Hospice Care in the Philippines

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Much progress has been made during the last 30 years in the fields of medicine, science and technology. Today, because of all the discoveries made by researchers all over the world, we now can replace many organs of the human body, and technology can make artificial heart valves, arms, legs, etc. New drugs are being manufactured to treat diseases, save lives, or prolong lives. Many diseases which decades ago were considered incurable can now be cured with the right medication and treatment.

And yet, in spite of all this progress, we see men, women and children die of ailments which medicine normally consider treatable. Henry Ford II, an individual known all over the world for his wealth and power, recently died of pneumonia. The best specialists, the most sophisticated technology, and the most-expensive drugs were available to him, but he died of a disease from which thousands of other patients recover each day. This situation points to a very important fact, namely, that patients die, not because of the failure of medicine, but because a human being's life has its natural end.

If this is the case, then, it is most natural to ask the question: *What if cure is no longer possible*? Physicians are trained to cure diseases, but if cure is not possible, are there alternatives available to patients and the members of their families?

Several years ago a research study was made in Georgetown University Medical Center which was entitled, "*What if nobody died of*

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cancer?" The study caused a great deal of excitement, even in the Congress of the U.S. because the study could provide the clue to how human beings can live indefinitely. The results came after a few years, and it was a great disappointment because they simply stated: "*If no one died of cancer, they would die of something else!*" The study merely reaffirmed the fact that man, like any other specie, has a life span beyond which, at the present time, it is not possible to exceed, and death comes as a natural end.

Dr. Elisabeth Kubler-Ross, a psychiatrist from Switzerland, was the first one who made this statement in her famous book, *On Death and Dying*: "A human being should be alive until he or she dies." In other words, the last days or weeks or months of an individual's life can be and should be the most meaningful part of that life because it is the time when goodbyes can be said, the material things of life can be put in order, broken relationships mended, forgiveness extended or received, and when love, which may never have been expressed before, can be expressed.

Simply stated, the quality of life should be the maximum possible when the quantity of that life can no longer be increased. This is the answer to the question: *What If Cure Is No Longer Possible?* This is the alternative that should be available to patients and their families when the medical profession had tried everything in its power to cure the patient and treat the disease, and everything had failed. Many years ago, when this moment came, it was acceptable for the physicians to say to their patients: "There is nothing more that I can do for you." Today, such a statement is no longer acceptable, because while nothing more can be done for the patient in terms of cure, there is no limit to what can be done to make the patient as comfortable as possible, and provide him/her and the members of the family with the physical, the social, the psychological, and the spiritual support that they all need during this stressful time. This is in keeping with what Sir William Osler, one of the greatest Internists of all times, meant when he defined good medicine as "curing sometimes, palliating often, but comforting always."

This statement is also the basis of the hospice concept of care.

Hospice is not a place, not a brick and mortar structure, as the word so often mistakenly suggests. *Hospice* is a concept of care the goal of which is to maximize the quality of a patient's life when cure of

disease is no longer a realistic goal. When this point is reached in a patient's illness, the focus of management should shift from *curing* to *caring*.

Hospice maximizes the quality of a terminally ill patient's life by addressing the needs and the problems that are unique to the dying patient. Bishop Edward Crowther, of the Episcopal Church in Southern California, interviewed hundreds of dying patients in the United States and in England in the early 1970's and he listed their problems under three categories, namely, *Pain, Loneliness*, and *Loss of Control*.

(a) *Pain* in the patient who is going to recover is an important symptom because it tells the physicians that there is something wrong, being later on their task to find out what it is, treat it and the pain will be relieved. However, in the patient who is terminally ill, pain serves no useful purpose because the patient has been diagnosed, treated, and subjected to all kinds of procedures. In this patient, pain is —from the medical point of view— senseless, meaningless and unnecessary; and it is therefore cruel and inhumane to allow the patient to be in any kind of pain.

The hospice experience in the U.S. and in England has shown that pain in the terminally ill patient can be relieved. It is a question of identifying what is causing the pain —is it infection, inflammation, pressure on a nerve, a distended viscus, etc.— and then finding the right drug or combination of drugs appropriate to the cause of the pain, the right dose, the correct mode of administration, and the right interval, and the pain will go away. A study made at St. Christopher's Hospice (located in a suburb of London, where the modern hospice movement originated), involving 10,000 cancer patients who died in the facility over a period of ten years, showed that in only 5% of those patients was the pain not completely relieved.

Relief from pain and other symptoms in the dying patient is of tremendous importance because it would be impossible for the patient to deal with the unfinished business of his/her life if constantly wracked with pain. It has been written by many authors that a physician may have provided a patient with excellent care for years, but if he allows his patient to die screaming in pain, the family will forget all the good things the physician had done for the patient. All they will remember is their loved one's pain, and they will be angry. These memories are difficult to forget and they make the grieving process so much harder

to manage. How often do we meet family members who tell us, even years after the death of someone they loved, "If only I could forget my father's screams of pain!" or "If only I could forget my sister's begging the nurse for an injection to relieve her pain, and the nurse's saying 'you have to wait two more hours because that is what is written on the chart!'"

(b) *Loneliness* is the second problem in the terminally ill patient. The pain of loneliness can be as excrucitating as physical pain. Unfortunately, the pain of loneliness cannot be relieved with drugs or medication; it can be alleviated only with a great deal of loving care and attention. That is why in hospice care, the family is assisted to get involved in the care of the patient. That is why also in hospice care, Volunteers play a crucial role. Volunteers do the many thoughtful things that they do for patients and families, not precisely because they get paid, but because they want to do them. And this caring makes the *loving* part of hospice so much more visible and so much more tangible.

(c) *Loss of control* is another problem in the dying. The patient should be allowed to feel that he is not a number on a chart or a diagnosis, but that he is an individual who matters. That is why in hospice care, the patient is encouraged to make the decisions that he is able to make. Is the pain medication working? Is the dose too much, or too little? If he says he wants breakfast at 3:00 in the morning and he wants a mushroom omelette, why should he be asked to wait until 6:30 in the morning when it is more convenient for everyone?

Dealing with these unique needs and problems in the terminally ill, gives hospice care unique features that are not usual in any conventional health care system. These unique features are:

(1) In hospice care, the unit of care is concerned with both the patient and the members of his family. Thus, while the hospice team is looking at how to make the patient as comfortable as possible, the team is also addressing the needs of the family. Do the children understand what is going on? Is the spouse getting enough sleep? What is the money situation? The team also tries to help the family cope with the impending separation, before, during and after the death of the loved one. This implies a bereavement follow-up which lasts for 13 months after the patient's death to ensure that the grieving process is a normal one.

(2) Hospice recognizes that a human being is not just composed of a physical body that can get disease, but that is a person, a composite of physical, social, psychological, and the spiritual elements. That is why hospice care is provided not by a group of physicians alone, nor by a sole group of nurses either, but by a multidisciplinary team that is composed of physicians, nurses, social workers, clergy, and volunteers, all of them competently trained to address the problems and needs of the patients and their families. The members of the team play equally important roles and they meet regularly to discuss each case. Thus, at any given time, any member of the team is aware of the problems that have to be addressed.

(3) Hospice care is provided in the patient's own home whenever care in the home is practical and feasible. Studies of dying patients have shown that the big majority prefer to die in their own homes, surrounded by familiar things and be with the people they love. Admission into a hospice facility or a hospice bed in a hospital or nursing home is allowed for 3-5 days only for two reasons: (a) if the patient's symptoms are not effectively managed in the home, or (b) if the family is exhausted from taking care of the patient for weeks or days, and they need a respite. This latter admission is called "respite admission" and is in keeping with the hospice philosophy that the unit of care is concerned with both the patient and his family members.

Is Hospice care needed in the Philippines?

More than 50% of the cancer patients diagnosed in our country are already in an advanced stage because people do not go for early checkups due to ignorance, fear or poverty. More than 75% of these cancer patients will have from moderate to severe pain as death approaches. No one should be allowed to die in pain, since hospice care now makes morphine, the drug of choice for pain control, available through the Department of Health.

What is imperative in the Philippines is to help the medical profession believe that *death is not due to the failure of medicine*, but that it is the natural end of life. Physicians should therefore be willing to tell their patients for whom cure is no longer possible: "I can no longer *cure* you, but I will continue to *care* for you".

Howard Brody, M.D., Ph.D, one of the most outstanding Bioethicists in the U.S., defines a "good death" as one where the physician tried everything in his power to cure his patient of disease;

but when he could not do so, he did not spare any effort to make his patient as comfortable and as free from pain as possible, so death could come painlessly, peacefully and with dignity. Dr. Brody calls this type of death a "medical success story." (*New England Journal of Medicine*, Nov. 5/1992).

On the other hand, Dr. Timothy Quill defined a "bad death" as one where the physician tried to cure his patient of disease, but when he failed to do so, he merely turned his back on the patient and walked away, leaving the patient, abandoned and in great pain. (*Journal of the American Medical Association*. August 18/1993).

Hospice care does not hasten death; neither does it prolong the dying process. Hospice is the alternative to euthanasia because hospice can relieve suffering, can alleviate loneliness, and can help provide meaning to life, which are the three main causes why patients sometimes seek termination of their lives. For instance, patients who are often admitted into St. Christopher's Hospice in great pain and begging the physicians to end their lives, after three days of pain relief and of loving care by the hospice staff, do no longer want to die.