Family Conference in the Care of the Cancer Patient

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The patient with cancer faces a crisis involving many basic questions and major life adjustments. The natural history of the illness may involve progressive loss in the patient's functional capacity, and the patient needs medical, psychologic, and social support. The family of the patient with cancer can provide much help if their potential resources are fully utilized. Conferences involving the patient, family members, and health care professionals allow for open communication, problem-solving, and support for the patient and family through this difficult time. A case is reported illustrating the value of periodic family conferences in the care of a patient with metastatic disease.

The cancer patient faces many problems. The recent upsurge of interest in the human process of death has stimulated increased concern with the dying patient. These observations are focused on the intrapsychic phenomena of the patient, a most significant area of concern.[1] It remains for future work with cancer patients to reveal the quantitative impact (in terms of numbers of cancer patients) of these intensely personal encounters. It may be that the dramatic intrapsychic events, so illuminating to us and the patient, will not take place in the majority of patients. There are, however, universal areas of need in the patient with cancer.

Cancer patients, especially those who have not been cured, face a multitude of catastrophic problems in living. Those with marginal finances and/or tenuous personal relations have a great need for attention, and even those in the best of social circumstances will experience serious changes in their way of life. In the dying cancer patient, the course of his illness will lead to a step-by-step relinquishment of the ability to function. Social and interpersonal changes and losses inevitably accompany the progressive biologic dysfunction. The myriad of social problems of cancer patients has been well documented.[2] They encompass every area of the patient's social existence and will vary in severity and kind depending on patient and family resources. Needs for care increase progressively with disability and require awareness by the family physician so that the available resources can be mobilized.

The family of the cancer patient is the first line of support and therefore requires attention. The patient's needs will have a profound impact on the family's life. It is important not only to attend to the patient's welfare, but also to give sustenance to the family members during their period of trial and loss. Spouse and children need understanding of their own individual struggles with the new family situation. Meetings with individual family members will often be necessary for specific purposes, but meeting with a family as a group may afford a unique experience for the family physician and family members.

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Case History

The following case illustrates the usefulness and ramifications of family conferences in the care of cancer patients.

Mrs. S. H. was a 43-year-old woman who presented to the Family Practice Center on the evening of August 21, 1974, accompanied by several members of her family. She was in pain and her need for medical care was at a crisis point. She had recently been dismissed by a previous physician who, according to the patient, said that he could no longer help her. He had recommended nursing home placement so that the patient could receive injections for pain relief.

Mrs. S. H. complained of severe pain in the right lower chest and indicated that she was unable to sleep because of the pain. She had been receiving Darvon compound. The history disclosed that the patient had had a right hemicolectomy for a perforated carcinoma of the cecum in September 1973. Following surgery, she had received weekly injections of 5-fluorouracil. The most striking physical finding at this time was a markedly enlarged, stone-hard liver. The patient was given a small amount of codeine for pain, and an appointment was made for further examination the following day. At the suggestion of the family practice resident, a family conference was arranged for the same day, so that the staff could more effectively arrive at a plan of care for the patient.

This initial family conference in-

cluded the patient, two sons, a daughter, a daughter-in-law, two sisters, and a friend. The family practice resident who had assumed responsibility for the patient's care and two faculty members of the Family Practice Department were present. One son and daughter had been called home from their assignments in the armed forces and were attempting to arrange transfers to local bases. The patient and family members were concerned with many issues and were eager to speak of them. The patient had many questions: Could she go back to work? What should she do if she could not? Could she obtain continued care from us? How bad was her illness? Was there any hope? What could be done for her now? Was it true that all she could do was to take stronger pain pills and go to a nursing home when she needed injections for the pain? Was there a cure? Were there other medicines? What was the cause of the pain in her chest and her sputum production? Why did she experience nausea and vomiting? She said that she always became ill when she received intravenous 5-fluorouracil in the doctor's office, and returning home the same day was most difficult. She lived in her own apartment, but she raised the possibility of moving in with a sister.

One son brought up the question of a liver transplant. The family wondered about an appropriate diet for the patient. They asked if there were any surgical techniques for relief of pain. One member of the family indicated that there was a problem helping the patient because she still wanted to maintain her independence. During the meeting the family practice staff clearly stated that the patient was not well enough to work and advised her not to return at this time.

The patient was concerned about finances, and it was recommended that she apply for disability benefits because of the chronicity and indeterminate duration of the illness. She expressed some reluctance to do this, but one son pointed out that she had paid into social security all the years that she had been working and had, therefore, earned the right to this financial help during her illness. The meeting disclosed that her two sisters could be of help were the patient to remain at home; one was a daily visitor there. The daughter seemed somewhat fragile, worked all day and was preoccupied with a reunion with her boyfriend and their impending marriage. The daughter-in-law was supportive though pregnant at this time. It was agreed that the patient could return home and would receive adequate pain relief. The records of her previous treatment would be obtained, and her current biological problems would be evaluated on an outpatient basis by appropriate examinations and laboratory determinations. During the period of evaluation, the patient received adequate pain relief with oral medications.

On September 5, 1974, the patient was admitted to the hospital with a view to further chemotherapy. The consultant in chemotherapy proposed the possibility of more intensive systemic chemotherapy or the alternative of regional perfusion of the liver with 5-fluorouracil via the hepatic artery. The patient had much difficulty making a decision, and both she and the medical staff agreed that a second family conference was desirable. Again at this conference, the family had the opportunity to ask questions and the family practice staff could further evaluate assets of the various members of the family which could be utilized in the patient's care. The alternative modes of treatment were thoroughly discussed, as well as other pertinent issues.

Following this meeting, both the patient and the family chose to accept a surgical procedure to insert a catheter into the hepatic artery for regional perfusion of the liver. At operation, however, the surgeon elected not to insert the catheter because of involvement of the omentum and other lymph nodes in the abdomen. This change in decision was traumatic to the patient and family. The sagging of their hopes was apparent. It appeared, however, that the rapport and trust established in the previous meetings enabled the patient and family to cope with this disappointment. A regimen of adjuvant immunotherapy was recommended by the consulting oncologist. Later in this hospital stay, the patient developed a pleural effusion, but she gradually improved and returned home on October 25, 1974. She was seen at home by the family practice resident and a visiting nurse. The major responsibility for day-to-day personal care was assumed by a daughter-in-law. Effective pain relief was maintained. The patient was relatively comfortable at home until her need for nursing care had increased beyond the family's capacity.

The final hospital admission was on November 13, 1974. There was marked evidence of increased metastatic disease in the patient's lungs and the liver had enlarged further. It was in this context that a family conference was again held in order to discuss the patient's failing condition, what could be expected, and what could be done. In the interim, the patient's daughter had broken her engagement and wedding plans were cancelled. She was being seen in the Family Practice Center because of arthralgias. The cancellation of the wedding was a serious blow to the patient who had planned on a big, festive event and had indicated that all she had desired was to see her daughter married. All the responsibility for the patient's care had fallen on a daughter-in-law and son, and the question of nursing home placement had been raised. During this conference it was apparent that the family members present felt much criticism and pressure from the more removed family members regarding the patient's care. Their guilt and anger were apparent, and the meeting afforded an opportunity for open communication of these feelings. Reluctantly, nursing home placement was agreed upon. The patient was now terminal and she died five days later.

Discussion

The communication process in the family conferences was an open one. The family members and staff were free to discuss any concerns that they had at a particular time. Although the communication focused on the care of the patient, the staff necessarily learned much about the lives of the individual family members. This knowledge was of importance in formulating reasonable expectations of the family members. A side effect of the family conferences was that individual family members began to look to the family practice staff not only for medical care, but also for counseling and assistance with personal problems.

The timing of each family conference was related to the course of the patient's illness. The first conference presented the opportunity for

physicians and family members to become acquainted. The circumstances leading to the patient's self-referral were reviewed and information about the current needs of the patient was transmitted to both physicians and family. Confusion regarding previous treatment and the course of the illness was aired. The future could be discussed so that the family as well as the patient could understand what might be needed of them. The physicians had the opportunity to assess the strengths of the various family members. Such an assessment later proved helpful when decisions and social life-support measures were needed.

The second conference occurred in the context of the need for a decision regarding treatment. Medical consultation between the oncology and family practice staffs had arrived at a recommendation to use intra-arterial perfusion of the liver with 5-fluorouracil. The patient was extremely apprehensive about the procedure. She had much difficulty reaching decisions on her own and indicated a need for the family to participate in the decision-making process. The unilateral decision of the surgeon at operation not to insert the hepatic artery catheter posed a credibility problem in the postoperative period. Certainly the trust engendered by the previous conferences may well have averted a serious loss of confidence in the physicians and loss of hope.

The third conference focused on the patient's need for nursing care beyond the family's capacity. In this setting, the family practice staff was able to be supportive and a decision could be reached in an atmosphere of mutuality.

Summary

Some of the positive contributions of the family conference in the care of a cancer patient include the following:

1. The feeling of a sense of inclusion by the family members.
2. The recognition of the family members' desire to understand the patient's illness.
3. The transmission of information regarding the patient's needs to the family.
4. The opportunity to give the family direct, accurate medical information in order to avoid confusion and misinterpretation.
5. The patient's increased sense of security as a result of the inclusion of the family.
6. The recognition by the physicians of the contribution of the family members to the patient's care.
7. The contribution of family members' information regarding the patient's living situation and requirements in this area.
8. Family members' contribution about the personal characteristics and patterns of the patient's behavior (such information is extremely relevant so that optimum treatment can take place).
9. The development of a sense of trust between patient, family, and physicians.

In a more general sense, such communication renews the faith of patient, family, and physicians in the human process of sustaining and supporting the efforts for life and well-being even in the face of catastrophic illness.

References

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