Class 9

The Home Hospice: A Profile of a Palliative Home-Care Unit

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Death is essentially a family event and home-care philosophy acknowledges and encourages the family's role in treating the chronically or terminally ill patient at home. This article describes the aims and organization of a palliative home-care unit specializing in the care of the terminally ill. The unit is affiliated with the Ichilov Hospital, a 1,000-bed Tel Aviv University teaching hospital. We attempt to illustrate the advantages of a multidisciplinary approach to providing comprehensive family care. Palliative home care should not be viewed as "second best," turned to because of a lack of alternatives, but as a legitimate and valuable approach to care in its own right.

INTRODUCTION

There is an increasing tendency today to care for incurable, terminally ill patients at home, instead of in the hospital. The hospice movement, which was initiated at St. Christopher's in London, has made a remarkable impact on the concept of care of the dying patient. Cicely Saunders, the driving force and most inspiring figure in the hospice movement, outlined the goal of terminal or palliative care: To provide treatment to relieve the patient of physical distress and to free him or her to concentrate on other matters. Terminal care is designed to overcome the sense of failure that tends to pervade the atmosphere surrounding the dying. Saunders's contribution to the movement and the hospital was to provide the first serious attempt to balance science-oriented medical practice with equal concern for the psychosocial and spiritual needs of the whole person that comprises the patient.

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The well-staffed and highly motivated hospice personnel have traditionally provided a high quality of care. Relatives and friends of the hospitalized patients were briefed at regular intervals and allowed to visit and stay with their dying relative as long as they wished. In hundreds of hospices that have been established since in various countries, palliative-care teams have been active in the development of improved procedures to cope with day-to-day problems of terminal care.

But, in spite of the impressive effort, it became clear that for a large number of terminally ill patients and their families, this model was not always acceptable and many hospitalized patients expressed a wish to return and die at home. Other patients did not meet the prerequisites of the hospice and their families had to choose between hospital or home. Those who opted for this alternative believed that the home setting would provide a better and more appropriate framework of individualized care; a closer contact with relatives; a more intimate, empathetic, informal relationship in the last stages of terminal cancer.

The scarcity of organized palliative home-care services has limited the number of terminally ill patients who could have been provided with a comprehensive system of home-care services. Many families who could not rely on such an ongoing system of regular support were compelled to re-hospitalize their dying relative, unable to cope with the multitude of tasks involved in terminal care.

This article describes the activities of an organized home-care service that has provided palliative care to dying cancer patients in the Tel Aviv City area for the last seven years.

Organized and hospital-based palliative care has proved to be an efficient method of support for many homebound patients and their families. The interdisciplinary team approach practiced by the care-givers and the effective availability of the home-care teams provided the patient and his family with expert professional support. The ongoing informative talks, the skilled palliative-care procedures, the direct participation of the family in all the decision-making sessions, and, above all, the expert and continuous psychological family-therapy support enabled most of the families who joined this program to cope with and survive the difficult situations in terminal care.

Palliative care at home is definitely a promising and efficient alternative to institutionalized terminal care. It is also an economical and facilities-saving system: The costs involved in the delivery of palliative care at home barely exceed one fifth of the costs involved in similar palliative care carried out in institutions.

The main advantage and attribute of this concept is the unique support it offers to the patient and his family at home, the ongoing availability, the urgency of response, and the comprehensive assistance it provides through all the stages of the dying process of a terminally ill patient.

Palliative home care is perhaps best suited to deal with the difficult and complex process of separation that precedes the impending death. As one

relative expressed it, palliative care can help families "to accept dying as a controlled and gradual process and not as an abrupt event."

THE PALLIATIVE-CARE UNIT (PCU)

Six years ago, the Palliative Home Care Unit (PCU) was established as an independent and self-budgeting department at the Ichilov Medical Center, Tel Aviv, Israel. A need was perceived for a unit that could provide a different quality and quantity of care for the special physical, psychosocial, and spiritual needs of terminally ill patients and their families. The activities of the PCU are carried out by well-coordinated multidisciplinary teams that are available 24 hours a day, seven days a week. The teams are assisted by volunteers and employ approximately 35 professionals, including physicians, family therapists, nurses, social workers, physiotherapists, and occupational and speech therapists. A small group of full-time employees—the logistic team—directs the unit as a whole.

Limited financial assistance is provided to the unit by the Israeli Anti-Cancer League, a nonprofit organization that receives support from the public. Ichilov Hospital provides free of charge premises, some administrative and diagnostic procedures; all other expenses are billed directly to the relevant private or national health-insurance companies.

The PCU forms an integral part of the Home Care Department at the Ichilov Hospital, a 1,000-bed Tel Aviv University teaching hospital. Incorporation of the unit into the hospital infrastructure enables the unit to take advantage of the large variety of facilities provided by the hospital. Thus, because the unit is "hospital-based," it enjoys the backup support of the hospital and can provide a wide range of diagnostic, therapeutic, and advisory services.

Most of the 15,000 home visits made in 1986 were initiated by members of the PCU; the rest were emergency calls requesting medical attention or intervention in family-crisis situations. The PCU averages 13 monthly home visits per patient, and in some cases patients in the terminal phase of their disease are visited daily by several team members.

There is obviously an acute and growing need for home-care treatment, particularly in the case of terminally ill patients. In the greater Tel Aviv area (population 300,000), 2,500 (new) cancer cases are registered yearly. Of these, 250 patients in the terminal stages of the disease are admitted to the PCU. To date, more than 1,000 terminally ill, homebound patients have been treated by the PCU at the Ichilov Medical Center. At any one time there are approximately 80 patients under care and the average stay in the unit is three to four weeks.

The Ichilov Hospital serves large urban areas with an aging population (1), which accounts for the high percentage of patients who are 65 years or older (~ 80%) in the Home Care Department (see Table 1). In turn, this

explains the preponderance of malignant diseases (~ 40%) shown in Table 2.

The Logistic Team

The PCU operations are directed by a small supervisory team located at the Ichilov Hospital. This multidisciplinary team consists of a medical director (MD) in charge of the program, policy-making, and research; project coordinator (senior social worker) in charge of organization and training of social workers and inviting guest lecturers; family therapist (senior clinical psychologist); chief nurse (RN) in charge of nursing staff and their training; liaison nurse who decides on patient acceptability; accountant and chief clerk in charge of billing, salaries, and office activities; volunteer director (MD); social worker; communications and admissions clerk (part-time); and computer operator and office help (part-time) (see Figure 1).

The logistic team is responsible for supervising and coordinating the diverse activities of the home-care teams and auxiliary staff, patient and family welfare, and providing information to the authorities. The team's functions can be summarized as follows:

TABLE 1
Age Distribution of Patients Treated by the Home-Care Department in 1983

Age (years)	No. patients	% total
0–29	7	1
30–49	23	4
50–64	80	17
65–74	195	42
75–93	166	36
Total	471	100

TABLE 2
Diagnostic Categories of Patients Treated by the Home-Care Department in 1983

Diagnosis	No. patients	% total
Malignant disease	193	41
Cerebrovascular accident	85	18
Cardiovascular disease	71	15
Degenerative disease	27	6
Fractures	39	8
Post-operative	28	6
Other	28	6
Total	471	100

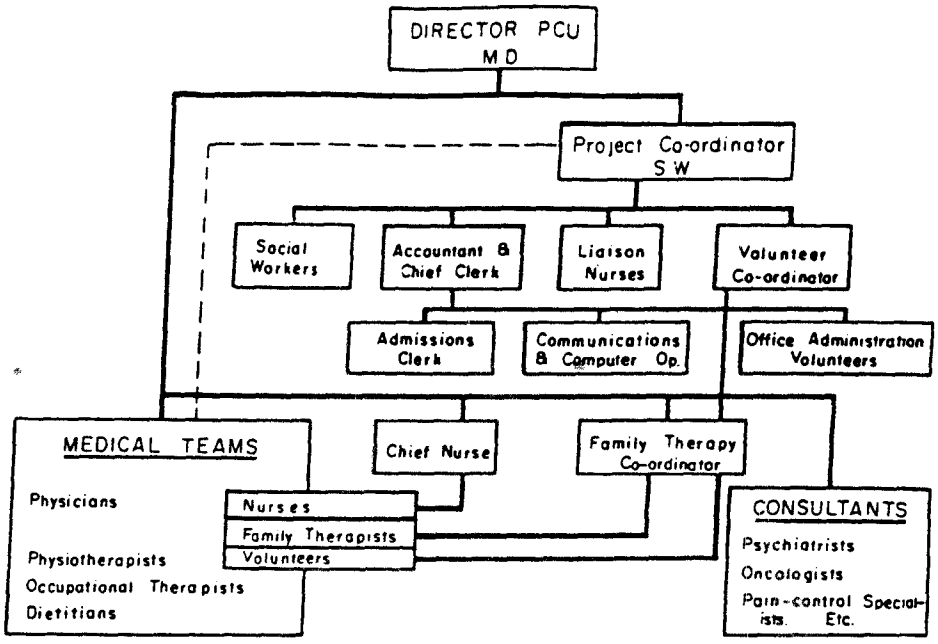

Figure 1. Schematic Representation of the Organizational Relationships within the PCU

- Admittance and discharge of patients;
- Supplying information to the affected families and interested organizations;
- Coordination of all diagnostic procedures requested by the subsidiary PCU teams;
- Preparation and scheduling of all staff meetings;
- Administration and financial management of PCU; and
- Supervising Volunteer Recruiting Center.

Home-Care Teams

For the purposes of the PCU, the greater Tel Aviv area is arbitrarily divided into three districts, and each district is allocated a multidisciplinary team. Each of these home-care teams is led by an MD, assisted by a nurse, family therapist, and social worker, with further support available from physiotherapists and speech and occupational therapists should the need arise. The PCU's policy is to employ MD specialists in various medical fields, so that the unit can rely on its own employees to act as specialist consultants, in addition to their duties on the home teams.

This decentralized approach of providing a group of patients with their own team ensures optimal accessibility to staff and swift response to calls for help. Patients are encouraged to contact their team members directly and are provided with the telephone numbers and paging codes of all team members and substitutes.

It is interesting to note that despite the exceptionally arduous working conditions characteristic of palliative home care, and the very low remuneration for home visits, most of the MDs employed by the PCU have remained with it for four years or more. All senior nursing personnel who joined the unit at its inception are still with the unit. A faster turnover was recorded among the physiotherapy staff.

Each home-care team meets regularly, formally once a week, at the home of a patient or in the office. The formal meetings are multidisciplinary in character and provide a forum for discussion and counseling. Each case is analyzed and evaluated within this framework and the decisions that are reached reflect a consensus representing several disciplines. The minutes of each meeting are recorded and patients' files updated accordingly.

Auxiliary Staff

In addition to the above, there are five volunteers helping the unit on a regular basis with office work, and another 10 working in the field with the home-care teams and performing special tasks, such as transportation of outpatients and their families.

HOME-CARE PROGRAM

Aims

The aims of the PCU are to maintain the dignity of the patient and to improve the quality of remaining life within the family framework and home environment. More specifically, this means providing symptomatic relief, especially from pain, and attending to the emotional needs of the patient and family. While maintaining the family routine, the home-care team must also prepare the family for the inevitable end and subsequently help the family through bereavement.

Procedure

After the family has completed formalities at the PCU Center, the coordinator of the program talks to the family to assess their willingness to cooperate. Additionally, the procedures, activities, and services of the PCU team are outlined. The coordinator informs the family of other agencies that may offer assistance in supplying equipment or nursing care, should the need arise. The chief nurse and the home-care team members (i.e., the team leader, family therapist, nurse, dietitian, social worker) are then informed of the newly enrolled patient and instructed to schedule home visits.

The chief nurse is the first to make the home visit, not later than 24 hours after the patient's admission to the program. The chief nurse's responsibilities include:

1) Preparation of a detailed report on home conditions, to be discussed later with the home-care team;
2) Assessing the need for special nursing care, such as care of stomas, catheters, respiratory equipment;
3) Preparation of a training program for the family to delegate to them tasks that would otherwise have to be carried out by trained personnel. Such functions include medication, preparation of special foods (e.g., nasogastric, gastrostomy feeding), and the maintenance of hygienic conditions;
4) Monitoring the performance of the nurses on the auxiliary teams and providing them with assistance and advice; and
5) Instructions of nonprofessionals, such as home helpers, for bed transfers, toilet care, bathing, and so on.

The physician in charge will also call on the patient at home within 24 hours of admission to the program. After examining the patient, s/he will prepare a medical program to be followed by the team members and the family. This includes instructions on analgesic treatment, mobility of the patient, daily routine of treatment, and necessary biochemical tests. The physician will explain the value and importance of palliative home care to the family, while stressing that should the family have a change of mind, for whatever reason, and decide to hospitalize their relative, the PCU team would support such a decision, regardless of professional considerations. The physician pays regular calls, but in the event of deterioration in the patient's condition, the family may request additional visits. Should further treatment of a palliative or curative nature be necessary, the physician is responsible for contacting the relevant departments in the medical center or hospital.

Regular meetings of team members to discuss the condition of patients enables the dissemination of pertinent and up-to-date information. Such discussions may lead to a call for additional professional or nonprofessional support, such as the introduction of physiotherapists, social workers, or the temporary replacement of family members with volunteers. Changes in treatment may be considered and introduced. Care may be intensified, for example, by introducing parenteral feeding or respiration aids; alternatively, it may be decided to lessen care intensity and gradually prepare the patient and his family for the impending death.

Bereavement Follow-Up

Home care does not stop when the patient dies. Contact with the family may continue for as long as four to five years after the patient's death. Generally, however, intensive contact is maintained for about six months after the death. The PCU recognizes that the bereaved constitute a high-risk population with a documented increased incidence of suicide and mental and physical disease (2).

CASE STUDY

A.Y., a 54-year-old mother of three boys, was returned home after several attempts to remove a malignant brain tumor proved unsuccessful and rendered her unconscious, incontinent, and blind. Husband and sons expressed the wish to treat their wife and mother at home. The PCU assisted in attaching the patient to the necessary equipment: suction, nasogastric feeding tube, catheters. The family therapists maintained close contact with the family in an attempt to coordinate their efforts to ensure the boys' regular attendance at school and the father's at his office. Finally, the family accepted "some qualified nursing help," and a precise daily schedule was organized, which defined each member's duties. Close watch was kept on the family to detect any signs of stress or discontent.

Initially, dialogue was initiated by the team; later, however, it was requested by the family. The family was constantly reminded that hospitalization was an acceptable alternative. Every attempt was made to fulfill family requests and, as a result, several specialists were consulted by the team (opthalmologist, neurologists). Severe respiratory distress, which could not be controlled at home, resulted in the family's decision to hospitalize the patient. The team organized the transfer and continued their visits to the patient until she died.

The Special Role of the Family Therapist

The family therapist (FT), generally a clinical psychologist, is an essential member of any PC team. The family therapist is expected to contact the family at an early stage, if possible while the patient is still hospitalized.

The FT talks with family members and advises them on expected changes in routine on the return home of a terminally ill patient. The FT advises on possible reorganization of functions in the family to compensate for the financial and household responsibilities the patient can no longer maintain. The FT will see to it that the family structure is maintained and that outside help, which often increases tension, is introduced as smoothly as possible.

The FT provides team members with valuable advice on strategies of approach and the care that is best suited to specific families. The FT will be on the alert for deviations from prescribed treatment. Advice is often requested, especially at the critical phases of care, such as in the case of deterioration that may justify transfer of the patient to a hospice or hospital.

The FT evaluates the spiritual and financial sources of the family to advise the family and caring team on continuation of home care or hospitalization. The FT induces the first conversations about dying and bereavement and will prepare the family for the bereavement while the patient is still alive.

The FT is often called upon to assist and protect the family from exterior pressure, which frequently comes from other relatives who feel they have

a right to interfere. It takes tact and determination to impose order and cooperation in the tense atmosphere of terminal palliative care.

CASE STUDY

B.E., 32 years old, mother of a six-year-old girl, succeeded in concealing her malignant disease and weekly treatments from the family for over two years. As the disease progressed, B.E. had to be confined to bed and the PCU was called in to help. The family therapist was faced with the task of preventing deterioration in the family relationships because of the overt animosity and tension between B.E.'s mother and B.E.'s husband. B.E. insisted on directing the household, dressing her daughter and sending her off to school. The therapist tried to gain the cooperation of the family, but as B.E. became weaker and her authority waned, the fragile intrafamilial network collapsed, medical procedures were disregarded or delayed, and nursing care was neglected. Other relatives joined in taking sides. B.E. had to be transferred to a hospital where she died two days later. Efforts were continued by the family therapist to reinstate some order and to regroup the family to help the child. The efforts were not very successful, as both the husband and the mother objected to the intervention, and the PCU was forced to pull out.

CONCLUSION

Terminal care at home is possible if carried out by expert multidisciplinary teams supported by families willing to cooperate, even if this involves the use of complex nursing procedures and/or frequent interventions by a family therapist. Control of pain and symptoms at home can be brought about with new and efficient procedures, easily administered analgesic drugs, and a growing trend of families assuming the responsibilities of terminal care.

The multidisciplinary approach, which is the main contribution to the success of palliative home care, provides the advantage of comprehensive care. PC teams have amassed extensive experience and expertise enabling them to predict and cope with the acutely distressing situations encountered by the patient and his family. Palliative home care should be viewed as a legitimate and valuable mode of treatment in its own right, and not as a second-best solution turned to because of a lack of other alternatives.

The prerequisites for the successful functioning of a home-care program can be summarized as follows:

1) The patient's family must be willing to cooperate with various medical, paramedical, and nonprofessional personnel involved in the home-care program. This means making concessions, regrouping and delegating authority, and sometimes accepting outside help. The family should be

ready to take over medical and nursing responsibilities for long periods of time.

2) The PC team has to provide expert multidisciplinary professional care, despite the often makeshift conditions prevailing in the home. No amount of tender loving care, however important this is, will relieve an impacted bowel or subdue metastatic pain. This professional help must be available round the clock, seven days a week. The team must be mobile and able to respond to emergency calls swiftly.

3) Ancillary support must be supplied by a general hospital. Specialist consultants and diagnostic procedures should also be readily available. Terminally ill home-care patients must take priority in readmission if necessary.

4) The palliative-care program must have clear-cut policies and well-defined procedures that are acceptable to all the associates and professionals employed by the unit. Dealing with a multidisciplinary team requires tact and diplomacy.

5) The attitude of the care-givers must be objective and not one of competition for leadership. The role of PCU members is one of assistance and support. The ultimate decision to undertake and continue home-care treatment of a terminally ill patient rests with the family. The care-givers must be aware that family patterns are set over years, and the relatively short time the PC team has to assist the dying patient and his family is too little to influence ingrained patterns of behavior.

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