# The dignity of life until the last breath – International Conference, September 12-14, 2013 Bologna

Stephan Tanneberger

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Correspondence to:
Prof. Dr. Stephan Tanneberger,
17406 Rankwitz/Liepe,
Hauptstrasse 11,
Germany
**h.s.tanneberger@gmx.de**

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## 1. THE GLOBAL SITUATION OF PALLIATIVE CANCER CARE

The age profile of cancer patients in the industrialized world is changing rapidly: in 2025, while 20% to 25% of the population will be older than 65 years, 50% to 60% of those dying from cancer will be older than 75. It would be wrong, both professionally and morally, to ignore these facts and it is but proper that palliative oncology has developed rapidly in the last 30 years. Palliative medicine has a history of critical appraisal dating back to the start of the "modern" hospice movement in the 1960s. However, based on the work of some pioneers, such as Dame Cecile Saunders and Vittorio Ventafridda, palliative oncology has now gained recognition as a medical specialty within oncology, internal medicine, and radiotherapy (1). A cornerstone was when Franco Pannuti introduced already in 1978 the first hospital-at-home for palliative care (2, 3). 1985-2013 Pannuti's Associazione Nazionale Tumori (ANT) provided nearly 100 000 advanced cancer patients with hospital-at-home care in all parts of Italy and 77% died at home in dignity (4). During September 12-14, ANT has invited experts from all over the world to discuss what was achieved and what is necessary to do in future in palliative cancer care. In the following some of the main messages of the conference are summarized

## 2. OBJECTIVES OF THE CONFERENCE

*Franco Pannuti, Founder and Honorary President of ANT* has designated the aims of the event very clear in his welcome address. The idea of the conference "The Dignity of Life Until the Last Breath" was born from the assumption of confronting with specialists, structures and institutions dealing with cancer care and palliative care, both in Italy and other countries , in order to share their experiences and contribute to the creation of a more effective and efficient network of care. The topics, from clinical issues to those most relevant organizational models, are numerous and absolutely central, as regards the present and especially the future of palliative care. According to Pannuti, future must be built by all of us, together, in other words from everybody who has the privilege of taking care of sufferers from cancer and their families.

## 3. MESSAGES OF THE CONGRESS

### 3.1. Eubiosia instead of Euthanasia

Since its beginning, the ANT foundation has been committed to supporting the idea of the dignity of life and around this concept which may seem elementary and obvious, but that encompasses a universal moral and ethical principle, proposed the Eubiosia, namely the defense of the "good life" as a set of qualities giving dignity to life *(Franco Pannuti, Bologna).* According to the majority of participants, Eubiosia excludes legalized euthanasia. However, it was to recognize that some speakers avoided a clear contra-position. Moreover, *Paul Vanden Berghe, Belgium* was defending the legalization of euthanasia in his country and the Netherlands. He reported that "palliative teams are multidisciplinary and have the best palliative skills, including communication skills and thus are well qualified to practice end-of-life care including support for euthanasia: both in a careful (regarding the law) and caring way". How complicated the Euthanasia discussion in Europe is, was also demonstrated looking on the situation in Germany (*Stephan Tanneberger, Bologna*). Available data show that more than 70% of the population support legal approaches of Euthanasia (5). The opinion of German physicians is varyingly (6, 7). However, it cannot be overseen that in 2012 about 50% of physicians supported assisted suicide (8). Nevertheless, from Germany came also very important words against euthanasia as: "The argument of autonomy creates reduction of patient's rights. At the end, the perversion of freedom for dying leads in contrast to non-freedom for life. What we need is dying in dignity by more culture of dying" (9). Certainly, this is a position in full accordance with the conception of Eubiosia as supported during the Bologna Conference.

### 3.2. For the majority of patients Eubiosia means dying at home

As underlined by *Phil Mc Carvill, London* we know a considerable amount about people's preferences and priorities at the end of life. As a broad rule, just short of two thirds of the public say that they would prefer to die at home, although this number falls significantly for older people and those who are ill or have a terminal diagnosis. We also know that it is choice, rather than the specific right to die at home which is important. The reality is that there is a significant disconnection between what people want and what they experience – the latest figures show that for example in UK where 53% of people die in hospital, 18% in a care-home, and 5% in a hospice. Although it was seen a small rise in the number of deaths at home between 2004 and 2010 from 18.3 to 20.8%. Figures presented from Germany are similar. There 66% of advanced cancer patients prefer to be self- determined until the end and to die at home (10). However, a study in Rhineland-Palatinate shows that only 38.2 % of the deceased died at home (11).

Dying at home is possible if effective structures are established for palliative care at home. Italy did pioneer work, summarized by speakers from Bologna, Padova, and Livorno *(Maurizio Mineo, Vittorina Zagonel, Luca Moroni*). In Italy the simultaneous care model, the new paradigm of care for cancer patients, was included in the National Cancer Plan 2010-2013 as priority objective for the quality of life of patients. Within the limits of the Italian National Health Service, universalistic and deeply rooted in the territory, general practitioner (GP) play an essential role, that cannot be disregarded particularly when home care is taken into consideration *(Marcello Salera et al, Bologna*). Similar efforts can be seen in Germany. In Germany, an inpatient strategy for advanced cancer would need at least 4-5000 beds for terminal care. Actually, there are in Germany 2,600 beds in 300 hospices und PCU (30 per million populations) available (12). This means that, even in case that all beds for end of life care in Germany would be occupied by cancer patients this can cover not more than 50% of oncologic needs. It was a great progress when on 01.04.2007 the government decided the right of patients for specialized outpatient care (SAPV) and started to establish state-financed outpatient care for anybody who wants it (13). The majority of cancer patients feel comfortable with their transition from inpatient to outpatient care (14). There are continuous efforts to qualify this system. It works very well in case of inclusion of GPs well-educated in palliative care (15) and in case that palliative symptom control in outpatients is performed by qualified and interdisciplinary palliative care teams (16). Certainly, it is very positive that since 2007 in Germany there is a patients‘ right for specialized outpatient care, but still are many gaps in the network, particularly on the countryside. A study performed in 2011 including 11 584 patients with cancer showed 15.8 % of patients classified as having palliative care needs (17).

A basic precondition for qualified home care is the recognition of voluntary organizations. *Luca Moroni (Federazione Cure Palliative, Italy*) underlined that the agreement between State-Regions of 25 July, Article 5, paragraph 3, recognizes the value of participation of non-profit organizations to the network services. With article 8 the law recognizes the value of volunteers in CP and defines the need for a “homogenous training in the national territory.”

In this respect it was reported that in Germany a large network of voluntary organizations exists supporting families and providing patients particularly with psychic care. The German Hospice and Palliative Association now has 1000 hospice structures with about 80 000 volunteers, which mainly take care for cancer patients (15, 18). Without such engagement there is no chance for Eubiosia at the end of life for advanced cancer patients.

### 3.3. Eubiosia means pain relief

The second basic element of Eubiosia is pain relief. The message of the congress was that pain is worldwide and even in Europe it is still a problem, which calls for intervention. *Boaz Samolsky-Dekel, Bologna* evaluated that despite the fact that we have both the means and the knowledge to ameliorate most forms of pain effectively, a significant number of cancer patients still experience unacceptable levels of pain. This is well known for developing countries (19). However, also from Italy it was reported that although the Italian Law 38/2010 aims was to improve the management of pain and, consequently, its treatment, the use of opiates is at a very low level. Even available data from Germany show that in countries with high-developed health care more patients are suffering from unrelieved pain than necessary. In a cross sectional study including 600 advanced NSCL patients about 90% were suffering from pain with negative impact on patient reported disease specific HRQOL (20). Regional differences cannot be overseen. Oechsle reports for Hamburg 80% pain in the moment when advanced cancer patients are admitted to a palliative care inpatient ward (21). Even for Mannheim in South of the country it was reported that treatment of pain appeared to be inadequate in patients with metastatic gastrointestinal cancer (22). In contrast, more optimistic reports are coming from Essen and Neubrandenburg (23, 24). The reason for unacceptable levels of pain in developing countries is very often lack of analgesics, mainly opiates. Possible reasons for insufficient treatment of pain in industrialized countries are non-availability of doctors, their training but even inadequate organizational structures. However, also patient-related barriers toward cancer pain management exist. The way patients decide on the use of analgesics remains often unclear. Individually tailored counseling by a professional within the education-program helps the patients to adopt new attitudes toward analgesics and gradually reduces their pain level (25). Moreover, this will stop the march forward of business-making alternative medicine. In 2012-2013 Alitti Foundation and ANT have carried a special project to give a contribution to the application of Italian law 38/2010. *(Silvia Leoni, Bologna*) This project shows that a correct approach to pain management is possible in home settings thanks to instruments like “kit for pain relief” and thanks to home round the clock assistance. Existing deficits in pain relief may be ascribed to the nature of the various organizational barriers to effective pain management. There is also ample evidence to demonstrate that both physicians and nurses lack experience and knowledge regarding modern methods of pain. This calls for consideration of education in palliative care.

### 3.4. Eubiosia means qualified training in palliative care

As underlined by *Adriana Turriziani, Roma* it is necessary to harmonize and enhance the value of competences of various professionals who interact during the period of care and assistance. Article 8 of Italian law n. 38/10 calls this “training and refresher courses for medical and health professionals in palliative care and pain management.” There are to consider two aspects: methodology and contents of teaching. *Guido Biasco, Bologna* evaluated that international programs are very heterogeneous. In Italy aspects relating to university education in palliative care are divided into two settings: the pre-graduate and post-graduate education. The educational programs of post-graduate courses (masters) in palliative care and pain treatment have been recently approved by the Government. For the first time training post-graduate programs are regulated by national rules. Only experienced universities of educational activities in palliative care are authorized to organize the courses. The universities should have also specific agreement with certified structures like hospices or home care organizations.

According to *Luigi Grassi and Rosaangela Caruso,* Ferrara communication between palliative care providers (e.g. physicians, nurses, social worker) patients and their families is a major area in clinical care, research and training. Breaking bad news, dealing with anxiety, demoralization or denial, maintaining hope while discussing poor prognosis as well as addressing end of life and bereavement issues, are some of the challenging topics of communication for health care professionals.

Education in palliative care is fundamental for Eubiosia. In the European scene, the Italian Law 38/2010 sets an example because it establishes the ethical responsibility to guarantee access to palliative care and pain therapy for patients and their families. First time an outline law obliges a health care system to face palliative care and pain therapy in all possible intervention areas. It was welcome that the Italian Society for Palliative care (SIPC) has decided to realize the "Core Curriculum of Palliative Physician" emerged from the work of experts along with the specific curricula of general practitioners, nurses, psychologists, physiotherapists and social worker. This was an authoritative contribution to the definition of the contents provided to the compulsory training, as requires by article 8 paragraph 3 of the law (*Adriana Turrizianin, Roma*).

### 3.5. Eubiosia means patients rights in health policy

The need of governmental and legislative activities as seen in the former message underlines the importance of clear political decisions also in palliative care. For a worlds view of palliative care we need to provide the evidence that integrating palliative care into a national health system is the best approach to provide humane, competent, compassionate care to those who need it (*Kathleen M. Foley, New York*). However we are far from this in many countries. Cancer deaths and dying are still considered as taboo subjects; consequently, caring and dying are also looked at as taboo questions. It seems to be the main causes of misbelieves – and not only in Hungary, evaluated *Katalin Hegedus, Budapest* the situation. Even from Germany it was reported that there is no guarantee of Eubiosia for all (26). The actual main problem is that the political pressure to push through Eubiosia as a human right is low. Moreover, commercial interests promote imbalance between expensive overtreatment and palliative care (27). Eighty-two percent of general practitioners in Germany call for basic changes in the German Health Care (28). In 2008 there were 215 442 cases of death from cancer registries (29). The absolute 5-year-survival is 50% for men and 57% for women. This situation is unsatisfactory and it was criticized at the German Cancer Congress in 2012 (30, 31). There are several proposals to change the situation as the call for more innovations (32), better cancer registry (33, 34), all within a National Cancer Plan (35). Unfortunately all over the world rapid changes are not to recognize. Still we are living in a world which spent year for year about 2000 billion $ for arms and war. However, we need a world of globalization for peace and health (19). Therefore, *Franco Pannuti's* warning "a community without universal and shared values is a community without future" was very justified.

### 3.6. Eubiosia means new ideas for cost-benefit in health care

It was certainly right when *Raffaella Pannuti, President of ANT Italia Foundation* at the beginning of the congress assessed the inadequacy of current institutions to sustain essential standards of care. She underlined that nowadays in Italy and other European countries a spending review of the costs of health care is taking place aimed at the demolition of waste and obvious inconsistencies, but also coursing a substantial shortage of hospital beds. She underlined that it is not only the cutting, but also the reviewing of the process that will help obtaining lower costs and better services. As the way to Eubiosia she recommended to give up the idea of a "public health for few people and lean towards a more integrated health care for everybody." Within the European scene palliative care is already a challenge, but definitively home care is the social innovation that health care needs. The German philosophy of invitation of "cheap" immigrants is no solution in health economy (36, 37). State pressure directed on cost-reduction in the field of palliative care for cancer patients is not justified. Home care is first an innovation with more benefit for patients. However, according to a careful analysis of ANT already in 1998, there is evidence that hospital-at home care cost about 50% of in-bed care (38, 39). In this calculation, as necessary, direct and indirect family cost are taken into account. There is no doubt that Eubiosia can be achieved with reasonable cost-benefit. This calls for changing policy in health care economy to avoid a situation as criticized from the German Society for Pain. In 2009 were available for end of life care 28 Million Euro. From that only 9.6 million were used for outpatient care (40). No doubt that political decision like this has to be changed. It's time to seriously rethink the assistance by integrating social and health support, in order to respond effectively not only the current challenges but especially to those of the future.

As Raffaella Pannuti has underlined, the field of palliative care shows more clearly than others the role played by non-profit organizations with respect to high benefit and low cost. This can be seen looking on the ANT Italia Foundation, the Saiatu Project in Spain (*Naomi Hasson*) or networks like the German Hospice and Palliative Association.

### 3.7. Eubiosia means e-care without lowering of patient's dignity of life

Adequate home care needs a 24-hours service at home. Doctor's visits include monitoring of cardiopulmonary parameters as blood pressure, heart function. Often also body temperature has to be controlled. However, a decreasing physician's density for OECD is predicted (minus 10% to 15% between 2007 and 2020). In summary, this means care at home is at risk in a world with rapidly growing numbers of palliative care patients (41, 42). In this situation the idea of e-care was born. If the number of well-trained doctors for palliative care at home is too low it is an alternative to equip the available staff with instruments to increase their efficiency and to meet patient's needs at least in part. Until now 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 data collection for patient's registration and economical analysis. The following approaches can minimize the problem:

- Electronic emergency equipment (SOS system)
- Visual-vocal contact between patient and doctor by mobile phone (flying visits)
- Monitoring of key data by mini-detectors and transfer of data to the mobile of the care giving staff or a control-centre
- Mobile phone-based data bank
- Individualized drug therapy by electronic device (phone-adapted call for taking drugs)
- Individualized psycho-assistance (CD-ROM)

In between there is good evidence that patients respond much more positive to telemedicine than expected initially. Moreover, there is no doubt that coming generations of patients, who are growing up with highly sophisticated communication technologies, accept e-care much better. Also professionals evaluate this approach positive and many feel that e-care led to a reduction in costs due to time saving and avoidance of travelling.

**Flying visits** by mobile phone are worthy of note because these have five basic advantages:

- Patients feel "visited" by the doctor at least once a day "personally"
- Doctor's visual-vocal impression of the patient helps very much for correct evaluation of patients actual situation
- Doctor's knowledge of some key data via mobile by aid of the rapid developing sensor- technologies support objective evaluation
- The doctor in charge can better select those patients which she/he has to see on the given day
- Better planning of the nursing service based on the actual patients situation

There is no doubt that further efforts on e-care are necessary. Cost should not be an obstacle. Actually in countries like Germany yearly about 7000 Euro for each retired person are calculated for health care (43). Cost for the introduction of mobile-computer devices for flying visits of those who need should be less than 1%-2% of that amount. It is no doubt that a sympathetic family doctor 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. Therefore thinking on Techno-Eubiosie is satisfied and necessary (4).

## List of Speakers at the conference who are mentioned in the paper

- Biasco, Guido, Accademia delle Scienze di Medicina Palliativa, Bentivoglio (Italy)
- Foley, Kathleen M, Memorial Sloan Kettering Cancer Center, New York (USA)
- Hasson, Naomi, The Saiatu Project, (Spain)
- Hegedus, Katalin, Semmelweis University Budapest (Hungary)
- Leoni, Silvia, Fondazione ANT Italia, Bologna (Italy)
- McCarvill, Phil, Marie Curie Cancer Care, London (UK)
- Mineo, Maurizio, Fondazion ANT Italia, Bologna (Italy)
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- Vanden Berghe, Paul, Federation Palliative Care Flanders (Belgium)
- Zagonel, Vittorina, Instituto Oncologico Veneto, Padova (Italy)

## Conflict of interest

We declare no conflicts of interest.

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