

DISCUSSION

End-of-life issues neglected in India

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As an invasive cardiologist in the US I deal with end-of-life issues almost daily. It is my experience that many elderly patients survive cardiac arrests with a very poor quality of life or in a vegetative state. I have seen too many such patients living a miserable life for months in a hospital or nursing home bed, with the family suffering too. With advances in intensive medical care and life support systems, life can be prolonged indefinitely making it difficult to die in peace.

I was worried about similar suffering when my 81-year-old mother was admitted to a private hospital in Delhi, having suffered a stroke and spine fracture. She stayed there for over three weeks. She was seen and followed by two internists, a spine surgeon, a general surgeon, a cardiologist, a neurologist, a dermatologist and a gastroenterologist in addition to an intensive care specialist and an anaesthesiologist.

I felt that the doctors did not work with the family to make proper end-of-life decisions for my mother. It appeared that they were more interested in prolonging life (by machines) regardless of the continued suffering even when there was no hope for recovery, indirectly to collect the daily intensive care charges.

This was a well-reputed private hospital in South Delhi, but the doctors were very difficult to communicate with. When I called from the USA – after postponing my own scheduled surgery – they would shut off their cell phone or ask me to call later, at times requiring me to place a call after midnight US time. When my mother went into a coma after an episode of cardiopulmonary arrest, all the doctors, including the specialists, told me and the family that there was no hope of her coming back to a meaningful life. They felt that even if she lived she would be bed-ridden permanently. At this point the family decided to request that no life support or repeat intubation be performed. Care would be restricted to providing comfort. I personally communicated this to the attending physician.

My mother was still in a coma but was able to breathe and hence the ventilator was removed. The family had already decided not to place her back on the ventilator so as not to prolong her suffering. The doctors were informed of this decision. We were even willing to give our wishes in writing to the doctors to avoid any legal liability.

However one morning we were surprised to see her tied to the bed, intubated and placed on the ventilator again. The physicians were rude to the family. The attending physician said

that he was obliged to keep her alive with machines even if this was against the family's wishes. I personally begged him not to make her suffer, and not to artificially prolong her life since he had determined that there was no hope of her coming back to a meaningful life after cardiac arrest and coma. He seemed to have no idea of the concept of "end-of-life care". He said, "This is not done in India."

Finally, the attending physician advised the family to sign a form indicating that she was leaving against medical advice. With no other option, the family signed a "discharged against medical advice" form – on the advice of doctors! This was the only option we had to avoid further suffering. My mother was still in a coma, intubated and on oxygen when she was taken home transported by an ambulance. She passed away peacefully surrounded by the entire family within two hours of arrival in our family home on February 13, 2005.

For the last 25 years that I have practiced in the US I have always made sure that in similar circumstances I go out of my way to help the family. I call one family member every day so he/she does not have to hunt me down. I make sure that the family's wishes are carried out. I return every phone call promptly, especially when it is from out of town. When there is no hope for the patient's life or quality of life, it is my feeling that everything possible must be done to make the patient comfortable and avoid suffering. The family becomes very important, since the family survives the death and deals with the doctor and hospital afterwards.

End-of-life or hospice care in the US is very important – so important that recent regulations require that doctors wishing to renew their medical licenses must spend many hours of Continuing Medical Education in the field of "End of Life care" and "Pain Control". Now there are many law suits connected to similar issues where life support was implemented or continued against the wishes of patient and family. Ironically studies have shown that approx. 80 per cent of health-care expenses are spent in the last few weeks of life.

I am sure in future years Indian medical education will recognise the importance of end-of-life care. We all know that when it comes to us personally we do not want to live and suffer in a hospital or nursing home before we die. We all want to die quickly without suffering. When we cannot make such decisions for ourselves we depend on our family members to decide for us. This is a very difficult decision for the family but it has to be

made. Once this decision is conveyed to the doctor, it is the doctor's duty to carry it out and work with the family to make patient pain free and comfortable.

Our family was very unhappy with the attitude of doctors with their hostile nature and lack of cooperation, especially during the last few days of our mother's life. After her death I did have a long talk with the medical director of the hospital and he did agree that they could have done better. He told me that this could be a learning experience for the doctors. He was very receptive and apologetic.

It is time to take action now, or some else will undergo a similar ordeal. I suggest that every hospital in India should have an ethics committee, similar to what we have here in the USA to deal with such matters. The committee must include physicians, nurses and also someone non-medical from the community such as a priest or well respected volunteer. It should advise the attending physician who has the ultimate authority. Hospice services should be available to patients and families in India. My family and I are writing this to improve conditions in India, a final gift from our mother to our motherland.

OBITUARY

Dr AM Pai

My introduction to Dr Pai was as a telephone voice. Although he had become so familiar with Sahyog and with us, for a long time, I never met Dr Pai face to face. Through a mutual friend, he had organised some donations for our school and clinic at Sahyog. Little did I know that what I had expected to be a one-time affair would turn into a long-term relationship. As the head of a community-based organisation which works with children, one of my difficult duties is interacting with individual donors. However, unlike them all, Dr Pai never put us through the indignity of exhibiting the children for him or made a show of his generosity. In fact, he never even let us say thank you. Even more importantly, not only did he support us himself, he spent a good deal of time and effort to get the support of others as well.

Every few months I would get a call asking me what I needed and offering to arrange for it. A friend fondly called him "Dr Kabadiwala" for his enthusiasm for collecting things that could be used by small organisations such as ours. I always appreciated his talent for reaching out to the smallest organisations and linking them to those who wanted to do some charity. To me, he seemed to represent the finest example of what we would like our doctors to be - people who are honest and socially committed in their professional lives and in their personal and public lives as well. When I first visited his clinic, I was amazed to see a little sign wishing his patients the best of health, so that they did not need to use his services! Surely, I thought, this is a person whom no one would mistrust! Undoubtedly, Dr Pai's meticulousness and integrity made it possible for him to link all kinds of people, from his patients and friends to organisations and associations of varied hues, for a larger good.

The last time I called him, he said to me, "Neha Madhiwalla is always welcome in my clinic!" Dr Pai, what a pity that you are not there anymore to welcome me in.

Neha Madhiwalla