THEME: HEALING AND DYING WITH DIGNITY

The caregivers' point of view

SHEELA JAYWANT

I worked in the customer service department of a multispecialty tertiary care private hospital in an Indian metropolis. Whenever the staff/doctors did not know whom to call, they would page me to sort out matters, for example:

- when someone was throwing a tantrum because he or she felt the bill was unfair,
- when there were no sheets/gloves/wardboys available, or, worst of all for me,
- *when they had no time to spend on or deal with the relatives of dying patients, either admitted or coerced into getting discharged.*

The last was relegated responsibility. Since I was middle-aged and grey-haired, it was assumed that I would know what to say or do. As I was untrained to counsel, I was often at a loss when it came to finding comforting words. I went by personal experience and that of family and friends who had dealt with loved ones who were dying.

A few incidents stand out.

- An old man who was dehydrated was brought into the casualty ward. He said that for many days his daughter-in-law had not given him water, tea or coffee, except a sip or two with which to swallow his medicines. I confronted her with this and she agreed: "We live in a *chawl*. My husband is out from eight to eight. I fill the drum with water, do the shopping, cutting, chopping, dusting, sweeping, mopping and cooking, and wash the clothes… I have to feed both my children and my father-in-law. My father-in-law can't hold his urine. I can't keep taking him to the toilet. I tried to put a mug and a plastic bottle next to him. His hands shake. The urine spills. In the beginning, I helped him change his pyjamas. Then I tied a lungi around him because that was easier to handle. Our house stank of urine. The neighbours complained. Finally, I stopped giving him liquid." His end was near and she was hoping it would come soon. She could neither keep him in hospital, nor did she want him at home. They could not afford disposable diapers and part-time help. "He's been good to me," she wept, with guilt written all over her face. "My husband is caring; it's my *naseeb* (fate) that's at fault." The *naseeb* factor seems to help people tide over severe difficulties, or at least accept them uncomplainingly. For caregivers like this one, organised associations could help with time-sharing or pooling of some chores, such as shopping and dropping children to school.
- An 11-year-old girl with a congenital problem was admitted for respiratory distress. However, she moaned for 24 hours due to her contracted muscles and constant pain. Her parents had come to Mumbai, having sold all they had for her sake. The doctors had told them that there was no hope for the girl, but with good care, she could live for another two years. "I don't want her to," the mother said within the girl's hearing. "If she has to go, let her go. Why this *natak* (drama)?" I was appalled by her cruel attitude. She said, "The girl knows she's going to die; she's been hearing doctors say it for years. (I was more shocked still that some doctors had said this in the girl's presence.) We've reduced ourselves to poverty for her, fasted, prayed. This child has brought us nothing but misfortune. Even my goat is more valuable." Her voice spoke of despair and deep sorrow. Nothing – whether it is family support or community backing –works when there is a shortage of finances. For such patients, we need volunteer-based residential or at least day-care institutions, run privately or by the government, possibly at the taluka level.
- A stench hit my nostrils as I entered a ward one morning, as if there was a putrefying rat somewhere. The patients and relatives pointed to a corner of the room. On the bed indicated by them lay an end-stage tongue cancer patient, whose family had paid a deposit and abandoned him. Everyone did their best to alleviate his agony. He gestured, moving the handle of a spoon across his throat, to tell me to kill him. We moved him to an end-of-life care home. He was tired of the suffering and his own people were tired of him. In contrast, my sister-in-law died of breast cancer in the USA, by chance over a weekend, knowing what to expect, with her pain controlled, on her own bed, with her husband, children and grandchildren by her side. Her end reminded me of all the paralysed/bedridden elders I had seen in the middle-class homes of my relatives or neighbours during my childhood. They were made to lie in an inner room, but were still kept up-to-date about the happenings in the community. Even when very ill, they were seldom transferred to hospital. There would be no tubes and ventilators, no chance of prolonging life/death. Some of them might have lived longer, but the philosophy

Author: Sheela Jaywant(sheelajaywant@yahoo.co.in).Independent journalist, Village Sangolda, Bardez, Goa.

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was that "it was better they (went), their time was up".

- An intelligent and aware patient had guessed the "secret" that her condition was grim and was miserable about it. She got no counselling and had no happy moments, and was not prepared by anybody for the inevitable. Those looking after her lied when she asked, "Am I going to die?" They said,"no" even hours before she died. For a long time, one of her children felt guilty about having lied. There was no need to. The patient wanted to know and had a right to know. However, there was no one who could give appropriate guidance to the relatives.

Families which can afford to keep their end-stage patients in hospital tell themselves, "*Sab kuch theek hone vala hai* (Everything's going to be fine)."It is only in rare cases, mostly if the patient is very old, that the family takes the patient home willingly. This happens when a family "elder" takes the call.

As for the medical team, even after it has told the patient's relatives that death is near, it often continues treating the patient without consent. Patients' relatives have often asked me, "If nothing's going to improve, why are they taking blood/ urine for tests, giving medicines and charging consultation fees?" One woman with end-stage liver failure had to undergo routine checks with her finger pricked thrice a day for assessments of her blood sugar levels. One hospital told a patient it was compulsory for him to buy a thermometer, even though he had but a few days of life left in him.(The compulsory sale of thermometers is unethical anyway. When I asked the assistant director of that hospital's administration why this rule existed, I was told "to prevent infections". I want to know which infection travels from armpit to armpit via properly cleaned thermometer bulbs. However, more on that in another article.)

When my 84-year-old father-in-law neared his end, our general practitioner politely told us that we could transfer him to a nursing home if we wanted to, but reminded us that there would be zero outcome. On the other hand, a friend's father, who was of the same age as my father-in-law, had tubes inserted into him, underwent a tracheostomy, and was pumped with plenty of complicated-sounding drugs. He lived for almost a month after the ambulance had brought him to the intensive care unit (ICU). He was unconscious and his life's savings went into that final bill. The serious-faced doctors must have known that nothing could be done. No lay relative would have the courage to say, "Stop," if a doctor said, "…let's try this…" Some doctors do not openly say that the end is near. Sadly, we also have cruel staff/doctors who bluntly say, "*Ghar le jao, kuch nahin hone wala. Khattam* (Take him home. Nothing is about to happen. It's all over*)*." Sensitivity matters. Soft skills matter.

For the NABH certification, I had tried to find priests of different faiths for last-minute religious counselling/prayers for the relatives of patients. Only the Roman Catholic Church was organised in this respect. The Protestants had many sects, the Muslims did not know what I was talking about, the Parsis said they would handle the case after the death and the Hindus looked at me blankly. Let a family member put *tulsi* leaves or *gangajal* in the mouth, a practical Brahmin advised. There was no religious support for caregivers.

The mother of a patient with Duchenne muscular dystrophy told me she had called a psychiatrist and a Hindu priest home to prepare him for the end. She kept those visits private and did not ask her son about the conversation, allowing him to dwell on his thoughts. However, she did not get any counselling for herself and was shattered when her son was gone. In nuclear families, those who are left behind definitely need counselling. I used to get calls from parents/widow(er) s/middle-aged children that had some sentences in common, such as, "I feel the presence," and, "I can't stand the silence/lack of routine." We have no support groups to deal with loneliness or the sense of guilt that especially the bereaved feel. In my experience, families often worsen the situation/condition of the bereaved because of their social conditioning and their expectations regarding behaviour. No hospital that I know of encourages post-death calls from the recently bereaved or, for that matter, from those who are desperate to know that the patient is not dying. The parents of D, who had been a quadriplegic since the age of 18 years, looked after him through four decades. When his mother passed away and his ageing father could barely cope, even with the help of paid servants, there was a time when the thought of killing the son crossed the father's mind. This is not uncommon (the thought, not the deed). In another case, the mother of a middle-aged severely spastic, mentally retarded and profoundly deaf daughter asked me whether I could request one of the doctors to "give the daughter an injection". In both the instances cited above, the stage was not "the end" for the patients, but the parents wanted it to be lest they were outlived by their children.

Special training should be given to those who deal with caregivers. In the case of a brain-dead donor, the family had nearly accepted a brain death, but a young nurse said, "Don't worry, we're doing our best, no?" There was havoc after that; the furious family disbelieved every word I said about cadaveric organ donation. All the doctors/nurses/ technicians should say the same thing about a patient and there should be two representatives from the family so that there's no misunderstanding about what the doctor has said. Go-between general practitioners are a great help. The medical records file should contain a counselling paper, which should bear the signature of all present.

I think the following measures are necessary.

a. There should be an audit of dying patients so that with professional inputs, families can decide when and how to tackle the end, whether in hospital or at home.
b. Retired nurses should be employed as "death-midwives".
c. Simple information on end-of-life care should be painted on the walls or printed on posters, which should be prominently displayed (like the "no smoking" signs) outside ICUs and health check areas (where the healthy

spend a curious but bored day). Do not resuscitate(DNR) directives should also be displayed, as should information on the withdrawal and withholding of expensive and futile therapies, as well as terminal care. Pamphlets are not effective. The relatives of patients who are temporarily admitted and likely to recover will also read about and possibly discuss palliative care and euthanasia with other visitors/relatives, and become aware of the differences between administering no treatment, some treatment and aggressive treatment.

d. The contact details of nursing bureaus that have trained palliative care nurses, charitable trusts that help with money, shops that sell/rent special beds/oxygen cylinders, those who undertake home delivery of diapers and medicines,etc. should also be displayed prominently.

e. As a rule, except in acute, unexplained conditions that lead to death or in fatal trauma cases, the relatives of patients listen to physicians. Other than knowing what to say, doctors and their teams must be taught *how* to say it. The tone is a give-away. It is useful to activate volunteers from among those who have been through the experience of caring for an end-stage patient.

Caregivers must know what *can* be done at home, together with which services are available and their prices, and should be encouraged to reach out and help others. Unless the people are involved, the onus of end-of-life care falls on the already burdened healthcare professionals.

Access to palliative care: insights into ground realities post-2014 amendment to NDPS Act

M R RAJAGOPAL

Abstract

Medical practice today is disease-focused, ignoring the universally accepted definition of health as not just the absence of disease, but the promotion of complete physical, social and mental well-being. Generations of doctors in India have not studied modern pain management, and palliative care is practically unknown in most parts of the country, causing patients to be rejected by hospitals and doctors when they need help the most. The draconian Narcotic Drugs and Psychotropic Substances (NDPS) Act of 1985, outdated medical and nursing education, lack of public awareness and lack of clear governmental policy are responsible for this sorry state of affairs.

The development of a community-oriented palliative care network eventually led to the formulation of a state palliative care policy in Kerala. The acceptance of palliative care as a medical specialty by the Medical Council of India and introduction of a postgraduate degree course in palliative medicine in 2010, the development of a National Programme for Palliative Care in 2012 by the Ministry of Health of the Government of India, and the amendment of the NDPS Act in 2014 have been major positive developments which have the potential to change the current state of affairs. However, these recent achievements represent but one step in the right direction. An improvement in palliative care education, a realistic palliative care policy and implementation of the NDPS Amendment Act are necessary for doing away with the gross, needless violation of the human right to life with dignity.

Author: **Pallium India**, Arumana Hospital, Airport Road, Subash Nagar, Vallakadavu PO, Thiruvananthapuram 695 008, Kerala, INDIA – MR Rajagopal (chairman@palliumindia.org), Chairman.

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Introduction

For centuries, medical students have learned the 15th century aphorism that a doctor's duty "is to cure sometimes, relieve often and comfort always" (1). In 1948, the World Health Organisation (WHO) defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (2). This definition is still valid.

However, do these principles translate into clinical practice? With the advent of technology, healthcare has become so disease-focused as to ignore domains of disease-related suffering, including symptoms and sociocultural and humanistic factors (3). The situation is particularly bad in developing countries. While access to palliative care is admittedly difficult to measure, the per capita consumption of opioids does provide an index. There is virtually no opioid consumption among 66% of the world's population. Among 10%, it is very low, among 3% low, 4% moderate, and only among 7.5% is it adequate. India ranks among the lowest, with only 0.22% of its citizens having access to opioids for pain relief (4, 5).

Along with the growth of technology and therapeutics came commercialisation of medicine. The average doctor in India had seldom heard of the phrase "healthcare industry" till the 1970s; in those days, we knew about "health service". Today, we do not hide the fact that healthcare is an industry. The very purpose of an industry is to make profit. Unfortunately, in the context of healthcare, the profit has to be made out of human suffering. The pharmaceutical industry is the most profitable business