

Home care for advanced cancer: results and challenges

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SUMMARY

The majority of palliative care patients prefer home care and 70% of terminal cancer patients want to die at home. Only a well-organized network of specialized oncology, home care and hospices/palliative care units can guarantee the fundamental human right of advanced cancer patients to live and die with dignity, what we call Eubiosia. We consider the Bologna Eubiosia Project initiated by ANT in 1985 and supported by numerous political, religious and private bodies independent from their political color, as an example of successful fighting against human suffering. However, there is no doubt that Eubiosia has to be realized at the beginning of the 21st century in a way, different from the one of 30 years ago. Globalization and demographic changes create needs for new approaches. Telecare is a reasonable approach to overcome existing problems. ANT has started the first steps to preserve our moral values in a rapid developing world by using new highly sophisticated health technologies. We believe that Techno-Eubiosia is a new challenge for caregivers and for the producers of medical devices in the 21st century.

KEY WORDS: Neoplasms; Palliative Care; Home Care Services; Quality of Life

INTRODUCTION

In spite of many hopes and some illusions, the cancer problem is far from being „solved“. Global data show that cancer mortality in the world is increasing (1). In the developing countries, cancer is one of the great challenges for health in this century (2). The WHO predicts that by 2020 there will be about 10 million cancer deaths, of which 7-8 million will be accounted for by the developing countries, while the figure for the industrialized countries will remain unchanged at 2-3 million. On the positive side, there will be a slight decrease of cancer mortality of younger people in the industrialized world, but this will be offset by the growing size of the aged population with a high incidence rate of cancer in the post 75 year- old group. On average across OECD countries, life expectancy at birth for the whole population reached 79.1 years in 2007, a full ten years longer than in 1960 (3). In 2025, while 20-25% of the population will be older than 65 years, 50-60% of those dying of cancer will be older than 75. Palliative care is the most urgent and most rapid way to less suffering from cancer, both for the developing countries as long as curative strategies are underdeveloped and for the industrialized world with many incurable patients at the biological end of life. It would be wrong to ignore these facts and palliative oncology has been developing rapidly during these last 20 years. Palliative care is often supported by volunteers and volunteer organizations. This is an enormous contribution to dignity of patient's life and deserves respect of medical professionals and health administrators.

Where is the best place for palliative care in advanced cancer?

The answer to this question is simple. The best place is the place that offers the best quality of life to the patient. Palliative care was first developed in the in-patient hospice setting. However, the principles of palliative care were quickly adapted to the care of terminally ill patients at home. Within two years of opening, St Christopher Hospice developed the first specialist home-care service (4). Quality of life, for about 70% of advanced cancer patients, is to be treated at home and to die there. We can offer support by bringing palliative care to the patient and not the patient to palliative care.

The most simple approach for home care is treating patients in a **day-hospital** including admission of the patient to the hospital in case of emergency or inability for visiting the day-hospital. There is no doubt that often there is no other choice. Nevertheless, transportation, sitting in the waiting room and usually the superficial contact with an overworked staff, reduces care quality considerably.

The **hospital/hospice-at-home** approach assures much better comfort and dignity of life during the advanced and terminal phases of a neoplastic disease. Hospital-at-home means that a professional, full-time palliative care team brings to patient's home all that is necessary and available in a traditional hospital in order to ensure good palliative care. A hospital-at-home service should be multidisciplinary and ideally a 24 hour service. Patients are visited at home, if required, every day and are in constant contact over the phone. This approach was initiated in the 1970's (5,6) and is actually strongly supported particularly for geriatric (7) and oncological patients (8). In case of cancer it has the advantage of starting care of the patient at an early phase of disease progression and can offer outpatient-chemotherapy if necessary. Moreover, interventions like ultrasound at home, x-ray at home, blood transfusion and home artificial nutrition are available. The hospital-at-home has qualified and specialized staff that is trained in palliative care.

In case the hospital-at-home approach is not possible, palliative home care for advanced cancer patients can be realized by a **general practitioner (GP)** with special education in palliative care and enough time to practice this training. What is essential is close collaboration among the GP, the medical oncologist, the pain specialist or the day-hospital. This can extend to the local network of social assistance and palliative nursing at home which will help to further guarantee patient's dignity of life. Partnership and a spirit of collaboration between the different components of this multidisciplinary approach is essential. This approach can pose a challenge to the local health authorities bogged down by bureaucracy. Unfortunately in some countries as Germany, there is insufficient support for GPs to take over the responsibility for palliative care (9). A positive example is Italy where the University of Bologna organized a 2-years master course in palliative care for GPs of Northern Italy (10).

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When the patient does not wish to stay at home or there is no caregiver available to nurse her or him at home, admission in a **palliative care unit or in a hospice** can be an alternative. While hospice care remains an ideal model of care for cancer patients with terminal disease, many obstacles are present in the clinical setting that impede or prevent the otherwise appropriate referral of patients eligible for this type of end of life care. Some of these are: a limited number of beds, high costs, issues surrounding prognosis determination and communication, reimbursement, etc. Costs can be reduced combining hospice care with an outpatient service (hospice-at-home). This model represents a great advantage for patients. The same doctor takes care for patients during the outpatient and the inpatient phases of terminal assistance.

The decision, which of these options is used in a single case, is influenced by **economical considerations** of families, care providing doctors and health insurances. The cost explosion in health care affects our strategies and because the demand on health care systems often goes beyond their capacity, health care providers are more and more engaged in convincing patients and families to use more rational and less-cost intensive technologies in cancer management. Evidence on the cost of cancer therapy is scarce and the lack of meaningful economic information about routine oncology treatment limits the debate to opinions without facts (11). Recently Frick et al. estimated cost for hospital-at-home care as about 20% less than the cost of a traditional hospital (12). However, home care will never be a magic solution for public health systems in crisis. Moreover, adequate financial support has to be organized for families. Otherwise, home care means an unfair transfer of care costs from the state's health care budget to the family's pocket. Therefore, although the economic advantage of home care certainly is important, we would like to stress that quality and dignity of life should be underlined supporting the idea of home care. A much better argument is that most advanced cancer patients prefer to be and to die at home. However, only a minority of these patients will actually achieve their choice.

The question remains: Who makes **the final decision about the place of palliative care**? As we can see, there are different approaches for palliative care and for dying with dignity. We believe that a free and personal decision of the patients about the circumstances of their dying is of fundamental importance. If a patient prefers to die in hospital he should receive our support to find an adequate place there; but if he expresses the wish to stay at home it is then our task to assist him at home, together with or without his family. This was and is the message of the Bologna oncology.

More than 30 years ANT experience with hospital/hospice-at home

The message of Bologna is very simple. As long as cure is not possible, we have to consider as the most fundamental right of cancer patients the right to die in dignity, what we call Eubiosia. At least this right should be guaranteed for everybody. The idea of the Bologna Eubiosia Project was born in 1985 (6,13). Literally, Eubiosia means simply good life, but we would like to define Eubiosia more comprehensively, i.e. as "set of qualities that gives life dignity." The term Eubiosia was chosen to counteract the triumphant march towards euthanasia in Europe. We consider euthanasia to be the expression of the medical and social inability to realize a basic human right, a death in peace and dignity as the harmonious end of biological

life (14). It was reported that loss of dignity (50-60%) and pain (40-50%) are the main arguments for requests for euthanasia (15). The history of the "Bologna Eubiosia Project" seems to be an example how both can be mastered. Maybe this could encourage others to follow our philosophy and to overcome the lack of resources for health care present in all countries. The Eubiosia Project started under the aegis of the Associazione Nazionale per lo Studio e la Cura dei Tumori Solidi (ANT), an Italian non-governmental organization founded in 1985. This organization worked based on voluntary activities, grants and donations, though some support was also provided by contracts with several Italian communities. The scientific center of the organization was the Division of Medical Oncology, Ospedale Sant'Orsola Malpighi, in Bologna. Twenty-five years after the start of the Bologna Eubiosia Project, it is supported by 250-300 000 members and sympathizers. At present it is carried out by a professional staff of 334 medical doctors, psychologists, nurses, technicians, pharmacists, and clerks. The staff is working in 20 hospitals/hospices-at-home in all parts of Italy, daily assuring 3243 advanced cancer patients their dignity of life (16). Only 12%-18% of the annual budget of 6-7 million Euros is covered by the Italian Health Service, the remaining is covered by private donations derived from the enormous activity of thousands of fund-raising volunteers. The organization expanded quickly and in 2002, it was transformed into a Foundation (ANT Foundation) to strengthen the achievement of the final goal, an ANT Institute gathering all activities of the Foundation under one roof. The "Institute for Oncological Sciences, Solidarity and Volunteer Service" was inaugurated in August 2005.

An organization collecting each year millions of Euros and taking care of more than 3000 terminal cancer patients a day needs simple rules, well understandable to everybody. We have defined these rules early at the beginning of the ANT history as the following **Decalogue**:

1. CONSIDER LIFE A SACRED AND INVOLABLE VALUE, ALWAYS
2. CONSIDER EUBIOSIA (A-GOOD-LIFE, A DIGNIFIED LIFE) A PRIMARY GOAL TO BE CONQUERED DAILY
3. ACCEPT NATURAL DEATH AS NATURAL CONCLUSION TO EUBIOSIA
4. CONSIDER EVERY STEP OF ILLNESS REVERSIBLE
5. FIGHT SUFFERING (PHYSICAL, MORAL AND SOCIAL), YOUR OWN SUFFERING AND OTHERS', IN EVERY POSSIBLE WAY AND WITH THE SAME ENGAGEMENT
6. CONSIDER EVERYBODY AS YOUR BROTHER OR SISTER
7. THE SUFFERER NEEDS YOUR UNDERSTANDING AND YOUR SOLIDARITY, NOT YOUR PITY
8. AVOID EXCESSES, ALWAYS
9. GIVE YOUR HELP TO THE SUFFERER'S FAMILY, ALSO "AFTERWARDS"
10. YOUR HELP IS ALWAYS IMPORTANT AND REMEMBER: OUR LOT WOULD BE NOTHING WITHOUT LITTLE FROM MANY!

The results of the Bologna Eubiosia Program show that a non-profit organization can help impressively to overcome problems in health care. During 25 years of activity, 75,071 patients were treated, i.e. there were 12 098 562 days of assistance. On average, patients were assisted 113 days. In 2009, 5,735 new patients entered the care program. The mean age of the treated patients was over 75 years with increasing tendency. Of all deceased patients, 80% died at home. In the meanwhile, we have tried to transfer our hospital-at-home experience to Albania and India through

pilot projects. We feel that the cost-effectiveness of the Bologna Eubiosia program could be useful for further dissemination of the approach in other countries (17,18). A careful evaluation of the costs for the ANT Bologna hospital-at-home for 802 advanced cancer patients treated in the period 1992–1998 showed a mean value of 38.76 € a day per patient. Home chemotherapy costs were on average 26% less than in hospital while non-chemotherapy, palliative care was significantly (65%) lower at home vs. in-hospital care (19).

We consider the Bologna Eubiosia Project a useful contribution to worldwide anticancer activities. It is an example to be achieved in fighting human suffering. The Eubiosia program supported by political, religious, and private bodies independent from their political color, seems to be a reasonable approach to the moral aims of our civilization as defined 2000 years ago but not as yet achieved. Oncologists can make significant contribution to overcoming this historical challenge, and will be motivated by the enormous and sometimes unnecessary suffering of millions of cancer patients.

Future problems of home care

Adequate home care needs a 24-hours service at home. The care-giving staff can be the family or a professional caregiver (full-time home nurse/professional home assistance service). However, the demographic change in the industrialized world and globalization of the jobs destroy the traditional family nucleus. For OECD countries, the share of the population aged 65 or more increased between 1960 and 2007 from 9.0% to 14.7% and in contrast, the fertility rate decreased from 3.2 to 1.6 children per women aged 15-49 (3). Therefore, many families feel unable to provide their relatives an adequate assistance. Moreover, much assistance for cancer patients is delivered at home by informal caregivers, often without adequate training, with limited resources and high additional demand (20).

The problem of a professional home assistance is the price. Nowadays, adequate service costs are between 1000-2000 Euros a month, which is unacceptable for majority of patients. The problem is reduced in part by an army of foreigners coming as caregivers from the poor countries to the rich ones. The number of international migrants in the world rose from 75 million in 1965 to 191 million in 2006. Net international migration contributed 45% of the overall population growth in the developed world for 1990-1995 (21,22). However, this creates a world of mobility and suffering for many of the caregivers living for years far from their families and friends in a strange cultural environment. The second pre-condition for qualified home assistance is the availability of physicians for doing the job including numerous home visits a day. The problems cannot be overseen. Payment for medical service at patients home is far from the payment of in-bed services and the job is hard with many hours of car-driving a day (9).

In summary, care at home is at risk in the world with rapidly growing number of palliative care patients and we are far from the realization of an end of life in dignity at home. Nevertheless, solutions are possible.

The revolution in communication and medical care: telemedicine, data banks

Enormous development of computer technologies during 1960-1970 influenced rapidly the field of medicine. Two impressive examples in oncology are the computerization of population- or hospital-based cancer

registries and computer-based radiotherapy planning. Computers are now part of the daily hospital work and telemedicine is a useful tool to improve diagnostic quality in areas with decentralized diagnostic equipment and permanent need for consultation of experts. Development and marketing of products for the use of computerized systems for in-bed care in hospitals is a growing and very active business (<http://www.clinicall.de/>; <http://www.biomedme.com/about>).

With respect to palliative care, the actual situation was analyzed in a review on home telecare for elderly patients suffering from chronic diseases. Articles published between 1990 and 2007 were identified via the PubMed database. The literature search yielded a result of 485 papers. After reviewing the title and abstract from each, 54 were selected for closer examination. They were published in 37 different journals. The number of papers increased from one in 1997 to 14 in 2006. The diseases in which home telecare had been used were diabetes (14 studies), heart failure (13 studies), cognitive impairment (dementia and/or Alzheimer's disease, 10 studies), chronic obstructive pulmonary disease (5 studies), chronic wounds (4 studies) and mobility disabilities (4 studies). Patients were generally satisfied with home telecare, but they preferred a combination of home telecare with conventional health-care delivery. Health-care professionals were positive about telecare. Users felt that on many occasions telecare led to a reduction in costs due to time saving and avoidance of traveling. Even though there were important benefits from home telecare, there are organizational, ethical, legal matters, design, usability, and other matters that need to be resolved before widespread implementation can occur (23). However, until now the great potential of modern communication technologies and telemedicine are not fully used to overcome the growing home care problems. In contrast, sometimes there is an overuse of computers in the data collection of hospitals for patient's registration and economical analysis. This underlines urgent need for more research and technology development in the field of telemedicine-based home care (e-health).

Telemedicine a chance to overcome existing needs for home care

There are a number of well-known needs of patients receiving palliative care at home. These are the following:

- first aid in emergency situations
- close contact with the care giving physician if possible at patient's home (hospital/hospice-at-home care)
- monitoring of actual key data for making correct medical decisions
- control and monitoring of the drug treatment (24)
- psychological support in case of living alone

Certainly, a qualified care person and frequent home visits by the doctor are the best approaches to meet these needs. However, as shown, there are growing difficulties to overcome the lack of caregivers and home care doctors. The following approaches can minimize the problem:

- electronic emergency equipment (SOS system)
- monitoring of key data by mini-detectors and transfer of data to the mobile of the care giving staff or a control-center
- mobile phone-based data bank
- visual-vocal contact between a patient and a doctor by mobile phone (flying visits)

- individualized drug therapy by electronic device (TV-adapted call for taking drugs)
- individualized psycho-assistance (CD-Rom)

Technical solutions, investigated by observational studies, already exist for some of these approaches. Bertera et al. (25) examined the readiness of an elderly minority population to use various technologies for telecare. Eighty-five people with an average age of 73 years living in affordable housing completed a self-administered survey (a response rate of 43%). The technology that would be most likely used was environmental sensors in their home. The top five situations in which respondents would be receptive to new technology were all related to improving communications with a doctor or a nurse, especially when a medical emergency occurred. These included devices to send information to a doctor, to call for medical help, to signal to a nurse that 'I am OK' and to detect falls. This highlights the importance of including numerous opportunities for the individual to communicate better with their medical providers. One situation that gave respondents the most concern was the 'use of a camera to check on me when I am unwell'. The study provides some evidence that elderly minorities residing in affordable housing were receptive to the introduction of new telecare technologies.

As an example of our own activities, we describe the recent ANT developments in this field.

Techno-Eubiosia: recent ANT developments

ANT started almost 15 years ago with centralized computer-based annual statistics. The first project about exchange of data between the central computer and mobile devices in hands of the operators started in Bologna in 2004. The operators were able to check patient's data and put in main information about their daily activities. The most important result from this first experience was to understand the importance of choosing the right device for data collection and distribution. ANT chose to provide operators with smartphones, obtaining three main results:

- operators have to handle just one simple device for voice and data communication
- operators can use the system to input data through the device after the visit, dedicating full time to patients
- it is a low cost but easy-to-use and efficient solution

In 2009 the hospitals/hospices-at-home involved in this service were 19 out of 23, spread in 10 different regions and in the following areas: Alto Polesine, Bari, Bologna, Brescia, Brindisi, Ferrara, Firenze, Foggia, Lecce, Marche Sud, Monopoli, Napoli, Ostia, Pesaro, Potenza, Taranto, Trani-Molfetta, Urbino, Valdagni, Verona, Vignola-Modena.

Altogether 229 operators were involved taking care for 4142 patients. 94 852 home visits to patients and 76 955 data requests by operators were registered.

Actually, the next step is made. In 2010, ANT started to test Vitaever (<http://www.vitaever.com/>), a new SaaS solution (software as-a-service) for hospital-at-homes. Vitaever is a smart and intuitive technology to manage home-based healthcare as well as assistance services. Using Vitaever generates great advantages for both patients and medical organizations. The final goal of this development is to realize so-called flying visits. However, this includes not only improved software for data management but first of

all new hardware solutions as mini-telecameras, patient-tailored detectors of key data etc.

Ethical aspects of techno-Eubiosia: warm Hand vs. cold computers

There is no doubt that a well-acting caregiver and a high professional doctor sitting close to the patient is the optimal approach for palliative care. Certainly, the introduction of high-sophisticated technical equipment in the care procedures creates problems particularly for older people and doubtless, the installation of a video camera in patients home can influence patient's privacy. However, even receiving care in an intensive care unit changes privacy. It is a fact that the use of a mobile phone for telecommunication with the medical staff is better than feeling helpless and alone. Moreover, procedures, like home control of blood pressure, are already usual and the implementation of small detectors for measuring body temperature and other key data with data transfer to the mobile phone of the home care doctor is no burden for patient's quality of life. In summary, there is no doubt that a sympathetic family member close to the patient is the best solution for palliative care and Eubiosia. However, this is a dream and as in other parts of our life, we have to look for compromising needs and facts.

There is the first evidence that patients respond much more positive to telecare than expected initially. Onor et al. (26) studied the level of satisfaction with 3 types of formal care systems of the elderly: (a) a day care center, (b) a nursing home, and (c) telecare service in a group of oldest frail elderly. The study involved a population of 162 oldest elderly using these 3 different types of formal care services. Study participants were asked to complete a questionnaire, investigating socio-demographic characteristics and degree of overall satisfaction with the service, as well as eliciting possible suggestions for improvement. In this study, nearly all subjects using the telecare service were satisfied or very satisfied (98.5%), as compared to 75.3% of those residing in a nursing home, and 76.5% of those attending the day care center. This result confirms the findings of previous studies on elderly subjects' satisfaction with telecare services. Telecare, therefore, seems to be the service achieving the greatest levels of satisfaction, a service that can also be used by low-income subjects, who also perceive it as a source of social support.

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