Chapter 9
To Treat or Not to Treat

O thou the last fulfillment of life,
Death, my death, come and whisper to me!
Day after day I have kept watch for thee;
for thee have I borne the joys and pangs of life.
All that I am, that I have, that I hope, and all my love has ever flowed towards thee in depth of secrecy.
One final glance from thine eyes and my life will be ever thine own.
The flowers have been woven and the garland is ready for the bridegroom.
After the wedding, the bride shall leave her home
and meet her lord alone in the solitude of night [1].
Noble laureate Rabindranath Tagore

9.1 Managing Terminally Ill Patients with Situational Challenges

In this famous poem, Nobel Laureate Rabindranath Tagore welcomes death as a natural closure to life. But how many of us possess this clarity of considering death as a natural course of life itself, particularly when we are approaching our latter half of life. In this chapter, I would like to discuss the moment that often comes during every doctor's practice and is always a difficult choice.

On a busy afternoon of 16 April 2016, I received a forwarded email from our head of the department Dr. A. B Dey, who was in Toronto for an official trip:

Dear Doctors,

I have been informed by the Prime Minister Office *that the Department of Geriatric Medicine at A.I.I.M.S is best equipped (with dedicated beds for 80 plus patients) to look into my concern regarding the below-mentioned case:*

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The patient Mr. Robin Wilson, 90 years old, is an awarded poet suffering from Alzheimer's disease. He is currently dying because of pneumonia gone amiss. He was last, known to be, in the ICU of a private hospital for 30 days. His wife, who is over 88 years old, can no longer afford to pay the hospital bills. I can assure you that we are not painful people, only educated citizens who have paid our taxes and are seeking help for an awarded gentleman, who is now incapacitated due to old age. The gentleman does not deserve to die of pneumonia – nobody does. Hoping for a positive response. – Dr. Uma

I immediately responded to the mail and contacted Dr. Uma, who was Robin Wilson's neighbour and had read his literary works, to inquire about his detailed case history. After the call, I inferred that Mr. Robin Wilson, at the age of 90 years, was admitted in a private hospital's ICU in Delhi. He was placed on a ventilator because of his complicated pneumonia and chronic obstructive pulmonary disease (COPD), from which he was suffering for over 10 years. He was also suffering from moderate-to-severe dementia since the last 5 years. The family had come to understand that placing him on a ventilator for an ultrashort duration of 2 to 3 days would help him get back to the life he had led, before the onset of pneumonia. However, hospitals had also inserted a caveat of a slim possibility that Mr. Wilson could be on the ventilator for a period longer than a few days. However, the consultants had neither explained the consequences of being on a ventilator nor had they given enough time for Mr. Wilson to weigh options and take an informed decision. Of course, to be safe, they had mentioned that there were chances that he might remain on the ventilator for a long time. However, the consequences of being on ventilator support were not mentioned. By the time Dr. Amar Wilson, Mr. Wilson' younger son, reached Delhi from the USA, Ms. Wilson had already spent 30 days without sleep outside the ICU sitting on a sofa and looking at her husband through a small window.

In fact, it was Ms. Wilson who had implored Dr. Uma to "relieve him". She said, "He was always my hero. I cannot imagine even in my dream that he would be so helpless lying comatose with so many pipes in and out of him". Even Mr. Wilson's children, Dr. Amar and Ms. Sumita, wanted their father to have a dignified death. Of course, there was the financial burden of ICU too. Ms. Wilson was facing financial difficulties that she was hesitant to express to her children. When Mr. Amar met me, he expressed his helpless dilemma, "You know Dr. Chatterjee, being a medical practitioner in Chicago for the last 40 years, I have come to a position where we value not only for life but also have an immense respect for the process of death, which should be really dignified with peace and autonomy".

In the USA, over 90% of American ICU patients have rights to withhold or withdraw a medical treatment process [2]. In the UK, the British Medical Association and the Resuscitation Council (UK) have a very well laid out procedure for what is more commonly known as do not resuscitate (DNR) for older people. The DNR guidelines define the priority list for ensuring resuscitation facilities are available in publicly funded hospitals, with older adults such as the coloured, non-English speakers, HIV-infected individuals being considered as "who is not worth saving" [2].

In India, the Honourable Supreme Court in its landmark verdict on 9 March 2018 stated that a terminally ill patient with advanced health directive should not be resuscitated. The same is true for a person who is in permanent vegetative state where withholding support system in the form of hydration or nutritional support is permissible [3]. However, awareness on the same is still minimal in this country.

Furthermore, Mr. Wilson's children wanted their father to die peacefully, without suffering from the agony of having stiff tubes in his mouth, the constant beeping of machines, a tube in his wind pipe and a nebulizing mask covering his mouth. No one would ever want to die with artificial support to lungs and external fluid support to the body, where some masked unknown faces of medical fraternity would administer all types of medicines and toxins to save the degenerating cells.

Truly, death is one of the most common preoccupations of the human mind. For elderly people, death and process leading to the end of life is a matter of everyday contemplation. Tagore, in a poem, had compared death to a union with God. But until such a union happens, the process of dying remains a worrying thought. Hence, the most common apprehension in elderly patients is "How am I going to die?" They are also pertured with thoughts like, "Will I live my last few days or years at the mercy of others?" or "Will I be a guinea pig for the doctor who will experiment some new drug on me?"

I have often questioned older adults about dignified death. When asked how long they would want to live, older adults across varied socio-economic and multicultural backgrounds have responded with "*as long as I am* independent" and "as long as I am productive". On being asked how would they like to die, the predominant answer would be "I don't know" or "I will accept the way it comes".

Some wish for a peaceful death like Dr. A.P.J. Abdul Kalam. Others simply pray for "a dignified death" and that they "should not be a burden to the family".

The three major concerns of older adults are decrease in ability to perform life's enjoyable activities, loss of autonomy and human dignity [4].

A famous writer, Mr. Robin Wilson, born to a Bengali mother and a British father, was a lion-hearted man and inheritor of a rich intercultural and interracial lineage. Mr. Amar recounted how his father was an "honest, straight-forward writer who mirrored society as it was in his write up. He never deformed the realities of life in his literature. His concept of death was to slowly merge with Lord Shiva. He was an ardent follower of Shiva and probably the only writer in the world who had written a thousand poems on Shiva in Urdu". I was listening with great respect, and my spontaneous response was "a human without religious boundary". Mr. Amar resided in Chicago where the decision about resuscitation was in the hands of doctors. Documented studies suggested that if patients had not already chosen against resuscitation, doctors took the call many times even if the patient had the advance directive. The Supreme Court of India has given a verdict in support of this concept of DNR, provided the person has given advance directive. Further, a multiple layered protection has been given to the patient in the following format: DNR or withdrawing/withholding treatment has to be a collective decision by both internal and external medical board followed by jurisdictional judicial magistrate of first class of the respective places [5].

Mr. Wilson who was suffering from moderate-to-severe Alzheimer's disease for the past 5 years and COPD for more than a decade should not have been put on a ventilator. My opinion would be seconded by most of the guidelines from developed nations [6]. A person with severe dementia and end-stage COPD should not be resuscitated. His chances of survival from ventilator support were extremely remote, and prolonging his life with artificial respiration was merely prolonging his agony. Cardiorespiratory resuscitation for such patients is unlikely to be successful; hence, the discussion about "do not resuscitate" should be started by doctors and those in-charge of patients when they are mentally fit to make a decision. Discussion about living will or advance directive should start much earlier voluntarily, understanding the consequences of signing the DNR. However, there is always a scope for revision for advance directive. In case of multiple advance health directive by an individual, the latest document should be followed by the team. *It shouldn't be too late to take the call*. It is also important to take other medical professionals on board so that the opinion transferred by the treating physician along with medical team should be in sync. As per the Supreme Court verdict, the intervening medical board should comprise at least three specialists each with a minimum of 20 years of experience [5].

At the time Mr. Wilson had been placed on ventilator support, neither the doctor nor the patient or his family members were primed to handle it. Even if Ms. Sumita had the medical power of attorney, she could not have decided during the crisis what exactly would be the right course of care. She said ruefully, "I couldn't judge between my limited medical knowledge and emotional quotient. The doctor asked me to take a decision in a matter of few minutes and sign the consent form".

9.1.1 Discussing DNR: Need and Importance

Ms. Sumita had partial knowledge of DNR, but she had not been sensitized enough to take a tough call; her heart did not permit. In India, the medical curriculum is yet to include "how to put forward issues" such as do or do not resuscitate. Doctors need to learn to have a more sensible and unbiased approach to explain to caregivers the malady of putting a very elderly patient with multimorbidity on a ventilator. Problems increase specifically during multiple end-stage diseases, resulting in a poor quality of life and loss of autonomy.

Studies suggested that documented severe COPD, poor quality of life due to a disease resulting in patient being house-bound despite maximum therapy, and severe comorbidity, are the factors that discourage the use of artificial ventilator support [7, 8].

But this particular case was somewhat different considering its Indian context. Mr. Amar and Ms. Sumita wanted to withdraw ventilator support from their father, which was not permissible that time under Indian laws. At the hospital where Mr. Wilson had been admitted, the consultants refused to withdraw the ventilator support

despite repeated requests. Mr. Wilson had legally authorized his daughter, through a Power of Attorney, to take medical decisions on his behalf. Mr. William's family was well-educated and well-informed, so Mr. Wilson had the foresight to sign a medical Power of Attorney, which made his daughter the final authority in any eventuality related to his health.

Even if we consider that for the sake of patient and caregivers, as well as to save the hospital's budget and for the benefit of more needy members of the society, it was a desirable step to withdraw Mr. Wilson from ventilator support, yet we could not ask Ms. Sumita that we should remove the ventilator once Mr. Wilson was shifted to AIIMS. They shifted him under our supervision with an assurance that we will provide the best of the care available and not prolong his life without dignity and autonomy.

Thus, Mr. Robin Wilson was shifted to AIIMS on 7 April 2017. We assessed his condition, and he was found to be in septic shock on artificial ventilation. Septic shock is a condition when the affected organism spreads through the blood being pumped through the heart to multiple organs, which ultimately damages them. Usually, septicaemia is observed in very elderly people having a weakened immune system as well as physical, functional and cognitive health; thus, it carries a grave prognosis. Chance of revival from septicaemia in elderly patients is less than 10% [9]. Our patient's health went through a waxing and waning course for the next 2–3 days; however, caregivers were getting anxious with each passing day and met all of my team members to request us to remove ventilator support. Also, I was waiting for Dr. Dey to return from his official trip. On Dr. Dey's arrival, Mr. Amar and Ms. Sumita met him to request him to withdraw their father from ventilator support. After three sessions of discussions, Dr. Dey tried to make the siblings understand that we, the treating physicians, could not withdraw the ventilator from their father, as such a provision in the Indian law does not exist. However, they, the next of kin, were free to take the call. DNR is a comparatively easy decision endorsed by law, but the process of withdrawing treatment is more complex and has legal implications, which was not possible for us to handle. Whether caregivers themselves can do that as a hospital practice is also questionable. I had a discussion with the palliative care consultants at the medical administration, AIIMS. But even they could not make our future course simpler.

Eventually, I also did a literature review, which revealed a multi-faceted consensus statement, i.e. "would be withholding life-prolonging treatment". Every decision is weighted either in terms of a precise situation or patient's treatment. A patient's ability to understand his/her situation and the details about end-of-life care (EOLC) issues, as shown in Mr. Wilson's example, is a definite prerequisite.

When he was writing his autobiography, which was also his last book, titled aptly *Life of a Poet- Now and Then*, Mr. Robin Wilson had discussed EOLC issues with his daughter. In his book, he mentioned: "I read throughout my life, every book has added a new dimension to understand the life better. I respect life a lot. But I can't disown death too. I pray to the almighty the process of death should also be respectful. I am ready for it and I have discussed this with my daughter".

We were in favour of the decision of the next of kin, as the anticipatory writing documents of advance directive for refusing organ support treatment for Mr. Wilson were already available to us. We had prognosticated that Mr. Wilson was unlikely to survive, regardless of any medical intervention.

The situation, however, becomes complex when the doctor believes that the patient is likely to recover through a treatment/intervention even if there is a contradictory directive issued in advance [10]. In India, the fundamental right to life (Article 21 of the Constitution of India) only ensures the right to live. But, the right to die neither exists nor is very favourably supported by legal, social or civil society groups. Hence, in Indian law, a clear consensus for DNR is yet to be brought in, although Article 21 of the Constitution of India says that a doctor can decide the end-of-life issues with the next of kin's approval [11]. Mr. Wilson's family finally agreed to remove the ventilator tube from their father and switch off the ventilator.

On 23 April 2017 at 7:30 AM, Mr. Amar and Ms. Sumita arrived, and they had made up their mind; they enquired about the final procedure from our duty resident Dr. Samir. To remove the ventilator support from their father—the man who had shown them how to live—was not an easy decision. They insisted Dr. Samir to not give sedatives to their father, and we agreed to their request. Sedatives are routinely given to patients who are on ventilator to calm them down. At 10 AM, everybody was ready, and they had come to meet their father, grandfather, and mentor to bid him a final farewell. Mr. Robin was responsive to the painful stimuli and probably to a divine gesture that only family members could understand. There was a Hindu priest chanting the Maha Mrityunjay Mantra, a prayer to Lord Shiva—as per Hindu mythology, Shiva is a God who plays the role of the generator, operator and destroyer—and requesting him to liberate the dying soul. Around six of the family members stood around Mr. Robin and conveyed their last messages, "We don't want you to suffer further; we know you wouldn't have allowed this if you had the capacity to express your wish. Just imagine that your soul is leaving this body and that you *are going to the almighty, you are lion-hearted, you are brave, you have done your best for your family and you are going to the heaven and your Soul will remain immortal*". With this prayer, they switched off the ventilator. With two or three gasping sounds and after a few seconds, Mr. Wilson closed his eyes to rest in peace. All family members including our junior residents were emotional with tearful eyes; however, it was a considered and conscious decision by the family. Both Mr. Amar and Ms. Sumita thanked me and my team for the care we had given to their father.

The decision to place a patient on the ventilator, particularly a very elderly one, with age over 80, is always a matter of prolonged discussion with the patient, when they are lucid, or the caregiver. As a decision, it has profound implications in long-term management, cost-effectiveness and, most importantly, restoration of quality of life. So, caregivers must be well-informed about the disease and its possible prognosis. In fact, it could be difficult for trained and experienced geriatricians to often prognosticate too. But this limitation should not affect the treating doctor who should have an elaborate discussion with the caregiver. Although you need to understand a patient's wish, respecting their tradition and the patient's family culture, clinical decisions must be based on evidence, previous experiences and availability

of human resources. After all, as per the Supreme Court order, the decision should be taken collectively, not by the treating doctor alone. However, it should be initiated by the treating doctor.

In a country that has limited resources and the public usually pays from their own pocket for treatment, it is a challenge to get a bed in a publicly funded tertiary care setup. It is disheartening to witness such disparity in this democratic country. On the one hand, millions die without access to primary healthcare facilities; very few are lucky to get an opportunity to avail ventilator support without any fruitful results. On the other hand, patients who are salvageable and require ventilator support for a short span of time are often denied because of lack of availability of beds. There could be multiple hypotheses, but there is a lack of indigenous guidelines with a tremendous load of patients at public hospitals. Moreover, emergency care by inadequately skilled manpower and scarcity of artificial support system are few important factors that need to be addressed [12]. Hence, triaging who should be provided with ventilator support has multiple confounding factors, and often, it is a subjective decision rather than an evidence-based selection.

I know many educated and economically sound elderly people who with or without their consent went through this painfully failed venture of ventilator support at the insistence of their family. This is clearly depicted in our next story.

9.2 Creating Awareness About DNR and Passive Euthanasia

Ms. Durga Das was admitted under my care at AIIMS. At 83, she was diagnosed with hypertension, diabetes mellitus, chronic obstructive pulmonary disease, constipation and Parkinsonism that had progressed to an advanced stage. For more than 5 years, she had been on multiple drugs and gradually had progressed from subclinical frailty to severe frailty and became dependent on others for her daily chores. She could only take a few steps without support; moreover, she had frequent falls/tendency to fall both because of advanced Parkinsonism and frailty.

She was admitted because of a urinary tract infection followed by delirium, which is common in Parkinsonism and frailty. She showed partial responses initially, but the situation worsened after day 5 of her admission. She developed septicaemia with respiratory failure and was unable to maintain oxygen saturation with the mask. It was through a doctor's reference that Ms. Durga was admitted to AIIMS. Her son Mr. Prabhat, a social activist, had been working towards providing equal opportunities for all.

I sat with him and Dr. Amitya, a faculty of community medicine at Rishikesh, for an hour. Interestingly, Dr. Amitya was attached to the Indian Academy of Geriatrics, a national scientific body that endeavours to recruit members interested in geriatrics. As a public health expert, he had a keen interest in community geriatrics. I started explaining to them that Ms. Durga was terminally ill. In addition to multimorbidity, she was an 83-year-old elderly lady suffering from respiratory failure. Her prognosis was extremely poor with almost 90% mortality [13]; therefore, given these complications she was unlikely to survive.

I continued, “As a universal practice, we should not resuscitate where it is unlikely to lead to a prolonged and useful survival”. But Mr. Prabhat disagreed and insisted on further treatment. Often, an elderly patient’s next of kin clings to dismal chances of survival without a decent quality of life, although they realize that significant private and public resources could be spent in vain.

However, for Ms. Durga’s son, Mr. Prabhat, “useful survival” was a subjective term. He said, “What looks useless to you may be useful to us. For me, my mom is in a living body. It is enough for me to have her looking at me and blessing me”. At this point, I even appealed to her son’s egalitarian vocation by reporting that we had only four ventilators available in our department, which could be used for somebody who had better chances of recovery. But I failed to convince them.

In India, the role of community medicine specialist is to create large-scale public health education on concepts such as EOLC. Probably even for Dr. Amitya, this discussion was quite new.

Similarly, Mr. Prabhat, a change-maker in the society who had dedicated his life to improve the life of the tribal population in remote villages, did not want to leave any stone unturned in increasing his mother’s chances of survival. It was hurting him to be aware of the fact that he had left his mother to the mercy of neighbours in the village while pursuing his passion for the last 30 years. I felt perhaps “the inner guilt perception”, societal pressure and other multifactorial issues were making him proactive for this act.

Ms. Durga was placed on the ventilator for almost 15 days with a waxing-waning course. During this period, Mr. Prabhat came to see me almost daily and tried to convince me that his mother’s condition was improving, which I generally denied. This attitude made him, and his family to develop a negative image about my approach towards Ms. Durga’s treatment. They approached Dr. Dey and reverted on my line of thinking, “As per Dr. Amitya, Dr. Chatterjee’s approach is not very proactive”. But, Dr. Dey reconfirmed my prognosis and ascertained that “if Dr. Chatterjee is not very proactive for your mother, then she had a minimal chance of recovery” and it was a reflection of a geriatrician’s expertise. One of our professors from AIIMS was so upset when I explained to him about DNR and told him to sign a DNR for his mother who was suffering from end-stage cancer with breathlessness. He filed a complaint against me to Dr. Dey and said, “How can Dr. Chatterjee ask me to sign a DNR and who is he to decide on a DNR for my mother. How is he so much sure that my mother will immediately require ventilator support?”

Personally, I believe my only fault was to inform the professor to consider for a DNR for his mother who was an 80-year-old frail lady and was suffering from stage IV cancer with recurrent massive pleural effusion (fluid in the lung). In fact, a frail 80-year-old heart and lung can fail at any stage. So, it was judicious to discuss about end-of-life issues and request the caregiver to “not to resuscitate issues”, in a non-judgmental manner.

To my surprise, the professor even did not hesitate to say, “Prof. Dey, after you retire the Department of Geriatric Medicine would become a Department of Euthanasia”. Probably, just like most Indian doctors, that professor was not oriented (which is a usual phenomenon) towards the fact that end-of-life issues, particularly

the DNR discussion, should be done in advance when patient has sufficient time to comprehend and participate in the discussion. Indeed, it is a family's grappling with multiple emotions, ranging from love to feelings of guilt and societal pressure which pushes them towards what they believe to be "the best of care". Instead, patients simply undergo isolation, pain and suffering while engaging vital amenities that could actually have ensured another patient's survival.

Because of overall unpreparedness, I failed to convince them. Even faculty from AIIMS, New Delhi—who are actually up-to-date about various guidelines related to managing patients—their orientation about end-of-life care is abysmally low. From a doctor's perspective, handling a situation with a possibility of ventilator support is quite complex. The Supreme Court of India had permitted "living will" by patients for withdrawing medical support if they slip into an irreversible coma. However, there is a long way to go from the Supreme Court's directive to legislation and on-ground implementation. Euthanasia is an emotionally charged word with lot of definitional confusion. It raises numerous questions for the common people, law makers and medical fraternity. I would like to define euthanasia as an evidence-based medical act to smoothen the process of death with dignity in a terminally ill patient with no prospect of recovery. The act is to protect the uber right of human beings that is autonomy and always in the best interest of the patient, must be safeguarded against slippery slope.

We need to have extensive discussions among multiple stakeholders, the elderly people, medical fraternity, politicians, caregivers and family members on public forums. In fact, informed older adults who are on the verge of retirement can start preparing their to-do list about future medical treatment, which could include an advanced care plan for inadvertent circumstances as a preparation for a healthy and dignified exit process. Furthermore, sensitization is mandatory for the general public to judiciously use a hospital's facilities and help others to survive. The process of peaceful death should be made easier by next of kin when we are aware that death is inevitable in a poor premorbid state with multimorbidity and minimal or no cognitive/physical reserves. It would be best that every retired employee had a medical power of attorney that is regularly updated for future reference. The medical power of attorney should be written by individual in the presence of two witnesses, who are preferably nonfamily members, with further documentation with jurisdictional judicial magistrate of first class. Passive euthanasia should be discussed across the generations as it not only includes the withdrawal of ventilator support but also withholding life-support mechanisms like hydrational and nutritional care in case of patients who are in permanent vegetative state. The Supreme Court of India has very rightly discussed the case of Aruna Shanbaug who was working as a nurse at a private hospital in Mumbai. She was sexually assaulted by one of her colleagues. He choked her with a dog chain and sodomized her. The asphyxiation cut off oxygen to her brain, resulting in brain stem contusion injury, cervical cord injury and cortical blindness. She went to permanent vegetative state as there was injury to her cerebral cortex which is the highest centre of the mind or brain. But the lower centre which controls the vital organs like the heart and lung were intact, so her vital functions were normal. She was unable to recognize anyone. Though she existed physically,

her quality of life sunk. On empathetic ground, her colleagues who were also nursing staff from the same institute were taking care of her for almost for 42 years. Pinki Virani, a noted journalist, lodged a complaint in the Supreme Court of India mentioning that the way Aruna Shanbaug was existent was against a dignified life. In 2011, the Supreme Court had recognized passive euthanasia in Aruna Shanbaug's case by which it had permitted withdrawal of life-sustaining treatment from patients not in a position to make an informed decision [14].

Media should also participate in a large way by sharing a positive outlook towards the end-of-life issues. With additional social coherence and compassion for others, the situation as it stands today can be definitely improved.

After all, *if preparation for the process of birth needs about 10 months, why can't we plan the process of death in advance*!

I will move onto the next story that highlights wasteful expenditure of resources.

9.3 Sentiment Versus Science

"You know, Dr. Chatterjee, probably I could have done better for my mother", said Mr. Kaushik, a software engineer, hailing from a small village who was living in South Delhi for the past 40 years. He had brought his mother to my OPD in an unresponsive state. She had a fall in her bathroom at their native place in Midnapore, West Bengal. By the time he spoke about his mother's ailment, he broke down in front of me with a series of regrets.

"I couldn't balance my life between mother and wife".

"I feel I could have at least stayed with her in the last few months or years with her".

"Do something and save my mother. Give me a chance to serve her. I know God will not forgive me otherwise".

His mother was a 75-year-old lady who had never attended school because of poverty, but she valued education more than anything. After her husband's demise, when Mr. Kaushik was only 10 years old, she started working as a housemaid to care for her only son.

She was determined to ensure that her son continues with his studies.

"But, you know Dr. Chatterjee, as she could handle any difficulty in her life single-handedly gradually she became very dominant".

"All of my life's decisions, including my marriage, were taken by her".

She had suffered a fall 2 days before getting admitted to the hospital when she got locked inside her bathroom in an unconscious state for the whole night. In the morning, her helper broke the door and found her, and she was then airlifted to Delhi. Two years ago, she had been brought to Delhi by Mr. Kaushik and was diagnosed with a long-term uncontrolled diabetes mellitus and hypertension at AIIMS.

Of late, she had developed dementia with behavioural abnormality in the form of suspicious behaviour. "It was well controlled with your medication (Donepezil and

Quitipin). But, there was a steady decline in her course with her forgetfulness of not understanding where to urinate".

"My wife grew tired of caring for my mother who was almost completely dependent on her to perform her daily chores".

"I could have appointed somebody to take care of my mother. But my wife was not very keen to keep her in Delhi. When my mother was lucid, she couldn't cope up with my wife because she would try to control everybody, including my adolescent son and daughter, which led to quarrels every day".

She herself told me, "Please leave me in my village. I will be comfortable there".

"She couldn't adjust with the next generation, neither could we adjust to her".

"My mother had been alone for the last 10 years at home before developing dementia".

He ended this ordeal by pathetically uttering, "Please save her".

Kaushik's mother's predicament was a common scenario in which the next of kin of an elderly patient is unable to fulfil their responsibilities and cater to their parents' requirements, which is not only a duty but also deeply imbibed in our country's culture. So, we had to intubate his mother on his request but without a positive outcome.

9.4 Scenario for DNR: Public Versus Private Hospitals

When examining DNR situations at a private hospital's ICU, the scenario is quite different. Treatment cost has a major implication in decision-making, especially in cases involving older adults. My friend Babulal, a primary school teacher in West Bengal, was speaking about his grandfather's case.

"It was a traumatic experience for us. Probably my grandpa never wanted that".

"What had happened?", I asked.

"He was diagnosed with extensive Tuberculosis. It did not spare any of his organs, including lungs, abdomen, urinary tract and, to my shock, even his brain. You know, he was a farmer. He enjoyed farming till his last breath. My father took over farming when he grew up".

Generally, people in villages tend to age faster as they have little knowledge of a healthy diet and physical therapy [15, 16].

Babulal was from a tribal community from my village, Digha, West Bengal, where most families from his community worked as daily wagers. They work hard, from morning to evening, to fulfil their needs. In the evening, they will drink local alcohol and eat food by evening, followed by lively sessions of community singing and dancing around a campfire. In their community, smoking and alcoholism were widespread with widely disparate aspirations, requirements and understanding of the whole world compared to inhabitants of a metropolitan city.

"My dadu was a chronic Bidi smoker, who also took 'Chulai' – an alcohol prepared by fermentation of rice, almost for the last 50 years and never visited a doctor".

In our village, the primary healthcare providers were the Anganwari workers who possessed a basic medicine kit for managing diarrhoea by providing ORS sachets, paracetamol for fever and bandages for small cuts. The first alarming signs observed in a person meant a referral to the hospital. However, Asha didi taught us basic cleanliness in life.

"Dadu had cough with fever for the last two months. Initially, the Anganwari worker did give Paracetamol (650 mg) three times a day and two bottles of cough syrup. Dadu started consuming more alcohol but reduced smoking. Once I joined as a school teacher, he asked me for some housekeeping cost for himself. I heard that he had begun purchasing foreign liquor (Whisky/Vodka) sometimes from the nearest town".

In their culture, family hierarchy is quite strong. Family was bound to take care of older adults in the family. The grandson, even sons, cannot considerably argue with grandparents who help them to maintain peace and harmony in family.

In our village, they had a good amount of land and two houses for the family.

"Why didn't you take your Dadu to a specialist for check-up?"

"You have shifted to Delhi, I don't disturb you as I know you are extremely busy. It is great to know that critical patients from North India are getting treated by you, but we are devoid of your care despite the fact that you are from this village. We cannot come to Delhi often, which is almost 1400 km away, and there is no direct connection".

It is agonizing to me to see that geriatric medicine is yet to be established in West Bengal. In fact, the National Programme for the Health Care of Elderly (NPHCE), which was supposed to start centres in 100 districts, spread all over the country is still not functional in many places. There are hardly 4–5 tertiary centres that have qualified geriatricians with proper geriatric training. So, I feel it is my responsibility to create additional qualified geriatricians from AIIMS, including from West Bengal, who can serve people.

Babulal rightly mentioned, "Most specialists are at least 60 km away from our village". I believe this is a realistic scenario of the most part of the Indian territory. They reached a secondary care centre around 12 noon in the winter of 2016.

"Dadu was on IV fluid and he was catheterized as he didn't pass urine".

Doctors started the investigation for urinary tract and lower respiratory tract infections by sending urine and blood test reports, chest X-ray report and scan report of the abdomen. The blood report suggested hyponatraemia (low sodium) and ultrasound of abdomen suggested that there were multiple diffused matted lymph nodes throughout the peritoneum.

During the first 2 days, his condition improved. But suddenly on the third day, his consciousness began to deteriorate.

"The doctor suggested that we shift Dadu to a Government tertiary care hospital, which was 200 km away".

They shifted him to a slightly closer private hospital that provided all the necessary specialist care. As advance, the hospital took 50,000/− INR and shifted him to ICU which cost 5000/− INR per day as the doctor had "immediately put Dadu on the ventilator" considering the failing consciousness of a delirious patient.

They performed a battery of investigations such as MRI of the brain, CSF study, metabolic and hormonal profile of blood as well as CT scan of the chest and abdomen.

The doctor concluded that TB had disseminated, which had infected the lungs, brain and abdomen.

“Dadu was recovering, so the doctors removed ventilator support”.

“How did you manage the hospital bill?” I asked.

“Our relatives contributed, actually the whole village came forward to rescue us. Even the local MLA helped us while the nursing home owner also gave some consideration”.

“My father was determined he would keep asking me to save Dadu”.

“But as you know man proposes God disposes. Dadu again slipped into coma, after 7 days of General Ward care, where he developed jaundice and liver disturbances,” Babulal told me.

Probably, he couldn’t tolerate the drugs against TB. His liver had been compromised because of chronic alcohol intake. Elderly people with multimorbidity, frailty and a vulnerable liver are more prone to develop antitubercular drug-induced hepatotoxicity [17]. This may be caused by multiple factors in ageing population such as genetics, metabolism, immunologic reactions, absorption/distribution, inflammation, co-exposures and nutritional status, which have been reported in previous studies too [18].

So, they again shifted him to ICU; where after 2 days of ICU care, the doctor asked Babulal if the patient could be intubated.

At this stage, Babulal took the tough call without telling his father and the village seniors.

I said, “No”.

He had already sold all their property and was paying off a bank loan with a service which he had joined just 2 years back. There was no way that he could afford the nursing home cost.

Of course, Babulal asked the doctor of nursing home, “What is the chance that Dadu would recover?”

But Babulal didn’t receive satisfactory response, he told me, “Doctor couldn’t tell, instead he told Dadu is serious. TB had spread to almost all the organs”.

This was an intolerable state to describe, and there was no solace. Even the doctor described him “as a chronic smoker and alcoholic at 70 years of age with poor nutrition. The current extensive spread of TB had destroyed his immune system further, so he was unlikely to recover”.

So Babulal had to instruct the doctor to withhold artificial support because of financial reasons, but there was a general guidance by the doctor from the private hospital about the prognosis.

The doctor said, “Mr. Babulal if you want we can waive some of ICU cost. But, you know, we have to run the hospital”.

The law would not permit to implement DNR only on financial grounds. No hospital/nursing home can force a person to sign a DNR only on the grounds of the patient's inability to pay for advance care [19]. However, there is no mechanism in place that secures the financial obligation of both the nursing home and the patient from all socio-economic status, similar to that in developed countries where insurance covers medical expenditure.

9.4.1 Can Doctors Be Wrong?

Recently, during my rounds, I saw a 96-year-old female patient suffering from dyspnoea, surviving on oxygen and partially responsive but delirious. She was accompanied by her granddaughter, a trainee gynaecologist. As per the patient's medical history and examination, I realized that the lady was absolutely perfect (age appropriate) until this episode. She suffered from no other comorbidity like hypertension, diabetes mellitus or COPD; however, she had developed breathlessness and chest pain on her right side for 7 days. Also, she was diagnosed with a lower respiratory tract infection, and fluid had accumulated on one side of her chest as per the chest X-ray. Dr. Sushma, her granddaughter, took her to a private hospital where fluid from the outer covering of the lungs (pleura) was tapped; it was then sent to two different laboratories for benefit of doubt. One sample showed malignancy (cancer cell), whereas the other was inconclusive. The report mentioned "metastatic adenocarcinoma", which forced them to go for a CT scan of the chest and abdomen; unfortunately, they were again inconclusive for any malignancy.

Thus, Dr. Sushma came to our senior resident and requested to transfer her grandmother to our hospital because of her deteriorating condition. Dr. Sushma, who had a close childhood bond with the patient, decided not to intubate her granny.

During my rounds, after checking the details of the patient, I proposed to intubate her considering her consciousness level. Dr. Sushma objected to this saying that her grandmother would not have liked it if she was aware, "I know my decision is right as intubating would increase her agony further".

As she was the only doctor in the family, her decision was final. But, there was a situation where I, an experienced geriatrician, thought that the patient would recover, and she should be intubated for faster recovery, whereas the patient's caregiver herself opposed intubation. I did attempt to counsel her.

"I understand your attachment with your granny. I do accept that she is very old. But, she had a good premorbid functional status, and a good physical and cognitive reserve. So, I feel she should recover with aggressive management," I suggested.

"But doctor, the report says that it is a malignant pleural effusion," she protested.

"There was a doubt even if it is malignancy, once the LRTI improves she should have may be six months or so to be with you".

"No, I am convinced that she will not survive this time".

"If you are taking your decision from an emotional ground then maybe you are correct or maybe you are wrong, but I am talking on scientific basis. Evidence suggests that a functionally independent elderly, irrespective of their age, should be treated aggressively to come back to normalcy. But, after all, we will respect your decision. Please discuss with your family members and let us know the decision," I left the ward after my round.

She followed our advice but hesitantly. Her grandmother was intubated with a waxing and waning course; moreover, septicaemia worsened her condition. Dr. Sushma went back to Pune to join her duty, but she spoke to the senior residents to know her grandmother's condition.

We tried our best to give an appropriate diagnosis and help her to recover. But she never recovered from her delirious state.

Her granddaughter and family missed her last 96 precious hours, in which they could have stayed together, shared each other's wishes and unaddressed issues.

In hindsight, I was wrong. Sometimes, we are mistaken. After all, we are also human beings with a lot of emotion, judgement and error. But one thing was sure that the decision was taken keeping patient's best interest in mind. Prognosticating a very elderly patient is not only difficult but sometimes impossible too.

Science provides better answers but not always, rather science cannot win everywhere. Often, we, the doctors, fail to balance between medical knowledge, acceptance of a patient's caregiver's wishes and respecting the autonomy and wishes of the patients. A similar result was noted in the UK where 80% of cases were decided by doctors about the end-of-life issues over the individual's/patient's preferences in the interest of providing the best care [20].

9.4.2 Continuing Discussion About DNR in Society

After many episodes like that of Ms. Durga and her family, there has been an improvement in the current situation. Our team, including junior and senior residents, nursing staffs, physiotherapists and consultants, routinely discusses issues related to DNR with competent patients and their caregiver, in case it is necessary.

The Department of Geriatric Medicine, AIIMS, caters to both emergency acute cases and subacute cases with multimorbidity, multiple geriatric syndromes and global functional decline. So, in the process, we are learning how to explain and discuss or counsel caregivers.

If awareness about DNR is spread aggressively among doctors at tertiary care hospitals and the community itself, then the situations we discussed earlier in this chapter can very well be anticipated and resolved.

There is adequate evidence of a growing need to suggest the benefit of including social, familial and epigenetic features in medical training and medical education for healthcare professionals [21]. The undergraduate curriculum must cover concepts on advanced directives for both doctors and nurses.

Doctors, irrespective of their settings, should not deviate from their ethical responsibilities, which is "to do everything in the best interest of the patient".

Communication gap between the treating doctor and caregivers must be abolished. Caregivers should be taken on board for any decision in such complicated cases. Thus, as part of medical education, a paradigm shift is required to teach doctors with a medico-psychological approach. Doctors, policy-makers, lawmakers and politicians would have to sit together to devise guidelines about DNR and withdrawal treatment policy. After all, everybody has the right to live and the right to a humane and dignified death with minimal pain and without prolonged suffering.

A doctor's judgement could be wrong sometimes, but often they would be right when considering the decision of AD/DNR. All doubts and facts about health-related condition and prognosis of the patient must be clarified with the next of kin.

Consensus development is always a challenge as it has multifactorial implication ranging from families, social customs and financial implication.

Finally, the Supreme Court's verdict on "euthanasia and beyond" [22] should start the ball rolling to create a consensus among multiple stakeholders and practice to protect the treating doctors but, most importantly, the agony of a dying patient and family. The discussion of this chapter should dispel the myths about DNR and passive euthanasia in this country. This is a difficult decision to implement all over the country. However the conversation should be on! I tried this in my TEDx talk at IIT Indore on 21 october 2018. [23]

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