

ASSUMPTIONS AND PRINCIPLES UNDERLYING STANDARDS FOR CARE OF THE TERMINALLY ILL

Introduction

There is agreement that patients with life-threatening illnesses, including progressive malignancies, need appropriate therapy and treatment throughout the course of illness. At one stage, therapy is directed toward assessment and intervention in order to control and/or to cure such illness and alleviate associated symptoms. For some persons, however, the time comes when cure and remission are beyond current medical expertise. It is then that the intervention must shift to what is now often termed "palliative treatment," which is designed to control pain in the broadest sense and provide personal support for patients and family during the terminal phase of illness. In general, palliative care requires limited use of apparatus and technology, extensive personal care, and an ordering of the physical and social environment to be therapeutic in itself.

There are, as it were, two complementary systems of treatment which may often overlap: One system is concerned with eliminating a curable disease and the other with relieving the symptoms resulting from the relentless progress of an incurable illness. There must be openness, interchange, and overlap between the two systems so that the patient receives continuous appropriate care. The patient should not be subjected to aggressive treatment that offers no hope of being effective in curing or controlling the disease and may only cause further distress. Obviously, the clinician must be on the alert for any shifts that may occur in the course of a terminal illness, which make the patient again a candidate for active treatment.

Patients suffer not only from inappropriate active care, but also from inept terminal care. This is well documented by studies that only confirm what dying patients and their families know at first hand.

These principles have been prepared as an aid to those who have initiated or are planning programs for the terminally ill in delineating standards of care.

GENERAL ASSUMPTIONS AND PRINCIPLES

Assumptions Principles 1. The care of the dying is a process involving needs of the patient, family, and caregivers. The interaction of these three groups of individuals must constantly be assessed with the aim being the best possible care of the patient. This cannot be accomplished, however, if the needs of the family and/or caregiver are negated. 2. The problems of the patient-family facing terminal illness include a wide variety of issues: psychological, legal, social, spiritual, economic, and interpersonal. Care requires collaboration of many disciplines working as an integrated clinical team, meeting for frequent discussions, and with commonness of purpose. 3. Dying tends to produce a feeling of isolation. All that counteracts unwanted isolation should be encouraged; social events and shared work, inclusive of all involved, should be arranged so that meaningful relations can be sustained and developed. 4. It has been the tradition to train caregivers not to become emotionally involved, but in terminal illness the patient and family need to experience the personal concern of those taking care of them. Profound involvement without loss of objectivity should be allowed and fostered, realizing this may present certain risks to the caregiver. 5. Health care services customarily lack coordination. The organization structure must provide links with existing health care professionals in the community. 6. A supportive physical environment contributes to the sense of well being of patients, of family, and of caregivers. The environment should provide adequate space, furnishings that put people at ease, the reassuring presence of personal belongings, and symbols of life cycles.

PATIENT-ORIENTED ASSUMPTIONS AND PRINCIPLES

AssumptionsPrinciples7. There are patients for whom aggressive curative treatment becomes increasingly inappropriate. These patients need highly competent professionals, skilled in terminal care.8. The symptoms of terminal disease can be controlled. The patient should be kept as symptom free as possible. Pain in all its aspects should be controlled. The patient must remain alert and comfortable. 9. Patients' needs may change over time. Staff must recognize that other services may have to be involved, but that continuity of care should be provided. 10. Care is most effective when the patient's lifestyle is maintained and life philosophy respected. The terminally ill patient's own framework of values, preferences, and life outlook must be taken into account in planning and conducting treatment. 11. Patients are often treated as if incapable of understanding or of making decisions. Patients' wishes for information about their condition should be respected. They should be allowed full participation in their care and a continuing sense of self-determination and self-control. 12. Dying patients often suffer through helplessness, weakness, isolation, and loneliness. The patient should have a sense of security and protection. Involvement of family and friends should be encouraged. 13. The varied problems and anxieties associated with terminal illness can occur at any time of day or night. Twenty-four hour care must be available seven days a week for the patient/family where and when it is needed.

FAMILY-ORIENTED ASSUMPTIONS AND PRINCIPLES

AssumptionsPrinciples14. Care is usually directed towards the patient. In terminal illness the family must be the unit of care. Help should be available to all those involved whether patient, relation, or friend to sustain communication and involvement. 15. The course of the terminal illness involves a series of clinical and personal decisions. Interchange between patient, family, and clinical team is essential to enable an informed decision to be made. 16. Many people do not know what the dying process involves. The family should be given time and opportunity to discuss all aspects of dying, death, and related emotional needs with the staff. 17. The patient and family need the opportunity for privacy and being together. The patient and family should have time alone and privacy both while the patient is living and after death occurs. A special space may need to be provided. 18. Complexity of treatment and time-consuming procedures can cause disruption for the patient/family. Procedures must be so arranged as not to interfere with adequate time for patient, family, and friends to be together. 19. Patients and families facing death frequently experience a search for the meaning of their lives, making the provision of spiritual support essential. The religious, philosophic, and emotional components of care are as essential as the medical, nursing, and social components and must be available as part of the team approach. 20. Survivors are at risk emotionally and physically during bereavement. The provision of appropriate care to survivors is the responsibility of the team that gave care and support to the deceased.

STAFF-ORIENTED ASSUMPTIONS AND PRINCIPLES

AssumptionsPrinciples21. The growing body of knowledge in symptom control, patient/family-centered care, and other aspects of the care of the terminally ill is now readily available. Institutions and organizations providing terminal care must orient and educate new staff and keep all staff informed about developments as they occur. 22. Good terminal care presupposes emotional investment on the part of the staff. Staff needs time and encouragement to develop and maintain relationships with patients and relatives. 23. Emotional commitment to good terminal care will often produce emotional exhaustion. Effective staff support systems must be readily available.

