

The problem of caring for the dying in a general hospital; the palliative care unit as a possible solution

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The general hospital as a setting for terminal care has disturbing deficiencies: particularly, the medical, emotional and spiritual needs of the patients and their families are generally neglected. Consideration of the options for improving the situation led to the opening of the palliative care unit (PCU) at the Royal Victoria Hospital, Montreal, which is staffed by an interdisciplinary team with a positive and creative attitude to death and bereavement. The palliative care service comprises three areas of care — the PCU itself, a domiciliary service and a consultative service — as well as research, teaching and administrative functions.

On constate que l'hôpital général, en tant que centre de traitement pour les cas terminaux, présente d'étranges déficiences; en particulier, les besoins médicaux, émotionnels et spirituels des patients et de leurs familles sont généralement négligés. Une analyse des diverses options susceptibles d'améliorer cette situation a suscité la création d'une unité de soins palliatifs (USP) à l'hôpital Royal Victoria de Montréal; on y retrouve une équipe multidisciplinaire capable de faire preuve d'une attitude positive et créative devant la mort et l'affliction. Le service de soins palliatifs offre trois types de soins — l'USP elle-même, un service de soins à domicile et un service de consultation — et remplit des fonctions de recherche, d'enseignement et d'administration.

We emerge deserving of little credit; we who are capable of ignoring the conditions which make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced.¹

The problem: deficiencies in terminal care

Approximately 70% of Canadians now die in institutions.² There is increasing evidence that these patients and their families experience a wide variety of critical problems that usually go unrecognized by those responsible for their care. The terminally ill patient, instead of receiving sympathetic understanding and expertise in meeting his medical and emotional needs, may encounter isolation and depersonalization.^{1,3-7}

The hospital staff also find the situation difficult. Lasagna⁴ has suggested that the orientation of the medical team may foster a half-hearted approach in seeing to the welfare of the dying. Nurses, for example, do not welcome assignments to dying patients and many are uncomfortable in conversing with them.⁸ As death approaches, interaction between patient and staff becomes strained and patient care is affected.⁹ This problem is accentuated by the pressures of intrahospital routines that are designed to satisfy efficiency of operation and the needs of the staff.¹⁰ Physicians visit with decreasing frequency the longer a patient is hospitalized,^{7,11} and nursing care decreases as a patient's death becomes imminent.⁵ It takes longer for a nurse to answer the bell rung by a dying patient than by a patient expected to recover.¹² Isolation, suspicion and distrust develop owing to the lack of communication

between patients, family members, nurses and physicians. This is fostered by physicians' reluctance to inform the patient of the diagnosis and prognosis,⁶ a natural preference to treat disease rather than to deal with personal and social problems,⁶ and an endemic denial of death.^{6,13}

These deficiencies in our approach to the terminally ill were confirmed in a recent study of attitudes to dying at the Royal Victoria Hospital in Montreal.¹⁴ The data obtained indicated the patients' desire for complete openness and honesty in discussion of diagnosis and prognosis, the physicians' reluctance to be that candid, the residents' relative lack of concern for the patients' emotional needs, and the social workers' tendency to minimize the problem. The physician's attitude towards his own death was found to be an important variable in determining how he perceived his patients' needs: 84% of physicians who felt they would want to know their own prognosis if they were fatally ill thought that their patients also desired direct communication of prognosis, while only 45% of physicians not wanting to know their own prognosis thought their patients desired honesty of communication. One physician stated that he would not tell a patient that he had cancer unless he asked and that no patient had ever asked him; this tells us more about the physician's inability to hear what his patients are saying than about his patients' fears.

If terminal care is so poor, why is the problem not more generally recognized? The Royal Victoria Hospital study¹⁴ suggested two important factors that limit our perception. First, there is a general tendency to see ourselves

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as sensitive individuals and consequently we do not recognize our insensitivity to the needs of those around us. In each professional group the proportion who recognized deficiencies in the way in which their colleagues met the needs of the terminally ill was larger than the proportion who recognized that they themselves had deficiencies. Similarly, the proportion who felt that they personally avoided discussions with patients regarding dying was smaller than the proportion who felt that their colleagues avoided such discussions. Second, patients are reluctant to criticize those who care for them.^{7,14}

Why has this deficit in terminal care developed? The isolation and the lack of sensitivity, caring and expertise that these patients encounter cannot be explained on the basis of indifference of the medical team. There are other factors. As individuals we reflect the attitudes of our death-denying society.¹⁵ It is of utmost importance to recognize the misalignment between the needs of the terminally ill and the four goals of the general hospital: to investigate, to diagnose, to cure and to prolong life. As the rate of accumulating medical knowledge increases, so does the pressure on the medical team to concentrate its efforts in the direction of the four goals. The problem arises when we introduce into this general hospital environment patients for whom the hard-won expertise of the health care team is no longer appropriate. In the management of the dying, skills of investigating, diagnosing, curing and prolonging life are irrelevant. The appropriate goal is treatment aimed at producing the optimal quality of life for the patient and his family. The expertise of the staff and the needs of the patient are therefore mismatched. From the perspective of traditional hospital goals "nothing can be done" for the dying patient. Thus, the medical team feels impotent and may become angry or indifferent. Far from there being an absence of caring and concern, these very qualities often magnify the feelings of guilt and anxiety of members of the hospital staff. To cope with the situation the staff increasingly isolate the patient and family, and so the problem is reinforced.

With respect to malignant disease, there are three admissible goals: to cure, to prolong life and to palliate. Until now, interest, concern and financial resources have been applied towards improving the effectiveness of our action in curing patients and, if this is not possible, prolonging life. We must now seek ways to improve the lot of those for whom treatment aimed at improving the quality of life is the only appropriate goal.

The options

Given the significance of the problem and the economic constraints affecting the delivery of health care, we must consider our options carefully.¹⁶

To continue management of the dying as in the past

Having recognized the existing deficiencies and the potential for improving the lot of the terminally ill, we can no longer consider this a morally acceptable option.

To educate medical and paramedical teams concerning the problems of death and dying

More and more medical education programs are offering lectures and courses on death and dying. These measures, together with the increased coverage by the scientific press and by mass media, have increased our awareness of the needs of the terminally ill and their families. But much yet needs to be done. The basic problem remains: the difference between the needs of these patients and the aims of the acute treatment ward of a general hospital.

To develop separate institutions with special expertise in treating terminally ill patients

St. Christopher's Hospice and St. Joseph's Hospice, both in London, England, St. Luke's Hospice in Sheffield, England, Calvary Hospital in the Bronx, New York, and a number of other separate institutions have been established to provide improved care for the dying and their families.

The approach taken at St. Christopher's Hospice illustrates the operation of separate institutions. Founded 8 years ago, St. Christopher's Hospice is a caring community of 54 inpatient beds, with a domiciliary service, a day-care centre for the children of personnel, a number of bed-sitting rooms for the elderly and a vigorous research and teaching program. Most of the patients have advanced malignant disease or a progressing neurologic disorder. The common selection factor is the irrelevance of therapy attempting to modify the natural history of their diseases. Saunders and others¹⁷⁻²¹ have described the functioning of this remarkable institution. It provides a high standard of medical care, with close attention to detail in meeting the needs of the patient-family unit in all dimensions: medical, social, psychological and spiritual. Analysis of the economics of maintaining such institutions, however, suggests that society cannot afford to support an adequate number to meet the need.

To integrate within the general hospital a palliative care unit (PCU)

The PCU is a specialized unit within the general hospital, staffed by an interdisciplinary team and designed with goals aligned to the specific needs of the dying.

The results of the Royal Victoria Hospital study¹⁴ and an examination of related matters led to the recommendation that the Royal Victoria Hospital open a PCU as a 2-year pilot project. The aim of the project has been to establish the feasibility of a unit within the general hospital offering services similar to those provided by St. Christopher's Hospice. The premises^{7,16,17} on which this project is based are the following:

1. The medical, emotional and spiritual needs of the terminally ill and their families are, in general, neglected in the delivery of health care.

2. Suffering is greatly intensified by the isolation resulting from our present methods of dealing with the terminally ill.

3. The presence of terminally ill patients in a general hospital ward and the type of treatment they receive are demoralizing for the patient, his family, the ward staff and other patients.

4. Terminally ill patients must always be helped toward a positive outlook based on reality, confidence and trust, not dishonesty.

5. The health care system should support, facilitate and assist the terminally ill in their desire to be at home while that is feasible, and to die at home if that is possible.

6. It is important for the patient and his family not to be deserted by the hospital in which they have confidence.

7. A PCU would enable a general hospital to better meet the needs of the community it serves.

8. A highly motivated, trained team of nurses backed by physician, psychiatrist, social worker, physical and occupational therapists, dietitian, chaplain, music therapist, volunteers, receptionist and secretary can meet the multidimensional needs of the terminally ill and their families.

9. A PCU for the terminally ill may be effectively integrated into a general hospital.

10. It is possible for a PCU to provide a positive atmosphere of welcome and confidence rather than the negative one of "a home for the dying".

11. The challenges and rewards of PCU work are sufficient to sustain the nursing, physician and support staff involved in such work.

12. The PCU will allow observations regarding (a) the late effects of treatment; (b) the medical, social, psycho-

logical and spiritual needs of the terminally ill and their families; and (c) the means of meeting these needs.

13. With attention to detail and careful regulation of medication according to the patient's needs it is possible to achieve, with few exceptions, a pain-free state without excessive sedation, the medical management of bowel obstruction (without nasogastric tube, intravenous fluid and colostomy) and the satisfactory control of other symptoms.

14. It is possible for the period of terminal illness to be one of achievement, reconciliation and fulfilment for patient and family, facilitating the return of the family to a normal life after bereavement.

15. The supportive relationship with the family should be continued, when necessary, following the patient's death.

16. A PCU should be a monument not to the incurability of some disease but to the dignity of man.

The palliative care service

The palliative care service, opened in January 1975, comprises three areas of care as well as research, teaching and administrative functions: the PCU itself, a domiciliary service and a consultation service.

The PCU

The 12-bed unit is staffed by a multi-disciplinary team. Because of the size of the unit during the pilot project phase, the patient pool has been limited to Royal Victoria Hospital patients with malignant disease for whom care aimed at improving the quality of life is the only appropriate therapy. The "team approach" is emphasized in the quest for an improved quality of life. Family members are encouraged to participate in patient care. When necessary to meet the individual needs of

the patient-family unit, hospital regulations are relaxed to allow relatives to stay overnight and children — and even pets — to visit. Care is individualized. Blood pressure, pulse and temperature are not taken routinely. The only investigations and treatments performed are those directly related to the alleviation of problematic symptoms.

Family members particularly close to the patient are assessed prospectively for their risk of impairment of health and psychosocial adjustment. Minimum follow-up of relatives after the patient's death includes a visit with the bereaved at 2 and 4 weeks and a letter at 1 year. More extensive follow-up is available when indicated.

The domiciliary service

The domiciliary service, staffed by nurse practitioners, facilitates comprehensive home care, with emphasis again placed on the total needs of the patient and the family. Care includes controlling pain and symptoms as well as seeking a resolution of emotional, interpersonal, spiritual and financial difficulties. The domiciliary team works with available visiting nurses and persons from other community resources. Such support assists the patient in remaining at home as long as possible and, if feasible, dying at home.

The consultation service

The palliative-care-service physician and consultation nurse visit patients in other parts of the hospital for evaluation regarding PCU admission or domiciliary care. When these goals are not possible or advisable the patient may be followed on his original service by members of the PCU team.

Evaluation

We are currently evaluating the palliative care service to assess the impact

of this approach on the needs of the patients and their families and on the palliative-care-service staff itself.

Conclusion

The PCU has resulted less from the discovery of new techniques for treating the dying patient than from the assertion of a positive, creative attitude to death and bereavement. The changes in the health care system that such a unit embodies may have significant implications for the majority of Canadians — the 70% who will die in institutions.

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Care required by the dying in general practice

An opportunity to integrate medical care is presented in the care of the dying. This was the conclusion reached by Levy and Sclare (J R Coll Gen Pract 26: 303, 1976), who studied patterns of fatal illness in 58 patients in a Glasgow general practice. The main causes of death were malignant neoplasms (20 patients), cardiac disease (18) and respiratory disease (10). Approximately 50% died in hospital, and

of these patients one half were admitted for social rather than medical reasons: the patient was living alone or relatives were unable to care for the patient. Thus the hospital became a hospice; rest and accommodation, rather than the specialist services of a general hospital, were provided this latter group of patients.

The Glasgow study provoked several pertinent questions. In hospital who should be responsible for a patient's care? Should it be a consultant who

had previously looked after the patient, whether this be a surgeon, radiotherapist or geriatrician? Could a family practitioner assume responsibility for the care of such patients in hospital? Is an acute ward the best place for a dying patient?

The authors of this study suggest that "our society requires a broader range of facilities and more interested professional staff in the management and care of the terminally ill and their relatives".