DISCUSSION

# Issues faced by a hospice

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As one reaches the final station of life, there is a plethora of issues that we confront, involving the patient, the family and the caregiver. While much work has been done on the joyous beginning of life, death is a neglected subject.

Over the last decade, the Bangalore Hospice Trust, which runs Karunashraya, a 50-bed hospice for the care of advanced cancer patients, has, through its free home care and inpatient service, looked after over 4,500 patients and their families.

One would presume that all the patients we see for advanced disease and end-stage care would know of their diagnosis and prognosis. Regretfully, we find that about a quarter are oblivious of their diagnosis, or know it but are unaware of the stage of their disease. Should one tell patients that they have a life threatening illness?

The few supporters of the "don't tell" policy believe that hope is lost once the truth is out. The "will to live" wanes, the patient is depressed and literally withers away. However, when such patients come to know the truth very late in their illness, it is common to see them manifest feelings of fear and anger. Depression may occur in a few; most are overwhelmed by the news and are unable to come to terms with reality. When news of the life-threatening illness is broken very late, the time left is too short for them to deal with the issues of life facing them.

The policy at Karunashraya is for us to tell patients of their disease status. Past experience shows that hiding the diagnosis makes care more stressful for all; expectations are unrealistic. A lot of preparatory counselling needs to be done for the family which most times is reluctant for the patient to be informed. All levels of staff including volunteers undergo a series of training sessions on communication skills.

Patients whose fear of death is not addressed properly or who have unresolved issues do not die peacefully but with terminal agitation, often needing high doses of sedatives. The death occurs slowly and is disturbing to the family. The staff finds it difficult to explain the symptoms to them.

This leads us to the concept of 'total pain'. Pain is an unpleasant sensory or emotional experience, having a physical and a psychological component. It is not uncommon to find a well settled, pain-free patient suddenly manifesting pain or symptoms like vomiting. While physical causes may be responsible, at times this reaction is triggered by sudden psychological stress.

Due to poor pain relief before admission, the patient at times requests euthanasia. This desire most times disappears with adequate analgesia, even raising hopes of a cure!

The most commonly asked question by patients is "Why me?", complaining to the Powers Above, claiming to be good honest individuals undeserving of suffering. This is part of 'total pain', the third dimension of spirituality.

The issue of spirituality is complex and needs to be addressed. It is imperative to keep in mind that patients, at their end, are very vulnerable to suggestions and counsellors must assiduously desist from imposing their beliefs. In most instances a sympathetic hearing is all that is needed, helping individuals to come to their own conclusions.

In most instances, family issues occupy centre stage. Worries about the future of family members, particularly children, marriage and property, bother most people nearer their end.

Another question that is asked is: "How long?" No palliative caregiver must ever attempt to give a definite time frame.

Handling children is difficult, both as patients and as members of the family. In much younger patients, counselling is more for the adult members. Slightly older children at times show an uncanny awareness of their impending end and mouth adult-like philosophy. In many instances, the problem in counselling children is the distress felt by the counsellor! Preparing children who are to soon lose an important family member helps the child to cope better.

An interesting observation is that some patients, very close to their end, tend to distance themselves from their loved ones, many times hurting them. This could be a way for both of them to cope with the separation that looms in the horizon. Another fact is that nearer to the end people report visions of seeing loved ones who have died long back.

Finally, many patients – rather, their families -- would like the death to occur at home. Sentimental reasons apart, it is cheaper to transport a dying man than a dead body!

Staff stress does exist and needs careful handling. This is done by regular sharing sessions, counselling by external counsellor, and holding lectures and workshops on handling stress.

Thus, end-of-life care is a sensitive subject, needing patience and understanding. Health care professionals must be made aware of the issues involved.