Continuing Care of the Cancer Patient as a Social Engineering Problem

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Abstract

Care of the cancer patient has become fractionated toward maintaining the physiological integrity of the patient’s life support systems, e.g., the hematopoietic or neurological systems. The concept of total continuing care for the cancer patient is illustrated in this description of a pilot hospice project in a community medical center. The project also illustrates the concept of team support by the health care staff and volunteers. The total continuing care unit described provides support and care which makes living not just possible, but worthwhile, for cancer patients.

Introduction

Continuing care of the cancer patient can be total or fractional. Fractional care refers to maintaining physiological integrity, a life support system, e.g., hematopoietic, renal, neurological, respiratory, or circulatory integrity. Singly or in combination, these are easily identified as the more commonly recognized vectors along which care, concern, and treatment are traditionally directed.

For the past 30 to 40 years, training, internship, residency, and specialty training in medical school have been directed toward making us more proficient and efficient in coping with the microminiatae of the subparts of the human organism. This has led to better and more skilled nephrologists, hematologists, cardiologists, oncologists, and vascular and heart surgeons, but I am not entirely certain that it has led to better total care of the patient.

Fractionating care may have moved us toward subset perfection, while at the same time allowing for gross imperfection to evolve or to be ignored. Many of us tend to forget or misplace the total human being in our overwhelming pursuit of the mitotic figure.

For me, the title “Continuing Care of the Cancer Patient” implies that we must remind ourselves that our goal is to try to help provide that level of support and care which makes living not only possible, but worthwhile, for our patients. If we cannot do this as individual physicians, our ethical code demands that a “physician should seek consultation in doubtful or difficult cases; or whenever it appears that the quality of medical service may be enhanced thereby (1).”

I do not wish to be a party to the creation of another subspecialty. I do not wish to support the creation of a specialist, the “terminal doctor” (thanatologist). I shudder at the term. I do wish to reaffirm the profession and provide the physician with the skills and support necessary to care for that patient who enters the final stages of illness, the terminal event.

The hospice program that we have developed as the Northern California Kaiser-Permanente Hospice Pilot Project at the Hayward Medical Center has provided me and a number of other physicians with a viable choice.

The Goal of the Hospice Program

The goal of the hospice program is the integration and coordination of medical, social, and community services to support the patient and family that face a terminal illness.

The following elements are necessary for the creation of a hospice.

1. Commitment.
2. Sharing of the same goal by all of the parts of the program.
3. Reality awareness. There are certain hard realities with which one must deal. Among these is the recognition that “virtue” is not necessarily the same attribute as “wisdom.” Wisdom is almost a neutral quality. It can be used by people with evil motives as well as by those with good motives. To develop a hospice program which is successful, we need to combine both virtue and wisdom, preferably in the same people. Virtue alone is not sufficient. We must be aware of tiresome clichés, prefabricated jargon that is a substitute for thought. We must always keep clearly in mind the goal of integrating the delivery of a number of different, yet related, services for the benefit of the patient/family constellation and the physicians and nurses.
4. Skills of trained professionals and volunteers working together as peers.
5. Flexibility. There are many things which we must learn, and our best teacher is quite frequently the patient.
6. Staff and volunteers who are comfortable working with ambiguity. When one strives to individualize care, one must be prepared not only to be flexible but to be able to tolerate changing patterns and strategies. If we truly believe that care must be individualized, then as providers we must be prepared to individualize services, which means we cannot try to squeeze the patient and the family into the system. The system must be responsive to the patient and family.
7. A built-in system for self-evaluation and self-improvement. The program should also subscribe to the philosophy that external evaluation and constructive criticism are welcome. At the same time, the evaluators might keep in mind what George Pickering once said, “Not everything that counts can be counted, and not everything that can be counted counts.”
8. Ability to distinguish between program evaluation and research. Both are useful and productive objectives. Research is useful in the long run to improve our knowledge and thereby to improve our services. Evaluation is useful as an assessment of the adequacy and the quality, the appropriateness and the effectiveness, with which hospice program services are rendered.
10. A program that supports the patient and the family at home and in the hospital.

11. Awareness on the part of the program developers that good judgment comes from experience and experience comes from poor judgement. Therefore, we must share our hard-won knowledge in this area. The example has been well set by people like Dr. Saunders, Dr. Lamerton, and Dr. Wilkes, in England, and in the U. S. by Dr. Lack, Dr. Mount, and others.

A Model of a Hospice Program Integrated with a Medical Center Total Service Program

The hospice program is for the patient who is afflicted with an illness which is expected to end life within approximately 6 months and for whom maintaining or improving the quality of life becomes a major goal during the intervening period. Patients/families in the program need to understand and accept the concept of palliative care. The attending physician must understand and accept the concept of palliative care. All must understand and accept the "no code blue" philosophy. The hospice program is designed to develop trust and support between the patient, the family, and the medical delivery system.

Essential Features of the Kaiser-Permanente, Hayward Hospice Pilot Project

The essential features of the Kaiser-Permanente, Hayward Hospice Pilot Project are as follows.

Inpatient Unit. The inpatient unit serves 2 functions: (a) provides patient beds for achieving or modifying symptom control strategies when this cannot be accomplished on an outpatient or at-home basis and (b) provides family respite for brief periods.

Home Care Program. The home care program serves 3 functions: (a) provides support to the family in caring for the patient in the home; (b) provides for continuity in medical care; and (c) provides the home care nurse, who is truly a physician extender.

Medical Staff Center Educational Program. The hospice program has designed an educational program to teach physicians, nurses, housekeeping, pharmacy, and all the various paramedical service providers the objectives of the program and the methods, the procedures, and the strategies used under the concept of the hospice program.

Patient/Family Weekly Status Review. The status review is a regular weekly review of all patients and family members being cared for in the hospice program, both inpatient and outpatient. This review constitutes a situation report, strategy planning conference, and bereavement follow-up report. Present at this weekly review are (a) the hospice program coordinator, (b) the nurse responsible for providing home care service, (c) the nurse on the day shift of the inpatient unit, (d) the nursing supervisor, (e) the social worker, (f) the home health aide, (g) the physician in charge of the home care program (internist; M.D.), (h) the medical director of the hospice program (surgeon; M.D.), and (i) guest participants, e.g., other nurses, aides, volunteers, and physicians. The oncology department often participates.

Hospice Staff and Support Strategies. The hospice coordinator interviews potential nurses, aides, and volunteers as a prestaffing screening device. Also involved in this interview process are the supervisor of nurses and the director of volunteers.

A preparatory indoctrination of all potential staff members and volunteers includes history, hospice philosophy, reasons for hospice, our program structure, expectations, and strategies for coping with stress.

Inservice ongoing education is provided on a regular basis. Topics thus far presented have been: cancer, what is it?; chemotherapy, what has it all been about?; symptom control and management; dealing with bereavement; enterostomal care; dealing with the dying patient "who is so much like myself," i.e., identification; dealing with family members who express affection toward the hospice staff; and dealing with anger and hostility.

Formal regularly scheduled time slots are available for meetings at which psychiatry and psychology staff are available as facilitators or "leavening agents." (They sometimes get a rise out of us.)

Social events are available (a) for hospice program and staff volunteers periodically and (b) for hospice program family and friends who are survivors (bereaved), along with available staff.

Informal staff support strategies evolve out of what I consider to be mutually intrasupportive dynamics to establish relationships between various staff members, between staff members and the program coordinator, and between the medical director and other members of the staff or volunteers.

Hospice Program Coordinator. This is a person with superb skill and patience, skilled in leadership techniques which are gentle but persuasive, supportive but not stifling, consistent but not rigid, reliable, dependable, dedicated, and available. The hospice program coordinator should be a person skilled in many roles, but not one who needs to "take over" or "usurp" others' duties and responsibilities. The hospice program coordinator must be able to understand and tolerate ambiguities while gently working to avoid them.

The hospice program coordinator provides for the day-to-day management of the program and coordinates patient services.

The coordinator also serves as liaison between the hospice program and the other medical center departments which are not directly represented on the planning committee or the administrative committee, e.g., the housekeeping, engineering, dietary, and physiotherapy departments.

Medical Director. The medical director should be a person who understands the medical community which uses the medical center and the administrative structure responsible for the medical center. It is also helpful if this person is respected by both of these communities. The medical director needs to be a person who fully understands the principles of the hospice program, palliative care, and symptom control, as well as the techniques and appropriateness of active intervention in the traditional modality.

Medical Center Administrative Hierarchy. The administrative hierarchy must be a group which understands the needs and priorities of the hospice program and is committed to support them. This means that they are not just "desirous" or "interested" in supporting hospice, but are committed to the concepts and the philosophy of the program, and are therefore willing to make sacrifices to see the program succeed. For example, in our medical center the director of nursing is a member and has been a member of the planning committee for...
hospice from its inception and has been a member of the hospice administrative team from its beginning.

**Hospice Program Administrative Team.** This committee is comprised of the hospice medical director, the hospice program coordinator, the medical and hospice supervisor of nursing, the director of nurses, and the assistant hospital administrator. This team meets weekly or biweekly to discuss the problems that the hospice program faces and the potential solutions.

The committee meets to ensure that the program is integrated into the medical center activities and to reaffirm that the program continues to live up to its commitment to patients/family and staff to provide the services as promised.

The administrative team reviews weekly data collection and monthly reports on the various utilization patterns, services provided or required, patient/family constellations served, needs discovered, in-service training requirements, program modifications, costs, and future strategies. The administrative team delegates the responsibilities for development of solutions or execution of plans to the appropriate departments of the medical center or members of the hospice team.

**Assistant to the Program Coordinator.** This is an individual well skilled in secretarial functions as well as data-gathering functions. This person provides superb secretarial support and does the primary data gathering, collation, and data organization for the administrative team, as well as for the project’s separate evaluations team. Data are collected to determine utilization patterns by physicians, by illness, and by family structure. Data are also collected on lengths of stay, home care services required, inpatient utilization, and family needs.

**Volunteer Coordinator.** The volunteer group consists of a very dedicated group of individuals who are viewed by patients and families as their peers and who frequently provide the kind of human contact which gives the other members of the hospice team a much clearer insight into patient and family needs. Volunteers provide the rest of the team with the kind of support and reassurance that enables us to provide the personal attention to which we are committed. A hospice program cannot reach its full level of achievement without volunteers. They have provided patient and family support in ways and at times when professional teams would have been inappropriate and inadequate. Members of the staff, too, view the volunteers as peers.

**Social Service Support.** The social service department has provided the hospice program with personnel who carry the hospice patients as a major part of their case load responsibility. Social services are used as a part of the strategy planning for responding to patient and family needs, for discharge planning, and as a part of the psychosocial support system.

**Hospice Program Planning Committee.** This committee was formed prior to the establishment of the hospice program. It began to meet approximately 1 year prior to the opening of the full program, first monthly and then, as needs arose, biweekly; within 4 months after the beginning of the complete services program, a meeting pattern developed of approximately once every 6 to 8 weeks. The hospice program planning committee consists of the medical director of the hospice program (M.D.), hospice program coordinator (layperson), director of nursing at the medical center (R.N.), nursing supervisor (R.N.), assistant hospital administrator (M.B.A.), director of social services (social worker), director of medical center volunteers (layperson), former chief of psychiatry (M.D.), medical director of the home care services division (M.D.), regional administration liaison (R.N.; Ed.D.), and primary home care nurse (R.N.). This committee meets to discuss program needs and strategies and serves as a resource to the hospice administrative team and as a sounding board for any and all members of the hospice team.

At times, nurses with various concerns have presented these concerns to the planning committee for their consideration, suggestions, and recommendations. This committee has served a very useful function in many respects; although it has no administrative power as such, it certainly has great powers of persuasion. The hospice administrative team has found the hospice program planning committee to be a great resource.

**Essential Elements Necessary for Producing a Hospice Program**

1. There must be an essential need in the community which is not being met within the existing system.
2. There must be a heightened degree of sensitivity on the part of medical staff, nursing staff, social workers, ministry, and lay public.
3. There must be cooperation and active support by the medical community and the medical staff. They must recognize that when a patient is admitted into the hospice program, the aim is not to suspend therapy but to redirect therapy. The goal is to try to keep the morbidity of the disease and the morbidity of the treatment to a minimum.
4. There must be the cooperation of the medical center administrators, who must not allow their traditional priorities to stand in the way of the hospice program. By that I mean that the traditional techniques of cost containment by virtue of minimal nurse/patient staffing ratios and keeping bed utilization figures high must be reassessed and reevaluated. The use of these techniques mitigates the chance of success of a hospice program.
5. There must be adequate reimbursement for the services rendered.
6. The hospice provider of services has 3 consumers: the patient; the patient's family; and the traditional medical services team. Evaluating a hospice program depends upon the assessments of these 3 different consumers.

**Conclusion**

I consider the revamping of the care of the terminally ill to be a social engineering problem. If one were to carefully review a well-run hospice program, one would recognize that most of the parts of such a program are already in place in many communities. Why have they not been successfully integrated before this? Are there individual factors and pressures that run counter to the thrust of a hospice program? Are there social centrifugal forces at work mitigating such integration?

In my opinion, the answers must be qualified affirmatives. Among individual factors, one quickly perceives that fear, pain, isolation, and lack of knowledge or skills will tend to drive people to institutions or agencies. Along with this, there is the social pressure that supports institutional care over home care, the notion that only in a hospital can one receive optimal care.

In the past 50 to 75 years, we have seen a profound displacement of "responsibility" from family to societally created "bits" of "community agencies." In many instances, such agencies
or institutions develop rules and function in a manner which disrupts family lines of mutual support.

On a much broader scale, one can recognize that the forces which lead to the disruption of the family and the neighborhood work against "hospice." In the hospice program, we try to reinforce family and neighbor interdependence. We try to rekindle self-help within the family and the neighborhood. When "family" and "neighborhood" cannot be identified or reconstructed, the task becomes truly formidable.

In the final analysis, individual choice, even when allowed to be expressed, has been conditioned to respond to social pressure and agency or institutional pressure. The decision as to the mode and place of care has often been removed from the patient and the family. At the very least, the "where" and the "how" of one's death must remain the choice of the patient.

References

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