EDITORIAL COMMENTARY

CHALLENGES IN THE CARE OF THE DYING

Death is the end of life; a state when all vital bodily functions permanently cease. Across several cultures and religions, death is seen as representing the transition between the present and the afterlife.

Death may or may not be expected. The victim of a fatal road traffic accident may never have contemplated death before it happened. On the other hand, the patient with a terminal condition who is dying slowly has a lot of time to consider physical and medical issues, especially with regards to comfort and pain relief, spiritual and emotional concerns, cultural and religious beliefs and expectations, as well as legal issues and other formalities. The dying individual's perception of death is also influenced by their beliefs and other life experiences.

Terminally ill individuals do come in contact with a wide variety of people including health professionals, traditional healers, friends, relatives, spiritual advisers etc. while being cared for. The depth of interaction between the patient and any of these caregivers, as well as their responsiveness to care are influenced by how much the patient knows about the condition, the openness and empathy shown by the caregiver and the trust and confidence the patient has in them.

In this issue of the journal is a report by Appiah-Poku on the expressed needs of terminally ill patients. The author found that the concerns of such patients are mainly psychological. Home-based patients had fewer complaints about pain control than their hospital-based counterparts. It was also observed that all the patients studied knew about the terminal nature of their condition and did not expect to get well.

Empirical evidence shows that not all terminally ill patients understand the nature of their illness. This is because medical professionals differ markedly in their willingness to disclose "negative" information to patients. The attitude that tends to "protect" patients from unpleasant news, though well-intentioned is paternalistic and could prove to be counterproductive.

Currently in Ghana terminally ill patients spend their last days either in a hospital or at home with relatives. Hospitals provide the best medical interventions but at a high financial cost. Healthcare professionals may be too busy or inadequately trained to attend to the more subtle and non-medical needs of these patients. Contacts between the patient and the healthcare workers are usually brief and business-like. Visits by relatives are restricted to designated hours and a prolonged stay beyond the time allowed is seen as interference with the smooth running of the ward. In such circumstances, the hospital-based terminally ill patient may feel deprived of the attention of their loved ones. They have a "time gap of loneliness" when they are surrounded by helpful but distant and strange people.

Home-based care as an alternative to hospital-based care offers the advantages of providing the patient with more frequent contacts with loved ones and low financial cost. However, emergency medical problems may not be well managed. Furthermore, relatives may feel overburdened and burnt out from the total dependence of the dying patient on them. Such relatives do appreciate the relief that institutional care provides as it allows them the space to have a semblance of a normal life. Paradoxically, this relief afforded by hospitalization may also induce feelings of guilt about abandoning a loved one into the care of strangers.

Healthcare personnel who are directly involved in caring for the terminally ill patient are also affected by the unfolding event. Communicating unpleasant news about the diagnosis to the patient and relatives, maintaining a reassuring and cheerful countenance in the face of the inevitable demise of a patient over whom they have toiled and feeling inadequate in dealing with death and death-related issues could be stressful.

Though health professionals are comfortable with battling against an acute ailment to keep a patient
alive, it is not always so when it comes to watching a patient die slowly from an incurable disease. Other professionals are usually better equipped to deal with the psychological, spiritual, emotional and legal concerns of these patients. There is therefore the need for team building to include the patient, relatives, other caregivers, psychologists, priests, imams, lawyers and others. With each team member playing their special role appropriately, a more holistic and dignified care for the dying patient would be ensured.

Serious attention should be given to the establishment of halfway houses or hospices in this country. Here the benefits of organized institutional care and unrestricted access for family members could be combined under the same roof. Such places which would be staffed by a multidisciplinary team of caregivers, should have the necessary expertise to deal with all the concerns of the terminally ill and offer a peaceful and dignified departure.

In the interim, hospital-based care could be modified and made more sensitive to the needs of the terminally ill as well as their relatives. Home-based care on the other hand need not result in the abandonment of the patient but should rather be an extension of professional care in a non-institutional setting. Some of the benefits of such an approach would include a lessening of the stress associated with dying for the patient, and a shortening of the grieving period for the bereaved.

If death merely represents the passage into another life, as the Akans believe, then the dying must be cared for with the same degree of compassion as the living albeit with a different emphasis.

REFERENCES

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