor in addition dons a head shield, apron, and gloves if he has to examine a patient the patient hardly gets to see the face of the doctor. So, most have resorted to the next best option virtual communication which is hardly an appropriate media for a heart to heart talk.. at best physical problems can be discussed and advice given, giving a go by to physical examination.. errors can occur. But everyone realises that this better than nothing.

If you have been the one frowning on AI (Artificial Intelligence) well, you have to reconcile yourself. It has not only come, but it has come to stay and expand in all spheres. In medicine humanised robots are replacing nurses.. if you have seen it in movies and enjoyed it as fiction.. you can have a taste of it now, it is as close to you now, as close as Stanley medical college is to you; for that is where an indigenous robot has been employed in the Corona wards. Recently I happened to see a Malayalam movie 'Android Kunjappan'. Highly entertaining, as long as I thought it was fiction, but a little apprehensive now, wondering if it would become a reality! In the movie, a highly qualified engineer cannot convince his aged father, who is his only relative, to move out with him.

The father is stubborn that he will continue to live in his village, untouched by modernity and live the way he is used to, spurning all help. He successfully manages to chase away all caretakers. The son who is now working in Russia, in the field of Robotics, is at his wits end, not knowing how to take care of his father. He then hits on an idea to try out a humanised robot, which is still on an experimental basis, on his father. The robot lands in his village and though the father rebels at first, soon is fascinated by the things that the robot can do in response to his commands. He slowly gets fond of the robot which is christened 'Kunjappan' by the villagers. The fondness becomes attachment Kunjappan is now his younger son and he starts believing it too.. he even stitches clothes for Kunjappan! Meanwhile the son realises that the robot is not foolproof... it is even dangerous... in the previous experiment, the owner in a fit of rage, yells at the robot, when he does something wrong (like spilling hot coffee on him) "Kill me, you fool" and the robot promptly kills him; for after all robots are taught to obey, not analyse feelings! The son hurries back to decommission and retrieve the robot... to his dismay, his father refuses to let go of him. How he manages is the rest of the story... but his father has gone too far into believing that his Kunjappan exists. That he actually sees Kunjappan in his own son. Now definitely this has got me thinking... is it going to be a world of Kunjappans.. now, or after I have gone? Isn't truth stranger than fiction? Hasn't history taught us that today's dream is tomorrow's reality? Only time can tell!

I am just waiting for someone to tell me that all this is only a nightmare and when I wake up everything will be fine and back to normal; perhaps even better.. Why not? Human resilience is legendary and humans are survivors.



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