

Programme: Erasmus+ Action: Strategic Partnerships

National research about the procedures on palliative medicine in Italy

The aim of this activity is to research & evaluate the medical literature talking about the procedures on palliative medicine, reflect on the palliative medicine and strategies and on the current procedures used in the training of the first years students enrolled in EU medical universities or used by the professionals & volunteers active in the medical world of work.

Objectives:

- Identification of the operational procedures reported to be used by the students during the hospital internship in pre-clinical years; identify the needs of the target groups in connection to the use of specific procedures
- Research of specialised recent literature in connection to these procedures
- Identify the ways to introduce new & consensually agreed procedures on palliative medicine to the academic medical field (university) and the medical world of work (hospitals, hospices)
- Collect information on specific sectorial impact, country differences, cultural specific aspects, etc.
- Identify innovative solutions that have been implemented & found to be effective to meet the needs of those who use/will use procedures on palliative medicine

Structure:

1. Identification of the concepts which define medical operational procedures from the point of view of palliative medicine/care

In the daily activities, the terms "palliative care" and "palliative medicine" are interchangeable. The term "palliative medicine" is considered as related to a medicine specialization, while the term "palliative care" is related to a multiprofessional and multidimensional dimension of the taking care of the person and of his/her family during the last period of life. When the patient lives an unfavourable prognosis, a "total suffering and pain" situation is evident: beyond the physical problems, the psychological and spiritual aspects are evident, together with social and interpersonal relationships problems and economics complications. Taking care of the patient with unfavourable prognosis means to face all questions related to pain and suffering of the patient, so applying the philosophy of palliative care.





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WHO Definition of Palliative Care

Palliative care 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:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death:
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children 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.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.





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There are four main ways in which definitions of palliative care may differ.

- 1. Palliative care is sometimes defined as solely being care that alleviates pain and other symptoms. With these definitions palliative care does not include any other support for either the patient or their family.
- 2. In the 1960s hospices provided palliative care for people who were dying of cancer. As a result palliative care was defined as being care that was provided for people who were not receiving any treatment to actively treat their disease. It has since been realised that many aspects of palliative care are applicable earlier in the course of a disease and that palliative care can, and often should, be provided alongside disease modifying treatment. Some definitions of palliative care such as the one given above, either implicitly or explicitly allow for this.
- Palliative care is still sometimes defined as solely being for people with cancer, but palliative care is more often now defined as being for people facing a life-threatening illness. Palliative care is not usually defined as being for people with chronic conditions such as diabetes.
- 4. When palliative care first began to be provided for people with AIDS in the 1980s, it was realised that the provision of palliative care for a "family" could exclude the person who mattered most to a person with AIDS. Some definitions of palliative care now try to ensure that the word "family" is interpreted as including everyone who matters most whether a "blood" relative or not.

<u>End of life care</u> is an important part of palliative care, and usually refers to the care of a person living with a progressive condition during the last part of their life, from the point at which it has become clear that the person is in a progressive state of decline.

"You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die." *Dame Cicely Saunders*

End of life care is usually a longer period than the time during which someone is considered to be "dying". Hospice care is no longer provided only in buildings known as hospices, but many hospices now provide a "hospice at home" service. The difficulty with the word "hospice" can be the same as that of palliative care more generally, which is that when people go into a hospice, it is very often perceived by both the patient and their family, that it is not going to be long before they are going to die.

2. Provision of statistical data, at national level, on the following aspects:

The Italian national healthcare service (SSN) was created in 1978 to replace a previous system based on a multitude of insurance schemes. The SSN was inspired by the British National Health Service and has two underlying principles. Firstly, every Italian citizen and foreign resident has the right to healthcare and, secondly, the system covers all necessary treatments.

Although the Ministry of health is ultimately responsible for the administration of the Health Service, much of the control has been passed to the Regions and onto the local health





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authorities known as ASL (Azienda di Sanità Locale). ASL are responsible for the management of all health services in their area and private providers can also operate within the SSN.

There have been a number of reforms to the SSN since the early 90s. Competition has been increased by allowing citizens to choose their healthcare provider. Payments have been regularised using a Diagnostic Related Group (DRG) system and a small amount of copayment has been introduced. Later reforms were aimed at increasing planning at the regional level and increasing efficiency of all managers within the SSN. Managers were placed on fixed contracts with regular performance reviews.

Italy, officially the Italian Republic (Italian: Republica italiana), is a unitary parliamentary republic in Europe. Italy covers an area of 301,338 km2 (116,347 sq mi) and has a largely temperate climate; due to its shape, it is often referred to in Italy as lo Stivale (the Boot). With 61 million inhabitants, it is the 5th most populous country in Europe. Italy is a very highly developed country and has the third largest economy in the Eurozone and the eighth-largest in the world.

Health care spending in Italy accounted for 9.0% of GDP in 2006 (about \$2,600 per capita) of which about 75% is public, slightly more than the average of 8.9% in OECD countries. In 2000 Italy's healthcare system was regarded, by World Health Organization's ranking, as the 2nd best in the world after France, and according to the CIA World fact book, Italy has the world's 6th highest life expectancy. Thanks to its good healthcare system, the life expectancy at birth in Italy was 80.9 years in 2004, which is two years above the OECD average.

Healthcare is provided to all citizens and residents by a mixed public-private system. The public part is the National Health Service (SSN) which is organized under the Ministry of Health and it's administered on a regional basis.

Family doctors are entirely paid by the SSN, must offer visiting time at least five days a week and have a limit of 1500 patients. Patients are assigned a doctor by the SSN but if they are dissatisfied with the assigned doctor they are free to change doctors, provided the doctor they choose has availability.

Prescription drugs can be acquired only if prescribed by a doctor. If prescribed by the family doctor, they are generally subsidized, requiring only a copay that depends on the medicine type and on the patient income (in many regions all the prescribed drugs are free for the poor). Over-the-counter drugs are paid out-of-pocket. Both prescription and over-the-counter drugs can only be sold in specialized shops (farmacia).

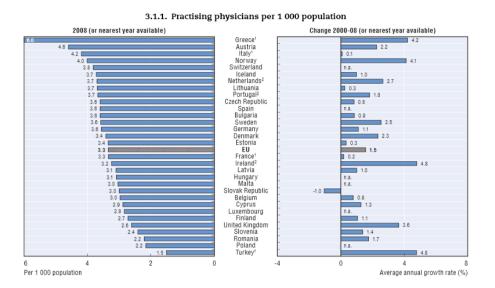
Visits by specialist doctors or diagnostic tests are provided by the public hospitals or by conventioned private ones, and if prescribed by the family doctor require only a copay (of the order of \$40 for a visit without any diagnostic test) and are free for the poor. Waiting times are usually up to a few months in the big public facilities and up to a few weeks in the small conventioned private facilities. Patients, however, can opt for the "free market" option, provided by both public and private hospitals, which is paid completely out-of-pocket and has generally much shorter[citation needed] waiting times.



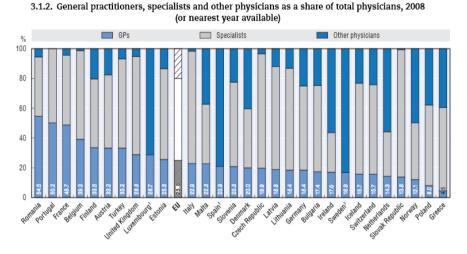
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Total health spending as a percentage of GDP in Italy compared with other developed nations in the period 2005-2008.

Surgeries and hospitalization provided by the public hospitals or by conventioned private ones are completely free of charge for everyone, regardless of the income. For the planned surgeries waiting times can be up to many months, especially in the big cities.



Source: OECD Health Data 2010; Eurostat Statistics Database.



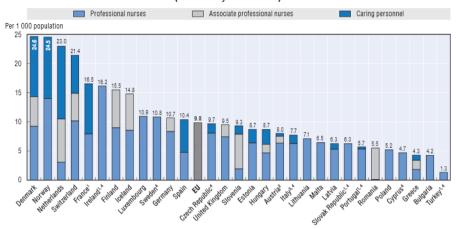
Source: OECD Health Data 2010; Eurostat Statistics Database.





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3.2.1. Professional nurses, associate professional nurses and caring personnel per 1 000 population, 2008 (or nearest year available)



Source: OECD Health Data 2010; Eurostat Statistics Database.

3.2.2. Ratio of nurses to physicians, 2008 (or nearest year available)

Source: OECD Health Data 2010; Eurostat Statistics Database.

3. Is the palliative medicine/care supported by legislation?

Lay National n.38/2010 about the palliative care and therapy for the management of pain.

Piemonte Region

Regional Law n. 30-866 del 25.10.2010

"Regional network for palliative care and Pain Centers" . 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 Law n. 31-1482 del 11.02.2011

individuation of members and functioning procedures of Regional Committee about the Coordination of Palliative Care and Pain Centers





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4. Identification of National Strategies in palliative care.

In order to describe our healthcare system regarding the palliative care, a working group was been prepared the position paper "PALLIATIVE CARE, PEDIATRIC PALLIATIVE CARE AND PAIN THERAPY: HUMANIZATION OF CARE".

The aim of this document was to share with all MS the main concepts and structures of palliative care and pain therapy during the semester of Italian Presidency of european union.

A good example of this is represented by recent figures released by the Italian Parliament, that detect as in the period between 2012 and 2014 national expenditure for opiates grew 26%, while patients who died in hospital with an oncological diagnosis diminished from 47537 in 2012 to 44725 in 2014, thereby indicating a significant increase in home care and in palliative care.

Nevertheless, the continuing development of palliative care must be accompanied by an extraordinary attention on some strategic points, to make them available to all patients who need them, and to ensure that they best express the level of social and health care evolution, so that we can say they are developing not only in number, but in quality too.

The first aspect is the **appropriateness** of our care: we have to get better systems to recognize the need of care, the timing of care, and to develop quality assessment and performance improvement.

The second aspect is the attention to **human** factor, (someone called the Palliative Care the Science of Compassion - The National Institute of Nursing Research Summit, USA, 2011): we have to bring with us to patient's home technology but also *good skills in helping relationship*, and this means to improve strategies and programs to provide health professionals with specific personal training and team training, education and support.

The third aspect is the attention to **multidisciplinary approach** in palliative care: we know we rely on cooperation among physicians, nurses, psychologists and other health professionals, and no less important are social workers, chaplains and every other allied people who can contribute to diminish patient's suffering. This means *promoting and implementing a specific and firm network which needs maintenance and updating* to be appropriate to the needs of the patient and of the care team.

Finally, the fourth aspect is the indispensability of involving all the patient's family in our care; we know that palliative care is a **family centered approach** that embraces all the family members, (and the family is defined by the patient), during the patient's illness and after his death, in the bereavement process.

The WHO definition of Palliative Care and the Guidelines published all over the world stress this aspect, that becomes particularly necessary and complex when the dying patient is a mother or a father of young children, or when the patient is a child.

So we need specific, affordable and flexible guidelines of care, because in these cases the bereavement processes last longer, and have multiple and maybe unexpected effects.





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That's why we also need to better identify guidelines for <u>Palliative Care in Primary Care</u> Settings and Specialty Level Palliative Care

Moreover, we think that our organization must be able to look beyond the formal systems of care, and have to research in the community other resources, *such as self-help or mutual aid*, or other non-formal systems of care, whose extraordinary effectiveness we observed in many fields, like addiction, disability, and so on.

This leads me to attribute a strategic importance to <u>a multicultural approach</u> in Palliative Care, and not only to a multi-professional care strategy.

Palliative care is the result of the work of many different professionals, but also of many different components of society.

5. Identification of **specialized services** in palliative care.

Hospital services

You or your primary doctor can request palliative care services at any time while you are for treatment. Specialists initially meet with you and your family to begin building a care plan that meets your physical, emotional and spiritual needs. Research indicates that early use of palliative care services can extend life and provide you with a better quality of life.

Outpatient services

Palliative care services are not always available locally or through your own health care clinic. Outpatient services help you and your local doctor evaluate your needs and develop a care plan that is right for you. Outpatient service can supplement your care even if you are not being treated by a doctors.

Pediatric services

In addition to all the disciplines and specialists represented in an adult palliative care team, pediatric palliative care programs often include child life specialists who offer developmentally appropriate education and therapeutic play activities related to the health care experience.

The distribution of palliative care centres in Italy is the following:

	HOSPICE CURE PALLIATIVE	CENTRI TERAPIA DEL DOLORE
TOSCANA	18	28
VENETO	21	40
CAMPANIA	7	8
CALABRIA	18	6
PIEMONTE	13	29
LOMBARDIA	70	23
FRIULI V. GIULIA	8	16
SICILIA	10	9
UMBRIA	3	8





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	HOSPICE CURE PALLIATIVE	CENTRI TERAPIA DEL DOLORE
EMILIA ROMAGNA	22	26
BASILICATA	8	6
LAZIO	26	48
MOLISE	1	3
SARDEGNA	8	9
ABRUZZO	6	6
VALLE D'AOSTA	1	1
LIGURIA	6	7
PUGLIA	7	0
MARCHE	7	5
TRENTINO A. ADIGE	4	3
	264	281

6. Identification of support **specialized literature or organizations**. (provide links if available)

Specialized recent literature in palliative care:

www.fremedicaljournals.com

www.academicjournals.org

www.biomedcentral.com

www.bmj.com.bvs.cilea.it

www.ncbi.nlm.nih.gov

www.sciencedirect.com

http://jama.jamanetwork.com

National associations in palliative care:

- ACCD
 - Sito dell'Associazione cremonese per la cura del dolore
- ACP Bergamo
 - Sito Associazione Cure Palliative Bergamo
- ANLAIDS
 - Associazione nazionale per la lotta all'AIDS
- Associazione Antea
 - Sito di Antea
- <u>Associazione Volontari Presenza Amica</u>
 Collegamento al Sito dell'Associazione
- Federazione Cure Palliative (FCP) Onlus
 - Federazione che riunisce oltre 70 organizzazione No Profit Italiane
- Fondazione Floriani
 - Sito della Fondazione



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- <u>Fondazione italiana di leniterapia</u>
 Collegamento al sito ufficiale della Fondazione Italiana di Leniterapia
- <u>Fondazione Maruzza Lefebvre D'Ovidio Onlus</u>
 Sito Fondazione Maruzza Lefebvre D'Ovidio Onlus
- <u>Fondazione Lu.V.I.</u>
 Sito della Fondazione
- <u>Fondazione Maria Teresa Chiantore Seràgnoli</u>
 Sito della fondazione
- <u>Lega italiana per la lotta contro i tumori</u>
 Collegamento al sito della Lega Tumori
- S.A.M.O.T. Onlus Sito Società per l'Assistenza al Malato Oncologico Terminale

7. Is the palliative care visible/debated at national level?

National conferences/events on palliative care (some examples):

- Ciclo di incontri "STARE vicino a chi vive il dolore di una perdita" Firenze, 16 gennaio - 15 maggio 2015
- Approccio palliativo nelle malattie avanzate inguaribili e nelle gravi fragilità psicofisico-sociali che vivono nella Comunità
 Milano. 17 gennaio - 10 luglio 2015
- CORSO "GIORNATE MONOTEMATICHE IN CURE PALLIATIVE" Milano, 19 gennaio - 15 giugno 2015
- PROGETTO "IN RETE NODO TERRITORIALE"
 Piacenza, 21 gennaio 13 maggio 2015
- Audit clinico in Cure Palliative Bologna, 28 gennaio - 31 marzo 2015
- LONG TERM CARE
 - Massa Carrara, 6 febbraio 27 settembre 2015
- IL SENSO E L'UTILITA' DEL LAVORO DI ÉQUIPE
 Albinea (Reggio Emilia), 10 febbraio 13 maggio 2015
- La gioia che cura
 - Borgo Val di Taro (PR), 28 febbraio 14 novembre 2015
- Corso di formazione per volontari dedicati al Centro di Ascolto e all'Hospice
 Verona, 12 marzo 14 maggio 2015
- RIANIMAZIONE E CURE PALLIATIVE
 - Bologna, 27 marzo 2015
- L'evoluzione della Rete delle Cure Palliative The Early Palliative Care Bologna, 27 marzo 2015
- IL FINE VITA DI UN BAMBINO Assistenza, comunicazione e modelli gestionali nelle Cure Palliative pediatriche
 - Milano, 27 marzo 15 maggio 2015
- 20th ANNUAL RIMS CONFERENCE (REHABILITATION IN MULTIPLE SCLEROSIS)
 - Milano, 9-11 aprile 2015
- Medicina palliativa in Sicilia Palermo, 10-11 aprile 2015
- LE RAGIONI DELL'ETICA Professionisti in Cure Palliative eticamente consapevoli Milano. 10 aprile - 8 maggio 2015
- Corso di Perfezionamento "Pratiche di narrazione e scrittura nella cura educativa e medico - sanitaria"
 - Milano, 10 aprile 4 dicembre 2015



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 Corso di Alta Formazione e Aggiornamento Professionale Trieste, 31 gennaio - 16 maggio 2015

Concorso premio "Il Mantello"

Agrigento, 10 aprile - 4 dicembre 2015

Psico-Oncologia: dalla ricerca alle relazioni che curano Bologna, 15 aprile 2015

AIOM INCONTRA SICP

ROMA, 16 aprile 2015

VIOLA

Piacenza, 16 aprile 2015

• PALLIATIVE CARE CHAMPIONS 2015

PALERMO, 16-18 aprile 2015

• WORKSHOP INTERSOCIETARIO AIP-SIAARTI-SIC-SIGG-SINDEM Firenze, 18 aprile 2015

• IL CONFINE INCERTO FRA CURE INTENSIVE E CURE PALLIATIVE IN DIALISI Fossano (CN), 7-8 maggio 2015

• IV Incontro Pontino sulle Cure Palliative: "Stato dell'arte sulle Cure Palliative nella realtà pontina"

Latina, 8 maggio 2015

EAPC 2015: 14° CONGRESSO MONDIALE DELL'EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (EAPC)

Copenhagen, 8-10 maggio 2015

11° Congresso Nazionale SIARED

Riva del Garda (TN), 11-13 maggio 2015

 CURE PALLIATIVE: LE BUONE PRATICHE CLINICO-ASSISTENZIALI SALSOMAGGIORE TERME, 14 maggio 2015

COLORARE IL FUTURO - 1°Edizione

Biella, 14-15 maggio 2015

PALLIUM MARCHE 2015

Macerata, 15-16 maggio 2015

PALLIUM 2015

Macerata, 15-16 maggio 2015

La Persona centro della cura

VENEZIA, 15-16 maggio 2015

DAL DIRE AL FARE

Milano, 16 maggio - 12 dicembre 2015

QUALE RETE DI CURE PALLIATIVE PER IL MONDO INVISIBILE DELLA

FRAGILITA'

UDINE, 22 maggio 2015

MINDFULNESS PRATICA PER IL BEN-ESSERE

TORINO, 27 maggio 2015

H OPEN DAY SUL DOLORE

TUTTA ITALIA, 31 maggio 2015

VolontariaMente

Milano, 5 giugno 2015

ADVANCE CARE PLANNING AND END OF LIFE CARE

Munich (Germany), 9-12 settembre 2015

COLORARE IL FUTURO - 2°Edizione

Biella, 1-2 ottobre 2015

XXII CONGRESSO NAZIONALE SICP

Sorrento, 4-7 novembre 2015





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Scientific journals on palliative care:

- Annals of Internal Medicine
 Journal of American College of Physicians
- Annals of Oncology
 Journal of European Society for Medical Oncology ESMO
- BMC Palliative Care
 Journal of BMC of Palliative Care
- BMJ Supportive and Palliative Care
 Journal of BMJ for palliative care
- End of Life Journal
 Journal of nurses who work in palliative care
- <u>European Journal of Palliative Care (EJPC)</u>
 Journal of European Association of Palliative Care EAPC
- <u>JAMA</u>

website of American Medical Association

- <u>Journal Clinical Oncology</u>
 Journal of American Society of Clinical Oncology ASCO
- Journal of Pain and Symptom Management
- Journal of Palliative Medicine
- Palliative Medicine

Journal of European Association of Palliative Care EAPC

- Progress in palliative care published by Leeds Medical Information
- <u>published by Leeds Medical Information</u>
 Support Care Cancer
- Journal of Multinational Association of Supportive Care in Cancer MASCC

 The Gerontologist
 Journal of Gerontological Society of America
- The Lancet
- The New England Journal of Medicine
 Published by Massachusetts Medical Society
- 8. Identification of the operational procedures on palliative care reported to be taught to the students during the hospital internship in pre-clinical years.

Curriculum structure:

- EAPC (EUROPEAN JOURNAL OF PALLIATIVE CARE, 2013; 20(3)):
 The ten core competencies on palliative care
- 1.Apply the core constituents of palliative care in the setting where patients and families are based
- 2. Enhance physical comfort throughout patients' disease trajectories
- 3. Meet patients' psychological needs
- 4. Meet patients' social needs
- 5. Meet patients' spiritual needs
- 6. Respond to the needs of family carers in relation to short-, medium- and long-term patient care goals
- 7. Respond to the challenges of clinical and ethical decision-making in palliative care
- 8. Practise comprehensive care co-ordination and interdisciplinary teamwork across all settings where palliative care is offered
- 9. Develop interpersonal and communication skills appropriate to palliative care
- 10. Practise self-awareness and undergo continuing professional development





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Carta di Trieste: paper of dying children rights

 Core curriculum about the different rules: www.sicp.it/web/eventi/SICP/corecurriculum.cfm

www.ipasvi.it

- American Association of Colleges of Nursing (AACN) (1997) Peaceful death: recommended competencies and curricula;
- Hospice and Palliative Nurse Association (HPNA) (2010) Competencies for generalist hospice and palliative care nurses;
- Hospice and Palliative Nurse Association (HPNA) (2002) Competencies for advanced practice hospice and palliative care nurses;
- Palliative Care Australia; Canning, D., Yates, P. & Rosenberg, J.P. (2005)
 Competency Standards for Specialist Palliative Care Nursing Practice. Brisbane:
 Queensland University of Technology;
- Canadian Hospice and Palliative Care nursing. (2009) Nursing assumption and competencies;
- Ministry of Health. (2008). A National Professional Development Framework for Palliative:
- Care Nursing in Aotearoa New Zealand. Wellington: Ministry of Health Royal College of Nursing (2002) A framework for nurses working in specialist palliative care: Competencies Project.

University Master Courses (by SICP)

- MASTER UNIVERSITARIO II LIVELLO ALTA FORMAZIONE E QUALIFICAZIONE IN CURE PALLIATIVE
 Roma, 1 settembre 2014 - 30 giugno 2016
- MASTER DI I LIV. IN BIOETICA E BIODIRITTO PER LA PRATICA CLINICA Milano, 24 settembre 2014 - 21 novembre 2015
- MASTER UNIVERSITARIO I LIVELLO CURE PALLIATIVE E TERAPIA DEL DOLORE PER PROFESSIONI SANITARIE
 Roma, 15 dicembre 2014 30 giugno 2015
- Master Universitario di I livello in Cure Palliative e Terapia del Dolore Bentivoglio, Bologna, 29 gennaio 2015 17 dicembre 2016
- Master Universitario in Alta Formazione e Qualificazione in Cure Palliative Bentivoglio, Bologna, 29 gennaio 2015 - 17 dicembre 2016
- 9. Identification of ways to introduce new and consensually agreed basic medical procedures to the academic medical field (university) and the medical world of work (hospitals and dispensaries)
- Sites of single Orders/Sindacate or National Reserch Institute
- program of "Continuous Education in Medicine" (ECM)
- National, International academic/scientific articles
- Recomendations and Guide Lines (PNLG: Piano Nazionale per le Linee Guida www.plng.it)
- reports and laws www.assr.it; www.salute.gov.it; www.iss.it; www.parlamento.it
- Consensus Conferences: Peer rewiews





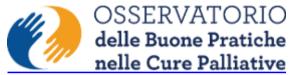
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10. Provision of **examples of best practices/ projects** on innovative solutions that have been implemented and found to be effective to meet the needs of those who use / will use medical procedures

www.cure-domiciliari.it/files/Testimonianza.pdf

www.aniarti.it

cplps2.altervista.org/...ambrosini%20nutrizione%20...



Osservatorio delle Buone Pratiche nelle Cure Palliative



Federazione Cure Palliative

