



Planning Care for Non-Oncologic Terminal Illness in Advanced Age

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Key words: planning care, non-oncologic terminal illness, advanced age, continuity of treatment, end of life

Abstract

Due to the increase in longevity today, advanced illness in the elderly exists together with severe disability and often dementia that generally become less responsive to known treatment. This leads to repeated admissions to an internal ward in a general hospital, which results not only in a lack of treatment continuity but also in inappropriate management resulting in over- or under-treatment. Towards the end of their lives, the treatment problems of non-oncologic elderly patients with advanced diseases stem from a number of factors: multiple pathology, difficulty in predicting irreversibility, staff reluctance to discontinue active specific treatment and resort to palliative care only, and the lack of a framework to ensure continuity of treatment in the community or hospital. These advanced systemic illnesses are characterized by fluctuating exacerbations and remissions, making it very difficult to assess irreversibility. This article proposes the establishment of advanced centralized care planning, based on community care, the geriatric hospital and, in particular, a geriatric support unit within the skilled nursing department, catering holistically for the ongoing needs of the patient and his/her family and supplying a backup to the community care.

IMAJ 2005;7:5-8

For Editorial see page 39

In the United States and Western Europe the percentage of those aged over 65 is 12.4% and 14.6% respectively, and this figure is progressively increasing, with 3.2% and 3.9% of them respectively above the age of 90 [1]. In Israel, the percentage of people over 65 has increased to 10% during the past 20 years and, in those over 80, doubled from 1.2% in 1980 to 2.1% in 1998 [2].

In the management of chronic systemic illnesses such as end-stage diabetes mellitus, liver and renal failure, respiratory and heart failure, and degenerative brain disease, developments are such that the patient reaches the stage of multi-organ failure when the disease no longer responds to accepted medical treatment (e.g., infection, pulmonary congestion), and degenerative brain diseases. Thus, the pattern and management requirements of patients with non-oncologic diseases are changing, and their medical treatment in old age requires rethinking and new methods [3].

In this article we examine the clinical course of these patients

and the treatment needs of elderly patients with advanced non-oncologic illnesses towards the end of their lives – a period varying from a few weeks to almost a year. We focus on specific problems that have not received sufficient attention and propose a workable solution – namely, a geriatric support unit within the skilled nursing department, catering holistically for the ongoing needs of the patient and his/her family during acute phases, and providing a backup for the primary care team in the community during stable phases.

Only 20% of this elderly population dies as a result of malignant disease. In the last year of their life, and especially in the few months preceding their death, many of the old and very old suffer from increasing disability due to chronic disease, a high rate of comorbidity, and repeated acute episodes of one or another of their chronic illnesses, which include cardiovascular, cerebrovascular, chronic obstructive pulmonary disease, infection (pneumonia, influenza), and diabetes [4,5].

For patients with cancer, much attention is often given to the psychological and familial aspects that accompany the final process, and there is a central home or hospital treatment plan for palliative hospice care [6]. By contrast, for very old patients with serious non-oncologic illness there is often neither a centralized care plan nor a place for treatment during the final phase of these advanced illnesses. Particularly during the acute episodes, many of these patients are maintained in internal and surgical wards of general hospitals with staff who are unfamiliar to them, and this can cause them unnecessary discomfort and anxiety in the weeks and months preceding their death. The introduction of a centralized care plan would offer a new direction to an interdisciplinary team dealing with the medical, personal and psychological needs of patients and families during this difficult last stage.

The absence of directed care planning has been demonstrated in a research program carried out in five teaching hospitals in the USA, known as the SUPPORT study (Study to Understand the Prognosis and Preferences for Outcome and Risk of Treatment). This study of patients with terminal non-malignant diseases showed that 50% were suffering from untreated moderate to severe pain in the final 3 days of their lives, and only 41% of patients were talking to their physician about prognosis or cardiopulmonary resuscitation.

Physicians misunderstood patients' preferences regarding CPR in 80% of cases [7]. Lynn et al. [8] found that of the 50% of the study population who were conscious, 80% complained of fatigue, 40% of severe pain, and 50% of shortness of breath. In this group, 10% received treatment against their wishes (ventilator, feeding tube, or resuscitation). Seventeen percent of family members reported feeling abandoned during those final days. That survey paints a gloomy picture of hospitalized patients receiving insufficient treatment for the pain, feeling anxiety and discomfort, along with poor communication between them and the physicians.

Zerzan et al. [9] found that although 20% of deaths occur in nursing homes, in the final stages of the illness patients have limited access to palliative treatment and little help offered to their families. Recent studies by Sonnenblick and co-workers [10] conducted over 3 months in a hospital in Israel showed that 10% of all patients admitted to internal medical divisions during acute episodes (of these, in particular, the 23% admitted to geriatric departments) were documented as not designated for life-sustaining treatment ("do not resuscitate"). In these cases, only 30% of the families were involved in this decision, which was taken by the attending physician who usually had no prior knowledge of the patient before that hospitalization. The irony is that only 40% of these patients actually died during that admission [10]. Moreover, many of these patients undergo aggressive intensive care and diagnostic-therapeutic procedures, particularly during acute episodes. This often overshadows the treatment needs appropriate to the patient's situation and the palliative treatment for relief of symptoms such as pain and discomfort.

Care at the end of the elderly patient's life: what is lacking?

We are all familiar with the moment when a physician in an internal medicine ward, standing by the bed of an elderly patient with a serious illness, becomes resigned to the fact that nothing more can be done. It might be a patient of advanced age with end-stage cardiac failure who has undergone recurrent pulmonary edema, a patient with recurrent aspiration, or a patient with renal insufficiency and a history of severely advanced dementia or severely disabling cerebrovascular disease. Without a clear treatment goal, the medical team often lacks coping skills when the end is inevitable. They may make one of two choices: a) prescribe even more aggressive therapy, meaning an extended stay in intensive care and the use of advanced technologies (tubes, respirator, dialysis, etc.), or b) discharge the patient to his home or to a long-term nursing facility. Whatever course is taken the patient usually dies, but with insufficient attention given to his human and nursing needs, or to relieving the pain, distress and anxiety that he and his family are going through.

Differences between elderly oncologic and non-oncologic patients

Although this final stage may last from a few days to several months in both oncologic and non-oncologic patients, the latter, if elderly,

require considerations other than for those with terminal malignant disease in the following two areas [11]:

- In elderly patients these advanced systemic illnesses are characterized by fluctuating exacerbations and remissions. There is often an unknown time frame and the absence of a clear agreed-upon time as to when to stop treatment. In contrast to the above, the oncologic patient in the terminal stage usually exhibits a well-defined point at which he should be transferred from curative to palliative care. This stage is often characterized by the withholding or withdrawing of specific medical treatment such as chemotherapy when there is no hope for cure, arrest or temporary remission, and the patient's remaining days can often be predicted at a few days to about 3 months.
- For the elderly non-oncologic patient, it is not clear when to stop the multiple ongoing medical procedures, like blood analysis, medication such as antibiotics, diuretics and other aggressive treatment (tube feeding, infusion, etc). Specialists of a particular discipline, such as cardiologists, urologists and others, may continue to be consulted although their orientation may not be to the patient as a whole.

Problems in caring for the non-oncologic elderly

Treatment problems of non-oncologic elderly patients towards the end of their lives include [12]:

- Recurrent difficulties in communication between the medical team, the patient and the family, particularly in explaining the seriousness of the patient's situation.
- Unrealistic expectations on the part of the patient and his family that the doctor can change the course of the disease.
- Many physicians consider the death of their patient to be a failure of their treatment, with the result that more aggressive treatment is given to keep the patient alive. This attitude is typical of the western world where death is not accepted as part of life and extending life duration is thus a goal in itself.
- Difficulty in identifying the "point of no return" – the point at which it is agreed that the disease no longer responds to the treatment, and the aim of treatment changes from intensive care to basic stabilizing and palliative care only.

Methods of evaluating when the patient is reaching the 'point of no return' include [13]

- Frequent observations of basic vital signs (O₂ saturation, blood pressure, pulse, number of respirations, etc), mental state (vitality, cognition, mood and alertness), and monitoring of pain, discomfort and suffering.
- The medical history pattern over recent months or year: increase in mental and physical functional disability and dependency [Figure 1], the number of exacerbations of the illness and the non-efficacy of the treatment, the number of visits to emergency rooms and of hospitalizations, and the extent to which the disease is exhausting the patient.
- Deteriorating objective nutritional parameters (weight loss, low plasma level of albumin and cholesterol, anthropometric measures such as low muscle mass, and low total lymphocyte count), reflecting ongoing progress of the disease and worsening of the patient's condition.

CPR = cardiopulmonary resuscitation

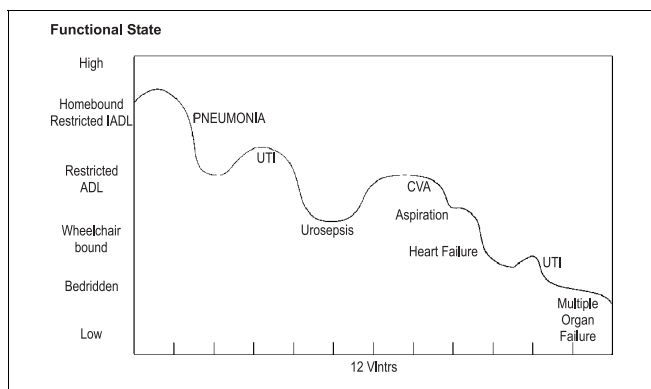


Figure 1. A course of progressive deterioration over a year. The bottom of each curve represents an acute event, such as pneumonia, urinary tract infection (UTI), sepsis, aspiration, cardiac failure, gastrointestinal bleeding, cerebrovascular accident (CVA), etc. ADL = activities of daily living, IADL = instrumental ADL.

Aims of treatment

There is currently no centralized plan for elderly patients whose illnesses are not oncologic. Therefore, our concept is to provide continuity, not episodic treatment during acute episodes, in a support care unit within the geriatric skilled nursing department. This unit could cater holistically for the ongoing needs of the patient and his/her family and reduce repeated admissions to an emergency room and internal ward in a general hospital. The aims of treatment are [14,15]:

- To provide medical help appropriate to the patient's situation and preferences, minimizing intensive care treatments if discomfort or risk caused by such treatment exceeds benefit derived, or affects survival.
- To relieve pain, anxiety, discomfort and agitation.
- To improve communication between the interdisciplinary team and the patient and his family.
- To treat the patient with respect, to observe his autonomy and ensure his privacy, without unnecessary movement or disturbance.
- To speak with the patient and/or family at an appropriate time about advanced directives, drawing up a living will, and consideration of the appointment of a proxy of the patient's own choice or a legal guardian.

Location of treatment

To achieve these aims, an appropriate framework needs to be found for accommodating non-oncologic patients towards the end of their lives. This idea has already been implemented in some countries [16–18]. Our argument is based on the situation in Israel where, since 1995, the entire population is insured under a National Health Insurance Law working through four health maintenance organizations (sick funds). Miller and Fins [19] identify the following existing options.

- *Home and community resources:* This would seem to be the ideal place for the patient toward the end of his life. The responsibility for care is placed on: a) the primary medical team from the local HMO clinic (family physician and nurse); b) the family whether

nuclear or extended; c) the community social worker from the local social welfare office, with resources (such as assistance to the caregiver at home and the possibility of attendance at a day care center – facilities that have been available since 1988 under Israel's National Insurance Nursing Law); and d) volunteer organizations and neighbors. Additional assistance in the form of physical therapy and occupational therapy can be obtained in every district through the HMO's Continuing Care Units. Additionally, supplemental medical and nursing care is available from one of the HMOs in the Jerusalem area, within the framework of home hospitalization [20] in an attempt to reduce or prevent hospitalization. Before deciding on such a program, the healthcare team must determine what strengths they can draw on from the patient's family, the family's expectations, willingness to help and their understanding of the patient's condition. It is important to consider the difficulties faced by a family in coping with all the patient's needs, and their fear and insecurity at taking responsibility, particularly during the patient's last days [21]. The primary medical team would share the responsibility with the patient and the family in critical decisions, especially regarding the possibility of the patient spending the final days at home.

- *Nursing departments in old-age homes:* In Israel, most of the patients in these institutions are long-term permanent residents who are wheelchair-bound, receiving nursing care and, where possible, restorative care but not hospice care. They are usually referred and reimbursed by the Ministry of Health, and there are long waiting lists for these places. They constitute 3% of the elderly population. These departments serve as the patient's home. If a patient deteriorates, develops frequent changes in his condition, or his illness becomes acute, these institutions may be unable to cope with these and other palliative needs and often transfer the patient to a general hospital, resulting in multiple admissions and discharges [9,22,23].
- *Skilled geriatric nursing facilities in geriatric hospitals:* These departments are set up to deal with serious advanced medical cases and with end-of-life patients. The criteria set by the HMOs for reimbursement are extensive pressure sores and/or nasogastric enteral feeding tubes. Recurrent terminal events are not, unfortunately, considered as warranting coverage by the HMOs.
- *Hospices:* Although these are specifically designed to deal with advanced (mainly oncologic) illness and focus on palliative treatment, the care they currently provide is not always geared to dealing with the type of fluctuating acute illness in old people as described above, such as infection or pulmonary congestion in those with a high level of co-morbidity and severe disability [24].

Proposal to establish a treatment policy and personnel training

We propose the establishment of a Support Care Unit within the Geriatric Skilled Nursing Department that will answer the non-oncologic patient's needs. Those skilled nursing departments are well attuned to the special philosophy in treating geriatric patients

HMO = health maintenance organization

with advanced and terminal diseases, about whom a decision has been made by the family physician, the family and the patient that his treatment should henceforth be solely palliative. The Support Care Unit will be informed by the family physician about such a patient on his discharge home from a general hospital after a severe acute exacerbation. The Unit can then serve as a backup and offer consultation with the family physician, which will also provide the family and the community care team with a feeling of security. If there is further (expected) deterioration, the patient can be referred directly to the Unit, where his history is known and where suitable palliative care would be given. Thus there would be continuity of services by the experienced geriatric staff of the skilled nursing department, by the family physician, and by nurses and community social workers in the context of home care.

The home care team, including the district social worker, nurse and caregiver together with the Unit's personnel, would be given appropriate training with regard to the medical and emotional needs of the patient and his family. This should include knowledge of the physiology and pathology of the aged, the relevant ethical and legal problems, and the extended process of deterioration.

Conclusions

There is no single solution that is appropriate for every patient and, in each case, consideration should be given to the patient's physical condition, his own wishes, and the willingness of the family to cope with the task of caring for him during the various stages of his illness. There must be awareness of the resources available in the community to support the emergency care process, the availability of medical care, and the backup of a geriatric nursing department.

From the start of the elderly patient's decline, a treatment policy must be formulated by an interdisciplinary team consisting of the family physician, nurses, social workers, physiotherapists and occupational therapists, together with the team of the Support Care Unit. Taylor and Ford [25] also note the role of the "case manager," whose task includes serving as the first point of contact for the patient and his family, coordinating treatment and calling on appropriate team members in line with the patient's needs.

Successful treatment does not necessarily mean an improvement in the patient's underlying diseases, but relief of the patient's suffering during the final months or weeks of his life. This does not imply the withdrawal of treatment but giving what is appropriate for the patient's symptomatic condition, with the aim of lessening the patient's suffering, reducing pain, and easing the discomfort and anxiety felt by the patient and his family [26].

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A drug is a substance which when injected into a guinea pig produces a scientific paper

Anonymous