



## POSITION PAPER

### PALLIATIVE CARE, PEDIATRIC PALLIATIVE CARE AND PAIN THERAPY: HUMANIZATION OF CARE

**GROUP LEADER:** Basilicata Region

**OTHER PARTNERS:** Calabria; Campania; Lazio; Marche; Piemonte; Prov. Aut. di Trento; Sicilia; Toscana; Umbria; Veneto.

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## 1. Introduction

Demographic change and aging are among the greatest and complex challenges faced by Europe. Recent projections show that the number of European adults aged 65 will almost double over the next 50 years, rising from 87 million in 2010 to 148 million in 2060. The European Innovation Partnership on Active and Healthy Ageing (EIP-AHA) aims at increasing the average healthy lifespan of EU citizens by two years by 2020 and ensuring a healthier and longer working life.

In this context it is crucial to guarantee adequate pain management and pain treatment as well as prevention, diagnosis and treatment, especially in the field of chronic illness. Due to the increase of lifespan expectancy, a great number of people in Europe is already suffering from several chronic degenerative diseases which are common in elderly people (such as cardiac, respiratory, cerebrovascular, neoplastic diseases). People affected by these diseases often suffer of acute pain and in many cases this distress lasts until the end of their lives. These people must be entitled to high-quality palliative care for extended period.

**Palliative Care** (WHO Definition, 2002) is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

**Palliative Care for Children** (WHO Definition, 2002) is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Palliative Care for Children must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care [for Children] requires a broad multidisciplinary approach that includes the family and makes use of available community resources.

**Pain Therapy.** The International Association for the Study of Pain (IASP) defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. Chronic pain is any pain lasting more than 3 weeks or that persists beyond the time one would expect normal healing to occur (Bonica, 1953).

The European Charter of Patients’ Rights (Council of Europe Recommendation Rec (2003) 24 of the Committee of Ministers to Member States on the organisation of palliative care) states that each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. Therefore, in addition to prevention, diagnosis and treatment of the diseases, all patients



should be provided with an optimal level of pain control, alongside psychological and emotional support.

**Humanization of care** is identified as the focus on the person as a whole, taking into consideration physical, psychological and relational needs.

It must bear in mind that humanization of care should proceed in parallel with the scientific and technological progress in the field of health. This means that health providers need to be aware about the patients', and their families, needs.

## 2. WHY DRAW UP A POSITION PAPER?

The Italian system is at the cutting edge of the palliative care law in Europe. As a matter of fact, Italy has a specific legislation in this field since 2010 when the Law n. 38 has been adopted (*Law on Provisions to ensure the access to palliative care and pain therapies*). This law for the first time, protects and guarantees the access to care and treatment as part of the essential levels of assistance and ensures respect for the dignity and autonomy of the individual, equity, appropriateness, protection and promotion of quality of life in each phase of the illness, particularly in the final stages. In order to ensure these treatments, in any evolving pathology, for each age and setting, the implementation of national and local networks has been strengthened. These networks bring together all stakeholders and resources available in the territory, including non-profit organisations and social sector.

Italian Regions have adapted their organizational models in adherence with the Law n. 38/ 2010, in order to:

- Make the access to palliative treatments easier according to an integrate and continuative path care;
- Set up public campaigns to raise awareness about the culture of relief from physical and spiritual pain, fully respecting the patients' rights and considering that the relief is not only desirable, but also a possible and concrete choice for the patients and their families;
- Ensure the quality of treatments in compliance with the minimum standards set up by the national legislation;
- Ensure specific training for all concerned healthcare providers.

The Italian best practices can be identified in three main areas:

1. the organizational model based on networks:

- **"Regional network for palliative care"** (MoU State-Regions rep 152, 25 July 2012). This network promotes an integrated and interoperable approach among acute care hospitals, general practitioners, home care, units of pain management and palliative care, hospice for palliative care;
- **"Regional Network for pain therapy"** (MoU State-Regions rep 152, 25 July 2012), This network brings together a wide range of centres such as day hospital and out-patient clinics, out-patient pain therapy centres, hospices for pain therapy. This network includes specialized activities oriented to the diagnosis, treatment and rehabilitation of painful pathology.



• **Network for Paediatric Palliative Care and Paediatric Pain Management.** The network foresees an integrated care pathway for pain therapy and palliative care for children delivered in different care settings (clinics and hospitals), as defined at regional level. The Italian Excellence started in 2008 when the Project “Palliative care for children with chronic diseases” was launched. The project, supported by the Italian Regions, aimed at ensuring the best possible quality of life for children with irreversible disease and their families.

2. the health system governance, which foresees three levels of coordination: national, regional and local (health and hospital trusts), as laid down in the State-Regions Agreement rep n. 239 of 16.12.2010.

3. uniformity and universality of healthcare service delivery throughout the country, with specific reference to the Regional dimension as per the MoU approved on July 25, 2012 between the State and the Italian Regions.

In some Regions, palliative care is considered as a strategic objective within the regional health policy framework and consequentially specific indicators have been adopted in order to assess and measure the effective health service delivery.

### 3. SCOPE AND AREA OF INTEREST

The debate between the central level (Ministry of Health) and the regional level in regard to palliative care, paediatric palliative care, pain therapy (humanization of care) has generated an interesting discussion which shall produce the following actions:

- 1) Awareness-raising campaign;
- 2) Offering practical support to patients and their families to cope with death, grief and loss, offering when needed spiritual and moral support;
- 3) Continuing education and training to GPs which should be constantly validated and monitored;
- 4) Promotion and partnership of the Non-profit sector within an integrated care approach;
- 5) Evaluation of alternative approaches to the pain treatment;  
Non-pharmacological therapies in paediatric pain
- 6) Testing and validation of antalgic approaches in patients who do not respond to conventional therapies;
- 7) Humanization of care;  
Establishment of national and European courses in the field of humanization of care



## 8) Narrative Medicine

**4. CONCLUSIONS AND FINAL RECOMMENDATIONS**

In Italy it is possible to identify, with reference to the Law 38/2010, networks focusing on palliative care, paediatric palliative care and pain therapy. There is a strong need of enhancing their role and activities. Specifically these main aspects should be addressed in close collaboration with the Commission and the Member States:

- Creation and consolidation of National Networks related to palliative care, paediatric palliative care and pain therapy. This should be done in accordance with the Italian national and regional strategy, which must include the basic elements of: prevention, diagnosis, treatment and monitoring.
- Establish stronger synergies among health authorities, patients and medical staff, with the goal to increase the treatment standards. This may be obtained through the development of guidelines on pharmacological and non-pharmacological treatment of chronic pain and its monitoring.
- Ensure an equitable access to therapy and medicines, at all the levels and with special attention to the opioids. This to diminish inequalities in health at regional and national level in Europe.
- Pay particular attention to the identification of therapies for vulnerable patients such as children, elders, and disabled people at neurocognitive and sensorial level.
- Promote national communication campaigns with the aim to influence a broad audience explaining which social, medical and financial impact has palliative care on families, patients, social workers, health workers. In addition citizen should be informed on their rights and access methodologies.
- Establish university and post-university courses, together with permanent trainings to upgrade medical staff and social workers involved in the assistance in the field of palliative care. This with the aim to create a culture around the topic and rise awareness in relation to prevention, diagnosis, management of chronic pain and palliative care, having always in mind the child dimension.

The Italian Regions would like to receive some feedback on the following topics from the European Commission and the Member States:

- Sharing of data, strategies and models at European level in the field of pain therapy and palliative care. With a special focus on the activities conducted by high level centers, with the goal to share best practices.



- Promote local initiatives to support the civil society and its organizations to educate and inform patients on their rights to palliative care.
- Ensure access to therapy to all the children both for palliative care and chronic pain.
- The European Commission should refer to the topic of research in the field of palliative care in the future work programme of Horizon2020.
- Establish a national European day against pain, or more generally patients’ rights, with the aim to raise awareness among the public opinion in collaboration with the non –profit sector and the patients organizations.
- Create a European Day for Palliative Care with the above mentioned goals and in addition access to care for everybody effected by a chronic-degenerative disorder in a late stage.

To conclude the European Commission should:

- Support the Member States to establish a European Network including National Health Authorities involved in the field of palliative care and pain therapy, with the goal to share best practices, conduct benchmarking activities, monitoring and evaluation.
- Support the Member States in the harmonization of practices and the definition of quality standards. This can be achieved through the definition of national and international guidelines.
- Promote a harmonized system to measure the degree of pain and its evaluation. This to report in the patient file the scale of pain together with the therapy against pain implemented and the medicines prescribed in the frame of the implementation of the Directive 2011/24/UE.
- Support the Member States in the development of a database useful to monitor structural indicators.

##### **5. Ministers/Heads of Delegations shall consider the following questions for the debate:**

- The Italian Law 2010/38 (Provisions to ensure the access to palliative care and pain therapies) constrains the competent authorities to ensure palliative care and pain therapy both to adult and paediatric patients. How is the right of access to palliative care guaranteed to EU citizens?
- The Italian commitment during the implementation of the Law 2010/38 focused on setting up specific networks (hospices, home care, etc.) in close collaboration with the Italian Regions. Are there similar networks in other European countries which can foster the creation of an European network on palliative care?
- The Law 2010/38 has been adopted thanks to effective lobbying and support of the patient associations. Are there similar actions in other European countries?
- The Law 2010/38 sanctioned that the pain is not only a symptom but a disease in a patient with chronic, moderate to severe pain. Is the care pathway adapted to the real care needs also considering pharmaceutical appropriateness?

