



An Indian Primer of Palliative Care

For medical students and doctors

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5. OPTIMISATION OF CARE



*“You matter because you are you.
You matter to the last moment of your life,
and we will do all we can, not only
to help you die peacefully,
but also to live until you die.”*

--Dame Cicely Saunders



62 year old Raj has lung cancer with distant metastasis. He is brought to the hospital with severe respiratory distress, chest pain, cough, fever, delirium and poor urine output. His arterial blood gases (ABG) and hemodynamics being unstable, he is admitted in the ICU, paralysed, intubated, given IV fluids and diuretics and started on ventilator support. Invasive monitoring is established, IV antibiotics are started after blood and urine cultures and on the third day, he receives hemodialysis to tide over the crisis. Once the ABG and kidney parameters are showing some improvement, trials are now on to wean him off ventilator.

Would you consider this line of management appropriate for Raj?

The primary goal of medical training is to help choose the appropriate line of management based on a clinical situation. This will depend on the general condition of the patient, functionality, reversibility of the pathological process which led to the clinical deterioration, co-morbid-ities and the response to treatment which the patient has received until then and most importantly on the informed decision of the person.

Let us bring more clarity to this concept with two background scenarios for this patient Raj.

Scenario 1

Let us consider that Raj was responding well to chemotherapy. He was leading an active and ambulatory life with normal food intake, sleep and activity level and deteriorated only a few days prior to admission. Here, deterioration could be due to reversible conditions like transient neutropenia, lower respiratory tract infection, electrolyte disturbances, dehydration etc. Under such a circumstance, looking for all reversible contributory factors and considering an aggressive line of management is justifiable if financially feasible and if so desired by Raj and his family. After communicating with the family about the chances of recovery, this aggressive line of management could be considered appropriate.

Raj might be successfully weaned of the ventilator and recover close to his previous health status.

Scenario 2

Let us now consider that Raj, a retired school teacher, had been diagnosed with advanced lung cancer, multiple disseminated metastases and multiple comorbidities. He is unaware of the diagnosis. The treating team suggested chemotherapy with palliative intent. Though financially burdened, the family opted for the chemotherapy, believing it would be curative. They had not understood the medical language including “percentages of median survival.” While on chemotherapy, Raj had intolerable side effects. His general condition worsened due to disease progression. He was bed-bound most of the time with persistent breathlessness, cough, poor food intake, sleep and severe fatigue. He was brought to the hospital.

As we often see, for this patient, the story would mostly proceed as follows: after a few days when some parameters show improvement, weaning him off the ventilator is attempted but not successful. He is now confined to the ICU, started on tube feeds and isolated from his caring family. Family is allowed to see him only for a few minutes every day. His wife and son are distressed with the condition of Raj in the ICU. When the effect of the paralytic drug lightens, he coughs on the endotracheal tube. From the anguish on his face and the tears in his eyes, they perceive the deep distress that he is experiencing. They are desperate to be with him. As he is not covered under any insurance, they are also finding it difficult to pay the daily ICU bills and his wife has pawned her ornaments to tide over the financial crisis. His son, who has exhausted his paid leave, is now worried about the uncertain outcome and also about his own job security.

Let us analyse this situation

Raj’s admission to the hospital was consequent on progressive deterioration and irreversible multi-system failure. Here it is most likely that he may die in the ICU on the ventilator. Hence in this scenario, this line of management cannot be considered appropriate.

An intervention that is appropriate at an early stage of the disease may not be appropriate in the same patient at a later stage.

So what is appropriate line of management for patients with advanced disease and multi system dysfunction?

‘Curing’ or ‘not curing’ is not the sole responsibility of medical professionals; caring and comforting are our responsibility too.

For caring to happen, we need to understand the priorities and needs of patients like Raj and his family. Evaluating, acknowledging and optimising the total needs of Raj and his family with early, honest and empathetic communications is crucial. Making individualised shared decisions aiming at “Quality of Life” would be considered appropriate line of management.

We should take shared decisions based on discussions with the patient and family. The decisions to be taken are regarding goals of care emphasising what is “quality of life” for them and not what we decide based on organ function.

“...it almost always takes less time to explain the side effects and schedule of a new treatment than it does to discuss death and dying.”

Daugherty CK

Quality of Life (QOL)

Health has conventionally been measured narrowly, often using measures of morbidity or mortality.

The Health Related QOL - (HRQOL) is the functional effect of a medical condition and/or its consequent therapy upon a patient. This measures physical and mental health perceptions and their correlates... including symptom control, functional status, relationships, socioeconomic support and alignment with meaning and fulfillment for the individual. Adapted from World Health Organisation HRQOL

The evaluation of QOL³⁴ is useful to guide health care inputs because it helps the practitioner to take the best decisions regarding patient care. Care thus becomes more meaningful.

What are the QOL issues for this patient?

Let us go back to the point of time, when Raj was brought to hospital in distress and review our line of management from this perspective. He had multiple physical symptoms like cough, breathlessness bordering on panic, and delirium. Reducing his symptom load would improve his QOL.

Optimisation of physical symptoms: As the disease-modifying treatment is no longer applicable, we start him on morphine (5 mg Q6H), which is also an antitussive, along with dexamethasone (8mg IV OD), and nebulisation with salbutamol-ipratropium to relieve his dyspnoea. An initial trial of oxygen is given via nasal cannula after explaining to the family that it would be continued only if it is beneficial for his comfort. Raj was uncomfortable with it also since it did not relieve the symptom, oxygen was discontinued³⁵.

Delirium is acute psychotic behaviour, a common symptom in late stages of progressive diseases. It compromises the fabric of QOL for the patient and family. Reversible contributory factors are electrolyte disturbances, infection and dehydration were looked for and corrected³⁶. Symptomatic management of delirium was then initiated using haloperidol (2.5mg SC³⁷/ dose) and was slowly titrated up according to the response. By managing these symptoms Raj's physical distress was brought under control and the family felt supported.

As panic reinforces breathlessness and works to maintain the vicious cycle, lorazepam 1mg was given sublingually for quick anxiolytic effect³⁸.

³⁴ World Health Organization. Measuring Quality of Life. Available at http://www.who.int/mental_health/media/68.pdf

³⁵ Putting the patient under continuous oxygen is a carefully considered decision and not a routine intervention.

³⁶ The strange in-patient environment, and lack of exposure to day / night rhythm and inaccessibility to their visual / auditory aids itself can provoke delirium.

³⁷ Subcutaneous

³⁸ Alternative is Inj. Midazolam 2mg, subcutaneously. For details, refer to Introduction to Palliative Care 4th Edition by Robert Twycross.`

Emotional issues

We have already mentioned many of the elements of psychological distress and anxiety in Raj's case that happened more due to gaps in early and honest communication, failure to tailor the management to Raj's present disease status and the socio-economic capacity of the family. The spiritual concerns, which surface intensely during severe illnesses were also left unexplored.

Raj was not told about the diagnosis. He was not consulted about what his wishes were regarding management.

Often it is the lack of clarity and uncertainty which is more distressing to the patient and family than an empathetic communication of the necessary truth about poor prognosis with continued support and care.

What did we do to help him?

While admitted to the inpatient palliative care unit, we had a few meetings with Raj and his family. Raj was initially a bit delirious. The poor prognosis was first conveyed to the family. They were hesitant initially about including Raj in discussions on future plans regarding his care, like place of care, decision on aggressive interventions in case of a critical event and so on. It was acknowledged to the family that the team understood that their affection was the basis for such a step. Subsequently they agreed to an open discussion in Raj's presence. It was then apparent that Raj had already guessed the diagnosis but had hesitated to clarify his doubts because of "silence" on the part of his family and also because he did not want to distress his family. The advanced nature of the disease and futility of aggressive management were thus made clear to both Raj and his family, they were now empowered in participating in the planning of care inputs.

Home based Care

The family opted for home as place of future care and were introduced to the home care team of the hospital so that Raj's day to day problems could be managed by his family with input from the home care team

Essential care

Prior to discharge from the inpatient unit, we reviewed his medication schedule including anti-hypertensives, hypoglycaemic agents, anti-anginal medicines, anticoagulants and cholesterol lowering agents. With due consideration to his poor food intake, cachexia and poor haemodynamic status, we could discontinue many of the medications except the essential ones needed for symptom relief, the anti-anginal drug and essential hypoglycaemic medication.

Anticipatory prescription

His family was educated regarding management of breathlessness, panic and delirium in case of their recurrence at home and a clear discharge summary with anticipatory usage of medications for each symptom was provided. This was also to assist the local general practitioner to support the family in case of need.

We also discussed a 'living will'. Raj and the family opted against cardio-pulmonary resuscitation and invasive interventions and this was documented.

We must tackle the subject of expected death very sensitively and with empathy. This is on everybody's mind, but seldom talked about.

It helps to get the patient and family mentally prepared, to close unfinished business like legalities, to make arrangements for religious / spiritual affairs and to say the final good bye to relatives and close friends. It also permits preparation of a "living will" to avoid undignified over-medicalized deaths.

Living will (Advance Health Directive)

When a life-limiting disease becomes unresponsive to available therapy, it is important to talk about personal choices regarding resuscitation or invasive interventions with the patient and the family in a personalised, culturally acceptable manner. In the current scenario of technologically assisted health care, which is sometimes used with-out wisdom and discrimination a living will gives an opportunity to the sick person to choose a natural death process³⁹.

Living will OR Advance directive:

This is a legal document that expresses the patient's wishes and desires for one's own health care and treatment in case he or she becomes terminally ill and unable to speak for oneself. These directives will act in the place of the patient's verbal requests and serve as assurance that the patient's end-of-life decisions will be honored. It recognizes the patient's desire not to be kept alive artificially and sets limits to the extent that the health care providers may proceed with aggressive and invasive interventions.

³⁹ Indian Journal of Critical Care Medicine Vol 9; issue 2; 2005

Reconsidering Cardiopulmonary Resuscitation (CPR)

CPR is an efficient intervention for patients in reversible critical care situations such as poisoning, near-drowning, trauma etc. However if used indiscriminately and inappropriately it could hinder a dignified death.

Death is the inevitable consequence of life and should happen with dignity.

In conditions such as advanced cancer with multiple organ failure OR persistent vegetative state due to irreversible neurological damage, CPR is clearly inappropriate. Honest communications needs to be initiated with the patient and family to help prepare advance directives on resuscitation and other interventions.



Fig 5.1: Home care team on their way to attend to Raj

What happened to Raj at home?

With empowered caring by his wife and regular visits by the home care team, Raj though bedridden, continued to have satisfactory symptom control for few weeks. However, due to the disease progression, his general condition deteriorated gradually.

THE TERMINAL PHASE

The terminal phase is the period when day to day deterioration occurs particularly of strength, appetite and awareness. At this phase, we must ensure the patient's comfort physically, emotionally and spiritually and make the end of life peaceful and dignified. We can also make the memory of the dying process as positive as possible for those left behind, by care and support given to the dying patient and the family.

Nutrition in terminal stage

He was soon unable to swallow solid food. There was a discussion whether tube feeding was to be initiated. The home care team had a discussion with Raj for his opinion. He clearly expressed his preference for continued natural oral intake. His words were, “Doctor, I know that I have very little time ahead. I don’t want a tube.”

The home care team counselled the family regarding diminishing needs of the body with onset of terminal stage and the load on the digestive system by force-feeding. This allowed them to accept the situation. They continued to feed him small frequent sips of fluids and soft feeds as much as he was comfortable with.

Raj’s statement also led to a discussion regarding approaching death. He had accepted the situation and completed the legal issues regarding his assets. He expressed a desire to see his daughter and grandson again to say the final good bye. The family was distraught, but readily made arrangements for this. Raj and family closely bonded during these days.

The last 48 hours is a crucial period in care for the person, family and the caring team. There is only one chance to get it right and when things do not go well, families and staff can be left with long-term guilt and regrets.

Dying Phase

Key to “getting it right” is anticipating that this stage has been reached. Carers who are regularly looking after the patient, spending the most time with the patient, often intuitively pick up subtle signs of global deterioration. They are sometimes quite accurate at predicting approaching death than professionals.

Table 5.1: Symptoms and signs of dying phase

Symptoms	Signs
Profound weakness/bed bound state Needs assistance for basic needs Diminished intake of food and fluids Disoriented in time, place and person Difficulty in concentrating and cooperating	Gaunt appearance Drowsiness Loss of skin turgor and lustre Dry mouth and conjunctiva Cold extremities

Can we predict death?

We cannot accurately predict exactly in how many hours or days or weeks that a person would die. A useful starting point is asking the “surprise question” to ourselves i.e. would I be surprised if this person were to die within the next few ...weeks...days?

A practical way to answer the question on ‘how long’ in the background of a chronic progressive disease trajectory is as follows; if each week is worse than the previous, then we may suspect that there are just weeks left; if each day is worse than the previous, we may suspect that there are not more than days left... and so on...

To anticipate needs and meet them, rather than to predict exact time of death, it is useful to understand the situation with as much clarity as possible.

When a patient asks... *“Doctor, how long do I have?” the implicit question could be, “Doctor... now that I have very little time left, what can I expect, how can you help me?”*

As days passed, Raj became profoundly weak, gaunt in appearance, totally bed bound and needing assistance for all activities, drowsy, without any food intake, with difficulty in taking his medications and with abnormal patterns of breathing. With these signs of impending death, we again communicated with the family to help them get prepared. They informed his close friends and relatives and also arranged for rituals according to their belief.

What is dignified dying?

It is natural death free from avoidable distress and suffering for patients, families and care givers, in accordance with wishes of patients and families and consistent with clinical, cultural and ethical standards.

Withholding Treatment:

Considered decision not to institute new treatment or escalate existing treatments for life support with the understanding that the treatment has the potential to cause pain and suffering, rather than to improve quality of life.

In Raj’s case, his death is expected and understood as a natural consequence of disease progression. It is not taken as failure of medical treatment. He is not chained to the ventilator, isolated within the ICU. He is at home surrounded and cared for by his family and friends. His distressing symptoms are under control and he is reasonably in control of his situation (nothing being forced e.g. tube feeds). His wish to see his daughter and grandson has been fulfilled; he has completed all legal formalities. He has had the chance to express his love and affection and to bid good bye to his friends and relatives. His family has had regular support throughout this difficult phase from the palliative care team and have the satisfaction of meaningfully looking after and caring for Raj. They are fully aware of Raj’s impending death and understand the futility of hospitalisation.

Thus Raj died peacefully at home amidst those he loved, after a meaningful period of bonding with his loved ones.

“The pain of loss is still immense, but to feel that everything that could have been done was done, that those who cared did so with knowledge, professionalism, devotion, and even love, and that the person died without pain, comfortably, with those they loved around them, is to feel immense gratitude and a curious humility.”

Julia Neuberger