

**THE DIGNITY OF LIFE
UNTIL THE LAST BREATH**

Innovative models in cancer palliative care

SEPTEMBER 12th - 14th, 2013

ABSTRACT BOOK



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Innovative Models in Cancer Palliative Care

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ABSTRACTS

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Regione Emilia-Romagna



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Federazione Cure Palliative



Federazione Nazionale collegi Infermieri



Società Italiana di Cure Palliative



Società Italiana di Psico-Oncologia

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Dear Congress participant,

Since its beginnings, 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.

This is our Ethical Code:

1. Always consider life as a sacred and inviolable value.
2. Consider Eubiosia (“life with dignity ”) as a daily primary objective.
3. Welcome natural death as the natural end.
4. Consider each disease development as being reversible.
5. Combat your own physical, moral and social suffering as well as that of others with the same commitment.
6. Consider all people brothers.
7. The sufferer needs your understanding and solidarity, not your pity.
8. Avoid excesses.
9. Help the sufferer’s relatives as well: Do not forget them even “afterwards”.
10. Our “much” will be nothing without the “little” of many.

35 years have passed since May 15, 1978, when with other 12 friends, we founded ANT in Bologna with the intent of doing research and launching a project of home care for helping cancer patients and their families. In my daily work as the Head oncologist at Sant’Orsola Malpighi Hospital, I was aware of the difficulties that I had every time I had to dismiss patients to “free beds”, always too scarce, to be given to other patients a waiting chemotherapy. I was in trouble because I wanted to help them even after treatment. Until the end. I understood that this was what they were asking me, and so were their families.

Since then ANT has assisted nearly 100,000 Sufferers, of which 6,800 only in the first half of 2013.

The 3,900 Sufferers are assisted every day by more than 250 ANT Healthcare Professionals (doctors, psychologists, nurses and physiotherapists) with 20 offices located in 9 Italian Regions, taking care of their patients 24 hours a day, 7 days a week, offering not only health care but also social and spiritual support. From that beautiful sunny day in Bologna on May 15, 1978 we have come that far, and this is thanks to our operators, our collaborators, our volunteers (the “ANT ants”) and especially thanks to the people who daily believe in our work and with their gestures of solidarity allow this to continue and improve evermore. The charitable model of ANT, like all models, may still be lacking, in the sense that it needs to be improved and expanded in order to assist more and more people and offer them more services. And to do this we must build solid paths of cooperation with other local, public and private, organizations, in order to achieve increasingly higher standard of care, while all of them maintaining their own specific areas.

The idea of the conference The Dignity of Life Until The Last Breath was actually born from the assumption of confronting with specialists, structures and institutions dealing with cancer care and palliative care, both in Italy and in 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 I believe absolutely central as regards the present and especially the future of palliative care. Future must be built by all of us, together, in other words from everybody who has, and will have, the privilege of taking care of Sufferers from cancer and their families.

Felice Eubiosia



Professor Franco Pannuti

Founder and Honorary President of ANT Italia Foundation

Dear Congress participant,

The health and social costs of cancer are increasing. Health spending on cancer care is growing in light of the progress achieved in the field of diagnosis and treatment, leading to an increase of survival and higher economic impact of techniques.

To this we must add the weight of the social costs related to oncological pathology, ie the set of tangible and intangible costs that cancer patients and their families are called to face. The need to find the necessary resources to ensure adequate cancer care is in contrast with the current economic crisis which is going throughout the European Union and more generally the Western world. This highlights the inadequacy of current institutions to sustain essential standards of care.

Nowadays in Italy and in 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 causing a substantial shortage of hospital beds.

It's clear that this trend of health policies is necessary to provide the "shock absorbers" that can meet the needs of an aging population at a steady rate and for which it must provide in the future an expansion of investments.

In this sense, the spending review can not be understood only as an instrument of control over expenditure, but it's necessary to reconsider how to spend.

It is therefore not only the "cutting", but the reviewing of the processes that will help obtaining lower costs and better services. It's time to seriously rethink the assistance by integrating social and health support, in order to respond effectively not only to the current challenges, but especially to those of the future. For a truly sustainable health care it is desirable to adopt a view of public-private capital integration.

We have to give up the idea of a "public health for few people" and lean towards a more integrated health care for everybody.

Nowadays this type of universalistic welfare state is not sustainable so we have two possibilities: neo-liberalism, as the one that exists in America, where the services are entrusted to the individual, perhaps through private insurance; or welfare society in which the service public assistance is helped by the free initiative of the citizens. If we do not think of going through the welfare state to welfare society we would never think to keep the universalism of services, that is one of the most significant achievements of European civilization. Within the European scene palliative care is already a challenge, but definitely home care is the social innovation that health care needs and that we want to discuss at this conference.

But the big challenge in front of us is the renewed relationship between doctor and Sufferers, away from the mechanical nature of the performance, but close to the soul of the person.

In a time of telemedicine the relationship Man to Man has to be regained with the idea that machines should be a means, not an end.

The field of palliative care shows more clearly than others the role played by non-profit organizations (NPOs) - precisely expression of civil society - actively engaged in this area of interest.

In recent decades it's also thanks to the contribution of a private non profit organization that palliative care in Italy has been able to develop: first in the field and later in a more structured way through a legislative formalization initiated by Bill of Law 38 of 2010. This Bill of Law identifies palliative care among health care disciplines, as ratified by the State-Regions agreement in February 2013. And it is thanks to the initiative of a private foundation if a meeting on these issues was organized on 25th September 2012 at the European Parliament.

So here's the Man to Man approach ensuring the EUBIOSIA, the dignity of life from the first to the last breath through solidarity and love to oneself and to the others.



Raffaella Pannuti
President of ANT Italia Foundation

THE DIGNITY OF LIFE UNTIL THE LAST BREATH
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THE EUBIOSIA PROJECT
ETHICAL VALUES AND PRACTICAL EXPERIENCE

Franco Pannuti

HISTORICAL STEPS OF ANT'S EVOLUTION

- MORAL → EUBIOSIA
- LEGAL → ANT ASSOCIATION/
ANT FOUNDATION/
- SCIENTIFIC → LAB-ANT/IST-ANT
- SOLIDARITY → EUBIOSIA PROJECT

ANT STAFF (NON VOLUNTEER)

Physicians 132	Psychologists 26	Nurses 88
Nutritionists 4	Physiotherapists 3	Chemists 3
Social worker 1	Employees 115	Promoters 28
TOTAL 400		

GASDI GRUPPO ASSISTENZA SPECIALISTICA DOMICILIARE ITALIANO

ODO FREE SERVICES AT HOME

- 24 HOUR MEDICAL CARE
- PSYCHOLOGICAL CARE
- SPIRITUAL CARE
- SOCIAL CARE
- NURSING
- ARTIFICIAL NUTRITION
- PICC SERVICE
- PHYSIOTHERAPY

ODO FREE SERVICES AT HOME

- PERSONAL HYGIENE CARE
- WASHING AND IRONING OF BEDSHEETS, BEDCOVERS AND CLOTHES (PROJECT "CLEAN BED")
- DELIVERY OF HEALTH AIDS AND DRUGS
- TRANSPORT (PROJECT "DOOR-TO-DOOR")
- BOOKS AND FILMS
- CALL CENTER FOR CANCER INFORMATION

ANT HOSPITALS-AT-HOME (ODO)*: 19

- *ODO-BOLOGNA
PATIENTS ASSISTED PER DAY: 1,409
- *ODO-TARANTO
PATIENTS ASSISTED PER DAY: 418

*ODO = OSPEDALE DOMICILIARE ONCOLOGICO

LOCATION OF "OUR HOSPITALS-AT-HOME" (ODO) IN ITALY



The Eubiosia project

35 ANT

The Eubiosia project

ANT "FRONT LINE": THE FAMILY



The Eubiosia project

35 ANT

ANT NUMBERS

FIRST SEMESTER 2013

PATIENTS ASSISTED	6.808
DAYS OF ASSISTANCE PER PATIENT (MEAN)	99
PATIENTS ON LINE (JUNE 30, 2013)	3.943

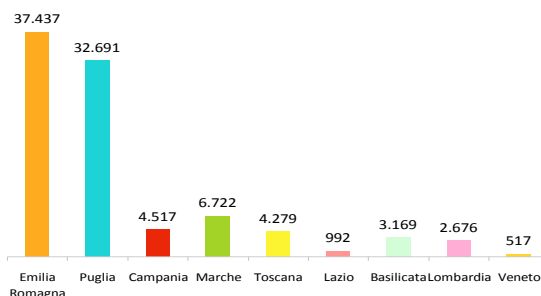
DECEMBER 1985-JUNE 2013

TOTAL PATIENTS ASSISTED	96.289
TOTAL DAYS OF ASSISTANCE	16.566.881
ANT HOSPITALS (ODO)	19

The Eubiosia project

35 ANT

PATIENTS ASSISTED IN ITALY DECEMBER 1985 - JUNE 2013

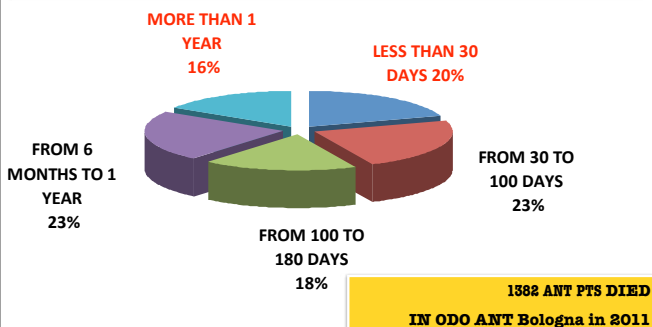


PILOT PROJECTS IN ITALY AND ABROAD: 3.289 (ALBANIA AND INDIA 2.888)

The Eubiosia project

35 ANT

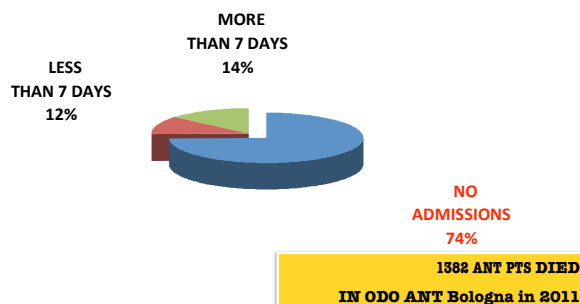
DURATION OF ASSISTANCE



The Eubiosia project

35 ANT

PERCENTAGE OF HOSPITAL ADMISSIONS (LAST 30 DAYS)



The Eubiosia project 35 ANT

PATIENTS DIE IN THEIR OWN HOMES

77% ANT ITALY

57,9% ITALIAN MINISTRY OF HEALTH SURVEY OF CANCER DEATHS
(Beccaro M, Costantini M 2012)

PLACE OF DEATH

THE CHOICE OF HOME AS THE PLACE OF DEATH IS FAVOURED BY

- 1) THE HIGHER AGE OF THE PATIENT AND
- 2) HIGHER FREQUENCY OF MEDICAL VISITS

The Eubiosia project 35 ANT

ANOTHER "FRONT": PREVENTION

THYROID	6.355
WOMAN PROJECT (Gynaecology)	1.080
BREAST (<45 years of age with DOBI)	1.100
MELANOMA	67.283
<u>TOTAL FREE VISITS:</u>	<u>75.818</u>

The Eubiosia project 35 ANT

REVENUE*

Year	Revenue (EURO)
2011	21,475,769.00
2012	21,979,224.00

+ 2,34% * EURO

The Eubiosia project 35 ANT

SURPLUS

Year	Surplus
2011	1,549,501.00
2012	1,181,879.00

-23,73%

The Eubiosia project 35 ANT

INCOME SOURCES 2012

INCOME SOURCES	PERCENTAGE
PUBLIC HEALTH CARE	17%
FUND RAISING	56%
LEGACIES	12%
5X1000	11%
BANKS AND FOUNDATIONS	4%

The Eubiosia project 35 ANT

EXPENDITURES 2012

INVESTMENTS	PERCENTAGE
CARE, PREVENTION AND EDUCATION	56%
ORGANISATION EXPENDITURES	43%
TAXES	1%

The Eubiosia project 35 ANT

HOME CARE EXPENSES (€) 2004-2012

YEAR	TOTAL	PTS	EXP/PTS*
2004	13.625.000	7.313	1.863
2005	14.370.000	7.602	1.890
2006	15.189.356	7.862	1.932
2007	15.563.986	8.194	1.899
2008	16.626.825	8.373	1.986
2009	17.834.154	8.681	2.054
2010	18.421.167	8.614	2.139
2011	19.761.902	9.297	2.126
2012	20.622.012	9.562	2.157**

*Yearly mean expense per Patient ** per Patient/per day = < 30 €

The Eubiosia project 35 ANT

THE "CASUS BELLI"

EUTHANASIA

The Eubiosia project 35 ANT

EUTHANASIA

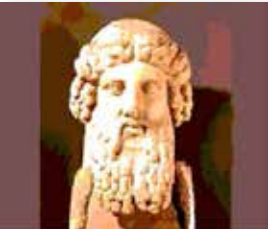
GREEK ETYMOLOGY

eu = WELL, thanatos = DEATH , "GOOD DEATH "

NOT AN
"ANTICIPATED" DEATH
NOT AN
"INDUCED" DEATH

The Eubiosia project 35 ANT

EUTHANASIA: THE GREEK PHILOSOPHY




**ARISTOCLES
CALLED
PLATO 427-327 BC**

DEATH OF TERMINAL
PATIENTS
CAUSED BY PHYSICIANS

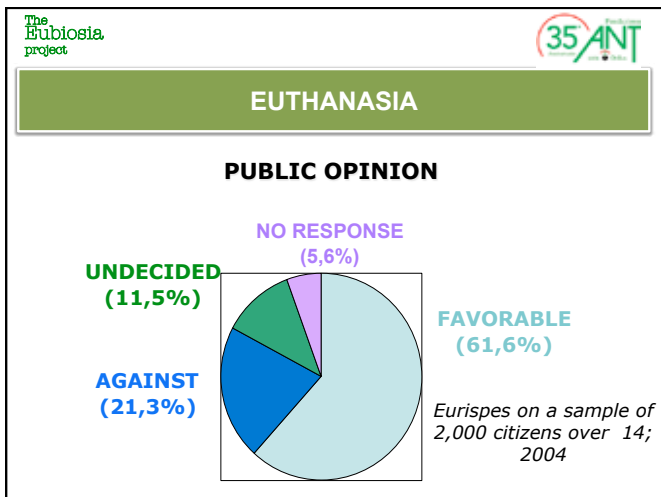
REPUBLICA AND
CONVITO

The Eubiosia project 35 ANT

EUTHANASIA: THE NAZI PHILOSOPHY



A. HITLER 1889-1945




The Eubiosia project 35 ANT

1978: BEGINNING OF ANT

EUBIOSIA
ALL THE QUALITIES THAT LEND DIGNITY TO LIFE

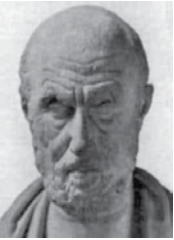
DIGNITY OF LIFE
ACKNOWLEDGEMENT AND AFFIRMATION OF UNIVERSAL RIGHTS, WITH LOVE



The Eubiosia project 35 ANT

FIRST EXAMPLE OF EUBIOSIA

THE HIPPOCRATIC OATH 470-410 A.C




"I swear ... I will refrain from harm and offense. Do not administer to anyone, even if required, a deadly drug, nor suggest such counsel."

In any home will go, I will come into it for the relief of sick and I shall refrain from offensive and malicious damage and any action corrupting the bodies of women and men, both free and slave."

- The Eubiosia project 35 ANT
- ## MORAL VALUES: ANT CODE
1. ALWAYS CONSIDER LIFE AS A SACRED AND INVOLABLE VALUE
 2. CONSIDER EUBIOSIA ("LIFE WITH DIGNITY") AS A DAILY PRIMARY OBJECTIVE
 3. WELCOME NATURAL DEATH AS THE NATURAL END
 4. CONSIDER EACH DISEASE DEVELOPMENT AS BEING REVERSIBLE
 5. COMBAT YOUR OWN PHYSICAL, MORAL AND SOCIAL SUFFERING AS WELL AS THAT OF OTHERS WITH THE SAME COMMITMENT

- The Eubiosia project 35 ANT
- ## MORAL VALUES : ANT CODE
6. CONSIDER ALL PEOPLE BROTHERS
 7. THE SUFFERER NEEDS YOUR UNDERSTANDING AND SOLIDARITY, NOT YOUR PITY
 8. AVOID EXCESSES
 9. HELP THE SUFFERER' S RELATIVES AS WELL: DO NOT FORGET THEM EVEN "AFTERWARDS"
 10. OUR "MUCH" WOULD BE NOTHING WITHOUT THE "LITTLE" OF MANY

- The Eubiosia project 35 ANT
- ## THE RIGHTS OF THE DYING THE RIGHTS OF THE LAST 100 DAYS
1. EUBIOSIA IS A BASIC RIGHT UNTIL DEATH.
 2. THE DYING AND THEIR FAMILIES ARE ENTITLED TO COMPLETE CLINICAL INFORMATION.
 3. THE COMMUNITY MUST NOT BECOME THE CAUSE OR THE MEANS TO A PREMATURE END.
 4. THE COMMUNITY MUST GUARANTEE THE DYING THE EXERCISE OF ALL THEIR CIVIL RIGHTS.
 5. THE COMMUNITY MUST GUARANTEE THE DYING AND THEIR FAMILIES THE MAINTENANCE OF A POSITIVE ON-GOING RELATIONSHIP WITH THEIR SURROUNDINGS.

The Eubiosia project 

**THE RIGHTS OF THE DYING
THE RIGHTS OF THE LAST 100 DAYS**

6. THE COMMUNITY MUST ENSURE THE DYING THE FREEDOM TO DECIDE THEIR FUTURE IN COMPLETE RESPECT OF EUBIOSIA.
7. THE COMMUNITY MUST GUARANTEE FREE AND CONTINUOUS TREATMENT.
8. THE COMMUNITY MUST ENSURE ALL DYING A UNIFORM LEVEL OF ASSISTANCE (PHYSICAL, MORAL AND SPIRITUAL).
9. THE DYING ARE ENTITLED TO CHOOSE FREELY WHERE TO BE TREATED (AT HOME, IN HOSPITAL OR IN HOSPICE).
10. THE COMMUNITY MUST GUARANTEE THE DYING THE CHOICE OF THE MEDICAL TEAM.

The Eubiosia project 

***"A COMMUNITY
WITHOUT UNIVERSAL AND
SHARED VALUES
IS A COMMUNITY
WITHOUT A FUTURE"***

**SUMMA SALUS
SUMMA CURA IN CARITATE**



AI NOSTRI NUMERI
OGGI AGGIUNGIAMO IL

35

100° ANNIVERSARIO DELLA FONDAZIONE
75.000 INQUADRI DI TUBERIE ADOTTATE
INUTILIZZABILI
3.500 ESIGENTI-DONE DONNE E DONICOLE
500 PROFESSIONISTI SANITARI
1.500 VOLONTARI DEL TERRITORIO
25.000 PORE DI PREVENZIONE GRATUITA
PER LA DONAZIONE DI SANGUE

Grazie!



Survey on Palliative Care in General Practice: State of the Art and Expectations in Bologna Area

Marcello Salera, Giandomenico Savorani, Roberto Cau, Sandra Degli Esposti, Rosanna Giordani, Mara Morini

Azienda Unità Sanitaria Locale, Bologna; Italy

Within the limits of the Italian National Health Service, universalistic and deeply rooted in the territory, General Practitioners (GPs) play an essential role, that cannot be disregarded particularly when home care is taken into consideration. Recently, in collaboration with the Primary Care Department of ASL 105 of Bologna, we investigated the GPs expectations and turns for home palliative care in Bologna metropolitan area.

An on-line questionnaire was specifically developed and sent to all the 595 GPs working in Bologna territory; the answers were 218 (36.6%).

Results

First of all, we observed a wide agreement between GPs on the meaning of home palliative care. 86% of them converged on the following definition: home health care interventions, health and social welfare and the treatment of pain in persons with cancer or other serious disease in terminal phase. Hence, for the majority of interviewed physicians palliative care should not be reserved only to oncologic patients and should be started in advanced stage of illness, when clinical recovery is considered no more achievable, without any pre-established time schedule (87% of GPs). There was discordance of opinions about diseases that could require palliative care: complete agreement was got only on cancer (100%), whereas heart, renal and hepatic failure and severe chronic obstructive pneumopathies (COPD) settled around 20-30% of consent (fig.1). This suggests that a common way of thinking about purpose and target of palliative care is still lacking.

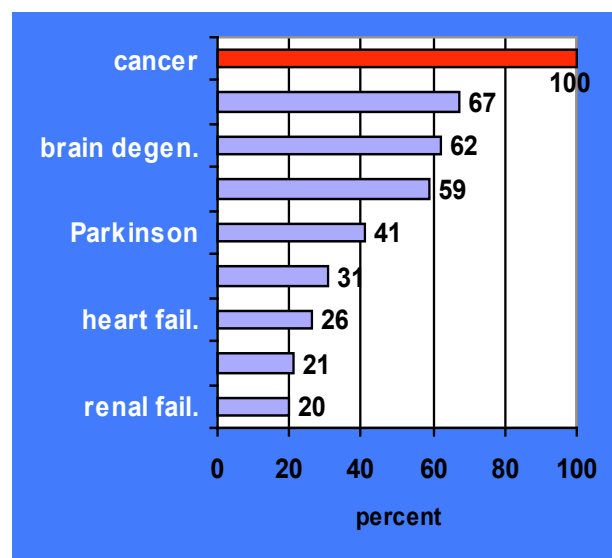


Fig. 1
Diseases which can require home palliative care.

According to 85% of interviewed, palliative care are to be delivered by specialized and specifically trained personnel; four professional figures were considered fundamental: nurse (96%), pal-

liative physician (85%), general practitioner (82%) and psychologist (74%) (fig 2). For the majority of interviewed the GPs should become part of the integrated care network. It should be noted, however, that a small but not negligible percentage of GPs (15%) prefer to delegate home palliative care to specialized teams, considering this commitment inconsistent with the ordinary daily overwork of the general practitioner (fig.3).

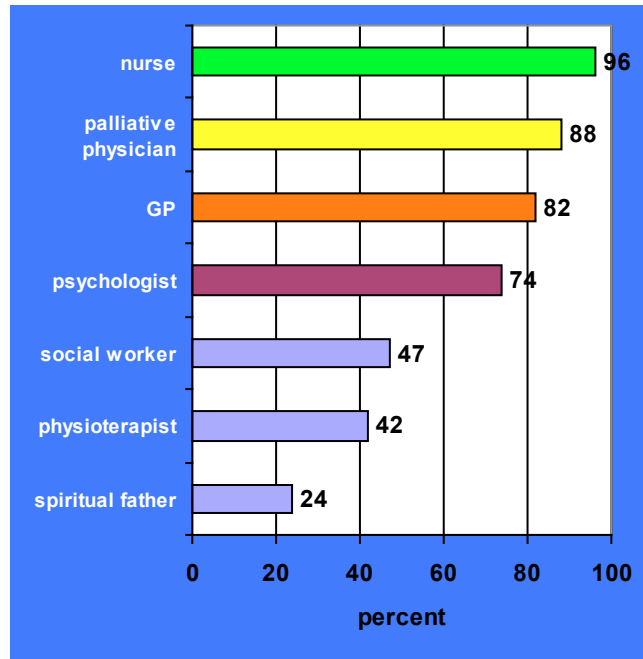


Fig. 2
Professional figures that should be part of the group of home palliative care.

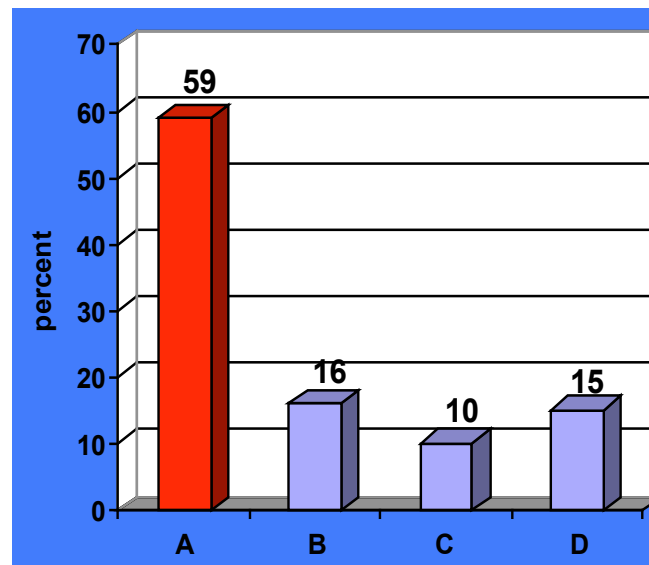


Fig. 3
The role of GP within the palliative care team: A. inserts oneself in palliative care unit and does a coordinated teamwork; B. manages the case on his own and activates time after time medical consultants, depending on the contingent needs of the patient; C. collaborates with the palliative care unit only when it is requested (supporting role) D. delegates palliative care to specialized teams, because the burdensome tasks of general practitioners are not compatible with this further commitment.

Most of GPs regard Hospice as an intrinsic part of home palliative care network: it should not limit itself to admit patients in the last months of life but it should also offer temporary hospitalization, bringing relief to families and contributing to overcome critical events. Moreover, the Hospice should deliver specialistic home support and counselling for families (fig.4).

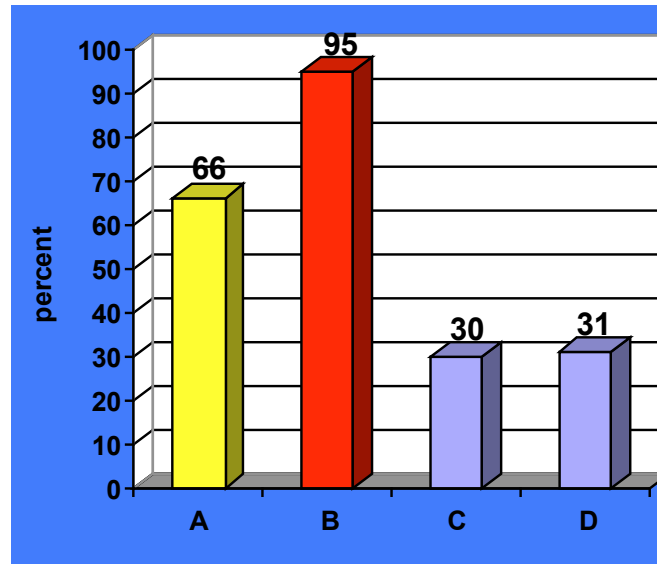


Fig. 4
The role of Hospice within the palliative care network: A. Admission in the last months of life; B. Temporary hospitalization (relief for families; in critical events); C. Outpatient and at home counselling; D. support and advice to families.

The role of the Hospital has given rise to much controversy: for 63% of GPs the hospital should offer specialistic support and admissions “oriented” only when a proper home palliative care network has not been realized in the territory. 25% of GPs even go so far to say that hospital should not play any role since palliative care is the prerogative of community (home, Hospice) (fig. 5). Anyway, 88% of GPs considered the integrated home care service as a valid instrument to avoid inappropriate admissions to hospital.

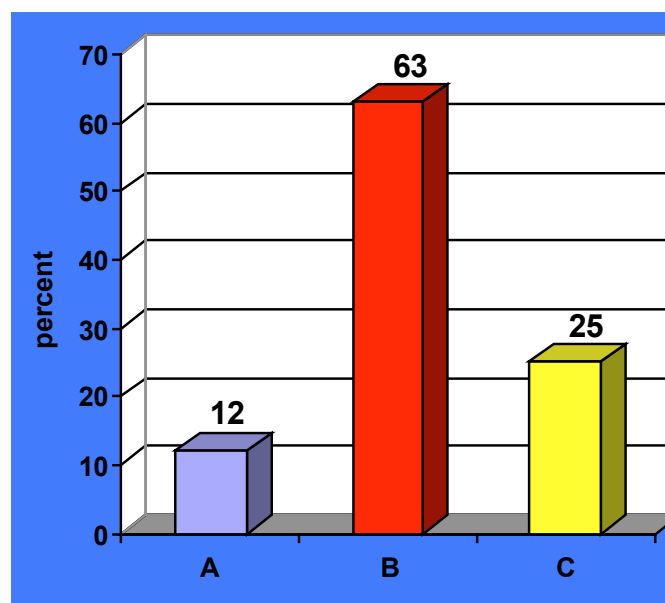


Fig. 5

The role of Hospital in palliative care network: A. prepare palliative care paths within the departments of care; B. provide specialized counselling and the possibility of admissions “oriented” where the territory is not organized for this purpose; C. no role, because palliative care is the prerogative of community (home, hospice)

Conclusions

The General Practitioners working in Bologna metropolitan area deem necessary a specific training for medical and nursing personnel involved in home palliative care, require more homogeneous territorial allotment of home palliative care units, propose to be actively involved in an integrated teamwork, and finally ask for a more flexible and diversified role for Hospice.

The Network of Palliative Care: Hospital

Sergio Venturi

Policlinico Sant'Orsola-Malpighi, Bologna; Italy

By Act 38 of 2010, Italy was among the first countries in Europe to guarantee citizens the right to pain relief and palliative care. In its systematic and innovative coverage, Law 38 is an example of legislation tailored to meet the need for medication and nursing support by both the patient and his family, ensuring a life without unnecessary suffering. The law cites principles and values, the precise basis on which those principles rest, and provides the essential references for developing networks of pain management and palliative care across the national territory, identifying a national framework in which to build the tools needed, implement treatment of pain and give full assistance to those who are at life's end.

The range of support services for the sick works through a national network for palliative care and for pain therapy designed to optimize management and service delivery across the whole country and to ensure continuity of patient care from the hospital to his home. The network extends to all health care facilities, hospitals and territorial health units; professional assistance in the form of diagnosis and therapy will be available in all regions and autonomous provinces, ensuring provision of palliative care and pain control at all stages of disease, with particular reference to advanced-stage and terminal cases, as well as support for sufferers and their families.

Pain therapy

The Pain-Free Hospital Committee (COSD) was set up in 2002 within the Pain-Free Hospital Project at Sant' Orsola-Malpighi Hospital in Bologna.

In January 2003 the Oncology Unit (OU) brought in systematic monitoring of pain as perceived by patients in the ward.

After a training course involving the whole of the Department's nursing staff, throughout the Oncology, Hematology and Radiotherapy Department (OHRD) systematic pain measurement was introduced using the NRS scale.

In 2007 the OHRD implemented a common approach to pain by means of systematic monitoring and therapeutic strategies based on guidelines. This model provides an innovative system employing the basic tools of quality management (ISO), combined with those of local health facilities, allowing for personalization of new materials with issues relating to clinical practice. In May 2009, the Pain-Free Hospital programme related to cancer pain in adults achieved the certified service provision standard.

Palliative care

The clinical care pathway of cancer patients at an advanced stage, when they are no longer likely to obtain benefit from cancer therapies, requires close integration between the hospital, generally represented by the departments of oncology, haematology and radiation, and the professionals and facilities whose mission is to provide such patients with palliative care. Closer integration between hospital and territory could improve the functioning of the Network of Palliative Care (PC) whose nodes are: the general practitioner (GP), home care assistant, hospice, palliative specialist and specialist advice bureau.

The PC Network is, according to the State-Regions document of agreement of 25 July 2012, managed and coordinated by Palliative Care Units.

The PC Units interact with the various inpatient hospitals or DHs, with the GP and the voluntary organizations working in the field of oncology and palliative care.

Further attention should be given to simultaneous experiences of care because, on the one hand they provide a smoother transition to the palliative care mode, while on the other hand they form an excellent basis for interdisciplinary collaboration first with oncologists working to improve the appropriateness of chemotherapy and in some cases prolong the survival of patients with advanced cancer and, secondly, with specialists treating the chronic non-cancer sector, which is coming to absorb a growing share of Local Health resources.

As of March 2011 a pilot project at the S. Orsola-Malpighi Hospital has aimed to improve relations between the hospital, professionals and units that are committed to assisting these patients across the territory.

The project moves from merely “bureaucratic” integration to integration of a “real” palliative care network. The practical method of operation entails one weekly session at an outpatients or Oncology Day Hospital in which patients participate directly or through direct contact (phone, mail, etc..) with the hospital oncologist, the nurse, hospital and home care psychologist, general practitioner (GP) and hospital and home-care palliative doctor (LHU or specialist outpatients at a voluntary structure or hospice). Each case is collectively discussed among professionals before the patient arrives.

This small pilot project confirms that it is possible to obtain hospital-hinterland integration, as part of a Palliative Care Network, with a multi-professional team creating a personalized treatment plan.

The primary objective of improving the integration between the hospital and its catchment area is to improve “coverage” by the entire care network and to reduce emergency admissions to A & E.

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The Eubiosia Project

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Ant was born in May 1978 on the initiative of Professor Franco Pannuti with the intent to implement support services for cancer patients in advanced stages of disease, starting from an ethical base that has found its expression in the concept of Eubiosia (defense of the dignity of life in all its phases, as opposed to the idea of euthanasia seen as early death).

Specifically, in 1985, after 7 years of promotional activities, disseminating information and raising funds, was launched in Bologna the activity of Hospitalization Homecare Oncology (HHO).

It was a program of social and health services, provided free of charge, for cancer patients and their families who request it. That service has been supplied by a team of doctors (specialist in supporting cancer care), nurses and psychologists.

Even today, after 28 years of business and nearly 100,000 Suffering assisted in home care, in 9 different Italian Regions, the basic structure is formed in the same way.

Referring to the reality of Bologna, the most important HHO in size and organization, the team consists of 6-8 Doctors, 3-6 nurses plus 1-2 psychologists. Each team is in charge of between 180 and 250 Suffering (obviously with very different situations of need of care).

There is also a social worker ANT, also through a cooperative of services for the care of personal hygiene supports patients with families in need.

The comprehensiveness of services offered, as well as the intensity of care guaranteed in accordance to the need of the individual patient, leads us to define the team as Ant Hospital Homecare Oncology (HHO), knowing that this definition is not supported by law. The quality and quantity of service must be (and is) of the same level or even higher than the patients could receive in a normal hospital ward.

The Ant physicians are partly oncologists (now a small percentage), all of them are supported with adequate training in complementary cancer therapies and in the palliative treatment of cancer-related symptoms, with particular attention to pain control. Throughout the year, participating in events organized by Ant Training and Development Department.

In addition to a large number of nurses (essential in the care of Suffering), the team uses a group of psychologists specialized in psycho-oncology dedicated to the support of Suffering, but mostly of family members and members of the team.

Another significant factor that distinguishes the ANT HHO is the on-call medical service active 24h/24. In this way the physicians of the team, assisted during daylight hours by the nursing staff, provide continuous coverage of the service, allowing families to have at all times a sure point of reference to turn to in case of need. In this way, we try to avoid as much as possible inappropriate hospital admissions and visits to First Aid.

To activate the ANT assistance every HHO has a Reception Office ran by paid staff prepared specifically for this delicate task (many of these offices are managed by our ANT psychologists).

In any case the activation of the service is based on the written consent of the GPs, who is still the trusted doctors of Suffering and the Family, which we seek in every way to establish a level of optimal cooperation with. We try to do the same thing with the referring hospital doctors in order to ensure the best continuity of care possible.

In conclusion what are the relevant and peculiar aspects of the ANT HHO model?

- The new idea. In a historical moment in which the health care organization was geared to long-

term care and classical hospitalization Prof. Pannuti proposed a model absolutely revolutionary and yet extraordinarily timely.

- Reproducibility of the model that in fact it has been realizing in very different local, socio-economic and cultural environment.
- Different ethical-cultural basic compared to the usual canons of medicine, in which there is an enhanced and central relationship between physician and patient instead of bureaucracy and protocols. Ability to offer a model of medicine geared to positivity and hope even in the most delicate phase of life, bringing the patient and families to still have the desire to live, not to end it.
- The cheapness of the system. The costs of the service offered by Ant are vastly lower than those for admissions in hospital or in hospice.

Affirmation and realization of the true principles of subsidiarity, freedom of choice, equal dignity between public and private.

Simultaneous Care in Oncology

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Despite significant improvements in recent decades for early diagnosis and treatment of cancer, 30-35% of patients occurs at the onset of disease in the metastatic phase, and die within 12-24 months. Patients with advanced incurable cancer face complex physical, psychological, social and spiritual consequences of disease and its treatment. Care for these patients should include an individualised assessment of the patient's needs, goals, and preferences throughout the course of illness. In recent years a large number of studies have demonstrated the importance of associating in a systematic way both palliative care for symptoms relief and cancer therapies in patients in advanced phase, obtaining not only a benefit on all the parameters of quality of life, and reduced aggressive treatment at the end of life, but in some cases, even a prolonged survival.

Palliative care concurrent with usual oncology care is now endorsed by ASCO because it results in better quality of life, better quality of care, improved symptom management, and equal or better survival. In particular ASCO identified the Key elements of individualized care for patients with advanced cancer:

1. Patients should be well informed about their prognosis and treatment, ensuring that they have opportunities to make their preferences and concerns regarding treatment and supportive care known;
2. Anticancer therapy should be discussed and offered when evidence supports a reasonable chance of providing meaningful clinical benefit;
3. Options to prioritize and enhance patient's quality of life should be discussed at the time advanced cancer is diagnosed and throughout the course of illness along with development of a treatment plan that includes goals of therapy;
4. Conversation about anticancer interventions should include information on likelihood of response, the nature of response, and the adverse effects and risks of any therapy.
5. Whenever possible, patients with advanced cancer should be given the opportunity to participate in clinical trials or other forms of research that may improve their outcomes or improve the care of future patients.
6. When disease-directed options are exhausted, patients should be encouraged to transition to symptom-directed palliative care alone with the goal of minimizing physical and emotional suffering and ensuring that patients with advanced cancer are given the opportunity to die with dignity and peace of mind.

In this approach, it is necessary that the oncologist and the patient work together to address the issue of prognosis of cancer treatments in a frank, realistic and honest balance between a potential efficacy and toxicity waiting, avoiding unrealistic hopes. Today this attitude as well as being the most appropriate for the patient to ensure the best quality of life, is a categorical imperative in order to avoid unnecessary therapy and allowing a greater margin of medication use in patients who may benefit from them real.

The simultaneous care model, the new paradigm of care for cancer patients, was included in the National Cancer Plan 2010-13 as a priority objective for the quality of life of patients. The simultaneous care model require a strong cultural and organizational change essential for sharing purposes, values and programming at the level of oncological units, multidisciplinary teams, oncology departments and community services.

The Role of Non Profit Organizations in Palliative Care

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Is a fact that non-profit organizations (NPO) have had and continue to maintain a key role in the consolidation and growth of palliative care in Italy.

I believe that the origin of this phenomenon is to be found in the very definition of palliative care. A definition that defies conventional labels: palliative care is first and foremost a medical discipline, but the term “treatment” means also a global assistance. It is focused on paying close attention to communication, seeking answers to the psychological, spiritual, relational needs of patients and their family. But even that runs out the size of Palliative Care. They are a social movement aimed at promoting cultural growth, to assert fundamental rights and promote the development of services.

A movement that engages and mobilizes large sectors of civil society: it is motivated professionals and sensitive, but most of people, often marked by the experience of loss of a sick family member, able to unite their efforts in Associations, Foundations, Social Cooperatives, which constitute the body of ONP in palliative care. It is thanks to these forces and their twenty-year history that in March leads to the law 38, at the same time point of arrival and departure for the aging and the increase of palliative care. More than a passing of Law 38 refers to non-profit organizations, recognizing their role and giving them strong responsibility. In particular, the measure identifies three different areas:

- With the agreement between the State-Regions of 25 July, in detailing the provisions of Article 5, paragraph 3, is made explicit and recognizes the value of participation of ONP to the network services. With the reform of Title V of 2001, it is in fact reversed the assumption that, since the 80s, he starred assistance activities by NPOs as supplementary areas of inefficiency in the public sector. in accordance with the principle of subsidiarity instead “the State, regions, metropolitan cities, provinces and municipalities shall promote the autonomous initiatives of citizens, individually and in combination, to carry out activities of general interest. Nationals and especially to their forms of association is then recognized the legitimacy and responsibility of organizing to better respond to the needs that characterize their local community. The government has the task, just as active, to promote the initiative of the associations. Italian citizens responded significantly to this call to responsibility. today a quarter of Hospice and UCP home are managed by non-profit organizations, and other non-profit organization financially support the majority of public centers ensuring continuity.

- With Article 8, the law recognizes the value of the volunteer in CP and defines the need for a “homogeneous training on the national territory.” A so strong passage on the needs to train volunteers, implicitly identifies a complex role and can not be replaced by the professional team.

the idea that the volunteer in palliative care requires detailed important skills and limits itself to carry himself in a spontaneous way in the relationship with the patient. Once again a qualification entitling to citizens and voluntary associations spaces of intervention and responsibility, if not caught will leave these patients without response to specific needs.

The law 38 mentions once again the non-profit organization in the context of art. 4 on the “information campaign”. The law acknowledges that providing palliative care in Italy means promoting

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a cultural revolution. It means overcoming prejudices and myths about the potential and the role of medicine and doctors and introduce new values and rights provided by law and masterfully articulated in the 14 criteria on the understanding of 25 July.

Due to their widespread distribution in Italy and the local roots, associations have the potential to produce a cultural change in the contexts in which they operate. Especially thanks to the volunteers and their ability, in fact if properly trained to operate their transmission belt between the places of care and the context in which they live and work.

Thanks to the volunteer understands and moves in its environment due to the perception of how palliative care can cope with the illness and death with dignity, free of pain and close to their loved ones.

The development of palliative care is an example of how in some areas has made the principle of subsidiarity. In the professional component of the accredited service provider, NPOs have made possible the necessary services to their community.

In their part of voluntary associations are formed by people aware that the suffering of a patient and his family belong to the local community in which it is born. The answer can not be delegated to any institution, as a major component of the responses to the needs are in solidarity and closeness to the people. Hence the responsibility of the volunteer, but also that of every citizen.

Core Curriculum of the Palliative Care Physician

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Palliative Care is proposed as a therapeutic and care process aimed not only to control the symptoms, but especially to defend and to recover the best possible quality of life, implementing interventions that involve also the psychological, social and spiritual aspects.

In Italy, Law n. 38/2010 “Measures to ensure the access to palliative care and pain therapy” is the first law on palliative care that opens the way for the development of palliative care in our Country. This Law binds the physician and all the social and health workers to take care of pain and suffering, recognizing the protection of the dignity of the human person as a right.

In the European scenery, Law n. 38/10 sets an example because it establishes the ethical responsibility to guarantee access to palliative care and pain therapy for patients and their families; in Europe this is the first example where an outline law obliges a health care system to face palliative care and pain therapy in all the possible intervention areas.

Nowadays in many parts of our Country there are many units of Palliative Care, such as home care and hospices. The challenge for the coming years will be to let the nodes of that network have the best communication, in order to protect the dignity of the patient and preserve it throughout the course of treatment.

In the sphere of the Network of Palliative Care, in response to the needs of patients and their families, working as a team is the best operating mode: this requires a constant professional integration by all the operators involved. The specificity of skills in the context of palliative care services is determined by the ability to respond effectively to the patient and family during the last period of the disease, giving voice to the needs of the patients and respecting their values and their will and also creating an empathic relationship between patient and the care team. The setting and the management of the care pathway provides a clinical interdisciplinary and multi-professional approach centered on the patient, re-defining continually needs and goals of care in agreement with both patient and family.

Therefore it is necessary to harmonize and enhance the value of competences of various professionals who interact during the period of care and assistance.

In addition, to pay attention to the simplification of procedures for access to medicines used in the treatment of pain, Article 8 of Law n. 38/10 says: “training and refresher courses for medical and health professionals on palliative care and pain management”.

Article 8 paragraph 1 of Law n. 38/10, “identifies with one or more decrees the general criteria for the regulation of the teaching of specific courses in the field of palliative care and pain management related to neoplastic diseases and chronic conditions and degenerative diseases and with the same decrees are determined the criteria for the establishment of master's degree in palliative care and pain therapy “; article 8 paragraph 2 “it provides that the periodic update of the medical staff,

health and social-health, engaged in the treatment of pain associated with neoplastic diseases and chronic and degenerative diseases and assisting in the field of palliative care, and particular hospital doctors, medical specialists outpatient authorities, general practitioners and paediatricians, is realized through the achievement of credits of multidisciplinary and multi-professional care pathways “

Article 3 paragraph .8 “it identifies the contents of the mandatory training courses under the legislation in force, for the purpose of carrying out professional activities in public health facilities and private and non-profit organizations operating in the two networks for health and for the palliative treatment of pain, including the periods of compulsory internship at the facilities of the two networks “and, finally, article 8 paragraph 4” are defined uniform training courses throughout the national territory for the volunteers who work in the two networks. “

Although in different forms (specialty or sub-specialty) at an international level, since several years, palliative care has been recognized as an autonomous discipline. For some time, in many European Countries has been produced the Study Curriculum, specific for the training of physicians in Palliative Care; a specific body of knowledge and competences for Palliative Care is already recognized internationally and nationally. Even the European Association of Palliative Care (EAPC) has produced and is continually updating specific and autonomous study curricula for operators in Palliative Care.

That is because the Italian Society for Palliative Care (SICP) has decided to realize the “Core Curriculum of Palliative Physician” emerged from the work of a group of experts, along with the specific curricula of general practitioners, nurses, psychologists, physiotherapists and social workers who work in the Network, just to give an authoritative contribution to the definition of the contents provided by the compulsory training, as required by Article 8 paragraph 3 of Law n. 38/10.

The document outlines the map of competences of the physician in the field of palliative care; the document also defines the specificity of the training objectives to provide expertise and assistance to respond to the patient's changing condition. The core competences of the palliative physician are: 1. Knowing how to evaluate patients and families for their access to palliative care (PC); 2. Being able to receive a patient and his family in palliative care services (PC); 3. Knowing how to take care of the sick in different care settings; 4. Knowing how to take care of the family in different care settings; 5. Ability to work in teams in different care settings; 6. Knowing how to deal with ethical and medical-legal problems; 7. Knowing how to do research in palliative care (PC) 8. Knowing how to activate and manage a palliative care service (home care, hospice, hospital, Network), 9. Knowing how to train in palliative care (PC).

The “Core Curriculum of Palliative Physician” wants to be a chance to work on a sharing terminology, contents and objectives at a national level; at the same time it wants to foster communication among the teachers in the field of palliative care. The Core Curriculum represents a dedicated indispensable tool for the planning of the training program in Palliative Care: it aims to train physicians and professional workers so that they become expert in assisting patients with advanced and terminal disease and in managing the symptoms to relieve the patient from suffering.

The SICP has promoted and strongly supported the goal of a more and more precise definition of new disciplinary contents sure that this could be a decisive element for the recognition, even in our Country, of an autonomous discipline in Palliative Care.

The recent legislation considers Palliative Care as a field of Medicine with strong autonomy con-

tents which deserve professional and organizational autonomy, as well as specific training courses.

On G.U. 89 of 16 April 2012 were published the decrees relating to the establishment of five University Masters of training and qualification in palliative care and pain therapy, including one specifically dedicated to palliative care. The establishment of these highly qualified masters, in addition to those Masters of Palliative Care that have been organized in many Italian Universities from more than ten years, opened new opportunities for the training of professionals who work or would like to work in the Networks of Palliative Care.

The agreement State-Regions of 25 July 2012 defines the minimum requirements and the organizational arrangements necessary for the accreditation of assistance facilities to terminal patients, palliative care units and pain therapy, it provides expressly the establishment of the “Palliative Care” discipline for the purposes of the competition rules for the executive medical staff of the National Health System. It is a fundamental act, that if applied, will be able to develop networks in a uniform manner throughout the Country. Structural and process dimensions that characterize the Network of Palliative Care were defined with the Regions as a functional and integrated aggregation of activities provided in different care settings in a defined territory. All these activities must be able to meet several requirements among which the creation of organizational and coordinating structures, the operation of dedicated multi-professional teams, a unique path of home care through a Home Palliative Care Unit, the continuity of care between the hospital, the home and the hospice.

With the approval of the National Health Council, On February, the 7th of 2013, the Standing Conference for Relations between State and Regions and Autonomous Provinces marked the identification of “Palliative Care” discipline in the Area of diagnostic medicine and services for the professional category of doctors, including the disciplines in which may be conferred the complex structure of executive positions in public health institutions. In the Decree of 28 March 2013 published in the Official Gazette (22 April 2013) “Change and integration of Tables A and B referred to in the Decree of 30 January 1998 relating to the services and specializations equivalent”, were also agreed services and schools equivalent (Hematology, Geriatrics, infectious Diseases, Internal Medicine, Neurology, Oncology, Paediatrics, Radiation Therapy, Anesthesiology and Intensive Care).

Thanks to this Decree, Palliative Care, as an autonomous discipline, is confronted with equal dignity with other disciplines, with the aim of ensuring palliative care to all terminal patients, not only the oncological ones, in a well-defined organizational framework in both structural and process size. This Discipline is included among the disciplines in which may be conferred executive positions of complex structure for the professional profiles of the leadership role of health care, it is an historic achievement for the world of palliative care and it is an important milestone in the path of application of Law n. 38/10.

It has been then formally recognized, with full dignity, the “specificity” of knowledge and abilities that palliative care specialists, with their daily activities, have arduously built on the clinical, healthcare and scientific field.

The establishment of the Discipline has substantially contributed to the processing of Core Curricula for all professionals who work in the network that SICP has developed from the “Core Curriculum of Palliative Physician”, published by SICP in July 2012.

Nowadays there are all elements of security for the citizen. Just think about the concept of the “dignity of life until the end” of article 1 paragraph 2 of Law n. 38/10 and the concept of “Local Network of Palliative Care,” posing “the person and the family” at the center of an individualized, holistic, multidisciplinary and multi-professional intervention.

In our Country, the recent approval of an autonomous discipline of palliative care, the correct definition of specific competences relating to this new discipline and the publication of the curriculum of the Italian Society of Palliative Care for palliative care physicians, next to the growing recognition in many European Countries about the importance of a specialty in palliative medicine (already present in England since 1987) necessitates a further and deeper reflection on these issues in the field of SICP.

On the training plan, as a Scientific Society, our commitment will be the promotion of pre-graduate and post-graduate training courses in palliative care to create the conditions in order that professionals, meditating on embarking a palliative path, can look at Palliative Care with confidence, since in our Country it is an area of medicine already established and recognized.

The University Education and Training

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Aspects relating to university education in palliative care are divided into two settings: the pre-graduate and post-graduate education. In the international field programs are very heterogeneous. In Italy, the pre-graduate training has been examined by a committee established by the Conference of Presidents of Degree in Medicine and Surgery. The proposal is to create a sort of “teaching back” to cover the 6-year course planned for graduation.

The educational programs of post-graduate courses (masters) in palliative care and in pain treatment have been recently approved by the Ministry of the Health and the Ministry of the University. 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. The professional training on field must cover the half of the overall courses.

By the approval of such masters the availability of well trained professionals, nurses and physicians, who wish to work in the palliative care area, will be guaranteed.

Teaching to Communicate

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Communication between palliative care professionals (HPs) (e.g. physicians, nurses, social workers), 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, and addressing end of life and bereavement issues are some of the most common challenging topics of communication for HPs, because of the number of significant emotional and interpersonal implications. In fact, the need for communication skills training has become increasingly important in core curricula in oncology and palliative care. While the majority of training models have been developed and tested in the US, UK and northern Europe, available data suggest that southern Europe is moving in the same direction. Specific areas of need include dealing with depression and denial, managing uncertainty, assessing psychological symptoms, promoting open exchange of information between patients and family. Information regarding how to effectively address the communication training needs of HPs in southern Europe suggests that communication can be taught and that courses substantially help participants to include new communication techniques in their practice. Training workshops and course in communication have shown to be particularly helpful if organized in small groups, with a “student-centered” approach, and if based on techniques (such as role-play and socio-drama) addressing health care professionals emotions and behaviors, favoring the expression of participants’ feelings and mutual support between participants. Experiences, supported by research data, in Italy by using such methodology have proved to be efficacious among HPs working in palliative care.

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Pharmacological Basis of Pain

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A significant proportion of subjects in Western countries suffers from chronic pain for which treatments are frequently suboptimal either due to the occurrence of adverse events or for partial pain management. In particular, chronic pain control with opiate analgesics is often hampered by the development of analgesic tolerance and hyperalgesia, necessitating frequent dose adaptation or change in the administered drug to achieve pain relief. There is a major need for renewed focus on novel targets that will be effective in both neuropathic and nociceptive pain (Salvemini et al., 2013).

The pharmacologic basis of pain control is an extremely complex area of research as many factors contribute to the physiopathology of pain.

There is evidence to suggest that certain excitatory amino acids such as glycine and glutamate via the NMDA receptor play a central role in sustaining nociceptive transmission, particularly after deafferentation (Osenbach, 2013). It has been shown that competitive or noncompetitive NMDA receptor antagonists can reduce these hyperactive states, both in the spinal cord and in the cerebral cortex. Ketamine is a noncompetitive NMDA receptor antagonist that has been used for many years as an anesthetic agent. Ketamine also has well-recognized analgesic properties at subanesthetic doses, and it has been suggested that these analgesic effects are also mediated at the NMDA receptor site (Osenbach, 2013).

Prostaglandin E2 (PGE2) and its receptor are involved in the induction of pain. As we now know, prostaglandins are not themselves significant mediators of pain; instead, they increase the sensitivity of nociceptors to other stimuli in pathological tissues. They switch normally non-excitatory polymodal receptors ('silent nociceptors') into a state in which they are easily excitable (Steinmeyer et al., 2000).

GABA-A receptor agonists, including barbiturates and benzodiazepines, have also been shown to be effective in some patients. The analgesic effects of GABA-A receptor agonists probably occur through multiple mechanisms of antinociception, including membrane stabilization, inhibition of excitatory neurotransmitter release, suppression of calcium channels, lowering of postsynaptic receptor-mediated responses to excitatory amino acids, interference with intracellular second messengers, depression of sodium channels, and enhancement of the GABA neurotransmission. Some of the ultrashort-acting barbiturates have been reported to be successful in blocking the effects of excitatory amino acids in synaptic transmission (Osenbach, 2013).

Finally, morphine is an opioid agonist that has traditionally been believed to be very effective in nociceptive pain but unsatisfactory for the treatment of neuropathic pain. Morphine is most effective for nociceptive pain that is generated by the activation of peripheral nociceptors, a situation that is quite different from that encountered in central pain syndromes. Unfortunately, it is often difficult to identify the exact cause of intractable pain, and in some patients components of both deafferentation and nociceptive pain certainly coexist. It is not entirely clear why morphine

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is effective in some cases of central pain, although it is likely that fairly complex mechanisms are involved (Osenbach, 2013).

In conclusion, pain pharmacology is a highly complex area of clinical research due to the concomitant contribution of many actors that act either peripherally and centrally as well, and the unmet need of personalization of treatments to address the specific pain physiopathology on an individual basis.

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From the Pharmacological Basis of Pain to the Bed of the Patient

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Introduction

Appropriate use of opioids is crucial to reach analgesia in patients with chronic pain. Pharmacological proprieties and several clinical aspects should be considered to manage patients with opioids combined with other drugs. Also genetics aspect may interfere with opioids response and each patient has his own analgesic response after the administration of an opioid.

Receptor agonism

Opioids work by binding to the same receptors of some endogenous substances (encephalin, endorphins and dynorphins). Endogenous and exogenous agonists for the receptors (μ , κ and δ) can induce a variety of biological actions including analgesia. The activation of the receptor for opioids induces the activation of a G protein, which in turn leads to variation of cell permeability to ions involved in the neuronal transmission. Activation of opioid receptors decreases Ca^{2+} ion entry into the cell and reduces presynaptic neuro-transmitter release, including substance P. Also the GABAergic system seems to be involved in opioid mechanism. All these mechanisms, and other still poorly known, suggest that opioids can induce a different response in each subject according to the number of receptors available or the capacity of interaction between the agonist and the receptor itself.

Pharmacokinetic

The effects of opioids (analgesia, nausea, vomiting, etc.) are due to the pharmacodynamics activity common to all compounds available today, while the pharmacokinetic properties may vary significantly from one molecule to another (availability, lipophilicity, elimination half-life, metabolism). The analgesic response (subjective) and the pharmacokinetic differences suggest that the dose, route of administration, frequency of administration, may vary from subject to subject.

Dose of opioid and titration

The analgesic response induced by an opioid depends not only on affinity for their receptors, but also on the bioavailability, the ability to reach the site of action (distribution), on drug interactions, and also on the ability to express receptors by individual. This suggests that in any case we have to start the treatment with the lowest dose available, and then gradually increase the dose on the basis of subject's response. This soft start (titration) allows us to avoid initiation of treatment with a dose too high in relation to the needs and achieve the lowest effective dose for each patient.

For those same reasons, regulatory authorities suggest using slow release formulations only after the patient has achieved a stable dose of normal release opioid.

Often, if drug titration is rigorously applied and maintenance carefully scrutinized, side effects are limited and can be successfully controlled.

Low doses of opioids, rather than high doses of NSAIDs administered for long periods of time, should be favored by general practitioners. The use of the lowest dose may also allow to better manage chronic non cancer pain.

Route of administration

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The ideal route of administration is the oral route. However, there are clinical situations preventing the oral route and we are forced to use analgesic therapy in other ways. But there are also situations in which the alternative pathway appears to be more rapid in inducing pain relief. In fact, the treatment of breakthrough cancer pain can benefit from opioids such as rapid absorption via the nasal route. This route allows us to achieve the most rapid pain relief with a lower dose than other routes of administration.

Drug Interaction

Patients with cancer pain may receive multiple drugs due to several comorbidity and the related polypharmacy.

Pharmacokinetics and pharmacodynamic alteration can also result by food or chemical substance, not only by drug-drug interactions.

Interactions may result from interference during the phase of absorption (bioavailability), during transport and diffusion, during the binding step on the site of action (agonism-antagonism), during the metabolism and elimination. All interactions can induce a variation of the biological effect of the opioid (and of the combined drugs) with modification of the benefit-risk ratio. This suggests that in patients treated with many medications opioid therapy must be implemented with proper titration to search for the lowest effective dose and the lowest interacting dose.

Final suggestions

Analgesia is a personalized therapy. It must take account of the clinical situation, and pharmacological aspects of the urgency of the treatment.

Opioid therapy requires dose titration, and although some researchers are considering the initiation of treatment with alternative methods, it is not appropriate to apply a change of this standard in the routine.

Once the optimal dose of normal release opioid is reached we can carry out a rotation to another formulation. Optimal treatment of the baseline pain also causes a reduction in the number of BTP that can be effectively treated with a titration of rapid onset opioids.

In addition to the pharmacological properties, type of disease, and the clinical setting, also the patient's preference should be carefully considered.

Furthermore, the management of opioid therapy should be related with a proper communication in order to share with the patient (and the care giver) a therapeutic plan in order to enhance opioid compliance.

All patients should be screened for a systematic survey of pain and BTcP and the treatment should be rapidly implemented avoiding unnecessary pain to any sufferer. In this sense the Law 38 of 15 March 2010 invites every practitioner to fight pain. Also for patients at home is crucial to investigate oncologic pain as ANT Foundation is doing in synergy with Alitti Foundation.

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Pain Control in the Continuity of the Home-Care

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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. Among other reasons this may be ascribed to the nature of the various organizational barriers to effective pain management. There is ample evidence to demonstrate that both physicians and nurses lack experience and knowledge regarding modern methods of pain control. This situation not only results in poor clinical decision making, but has also generated a number of extraordinary myths and misconceptions about the use of opioids. Such myths and misconceptions often result in significant under-medication of the patient's pain. Problems can also exist with continuity of care; the patient may be seen by a number of different physicians across a number of different health care settings where unclear responsibility for the overall management of the patient's pain may exist. Further fragmentation can occur due to lack of communication between the hospital and the community care setting. This problem can be compounded by incomplete and inconsistent documentation of pain. An important and often overlooked problem relating to opioid use is the existence of bureaucratic regulations governing the supply, prescription and administration of opioids in many countries world wide.

Continuity of care is achieved by bridging discrete elements in the care pathway—whether different episodes, interventions by different providers, or changes in illness status—as well as by supporting aspects that endure intrinsically over time, such as patients' values, sustained relationships, and care plans. Processes designed to improve continuity—for example, care pathways and case management—do not themselves equate to continuity. For continuity to exist, care must be experienced as connected and coherent. For patients and their families, the experience of continuity is the perception that providers know what has happened before, that different providers agree on a management plan, and that a provider who knows them will care for them in the future. For providers, the experience of continuity relates to their perception that they have sufficient knowledge and information about a patient to best apply their professional competence and the confidence that their care inputs will be recognised and pursued by other providers. The experience of continuity may differ for the patient and the providers, posing a challenge to evaluators. Although the notion of continuity varies in different care contexts, whatever the context, all types of continuity can contribute to better quality of care.

The essential components of palliative care are effective control of symptoms and effective communication with patients, their families, and others involved in their care. Rehabilitation, with the aim of maximising independence, is also essential to good care. As a disease progresses, continuity of care becomes increasingly important—coordination between services is required, and information must be transferred promptly and efficiently between professionals in the community, in hospitals, and in hospices.

For most patients, physical pain is only one of several symptoms. Relief of pain should therefore be seen as part of a comprehensive pattern of care encompassing the physical, psychological, social, and spiritual aspects of suffering. Physical aspects of pain cannot be treated in isolation from other aspects, nor can patients' anxieties be effectively addressed when patients are suffering physically. The various components must be addressed simultaneously. The first principle of managing cancer pain is an adequate and full assessment of the cause of the pain, bearing in mind that

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most patients have more than one pain and different pains have different causes. A comprehensive knowledge of the underlying pathophysiology of pain is essential for effective management. With effective assessment and a systematic approach to the choice of analgesics, over 80% of cancer pain can be controlled with the use of inexpensive drugs that can be self administered by mouth at regular intervals. Consideration must always be given to treating the underlying cause of the pain by means of surgery, radiotherapy, chemotherapy, or other appropriate measures of analgesia techniques.

Some pains do not respond well to opioids. Although no pain can be assessed as unresponsive to opioids before a careful therapeutic trial of the drug, some pains are more commonly poorly responsive to opioids. These include bone, neuropathic, and visceral pain. Adjuvant drugs, radiotherapy, and anaesthetic block techniques may be helpful in such cases. The indications for administration of strong opioids by intrathecal or epidural routes remain somewhat controversial. There is agreement that patients with pain that is sensitive to opioids who experience intolerable adverse effects with systemic administration may be able to tolerate epidural or intrathecal administration, since much smaller doses of opioid are required to get the same analgesic effect. More relevant research is needed to sort out which interventions aiming to improve continuity of care in the follow-up of patients with cancer are the most beneficial to improve patient, provider and process of care outcomes. Future research should identify which outcomes are the most sensitive to change and the most meaningful regarding continuity of care. Also, it would be valuable to develop a standardised instrument to measure continuity of care in patients with cancer. In our region we have developed a pain diary as a follow up instrument. Patients self report their pain scores and therapy on this personal diary and ideally they may make it available anytime they interact with health care provider.

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Specific Approach to Breakthrough Pain in Daily Clinical Practice

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Breakthrough pain is still a challenge, that significantly affects the quality of life of patients with cancer pain, and has a deep impact on daily clinical practice. Physically, it adversely affects mobility (i.e. walking) and sleep; from the psychological point of view, it has important implications for anxiety, mood, depression, with serious social consequences and inability in the activities of daily living. (Portenoy, 1999; Caraceni, 2004)

Over the past 5 years much research and literature has been produced on this subject, trying to identify a shared language for definition, classification, and proper assessment; at the same time many advances have been recorded in the pharmacological treatment with the rise on the international scene of Rapid Onset Opioids.

Breakthrough pain was first defined in 1990 by Portenoy and Hagen in these terms: “in the cancer population, the term breakthrough pain typically refers to a transitory flare of pain in the setting of chronic (background) pain managed with opioid drugs”. (Portenoy 1990)

The current most reliable definition comes from the Association for Palliative medicine of Great Britain and Ireland, that consider BTP as “a transient exacerbation of pain that occurs either spontaneously, or in relation to a specific predictable or unpredictable trigger, despite relatively stable and adequately controlled background pain”, which takes into account predictable (volitional) or unpredictable (involuntary) trigger factors. (Davies, 2009; Zeppetella 2011)

This definition, however, gives way for some questions:

-What should be the difference in intensity between the baseline and transient exacerbation of pain to be defined BTP?

- Can it occur at different sites and have different characteristics from the baseline pain?

- Can it be considered really BTP, that one related to predictable, and therefore preventable, triggers (i.e. procedural pain)?

A group of Italian experts has proposed a very specific definition, although not currently validated by an international consensus: “transitory exacerbation of pain of high intensity (at least 3 points > baseline pain and absolute intensity between 7-10 NRS), usually with frequency not more than 4 episodes per day, which occurs either spontaneously or as a result of predictable or unpredictable trigger factors, compared with a baseline pain adequately controlled (i.e. NRS ≤ 4, defined as average pain in the last 24 hours) by means of an ATC (around the clock) opioid treatment “ (Corli 2011)

Epidemiology

BTP prevalence varies between 20 and 90% depending on the patient group and definition used. A task force of the International Association for the Study of Pain (IASP) evaluated the prevalence and characteristics of BTP as part of a prospective, cross-sectional survey of cancer pain (Caraceni 2004): clinicians reported breakthrough pain in 65% of patients. The first published survey of cancer patients who experienced breakthrough pain on top of well-controlled baseline pain reported a prevalence close to the 64% (Portenoy 1990).

A recent systematic review and a pooled analysis of published literature showed a mean BTP prevalence of 56% (p-value >0.0001) significantly differing based on the care setting, age and sex of

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patients, average and worse intensity of baseline pain (Corli 2011)

Classification

Until a few years ago three fundamental types of BTP were deemed: incident pain, which recognized a trigger mainly attributable to movement (i.e., characteristic of bone lesions); idiopathic breakthrough pain, not linked to the movement nor in general to a specific trigger; end-of-dose failure pain, associated to the declining level of the background analgesic.

However, currently this last specific subtype of BTP was critically questioned:

- it's related to inadequate background pain control, due to inadequate dose of drug, a too long interval between doses, or to an early depletion of the analgesic effect of a slow release formulation that does not adequately cover the expected time for analgesia;

- it's clinically slow and progressive, and tends to recur regularly over time related to the administration of medications. (Corli 2011)

The predictability of end-of-dose failure pain necessarily make it manageable with appropriate strategy; the typical approach is generally to increase the dose of ATC or to reduce the interval between doses.

Even the painful episodes that may occur during the initial opioid titration are not identified as BTP, but simply as "exacerbations of background pain "

The current classification of BTP refers to its relationship to specific events:

A. SPONTANEOUS (idiopathic pain): episodes are not correlated to any trigger factor, and therefore are unpredictable.

B. INCIDENT: episodes are related to trigger factors, and therefore are somewhat predictable. The incident pain is under-classified into 3 categories:

1. Volitional: Induced by voluntary activity, such as walking
2. Non volitional: Induced by involuntary activities, such as coughing
3. Procedural pain, related to therapeutic or care interventions, for example, a wound dressing (Davies 2009).



Breakthrough Pain classification
(Davies 2009)

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Making diagnosis and measuring BTP at the bedside in daily clinical context.

The most important issue is to assess the type of pain: are we truly treating breakthrough pain or are we instead treating pain resulting from undertreated baseline pain?

No validated tool for the clinical assessment of breakthrough pain currently exists, even if the Alberta Breakthrough Pain Assessment Tool has been validated in the original language in the context of clinical research. (Hagen 2008).

Breakthrough pain is usually characterized according to its location, severity, temporal characteristics, relationship to regular analgesia, precipitating factors, predictability, pathophysiology, aetiology, impact on quality of life and palliative factors. (Davis 2009)

It is important to differentiate breakthrough from background pain and, in particular, uncontrolled background pain, because inadequate assessment may lead to the utilization of ineffective or inappropriate treatment.

Clinical features of BTP

Breakthrough pain is not a single condition, but a range of very different conditions, and clinical features vary from individual to individual. Nevertheless, breakthrough pain is usually described as frequent in occurrence, acute in onset, short in duration, and moderate-to-severe in intensity. The clinical features of the breakthrough pain are often related to the clinical features of the background pain.

Breakthrough pain may result in a number of physical problems (i.e. related to reduced activity and movement), psychological problems (i.e. increased levels of anxiety and depression), and social complications (i.e. decreased levels of social interaction), with a consequent significant negative impact on the quality of life of the patient and carers. (Caraceni 2004, Corli 2011)

It has been stressed that patients who complain of breakthrough pain, in addition to requiring a rescue medication, require a greater dose escalation of ATC opioid compared to those who have not BTP, in direct proportion to the number of daily episodes. (Corli 2011)

Treatment of BTP

Currently there are no standard evidence based guidelines for the treatment of BTP, but mainly "Consensus statements" based on experts opinion, given the limited data and still many unknowns, such as the recommendations of the Association for Palliative Medicine of Great Britain and Ireland (APM, Davis 2009), the European Society of Medical Oncology clinical guidelines (ESMO, Ripamonti 2011), and the recommendations from the European Association for Palliative Care (EAPC, Caraceni 2012).

The use of supplemental doses of analgesics as needed (rescue medication) is the mainstay of treatment strategy for managing breakthrough pain.

The ideal rescue medication should be efficacious, patient friendly, with a rapid onset of action, a relatively short duration of action, and minimal adverse effects.

For unpredictable or non-volitional pains, rescue medication has to be used as soon as pain starts, whereas in predictable, volitional or procedural pains, it can be used prophylactically even before the expected event occurs.

Immediate release oral morphine, for its pharmacokinetic characteristics, does not fit the temporal characteristics of BTP; it may take up to 30 or 45 minutes to become effective, while the peak intensity of episodic pain can occur between 5 and 15 minutes. (Mercadante 2010, Caraceni 2012). The occurrence of so-called R.O.O. (rapid onset opioids) has updated the fundamentals of rescue therapy for BTP; among them fentanyl, administered by transmucosal route, has taken a dominant role.

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Fentanyl is an μ -agonist, 80 times more potent than morphine, highly lipophilic and well absorbed through the mucosa, either oral and nasal, making it much faster than morphine and oxycodone to penetrate the BBB and reach the CNS.

In recent years new formulations of fentanyl citrate have become available, in addition to the transmucosal formulation (OTFC), such as buccal (Fentanyl Buccal Tablet, Fentanyl Buccal Soluble Film), sublingual (Sublingual Fentanyl) and intranasal (Fentanyl intranasal Spray and Fentanyl Pectin Nasal Spray), with attractive features, from the point of view of both pharmacokinetic (rapid absorption, higher bioavailability and efficacy) and compliance (easier route of administration).

EAPC guidelines emphasize that buccal or intranasal fentanyl is preferable to immediate release oral opioid, for a more rapid action and shorter duration of effect, and indicate that immediate-release formulations of opioids may be otherwise used to pre-treat predictable episodes of BTP in the previous 20-30 minutes (weak recommendation) (Caraceni 2012)

An open question in daily clinical practice concerns the need or not to titrate the dose at the start of treatment with ROOs.

According to APM guidelines the proper dose must be identified by individual titration (Evidence B) (Davies 2009). Treatment, according to indications of individual drugs, should be started with the lowest dose (200 mcg for OTFC, 100 mcg for FBT, FSL and PeclNFS; 50 mcg for INFS); it should be used up to two doses/episode and for no more than 4 breakthrough episodes/day.

However, the need for titration may lead to several problems:

- It can make it difficult to use the ROO in the daily practice, particularly at home
- The need to use more tablets or spray for each episode can be "time-consuming", i.e. the time necessary to relieving may become greater than the spontaneous relief (as evidenced by the successful treatment of some patients with placebo)
- Most of patients may be reluctant to several tries, and may leave the ROO preferring at the end, the "good old" oral morphine. (Mercadante 2009, 2011)

Indeed, if the ROO is started at too low doses, the attempt to titrate individually the dosage can result in unnecessary suffering, lower compliance and refusal to continue the treatment. (Mercadante 2011)

Several studies have not clearly demonstrated correlations between ATC opioid dose and rescue dose of transmucosal fentanyl, but an association has been shown in 2 open-label studies and one observational cohort study. (EAPC 2002, Zeppetella 2011, Caraceni 2012)

In several studies, the "ex post" computed effective rescue dose determined by titration was quite similar, and reflected an average value of 15% of the daily dose, not far away from the hypothesis of a standardized and proportional dose. (Corli 2011)

The need to titrate the initial dose has never been determined on the basis of a real comparison between the two strategies: titration and non-titration.

Patients receiving high doses of ATC opioids would be not candidates for titration with low initial doses of ROO, either because tolerant, and because the titration process would take too long. A reasonable compromise could be to start with relatively higher doses of ROO in tolerant patients. (Mercadante 2009) Moreover, also EAPC guidelines stress that experienced professionals often begin treatment with higher doses than those recommended for starting titration in patients already receiving high doses of opioids (Caraceni 2012)

In conclusion, there is not enough evidence to make a strong recommendation for titration "tout court", and there is not enough evidence to suggest a dose proportionality, instead as it was in EAPC 2001 and 2002 guidelines for oral morphine.

The existing guidelines are based on "expert opinion"; the choice is, as always, customized and

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tailored to each individual patient. It is likely that factors such as patients' preference and ease of administration will continue to be key determinants in deciding the most appropriate formulation for individual patients.

Finally, patients and their carers require careful explanations and 'health education' to help them recognize persistent pain and differentiate it from episodes of breakthrough pain, as well as for a correct administration and taking rescue medications.

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“Kit for Pain Relief” Project

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Background

Pain is a global and subjective experience with a deep negative impact on persons' quality of life. Although the Italian law 38/2010's aim was to improve the management of pain and, consequently, its treatment, the use of opioids in the fight against pain is at a very low level in Italy.

In 2012-2013 Alitti Foundation and ANT Foundation have carried out a special project to give a contribution to the application of the Italian law 38 /2010.

Alitti Foundation was founded in 1993 under the holograph of Dr. Leonida Alitti which, thanks to its availability and its generosity, has designated a large portion of its possessions to the foundation, whose rents were useful to the attainment of institutional purposes. It is a not-for-profit and pursues exclusively charitable purposes social sectors on health care, education and training. These activities will be aimed at improving the quality of life of disadvantaged people, with particular reference to the sick in the terminal phase.

Ant Foundation, founded in Bologna in 1978 by Professor Franco Pannuti, is a not-for-profit organization and one of the leading private organizations working in the field of palliative care and pain management in Italy.

It's the most experienced provider of free home care to tumour sufferers in Italy and Europe: since 1985 ANT has assisted 93.042 sufferers in 20 home oncology clinics (Oncological hospital at home, OHH-ANT) in 9 Italian regions; there are currently 3800 patients receiving care throughout Italy. ANT offers specialized care provided by 400 healthcare professionals, including doctors, nurses, psychologists, nutritionists, physiotherapists, social-health workers, pharmacists and other employees, who are able to provide patients with round the clock care, 365 days of the year. ANT Foundation guarantees the fundamental rights of cancer patients through the Eubiosia project: eubiosia is defined as “set of qualities that gives life dignity”.

The project

Alitti Foundation has realized an instrument called “kit for pain relief” : it includes a pamphlet, a diary for the daily registration of pain, a ruler with pain scales, the text of law 38/2010.

The pamphlet contains information about pain: what it is, how it is measured, the pharmacological opportunity, the role of caregiver and the management of the therapy. It's complete, easy to read and translated in more languages.

The diary consists in two parts: the first is used for the daily registration of the basic pain intensity with NSR value (0-10) and the second is used for the registration of the number of BTcP episodes in a day (0-10). Patient directly, or helping by caregiver, completes diary one time a day for 15 days consecutively. Every patient is identified with a number.

The ruler facilitates the measurement of pain: Vas scale for adult and Visual scale for children is given to the patient who has to indicate on it the intensity of his own pain. Subsequently, we obtain the conversion of the algic intensity into a given number which is reported in the diary.

This kit is employed for patients with chronic pain and it's used to improve the self consciousness of patients and the communication with physicians who can establish or modified a pharmacological therapy, following the guidelines suggested by the WHO.

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The project has three purposes:

1. To inform the sufferer about the law 38/2010, about opportunity and prospects of pain care;
2. To give the patient an instrument for daily pain measurement that allows the monitoring of this symptom;
3. To analyse the relationship between pain and clinical characteristics of patients.

ANT Foundation's physicians have given this kit to all sufferers receiving care at home by Ant at the date of 1 December 2012 and to all new patients until 30 April 2013.

ANT doctors and nurses have the task to give the kit, explain the diary use, check the right compilation and take back the diary after 15 days. During this period the diary is used by doctors to establish or modified a pharmacological therapy.

Health care professionals insert patients' conditions, pain characteristics and clinical practices in an electronic patient's summary by informatic system Vitaever.

Vitaever is a SaaS solution (software as-a-service) for hospital-at home; it's a smart and intuitive technology to manage home-based healthcare as well as assistance services.

The diaries' schedule have been analysed by an automatic program; the program Vitaever has been used to analyse the relationship between pain and clinical characteristics of patients.

Results

At 1th of December 2012 ANT Foundation assists 3606 sufferers free at home; from 1th of December to 30 April 2013 there were 2584 new patients.

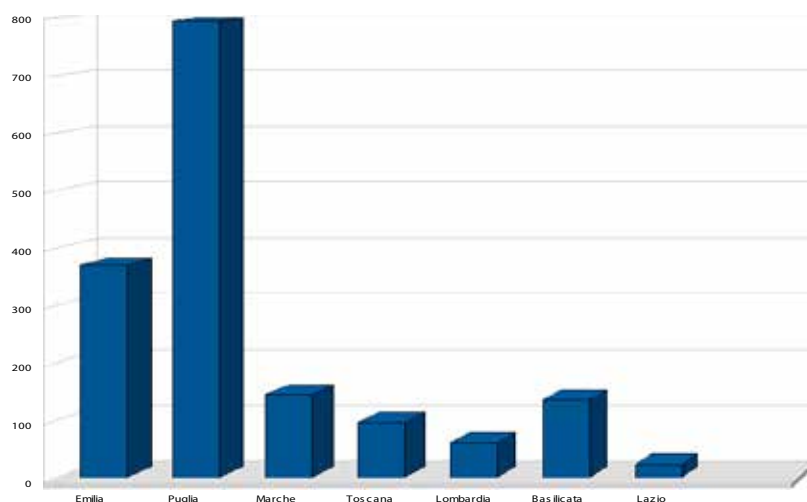
We distributed 4630 kits to cancer sufferers in Italy, without distinction of clinical conditions, cancer typology, disease stadium, current therapy.

The diary has been used directly by patients or by the caregivers' help. This method cannot be applied to individuals in a state of confusion, in a state of sedation or with an intellectual deficit. We collected 1695 (36,6%) pain diaries from 8 regions in Italy (fig.1).

We didn't collect empty, incomplete or not well completed diaries: the most frequent errors are the absence of the date or of the identification number of the patient and the presence of more than one mark in a single date.

About 40% of the diaries was not used: many patients didn't want to use the diary, many patients died during the first 15 days or became unable to use it because of intellectual impairment.

The analysis of pain and of relationship between pain and clinical characteristics of patients is in progress and the results will be presented at the site Congress.



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Conclusion

This project has obtained a good outcome: 4630 sufferers and their family have been informed about law 38/2010, about opportunities and prospects of pain care.

1695 patients have correctly used the diary to monitor their pain intensity and BTcP episodes.

This kit has been useful in the medical relationship between the doctor and the patient and it has been useful for the therapeutic efficacy in the fight against pain.

This project shows that a correct approach to pain management is possible in home setting, thanks to instruments like "kit for pain relief" and thanks to home round the clock assistance.

This methodology is useful to guarantee a dignified life right up until one's last breath, according to Eubiosia project.

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Palliative Care is now recognized as an important public health issue. This concept of palliative care within a public health framework had its origins in the seminal work of Dr. Jan Stjernsward, WHO's Cancer Unit Director. He developed the WHO Model for cancer control that advocated for a comprehensive approach to include cancer prevention, treatment and care. He emphasized that each country needed to develop its cancer control program based on the needs of its population and the available resources but that all countries needed to develop strategies that addressed prevention, early diagnosis and treatment, and palliative care. In resource limited countries, the majority of patients present with advanced incurable cancers and therefore, the need to provide care that addressed their quality of life and their symptom management was the ethical and moral approach to take. Palliative care was initially then defined in the context of care for the cancer patient and closely identified with end of life care. The definition stated that palliative care is "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount." The goal of palliative care is the achievement of the best possible quality of life for patients and families. This definition was revised in 2002 expanding its scope to patients with life limiting illnesses like patients with HIV/AIDS and Non- Communicable Diseases (NCD's) including public health language such as the word "prevention." The new WHO definition described palliative care "as an approach that seeks to improve the quality of life of patients and families facing life threatening illnesses through the prevention and relief of suffering and by means of early identification and impeccable assessment of pain and other problems, physical, psychosocial, and spiritual." This definition was further adjusted in the WHO pediatric palliative care monograph published in 1998 further expanding the role of palliative care emphasizing that it could begin at the time of diagnosis and be provided concurrently with active therapies creating a new framework to upstream palliative care approaches.

As of 2013, the term palliative care is embedded in WHO public health policies including those related to NCD's (Non- Communicable Diseases), TB, HIV/AIDS, Pediatrics and Geriatrics. Some actors have called for a reevaluation of the WHO definition and even the use of the term itself, but the term palliative care now has solid integration into both international and national public health policies making definition discussions a potentially risky endeavor.

Palliative care is now also recognized as fundamental to health and human dignity and is a basic human right. The United Nations Committee on Economic, Social, and Cultural Rights asserted that "states are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons...to preventative, curative and palliative health services." The Special Rapporteur on Torture is of the opinion that de facto denial of access to pain relief, if it causes severe pain and suffering, "constitutes cruel, inhuman or degrading treatments or punishment." Using rights-related language and rights-based strategies to support palliative care integration in national and international health policy has opened the door for a larger group of actors and activists to support the integration of palliative care into health systems through these right to health and torture frameworks.

The need for palliative care is enormous with WHO estimates that range from 4-6 million people with cancer needing palliative care to 100 million patients, their families and caregivers worldwi-

de if we include all causes of death. Worldwide, there are 7-9 million children with life limiting and life threatening conditions requiring palliative care and 80% of these live in resource limited countries. Yet, palliative care coverage even in high resource countries is no more than 50%-70% of those who might benefit and palliative care integration is slow and incremental. There are numerous models of palliative care integration that will be discussed in this conference demonstrating the range of approaches to create responsive healthcare systems to care for this population of patients. Numerous resource-limited countries like Uganda, Zambia, Kenya, and Vietnam to name only a few, have adopted palliative care policies into their cancer and HIV/AIDS strategies. Data on palliative care integration from several atlases, WHO, EAPC, LAPCA, describe both the progress and the variation. For example, palliative care for HIV/AIDS in Africa is most commonly delivered in home-based, community based programs. In the US, the greatest growth in palliative care has been in hospitals with more than 60% of large hospitals having palliative care consultation teams.

For a world's 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. National and international research in palliative care has demonstrated evidence to support palliative care's role in enhancing quality of life and mood, improving symptom management, reducing costs of end of life care and in some cases, prolonging life. Much of this data has come from studies in cancer patients receiving palliative care. Data on the impact of palliative care in HIV/ AIDS shows increased compliance with therapy and improved symptom management and improved quality of life. Research on palliative care in patients with dementia, cardiac disease, and neurodegenerative diseases have not yet yielded sufficient results except to say that palliative care services appear to improve quality of life and symptom management and contain costs. But lack of a rich resource base in palliative care research is not the only barrier to integrating palliative care into national health strategies. What continues to be a major barrier is the cultural variation about talking about and planning for end of life care and the value a country places on care for those who are dying.

What also remains a serious barrier worldwide is the lack of communication about decisions at the end of life between patients and their physicians and between patients and their families. In the US, the use of advanced directives has increased in the last 15 years, and studies demonstrate that when patients are informed about their prognosis and illness severity and participate in a process of shared decision making about their goals of care they will choose palliative care services earlier. Such a choice often saves health care dollars. Communication about these issues is critical yet thwarted by cultural attitudes, lack of professional expertise, and misguided fear of negatively impacting the patient and family with bad news. Other important barriers include the lack of specialty status for palliative care in many countries limiting the size of the workforce to care for the large number of patients who would benefit from such services and limiting physician reimbursement.

International and national advocacy efforts play a major role in asserting and inserting palliative care in all international health debates and discussions. These efforts are now showing some progress with palliative care now included in the new WHO definition of universal health coverage. Palliative care is seen as a "needed health service" and "part of a minimum set of health care services." There remains a need for a more focused advocacy approach to address some of these specific barriers related to communication, workforce and specialty status of palliative care if we are to be successful in developing a world view of palliative care which emphasizes that it is accessible to all that might benefit from it.

Palliative Care in UK

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Each year approximately 550,000 deaths are registered across the four nations of the United Kingdom. There are four health and social care systems and very clear national differences in patterns of mortality. However, each of the four nations has set out a clear and committed approach to improving end of life care. In England, the Government published a 10 year End of life Care Strategy in 2008; we have a Delivery plan in Wales; a Partnership in Scotland & a Palliative & End of life Care Strategy in Northern Ireland. The last decade has seen an enhanced understanding and stronger focus on end of life care across the UK.

Over coming decade(s), the biggest challenges facing end of life care in the UK will come from dealing with shifting demographics and on-going austerity. The UK has a rapidly ageing population; by 2030 we expect the number of people over 85 years of age to have doubled and that 80% of these people are likely to have multiple morbidities. With an ageing population comes a greater number of deaths amongst older people, with greater complexity of need and the potential for greater hospital use, particularly in the last year of life. Higginson et al estimate an increase of 17% is by 2030. Whilst it is suggested that the number of deaths amongst those aged 85 years+ will increase by 48%. This poses a fundamental challenge for end of life care and the wider health and social care system. Our task is to meet that challenge.

For those in the last weeks and months of life in the UK, care is delivered in a range of different settings - in hospitals, people's own homes, social care and nursing homes and hospices. A number of key factors which have helped underpin and strengthen palliative and end of life care in the UK over recent decades. First, is the development of a medical specialism in palliative medicine. From specialist education and training through to the deployment of specialist palliative care teams in major hospitals and other institutions, the role of palliative care is well established and highly respected. Second, the development of a strong research base with cutting edge academic and clinical research from the institutions such as the Marie Curie Institutes and Cicely Saunders Institute which help to shape both policy and practice, by testing complex healthcare interventions, with an increasing focus on a range of different conditions and population groups. Third, the role of NHS and specifically access to free health care and the role of General Practice. Fourth, the role and contribution of the voluntary sector in shaping and providing end of life and palliative care, both through hospices and community based nursing services. Charities have been at the forefront of driving innovation in palliative and end of life care. Charities such as Marie Curie deliver community based services which both enable more people to die in their place of choice and reduces A & E and hospital in-patient use in the last months of life.

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. When asked about their priorities, people say that pain relief is the top priority. The reality is that there is a significant disconnection between what people want and what they experience – the

latest figures show that 53% of people die in hospital, 21% at home, 18% in a care home and 5% in a hospice. Although we have seen a small rise in the number of deaths at home between 2004 and 2010 from 18.3% to 20.8%. Given the changing demographics this is too slow.

The VOICES Survey tells us so much about the experiences of bereaved families and their loved ones in the final weeks of life. The clear message is that hospitals are clearly not the best places for people to die – across measures such as quality of care, dignity and respect and even pain management hospitals score worse than other settings such as hospices and care homes.

People consistently say that hospitals are the place they least want to die, yet this is where the majority of people continue to die. The Francis, Cavendish and Neuberger reviews have all shone a renewed focus on care in hospitals.

When faced with the conundrum of how we deliver improved care, to more people with less money, then it is clear that we need a major shift in the way we deliver end of life care. This shift must be underpinned by a move away from acute, hospital based services to more responsive and flexible community services. The charitable sector must be at the heart of this shift. We have the track record in delivering high quality services, funding and academic and clinical research and innovation and the most effective use of ever scarce resources.

Palliative and End-of-Life Care in Flanders/Belgium

Paul Vanden Berghe

Federation Palliative Care Flanders; Belgium

Introduction

Palliative care and end-of-life care in Belgium, and especially in Flanders (the northern, Dutch-speaking part of the country), have an overall good reputation, due to the highly motivated volunteers and professionals that started the development of this young branch of public healthcare in the late 1980s. The legalisation of euthanasia did not harm this solid position, as over the past ten years this practice was gradually integrated into regular palliative care practice. Due to demographic and societal tendencies, with continuously growing workload, palliative care increasingly becomes the victim of its own success. Added to this workload is the support by specialised palliative caregivers of euthanasia requests and other decisions at the end of life (entailing not only medical but also ethical, psychological, spiritual and legal dimensions). At the same time, many needs (control of physical, psychological, social and spiritual symptoms) remain unmet as palliative care is called in too late.

1. Some Fact & Figures

- Good palliative care: Belgium ranks 4th/5th worldwide on the quality of death index of the Economist Intelligence Unit (2010).
- Provisions for specialised palliative care cover the whole country, 45 palliative care units in hospitals (379 beds), a hospital consultant team in every hospital, 28 Home Care Teams (15 in Flanders, 4 in Brussels and 9 in Wallonia) and 6 Palliative Day Services. A palliative reference person is available in a majority of homes for the elderly.
- Place of Death 2010 (in Flanders; no numbers for the country): 49,6% die in hospital, 22,9% at home, 24% in care homes for the elderly and 3,5% in other places.
- In 2011 almost one in two non-sudden Flemish deaths were supported by specialised palliative care, i.e. palliative care teams in hospitals and palliative care units, home for the elderly and in home care (data collected by palliative networks for the Flemish Community).
- The general budget for palliative care is modest (approx. < 0,5% of public Health Care Budget); for different locations see the Report of Evaluation of Palliative Care 2008 by the Federal Health Authority: p. 57 in French - for estimates of costs of treating terminal patients in different health care settings: 'Organisation of Palliative Care in Belgium' KCE-report 115 C, 2009, pp.144-169 (This first national study by the Belgian Health Care Knowledge Centre also deals with the definition of the palliative patient, palliative population (prevalence), patients' expectations and needs, and palliative care models.)

The Federation Palliative Care Flanders holds an emancipatory view: organised/specialised palliative care seeks to empower health care professionals to enhance their own palliative care knowledge, competencies and attitudes, with the help of palliative care professionals. In the same way the general population and patients are stimulated to reflect on and communicate their preferences, so as to assure optimal comfort at the end of life.

Following the vote in 2002 on the Euthanasia Act, Palliative Care Act and Patients' Rights Act, the Federation Palliative Care Flanders published its viewpoint on the relationship between palliative care and euthanasia in 2003 and 2011: 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.

2. Challenges

a. financial constraints on health care brought about by recent evolutions in medicine, demography, public finance and political structure of the Belgian state: choices need to be made.

b. need for further professionalization without losing the 'spirit' of palliative care: more competence building in spiritual care, introduction of educational programs for palliative care in all basic curricula, development and introduction of instruments in palliative care (e.g. guidelines and care pathways, quality indicators...), better bedside valorisation of the results of scientific research, capacity building in palliative care, better corporate governance in palliative care organisations.

c. sensitisation of the public improving end-of-life care:

- Threat of an instrumental approach to dealing with death and dying: just like illness, dying too is a social construct, and palliative care professional experience an unmistakeable tendency by e.g. family to regard dying as something 'undignified' that should not take too long. In this respect, the philosophy and values of palliative care deserve consideration: there is nothing wrong with dying taking time ['its course'], and – without idealising it – this need not be painful, if palliative care is sought in a timely manner (i.e., earlier than the average time now). Good palliative care is a matter not only of 'doing for', but also of 'being (present) with' the patient.

- Threat of overaccentuating the value of autonomy: just like life itself, so too dying is a social process, in which people are also profoundly related to each other: patient, family, friends and palliative care professionals. "It is ok to be dependent on others; you should not think of yourself as 'a burden'."

- Threat of legalism: good end-of-life practice (including Advance Care Planning and advance directives) has a legal basis, but good care goes beyond laws (and guidelines and care pathways...).

3. Options for the near future: New definition and identification of the palliative patient and new target groups of palliative and end-of-life care

- The definition of the palliative patient ("a patient suffering from (1) an incurable, (2) progressive, (3) life-threatening disease (4) with no possibility to obtain remission or stabilization or restraining of this illness" KCE-Report 115C 2009, p. 24) should be distinguished from access to financial support. In this sense all stakeholders in palliative care are currently working on a national level in the Federal Palliative Care Evaluation Committee on the more timely identification of the palliative patient (starting with the Surprise Question and a version of the Supportive and Palliative Care Indicators Tools (SPICT), adapted to Belgian health care. What is important is the distinction drawn between the palliative and the terminal status as well as the focus on the needs, rather than on the life expectancy, of the patient, who also may be suffering from non-oncological pathologies. This must result in a scale evaluating the palliative needs of a patient: basic (ACP), advanced and full palliative status with corresponding care provisions and allowances and/or reimbursement.

- The target groups of palliative and end-of-life care will profoundly enlarge due to a threefold evolution: (a) the described earlier identification of the palliative patient, (b) the taking charge by palliative care of patients with a request for euthanasia, and (c) the commitment to provide palliative care for children, psychiatric patients, people with a disability, and people suffering from non-oncological conditions.

Palliative Cancer Care in Germany

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The cancer problem in Germany is characterized by increasing incidence within a population becoming older and older. The life expectancy of the total population is about 80 years (1). Actually live about 1,45 million people with cancer diagnosed during the last 5 years in Germany (2). Cancer mortality is high. After a significant decrease in 1990 related with the unification of East and West Germany and the more effective cancer control in East Germany (3) mortality now is changing minimally (4). Last reports of the Robert Koch Institute report for 2008 an age-standardized cancer mortality of 205,6 (man) and 130,5 (women) per 100 000 Europe-population (4). The country takes up place 14/37 (man) and 15 /37 (women) in Europe far from the level of Nordic countries (5). This is in accordance with the analysis of the US-American Commonwealth Fund, reporting that 82% of GP's in Germany call for basic changes in the German Health Care (6). In 2008 there were 215 442 cases of death from cancer registered (4). The absolute 5-year-survival is 50% for man and 57% for women. This situation is unsatisfactory and was criticized at the German Cancer Congress in 2012 (7, 8). There are several proposals to change the situation as the call for more innovations (9), better cancer registry (10,11), all within a "National Cancer Plan (12).

Doubtless, there is urgent need for qualified palliative care for advanced cancer. Already during the "German Physician's Day" 2011 there was a long discussion on palliative medicine in general (13) with the conclusion that "palliative medicine in Germany is a concept for future". On the list of topics for this concept was a call for more outpatient structures, new chairs at universities, better financial support for research in the field and continuous support for existing and new in-bed structures (14). In 2010 there were 160 palliative care units in Germany with 1228 beds what means 15 beds /1 million inhabitants (15). Demand analysis consider 35 beds /million inhabitants. There are several efforts to improve the situation. Not to forget 140 in-bed hospices (16). Nevertheless, in 2012 it was evaluated "palliative care in Germany is a rag rug "(17). Certainly, it is very positive that since 2007 in Germany there is a patients right for specialized outpatient care (SAPV), but still are many gaps in the network, particularly on the country-side. A study performed 2011 including 11 584 patients with cancer showed 15,8 % of patients classified as having palliative care needs (18).

My specific evaluation of palliative cancer care in German will be based on Franco Pannuti's idea of Eubiosia which is a milestone in the field. Eubiosia means life and dying with an incurable disease without pain and in dignity which is a human right (19,20). After 35 years of ANT, Eubiosia is not more a dream, but a realistic aim to overcome human suffering from advanced cancer.

The main problem doing this evaluation is the fact that no definitive data are registered. Until 1990 there was a population-based National Cancer Registry in the former GDR (East Germany). In the moment of unification this registry was eliminated. However, based on reports from single regions in Germany at least an approximate view on the most important parts of palliative care is possible. I thank all German colleagues for active support.

Pain control

Based on the available data it seems to be sure that 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 (21). Regional differences can no be overseen. Oechsle reports for Hamburg 80% pain in the moment when advanced cancer patients are admitted to a palliative care inpatient ward (22). 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 (23). In contrast, more optimistic reports are coming from Essen and Neubrandenburg (24, 25). Possible reasons for insufficient treatment of pain are non-availability of doctors, their training but even inadequate organisational 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 counselling by a professional within the education programme help the patients to adopt new attitudes toward analgesics and gradually reduce their pain level (26). Moreover, this will stop the march forward of business-making alternative medicine visible also in Germany.

Dignity of life until the end

There are several aspects of dignity of life. The most important point is the place where patients receive palliative care. In Germany 66% of advanced cancer patients prefer to be self-determined until the end and to die at home (27). However, a study in Rhineland-Palatinate shows that only 38,2% of the deceased died at home (28). Dying at home is possible if effective structures are established for palliative care at home. 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 states-financed outpatient care for anybody who want it (29). The majority of cancer patients feels comfortable with their transition from inpatient to outpatient care (30). There are continuous efforts to qualify this system. It works very well in case of inclusion of GP's well-educated in palliative care (31) and in case that palliative symptom control in outpatients is performed by qualified and interdisciplinary palliative care teams (32). GP's evaluate that the perception of patients in specialized palliative care with its current focus on cancer patients is different from the perception in general practice (33). This may be a reason for the scepticism showed in studies investigating whether SAPV improves health care (34). Therefore actual efforts are focused on the expectations of GPs and their training. Expectation means adequate planning of resources. It can not be overseen that in Germany, particularly on the country side, there is a growing deficit of GPs (35). With respect to training it looks better. In 2010, 96% of GPs underlined the importance of SAPV and found the available guidelines very useful (36).

Close related with the problem of home care are the problems of care-giving families. There are quantitative and qualitative aspects. The first means that the low fertility of 1,3 in Germany creates growing problems to have care-giving family members. Even in Germany the public is not only concerned about medical problems in advanced cancer but also about being a burden. Female care givers need, above all, psychosocial support, whereas older caregivers need the most support in physical and social level (37,38). In this respect it is very positive that in Germany a large network of voluntary organisations 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 (31,39). Without this engagement would be no chance for dignity end of life of all advanced cancer patients in Germany. Unfortunately, this engagement can not overcome all existing problems. Most critical is the situation with respect to the professional care giving staff. The German philosophy of invitation of "cheap" immigrants is no solution (40, 41) and state pressure directed on cost-reduction in the field of palliative care for cancer patients is not justified. As reported several times by the German Society for Pain, financial support for outpatient palliative care is insufficient. 2009 were available

for end of life care 28 Million Euro. From that only 9.6 million were used for outpatient care (42). To look for a solution of this problem by more inpatient care is an illusion because of cost and it is in contrast to the wishes of patients. 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 population) available (43). 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. Doubtless, there are even other problems. To quantify these problems needs careful monitoring by data registration. However, until now there is no registration and documentation. Experts call for a simple documentation with overlap to available KISS Systems which can be used by internet (31).

In summary in Germany there are numerous problems concerning palliative care and there is no guarantee of Eubiosia for all (44). 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 (45). There are numerous activities of physicians and their organisations to reduce this imbalance. A main problem is the fact that underdeveloped palliative care promotes the call for Euthanasia and medical assisted suicide even in Germany. Available data show that more than 70% of the population support legal approaches of Euthanasia (46). The opinion of German physicians is very different (47 ,48) However, it can not be overseen that in 2012 about 50% of physicians supported assisted suicide (49) Very important words on euthanasia came in 2011 from Hohendorf in the "Deutsche Ärzteblatt" (50) writing: "The argument of autonomy creates reduction of patients 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." Certainly, this is a position in full accordance with the conception of Eubiosia.

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Palliative care in Hungary. Misbeliefs and Reality

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Aims: Hospice and palliative care exists in Hungary since 1991. Unfortunately, there are still misbeliefs about this subject which slow down progress and cause problems in all levels. The aim is to show common misbeliefs and face them with reality to help the social and professional acceptance of palliative care.

Results: The most common misbeliefs are: „hospice care is needed only in the few last days of life”, “hospice is a house where dying patients are put”, “there is no difference between hospice-palliative care and long-term care”, “there is no need to do more than holding the dying person’s hand”, “in Hungary, hospice does not really exist”, “you have to pay for hospice care”, “it is administered only through foundations”, “hospice is equal to old age care”. In reality, the 90 institutional and home hospice care providers, which have been financed through the national health insurance system since 2004, provided palliative care for over 7500 patients last year and have an essential role in education and raising awareness. Besides efficient multi-level professional staff hospice education, palliative care has been integrated into medical residency training. Furthermore, a sub-special training in palliative care will be introduced and the first university department for palliative care has been opened.

Conclusion: Cancer, death and dying are still considered as taboo subjects, consequently, caring for dying are also looked at as taboo questions. It seems to be the main causes of misbeliefs – and not only in Hungary.

Pediatric Palliative Home Care in Poland

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The aim of the study was to evaluate the current status of pediatric palliative home care in Poland. The survey based on the questionnaire, which analyzed annual number of patients and deaths, diagnoses, age, and place of living. The annual number of treated children per million of inhabitants was calculated. The data about 1240 patients (1176 children and 64 young adults with pediatric conditions) was obtained from 45 hospices. The total home care area covers for 95% of the population of Poland. The number of treated children per million inhabitants is diverse in different provinces, the highest in the Małopolski province and the lowest in the Lubuski province. There are still regions where pediatric palliative home care is not accessible. Therefore, the authors suggest establishment of two new hospices in Mława and Czuluchów.

Palliative Care in Spain

“Saiatu Project”: an In-Home Socio-Emotional End of Life Programme

Naomi Hasson

The Saiatu Project; Spain

A growing number of patients who have been diagnosed with a terminal illness would prefer to spend the last months of their lives at home.

Extensive research demonstrates that in home end of life treatment provides better quality care in the last phase of their lives, for both the patient and their family. Hospices provide a great quality service but given the choice, a large number of families would prefer to stay at home.

The current Health Care services offer good medical assistance but this is not enough to allow patients to die at home. Even if they have very good symptom control, relatives panic in moments of crisis and the patient is very often hospitalized unnecessarily.

Saiatu covers this gap in end of life care, preparing the main carer and the family for the whole dying process and offering 24 hour personal and professional support.

With this new approach, a significant number of families are able to remain at home feeling that they have received a much better service than had they been hospitalized.

The Health and Social services work in a more efficient way and direct savings are generated due to the reduction of emergency admissions, hospitalization and badly managed grieving process.

The present project organises the new portfolio of services provided by a social care service within palliative care.

Despite being a pilot study (i.e., the performance is expected to improve in the future), the SAIATU Programme shows how resources developed from a social care perspective, can be cost-effective & efficient for a healthcare system:

- Reducing the use of hospital resources & associated costs
- Promoting an increase in at-home treatment with a greater participation of primary care professionals
- While being rated as satisfactory by families
- With the lack of previous examples, SAIATU could become a model programme in the field.

In a recent study carried out by Herrera et al, a great impact on cost efficiency was observed but the data used was retrospective; accordingly, the scale of the programme should be extended & a prospective study undertaken to validate these preliminary results:

- The first evaluation of this pilot project demonstrates that most of the families supported by Saiatu die at home, having had a more positive experience than the traditional health care approach.
- Health and Social Care professionals also evaluate this service as complimentary to the existing resources and protocols.
- Saiatu significantly reduces the number of hospital admissions during the last 100 days of life. Initial calculations show that this services could generate savings of around 5000 euro per family in Spain.
- Saiatu primarily benefits the user (cancer patients) and the family, who receive a more comprehensive care service based on the needs expressed by the family as opposed to a standard solution. Professionals will have the necessary time to assess and prepare the patient and the family about the process they are going to live and will support them in moment of crisis.
- Above all, Saiatu will accompany the family in managing the spiritual needs that are such a huge

part of life and death. In some cases, it can even transform death from a traumatic experience into a more positive one.

- This project benefits health care assistants, informal carers and nurses to become more specialized and highly valued professionals in an area of growing needs.

- Saiatu also benefits the hospitals (Health Service) and social workers (Social services), by reducing the use of emergency, hospitalization and related services.

- In the specific field of cancer care, Saiatu fills the gap of providing rapid response during the last weeks of life, complementing a previously made expensive investment.

We express our thanks for all collaborators who have made this event possible.



TETRAPAK

Media Partner **VITA**

UN TUMORE CAMBIA LA VITA. NON IL SUO VALORE.

Lo staff medico che lavora per ANT assiste ogni giorno 4.000 malati di tumore nelle loro case, gratuitamente e con uno standard qualitativo pari a quello ospedaliero, permettendo loro di continuare ad avere il conforto del proprio ambiente familiare. Preservando la dignità di chi soffre, difendiamo il valore della vita.



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