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The study examines how the emotional needs of dying patients and their families are best met by the hospital staff. What is the best method for the health care professional to provide support to the terminally ill patient. Data gathered through literature reviews and personal interviews identified what emotional needs the patient required. Some alternatives discussed included a hospice program or a "Care Team" formulated to meet those emotional needs of the dying patient. The study presented a need for additional training of the physicians, nurses, family members and other health care members to deal with the emotional stress of the dying patient. Within current resources, the study provided a program to help the hospital staff assist the patient to die with dignity. *Keywords:*

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A STUDY OF MEETING THE EMOTIONAL
NEEDS OF DYING PATIENTS AND THEIR FAMILIES
AT WALTER REED ARMY MEDICAL CENTER
WASHINGTON, D. C.

A Problem Solving Project
Proposal Submitted to the Faculty of
Baylor University
In Partial Fulfillment of the
Requirements for the Degree
of
Master of Hospital Administration

By

Major Charles F. Mullaly, Jr.

August 1981

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INTRODUCTION

Opening Comments

"Go placidly amid the noise and haste and remember what peace there may be in silence. As far as possible without surrender be on good terms with all persons. Speak your truth quietly and clearly; and listen to others, even the dull and ignorant; they too have their story. Avoid loud and aggressive persons; they are vexations to the spirit. If you compare yourself with others, you may become vain and bitter; for always there will be greater and lesser persons than yourself. Enjoy your achievements as well as your plans. Keep interested in your own career, however humble; it is a real possession in the changing futures of time. Exercise caution in your business affairs; for the world is full of trickery. But let this not blind you to what virtue there is; many persons strive for high ideals; and everywhere life is full of heroism. Be yourself. Especially, do not feign affection. Neither be cynical about love; for in the face of aridity and disenchantment it is as perennial as the grass. Take kindly the counsel of the years, gracefully surrendering the things of youth. Nurture strength of spirit to shield you in sudden misfortune. But do not distress yourself with images. Many fears are born to fatigue and loneliness. Beyond a wholesome discipline, be gentle with yourself. You are a child of the universe, no less than the trees and the stars; you have the right to be here. And whether or not it is clear to you, have no doubt the universe is unfolding as it should. Therefore be at peace with God, whatever you conceive Him to be and whatever your labors and aspirations, in the noisy confusion of life keep peace with your soul. With all its sham, drudgery and

broken dreams, it is still a beautiful world. Be careful. Strive to be happy."¹

The 400 year old wisdom ascribed above provides a valuable set of guidelines for living a worthwhile life.

"... Therefore be at peace with God ... [and] keep peace with your soul." These words prepare each individual to face the end of his life, an end that comes with death. Death is no stranger, and eventually each and every individual must one day face its reality. Health professionals in the Army Medical Department as well as others, sometimes tend to set aside the subject of death because it is so depressing. Sometimes one might not allow himself to think of the death of others because it forces him to face the future reality in his own life. However, health professionals are in a position to reach out and help the dying. Dying patients (and their families) have definite needs that must be met. Certainly these patients have physical needs that must be met via medical intervention. But this is not all that is required. These patients, and their families, have emotional needs that also must be addressed. This study will examine how the personnel at one facility, Walter Reed Army Medical Center in Washington, DC, might best meet the emotional needs of its dying patients and their families.

Why This Study Was Needed -- Four Patient Cases

To begin, one might go back to a bright, cold winter day (a little over one year ago). A retired Army Colonel whom we'll call "Patient A" had just entered Walter Reed and stopped at the information desk in the lobby, when suddenly all

his breath seemed to be squeezed from his chest. But this caused him no great anxiety, for by now he was accustomed to this frightening ordeal. He then bravely made his way forward again, and proceeded until he reached the main elevator bank where he collapsed and slowly drifted into a state of unconsciousness. When he awoke he found himself hooked to a myriad of life-giving machines, but of utmost importance, he felt the warm touch of his wife and one of his sons (each stroking his hand). He had been unconscious for over eighty hours, and his family and the staff at the hospital had been desperately afraid that he would not survive this traumatic event. "Patient A" did survive - at least this time; however, he was terminally ill -he was dying of emphysema - and he would not survive his next acute bout with this disease. Of interest here is that his emphysema had been followed at Walter Reed Army Medical Center for a period of five years. But what about the patient himself? What had been done to meet the emotional needs of this dying patient and his family? Actually this new wrinkle - "their emotional needs" - had been given no attention whatsoever.²

This case is not the only one that depicts the need for this study. There are three others that seem to more than adequately demonstrate the need for the creation of some additional means of meeting the emotional needs of dying patients and their families. In other words, these show that something more must be done than is already being accomplished at Walter Reed!

This next case involved "Patient B" and his family. He was a forty year old inpatient whose disease process was so advanced that he was not expected to live more than a few months. A brain tumor was killing him, and in those moments when his speech was clear enough to be understood he explained, "I am so afraid.

This is all happening so fast and my brain just can't seem to keep up ... I don't want to die. I don't want to leave my family alone and unprotected. But I can't talk to my doctor. He's just too busy. He is doing everything he can to save me, but he just doesn't have the time to talk ... The nurses seem to change so often that I don't know who they are, and 'shrinks' give me the 'willies' ... I'd talk to a Chaplain, but I'm not religious ... I'm so scared ... God I need someone!"³

The next day, "Patient B's" wife added, "All they do is come in, medicate him and leave. With all the drugs he sounds drunk, and so none of them will listen when he talks. If only his doctor or nurse would stay long enough to help him ... He wants to be strong. He wants to die unafraid, but he just can't dump that on me because he knows I'm ready to fall apart at the seams myself ... I just can't handle this. I'm trying to hold my kids and me in one piece. Who will help me find some way for my kids, my husband, and me to accept what is happening?"⁴

The nightmare of death expressed itself in blasts of anger and confusion from "Patient C", an older man. "All my life I have been alone. Nobody needs me ... Do you know what it's like to go through heart surgery and have a zipper like this on your chest? ... I'm going to die! I am going to be dead soon ... You'll drive home along with all those other bastards who are going home to people who love them, and you'll see the beautiful trees along Rock Creek Park. And I've got to sit in this hole and wait to die ... They won't come and talk to me you know! They won't help me get rid of this damn mental baggage that I've been carrying around in my head ... I need someone and these bastards won't stop long

enough to help me ... It's death they're afraid of ... They don't want to have to chalk me up in the 'Loss' column ... They don't want to face me 'cause they know I'm going to die ... Come here all you bloody bastards [he shouts] and see me and HELP me ... Nobody ever comes ... Won't someone at least come in and hold my hand and tell me I'm a worthwhile human being?"⁵

The final case that demonstrates the need most profoundly came from "Patient D" a child who is dying of cancer. In simple, quiet, and yet profound words "Patient D" said, "I'm dying and my mommy and daddy know it. But my dying is not the part that worries me. My mommy and daddy are going to get a divorce because I'm dying. Nobody will help them ... Can you? ... Please?"⁶

The Health Professionals Are Surveyed

Numerous staff interviews were conducted at Walter Reed Army Medical Center as a part of this study. While the specific questions asked each person interviewed are listed in a later section entitled Research Methodology, the following examples of their responses more than adequately demonstrate the need for a new approach to meeting the emotional needs of dying patients and their families: "We don't meet their emotional needs - we don't have time. I'm in surgery so much I can only give each ward patient three minutes a day!"⁷ "We're not set up to meet their emotional needs."⁸ "We're not at all sensitive to their emotional needs."⁹ "We, as health professionals, must be able to cope with death ourselves before we can help others deal with it emotionally."¹⁰ "We fall down on the job because of the way we're organized; we just don't have enough people."¹¹ "We don't have an organized approach to meeting the emotional needs

of the dying patients and their families. It's hard. Every patient and family is different so you never know who can help them. We need a more organized approach."¹² "We're at a loss for what to say."¹³ "Meet their emotional needs? Are you kidding? I would never want to die here. They never allow death with dignity because everyone is always jabbing, poking, and medicating you so you'll live long after you should be dead. They don't have time for emotional needs - they're too busy with heroics."¹⁴ "We're too short sighted to meet the emotional needs of the dying patients and the nursing care is too poor."¹⁵ "Our approach to meeting the emotional needs of dying patients is at best make shift."¹⁶ "It must be an emotional hell to die with nothing but strangers around you-that's what happens here."¹⁷

One additional interview should be referenced at this juncture. It was conducted with COL Frank Jones, The Psychiatry Consultant to The Surgeon General. He said, "We're crying for an organized means of meeting the emotional needs of the Army's dying patients and their families. So many piecemeal attempts are being made. When the results of these attempts are evaluated we fall way short of our objective. Much more needs to be done at every hospital - including Walter Reed!"¹⁸

A Statement of the Problem

The problem was to determine the best approach available to health care professionals at Walter Reed Army Medical Center as they attempt to meet the emotional needs of dying patients and their families.

Limitations and Assumptions

This problem solving paper does not deal with/or evaluate the actual medical care rendered (the physiological intervention performed by the staff) the terminally ill patients at Walter Reed Army Medical Center. It is further limited to an organizational type approach to meeting the emotional needs of these patients. Finally, it is limited to addressing only the primary emotional needs of the dying - as found in the literature.

There are several assumptions that have been made in formulating this study:

(1) terminally ill patients and their families at Walter Reed Army Medical Center do indeed have specific emotional needs that must be, and can be met, (2) the health professionals at Walter Reed Army Medical Center must meet these needs, (3) there must be command support of the recommended alternative approach if it is to be successful in meeting these needs.

Research Methodology

The data gathering that took place was aimed at (1) identifying the emotional needs of the dying patient, (2) identifying the emotional needs of the patient's family, (3) identifying the alternative approaches to meeting these needs at Walter Reed Army Medical Center, and (4) identifying the criteria to be used for evaluating these approaches. This data gathering effort fell into two main categories: (1) literature review, and (2) personal interviews. The literature review was accomplished at numerous hospital and professional libraries (to include the Joint Medical Library in the Office of The Surgeon General, and the

National Library of Medicine in Washington, DC). Relevant information from this review has been organized for this study in two ways: (1) general information on death and dying has been included under the Literature Review section of this chapter, (2) specific information on the emotional needs of the patient and his family as well as information on the various approaches that can be taken to meet these needs has been included under the appropriate subheadings in the chapters entitled DISCUSSION.

Personal interviews were found to be the other preferred form of data gathering at Walter Reed. At an organization as large and as busy as Walter Reed Army Medical Center, personnel simply feel so busy and burdened that they don't always respond to questionnaires. In addition, one's personal and private feelings are often more easily extracted from an interviewer who does his best to remain sensitive and who can insure, if necessary, that those feelings or opinions will not become a matter of public record. The importance here was that every effort was made to provide a setting that was conducive to complete candor. One very helpful point seemed to be that the interviewer was not a member of the organization. In fact, several of the people interviewed indicated that this fact was helpful in making them feel more comfortable and open in their remarks. These personal interviews always included the following questions: (1) How well do the health professionals at this facility meet the emotional needs of the dying patients and their families? (2) Specifically, what do you see that is being done to meet these needs? (3) What do you, as an individual, feel is the best approach to be taken by health professionals in this facility as they attempt to meet these needs?, (4) Are there any other comments or feelings that you would like to add? Other questions were asked, as

appropriate, as follow-up to some of the comments made by the individual being interviewed.

Sometimes the personal interviews were conducted during specific appointments with the person being interviewed and at other times the person interviewed was queried at an unscheduled meeting (i.e., in the hall, on the wards, during the late night shifts when there wasn't much work to do, or during an informal conversation). However in all cases the basic questions asked were the same and the individual's comments were always recorded on paper by the interviewer. The interviews at Walter Reed involved ninety-seven different people including: (1) physicians, (2) patients, (3) nurses, (4) family members, (5) administrators, and (6) various other staff. In general, the results of these interviews (conducted from November 1980 through March 1981) have been absorbed into this study. In addition, where the person interviewed expressed no desire to be anonymous, and where his or her comments were noteworthy, their ideas were included in the study under the appropriate subheading and were documented in the footnote and bibliography sections.

This paper includes in its next two chapters: (1) a discussion of the emotional needs of the dying patient and his family, (2) a discussion of three alternative approaches to meeting these needs at Walter Reed Army Medical Center, (3) an application of the criteria used in evaluating these alternatives, and (4) recommendations concerning the alternative selected.

Review of the Literature

"Live every day to the fullest" is a saying that is commonplace. One might ask why this piece of country wisdom is repeated so often? The answer is simple: because we can come face to face with death at any moment! In the Western World we are probably more death-oriented today than we have been since the days of the infamous plague that wiped out millions during the middle ages. The dictionary defines death as the act or event or occasion of dying; the end of life. As far as the patient is concerned his death involves both the termination of all his vital physiological functions (breathing, etc.) as well as the complete cessation of his consciousness. Death is the ending of all living things; but only humans can conceptualize their own death. Death is the absence of life - and life, human life, is the life of the body, the life of the self, and the life of the mind. Death is "the enemy" to most. "The enemy" is seen as an experience that can be viewed in many different ways. It can be viewed as a noble, religious, frightening, natural, or just plain horrible experience. Much of an individual's view of death involves that individual's rather special psychological makeup. One difficulty with death is that most human beings feel (deep within themselves) that they are noble, indestructible, and all-surviving. Many attitudes toward death are sentimental, as individuals hope for a "heroic death" (particularly as a younger person). There are certain circumstances in which some individuals either welcome their own death or are essentially indifferent to it. But no matter what the individual's attitude may be, death is something which every human being must one day face. To most, death is not a tender retirement. It is not a warm autumn ending to a season of soft summer

growth. It is instead a cold winter night to inevitably be faced alone.¹⁹

Once it was possible to think about death in rather simple terms. The facts were plain: we knew when someone was dead and we knew (basically) when someone was dying. Life had to be preserved at all costs! A decision to end life could not be made outside a court of law and could not be defended by arguing that any particular life, or life setting, was less valuable to either society or the person, than it ought to be. However, some things are worse than death. To a member of the Jehovah's Witness, death is preferable to being the recipient of a blood transfusion. To a patient in excruciating pain with nothing to look forward to but a life of more pain, death may be preferable.²⁰

The high cost of health care sometimes makes death preferable to prolonged life. After all, what individual wants to leave their loved ones with horrendous bills to pay after their demise. Some individual's estates have been completely demolished via the high costs of health care for the dying patient. One example of these health care costs involved a ninety-four year old woman. The charges for her care amounted to \$31,000 (over a period of only a few months) by the time physicians fees, round the clock geriatric care, drugs, etc., were included. Her physician wanted the family to spend \$10,000 more on this patient just before she died. He wished for them to spend the money on additional diagnostic work for her. Finally the family said that she was to have no more "heroics" and no more "tests" because she was "just in too much pain", and she should be allowed "to die in peace". She was administered more powerful pain medications and she died quietly in her sleep three days later.²¹

A group calling itself "Concern for Dying" operates out of New York City. This

group, facing the fact that in some cases death is a preferable alternative, aims to assure a patient's right to determine his own treatment during terminal illness and to prevent unnecessary prolongation of the dying process. It handles some three hundred written inquiries each week, maintains a toll free phone service, gives counsel to doctors, lawyers, and priests, and sends out films and lecturers to hospitals and nursing homes all over the country.²²

Why are dying patients kept from dying in peace? Often patients tell their physicians it is time to quit trying to stay alive. Some physicians simply cannot face this reality because they feel guilty about losing a patient. They review all their therapeutic decisions, wondering whether things might have turned out differently if they had followed a different course of treatment. Some pursue this exercise until they virtually become convinced that the patient's death was their fault. Other physicians simply don't want to let go of the controls - even in hopeless cases. These physicians find themselves making empty therapeutic gestures in a clearly futile struggle against the inevitable. Other physicians are concerned with committee reviews and "how the chart would look" if a certain intervention were not conducted. A California report that examined physician care of the dying revealed the fact that most of them have become incapable of saying "It's time to quit", regardless of what is really in the patient's best interest. Pressures on physicians today seem to come from everywhere. Nurses are often primary motivators in getting the physician "to do something" to save the patient, and the family can similarly pressure the doctor to act in even the most helpless case because they are unwilling to "let the patient go".²³

"Of all the obstacles that prevent my patients from dying in peace, the number one factor is doctors," said Dr. Elizabeth Kubler-Ross, whom many still consider to be the world's foremost medical authority on death and dying. "Physicians are trained to prolong life and they often try to keep patients alive at any cost, even when they have reached a stage of acceptance and are ready to die"²⁴

Lately a great deal of work has been done in examining the doctor-patient relationship in terminal illness. In fact this work shows that physicians today (especially the younger ones) have difficulty in maintaining their equanimity when they have to treat and relate to terminal patients for a period of many months. Physicians in this setting may discover themselves engaging in defensive measures (psychiatrically speaking) that leave them puzzled, dismayed, and not infrequently depressed. In all of these cases anxiety is aroused, and the physician's manner of dealing with it becomes the primary question in considering the relationship between the doctor and the dying patient. The staff at the National Cancer Institute, troubled by the distress of their younger physicians who faced these anxieties, set up a seminar format to examine the experiences of these doctors. In this seminar they had an opportunity to express their feelings, and at the same time learn that there is a time when it appears likely that efforts to prevent a disease process from reaching a fatal stage may fail. As this time is approached certain aspects of the doctor-patient relationship, previously hidden, come out of concealment and show through in a very clear focus. If these factors are not understood and properly managed, the doctor's effectiveness is severely crippled and serious consequences may ensue. These factors or defensive measures, as mentioned earlier, include, most commonly, anger and denial. Anger is a well known

response to anxiety; particularly in its capacity to organize its possessor into a "war against an enemy." Sometimes "the enemy" will be a senior "staff" or "establishment" that seems callous and ineffective as the patient lies helplessly dying. Thus these physicians begin to find scapegoats and experience tremendous discontent as they feel they and their patient are helpless victims of a cruel and distant administration or "establishment". There is also a tendency for the individual physician, when working with a child who is dying, to sometimes become angry with the parent, taking up a strong adversary role where he sees the parent as a roadblock to his treatment efforts.²⁵

Denial is the second defensive measure seen in particularly young physicians who are treating dying patients. Perhaps the most disturbing type of physician denial takes place when the physician simply won't face the fact that he has a problem in dealing with dying patients. There is also group denial as physicians sometimes gravitate to their fellow colleagues and seek an exaggerated camaraderie with loud ghoulish joking, as they discuss their dying patients. Fortunately this is conducted outside the hearing of the patients and nursing staff. Denial is expressed in several other ways—one of the most popular is "being too busy." The physician in this case chases here and there, burdened down by "such a heavy work load" that it is simply impossible to deal with the dying patient. [Note the earlier quotes under the previous subtitle, "The Health Professional Are Surveyed"]. A final form of denial takes place when the physician once in a while "forgets" to visit the dying patient when he is making his rounds.²⁶

Physicians are not the only ones who have trouble dealing with dying patients.

Administrators face the same problem. Take, for example, one long term care administrator who said, "I always thought of myself as an involved administrator, participating with patients, engaged in their activities, getting to know them individually. Yet I could never get close to a dying patient. Worse than that, I never realized this contradiction."²⁷

Similarly, it was discovered at the Wayne State University Center for Psychological Studies of Dying, Death, and Lethal Behavior that volunteers consistently avoid contact with patients who are terminally ill.²⁸ Finally nurses, in a study conducted by Glaser and Strauss, took twice as long to answer the rings of dying patients as they did to answer the patients who were not terminally ill.²⁹

Nurses are the staff members who most often come in contact with dying patients. They are constantly faced with many real challenges and many real questions including: (1) What do I do if a terminally ill patient wants to talk about his condition, but his doctor and family insist he be kept "in the dark"? If he says "Am I going to die?", can I answer with the truth? If not, what answer can I give?; (2) How can I get a physician to level with me, or a social worker, or anybody who can try to help the patient?; (3) When I'm forced to pretend a patient is not dying, how can I successfully relate to him? Constantly making up evasive answers goes against the grain. Certainly such questions are extremely frustrating to nurses. Nurses must serve the physician's needs, please their supervisor, make notes, prepare charts, check medications, and above all take care of patients. But they are also human beings who bring all of their own personal frustrations, worries, enjoyments,

and conflicts to work with them. Then they must deal with angry, irrational, or depressed terminally ill patients. All the aforementioned obstacles are present as nurses deal with these patients, and these obstacles must be overcome if the nurses are to be effective members of the staff as it deals with dying patients and their families.³⁰

Certainly it must be said that the terminally ill patient and his family have some very special needs (which will be discussed thoroughly in the next chapter). These needs can be fulfilled if the staff takes time to sit and listen and find out what they are. The most important requirement, perhaps, is that the staff must let the patient know that it is ready and willing to share his concerns. To work with dying patients and their families requires a certain maturity which only comes from experience. Therefore each member of the staff at any hospital must take a good hard look at his own attitude toward death and dying and get this matter resolved in his own mind. Then he will be ready to take the next step which involves sitting quietly without anxiety, and dealing face to face with a terminally ill patient.³¹

In concluding the literature review, one cannot help but pay particular attention to the following personal advice offered by Dr. Kubler-Ross: "Think about your own death. How much time and energy have you put into examining your feelings, beliefs, hopes and fears, about the end of your life? What if you were told you had a limited time to live? Would it change the way you're presently conducting your life? Are there things you would feel an urgency to do before you died? Are you afraid of dying? Of death? Can you identify the sources of your fears? Consider the death of someone you love. What would you

talk about to a loved one who was dying? How would you spend your time together? Are you prepared to cope with all the legal details of the death of a relative? Have you talked with your family about death and dying? Are there things, emotional and practical, that you would feel a need to work out with your parents, children, siblings before your own death or theirs? Whatever the things are that would make your life more personally meaningful before you die - do them now, because you are going to die; and you may not have the time or energy when you get your final notice."32

Alternative Approaches

Three alternatives have been proposed as viable approaches to meeting the emotional needs of dying patients and their families at Walter Reed Army Medical Center. The first approach provides for maintaining the status quo. At the present time, meeting the emotional needs of the terminally ill is the joint responsibility of the Chaplains, the Psychiatry Liaison Service, and the nursing staff. In this approach the emotional needs are down played and almost completely lost to the omnipotent heroics of a tertiary, acute care center.

The second alternative calls for a hospice at Walter Reed. Here the entire concept of total care for the terminally ill - emotional and physiological - would be provided in a setting of support, pain control, and death with dignity. Sponsored by Health Services Command, this hospice would serve to put Walter Reed in the forefront of military care for the terminally ill patients and their families.

The third and final alternative provides for the creation of a special thanatology team called "The Care Team". This interdisciplinary team consisting of volunteer physicians, nurses, social workers, chaplains, etc., would be responsible for staff education and sensitization, as well as being responsible for providing direct patient and family assistance.

Criteria for Evaluation of Alternatives

Four vital criteria have been established for evaluating each alternative approach. The first is that the alternative must provide a means of meeting the emotional needs of the dying patients and their families at Walter Reed Army Medical Center. The second is that it must have the full support of the physicians at Walter Reed. The third is that it must provide a means of working with the staff as well as working with the patients and their families (for example, the staff first must be sensitized to the situations that they will face; then must be taught how to deal with them so that the patients and their families will derive the maximum available benefit). The fourth, and final criteria is that the alternative must be within current resource constraints for Walter Reed Army Medical Center.

II. DISCUSSION

The Emotional Needs of The Dying Patient

The dictionary defines the word "emotional" as showing emotion, especially strong emotion such as being quick to weep and quick to anger. It also says that being emotional means either being moved to tears or moving others to tears. Surely death is an emotional experience! After all, any individual's death puts him through every extreme emotion a person can face - from anger and denial to acceptance and peace. Furthermore it brings out similar emotional responses in that individual's family and other loved ones.

The primary emotional needs of the dying patient fall into several distinct categories. Elizabeth Kubler-Ross has helped to make our society aware of the first, and most important, emotional need of a terminally ill patient - helping him through his own grieving process with its denial, isolation, anger, bargaining, depression, and acceptance. This process of grief involves many different stages and it should be understood that these are not neat and orderly phases where the individual goes through one and then simply carries on through the next, and the next, until the process is completed. A patient may be in more than one stage of grief at a time, and he may repeat or even skip a specific stage. The first stage almost always begins with denial. Here the most often overheard terms are "Oh no!", or "It can't be!", or "I thought it would be all right". A shock anesthetic sets in (for which we can be extremely grateful). The patient's physical responses are slowed dramatically and he moves in a "fog" and often will not remember the terrible news that put him into this shocky phase. The patient may later remember this as though everything

happened in slow motion. His denial develops further in his not being able to cope. Sometimes the patient will continue to do whatever he was doing before being told (watching TV, reading, etc.) just as though the horrible news was never told to him. He may wake the next morning and say, "Was I dreaming?" His denial is real, and it works for a while.³³

The second stage is usually some type of emotional release. For many this means tears (both men and women will weep uncontrollably). The shaking and crying goes through his body in dreadful waves and there is a total loss of control. For some this emotional "letting down" doesn't happen until much later, but when it does occur the staff needs to avoid the natural tendency to say "There, there -- don't cry". At this point tears are needed, and they are helpful. In fact many experts feel that this stage must occur before any further progress will occur. While avoiding the "Don't cry" attitude, the staff needs to "just be there" with a comfortable silence that encourages the emotional release. Here a simple touch, embrace, or even a shared handkerchief will be all that are needed. His release is an emotional catharsis and it can be accomplished either in his bursting out in tears, or even in his expressing himself in writing!³⁴

The next stage is often depression, isolation, and self-pity. He may withdraw completely, saying "Nobody understands what I'm going through." Once in this setting of isolation he may fantasize that his situation is as it was before he was notified of his impending death. Some refuse to see friends. He may wallow in his self-pity to a point of enjoyment. This is quite naturally upsetting to all around him. The tendency is for the staff to answer back harshly - "to snap him out of it". The staff needs to remember that what he is really demonstra-

ting are his feelings of worthlessness, hopelessness, and helplessness. His obnoxiousness is best handled by giving him choices the way one gives a small child. "Would you rather have lunch in your room, or would you rather have me take you out onto the patio?" This is not a constant stage; it comes and goes. He feels lonely and is absolutely convinced that nobody understands.³⁵

The fourth stage involves physical symptoms and neurasthenia. In others words he's always just too tired. He'll say "I can't go on", or "I'm just weighted down." He may catch cold easily, have tension headaches, or experience problems in his gastro-intestinal tract. Each physical symptom is exaggerated (i.e., the headaches become the "worst" he has ever had). Sleeplessness is common and when he does get to sleep he may wake up in the middle of the night and lie awake until morning. His imagination may run wild and every little thing will be exaggerated out of proportion (i.e., a cold may be interpreted by him as lung cancer).³⁶

The fifth stage - panic and anxiety - may come and go at anytime. "I just can't make it", or "I'll never be able to go through this". At this stage the staff needs to remember that even while he is moaning that he "can't make it", he is. The anxiety is best fought with gentle encouragement - since he is "making it" - and each success needs to be reinforced. The panic usually gives way to the light of day or even the ligh of hope. Anxiety may move him ahead to anger as he says, "Look at me. Look what shape you've left me in." Neither panic nor anxiety are rational at this stage. The staff can best help him get through this stage by just having him address one day at a time - that's all he can handle. In this way he can go from "I can't make it" to "I'll show you I really

can make it after all."³⁷

Soon the guilt stage will come along. It may be an initial reaction or it may come late in the dying process. "If only I insisted on a checkup" or "Why didn't I change my habits when I had the chance?" There will always be some form of guilt - it might be the unkind words he used to someone he loves, something important left undone, or simply ignoring someone he shouldn't. What the staff needs to provide here is the opportunity to help him differentiate between real guilt and neurotic guilt. If he still carries guilt because he is an illegitimate child - this is neurotic guilt. Helping him to recognize the need to eliminate this unnecessary baggage should be the goal of the staff. Real guilt can often be eliminated by restitution - getting forgiveness for these unkind words or reestablishing contact with that individual he ignored. Any death will bring some guilt with it, but it need not be crippling.³⁸

One of the least understood stages of grief is hostility. Here anger and rage may erupt alongside affection and tenderness. "Why should this happen to me?" (It is interesting to note that he probably never asks himself why good things happen to him.) The hostility can take many forms: anger at the staff, family, hospital, church or community. It can also be seen in anger at God, his spouse who has just had something special happen (i.e., a promotion), or loved ones who have moved out-of-town. The staff needs to help him recognize his anger and release it, because unexpressed hostility often progresses to deep depression. This is often the most difficult time for the staff. After all they have their own problems and suddenly they may find themselves on the receiving end of a barrage of hostility - anger which they don't deserve. The staff must persevere

at this point because the patient will not find peace until his hostility is expelled.³⁹

The next state is often called negative concentration - in other words the inability to do normal activities. Not only will he avoid doing anything, he will often not even seem to hear the staff when they speak to him. If allowed, he might wear the same clothes day after day, or he might sit for long periods of time examining pictures or scenes from his past. He might spend hours simply staring into space with a picture or special object clutched in his hands. While hostility can be a catharsis, this stage can be a real roadblock. The staff, when working with the patient in this stage must remember that while it seems to last for an unreasonable time, it will pass and once this stage is past better things will happen.⁴⁰

The next stage is social sharing. This may be a real bore to even those who love him as he has a preoccupation to talk, think, refer, and hear of nothing except the objects of his affection. He will share the facts, the near-facts, the feelings, the innuendos, the before, and the after. This should be allowed, however, because social sharing is a vital catharsis. It should be remembered that staff who provide a "listening wall" to him will help more than they may even realize. It is also interesting to note that the inaction followed by the preoccupation stages seen in the grieving process are identical (to those experienced) by individuals who enter nursing homes.⁴¹

The next stage that is often done, and sometimes overdone, is that of rituals and appeasements. The more guilt and the more compulsion, the greater the need for rituals and appeasements. In some ways this stage is a reverting back to

denial as the rituals and appeasements are used to ease the reality of the situation. At this stage he may make out a will, choose a tombstone, and dispose of property. All of these may look as though he has accepted his death but he has not yet reached the stage of acceptance. These are only appeasements.⁴²

In all grieving there comes a time when the dying patient feels that "someday things will be better", or "maybe this treatment will work". This is the stage of hope and although it may filter in and out of all the stages of grief it finally becomes a reality here. New light is shed on the subject and bright areas may be seen in several different ways. His loved ones may be changed, or something good will happen and he will be able to see it. His children may come to see him from overseas, or old friends may make a special journey. Hope is light; and light brings a spark of life - a rekindling of life from within - hope leads to joy. Without hope there is only death and darkness.⁴³

The final stage is acceptance, readjustment, and integration. He is not the same, he cannot go back, and now he realizes it. He can readjust; even to the terrible reality of his own death. Now he can grow and integrate that growth into his being and into his relationship with the staff. He can get on with living now - for whatever period of time he has left. The staff and the patient have been through a long journey together. For a long time he has been pulled between living in the past and accepting reality, between letting go and accepting loss, between the wish to survive and the obsession with memories. He has progressed emotionally through peaks of rage and valleys of despair and he has finally leveled off on the high plane of acceptance. Now his travels will be reasonably lived - although rocky at times -but now he has reached that point

where he can continue to live until his time has come.⁴⁴

The second primary emotional need that must be addressed is the dying patient's need for help in coping with pain. The dictionary relates the emotional aspect of "pain" when it defines this word as the distress or suffering, mental or physical, caused by anxiety, anguish, grief, disappointment, etc. There are four different types of pain experienced by a dying patient. The first, and most obvious type of pain is physical. Physical pain can either be chronic or acute. Unlike acute pain, chronic pain is more often a continuing experience. It has no foreseeable end, a barely remembered beginning, and it seems unpredictable. It may fill his whole field of consciousness, isolating him from his surroundings. It may constitute a threat to his doing even the simplest activities as well as being a threat to his reasoning capabilities and his perception of reality. Its results are all encompassing and manifest themselves in physical distress and emotional suffering. Acute pain brings high peaks of physical distress and racks the body with a terrible vengeance for shorter periods of time. Periods of rest often occur between bouts with acute pain, so some light at the end of the tunnel can be seen for at least intermittent future periods (however brief). When it does arrive, it calls up all the patient's reserves and it may create tremendous periods of fear and anxiety as the patient waits for the "next bout" with that horrible experience. The patient's needs include medical intervention for physical pain control and an ever-available, ever-caring staff that is not afraid of touching or soothing a patient in distress. The dying patient who experiences such horrible fear and anxiety needs to be supported and reassured as tenderly as possible. In addition, where pain has clouded reality, the staff can help reestablish it within the patient's mind.⁴⁵

The second type of pain experienced by dying patients is mental or emotional pain. Emotional pain in a terminal illness is a reality which is too often disregarded or ignored. Most typically it is a combination of anxiety and depression. Anxiety is wholly understood as seeing no end to his illness and a patient who is dying may well find himself deteriorating in what is often felt to be an inexplicable fashion. Anxiety in such circumstances commonly responds better to the concerned listener than to tranquilizers given more or less automatically. A dying patient's fears are not always overtly or exclusively concerned with their disease; but whatever form they take, they tend to lose much of their power once they have been expressed in words. A great deal of this mental or emotional pain or distress stems from his loneliness and from his feelings of isolation. Once again the staff can help meet the patient's needs by being an attentive listener.⁴⁶

The third form of pain is social. The gradual or abrupt relinquishing of responsibilities may be one of the greatest pains experienced by a terminally ill patient. For example, he may be distressed because he must now surrender the responsibility for children who are not yet independent or for a partner who has needed and been given lifelong support. What the staff should do in dealing with this type of pain is to listen while giving the patient and the family room to work things out as best they can. There is no easy answer available to the patient here, and all the staff can do is to deal with the patient in a kind, honest, and simple manner.⁴⁷

The fourth, and final type of pain that creates an emotional need for the dying patient is spiritual pain. The feeling of his meaninglessness and questions of

"why?" can cause him great emotional suffering. Here the staff must be careful not to impose their own religious faith on the dying patient. At the same time, the staff who express their deep seated belief that there is love, meaning, and purpose hidden in all human experience, may well see their patients finding relief from their suffering and peace in their own very special ways. The staff should be watchful, caring, and "be there" when needed.⁴⁸

A third primary emotional need of dying patients could be called the needs for control, understanding, and devictimizing. Dying patients wish to maintain control over their destiny. Each patient will attempt to meet this need in several ways. He might ring the nurse constantly and ask questions such as, "Does every person in this hospital have to have an IV or could I get rid of mine?" Questions of this sort will be asked of the nurses, technicians, physicians, orderlies, etc. When a patient sends out these signals of need of control the staff must seek to be warm, ever-present, and sensitive. When the staff succeeds, the patient will sense security; he will be in "good hands." Thus he will be more at ease because the control over his destiny will seem to be in capable hands. A staff member who establishes a trusting and caring relationship with the patient when he first comes in can prevent many severe problems. Most dying patients want to be in charge of their own destiny for as long as possible. Guaranteeing them answers when and if they want them is part of the dignified treatment of a sick person. Similarly, the need for understanding technical language or procedures is present. After all, such understanding helps eliminate anxiety about the unknown or unfamiliar! This must be an accepted part of the daily operation at the facility where the dying patient is being treated. From the instant the patient arrives, he must be

given an opportunity to voice his questions concerning those terms or procedures that are routine to the staff. Thorough, simple explanations of terms and procedures help eliminate emotional frustration at not knowing "what is going on" and these help prevent, or at least lessen, anxiety and even depression. When allowed to go unchecked, the patient's imagination may run wild as he pictures what will happen to him through a distorted focus. Facts, presented in a straight-forward manner will do much to help alleviate this emotional burden. Likewise the need for devictimizing is expressed by the dying patient. This means that the patient has the powerful need to share with someone the feeling of being unjustly victimized and robbed of life itself. He must be afforded the opportunity to fully express these feelings, and not just when he's in a state of deep depression. By allowing these feelings to be fully expelled he can slowly begin to eliminate his feeling of being victimized and he can thus begin to move on to dealing with the other issues that trouble him.⁴⁹

The fourth and final primary emotional need of the dying patient is the need to maintain a will to live. "A person's will to live, or lack of it, has been recognized for many years as the determining factor in whether the individual lives or dies, and as such, it represents a degree of personal control over continuance or demise. Often one hears that a person has 'given up,' or 'died of a broken heart.' He may have been in perfect health, or if ill, then certainly not terminally so, yet because of the loss of a loved one, loss of feeling of self-worth and usefulness, boredom, or disillusionment with life, simply may have lost the will to live. Such persons rapidly decline and die. Man possesses an almost unlimited power of endurance. But take away hope, happy expectation, the fiction for which he suffers, and he dies. . . There are those

who refuse to die and live on long after the time of their expected death."⁵⁰ Medical specialists today appear blindly pointed toward efforts to extend life while overlooking the importance of purpose and selfworth necessary for survival. As death becomes unavoidable, the dying patient's will to live becomes increasingly necessary. He must have the will and desire to reach out, to cling to, and to be a part of life. To surrender one's self from all contact with life is to hasten the death. Certainly, although no patient can ever hope to escape death forever, the possession of a will to live can greatly help him to gain a tremendous emotional victory by postponing death for a while. The patient can be helped by the staff, at this juncture by providing him with support that validates the fact that he is a worthwhile and very special person. In addition, any steps that the staff take to eliminate the dying patient's feelings of uselessness or disillusionment with life will most likely enhance his will to live. Thus, they will have done a great deal toward helping him meet a primary emotional need.

The Emotional Needs of the Family

It has been said by Dr. Kubler-Ross that one cannot fully meet the emotional needs of the terminally ill patient if one does not include meeting the emotional needs of the patient's family as well. They play far too significant a role during the illness and their reactions to that illness will contribute a great deal to the patient's response to his own condition. For example, the patient's wife may suddenly find herself going from the role of housewife to the role of primary provider. This dramatic change in life may become a tremendous emotional burden. She may feel threatened by the loss of security and the end

of her dependence on her spouse. She will have to assume new responsibilities and will have to completely readjust her own schedule so they may be accomplished. When she visits her husband she may have to make special transportation or babysitting arrangements. All of these changes may create reactions from children in the household, thus adding another responsibility to the wife's already bulging list (because she must react to their responses). With the worries and concerns about her husband and her new responsibilities, there often comes loneliness, despair, and resentment. The hoped for help from friends and other family may not come or may take a different form than that expected by the wife. Friendly advice may actually add to her burdens instead of alleviating them. What she really needs is a friend who will relieve her of some of her many, motherly tasks (i.e., cook an occasional meal, or take the children to play). What she gets is quite often the opposite of what she needs. Certainly, her husband's feelings, emotional burdens and needs (as described in the preceding section) may well change their own relationship and that too will place an additional burden on her. Understanding, caring, patience, and concern by the staff is vital here.⁵¹

Similarly, the husband of a dying patient may face a loss that is equally as great. Furthermore he may not be as flexible as his wife, or at least not as used to concerning himself with matters relating to his children's school, meals, laundry, and routine housecleaning. Consciously or subconsciously he may resent his wife who lies in bed (even though it's a hospital bed) while he has to come home after a long day and then do all of her work too. For some men, assuming the chores of housewife means that he is changing a major role. Before he was served; now he is doing the serving. "Why did she do this to me?" he may

ask in all honesty, and his feelings must be adequately vented if he is going to be of help to his wife. The staff can truly help this family member by letting him express these feelings without interruption. Additionally the staff must never respond in a condescending manner - no matter how callous these remarks appear on the surface. Once they have been expelled they can be set aside and the husband is then in a key position to help enhance the emotional well-being of his wife.⁵²

Family members of dying patients should be encouraged by the staff to take time for themselves each week to reestablish themselves outside of the sickroom. It is unfair to constantly require the presence of a family member at the bed of the dying patient. Each family member needs some breathing room and the staff must be careful to be aware of, and protect, this need. A dying patient is a tremendous sponge who will tap all of the emotional resources of his family. If the family members aren't careful they will "burn out" long before the patient's death so that when they really need their emotional resources there will be none left. In addition it is important for the staff to encourage the family to make short "get away" trips when the patient's illness will allow such periods of relaxation. These trips allow the family to regroup and analyze what is happening to them in a setting far away from their dying loved one. Many families would feel guilty taking such trips but the staff can help them considerably by reassuring them that such actions are not something which should cause guilt. Just as the terminally ill patient cannot face death all the time, the family members cannot and should not give up all other interactions and activities for the sake of being with the patient exclusively. Early in the patient's terminal illness the family members will need to be allowed to

emotionally delay or avoid the inevitable reality of their loved one's death in order to face it with a more emotionally stable attitude at a later time. The staff must meet this need by being an understanding helper who contributes to the family's obtainment of a proper balance between serving the patient's emotional needs and respecting their own.⁵³

Family members go through the same, or at least similar, stages of grief as the ones described for dying patients. While a thorough review of what was contained in the previous section on the stages of grief appears unnecessary at this juncture, a few points still remain in order. At first the family members will deny the reality presented to them. They may refuse to believe that such an illness is in their family or then go from doctor to doctor trying to find some health professional who will say that their loved one does not have a terminal illness. They may seek the help of faith healers or famous clinics, but in the end they still must come face to face with the reality that a loved one is dying. When the reality finally sinks in they too will experience a tremendous emotional reaction. They may project rage at the staff or hospital. Interestingly, some of this anger may actually be a subconscious envy because they cannot be the ones to care for their loved ones. The more the staff helps the family members to express their emotions, the more comfortable the family members will be. Guilt is another very uncomfortable problem for the family members. "If only we had sent him to the hospital earlier," they may say. "I should have noticed his symptoms and forced him to go." Here the staff can greatly help meet this emotional dilemma of the family members by assuring that they probably did everything they could do. Some of their guilt may go back to angry thoughts that the family member has had about the dying patient in the

past. When the anger, resentment, and guilt has been resolved, the family will then go through preparatory grief. The more the staff can help the family members express this preparatory grief, the less unbearable it will be after the patient dies. The staff should help the family to realize that expression of their true emotions is much easier for the patient to take than a make-believe mask which a loved one can see through anyway. If members of the family can share their emotions together they can gradually face the reality of their loved one's death and they can then come to an acceptance of it together. One final phase that seems heartbreaking to many family members, is that a dying patient who has found emotional stability and inner peace in his death will separate himself, step by step, from all of his environment including his loved ones. These family members do not understand that a dying patient who has found peace is not rejecting them by this separation. He is actually undergoing a final task. Instead of the family's receiving this reality as a moment of grief and resentment, they should see it as a source of comfort. It is at this point that the emotionally distraught family may need the most support from the staff (and the patient the least).⁵⁴

The family's emotional needs do not cease when the patient dies. Not only must they grieve for the patient who is dead but they also must grieve for the loss and dislocation it will create in their own lives. In addition, family members will unavoidably grieve for their own death (which the death of their loved one has brought into full focus). The staff can be very helpful to family members even after the death of the patient. The staff is in a position to let the family members know what to expect. They must be given permission, via encouragement, to grieve. Crying is not a sign of weakness, so family members should

be encouraged to cry together, because while suffering and sharing their pain together, members can help one another. They should be helped to relinquish the memory of the deceased as an active force in family activities. They should be reminded that their loved one's death has created a change in the composition of the family group. A role has been vacated. The family must now go through a period of adjustment as it alters responsibilities and functions to fill that void. The socio-emotional functions need to be realigned (these functions are concerned with the giving and receiving of love). The staff must help them realize that there must also be a realignment of family roles with the "outside." For example, realignment may be necessary for the wife and her husband-wife bridge club, or for the son and his father-son baseball team. In addition the family will need help in going through role readjustment. If the dying patient was the "bread winner," who will now fill that role, and to what degree? The staff should also remind the family that one good thing that comes from the death of a family member is an increased solidarity of the family as a unit. Parents of a child who died will often deal with their grief by giving extra love to the remaining children. Or they may try to have another child (as a replacement), especially if the child that died was an only child. This wish for another child is not hard to understand. The same wish is expressed when the spouse of the deceased remarries. The composition of the family unit has been restored to its original size and if all have worked through their grief they are ready to accept their new member. If the staff allows the family to direct their emotions at them, at the hospital as an institution, at the dying or dead patient, or at God then it has helped the family meet vital emotional needs. If, on the other hand, the staff blames family members for daring to

vent such "socially unacceptable thoughts, reactions, and emotions" then it is blameworthy for prolonging the family's grief, shame and guilt.⁵⁵

Alternatives

As documented in the literature review and the personal interviews conducted at Walter Reed, the decision makers at WRAMC must realize that every possible consideration should be given to establishing a program for the terminally ill and their families. There appear to be three realistic alternatives: (1) maintain the status quo, (2) establish a fully operational hospice, or (3) establish a thanatology team that is specifically designed to help dying patients and their loved ones.

The First Alternative Approach

Status Quo

Walter Reed Army Medical Center is a tertiary, acute care facility that is the Army Medical Department's most widely known hospital. This facility is reputed to receive a full 10 percent of the entire resources allocated by the Army Medical Department, and when the workload accomplished by this hospital is examined, it is little wonder that WRAMC is so resource-intensive. Along with its tremendous investment in education (at all levels imaginable) and research (in so many areas that it boggles the mind), WRAMC workload data reflects the following daily averages: 841.5 beds occupied, 60.8 admissions, 4.3 births, 2,941.5 clinic visits. If the approximately 600 deaths seen each year at Walter Reed were to be recorded on a daily basis the figure would total to slightly less than two per day.

A few of the deaths at WRAMC are recorded as DOAs (dead on arrival). These are first seen in the Emergency Room. The terminally ill patients who first enter the emergency room at WRAMC are stabilized long enough for their disposition to be determined. Then they are moved to the appropriate unit (surgery suite, ward, etc.). Often the dying patients who are initially examined in the emergency room are there because of some unexpected traumatic accident or unanticipated medical event (i.e., a heart attack). Saving lives and patient disposition to the proper unit are the primary functions of the emergency room, and the physical needs of the patient may be so urgent and demanding that there is little time to think about his emotional needs. Yet the patient who is admitted in critical condition may well be aware of the seriousness of his situation and in desperate need of some kind of meaningful communication. He may be conscious but confused, and should be oriented to his situation calmly and in simple language that he can readily understand. He may ask, "Am I going to die?" But when he asks this he usually does not want to know. What he does want to know for certain is, first, that he is getting the best possible care and, then, that he is not going to be left alone. (One of his greatest fears is the fear of having to die alone.)⁵⁶ He might be told that his condition is serious and that everything is being done to help. But usually this is all that can be expected from the staff of the emergency room as they prepare him for his immediate transfer to the appropriate unit within the hospital.

The majority of deaths at WRAMC are seen on the fourth floor where one finds the Surgical Suites, the Surgical Intensive Care Unit, the Medical Intensive Care Unit, the Transplant Unit, the Thoracic Surgery Unit, and the Labor and Delivery Suites. This fact is simple enough to understand, because this area is where

you'll find most of the really sick patients. However, there are terminally-ill patients on the other inpatient floors as well. Unlike the staff in the emergency room, the staff in these other areas should have more time to develop a closer relationship and thus help meet the emotional needs of the dying patient and his family. However, there are some obvious obstacles to this at Walter Reed Army Medical Center, to include: (1) an extremely heavy workload, (2) a shortage of some key staff (i.e., nurses), (3) a heavy turnover of physicians (i.e., the constant rotation of interns and residents), and (4) those personal factors discussed in the literature review (i.e., it is difficult to meet the emotional needs of the dying patient until the staff member has dealt with the emotional aspects of his own death). Therefore the role of meeting the emotional needs of the dying patient at WRAMC (when they are addressed) falls into the hands of an occasional interested physician or nurse as well as falling under the organizational responsibility of the Psychiatry Liaison Service and the Department of Clinical Pastoral Services. Interestingly, there is no clear cut designation as to exactly when a staff member of the two aforementioned services is called, who calls them, etc., except that Psychiatry Liaison Service usually takes only referrals from physicians. The general guideline is that when the patient or family seems to need help an interested party calls them (or calls the chaplains). This does not mean, however, that the emotional needs of dying patients at WRAMC are being ignored. In fact, both the Department of Clinical Pastoral Services and the Psychiatry Liaison Services do an outstanding job in helping those patients with whom they come into contact.

COL Magelee, the Chief Chaplain at Walter Reed is a dynamic pastor and health professional. Under his direction numerous programs are ongoing which have

either a direct or indirect contact with the dying patients and their families:

(1) naturally the chaplains provide services to help the spiritual well-being of the patients and their loved ones; (2) various chaplains participate with the Hematology/Oncology Interdisciplinary Team that helps cancer patients; (3) chaplains are assigned to every inpatient floor at WRAMC and make themselves available night and day; (4) WRAMC runs a hospital chaplaincy program which includes an excellent teaching block on death and dying; (5) through the use of a technique called "guided imagery" several patients have been taught to come to grips with their own death. An example of this involved a terminally ill patient who could at least delay his impending death by following a certain prescribed regimen; unfortunately he had deliberately refused to follow his physician's advice. Through the use of "the relaxation response" (meditation), he was taught to release his thoughts and let them flow unimpeded. After one particular session with a chaplain, the patient revealed that in his mind (through "guided imagery") he had traveled on a long journey. At its end he came to a river. On the other side of the river was a tall man who called for him to cross the river. When the chaplain pursued the image with the dying patient, the individual was able to identify that the river represented the waters of death, and that the tall man was God. Then the patient broke into tears and said he really didn't wish to die. Once he had given the patient an opportunity to express his feelings the chaplain pointed out the fact that while death could not be postponed forever, it could at least be set aside for a short while if the patient would only follow his physician's advice. While the patient's eventual prognosis remains the same, he has none-the-less, been able to preclude his premature demise.⁵⁷

Along with the chaplains, the Psychiatry Liaison Service serves the dying patient and his family at Walter Reed. This service has two full time staff members and usually has two or three residents (who are rotating through the service). Usually this service first gets its referrals from the patient's attending physician and then the staff member will visit the patient in his room. The chief of this service, COL Devaris, is a delightful and caring individual who, along with helping dying patients, has the responsibility of helping other patients cope with chronic pain, depression and stress that stem from their hospital stay.⁵⁸

Additional help in meeting the emotional needs of the dying patients and their families at WRAMC is provided by various services (including Social Work Service and the Psychology Service); however, their involvement in specifically meeting the emotional needs of the dying patient and his family, generally speaking, is handled on a piecemeal basis at this hospital. Basically speaking then, WRAMC can be summarized as being a tertiary care center that sees its primary priority as heroic physiological intervention in the disease process. Meeting the emotional needs of its dying patients and their families is seen as a much lower priority and thus the meeting of these needs has been left in the hands of a few excellent, but outnumbered, health professionals. Outnumbered by those who need help because as the evidence presented in the introductory chapter of this paper indicates, there are still many patients whose needs are not being met)⁵⁹

Nevertheless, one approach that is available to the decision makers at WRAMC is to "leave things alone," or simply "ignore addressing this issue any further" by maintaining the status quo.

The Second Alternative Approach

A WRAMC Hospice

A hospice deals solely with terminally ill patients and their loved ones. It helps them prepare for death in a supportive and painfree (at least as painfree as medically possible) setting. Hospices are definitely supported by the health professionals at the "grass roots" levels and can be adjusted to the need of the terminally ill in a variety of settings.⁶⁰ In the past, too many terminally ill patients have spent their last days in cold, impersonal hospitals where little was done to meet their emotional needs and where not enough was done to stop their pain. The notion that "there must be a better death than this" has spawned a nationwide hospice movement. At the present time there are an estimated 300 working hospice programs in the United States. In the metropolitan area that surrounds Walter Reed Army Medical Center there are presently five hospice organizations: (1) Montgomery County Hospice in Chevy Chase, Maryland. This is a new hospice organization and is just getting established in the area; (2) Prince George's County Hospital Advisory Group in Cheverly, Maryland. This hospice is a part of the Prince George's General Hospital; (3) Hospice of Northern Virginia in Arlington, Virginia. This is the oldest hospice in the Washington Metropolitan area; (4) The Washington Hospice Society in Washington, DC. This is a home-care program for DC residents; (5) The Washington Home Hospice, also in Washington, DC. Currently this is the only local inpatient hospice program.⁶¹ One very interesting development that is currently in progress is that the Hospice of Northern Virginia plans to include children in their program. At the present time none of the hospice organizations within the Washington metropolitan area have a program for terminally ill children.

However, Northern Virginia's new plans includes for the provision of between 6 and 10 dying children at any given time. (This hospice organization was established by a student and friend of Dr. Kubbler-Ross).⁶²

A hospice is a program for the care of the terminally ill; it is not necessarily a facility. A hospice program can be carried out as a home care program, as a department of a general acute-care hospital, or as a free-standing facility (which can also be attached organizationally or physically to any hospital). Naturally a hospice program might involve any combination or mutation of these options. But a large number of organizations develop from either a home care program, or an inpatient facility and eventually seem to grow into a full hospice program offering both inpatient and home care. Hospices have been developed because of the void that exists as a result of the fact that acute-care hospitals are most often ill-suited to meeting the physical and emotional needs of the dying patient and his family. These acute-care hospitals are geared to cure patients and send them home as soon as possible so as to give efficient rather than individualized care. Hospices on the other hand, treat the symptoms (physical, emotional, and mental) rather than the disease. For example, medical management techniques commonly found in hospitals are not usually used in a hospice. In an acute-care center, like Walter Reed, basic goals (along with education and research) are: investigation, diagnosis, cure, and the prolongation of life. In a hospice, however, one will find that the goals are: relief from distressing symptoms of disease, security in a caring environment, sustained expert care, and the assurance that the patient's family won't be abandoned. The National Cancer Institute states these goals quite eloquently. It says the goals of a hospice program are to: "(1) ease the

physical discomfort of the terminal patient by employing pharmaceutical and advanced clinical techniques for effective symptom control; (2) ease the psychological discomfort of the terminal patient through programs allowing for active participation in scheduled activities or periods of peaceful withdrawal as determined by the patient; and (3) aid in maintaining the emotional equilibrium of the patient and the family as they go through the traumatic life experiences of progressive disease and ultimately the final separation of death."⁶³

The hospice concept does not suggest that normal hospital care is bad. Instead it merely recognizes the reality that neither general, teaching, nor research hospitals (WRAMC fills all of these roles) are oriented to providing care for terminally ill patients. Several different models of hospice are currently available for examination by the staff at WRAMC. In view of the fact that most individuals would truly prefer to die at home in a peaceful secure setting with their loved ones around them; a home care hospice program is often used as the initial model for establishing a program for meeting the physical and emotional needs of the dying patient and his family. However, it must be understood that the patient will not remain at home at all times, because there may be times when he must be treated as an inpatient for a while (long enough to gain control of new symptoms, provide a fresh environment for the patient, or give his family a break from the heavy burden of 24 hour-per-day service to him). When this has been accomplished he'll be moved back home again where he can once again be amidst the things that are so important to him. The dying patient has the need for many things that simply aren't provided in the sterile white rooms of an acute-care facility. He needs "life" around him. "Life" is loved ones, and "life" is other objects of importance. He needs unsanitary items-like his dog

at the foot of his bed, his own clothes, his own pictures, music, and even his own food. He needs all of these items of identity that he holds so dear. Most of all he needs his loved ones, people he can trust to really care about him. Hospices can certainly provide many of these things via the use of a hospice inpatient model but for many it is much better for this to happen at home.⁶⁴

A free-standing hospice is another model/option available to the staff at WRAMC, but this is a costly alternative. Certainly this is seen as one views the slow growth of free-standing hospices in this country versus the rapid growth of the home care hospice programs and the hospital-based program models. Home-care programs grow because of the inherent cost-savings featured by such a program (i.e., low overhead and low staff costs), whereas hospital-based hospices grow as a result of the excess hospital beds available throughout the country. Because of these excess hospital beds, capital construction funds for new free-standing facilities are hard to find. Therefore, more decision makers are going to hospital-based hospice programs rather than construct a new, separate facility. There is one drawback to hospital-based hospice programs, however; sometimes the philosophies of acute care health professionals clash with the philosophies of the palliative care of hospice health professionals to such a degree that the top management of the hospital will have to prioritize in some areas that it may not wish to take an "official" or publicized stand.

While utilization of the home care model at Walter Reed Army Medical Center might seem ideal (at first glance) for many of its patients, the geographical restrictions of the area preclude the selection of this model as the best possible setup for a hospice program at WRAMC. Not only do Walter Reed's dying

patients come from all over the country, they come from all over the world! Even "local" patients come from distances of 20 or 30 miles, effectively eliminating the possibility of periodic visits by the staff to the patient's home (to insure that the care that is being provided is appropriate). Thus, a home-care program, except in a few individual cases, simply does not seem reasonable. And in those rare instances when such a program was provided a great deal of coordination would have to be made regarding legal liability, drug administration, equipment utilization, etc.

Likewise, a free-standing hospice facility must be ruled out at this time because of the tremendous space shortage at Walter Reed Army Medical Center. The free-standing buildings that might normally have been considered for such a program are jammed with supplies that were excess from the old hospital as WRAMC moved into its new facility. In addition there are current shortages of enlisted barracks, etc., and the current Army Medical Department's construction budget is fully committed for the next five years, so it provides no opportunity for hope.

Therefore the only possible hospice program that appears feasible at WRAMC would be a hospital-based program. This program, if established, could draw on the many fabulously talented and extremely sensitive health professionals at WRAMC. These professionals (i.e., physicians like COL Hirata, the Chief of General Surgery, and chaplains like CH Stevens who has been doing a lot of work with holistic medicine and interdisciplinary teams) could combine the internal and external bodies of knowledge and experience concerning the establishment of a hospital-based hospice at Walter Reed. Through meetings with representatives of

the five local area hospice programs, meetings with their own personnel who have worked in or dealt with hospices previously, and meetings with people like Chaplain Farr and other staff who are active in establishing the hospice at the General Leonard Wood Army Hospital in Fort Leonard Wood, Missouri, a great deal of knowledge and experience could be pooled. This experience and knowledge could then be used in establishing a hospice program at WRAMC that deals with the physical and emotional needs of the dying patient (and his family). It is interesting to note that CH Farr almost single-handedly began the hospice at Leonard Wood. When he arrived at that hospital he took with him a burning desire to establish a hospice program for the terminally ill, and he was able to translate that desire into a reality with the full support of the hospital commander and several of the physicians, nurses, and other staff members at that facility. The chaplains office at Health Services Command in Fort Sam Houston, Texas, provided the funds for civilian experts to go to Leonard Wood and teach them how to get started, and then how to continue to operate their program. Additionally such funds would be available to WRAMC via the same office for similar, worthwhile programs where the staff needs expert help in laying the groundwork for such a project.⁶⁵

The director of the hospice at WRAMC should be a physician who is (in the chain-of-command) under the direct supervisory control of the Deputy Commander. Additionally the hospice staff should include an interdisciplinary staff of physicians (i.e., psychiatrists as well as experts from the medical and surgical specialties), nurses, chaplains, social workers, psychologists, pharmacists, dietitians, therapists (i.e., art, physical, and occupational), and technicians of other specialties as deemed appropriate by the director. Wherever possible

staff members should be a volunteer! Finally the hospice program at WRAMC should include the following elements: (1) 24 hour-per-day, seven day a week service; (2) For a few special, geographically close patients, home care service in collaboration with inpatient facilities; (3) Knowledge and expertise in the control of symptoms; (4) The provision of care by an interdisciplinary team; (5) Physician directed services; (6) Central administration by a staff that specifically supports the hospice program; (7) Use of hospital "volunteers" as an integral part of the health care team; (8) Treatment of the patient and family together as a unit of care; (9) A bereavement follow-up service.⁶⁶

Emotional care for the patient and his family is a primary function of any hospice program and so WRAMC's hospice must diligently strive to meet this vital need. Emotional support is vital to the success of the program. Each patient must be seen as a part of a family unit, whose total well-being and lifestyle is dramatically affected as a result of the care rendered by the staff. Flexibility must be geared to the patient's emotional as well as physical well-being. Physical and emotional comfort must characterize the hospice program. Visiting hours must be flexible (preferably with no restrictions) so that even children can visit the patient whenever he desires. Ideally, meals should be provided on request and even moderate levels of wine or liquor should be served if requested. Patients should be allowed to wear their own clothing and bring in favorite possessions wherever possible. In conclusion, with the proper command, physician, and other staff support, a hospital-based hospice program at WRAMC would provide an ideal means of meeting the physical as well as the emotional needs of the dying patient. In addition it would serve as an outstanding means of simultaneously meeting the emotional needs of the patient's

family.⁶⁷ In short, a hospital-based hospice could potentially put WRAMC in the forefront as the military's leading advocate of care for the terminally ill. [See appendix A for a conceptual drawing of The Hospice In Patient Care].

The Third Alternative Approach

A WRAMC Thanatology Team

To some the status quo is not acceptable, yet at the same time establishing a fully operational hospice at Walter Reed Army Medical Center may not be acceptable either, because it represents too big a "first step" in creating a program for the terminally ill and their families. Additionally, it is only fair to point out the fact that WRAMC is not alone in its lack of providing such a program. In fact, one survey of 150 hospitals (conducted in 1976) examined facilities in Delaware, Maryland, Virginia, West Virginia, and the District of Columbia revealed that only 3 of them had a program specifically designed to help the dying patient and his family!⁶⁸

A more moderate alternative that is available to Walter Reed's decision makers is the creation of a hospital thanatology team. Successful hospital thanatology teams have been developed to meet the needs of the dying patient and his family. These teams: (1) treat the patient as a total human being (psychosocial, emotional, and spiritual as well as physical problems are addressed and treated by appropriate personnel in a team approach); (2) recognize the unique needs of the dying patient's family as well as those unique needs of the staff that must help the patient face death (one excellent example is the team's assistance in helping both family and the staff deal with the actual death of the patient); (3) prepare a total treatment plan (covering the needs of the patient and

family, both before and after his death); (4) provide appropriate care in an appropriate setting (although they are hospital based they do not advocate unnecessary hospitalization, and thus recognize the fact that team members may see a terminally ill patient on an outpatient basis. (They realize that many patients who have a terminal illness may have periods when they can go home and then be followed on an outpatient basis during the "breaks" or "remissions" of their particular disease process.⁶⁹

The utilization of a thanatology team at Walter Reed would certainly fit half way between the status quo and the development of a full blown WRAMC hospice. The thanatology team recognizes two vital realities at WRAMC: (1) the status quo is not good enough (as evidenced in the introductory chapter of this study), and (2) key physicians will block the introduction of a hospice ("Key physicians will stop a hospice. It won't work here. My department won't support a hospice because we can't have our physicians running in every direction...the liability questions, other legal issues, and even supply accountability questions simply make it impossible to support. Therefore this department will block it!"⁷⁰).

The thanatology team should be called "The Care Team" in view of the fact that this name better projects both the attitude and the intent of such a team, as well as being a more socially acceptable title. "The Care Team" should have as its primary goals: (1) the coordination and development of a comprehensive program for meeting the physical and emotional needs of the terminally ill patient and his family at Walter Reed; (2) the development of a staff education program that helps them to first deal with their own death, and then teaches them how to meet the needs of dying patients and their families; and (3) the

provision of direct patient care (those members of the team who are not already directly involved in meeting the emotional needs of the dying can help by taking on some of the case work). Under this concept, "The Care Team" would oversee the care of terminal patients and their families. The patient would be the center of care [See Appendix B for a conceptual drawing of the program provided by "The Care Team"]. Next the family would be around him, followed by his attending physician, and then the team itself. Ideally the family will give to the patient and receive care from the staff as well. Since the patient has other than medical needs, the composition of the team must be provided by an interdisciplinary approach. This approach is widely accepted and well known.⁷¹ "The Care Team" could be composed of physicians (at least one psychiatrist, one physician from the Department of Medicine, and one physician from the Department of Surgery would be preferable), registered nurses, psychologists, social workers, chaplains, pharmacists, dieticians, physiotherapists, and hospital "volunteers". Additions or deletions could be made as deemed prudent. Using the attending physician as an active participant in any care discussions will insure continuity of care. Through continual assessment of patient and family needs, the team would determine the proper program of care and the setting for that care. Patients could be referred by the attending physician or the attending nursing staff. Or, since any implementation of the team would include a program to make the patients and their families aware of the team and what it does, "The Care Team" could be called in at the direct request of either the patient or his family. "The Care Team" coordinator should have immediate access to the Hospital Commander. The team and its coordinator would work in conjunction with the other departments at the hospital, and issues of dispute that

could not be settled between the appropriate department chief and the team coordinator could be resolved by either the Commander or his Deputy. Because of the unique responsibilities of "The Care Team", its members should be on a 24-hour on-call basis. This is, of course, is a very demanding reality, yet it is vital to the success of the team. Individual team members would follow individual patient cases along with the psychiatrists and chaplains who now handle this task. In addition to the specific items already mentioned, the team must be acutely aware of the mental health of its own team members as well as watching for signs of mental difficulties manifested by the staff. The team should hold periodic counseling sessions for all those individuals who handle the emotional and physical needs of the dying patients. These sessions can be scheduled on a regular basis and should provide the staff with an opportunity to express their real feelings about their patients, the families, and/or the general subject of death and dying.

Two additional points seem relative at this juncture. First, a physician should be the team coordinator. It is the physician who gives the general direction to the other members of the staff-nurses, etc. Furthermore, a physician team coordinator will be in the best position to generate understanding and support from his fellow physicians at WRAMC. Second, at least one "volunteer" has been included in this team because often physicians and nurses have acquired the image of being too busy. The person whom the patient and the family often confide in about their deepest emotions and concerns is the volunteer. In these cases the volunteer seems to be the one person who has "time and understanding".⁷²

From the standpoint of general staff education, several issues must be kept in mind by the team: (1) the staff must recognize the unique needs of the terminally ill and their families, (2) they must learn to view death as a part of life, (3) they must be encouraged to actively participate in the programs themselves, and (4) they must encourage the patient's family members to participate in the program.

"How To..." classes should be given by members of "The Care Team". For example, a step-by-step list of approaches for dealing with the parents of a still birth might include recommendations such as: (1) To help feelings of parental failure and guilt - (a) establish trust, show acceptance of feelings, show concern, (b) ask what they are feeling, (c) encourage them to verbalize, (d) provide privacy as needed, (e) try to be available, (f) reinforce that what they are feeling is normal; (2) To help feelings of parental grief - (a) encourage verbalization, (b) use touch as appropriate, (c) be human (cry if you're moved to do so), (d) explain the grieving process, (e) encourage the parents to grieve fully before trying to replace their loss with something or somebody else; and (3) to help the mother's feeling of "uncleanliness" that is often felt in such situations - (a) let the mother know that many other patients in this same situation feel "unclean", (b) allow the patient to wash as she wishes, (c) inform the patient the odors she senses will go away.⁷³ In this way the staff can offer valuable guidance.

When "The Care Team" members are involved in providing direct support to the terminally ill, they must remember that they are integrating that support with the support being given by the family. [See Appendix C for a conceptual drawing

of "The Relationship of 'The Care Team' To The Family as Support is Provided to the Terminally Ill Patient"]. The literature indicates that there are four types of support: (1) social support - which is also called caring, (2) instrumental support - which is counseling, (3) active support - which is mothering, (4) material support - which is furnishing goods or service). Social support (which is communicated by caring) is the most important. Social support consists of: (1) emotional support which leads the patient to feel loved and cared for, (2) esteem support - which leads the patient to feel esteemed and valued, (3) network support - which leads the patient to feel a sense of belonging to a network of mutual obligation.⁷⁴

"The Care Team" members who are working with the terminally ill patients should:

- (1) Facilitate communication. While this is an obvious task it is impeded by the fact that not every one involved (the team members, the attending staff, the patient, and the family) has the same level of understanding concerning the facts of the case - diagnosis, prognosis, treatment plans, and exactly what to expect. At different stages of grief, for example, the patient and/or family may be in the denial phase so it is easy to see how communication can be difficult when the people doing that communication are on two different levels of understanding. A second impediment is the patient's natural reluctance to share unexpressed feelings. However, with time and caring, both of these obstacles can be overcome;
- (2) Provide emotional support. When the lines of communication are open this emotional support can be provided in terms of listening, tolerating, and loving behavior. To give such support means that the team members will be helping maintain the patient's self-esteem and dignity in the face of a crumbling feeling of worth and self-image. Where necessary, the patient and the

family must be encouraged, urged, and even on a rare occasion, coerced into being involved with one another; (3) Promote autonomy. Wherever possible the patient should be allowed to participate in decision-making processes that involve his treatment plan. The small sense of control that may result is important for the patient's emotional well being; (4) Be an advocate of the patient. Of the four items mentioned here, this one is the least important and the most difficult to perform. This action may be necessary when the patient's low self-esteem precludes his being his own advocate. However, advocacy is a step that must be undertaken with great caution because it may be counter-productive to the more important task of promoting autonomy. When it comes to fulfilling the various roles of support the chaplains and psychiatrist on the team will most likely be in the best position to help, guide, counsel, and oversee the work of the team member or staff member who is providing the support. They may well be best adapted at recognizing the difference between effective and ineffective support, guide or train those members who are providing the support, counsel a group of members who are providing support, and even see the patient or family members as a backup when the necessary support either isn't being given or received. (They are the "strength in reserve").⁷⁵

III. CONCLUSION

How The Evaluators Apply

A careful review of the three alternatives via the first evaluator reveals that while each approach would provide a means of meeting the emotional needs of the dying patients and their families (as identified in the DISCUSSION chapter of this study) the second and third alternatives appear to be more capable of meeting this vital task. This evaluation in no way reflects unfavorably on the superb work being done by those health professionals at WRAMC who are currently engaged in this important role. However, this superb staff is simply outnumbered by the number of things that they know should be done and by the number of people to whom they want to offer an extended relationship. Therefore, via this criteria, the first alternative is eliminated. Either the alternative that provides a formal WRAMC hospice, or the compromise alternative that establishes "The Care Team" (which can help supplement the current efforts of the chaplains, psychiatrists, and others who are presently pursuing this important endeavor) offer the decision makers at WRAMC the best choice via this evaluator. The second evaluator is that the approach selected must have the support of the physicians at WRAMC. Under the limits of this evaluator the first and third alternatives can operate without restriction; however, the WRAMC hospice alternative would have to be eliminated (as shown in the DISCUSSION chapter where COL Strevey's interview validated the fact that his Department of Surgery would not support a hospice and would in fact "block it"). The third evaluator shows that while each alternative provides some capability of working with the staff (education, counseling, etc.) as well as working with the dying patient and his

family (helping to meet their emotional needs), the second and third evaluators are again in the best position to fulfill this criteria. "The Care Team" has a specific task of staff education, counseling, and support as well as providing direct patient and family support. Likewise the hospice would similarly be geared to meet these goals with a high degree of success. Finally, when applying the fourth and last evaluator, no alternative is eliminated. The status quo is certainly within the resource capabilities of WRAMC. In addition, with a reordering of priorities, where care for the terminally ill became an important issue to the decision makers at Walter Reed, either a hospice program or a thanatology team (drawn from the existing staff, and using the existing supplies and administrative support channels) could be no additional drain on the resources at WRAMC. Plus, Health Services Command could provide the funds necessary to help initially educate, counsel, and train the staff that is used to put either alternative into effect.

Recommendations

The recommendations to the Commanding General and the excellent staff at Walter Reed Army Medical Center are as follows: (1) first come to the realization (if they have not already done so) that the terminally ill patient: (a) must be given the possibility of achieving acceptance of death with dignity, (b) has rights, including the right to be involved in the decision-making processes, (c) should be allowed to die as he has lived, with his family and other loved ones playing a role in his care and support, (d) should be made as free from pain as possible, and (e) should be regarded as a person who is undergoing a natural process as opposed to being regarded as a patient who is undergoing an unnatural

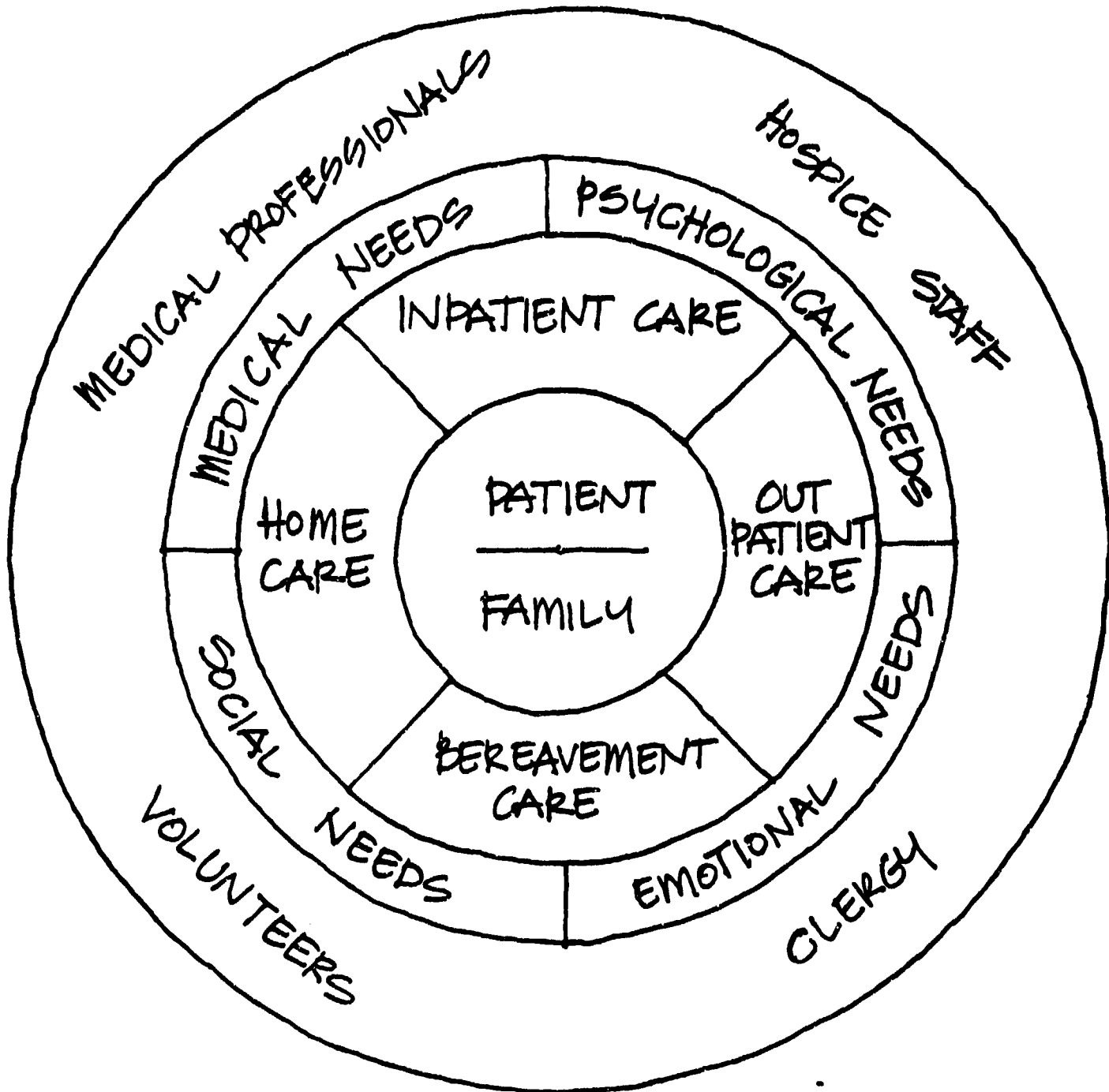
process that represents a failure on the part of a staff that is "unable to turn this one around;"⁷⁶ (2) form an immediate work committee of interested personnel and task it with the responsibility of establishing "The Care Team" as described in the DISCUSSION chapter of this study; (3) oversee the actual development of "The Care Team" into a reality as it becomes an integrated and vital part of WRAMC's pursuit of the provision of the finest quality care available anywhere in the world; (4) insure that strong command interest in "The Care Team" is clearly visible to all staff, patients, and families; (5) recognize that the benefit of such of a team will increase dramatically over a two year period (while its team members go through the different levels involved in coping with professional anxiety while caring for the terminally ill and their families. They will reach their levels of deepest compassion, professional self-realization, professional self-awareness, and professional self-actualization somewhere between twelve and twenty-four months after they have joined the team.⁷⁷); (6) choose a top flight team coordinator who has an excellent reputation among the staff -especially the physicians; (7) use the in-house experience and "lessons learned" from the interdisciplinary teams for oncology patients and for holistic medicine; (8) insure that the work committee and the subsequent meetings of "The Care Team" are efficiently run with interested participants; (9) provide clear lines of authority to the team as it goes about accomplishing its tasks; (10) provide the team with adequate office space (perhaps on the seventh floor) and conference facilities; (11) screen current staff as well as incoming personnel in order to find professionals with experience, and a sincere desire to participate as a member of such a team; (12) use the external resources of knowledgeable civilian and military authorities; (13) tap

the in-house knowledge and experience of the professionals at Walter Reed who recognize the vital need for meeting the emotional needs of the terminally ill and their families; (14) from existing space and equipment establish "screaming rooms" (a room for the staff to use to comfort itself -they need it too!) on each floor where terminally ill patients are cared for; (15) support the concept of death with dignity; (16) allow for yearly evaluations and upgrading of the team concept; (17) publish the results of this effort so other health professionals and other health facilities may benefit from this experience - good and bad; and finally (18) take pride in the fact that they have fully recognized their responsibility in meeting, wherever possible, the emotional needs of the dying patients and their families at WRAMC - and further be proud of the fact that they have taken another constructive step toward the accomplishment of this vital goal!

A Final Comment

"In order to be at peace, it is necessary to feel a sense of history--that you are both part of what has come before and part of what is yet to come. Being thus surrounded, you are not alone; and the sense of urgency that pervades the present is put in perspective: Do not frivolously use the time that is yours to spend. Cherish it, that each day may bring new growth, insight, and awareness. Use this growth not selfishly, but rather in service of what may be, in the future tide of time. Never allow a day to pass that did not add to what was understood before. Let each day be a stone in the path of growth. Do not rest until what was intended has been done. But remember--go as slowly as is necessary in order to sustain a steady pace; do not expend energy in waste. Finally,

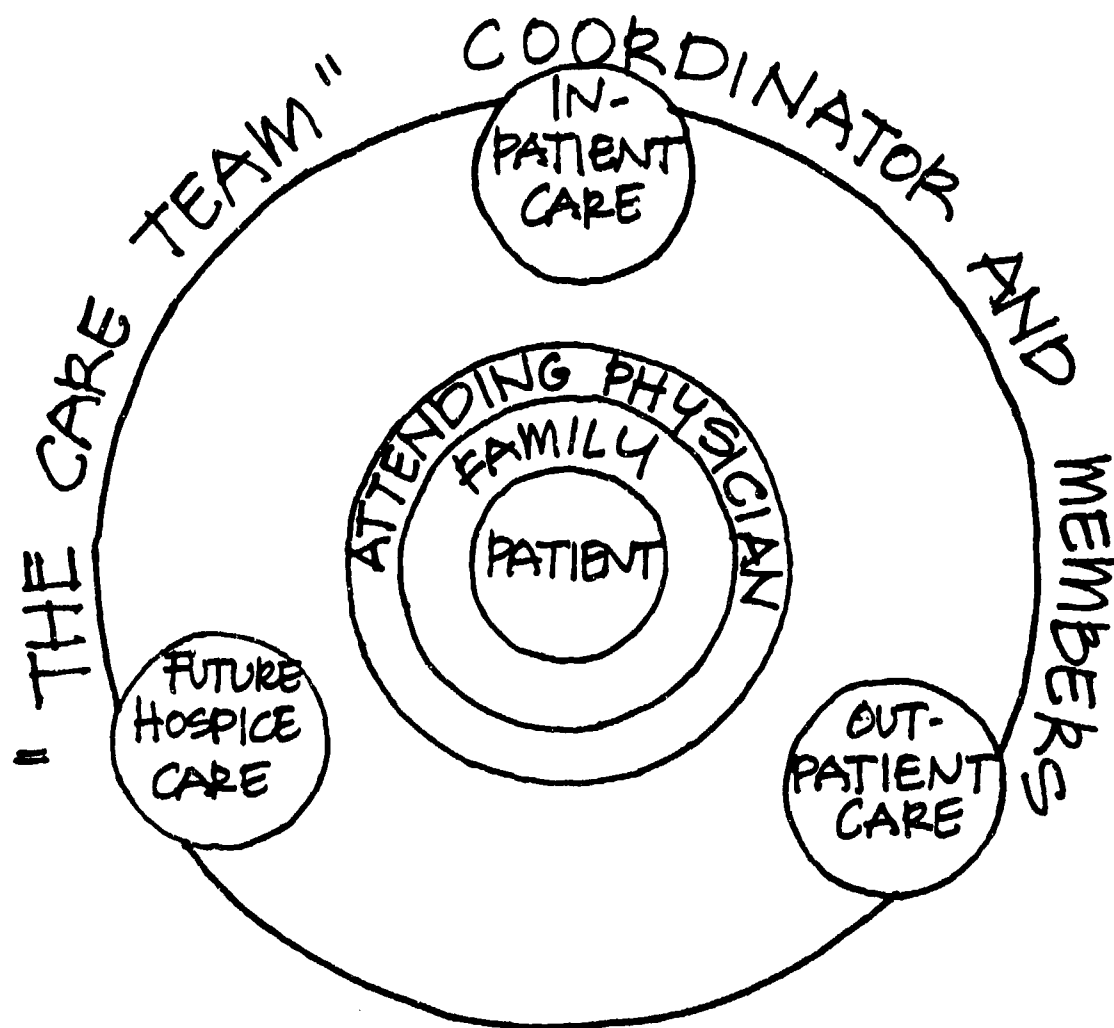
do not allow the illusory urgencies of the immediate to distract you from your
vision of the eternal.....78



THE HOSPICE IN-PATIENT CARE

Adapted from Kenneth P. Cohen, Hospice-Prescription for Terminal Care (London, England: Aspen Systems Corporation, 1979), Page 76.

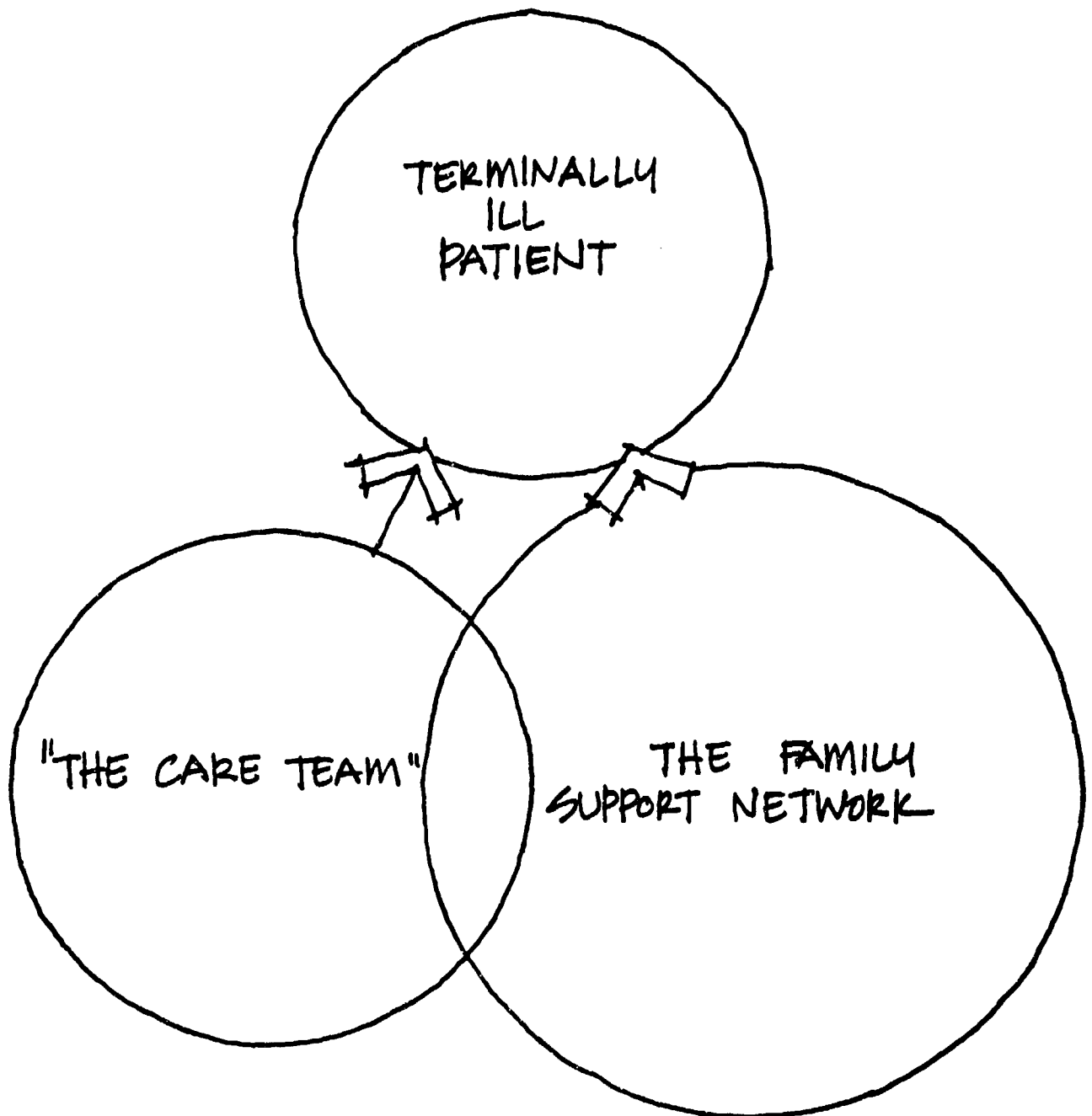
APPENDIX B



THE PROGRAM OF "THE CARE TEAM"

Adapted from Daniel R. Longo and Kurt Darr, "Hospital Care for the Terminally Ill," Hospital Progress 59 (March 1978), page 63.

APPENDIX C



THE RELATIONSHIP OF "THE CARE TEAM" TO THE FAMILY AS
SUPPORT IS PROVIDED TO THE TERMINALLY ILL PATIENT

Adapted from Sidney Cobb and Christine Erbe, "Social
Support for the Cancer Patient," Forum-On Medicine
(November 1978), page 25.

FOOTNOTES

1. Found in Old Saint Paul's Church, Baltimore, Maryland; dated 1692.
2. Wife of "Patient A" Personal Interview, Walter Reed Army Medical Center, Washington, DC 18 November 1980.
3. "Patient B" Personal Interviews, Walter Reed Army Medical Center, Washington, DC, 4 February 1981.
4. Wife of "Patient B," Personal Interview, Walter Reed Army Medical Center, Washington, DC 5 February 1981.
5. "Patient C," Personal Interview, Walter Reed Army Medical Center, Washington, DC, 9 January 1981.
6. "Patient D," Personal Interview, Walter Reed Army Medical Center, Washington, DC, 15 December 1980.
7. CPT Klara, Personal Interview, Resident, Neurosurgery Service, Walter Reed Army Medical Center, Washington, DC 10 November 1980.
8. COL Brott, Personal Interview, Chief, Thoracic Surgery, Walter Reed Army Medical Center, Washington, DC, 12 November 1980.
9. COL Henderson, Personal Interview, Chief, Otolaryngology Service, Walter Reed Army Medical Center, Washington, DC, 12 November 1980.
10. COL Hirate, Personal Interview, Chief, General Surgery, Walter Reed Army Medical Center, Washington, DC, 13 November 1980.
11. LTC Tramont, Personal Interview, Chief, Infectious Disease, Walter Reed Army Medical Center, Washington, DC, 4 November 1980.
12. LTC Berenberg, Personal Interview, Chief, Hematology/Oncology, Walter Reed Army Medical Center, Washington, DC, 3 Nov 1980.
13. LTC Thompson, Personal Interview, Assistant Chief, General Medicine, Walter Reed Army Medical Center, Washington, DC, 4 Nov 1980.
14. MAJ Griffin, Personal Interview, Floor Administrator (4th Floor - Intensive Care Area and Surgery Suites), Walter Reed Army Medical Center, Washington, DC, 30 Oct 1980.
15. MAJ Wilton, Personal Interview, Assistant Chief, Rheumatology/Clinical Immunology, Walter Reed Army Medical Center, Washington, DC, 6 Nov 1980.
16. COL Holmes, Personal Interview, Chief, Ambulatory Medicine/Emergency Medicine Service, Walter Reed Army Medical Center, Washington, DC, 6 Nov 1980.

17. LTC Wray, Personal Interview, Assistant Chief, Endocrine-Metabolic Service, WRAMC, Washington, DC, 6 Nov 80.
18. COL Jones, Personal Interview, Psychiatry Consultant, Office of The Surgeon General, Pentagon, Washington, DC, 10 Nov 80.
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22. Tom Prideaux, "The Doom Boom," Life (May 1979): 109-111.
23. Philip R. Alper, "Why we Keep the Dying from Dying in Peace," Medical Economics (October 18, 1976): 67.
24. Sam Keen, "An Interview with Dr. Elizabeth Kubler-Ross," Family Circle (September 1975): 46.
25. Kenneth L. Artiss and Arthur S. Levine, "Doctor-Patient Relation in Severe Illness," The New England Journal of Medicine 288 (June 7, 1973) 1210.
26. Ibid.
27. Theodore H. Koff, "Social Rehearsal for Death and Dying," The Journal of Long Term Care Administrators (Summer 1975): 81.
28. Nancy Doyle, "The Dying Person and the Family," The Public Affairs Series, (1972), 23.
29. B. G. Glaser and A. L. Strauss, Awareness of Dying, (1965): 84.
30. Elizabeth Kubler-Ross, "A Letter to A Nurse About Death and Dying," Nursing '73, 3 (October 1973): 11.
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59. Between November 1980 and April 1981 a total of 97 confidential personal interviews were conducted between the author of this study and various staff, terminally ill patients, and families of terminally ill patients at WRAMC. While the precise responses and identity of most of those interviewed must remain confidential, it can be stated that 87% of all the individuals questioned felt that the emotional needs of the dying patient and his family at WRAMC were not being met.
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Between November 1980 and April 1981, a total of 83 additional, confidential personal interviews were conducted between MAJ Mullaly, the Administrative Resident at the US Army Health Facility Planning Agency and various staff, terminally ill patients, and families of terminally ill patients at Walter Reed Army Medical Center (WRAMC) in Washington, DC. At the request of those interviewed, these personal interviews have not been documented in the footnote or bibliography portions of this study.