PALLIATIVE CARE IN INDIA
For freedom from pain

In India, where terminal illnesses like cancer are often detected too late, how many patients get to see a palliative care specialist to help mitigate pain and other socio-psychological trauma? Palliative care doesn't reach people who need them because it continues to be a neglected speciality, says DR. PRIYADARSHINI KULKARNI

Taking a holistic view of treatment...

Naina Patil (name changed) may not be aware that another World Cancer Day has come and gone. It has been a decade since she was diagnosed with chronic myeloid leukemia (CML). At 20, she is a bright and cheerful girl, doing her second year in BA and looking forward to becoming a fashion designer.

Such an aspiration was probably the last thing on her mind when she was admitted to my Centre about three years ago. She was confined to a wheelchair, contorted with pain and scared about life. Over the next few days, the transformation was dramatic. The girl who could not walk was merrily riding a bicycle.

There has been no miracle. Sad as it is, the cancer within her is getting worse. Just a few days ago, she chose to celebrate her birthday at Cipla Centre, her "second home". Her entire family was around. Everyone present, including other patients and their relatives, fed her a piece of cake and then wiped a tear out of her sight. We do not know about her next birthday. What we do know is that thanks to palliative care, she has regained her zest for life and her smile.

The challenges

The WHO defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." It has recognised palliative care as an integral and essential part of comprehensive care for cancer, HIV and other health conditions. It has urged countries to take action in three areas — policy making, education and drug availability. In India, we face major challenges in all three areas.
It is difficult to put an exact date to this but we believe that palliative care was introduced in India about 20 years ago. According to official estimates, at any given time, 25 lakh people have cancer in India. Almost two lakh new cases are diagnosed every year. Of these, 80 per cent cases are detected too late for any curative treatment to have an impact. About 1.6 million Indians endure cancer pain each year but only a tiny fraction, 0.4 per cent gets relief through palliative care.

Ironically, 80 per cent of the funds under the government’s Cancer Control Programme continue to be spent on treatment facilities. The remaining 20 per cent goes towards cancer awareness programmes and cancer detection facilities. Palliative care does not figure here at all, just as it does not figure in our medical curriculum.

My initiation into palliative care happened when I was a student of medicine. Someone close to me in the family was in pain. We tried several doctors but nobody could help her. Finally, when she did get some respite, I could feel the relief as much as she did. Like most other would-be doctors, I did not know what palliative care was all about. But I did resolve to devote my career to pain management. Talk to any palliative care practitioner today and you are likely to hear about a similar urge to help ease needless, unbearable pain.

Most of us still tend to confuse palliative care with tender loving care for someone about to die. This is the reason why we think palliative care is the same as hospice care. But the two are very different concepts. A hospice is a home for the terminally ill in the final stages. Palliative care is about ensuring better quality of life through pain and symptom management and through addressing various emotional, social and spiritual issues.

Palliative care does require passion and commitment. But it is as much a specialised science as any other branch of medicine. The developed world has accepted this and already put it into practice.

Many other countries, not all of them developed, have better facilities for detecting and treating cancer. There is also greater awareness about palliative care, as I gather from my colleagues working abroad. For example, at the National Cancer Centre in Singapore, the team that attends to the patient at the time of diagnosis comprises the radiation oncologist, the medical oncologist, the surgical oncologist and the palliative care worker. They are all present at one time and work hand in hand.

How many patients in India get to see a palliative care specialist in the hospital? How many patients are in a better position to go through with treatment and overcome cancer because a palliative care specialist is working with the surgeon or oncologist, to help control the pain and symptoms?
Even the most compassionate medical student in India who wants to consider palliative care as a career option has no options and will have to go abroad to acquire a qualification. The discipline is not recognised as a speciality by the Medical Council of India.

With a small number of healthcare professionals struggling to attend to millions and millions with various diseases, it is difficult for the average doctor to set aside time from his curative practice for palliative care. One of the popular subjects at the training programmes we conduct for doctors at our centre is “How to break bad news”. And the most-repeated question is “Why are we not taught in college how to communicate with the patient?” Not surprisingly, one core skill every palliative care team member must have is good communication skills.

Hope for India

For long, it has been our tradition to practise palliative care at home. We believe in the religious care of the dying according to age-old rituals and customs. There was no fear of dying at home because our family ties and bonds were very strong and the family always rallied round to help us tide through difficult situations.

However, times have changed drastically and the “nuclear family” is here to stay. More often than not death happens in hospitals and it is considered as a “failure” of medicine. An aggressive approach towards life preservation with little consideration for the financial and emotional impact on the patient and the family leaves very little scope for palliative care. Perhaps, depending on the diagnosis and the prognosis, it is high time that patients and families started asking for palliative care, possibly along with curative treatment to make things easier for all, especially the patient. Already, some physicians have started recommending palliative care, based on their assessment of the patient and also the overall condition of the family.

I have come across some unique cases, and each time I have learnt something new from either a patient or a family member. Patients who have lived through unbearable (and unnecessary pain) for months and years come to the Centre and find freedom from pain. When they tell us “I wish I had come here months ago”, we think of the millions out there who need help and the enormity of the task ahead of us.

Naina could have been another anonymous statistical dot among the “incurables”, waiting for an end to their pain and misery. Instead, for us, she is a lovely young lady, full of life, with definite ideas about fashion trends. We respect her right to freedom from pain. We love her spirit.

She is lucky to be among the minority. The challenge before us is to convert that into a majority. That can happen if all of us, especially the media, speak up for palliative care as a humanitarian cause.

*The writer is Medical Director, Cipla Palliative Care and Training Centre, Pune.*