

Short Communication

Hospice Care – helping cope with the inevitable

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Abstract: World Health Organization defines *palliative care* as “An approach that improves the quality of life of patients and their families facing the problems 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.” Hospice care, a model of palliative care, aims to help terminally ill patients cope with the psychological aspects associated with end of life while providing optimal symptom management. Faith and spirituality have a key role to play in end of life care which may allow patients to adapt to the accompanying stress better. Preferred place of death is also an important component of hospice care. While death at home may be associated with less emotional stress, this decision should take into account the quality of care that can be provided at home. In the developing world where there is a lack of formal setup of hospice care, physicians hold an additional responsibility of attending to all dimensions of a “dying” patient and assuming a holistic approach in the management of such patients.

Keywords: Hospice, Palliative, Multidisciplinary, Terminal illnesses, Spirituality, End-of-life, Grief, Holistic.

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World Health Organization defines *palliative care* as “An approach that improves the quality of life of patients and their families facing the problems 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” [1]. Hospice care is a model of palliative care offered to patients with terminal illness when curative therapy is no longer possible or indicated.

Comfort, rather than cure, is the goal of hospice – a multidisciplinary health care delivery system. To recognize the importance of hospice care is essential, as it provides the terminally ill patient a chance to die with dignity rather than death surrounded by technology and anonymity of Intensive Care Unit setting. While palliation of physical symptoms may appear as its foremost priority, it also aims to help patients cope with the emotional, spiritual and social aspects of end of life. To enumerate a few goals of hospice care: adequate control of pain and other physical symptoms; provide a sense of control to the patient; partially relieve the burden off family; gain a realistic understanding of illness; make important medical decisions such as ‘do not resuscitate’ orders; and to have financial and emotional affairs in order.

Recent studies conducted in the West and Far East [2-5] suggest that accurate prognostication of life

expectancy is important for both physicians and patients in order to have the opportunity to plan for care at life’s end. Having a realistic expectation of time to death can help physicians provide optimal symptom management and psychosocial and spiritual care to the patients and their families. In addition to that, it is equally if not more important for patients to make important end of life decisions and prepare for death. Some may argue against this based on social, cultural and religious beliefs. In our setting where patient autonomy is less well practiced and families have a bigger role to play in medical decision making, it is common for families to demand clinicians to maintain hopes of the patient. It is, therefore, required to evaluate whether being excessively optimistic about prognoses of terminal illnesses does more good *or* harm for the patient and loved ones. It also remains essential to realize that there is also a notion of trust, which is difficult to maintain if relations between physicians and patients are based on “lies”. Physicians should take family members into confidence via close communication which can also serve to overcome these difficulties.

Faith and spirituality have a central role to play in end-of-life care. Spiritual coping is relying on spiritual, cultural and/or religious beliefs to adapt to stress that terminal illness brings. Recent studies indicate that patients want doctors to talk about their religious and spiritual beliefs and benefit from such conversations [6, 7]. The concept of prayer, recitation of *Quran*, belief in life after death, for example, may all

provide means to cope with the difficult and at times even excruciatingly painful process of 'dying.'

Where to manage the patient at end of life is also an important decision to make for doctors and caregivers. International surveys indicate that most terminally ill patients prefer to die at home [8-11]. Death at home, compared to death at the hospital, is associated with less emotional and physical distress, better quality of life at end of life and a shorter period of grief for caregivers. However, it is also important to realize that most developing countries lack specialized home-based end-of-life-care programs which often include trained nurses attending to terminally ill patients at their homes with patient specific medical equipment available. Therefore, in our setting, decision on "place of death" needs to be reevaluated by the medical team for each patient according to his financial status, home setting, patient and caregivers' wishes and satisfaction. The decision also needs to take hospital burden into account as well as the availability of familial support.

The concept of hospice or palliative care is holistic in nature and looks at a person's need from different angles, defined by different persons with distinct backgrounds. Most developing countries are a long way from a formal set-up of multidisciplinary hospice care. In such circumstances, it becomes imperative for doctors to assume the roles and responsibilities of hospice towards critically ill patients. It is their ethical obligation to attend to all dimensions of a suffering patient and to have a holistic approach in the management of such patients. 'Total' pain that includes physical, psychological and spiritual pain needs to be addressed to make the patient's departure from this world as peaceful as possible.

End of life – the final stage of the journey of life – a period in which patients deserve that their beliefs and struggles are continually recognized and catered to. A leading figure in palliative care, Dr Ira Byock says: "Medical excellence and tender human caring can co-exist" [12] and what better a time to integrate these two together than when it is needed most.

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