

Giornate di Medicina di Base
Labin (Croazia) 2003

The Eubiosia Project: a New Dimension of Care for Advanced Cancer Patients

(Il progetto Eubiosia: una nuove dimensione dell'assistenza ai sofferenti di tumore in fase avanzatissima)

Franco Pannuti and Stephan Tanneberger

**Fondazione ANT Italia
Bologna**

mail: Prof. S. Tanneberger
Direzione ANT Italia
Via Curiel 7
40125 Bologna
ITALY
Phone:
e-mail: stephan.tanneberger@antitalia.org

1. Introduction

Cancer mortality for 2020 is estimated for the industrialized world as annually about 2.5 million people (25). There is not very much hope that this cancer burden can be reduced. However it can be expected that its composition will change drastically. Worldwide efforts in cancer research will reduce cancer mortality of people with age less than seventy but in parallel the cancer mortality of older people will increase. Simply, by the increasing age of the population and by more efficient treatment of young and middle age patients resulting in longer survival. The death from cancer, more and more, will be the normal biological end of life. Life is not endless (23) .

The consequence of this outlook is the need to reconsider the targets of oncology and of the actual cancer research. During the last decades oncology focused mainly on cancer treatment. Influenced by the pharmaceutical industry chemotherapy is booming. In radiotherapy more sophisticated techniques were developed improving treatment tolerance but not survival. Oncology is in the golden age of genetics and molecular biology. Small progress was achieved. Recent statistics show for countries with well-developed cancer control a decrease of about 5-10% in the overall cancer mortality. However, the new question is: How good we are prepared to guarantee dignity of life for the rapid increasing number of old and very old cancer patients in the moment of their non avoidable death. *The 21st century needs a different strategy in oncology: more prevention to save life of young people and more palliative care to save dignity of life for all those dying from cancer as the normal end of life* (22).

For long time palliative care was underestimated (1). Under public pressure and thanks to several engaged initiatives it becomes more and more an accepted part of medicine and nursing which concentrates on symptomatic care of patients (23). National and international societies for palliative care has been founded. Based on the first steps of Cecile Saunders, in most European countries hospice movement is engaged working (13). Now it is well understood that strategies to improve the dignity of life of cancer patients are becoming increasingly important as medical advances provide hope for longer survival and people become older. On the other hand, the cost-explosion in health care affects our strategies and because demand on health care systems often goes beyond their capacity, health care providers are more and more engaged in convincing oncologists to use more rational and less cost-intensive technologies in cancer management. Palliative care has numerous aspects. Some of the most critical points are: where we should provide patients with palliative care, how we should do and finally, what is the best place for patients ending their life if it is terminated by incurable cancer?

The results achieved with advanced home care technologies will help to deal with these problems. For cancer patients, in particular, home care technologies have special importance (10). These experience a basic struggle. They want to receive all the care they can get, which public opinion leads them to believe is only available in cancer hospitals, but on the other hand, they want to stay at home with their families and feel stressed by these two options. These facts were recognized in Italy early. ANT (Associazione Nazionale Tumori , founded 1978, since 2003 Fondazione ANT Italia) have started more than twenty years ago a hospital-at-home programme within the Bologna Eubiosia Project (5,7).

2. The Bologna Eubiosia Project

2.1. Background

Developing care policies has always to start looking on patients needs. Never commercial, political or other interests should play a major role. Analysing the situation of advanced cancer patients we

have recognized already 25 years ago numerous unmet needs. There is much physical and psychical suffering of this patients. Uncontrolled pain, anorexia, tumour ulceration has been seen in a high percentage of patients. The responsibility of our society for the end of peoples life is underdeveloped. End of life is "unpopular" in a consumption oriented society and political will to concentrate more resources and power on the old and oldest generation is weak (9, 23). As the result, the society more and more has difficulties to control this problem in proper way. The rapid spreading of Euthanasia is typically for this situation (14). At present in the Netherlands are dying year by year about 4500 patients by lethal injections (3.5% of overall mortality). Belgium and other countries are going to legalize Euthanasia. In particular in greater cities terminal patients are often abandoned. More than 60 % of patients like to die in dignity at home but only 30% find their end of life at home. Late minute admission is the rule .

To counteract the described development and to meet advanced cancer patients needs better, the Fondazione ANT Italia follows a very simple concept called EUBIOSIA, in contrast with the idea of euthanasia (6,8,11). Eubiosia (from Greece eu= good; bios=life) is defined as the sum of qualities which give life dignity (9). The concept has four cornerstones: (a) Eubiosia is a basic human right for all (b) the language of Eubiosia is the example (c) we can always do something against suffering (d) everybody is welcome to support the concept, independently of religious or political positions.

2.2. Results

Following the principle of Eubiosia, ANT started in the early 1980's a programme of free of charge medical and social home assistance for terminal cancer patients. This programme is now supported by 250 000 – 300 000 members and sympathizers. Up to 31/12/02, a total of 39 298 patients have been treated in the ANT Hospital- at-Home Programme operating in several parts of Italy. That means an overall total of 6 114 629 days of assistance. The present programme employs 111 physicians (including 17 specialists in oncology), 9 medical psychologists, 49 nurses, 3 physiotherapists and 17 consultants. The technical administrative staff consists of 43 people. The programme works on the basis of grants and donations, voluntary activities, though some support is provided by contracts with several Italian municipalities.

The Bologna Hospital-at-Home (BHH) is the flagship of the programme. The BHH works closely together with the *general practitioners* who sometimes delegate most of their responsibilities to the BHH staff and sometimes prefer team work. The BHH operates as an independent medical institution but it is professionally related with the local health service and several Bologna hospital divisions like the Department of Medical Oncology, Azienda Ospedaliera Sant'Orsola Malpighi. Drugs are paid through national health insurance. All other services of the program are financed with funds collected by ANT. The full-time staff doctors, nurses and psychologists of the BHH are *organized* in functionally autonomous groups on the model of a hospital ward, each directed by a senior physician. The head nurse and the sanitary director guarantee coordination between the wards and the individual home services. The home visits are carried out 1-2 times weekly but even more frequent in case of needs. Regarded as respect for patients, a special program of "*quality control*" substitutes the various quality control mechanisms in a traditional hospital. It follows the opinion that self-control goes for outside-control (20). The continuous *training* of the doctors and nurses includes individual and group training. ANT has as permanent education programme with monthly seminars and 2-3 monothematic meetings a year. All integrated in the States Programme for doctors and nurses education in Italy (ECM).

Clinical examinations, regularly performed at the patient's home are blood tests, ultrasounds, radiological and cardiographic examinations. From 01/12/85 – 31/12/2002 altogether 14 412 US examinations, 5800 X-ray examinations and 6 258 ECG were realized at home. Professional

psychologists assist patients in all problems of their living circumstances and support them in coping their suffering. Family members are included in the psychological service. Moreover psychologists are available even for the care-giving staff in case of needs. *Treatment* includes all types of oral cancer chemotherapy, pain relief, parenteral /enteral nutrition and blood transfusions as well. Some *special services* are directed to specific problems of specialized home care. These include:

- the "door-to-door" service, which consists in transporting the patients free of charge from their home to and from the hospital (243 741 km for 20 105 patients until now);
- round-the-clock emergency telephone and doctors visit assistance,
- the "kit-comfort" in which the patients are given, free of charge, a phone and a television at their bedside and, by request, hospital style beds, bedsores mattresses, respirators etc. (17 434 supplies up to now)
- and " meals at home" service (7 754 supplies up to now)
- the "social aid" service providing patients with social assistance including economical help for families in case of need.

Quality of assistance of patients admitted to the BHH was studied following the principles of Knowelden's evaluation of the Peterborough hospital-at-home scheme (4). Data collection was made by means of patient's clinical history and an interview conducted by the care-providing team six weeks after admission. Data included patient's characteristics, quantity of diagnostic and therapeutic measures, circumstances of life, satisfaction with the care received and intention for transfer to the alternative setting of nursing. In the study including 98 patients it was shown that the setting of assistance did not influence the provision of services. The frequency of contacts with the staff (17.5 per months) was high. The time of "talking to the doctor" (30 minutes in average per visite) was notably longer for BHH patients than in traditional hospitals. Concerning life circumstances dissatisfaction with meal provision and sleeping was expressed less often than in a traditional hospital. Quality of life was evaluated in average with 60% in a "100% good to worse scale". 90% of patients assessed care quality as good and only 6% of patients of BHH patients expressed interest for transfer to the alternative in-bed setting. Our study showed that delivery of services was not different for both a traditional hospital and the BHH. Moreover our assessment of several parameters of patient's quality of life favours the hospital at home model and indicates that this approach increases the dignity of patient's life considerably (21).

2.3. Costs

Evidence on the cost of cancer therapy is scarce and the lack of meaningful economic information about routine oncology treatment limits the debate often to opinions without facts. Available estimates made on the cost per course for specific cancer sites and for in-patient or out-patient settings favour therapy at home as being less costly and with advantages for patients' quality of life. Home care for cancer patients is additionally supported because several authors underline that costs for each patient's drugs are relatively low compared to the costs of in-patient care. However, reported results are often very approximate and give only a rough idea of the real costs. Our analysis was performed as a cost analysis considering several periods of time. Included were *direct and indirect costs*, no intangible costs have been found. The patient's perspective was selected for the analysis. *Average family costs* were assessed by interviews with 50 families who registered costs for several months. *Car costs* are based on the average number of visits per day.

Costs were analysed for altogether 802 patients admitted to the BHH between 1992 and 1998. In the first study the mean age was 67.9 +/- 2.9*(range 25-89) years, the performance status 45+/- 5% (range 20-90%). 63% of all patients reported pain or were suffering from anorexia. Patients were assisted in average 73.5 (range 3-90) days. In a second study only patients with intensive

assistance (performance status < 30%) were included. Patients, falling into this category, were assisted in average 120 days (range 3-150). The median daily costs of care were in the same order in 1993/94 (40,31 US\$) as in 1999 (46.37 US \$). Because intensity of care was higher in 1999, costs were slightly increasing. Moreover the BHH at the end of the 1990's was covering the "self-to pay" part of patient's drug cost (in Italy as in other countries several drugs are not full-paid by state/ health insurance). Cost-increasing was even the improved staff-patient-communication by portable phones and of rate of the inflation of about 3-4%.

Considering the well-known costs of hospitals in Europe (2,3) and particularly in Italy make highly probable that the BHH costs are lower than costs in traditional hospitals. In Germany in the study period daily hospital costs were calculated as 160 US\$ in average. In Italy costs are about 10% less. However two facts have to be underlined. In our study family costs were about 10 US \$ a day This means home care means even cost transfer from the States budget to the family budget. This fact should create a sense of partnership with care-giving families (17,18). Moreover it is certainly correct to keep in mind what was expressed by WHO. Home care can save money but only if the introduction of home technologies is accompanied by reduction of hospital beds (16). *Therefore we believe, calls for more home care should not be motivated with economical considerations but first of all by ethical arguments. Probably, patients care at home cost less, but surely patients have more dignity at home.*

2.3. Bioethical problems

Communication with the cancer patient and the problem of *information and truth* is one of the most discussed problems in medical ethics during the last decades. Noticeable are different positions between USA /Northern Europe and the European South. Discussions in this field often are very emotionally and in many cases the moral, religious or political positions of the partners in discussion determine the conclusions more than the understanding of patient's needs. These are much less good defined than the legal and professional rules for information and truth.

The Hospital-at-Home Programme of the Foundation ANT Italia (ANT) gave the chance to add facts to this discussion on a large scale. Obviously the strategy of ANT for patients communication works well. This strategy is simple. ANT is respecting the legal patient's right for truth in case of any request, but ANT is even respecting the moral patient's right for non-truth in case, she/he is not requesting the diagnosis .

Data from 4224 patients were collected, all treated in the programme during the last decade. Half of patients was informed. There was no statistical difference between man and women. The mean age of informed patients was slightly lower than this of non-informed patients. Partial information was characteristically for the category of very old patients (mean age 77 years). Data underline that actually in Italy the current approach of patients communication may be placed somewhere between the paternalistic view of the past and the modern trend which considers patients as autonomous individuals. *We conclude from this dates that any over-regulation in this field is opposite to patients needs. Important for end of life care is confidence and professionalism. Any schematism is negative. End of life care needs flexibility and adaptation to patients needs: Important is only one fact. Dignity of life until the last minute, what we call Eubiosia (12).*

An other field where ANT contributed to the international discussion on end of life care was the *assessment of the individual life expectancy*. Without doubt there are difficulties estimating the duration of life for patients with end of life cancer. These difficulties can become ethical dilemmas when physicians referring patients to hospice programmes are obliged to predict accurately a patient's prognosis. Moreover, these difficulties can create uncertainty that affect day-to-day patient

management in palliative care programmes including physician concern regarding the use of high dose morphine, enteral or nutritional support, and/or providing parenteral fluids during the terminal phase of illness. The available data concerning the accuracy of the clinical estimation of the duration of patient's life and the ethical dilemma are scarce. 20 – 25% correct predictions are reported. Authors noted a tendency to overestimate survival. As an alternative, various prognostic indices, scales and score models were proposed. These are certainly applicable for patients treated in specialized institutions. Nevertheless, for the majority of patients, subjective prognostic predictions of the care-giving staff will remain the daily practice. In exploring whether higher qualification will decrease errors in doctor's prognoses in terminally ill patients, we have already initiated in 1999 a study on accuracy of the clinical estimation of the duration of life for patients with end of life cancer. In contrast to the studies reported by others, the participating doctors had a high degree of experience in end of life care.

Altogether 8 doctors participated at the study completing a questionnaire at the first consultation. In the questionnaire they had to classify patients in one of five survival categories (0-2 weeks; 2-4 weeks, 4-9 weeks; 9-17 weeks; >17 weeks) and to indicate one or more of 13 easily assessable criteria for decision making. Doctors had a median duration of medical practice of 14 years and were all board certified. Half were specialized in oncology and all were full-time working in home care for end of life cancer patients for a medium duration of 9.5 years. Two-hundred and sixty nine patients (median age 74 years; mean age 72 years with range 34 – 96 years) were included in the study. Median survival of patients was 9.6 weeks (95% CI 8-10.7 weeks) and mean survival 23.5 weeks (range 0 – 484 weeks). In 33% of the patients the prediction was correct. Thirty nine percent survived less than estimated and 28% longer. Data show that long-term experience can improve the accuracy of the clinical estimation of the duration of patient's life. However, data also underline the difficulties of prognosis in advanced cancer even for doctors well trained in end of life care. We conclude from this study that clinical estimation of the duration of life for patients with end of life cancer needs experience and training. Prognosis should be based more on proven indices and less on intuition. However, there is no doubt that daily clinical practice limits the use of highly sophisticated computer-based score models. *Even maximal accuracy of prognosis will not exclude the risk of errors in a great part of patients. Therefore health care systems should avoid models for care with standards and budgets based on prognostic estimates (15,16)*

3. Conclusions

Home care in the last decade achieved more and more attention. WHO noticed in a policy statement: Patients should be able to receive palliative care in their own homes, should they wish (24). Certainly this is correct. As we discussed above the changing demographic situation and the changing needs and expectations of chronically ill patients create a new situation for health care in the 21st century.

To meet this challenge new dimensions for end of life care are requested. There is urgent need for models which meet patients requirements better than the present practise. These models has to be financed by the States budgets but volunteers initiatives in this field are essential. Dignity of life for all is a challenge to all of us. The idea of Eubiosia invites everybody to give his contribution.

The Bologna hospital at Home programme provides evidence that creative initiatives and their consequent realization can overcome urgent problems of our civilisation.

Literature:

1. ASCO Task Force. Cancer care during the Last Phase of Life. J. Clin. Oncol. 16(5), 1986-1996, 1998.
2. Editorial: Das kostet ein Tag im Krankenhaus. Durchschnittliche Pflegesätze 1996. Dtsches Aerzteblatt, 94 (20), C-975, 1997.
3. Editorial: Die Kosten-Brocken im Krankenhaus. Versicherungsmedizin, 48 (5), 174, 1996.
4. Knowelden J., Westlake L., Wright K., et al.: Peterborough Hospital at Home: an evaluation. J. Public Health Med., 13, 182-188, 1991.
5. Pannuti F.: Home Care for advanced and very advanced cancer patients: The Bologna experience. J. Pall. Care, 4, 54-57, 1988.
6. Pannuti F.: Pensieri in libertà 199+1, Aulo Gaggi Editore, Bologna, 1989.
7. Pannuti F., Tanneberger St.: The Bologna Eubiosia Project: Hospital at Home Care for Advanced Cancer Patients. J. Pall. Care, 8, 11-17, 1992.
8. Pannuti F., Tanneberger St., Farabegoli G.: Eubiosia instead Euthanasia for cancer patients: illusion, hope or human right XVI International Cancer Congress, New Delhi, 1994.
9. Pannuti F., Tanneberger St.: Dying with dignity: Illusion, hope or human right? World Health Forum, 14, 172-173, 1993.
10. Pannuti F, Tanneberger S, Zamagni C. Ospedalizzazione domiciliare: prospettive per una maggiore dignità di vita dei pazienti con cancro in fase avanzata. Eur. J. Oncol. 4, 43-55, 1999
11. Pannuti F.: Il progetto Eubiosia. Edizione La Formica, Bologna, 1995.
12. Pannuti F, Strocchi E, Tanneberger S. Should patients be told they have cancer: a view of the actual Italian reality Eur. J. Oncol. 2002; 7 (4): 309-310.
13. Saunders C.: Terminal care in medical oncology. In: Bagshaw K.D. (ed) Medical Oncology. 563-576, Blackwell, Oxford 1976.
14. Tanneberger S. Euthanasie - Ausdruck menschlicher Freiheit oder Unvermögen Menschenwürde zu garantieren. Z. ärztl. Fortbildung 87, 927-932, 1993.
15. Tanneberger S, Malavasi I, Mariano P et al. Planning palliative or terminal care: the dilemma of doctors' prognoses in terminally ill cancer patients. Ann. Oncol. 2002; 13: 1320-1322.
16. Tanneberger S, Pannuti F, Malavasi I et al. New challenges and old problems: end of life care and the dilemma of prognostic accuracy. Advances in Gerontology 2002; 10:131-135
17. Tanneberger S., Pannuti F., Houts P., et al.: Jemand in meiner Familie hat Krebs. Was kann ich tun? W. Zuckschwerdt Verlag. München-Bern-Wien-New York, 1995.

18. Tanneberger S, Pannuti F, Houts P et al. RAK. Sta mogu da ucinim. 2001; visio mundi academic press, Novy Sad (Yu)
19. Tanneberger St., Pannuti F.: Home care for cancer patients in developing countries. World Health Forum. 17, 400-401, 1996.
20. Tanneberger St., Pannuti F.: Quality control in oncology: Five year experience of the ANT-Hospital-at-Home, Bologna. Gli Ospedali della Vita, 25, 33-40, 1998.
21. Tanneberger St., Pannuti F., Mirri R. et al.: Hospital-at-home care for advanced cancer patients within the framework of the Bologna Eubiosia Project: an evaluation. Tumori, 84, 376-382, 1998.
22. Tanneberger S, Pannuti F.: New Challenges for oncology after the year 2000. 1. International Oncological Meeting at Val Gardena, Italy. Cancer Strategy 2, 2-6, 2000.
23. Tanneberger S, Pannuti F. Krebs im Endstadium. 2001; Zuckschwerdt Verlag Muenchen-Bern-Wien-New York
24. WHO: Palliative Cancer Care. Policy statement based on the recommendations of a WHO consultation, Leeds 10-11. February 1987. WHO Regional Office for Europe, Copenhagen 1989.
25. The World Health Report 1998. World health Organization, Geneva.