

### I Wish I Could Prevent My Grandma's Suffering....!!!

Sir,

It was 2012, and I was in my 3<sup>rd</sup> year of residency in anesthesia in one of the best institutes in Delhi. My grandmother was suffering from senile dementia. She could hardly remember any of the family members, would sometimes talk about the remote past memories of hers in Pakistan, most of the time would keep mum, would lie down in her bed. Initially, she would go and do her daily routines, gradually she became dependent, was not eating, we used to force feed her. She developed bed sores, underwent daily dressings without analgesia. She had painful movements from bed to table, and 1 day she suddenly went away, in pain, suffering.

She was a woman of pride, self-dependent, very careful of cleanliness, a firm believer of God, and how she suffered in her final phase of life...!!! She deserved a lot better, a lot calmer, and a lot more peaceful death.

This incident happened in the house where an anesthesia resident resides; ignorance of the subject of palliative care is so high that until then I was not even aware that comfort care should be provided to such patients.

Presently I am about to finish my senior residency in the Department of Anaesthesia, Pain and Palliative Care, IRCH AIIMS, giving palliative care to 100s of patients suffering on death bed. It was an eye opener, a truly divine field that I got to know of here. I was amazed and sad and then finally happy to know that from now on no grandmother or no human being would die in pain, without dignity.

In India, our medical teaching system is such that, in our graduation, we keep concentrating on curative care and are not taught about comfort care. The word palliative care is not even heard of by the medical practitioners.

When a condition is medically not curable, doctors would tell them "nothing can be done now," while palliative care teaches us "there is always something that can be done." We can at least try to make the patient pain free, talk to them and I can tell you, just few words of cheerful talk makes their day, and can even change the rest of their life entirely.

Working in a busy palliative care unit of AIIMS, New Delhi, I have come across, all sorts of patients suffering from incurable cancers. Young kids, who can hardly understand what is happening to them, for whom people with a stethoscope around their neck mean a needle prick.

Young kids are unable to express themselves in words, would keep crying bitterly, and even their mother would not understand that they have pain: Pain in infants is highly underdiagnosed.

While working here I came across the most vulnerable group adolescents and young adults. I was fortunate enough to have close interaction with many of them, and I got to know the mental, social and physical agony that they are going through and no one is bothered to ask about it. The overcrowded outpatient department do not provide their primary physicians; the surgical, medical and radiation oncologists, with enough time for each patient or have insight into the patient's suffering. Thus, these patients suffer in silence with all the unanswered questions hovering their mind regarding their spirituality, social life, sexuality, looks, financial aspects, familial responsibilities and so on. These aspects must be catered to at an early stage of the disease by a specialist who is a palliative medicine expert to keep their confidence strong and to help them comply with the treatment.

It is just lack of communication, lack of time, or probably a fear that they will not be able to answer the questions that will follow these talks, but surprisingly I found that all these people are very brave, courageous, and want the truth, and we must tell them in time, so that if we cannot add years to their life, we can at least help them add life to their remaining time.

They suffer not just physical pain, but the pain that is beyond the abilities of any drug to treat. They want someone to listen to them patiently, solve their problems other than the disease state. The reassurance of being there whenever they need, giving them a phone number to contact in case of any problem, works wonders to improve their self-confidence and compliance with the treatment. And what you get in return would be the most

gratifying moment of your life; a smile on a depressed face, a blessing hand on your head, or one of the most beautiful compliments that you could imagine.

Such is the beauty of palliative care. When I am penning down all this, so many patients come to my mind, who have made my life more meaningful, and have made me feel very special.

And as I always staunchly believe, “Be nice and smile to everyone you see, you do not know what they are going through, they might need that smile and treasure it.”

I feel being pain free is the most beautiful feeling that one can have, even if there is a lot happening inside your body, it could be a fast growing cancer too.

As I have learnt from my mentor, my teacher, Dr. Sushma Bhatnagar, I often try to instill positive thinking in my patients with advanced cancer by telling them to live the present day when they are pain free and try to make the best out of each day. We also counsel the family members to understand the psychology of the patients and try to maintain a positive and cheerful environment at home as it helps patients overcome their physical, mental and social pain.

But usually this humane touch by the treating doctor is missing. We are often more concerned with the physical aspect of every pathology; and forget to discuss patient's real concerns, resulting in the poor outcome, dissatisfaction among patients and even noncompliance with treatment.

Overall, barriers to pain management and palliative care are:

- Lack of awareness among doctors
- Lack of awareness among patients
- Lack of facilities.

The concept of palliative care is as important as curative care. Measures should be undertaken at all levels starting from central government and health ministry, state levels, regional and individual level to spread the word. For example:

- Inclusion of palliative medicine as a subject in MBBS curriculum so that all doctors have a basic knowledge of this branch and can refer the patients to specialists whenever required
- Recognition of palliative medicine as a separate branch of postgraduation; as has been started in Tata Memorial Hospital and will soon start in AIIMS, IRCH. This will generate more specialist doctors in the field
- To make it mandatory to have a separate department of Palliative medicine in all hospitals including corporate hospitals

- A clear “End of Life Care Policy” for all hospitals
- Organization of meetings and conferences to make more practicing doctors aware and to encourage referral to a palliative care physician early in the course of disease
- Organization of camps and awareness rallies for common man
- Encouraging the formation of cancer patient meeting groups, and other groups that will give patients and attendants a platform to discuss and share their experiences.

We all should take a pledge that no patient will die in pain, and we shall work as hard for the dignified death of our patients as we do for the curative care of our patients. At present, India is ranked last for the provision of palliative care services in the country, but together with all these measures and our personal efforts, I am sure that India has a bright future in palliative medicine too.

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