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The Role of the Physician When Cure is No Longer Possible

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Dr. Magno presented this paper at the annual meeting of the NFCPG at Notre Dame, in October 1990. She is presently Director of Hospice Education, Research and Development at the Henry Ford Hospital in Detroit, and is president of the International Hospice Institute.

One of the distinguished members of the National Federation of Catholic Physicians' Guilds, Dr. Harold Haley, told me recently that he had met me 14 years ago in Roanoke, Virginia, where I gave a talk on the hospice concept of care. He said he remembered the talk well, because hospice was very new in the U.S. at that time, and I had mentioned the difficulties I was encountering in trying to develop a hospice program at Georgetown University Hospital. These thoughts from Dr. Haley brought back memories of how I got involved with hospice in the first place.

It was 1975 and I had just started a Fellowship in Medical Oncology at Georgetown University Hospital, because my own experience with breast cancer had given me the desire to be an oncologist so that I could help the patients with malignant disease. I had been at Georgetown for six months when I began to realize that while we were doing sophisticated research to diagnose, treat, and even prevent cancer, we were also actually treating patients with all types of experimental drugs until the last days of life. This situation is not always the fault of the physicians, because the majority of patients always opt for more treatment, hoping against hope that theirs would be the .5% reported in the literature as responding to a new drug.

However, as I watched the patients gradually deteriorate while we were continuing to give them chemotherapy with all the unpleasant side effects that it causes, I began to wonder whether there might be a better way of taking care of those patients for whom cure was no longer possible. I had read a small paragraph in a book about "hospice" that Dame Cicely Saunders had written, and how it was meant to help people die painlessly, peacefully, and with dignity, and how it was an accepted part of the health care system in England. I wrote Dr. Saunders and asked her if I could visit St. Christopher's Hospice, the 55-bed facility that she had founded in 1967, and learn what I could about hospice care.

From St. Christopher's Hospice, I went to the Royal Victoria Hospital in Montreal where Dr. Balfour Mount, a urology surgeon, had established a "Palliative Care Unit (PCU)" patterned after St. Christopher's Hospice where he had previously trained in the care of the terminally ill, and then took as many courses as I could find at Harvard, Oxford, and other places, which had relevance to death and dying. The "first" hospice program in the U.S. had been established in Branford, Connecticut in 1974 (two years earlier) and there were no training courses available the way there are now.

Armed with this little knowledge, I approached the President of Georgetown University, the Rev. Timothy Healy, S.J., and asked him if he might consider having a hospice program at Georgetown University Hospital. I explained what the hospice concept of care was, and how important it was at that point in time to determine if hospice care is as suitable to American mores and culture as it was in the U.K. Father Healy's response was: "If hospice is humane care of the dying, that is the mission of a Catholic hospital, so Georgetown must not only have a hospice program, but it should provide a leadership role in the establishment of hospice programs in the U.S." He thus gave me permission to proceed with the establishment of the "Georgetown University/Blue Cross-Blue Shield Pilot Project on Hospice Care"—a hospice unit consisting of six beds in a Nursing Home (The Washington Home for Incurables) in Washington, DC which was affiliated with Georgetown University Hospital. The objectives of this pilot project were:

- 1) to define the role of the private insurance provider (Blue Cross/Blue Shield) in the delivery of hospice care;
- 2) to determine the cost effectiveness of hospice care in the American health care system;
- 3) to determine the impact of hospice care on patients and family members in the American culture.

This project was inaugurated in July, 1978, and it is still an active part of the Washington Home, and data from the project helped in the development of legislation that led to the Medicare reimbursement of hospice care. Its medical direction is now under George Washington University Hospital.

History of Involvement

I mention the history of my involvement with hospice care, because 14 years later, I find myself addressing a group of Catholic physicians on a subject that I am almost sure everybody in this room is probably already very familiar with, and therefore this talk is no longer necessary. But God works in very mysterious ways and we trust Him. It is possible that in much the same way that in 1976 (14 years ago), the President of a Catholic Hospital stated the "humane care of the dying is the responsibility of a Catholic hospital", that maybe the same statement can be made that "humane care of the dying is the responsibility of the Catholic physician".

The title of this talk, "The Role of the Physician When Cure Is No Longer Possible", can be stated in one short sentence which was quoted frequently

by Sir William Osler, but which has been attributed by some writers to Hippocrates himself: "GOOD MEDICINE CURES SOMETIMES, PALLIATES OFTEN, AND COMFORTS ALWAYS". In this modern day and age, unfortunately the statement has been twisted around to say "Good Medicine cures *always*, palliates *sometimes*, and comforts *never*". This explains why our medical schools and all the postgraduate training that physicians go through, teach us everything that modern medicine can do to CURE, to extend life, and to prevent death. This explains also why most physicians are so concerned with curing the patient of his/her disease, that if the patient dies, the physician feels that he/she had failed. And this fear of failure is what drives physicians to go on treating the patient until he dies, because it is much easier to go on treating rather than admit that there is nothing more that the physician can do to cure the patient.

Death is the natural end of life, and it is not the failure of medicine. If physicians can be helped to understand that, then it will be so much easier for them to admit, when the right moment comes, that cure is no longer possible. The phrase "nothing more can be done" applies only when we are thinking in terms of CURE: there is no limit to what the physician can do to PALLIATE, and to COMFORT. This is the moment when the physician can say to the patient, "I can no longer *cure you*, but *I will continue to care for you*". And what a luxury that is, because there is so much that can be done to make the patient as free from pain and as comfortable as possible, and to 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 most stressful time.

And in those words lie the definition of "hospice care", and they define the role of the physician when cure is no longer possible.

What is "hospice"? Hospice is *not* a place, as many individuals still believe it is because our model for hospice care came from St. Christopher's Hospice which is a brick and mortar structure in a suburb of London where dying patients are taken so that they can die painlessly, peacefully and with dignity. Hospice is a *concept of care*, the goal of which is to maximize the quality of life when the quantity of that life can no longer be increased, either because of disease or of age. Hospice is intended to "help a patient be alive until he/she dies", in the words of Dr. Elizabeth Kubler-Ross, whose book *Death and Dying* has helped revolutionize our attitudes towards death and dying. Hospice says that while a patient is "dying", the patient should be "living" until he/she takes that last breath of life. Hospice says that the last days or weeks or months of a human being'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 affairs of life can be put in order, when broken relationships can be healed, when forgiveness can be given or received, and when love, which may never have been expressed before, can finally be expressed. Thus, hospice is really dealing with "living" so that when the moment comes, death can come with peace and dignity, and the family can be assisted to face the death of the loved one with the support that it needs.

How does hospice care accomplish all the things that it is intended to accomplish for the patient and the family? By addressing the needs and the problems which are unique to the dying patient.

Many Studies on Subject

There are many studies in the literature on this subject, but one of the most applicable and the most useful one for me is an unpublished study by Bishop Edward Crowther, then a bishop in the Episcopal Church of Southern California. Bishop Crowther did a doctoral dissertation entitled "Care Versus Cure in Terminal Illness", and in the study, he interviewed hundreds of dying patients in the US and in England. He then categorized their needs and problems under the three big headings: 1) PAIN, 2) LONELINESS, and 3) LOSS OF CONTROL.

Pain will not be discussed in great detail in this presentation, because much progress has been made in the control of pain in the terminally ill patient during the last 10 years. It is probably important to reiterate what Dame Cicely Saunders has so often said in her writings, that "pain in the dying is senseless, it is meaningless, it is unnecessary, and it is both cruel and inhumane to allow a terminally ill patient to die in pain". Many writers have stressed the fact that the primary physician of a patient may have given him the best care possible for many years, but if the physician allows that patient to die screaming in pain, the family will forget all the wonderful care that their loved one received, and they will remember only that the physician failed to control the patient's pain. And they can be angry and their grieving can be so much more difficult to handle. Many of us have met family members or friends of patients who say, many years after the death of someone they love, "If only I can forget his screams of pain; if only I can forget his begging the nurse for an injection to relieve the pain, and the nurse's saying that he has to wait two more hours, or there are no orders in the chart". This explains why one of the most impressive talks on the control of pain in the terminally ill patient that I have heard was one given by an oncologist in Virginia. It was impressive because he entitled his talk, "Pain Control: Our Last Obligation to Our Patients". It is our obligation to control our patients' pain, and this pain extends to and includes all the other distressful symptoms which usually accompany terminal illness. This pain can be physical pain, and it usually is, but it can also be emotional pain, psychological pain, social pain or spiritual pain. It is these many aspects of pain which require of the physician, more than just a working knowledge of the pharmacology and the techniques for pain control. It asks the physician to accompany that patient during these last days of his journey so that the physician can listen and feel with his heart what to do to relieve the patient of his pain or his "suffering" as Eric J. Cassell, M.D. described so vividly in his article on human suffering. (*New England Journal of Medicine*, 3/18/82 Vol. 306 No. 11)

The second problem of the dying, as described by Dr. Crowther is "loneliness". When I first read this, I reacted by thinking that loneliness was not too big a problem, probably because in my training as a physician, I appreciated problems that I could hear with the stethoscope, or feel with my hands. Loneliness was so vague and so sentimental that I tended to dismiss

it as unimportant. But as one cares for the terminally ill, it becomes easier to understand that the pain of loneliness is as excruciating as physical pain. Unfortunately, the pain of loneliness cannot be prevented or alleviated with drugs or medication; the pain of loneliness can be prevented or alleviated only with a great deal of loving care and attention. That is why in hospice care, we try to involve the family in the care of the patient. Most families would like to care for the loved one, but they often feel incompetent and helpless to do so, and the tendency is to draw away. In hospice, we teach family members little ways of caring for the patient — to give subcutaneous injections of morphine, to turn the patient in bed, to sit and listen and be present. This “presence” and this involvement in the care of the patient not only alleviates the loneliness of the patient, but it allows for the expression of love. And the grieving process becomes so much easier because the family members can feel that they have done everything they could for the loved one.

Volunteers Alleviate Loneliness

Loneliness in the dying patient is alleviated also by the presence of volunteers who, in my opinion, are the “heart” of hospice care. Volunteers become the friend of the patient and the members of the family; they are the kind voice at the other end of the telephone when nights or days become unbearable; they are the ones who can sit by the patient’s bed, read to him, pray with him, or just be present to him so that the spouse or the primary caregiver can have a few hours of respite to go shopping or take a nap, or go to the hairdresser. I often say that I may be myself a caring physician, but the patient and family know I am doing a job and I get paid for it. But this same patient and family know that the volunteer who comes to help with the patient’s care is not being paid to do that — the volunteer is doing what he/she is doing for the patient and family members because he/she wants to do so. And immediately, the element of LOVE becomes so much more visible and tangible. Volunteers in hospice care have been quoted again and again in the literature as saying that they receive so much more than they give, and this is because what motivates them in the work that they are doing is LOVE.

The third problem in the dying patient is LOSS OF CONTROL. Again, it was easy for me to say that this problem was not as important as physical pain and I was wrong. In our culture, everyone is in control of his/her life, and we make the decisions which affect us, i.e., what job to take, what clothes to wear, what food to eat, etc. When an individual is nearing the end of life, it becomes much more important that he/she feels like an individual who matters; that he/she is not a number on a chart, or a diagnosis down the hall. This patient should therefore be allowed to make the little decisions which affect his care — is the pain medication working? is it too much or is it too little? If the patient says he wants breakfast at 3 o’clock in the morning and he wants a mushroom omelette, why shouldn’t he have breakfast at

3 o'clock in the morning and why shouldn't he have a mushroom omelette? If the patient says he does not want a catheter, it is the responsibility of the physician to think of other ways and means of accomplishing what the catheter is expected to accomplish in the patient's management.

Because of this unique quality of hospice care of maximizing quality of life rather than prolonging life, hospice has two unique features. These are: 1) Hospice recognizes that a human being is not just composed of a physical body which is afflicted by disease, but is a composite of the physical, the social, the psychological, and the spiritual. Consequently, for hospice to address the needs of the patient effectively, it cannot be provided by physicians alone, or by nurses alone, or by volunteers alone, or by clergymen alone, but it must be provided by an **INTERDISCIPLINARY TEAM** composed of physicians, nurses, social workers, clergy, and volunteers. These members of the TEAM meet regularly once a week to discuss the needs of the patient and the family, the plan of care developed, reviewed or updated during these meetings, so that at any time, any member of the team is aware of what is going on with the patient and the family. It is in this inter-disciplinary team that a "blurring of roles" is imperative for maximum effectiveness. This means that sometimes the physician is the pastoral person, the clergy can be the nurse, the social worker can be the minister, etc. 2) In hospice, the unit of care is both patient and the family. In other words, while the hospice team is looking after the patient's needs and problems, the team must also be looking at the needs and problems of the family. Is the spouse getting enough sleep? Do the children know what is going on? What is the financial situation? Are they coping well? This involvement with the family continues after the patient dies for a period of approximately 13 months, which is called "Bereavement follow-up" to ensure that the grieving process is going on at a normal pace, or to identify problems which might necessitate professional intervention.

State of the Art of Hospice Care in the US

Since the establishment of the first hospice program in Connecticut in 1974, the hospice movement has grown by leaps and bounds so that today," there are approximately 1,800 hospice programs of varying types and sizes in every state of the country. The first annual meeting of the National Hospice Organization (NHO) was held in Washington, DC in October, 1978, and I was the program director. Sen. Edward Kennedy delivered the keynote address, during which he described the hospice movement in America as being a "good movement, not because it was mandated by the Federal Government, nor was it legislated by Congress but because it evolved out of the hearts of people who care". Hospice thus became a "grassroots effort" where people in communities, large and small, felt the need for a better way of caring for the terminally ill in their midst, and they got together and formed hospice programs. There were no guidelines — people did the best they could, within the resources that they had or did not

have, but the hospice movement grew. That is why in the early days of the hospice movement in the US, there were almost as many types of hospice programs as there were communities, and the particular type which evolved in any given community depended on the particular needs of the community and on the type of individuals who provided the leadership. Some hospice programs were small, some were large, some were hospital-based, some were community-based, some were rural, some were urban, some were purely voluntary in nature, some charged for their services, etc. In this scenario, the National Hospice Organization hired its first executive director and I happened to be the one asked. During those first years, NHO developed standards and guidelines of care, the beginnings of hospice legislation were formulated which later resulted in the passage of the amendment of the Social Security Act which provided for reimbursement by Medicare of the cost of hospice services provided for eligible beneficiaries. Accreditation by the Joint Commission on the Accreditation of Hospitals was initiated, and the Kellogg Foundation gave funds amounting to almost \$700,000 to establish education and training for hospice caregivers. The number of hospice programs grew steadily so that by 1983 there were hospice programs in every state and a national directory allowed people to be referred to a hospice program wherever they were.

From the beginning years, the hospice movement in the US was confronted by two major problems (aside from the lack of funds): 1) the lack of involvement of the medical profession in the delivery of care, and 2) the lack of a solid base of knowledge on the hospice concept of care. Physicians were not only not referring their terminally ill patients to hospice programs, but they were actually resentful to the hospice concept of care. This was because in effect, hospice was the exact opposite of what physicians were taught and trained to do: physicians are taught not to treat pain, because pain tells the physician there is something wrong and it is his job to look for the cause of the pain, treat this cause, and the pain will go away. The same is true with other symptoms. In hospice care, the goal is to control the patient's pain at all costs because it is no longer necessary and useful. Physicians are taught to save lives and to prolong lives. Hospice is saying that this life is nearing its end, so there is no need to save it nor to prolong it. Physicians are taught to prevent death — hospice is saying, let death come naturally and do not prolong the dying process.

The second problem was related to the lack of involvement of physicians in hospice care, and this is "the lack of a solid base of knowledge on the hospice concept of care". Physicians rely on the scientific publications which keep them abreast of the new trends in medicine, and this new knowledge and information emanate from research work going on in all parts of the world. Because hospice was so new in the health care system, and because physicians, who are the potential researchers, are not involved in hospice care, there was no serious research going on, and consequently, no scientific articles on the hospice concept of care were appearing in the journals and publications which are read by physicians everywhere. This

dearth of new knowledge and documented information on hospice care further aggravated the lack of involvement of the medical profession in hospice care. Physicians either will not refer their terminally ill patients to hospice programs, or even if they do, they wait until the last few days of life before making a referral. A recent study made in the state of New York by Douglas MacDonald on the causes of non-admission to hospice programs, showed that one-third of the patients referred for hospice care, could not be admitted because "they died during the process of admission". This means that the patient's physician waited too long before making the referral.

Institute Established

It is in order to address these two problems that the INTERNATIONAL HOSPICE INSTITUTE (IHI) was established in late 1983 by a group of physicians in Washington, DC as a non-profit 501(c)(3) organization with only three objectives. These are: 1) to involve the medical profession in the delivery of hospice care; 2) to develop a solid base of knowledge on the hospice concept of care through research, and 3) to collaborate with already-existing national, regional, and international organizations in the achievement of these objectives.

The first task was to create a Task Force which would look at the reasons why physicians were not interested in hospice care. The Task Force was composed of presidents of medical societies, representatives from medical schools/centers, and outstanding practitioners of medicine in the various specialties. The Task Force's report showed that the major reason for physicians' indifference to the concept of hospice was "ignorance" — a lack of a thorough understanding of what the concept of hospice care is. Many physicians had heard of the word hospice, but they equated it with "loving care" and holding the patient's hand, and they were not prepared to turn over the care of their patients to a group who will hold the patient's hand. The physicians felt they could do that also.

Two Recommendations

To remedy this lack of understanding by physicians of what hospice is, the Task Force made two recommendations: 1) Organize an ACADEMY OF HOSPICE PHYSICIANS (AHP) which will provide interested physician with a forum where they can exchange ideas and information and provide peer support for one another; and 2) Develop an Annual Symposium on the "Management of Terminal Illness" which is geared to physicians, but may include other disciplines, and which will draw on the world's leading authorities on hospice care as faculty.

The ACADEMY OF HOSPICE PHYSICIANS (AHP) was organized in July, 1988 with 135 founding members from oncology, internal medicine and family practice. Less than three years later, the Academy has almost 1,000 members, not only from the US but from other countries. It has a powerful Research Committee, an Education Committee, and an Ethics

Committee. This year, the International Hospice Institute and the Academy, co-sponsored two pilot projects on the "Principles of Hospice Care" for physicians, one in West Palm Beach and the other in Amarillo, Texas. The pilots were attended by 15 participants each, and the hospice format and curriculum were tested on the "students", all of whom were already established practitioners, but who are interested in hospice care. The courses were given rave ratings by the participants, so now IHI/AHP are planning to give these courses three times a year in various regions of the US. After taking the course, a physician should be more comfortable in treating his terminally ill patients, and may qualify to function as medical director of a hospice program. A rationale for developing the course is the fact that Medicare requires that a hospice program must have a medical director in order to qualify for reimbursement. Most physicians do not feel competent enough to assume this new role, especially in the use of narcotics in the control of pain.

The IHI annual symposium just completed the sixth one at Estes Park, Colorado and it was attended by almost 300 people. The first one had 25 physicians in attendance. The 7th IHI symposium will be held in Washington DC at the Georgetown University Conference Center on July 10-14, 1991, and a bigger crowd is expected to attend it.

Thus, some progress has been made. What lies ahead of hospice in the US and in the rest of the world? With a greater awareness and understanding by physicians of the needs of the dying patient, and of the physician's role when there is no more hope for cure, it is reasonable to expect that more patients will be referred for hospice care when their primary physicians come to that point in the illness when both physician and patient can accept the fact that cure is no longer possible. From this moment on, the focus of the patient's management should shift from CURE to CARE. The latest World Health Organization data reveal that three-fourths of people dying all over the world today, die in pain. It is hoped that with greater involvement of physicians in hospice care, this number of patients in pain can be dramatically reduced.

On a personal note, I was invited several years ago by the International Congress of Women Physicians to talk on the hospice concept of care. The exciting thing about this invitation was that Mother Teresa of Calcutta was the other speaker and I was therefore blessed with the rare gift of being on the same platform with this great living saint. Mother Teresa talked about her care of the dying "poorest of the poor", and how today, when we talk of "poverty", we tend to think of lack of food, clothing and shelter. She said the "real poverty is the lack of love — having no one to love you and to care for you, and therefore life is lonely and has no meaning". She and her co-workers thus provide loving care to the dying poor and they hold them in their arms and help them to die with love.

What Makes Hospice Care Different:

I started to think of hospice care in that context and I asked myself, since

hospice is also loving care, what makes it different? The answer is that in addition to the loving care, hospice also offers professional expertise to relieve the dying patient of pain and other distressful symptoms. As Dame Cicely Saunders explains, "hospice is not just loving care; it is competent, appropriate, loving care". Hospice must have competent physicians, nurses, social workers, clergy and volunteers to take care of the dying patient and the members of the family. It is only if the team is competent and well-trained that it can go into the patient's home and say, "We will take care of you", and they will.

If we can combine Mother Teresa's care of the dying with what hospice can offer, then maybe we would have arrived at a formula which God in His goodness had intended all along for His dying children.

For the Catholic physician, and maybe for any other physician, hospice offers a special type of ministry. My spiritual director in Michigan was the director of a Catholic hospital in Michigan and one day he asked me to teach him about hospice because as he watched the patients in the hospital die, he found himself a witness and part of a miracle of God reaching down to His son or daughter to lift him or her to be united with Him in heaven. He said we in hospice care are privileged because we can be part of that miracle; we can actually accompany this soul as it journeys to that glorious moment when it is reunited with God. I attended a hospice workshop one day for ministers and clergy because there was no representative from the US and I felt I needed to transmit to our own clergy what I would learn from this workshop. I was surprised to note that those ministers present were complaining how the hospice staff rarely called for them, and that many patients died without any of the clergy being present. I felt compelled to remark that instead of being unhappy about this situation, it should be a cause for rejoicing because the laity may finally have started to take their royal priesthood seriously. In my own experience in taking care of dying patients, I have encountered many situations where I found myself in the role of the priest or minister. You see, the patients are closest to their physicians, and often, it becomes easier to look to the physician for spiritual comfort and support. It is a great privilege.

I would like to close this paper with a profound experience that I had very recently. I was invited by a large Jewish congregation to give a talk on hospice care in a large synagogue on a Friday evening. The synagogue was not only huge, but it was so solemn and it gave me the sense of being sacred. I felt I could not give a talk in such a sacred atmosphere because it would almost be like a desecration. But the rabbi took out the Scroll and he read a prayer from it which said: "Lord, please place your hand in mine, so that when I touch others, it will be your hand that will be touching them."

And isn't this the ultimate role of the physician?
