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THE EMOTIONAL CARE OF THE DYING PATIENT AND HIS FAMILY

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THE EMOTIONAL CARE OF THE DYING PATIENT AND HIS FAMILY

For the most part, men and women take health for granted. Not until something endangers this health, do they realize how precious life really is to each of them. Thus, when a person is diagnosed as having any major illness, such as cancer, it is not difficult to understand why this person would feel fear and depression, as well as a multitude of other emotions. "There is the loss of the sense of oneself as healthy, independent, and able to function, and there are the possibilities of pain, separation, and even one's own death. There is an immediate change in adult role, be it a temporary suspension of usual responsibilities and gratifications in family, work, and community, or a permanent modification in roles and life-styles."¹ The person's very life depends on trusting the people available to care for him--physicians, nurses, radiation therapists, etc. He must depend on these health care team members to provide him with every possible chance of survival. He feels as if he no longer controls his own life--they control it. The only time he has any say in the matter is when to stop their "help"--to let him die in peace and with dignity--but even this request is sometimes ignored.

"One could maintain that this is part of the human experience, hence we all know it or will know it eventually and will be challenged to find our meaning in illness. Because of this, we can identify with the fears, sadness, and depression of cancer patients; however, let it touch us too deeply, for example heighten our own sense of vulnerability and fragility, and we prefer to withdraw or to view the patient's fear and depression as

an aberration."² The dying patient is often seen as a symbol of what we know we will all face eventually, but still fear. It is often stated that a patient is denying his illness. But how often do nursing personnel deny that someone they are caring for is going to die? Death must be accepted by the nurse; that is, she must "accept the reality of her own mortality," for if she does not do this, she is separating herself from the patient because, by denying her common ground with him, she cannot actually realize and share his feelings.³ Even with all of her knowledge, the nurse must still "come to grips with her own feelings about pain, death, helplessness, grief, and loss."⁴ This also applies to the nurse's care of the family. They too are under a tremendous strain--they must deal with feelings of fear, depression, powerlessness, loneliness, and uncertainty. They may not know how the person actually feels about his illness or how much he really knows about his condition. They need a great deal of emotional support from other family members and friends, but especially from the nursing staff. The staff, by not being related to the patient and his family, can be objective as to what is occurring, while at the same time being empathetic toward the emotions present in each person. The nurse needs to get involved with the patient and his family instead of simply doing the physical tasks assigned to her and quickly leaving the room. "It does not take any more time than is already spent; it is just a matter of also using that time to minister to the patient's (and family's) needs as a human being with hopes and fears and questions and needs for meaningful contact with other human beings."⁵

The patient can receive emotional support from various sources. The physician can help by telling the patient the truth about his condition in person, and allowing him time to express his feelings and ask questions. It is usually best to prepare the patient gradually by letting him know,

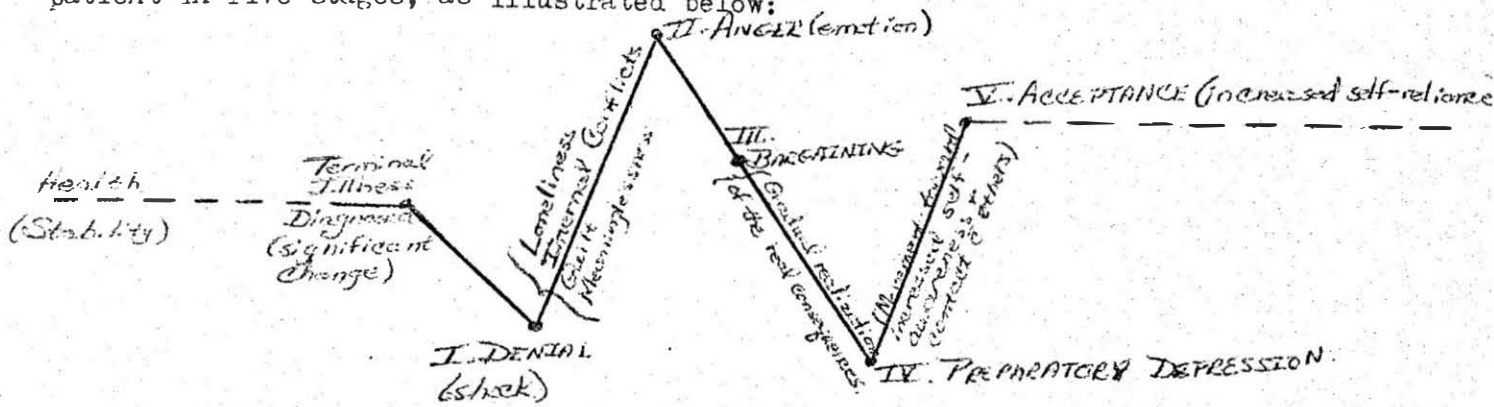
for example, that cancer is a possibility and that if it is confirmed, what type of treatment will probably be used. "Patients want to be reassured that their physician will not give up on them."⁶

Nurses can contribute to the patient's adjustment emotionally by being available to talk with the patient. This is especially valuable in times of crisis and depression, at night, and at times when no other resource is available. "Nurses can best help by listening for subtle clues of the patient's feelings and attempting to adapt to his moods, rather than by planning ahead of time what they will say to cheer the patient when they go into his room."⁷

The family can also assist the patient to adjust emotionally. This is best accomplished by "maintaining an emotional and social environment consistent with the patient's past lifestyle, when circumstances permit." This includes keeping the patient at home so that he can eat and sleep as normally as possible; including him in all decisions pertaining to his care and treatment; and showing him love and concern without making him seem like a large burden on the family.⁸

"Traditionally, the family is viewed as the first line of defense to support one of its members who faces a crisis. But an entire family may be in crisis because one of its members is diagnosed as having cancer."⁹ When this occurs, who supports the family? All members of the health care delivery system should ideally be involved in supporting the patient's family. However, this joint effort seldom takes place. The job usually falls on the shoulders of the professional nurse and therefore, she must be ready to accept the task without hesitation. Nurses need to know what type of emotional stages the family, just like the patient, goes through and how they can be helped to move through each one of these stages.

Elisabeth Kubler-Ross has summarized the grieving process of the dying patient in five stages, as illustrated below:¹⁰



Barbara Giacquinta, R.N., a co-practitioner in oncology in New York City, has developed a model of ten phases a family goes through within four stages: living with cancer, the living-dying interval, bereavement, and reestablishment.¹¹

Phase of Grief	Family Stage	Family Effect	Family Response	Goal of Intervention
Individual receives initial diagnosis of cancer, continues to carry out role obligations with the family, and functions in varying ways as a family member.	Living with Cancer	impact	despair	fostering hope
		functional disruption	isolation	fostering cohesion
		search for meaning	vulnerability	fostering security
		informing others	retreat	fostering courage
		engaging emotions	helplessness	fostering problem solving
Individual with cancer ceases to perform familiar roles and is cared for either at home or in the hospital.	Restructuring in the Living-Dying Interval	reorganization	competition	fostering cooperation
		framing memories	anonymity	fostering identity
Family must with cancer dies.	Bereavement	separation	self absorption	fostering intimacy
		mourning	guilt	fostering relief
	Reestablishment	expansion of the social network	alienation	fostering relatedness

The phases included can perhaps be best understood when applied to a true case. I will be using the case of my father, who died of cancer in 1976.

I will first relate a data summary of the facts of his case, and then go into the problems and feelings I encountered during his illness and what might have been done by nurses to help.

CASE STUDY:

Dad was admitted ambulatory to Mennonite Hospital on May 24, 1976, complaining of swelling of his neck, face, and eyes for approximately two to three weeks. After sleeping supine all night, his eyes would be swollen, gradually returning to normal during the morning. His face was flushed and his ears were cyanotic at times. There were areas of discoloration (dilated veins) on the left and right anterior chest wall. He had no history of dyspnea, dysphagia, or weight loss. Physical exam was negative except for the symptoms listed above. Chest x-ray showed a right hilar mass. Tomograms of the area showed compression to the bronchus supplied to the apical segment of the right upper lobe. A diagnosis of superior vena caval syndrome, probably due to carcinoma of the lung, was made. Electrocardiogram, complete blood count, urinalysis, basic chemistry, and pulmonary function tests were all normal. Arterial blood gas analysis showed an increased PCO_2 of 46 (normal 38-42), CO_2 content of 29 (normal 23-27), and HCO_3 of 28 (normal 22-26). Arrangements were made for him to be seen in Chicago for bronchoscopy. Dad was discharged from Mennonite Hospital on May 27 and entered Rush-Presbyterian-St. Luke's Hospital in Chicago on June 3, 1976. There he underwent one bronchoscopy which was inconclusive; an angiogram which showed a compression of the superior vena cava and development of collateral circulation in the chest wall; a liver scan which showed no metastasis; and a second bronchoscopy which did reveal lung cancer. It was determined by the specialists there that radiation therapy and chemotherapy would be the best medical treatment. Dad was dismissed from Rush on June 9, 1976, his 52nd birthday.

He began out-patient radiation therapy at St. Joseph's Hospital Medical Center on June 14, 1976, with a 14 minute treatment to his chest. This was followed by the following schedule: June 15--14 minutes to his chest; June 16 and 17--14 minutes to his back; June 18 and 21--7 minutes to his chest and 7 minutes to his back; and June 22-25, June 28-July 2, and July 6-9--alternated 7 minutes to his back one day and 7 minutes to his chest the next day. By the last treatment on July 9, 1976, Dad no longer had face edema, cyanotic ears, or chest wall vessel dilation. X-rays showed marked decrease in tumor size and compression of the superior vena cava. He did, however, have an extremely painful esophagus, "burned" by the radiation.

Dad began chemotherapy on June 21, 1976. Each week he received a complete blood count to check for bone marrow depression and an intravenous injection of 5-Fluorouracil (5-FU). These weekly injections caused increased esophageal pain and weakness, especially for two days after each injection. Dad was seen weekly until September 24. He returned to work October 11, mainly working four hours per day. He began receiving 5-FU I.V. every two weeks on October 25 and continued this until December 3, 1976. Dad was becoming progressively weaker this entire time and was experiencing shortness of breath upon the smallest exertion. His appetite was decreased more than ever. He was thus admitted to St. Joseph's on December 14, 1976. An I.V. of 1000 c.c. D5W was started. A chest x-ray showed a bilateral pleural effusion. Triglycerides, alkaline phosphatase, and L.D.H. were slightly elevated. The most dramatic change was in the arterial blood gases. They were as follows:

pH	7.47	(normal 7.38-7.42)
pO ₂	54.4	(normal 85-95)
pCO ₂	31.0	(normal 38-40)
TCO ₂	25.9	(normal 23-27)
HCO ₃	25.0	(normal 22-26)

O ₂ sat.	90%	(normal 94-98%)
Base excess	+4.5	(normal ± 2)

The only routine medication given throughout this hospitalization was Emperin with codeine grain $\frac{1}{4}$ every four hours (only if Dad requested it).

On December 16, a thoracentesis was performed. 1325c.c. of yellow fluid was removed and 40 mg. Mustorgen (nitrogen mustard) was instilled in the chest cavity. One hour after this procedure, Dad became extremely nauseated and was given Sparine 50 mg. An I.V. of 1000 c.c. D5W was again begun because of a weak, thready pulse and decreasing blood pressure. His condition continued to deteriorate on the 17th. Oxygen was begun per mask, but Dad did not want the mask on, so it was used only when he wanted it. At about 1 a.m. on December 18th, Dad started becoming very restless, trying to get out of bed, and seemed delirious. His respirations throughout the day became shallower, his blood pressure decreased, his pulse was rapid and thready, and his skin cold and clammy. At times no blood pressure could be found. He was given 15 mg. Talwin for restlessness (half dose due to shallow respirations). By 5 p.m., Dad was beginning to be cyanotic with Cheyne-Stokes respirations, despite the now continuous use of oxygen. He became unresponsive to verbal or painful stimuli, and at 6 p.m. was pronounced dead.

Several things occurred during Dad's illness that bothered me. These things involved opportunities for nurses to do something to resolve problems in Dad's care, but these opportunities were not utilized. I will attempt to relate what happened with Dad's illness to Ms. Giacquinta's chart of family phases and hurdles and the goals of nursing intervention involved.

When we first learned the diagnosis, the nurses initially allowed us to be alone. We were in the family phase of impact and needed to overcome the hurdle of despair. The goal of nursing intervention here, then, was to

foster hope. The nurses attempted to give us this hope by bringing up methods of treatment, how well these treatments might work, etc. This allowed us to imagine and plan for a future.

The second phase, that of functional disruption, occurred mainly when we went to Chicago. This phase occurs when family members "are separated from one another or from other systems of support in their interaction, communication, cooperation, and social and emotional involvement."¹² By being away from home, we were also away from the majority of our support systems. The family hurdle here is isolation and I definitely felt isolated. We were very small aliens in a big hospital, in a big city with all our hopes and Dad's life depending on test results. The goal of nursing intervention should have been to foster cohesion between us and our new environment. However, nothing was done by the nurses (or anyone else) to foster this. Nurses, medical students, doctors, etc. came in and out at first, usually to see Dad, since "superior vena caval syndrome is not seen very often." But after everyone had seen what they wanted, they left and we were again alone. What was needed here was a realization by the nurses that we were not from Chicago and thus did not know much about the city--where to eat outside the hospital, where to go to "get away" from the hospital, who we might talk to in the hospital. Here might have been a good time for referrals to other health team members--social workers, chaplains, etc.--if the nurses did not feel they were capable of discussing things with us.

Phase three, search for meaning, spanned most of Dad's illness because we attempted to absorb some knowledge from textbooks and medical personnel about Dad's disease. Ms. Giacquinta sees the hurdle here as that of vulnerability since family members often are viewing their own mortality and own chance of having the same disease. With Dad being ill, I did think about the possibility of perhaps having cancer myself someday. But then my

thoughts and concerns about Dad overcame this and I no longer thought of myself. The goal of nursing intervention in this phase is to foster security. This involves helping the patient and his family feel secure, not only about each one's own mortality, but also about the care the person is receiving. The patient and his family need to be kept informed as to what is happening now and what may happen in the future. This is where nurses could have helped tremendously by doing patient and family teaching about procedures, treatments, disease itself, etc., but failed to do so. Dad received no teaching about his bronchoscopy, angiogram, liver scan, or anything. Instead he had to depend on me to explain everything. This was especially difficult because I needed to fill two roles at once--that of a nurse and that of a daughter. If I had been only a nurse, I probably could have been almost totally objective, giving all the information without personal emotion. But no matter how hard I tried, it was impossible to be objective with my father's life at stake. I did not want my opinion to enter in on any of his decisions about procedures or treatment, but with my nursing education thus far, I ended up being the one he turned to for advice, putting a lot of pressure on me. Each procedure needed to be explained fully including any pre-procedure preparation, risks involved, the procedure itself, what to expect afterward in regard to physical care and feelings, and anything else Dad might have had a question about.

The fourth phase, informing others, occurred much earlier for us than this model suggests. We told all of our family members almost immediately and kept informing them of Dad's condition and treatment. They were shocked like us, but seemed to accept the information. They allowed us to "cry on their shoulders" and express our feelings without causing us to "retreat," the hurdle often present during this phase. Nursing intervention here involves fostering courage. We received courage, not from medical personnel,

however, but from within ourselves and from our family. We kept communication open among us, which I feel is very important to maintain support and courage. Nurses might have helped here by offering themselves as sources of support and information to maintain open communication between staff and our family.

The fifth and final phase in the "living with cancer" family stage is that of "engaging emotions." When a disease occurs in a family, especially one which may quickly end the person's life, emotions are present which are difficult to control. Another area of difficulty is trying to decide whether to allow these emotions to show in the presence of the ill person. Will his seeing his wife or daughter cry make him feel his situation is hopeless or will it show that they care? How can anyone be sure of how someone will react to such emotion? It was very difficult for Mom and I at this time because we tried to maintain Dad's hope while deep down inside we were constantly wondering if there was any hope left. Emotion may also be shown towards staff members. Following his first bronchoscopy, Dad coughed a great deal. I knew this was not unusual, but with the blood being "trapped" above the superior vena caval level and the tremendous increase in pressure from his coughing, Dad's face would turn almost black. I was concerned, and tried to explain my concern to the nurse, but all she said was, "they always cough after a bronchoscopy," took his vital signs once, and never came back. She certainly did not foster security in us about her abilities to problem-solve or her compassion for patients. Helplessness is the family hurdle needing to be overcome in this phase. This was felt many times during Dad's illness, especially when it appeared that no one really cared about what they were doing and would not explain things. The goal of nursing intervention here is to foster problem-solving. For one thing, they could have listened to our thoughts and concerns about Dad's care and illness. Then perhaps we

could all have been involved in planning Dad's care--to work toward commonly agreed upon goals. They could have done little things to increase our confidence in them--monitored vital signs more closely after procedures, done follow-up on complaints or questions, showed caring by their facial expressions or tone of voice, and checked in on Dad more often, if only to talk, listen, or say hello. Small things like these could have done so much towards inspiring confidence in us for their abilities.

A feeling which was prominent in me at this time was that the staff had already given up. This was strengthened in me when, upon Dad's return from his second bronchoscopy, I found out his pre-operative medication had not been given as ordered. It was as if the staff did not feel it was worthwhile to use their time and talents on someone who might die anyway. Perhaps I am wrong; perhaps it was just overlooked; but nurses need to realize that what may seem to be a small slip on their part, may have great consequences emotionally and physically for the patient and his family. Therefore, every detail of the patient's care needs to be checked for accuracy. This includes everything from the tone of voice and facial expressions of the staff members, periodic checking on the patient, etc., to diets, test completion, and doctors' orders.

The second family stage, "restructuring in the living-dying interval," lasted all summer and fall for us (during the radiation and chemotherapy). In this stage, the individual with cancer no longer performs his familiar roles and must be cared for at home or in the hospital. Here the family often goes through the sixth and seventh phases--reorganization and framing memories.

In reorganization, role obligations must be reevaluated and distributed among healthy family members to take some of the burden from the ill member. The family members must be willing to accept these added responsibilities

without complaint so that the patient does not feel he is a burden on his family. The hurdle to overcome here is that of competition among family members. Thus, the goal of nursing intervention here is to foster cooperation so that the family can work together to meet mutual goals. In our case, nurses were not really involved during this phase. Thus, our family worked in cooperation on our own. We never had a problem with competition. We each seemed to gradually take on more work so Dad would not have to work as hard. Mom began doing most of the driving; Mom and I mowed the yard; and my brother and I worked on the furnace.

The seventh phase, framing memories, involves the family's need for time to remember the dying person's life, in addition to seeing the person's impending death. Here anonymity of the person must be overcome since sometimes the family does not recall the person before his diagnosis. Nurses need to strive to help the family recall these memories and promote the identity of the dying person. As an image of the person strengthens, a family is better able to rely less on his physical presence and be more able to deal with his death. Nurses made no attempt to involve themselves in this phase. We talked among ourselves about Dad's life and illness and were able to recall good memories which we still hold close to our hearts, instead of dwelling only on his illness.

Stage three, following the person's death, is bereavement, which occurs during the time when death is imminent and then does occur. The eighth family phase, separation, is seen in this stage. It occurs when the person's level of consciousness lessens and he becomes unaware of his environment. This is a time of extreme loneliness. The family feels a tremendous loss and must deal with separation from their loved one. Self-absorption must be overcome here. We each could not withdraw within ourselves. We had to remain in communication with each other to give each other strength.

The role of the nurse during this stage is to promote this intimacy among family members to provide a support system in which to grieve. The nurses did not seem to want to get involved during this phase. They seldom entered Dad's room except for occasional vital sign checks. A nurse's aide stayed in the room to hold the oxygen mask, but the nurses stayed out. Perhaps they could not deal with dying and death themselves and did not feel they could be of any help to us. They could, however, have helped a great deal by simply talking and listening to us and allowing us to express the enormous amount of emotion we were feeling at the time.

We quickly moved into the ninth family phase--mourning. Here the family members must overcome feelings of guilt. Each person feels guilt in his own way and for his own reasons. I had several conflicts within myself which I had to resolve. These included such feelings as anger at myself for not noticing Dad's symptoms earlier and for not knowing their cause; uncertainty as to whether everything that could be done had been done; guilt as to whether I had done all I could to help him have good care and whether we were as honest with him as he was able to handle or wanted to hear. Here the nurse has a good opportunity to foster relief by dealing with each member individually and allowing that person to mourn as much as he needs to so he can return to normal living. The person often needs to mourn until he has resolved any conflicts within himself about the person and internalizes his memories of him. Thus the deceased person enriches the continued lives of his family. The nurses did not help us to mourn. They missed the perfect opportunity to allow us to express our conflicts and help us to resolve them through the logical thinking which we needed at that time.

The nursing interventions useful in these phases can be summarized in the following way:

- 1.) Identification of the meaning of illness for the patient and his family.
- 2.) Assessment of patient and family resources.
- 3.) Coping styles of the patient and family.
- 4.) Nurse-patient relationships and specific nursing actions:
 - a.) Specific explanation and reassurance.
 - b.) Supportive interventions and environmental change (scheduled rest periods, for example).
 - c.) Ventilation of feelings.¹³

Nurses should approach the patient with openness, warmth, caring, and show a willingness to listen. As one dying patient wrote:

"If only we could be honest, both admit of our fears, touch one another. If you really care, would you lose so much of your valuable professionalism if you even cried with me? Just person to person? Then, it might not be so hard to die---in a hospital --with friends close by." 14

The nurses' listening does not end with the patient's death. The family still needs help. A certain relief comes with death because the person is no longer suffering but there may also be feelings of guilt, anger, etc., that must be dealt with. "Persons in grief have a whole jungle of emotions in their guts which need to be expressed in some way. Sometimes openly, sometimes by talking, sometimes by crying, sometimes poetically, sometimes through ritual: there are many ways, but people must have the opportunity to express real feelings because unresolved grief is a destructive horror."¹⁵ I think the most important thing for nurses to remember is this: "...you must not lose your empathy for the patient and his family. If you do, where can they turn? What have you given that a machine couldn't give? And, deep within you, what have you gotten?"¹⁶

The final family stage is reestablishment, after the person completes the mourning phase. The tenth and final family phase is in this stage: expansion of the social network beyond the family. Here one must overcome

alienation from culture and society. The goal is to foster relatedness. For nurses to be involved in this area is rather difficult unless community health nurses or other health team members are referred to the family. Often the family must involve themselves in society, which at times can be very difficult. This is what we are still in the process of doing, and have made good progress. Mom got a job as a restaurant hostess at the airport in April 1977. Dad had wanted to be a pilot and had bought and worked on an airplane while he was ill. Following his death, I took over the flying lessons, became a private pilot, and am now working on my instrument rating. I am nearing graduation from nursing school and will then begin a job as a staff nurse on a hospital medical floor. Mom and I are each living our own lives and seem closer than ever before. We go out to new places in town, such as restaurants, often and have made many new friends, all of which have helped us a great deal.

I think my present situation can best be described by the following poem:

TRY AGAIN

"I'm tired of gloom;
I'm tired of pain;
I want to rejoin
The world again.

Life does proceed
When a loved one leaves
But it's difficult for me
Who is left to grieve.

Today I will try
To smile once more
Death disappeared
And left my door.

I'll pick myself up
And try again;
I'll make the effort
To function again.

It won't be easy
 As I well know,
 But I won't give up
 The change made me grow.

I loved him so much,
 And fate was unkind.
 He went away first,
 He left me behind.

The pain in my heart
 Will remain for awhile
 But yesterday's gone
 Today I will smile." 17

I have learned a great deal from this experience, but three main areas come to my mind. The first area is best summarized by one author, "There is more to an illness than what you see in the hospital. It was something I never realized--it took a situation like this to open my eyes. I know what an illness can do to the entire family unit. I hope that I will be a more compassionate and understanding nurse, having seen illness from both sides."¹⁸ The second area occurred rather unexpectedly. This involved the releasing of some of the emotions and feelings I had kept bottled up inside of me since Dad's death. It helped so much to sit down and write down all of my feelings. This final writing of this paper is nothing like my first draft of it, which was filled with emotion but little advice to improve patient care. It was a good release and enabled me to then resolve conflicts which were still present.

The third area was that I discovered research can expand to encompass more things than originally thought possible. I had originally planned on this paper being just for nurses--to show them how they often care for patients and their families and what they can do to change. It, however, enlarged to provide a release for me and I feel might help other families of dying patients to know that they are not alone in their grieving and that it is not unusual for them to feel such things as anger, isolation, or guilt.

I have hopefully learned my lesson, but the health profession still needs to learn one. "The health professions are not truly educated, for they have too long neglected this group which so desperately needs help. When will the profession realize that death, which was always thought of as the end, is the causative agent for another syndrome, and begin to treat and support those who are still alive?"¹⁹

ENDNOTES

1. Alice M. Costello and Mary T. Ramshorn, "Emotional Problems of Patients with Cancer: Nursing Interventions," reprinted from Proceedings of the National Conference on Cancer Nursing, by the American Cancer Society, Inc., 1974, p. 6.
2. Ibid, p. 6.
3. Marc Halman and John Suttinger, "Family-Centered Care for Cancer Patients," Nursing 78, March 1978, p. 42.
4. Josephine K. Draytor, "Talking with Persons Who Have Cancer," American Journal of Nursing, April 1969, p. 4.(of reprint).
5. Elisabeth Kubler-Ross, Death: The Final Stage of Growth, (Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1975), p. 25.
6. Ibid, p. 82.
7. Ibid, pp. 83-4.
8. Ibid, p. 82.
9. Barbara Giacquinta, "Helping Families Face the Crisis of Cancer," American Journal of Nursing, October 1977, p. 1585.
10. Kubler-Ross, p. 161.
11. Giacquinta, pp. 1586-7.
12. Ibid, p. 1586.
13. Costello and Ramshorn, pp. 7-8.
14. Kubler-Ross, p. 26.
15. Ibid, p. 93.
16. Halman and Suttinger, p. 43.
17. Kubler-Ross, p. 103.
18. Deborah J. Decker, "In the Valley of the Shadow," American Journal of Nursing, March 1978, p. 418.
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