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Care of The Dying Patient: A Neglected Issue in Pakistani Context

Waris Qidwai

Health care in Pakistan is undergoing change and it is appropriate to closely look at and reconsider humane aspects in clinical practice. In this context, care of the dying patient is an important and highly sacred part of a health care provider's responsibilities. Acceptance of death as a reality and culmination of life is not easy for patient, his or her family and health care providers. Our health care providers are trained to save and prolong life with little or no training on how to deal with dying patient and his/her family.

The issue of diagnosing dying patients is challenging, since one has to depend on set of evidence based indicators, which may predict death in hours or days. It is important to pick-up these indicators which includes patient's becoming bedbound, inability to take fluids and medicines orally and lack of responsiveness that may increase probability of patient's death.¹

In United Kingdom, one-fourth of the population die of cancer and half of them suffer needless pain.² Data is not available in Pakistan but situation is probably worse. Limited evidence is available to confirm the paucity of knowledge and skills among health care providers in dealing with dying patients and their families.³

Certain established evidence based principles ensure that patients die in peace and with dignity. It ensures that their families are well supported during the traumatic period and after patient's death during bereavement.⁴⁻⁶

Patient's greatest fear is that of suffering from distressing symptoms. This fear of suffering can be minimized by ensuring that symptoms are controlled. Pain is the most distressing factor and, therefore, analgesia should be started early and be given regularly, in appropriate dose and with the anticipation of next wave of pain. Opiates can be used based on patient's needs without fear of drug dependency or large dosage. Fear, anxiety, and depression should be addressed as these factors increase pain perception. Management of constipation, cough, dyspnoea, insomnia and vomiting improves quality of life. Correct uses of the medications with written instructions helps, since patients as well as relatives often forget.

Isolation of the patient or his/her family should be avoided. He should be given time to talk of fears and problems, with consultation based on honesty and truth and avoidance of un-necessary pessimism. A policy of 'gentle truth' is generally best as patients have idea about their condition and it helps develop trust in treating physician.

An unhurried approach, based on kindness and empathy is required when caring for dying patients. A caring touch of a considerate physician is considered important. Patient's customs and religious belief should be respected. One should not say that nothing can be done but at the same time false hopes should not be given. Often, doctor and the family know the disease, diagnosis and prognosis, but hide it from the patient. This is known as "conspiracy of silence", and should be avoided.

Inappropriate therapy in a dying patient adds pain to the dying process. A need for any invasive palliative procedure such as gastrostomy should be reviewed for pros and cons and patient's wishes should always be respected.

Involvement of family in caring and supporting dying patient is crucial. Prognosis and available symptomatic treatment should be explained to family to alleviate concerns. Family members providing care should be supported and told that they are giving help and support that no one else can, which is allowing the patient to die in bed. Care of the family does not end with the death of the patient and support of the bereaved is important responsibility of the treating physician.

Team work is important when looking after dying patients. Team should at least comprise of physician, nurse, and physiotherapist etc. among others from a long list of professionals. It is important to know the services available in area of practice including night nursing.

Continuity of patient and family care are important part of care provision for the dying patient and family. It is important to ensure that the patient and his/her family know that someone will be available round the clock. It is necessary to visit regularly rather than on request only and same doctor and nurse should visit the patient. The best drug a patient can be given is the time of doctors, relatives and friends.

Fears of a dying patient can be many. Fear of the dying process can be addressed by providing symptom relief

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and assurance. Fear of the unknown can be addressed by empathetically looking into the spiritual needs. Fear of separation and hardships for the family should be discussed and addressed. Fear of losing control and dependence on others should be addressed.

A doctor's responsibility does not end with death of the patient and care of the grieving relatives is part of the care provided to dying patient. Caring for the dying patient provides unique opportunity to develop rapport with family. A visit by the doctor after death of the patient is invaluable, with promise to continue support. Grief reaction varies and a relative showing no reaction may be heading for a serious emotional grief reaction. Sedatives may help initially but should be prescribed for a short duration only. In patients dying at home, mortality among the bereaved is less.

It is time that curriculum is updated and we incorporate training of medical students and postgraduate trainees in caring for the dying patient. A need exists to have awareness sessions for the public to educate them about dying and dying process. All stakeholders including academia and policy makers have to play their

role and make dying a dignified, humane, and pain-free process in Pakistan for patients and their families.

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