Ministry of Health

NATIONAL COMMITTEE FOR THE DEVELOPMENT & IMPLEMENTATION
OF A PALLIATIVE CARE STRATEGY IN GREECE

Palliative Care Feasibility Study for Greece

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ΙΔΡΥΜΑ ΣΤΑΥΡΟΣ ΝΙΑΡΧΟΣ
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ΥΠΟΥΡΓΕΙΟ ΥΓΕΙΑΣ

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The members of the Committee and other consultants are listed below:

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SNF Foundation Staff: Panos Vazaios and Panos Papoulios
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Executive Summary

Palliative Care has a long history in Greece, yet it has not developed in line with other high-income countries in the European Union. At present there are three programs delivering Specialized Palliative Care in the country serving about 600 patients per year. In addition, there are 40 oncology and 57 pain clinics in hospitals some of which offer General Palliative Care services. Finally, there is one program of Specialized Palliative Home Care under development.

In this report, the need for Palliative Care has been estimated at 120,000 to 135,000 patients and their families per year. This translates to approximately 15,000 patients per day. Over 95% of them could receive care in their home setting and only about 3.5% in inpatient facilities at any given time. A projection of 500 inpatient beds for Palliative Care has been made. To meet the entire current need would require about 300 home-based care teams each serving 50 patients per day and would likely take decades to achieve.

Approximately 37% of the need for Palliative Care in Greece is for cancer patients and 63% for other conditions such as cardiovascular disease, chronic obstructive pulmonary disease, drug resistant TB, HIV, diabetes, cirrhosis, kidney disease, dementias, and other complex chronic conditions. Moreover, Palliative Care services are needed for elderly adult patients with frailty and multimorbidity due to advanced age as well as infants/newborns and children affected by congenital and other chronic life-limiting or life-threatening conditions.

It is important to understand that these are estimates of the current need in a perfect world where everyone gets palliative care. In no country is the full need for Palliative Care being met. For example, in the 45 years that Palliative Care has been developing in the USA only about 75% of the current need is met. In Greece, it will likely take many years to meet most of the need for Palliative Care and planning must take this into account.

The gap between the need for and capacity to deliver Palliative Care in Greece is very wide. The need for decedents alone is about 62,000 people annually. Current capacity to deliver Palliative Care is less than 1% of the decedent need and less than 2% of the total need. While hospice and Palliative Care is primarily an outpatient and home-based care service there is some need for inpatient care as well, usually for brief periods for severe symptom management. At present the total need for inpatient Palliative Care beds is estimated at 500 beds while only 9 dedicated inpatient beds are currently available. This represents less than 0,5% of the ultimate need.

In order to close the gap in access to Palliative Care in Greece it will require actions such as changing existing laws that have not been implemented and interfere with correct Palliative Care development; educating a workforce of over 4,000 health professionals and many currently practicing prescribers; changing some current health budget flows to invest more in home based care; clarifying regulations on controlled substance prescribing and monitoring; creating a registry of patients receiving palliative care; developing standards of Palliative Care operation and clinical guidelines for provision of care; including primary care providers in Palliative Care delivery and setting up new Palliative Care interdisciplinary teams throughout the country for both adults and children.

This report identifies 19 major problems to be addressed and offers 40 recommendations to improve the provision of Palliative Care in Greece.

This report is an attempt to examine the current status of Palliative Care in Greece and to explore the feasibility of bridging the gap in lack of access to palliative care. The current structures for providing needed Palliative Care are not effective in bridging this gap. Much more work is needed to do the extensive planning that is needed to accomplish this task.

1. Aim and Methodology

1.1 Introduction

The Hellenic Ministry of Health (MoH) and the Stavros Niarchos Foundation (SNF), have for the first time initiated a process to investigate and address the slow progress on Palliative Care development in Greece. For this purpose, a special committee was established with experts that have extensive knowledge and experience in this field.

The SNF contacted the Worldwide Hospice Palliative Care Alliance (WHPCA) to assist in providing advice and guidance. This initiative is the first step in a three-stage project to further organize and implement a national strategy for Palliative Care in Greece. It involves the development of a **feasibility study** which explores the need for Palliative Care in Greece, assesses the capacity to deliver Palliative Care in the country, and puts forward recommendations for overcoming barriers to Palliative Care development.

The second stage will seek to elaborate a **national strategy** for Palliative Care in Greece, followed by a third stage involving the implementation of the approved national strategy.

1.2 Definitions

The assessment was based on the World Health Organization's (WHO) definitions of *Palliative Care* and *pediatric Palliative Care* (for the full definitions see **Appendix A**).

Palliative Care is an approach that improves the quality of life of patients and their families facing problems 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 represents a special, albeit closely related field to adult palliative care. Palliative Care for children is the active total care of the child's body, mind and spirit, and involves giving support to the family and significant others in a child's life.

Palliative Care is an approach to preventing and relieving suffering and promoting quality of life for patients and families living with potentially life-threatening illnesses. Palliative Care is not just end-of-life care, but **care given throughout the illness experience as well as during the grieving period of the family following the death of a patient**.

It is noted that in Greece, two different terms have been used as the translation of the English term "Palliative Care" namely Anakoufistiki Frontida and Parigoriki Frontida. The official Greek term adopted for "palliative care", by 8 out of 11 members[1] of the Committee, (present during a meeting specifically focused on this issue, following extensive discussions, presentations and debates), is **"Anakoufistiki Frondida"**.

Palliative Care is clearly distinct and opposed to "euthanasia" and "assisted suicide" as described in a white paper issued by the European Association for Palliative Care (Radbruch *et al.*, 2016).

[1] Eleven (11) members of the Committee were present. Eight (8) members of the Committee voted in favour of the term "Anakoufistiki Frondida", one (1) against and two (2) abstained.

Palliative Care for adults and for children can be delivered at different levels of the health system depending on the needs of patients, and the training of health care professionals (EAPC, 2009).

i. "Basic **palliative care**" is provided to all patients by health care professionals trained in the fundamental principles of the Palliative Care approach. It includes as a rule education/ information of patients and their families on issues related to their illnesses and care - in particular at home - as well as identification of patients in need of specialized support/care and their transfer/ handing over to Specialist Palliative Care Services.

ii. "**General palliative care**" is provided by health care professionals who treat patients with life-threatening diseases without specializing in Palliative Care treatment. It includes as a rule assessing/evaluating and treating symptoms, end-of-life care, communication with patients and their families regarding diagnosis and their cooperation and/or submission/ transfer/handing over to Specialist Palliative Care services.

iii. "**Specialist Palliative Care**" is provided by Palliative Care Patient Units to patients with life threatening diseases and complex health problems by health care professionals work exclusively/solely in Palliative Care. It includes comprehensive care services as outlined in the above definition.

1.3 Aim of the Study

The aim of this study is to describe the existing situation and offer recommendations to expand the provision of Palliative Care services in the Republic of Greece.

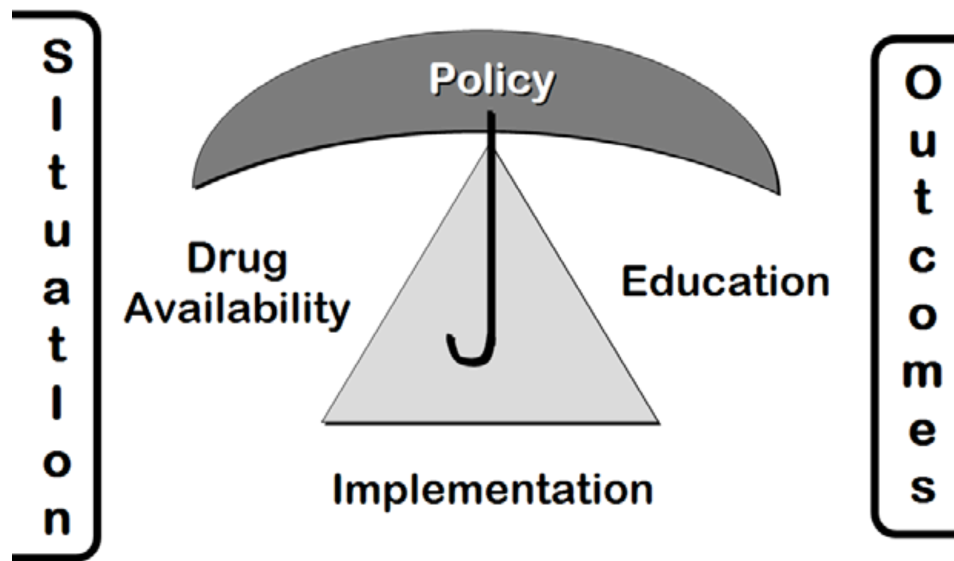
1.4 Methods

This study has been prepared by **Dr. Stephen Connor** of the Worldwide Hospice Palliative Care Alliance with the close involvement of the National Committee for the Development and Implementation of a Palliative Care Strategy in Greece of the Ministry of Health, through desk research, utilizing the latest international methods and publicly available data and analysis. **Dr. Eugenia Vathakou** facilitated and coordinated the dialogue with the members of the Committee and the work of the two sub-committees (on education and legislation) which collected the required data. Furthermore, she conducted the research concerning the role of NGOs and patients' associations in the promotion of PC and the provision of PC services in Greece and assisted in drafting the report.

1.4.1 The WHO Public Health Model

Believing that Palliative Care should be accessible to all patients, the authors took a **public health perspective** to assess the situation in Greece. The modified WHO Public Health Model (Figure 1) was used to provide a framework for the study and for this report. A public health approach aims to protect and improve the health and quality of life of a community by translating new knowledge and skills into evidence-based, cost-effective interventions that will be available to everyone in the population who needs them. As Palliative Care is an integral part of care for all patients, and the most beneficial approach to care for patients with advanced disease, it is important that all countries integrate Palliative Care into their healthcare systems at all levels.

Figure 1. WHO public health model for palliative care



Source: Stjernswärd *et al.* (2007).

1.4.2 Data Sources

This study utilized the following data sources:

- Lancet Commission Report on Palliative Care and Pain Control[2]
- Global Atlas of Palliative Care at the End of Life[3]
- The World Factbook at: https://www.cia.gov/library/publications/the-world-factbook/geos/gr.html
- Health Systems in Transition (HiT): Greece Health system review. Vol 19 No. 5 2017 http://www.euro.who.int/__data/assets/pdf_file/0006/373695/hit-greece-eng.pdf
- Data from the Greek Ministry of Health

1.4.3 Interviews

Table 1. Interviews with the following informants were conducted:

Name	Title	Organization
Key informants		
1. Mrs. Athina Vadalouka	Professor	Hellenic Society of Pain Management and Palliative Care - PARH.SY.A.

[2] Knaul F, Farmer P, Krakauer E, de Lima L, Bhadelia A, Xiaoxiao JK, Arreola-Ornelas H, Dantes OG, Rodriquez NM, Alleyne G, Connor, S, Hunter D, Lohman D, Radbruch L, Saenz R, Atun R, Foley K, Frenk J, Jamison D, & Rajagopal MR. (2017). Alleviating the Access Abyss in Palliative Care and Pain Relief: an imperative of universal health coverage: Report of the Lancet Commission on Global Access to Palliative Care and Pain Control. *Lancet* *http://www.thelancet.com/commissions/palliative-care*

[3] Global Atlas of Palliative Care at the End of Life. World Health Organization & Worldwide Palliative Care Alliance, (2014) S. Connor & C. Sepulveda (Eds).

2. Mrs. Ioanna Siafaka	Professor	Pain Clinic, Aretaieio Hospital, University of Athens
3. Dr. Aliki Tserkezoglou	Director	“GALILEE” Hospice
4. Mrs. Elisabeth Patiraki	Professor	Dept of Nursing, University of Athens
5. Dr. Ioannis Konstantinidis	Director	Pammakaristos Hospital, “Nosilia”
6. Mrs. Danai Papadatou	Professor, Board of Directors	Nursing Dept, University of Athens “Merimna” – Pediatric Palliative Home Care (PPHC) Service
7. Mrs. Spyridoula Tsaroucha	Admin. Director	“Merimna” – PPHC Service
8. Mrs. Vasiliki Kalliani	Staff	“Merimna” – PPHC Service
9. Mrs. Anastasia Tsadila	Staff	“Merimna” – PPHC Service
10. Dr. Efi Parpa	Staff	Pain Relief & Palliative Care Unit “Jenny Karezi”
11. Mrs. Eleni Tsilika	Staff	Pain Relief & Palliative Care Unit “Jenny Karezi”
Patients/Families		
1. Anonymous	Patient	Aretaieio Hospital
2. Anonymous	Patient	Galilee Hospice
3. Anonymous	Family member	Galilee Hospice
4. Anonymous	Parent	Merimna – PPHC service

2. The Country

(Source: The Hellenic Ministry of Health and the World Factbook, 2018)

2.1 Geography

Greece is a Southern European country bordering the Aegean Sea, Ionian Sea, and the Mediterranean Sea, between Albania and Turkey also bordering on Bulgaria and the Republic of North Macedonia.

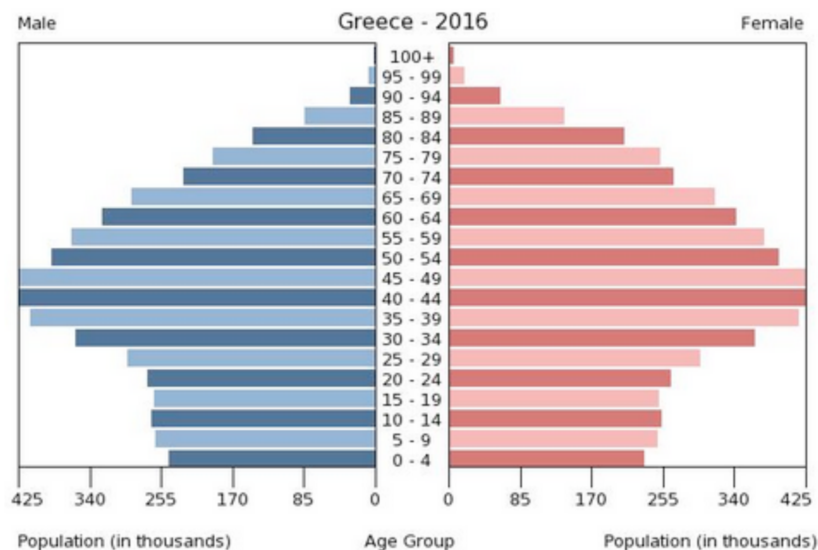
Figure 2. Map of Greece

- Greece has a total area of 131,957 square kilometers including 1,310 of water. It is 98th in size of 254 countries and territories.
- The climate is temperate (mild wet winters, hot dry summers). Terrain is mountainous including many chains of islands.
- Sixty-three percent (63.4) of the land is used for agriculture, 30.5% is forest, and 6.1% other.
- One third of the population lives in and around metropolitan Athens; the remainder of the country has moderate population density mixed with sizeable urban clusters.
- The country is divided into 13 administrative regions.

2.2 The People

The population is estimated by the World Bank at 10,768,477 inhabitants in 2017. Almost 20% of the population is aged 65 or over and this is likely to increase in the coming decades. Youth, aged 0-24, represent 23.5% of the population while 55.6% are aged 25-64.

Figure 3. Population age distribution



Greece has a high total dependency ratio at 52.7 with a low potential support ratio of 3.3 persons. Median age is 44.5 years and the population growth rate is -0.06.

The death rate is estimated at 11.3 deaths per 1,000 population (2017). Infant mortality is relatively low at 4.6 death per 1000 live births and life expectancy is high at 80.7 years (male 78 female 83.4 years).

Health expenditure is 8.3% of GDP (2014). Physician density is the third highest in the world at 6.26 per 1000 population and hospital bed density is moderate at 4.3 beds per 1000. HIV prevalence is low at 0.2% of the population with less than 100 deaths annually. Obesity is high at almost 25% of the adult population and literacy is high at 97.7%.

The population is 91,57 % Greek with only 8,43% foreign citizens (2011 census). Greek is the official language. Youth unemployment is very high at 44%.

2.3 The Economy

Greece has a capitalist economy with a public sector accounting for about 40% of GDP and with per capita GDP about two-thirds that of the leading euro-zone economies. Tourism provides 18% of GDP. Immigrants make up nearly one-fifth of the work force, mainly in agricultural and unskilled jobs. Greece is a major beneficiary of EU aid, equal to about 3.3% of annual GDP.

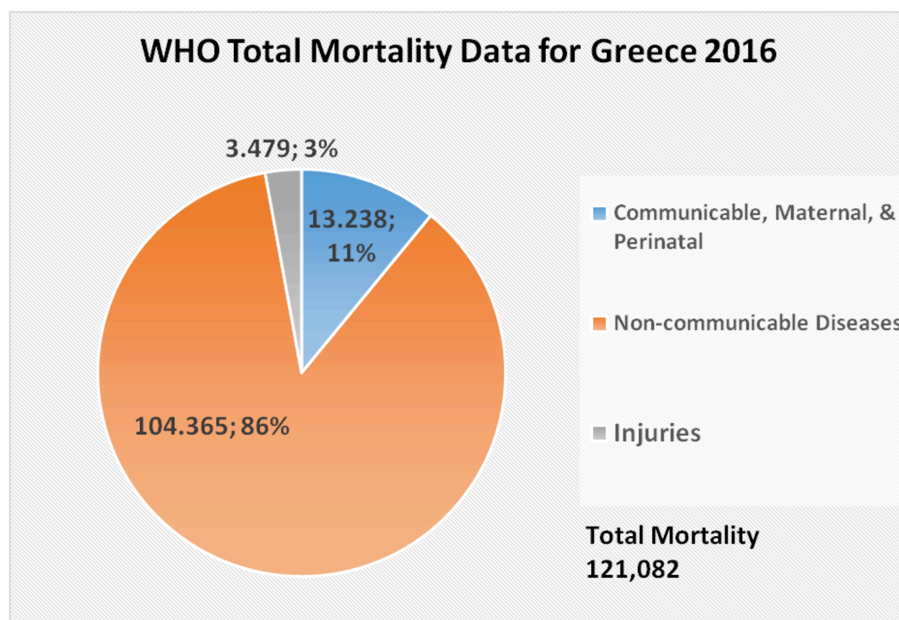
The Greek economy averaged growth of about 4% per year between 2003 and 2007, but then the economy went into recession in 2009 as a result of the world financial crisis, tightening credit conditions, and failure to address a growing budget deficit.

At the peak of the recent financial crisis, in April 2010, Greece was unable to secure the necessary funding and was thus forced to/ and had thus to participate in financial assistance facility programs. The Greek Government signed 3 Memoranda of Understanding aiming to tighten the country's public finances and gradually reduce its public deficit. In August 2018, the last such Program came to an end with Greece putting financial assistance programs behind it.

2.4 Health and Illness

Mortality – The total number of deaths in 2016 (latest WHO Data) was 121,082. The vast majority of deaths in Greece are from non-communicable diseases (see Figure 4). The global percentage of deaths from NCD's was 71% so Greece is much higher at 86%.

Figure 4. Total Greek Mortality



Mortality for NCD's breaks down as follows:

Table 2. Non-Communicable Disease Mortality 2016

Cause of Death	N	%
Cardiovascular Diseases	46,098	44.2
Malignant Neoplasms	30,408	29.1
Respiratory Diseases	10,499	10.1
Neurological Diseases	4,593	4.4
Kidney Diseases	3,338	3.2
Other NCD's	9,429	9.0
Total	**104,365**	**100**

Cancer mortality further breaks down as follows:

Table 3. Cancer mortality, 2016

Site	N	%
Trachea, bronchus, lung	7,526	24.8
Colon and rectum	3,245	10.7
Breast	2,466	8.1
Prostate	2,048	6.7
Pancreas	1,900	6.2
Liver	1,602	5.3
Stomach	1,602	5.3
Bladder	1,510	5.0
Leukemia	1,397	4.5
Brain and nervous system	1,349	4.4
Lymphomas	1,305	4.3
Other	4,458	14.7
Total	**30,408**	**100**

Within these groupings there are several breakdowns of non-cancer NCD deaths to note.

Table 4. Cause of death, 2016

Disease	Deaths
Cardiovascular disease	23,082 Ischemic heart disease 15,530 Stroke 7,486 Other
Respiratory diseases	6,645 COPD 3,824 Other
Neurological conditions	2,085 Alzheimer's disease 1,469 Parkinson's disease 147 Epilepsy 119 Multiple sclerosis
Other NCD deaths	3,811 Digestive disease 1,769 Diabetes

Table 5. Age at death, 2016

Age bracket (years)	Deaths
0-4	358
5-14	116
15-29	669
30-49	3,744
50-59	6,435
60-69	12,960
70+	96,800

3. The Greek Healthcare System

(Source: Hellenic Ministry of Health, 2019, HIT Greece Report, 2017)

Greece's health care system is a mixed system comprising elements from both the public and private sectors. In the public sector, a national health service type of system coexists with a social health insurance (SHI) model. Up to 2014, health care services in Greece were also provided by insurance organizations (all of) which in 2011 merged into EOPYY. Since late 2014, EOPYY has no longer been a service provider, its structures having been integrated into the National Health System (ESY).

The private sector includes profit-making hospitals, diagnostic centers and independent medical units. A large part of the private sector enters into contracts with EOPYY. After 2010, the role of voluntary initiatives, nongovernmental organizations (NGOs) and informal health care networks increased significantly. This was mainly a response to meeting the needs of the large portion of the population that lost insurance coverage and access to public health care, primarily through prolonged unemployment or other inability to pay contributions. Coverage was restored through remedial legislation in 2016.

The Ministry of Health is responsible for the planning and regulation of the ESY and EOPYY. Despite the establishment of regional health and welfare authorities as far back as 2001, and their renaming as regional health authorities (YPEs) in 2004, these entities, which were intended to carry out extensive health care planning, organization and provision, have exercised only limited powers to date. This may change with the implementation of more recent primary care reforms. In 2014, legislation formally transferred all public primary care facilities, health centers and rural clinics to the jurisdiction of the regional health authorities. These take up their primary care coordination roles more fully under the implementation of further reforms being rolled out from 2017 to 2020, to create a more integrated, two level primary care system.

3.1 Health Workforce Trends

Greece consistently has the highest ratio of physicians among EU countries, a rapid increase only slowing after 2008. In 2014, the number of practicing physicians reached 625 per 100,000

population, compared with the EU average of 350. In contrast to the ratio of specialist physicians, which also was the highest in the EU, the number of GPs was one of the lowest, at 39 per 100,000, compared with the EU average of 80.

There are several reasons for such a striking imbalance between the numbers of GPs and specialists, including historically undeveloped primary care, lack of quality training (Mariolis *et al.*, 2007) and the higher social status attached to being a specialist physician (Kaitelidou *et al*., 2012). In terms of policy impact, it has been argued that the high number of doctors, combined with providers' reimbursement methods, can lead to supplier-induced demand, regardless of the real health needs of the population, and also fuel informal payments (Kaitelidou *et al.*, 2012; Souliotis *et al.*, 2016).

In addition, Greece faces serious geographical inequities regarding the distribution of doctors. The density of physicians in 2014 varied from about 300 per 100,000 population in Western Macedonia and Central Greece to 874 per 100,000 in Attica (Hellenic Statistical Authority, 2018). Although some incentives (e.g. financial support) have been offered by the Ministry of Health for doctors practicing in rural parts of Greece, they have not been enough to recruit and retain staff in these areas. Greece has the lowest ratio of practicing nurses in the EU (344 vs 864 per 100,000 population) and, notably, this number has not changed since mid-2.000s. The ratio of practicing pharmacists was higher than the EU average (105 vs 85 per 100,000 population), with their number steadily increasing since the mid-2000s.

Table 6. Public sector health workforce total numbers

Category	November 2018
Physicians	24.636
Nurses	36.550
Social Workers	262
Pharmacists	93
Therapists	268
Psychologists	491

Source: Ministry of Health

3.2 Health Care Facilities

Health care facilities and services in Greece are broken down into the following categories:

1. Primary & ambulatory care
2. Specialized ambulatory outpatient care
3. Inpatient care
4. Emergency care
5. Home care, rehabilitation and intermediate care
6. Long-term care

1. Primary & ambulatory care

Primary care is delivered in Greece by a mixture of public and private health service providers. The main delivery models are:

- The National Health System (ESY) which includes health centers, regional clinics, rural clinics outpatient hospital clinics and local health units (TOMY) which constitute the basic structure of the reforms of the primary health care
- Municipal clinics
- Private clinics, laboratories, diagnostic centers, and outpatient clinics in private hospitals
- Clinics of NGOs

ESY provides for all patient's health services equally and free of charge. NGO's and local authorities also provide health services free while in the private sector are financed either by direct payment or government (EOPYY) contract.

Table 7. Number of health centers, by region, 2018

Region	Number of Health Centres
Estern Macedonia and Thrace	20
Central Macedonia	47
Western Macedonia	11
Epirus	20
Thessaly	21
Ionian Islands	11
Western Greece	29
Cetral Greece	20
Peloponnese	29
Attica	55
North Aegean islands	10
South Aegean islands	14
Crete	17
Total	**304**

Source: Ministry of Health (2019).

2. Specialized ambulatory outpatient care

Specialized ambulatory care may be provided through outpatient departments of public hospitals or private specialist medical practices. Most specialists are contracted with the EOPYY and charge a per visit co-pay. Specialist services availability is uneven with rural areas lacking many specialties. Most common specialties are cardiology, OB/GYN and orthopedics.

3. Inpatient care

Approximately 65% of inpatient hospital beds are in the public sector with the remaining 35% in the private sector serving also insured patients. Average length of stay is low at 4.9 days and occupancy rates average 74%.

Table 8. Hospitals by legal type, form of ownership and region, 2018

Region	Public Hospitals	Beds	Private clinics	Beds	Total Beds
Estern Macedonia and Thrace	6	2,345	11	869	3,214
Central Macedonia	11	4,851	26	3,270	8,121
Western Macedonia	6	1,495	6	485	1,980
Epirus	5	1,575	2	30	1,605
Thessaly	4	1,916	30	2,419	4,335
Ionian Islands	5	752	1	42	794
Western Greece	1	380	6	440	820
Cetral Greece	5	1,169	3	168	1,337
Peloponnese	10	3,265	3	66	3,331
Attica	29	12,855	69	8,324	21,179
North Aegean islands	4	610	2	54	664
South Aegean islands	8	1,299	1	107	1,406
Crete	5	2,265	8	491	2,756
Total	**99**	**34,777**	**168**	**16,765**	**51,542**
Total beds in Greece					**51,542**

Other Public Hospitals	Beds	Notes
Onasis Cardiac Surgery Center	127	
Dafni-Attica Psychiatric Hospital	1,125	875 beds are located in structures out of the hospital
Dromokaiteio Psychiatric Hospital	588	205 beds are located in structures out of the hospital

Source: Ministry of Health (2019)

4. Emergency care

Emergency services are provided free of charge in Greece in emergency departments of the public hospitals. Furthermore, in 1985 the National Center for Emergency Services (EKAV) was established, which covers the whole country, it is responsible for provision of first aid and emergency medical care as well as transportation to health care units.

5. Home care, rehabilitation and intermediate care

Post hospital care in Greece is underdeveloped and fragmented with few services available due to lack of required planning and coordination. In 2015 the Ministry of Health launched a pilot project for development of *home care* nationwide. A network of 13 hospitals and 4 health centers provide some care to post hospital patients and people with chronic and non-communicable diseases. Rehabilitation services for people with disabilities are available through Centers of Physical Medicine and Rehabilitation (KEFIAP) within public hospitals.

6. Long-term care

Existing services cover only a limited part of needs. The long-term care sector has developed slowly and in a fragmented way. There is no integrated supply of services to vulnerable groups of the population, particularly the elderly. There is no systematic needs assessment, nor assessment based on special needs regarding gender, age, health status, ethnicity and other relevant characteristics. Therefore, informal care within the family, provided by either informal or privately hired caregivers, plays a major role in meeting the needs of the population.

For people suffering from chronic and incurable diseases and those who are not self-sufficient, long-term inpatient care services in Greece are provided mainly by a network of 25 public chronic diseases infirmaries nationwide. In 2013, these independent public entities became decentralized units of the newly established social welfare centers, financed by the state budget and by per diem fees paid by the National Health Insurance (NHI).

Anecdotal evidence also suggests that some smaller private clinics provide long-term care to older patients with incapacitating conditions, such as stroke or respiratory disease, and for patients with cancer receiving terminal care. Church organizations also offer a variety of services, including facilities for people with incurable diseases, infirmaries for chronic diseases, institutions for the disabled and physiotherapy centers. There are also private clinics under contract with EOPYY that provide long-term care, mostly to the terminally ill. In 2013, a social welfare center was established in each regional administration and thereby transformed a considerable number of previously residential-oriented rehabilitation centers into decentralized units of these social welfare centers. While potentially the centers could play an important role in developing and improving services, an assessment has not been conducted of the restructuring in relation to effectiveness, efficiency, quality and access to services. One issue is that the medical centers for rehabilitation are under the jurisdiction of the Ministry of Health, given that they are units of public hospitals, while social welfare centers are under the jurisdiction of the Ministry of Labour and Social Solidarity, raising the question of integration and the interconnection between the two networks.

4. The Provision of Palliative Care in Greece today based on the Public Health Care Model

4.1 Overview

Palliative Care (provision) in Greece is rather fragmentary, both in terms of its scope and its accessibility to State funds. Greece is among the group of countries characterized by the scarcity of their hospice/specialized Palliative Care services, which are often provided by NGOs as outpatient and home-based services and limited in relation to the size of the population[4]. Furthermore, the funding for the NGOs which provide this kind of services comes from donors. The underdevelopment of Palliative Care can be attributed to a number of barriers including the lack of awareness and recognition of palliative care, the lack of a suitable legislation that would recognize the need for adult, and childhood Palliative Care services both within the community and the health care system, the limited availability and choice of opioid analgesics, the limited access to Palliative Care education at a post-graduate level, and of training programs for professionals, the lack of recognition of Palliative Care as a medical or nursing specialty, the limited funding for existing services, and the lack of coordination between state and NGO services and the absence of a legislation for the provision of voluntary services in Greece.

4.2 Palliative Care Services in Greece

Below are briefly described three services that provide specialized Palliative Care in Greece (see also Table 9). At this point it is critical that the establishment of Operational Standards for Palliative Care services, which will be accomplished in the next stage of the National Committee's works, will determine the preconditions for the development of new Palliative Care units and it will contribute to the clarification of the type of the existing structures and the improvement of these services.

1. The **Pain Relief and Palliative Care Unit "Jenny Karezi"** which is an official Unit of the Medical School of the University of Athens, (Dept. of Radiology) which has operated since 1992 as a branch of Aretaieion Hospital, with specialized interdisciplinary staff (full time basis) comprising physicians, nurses, psychologists, secretary and volunteers (i.e. complementary therapies, physiotherapist). It is the only public Palliative Care unit, exclusively, for patients with malignant and non-malignant chronic diseases.

2. "**GALILEE**" is an NGO, founded in 2010, that provides *adult Palliative Care at home* and supports families through bereavement with the help of its volunteers. In addition to home care it also provides *inpatient hospice care* (9 beds) and *day center activities*, via an interdisciplinary team of 26 full-time health care professionals, 7 administrative staff members, 4 cleaning employees, and 150 trained volunteers.

[4] Lynch T, Connor S, & Clark D. (2013). Mapping levels of Palliative Care development: A global update. *Journal of Pain & Symptom Management;* 45(6):1094-1106.

3. **“Merimna” the Society for the Care of Children and Families in Illness and Death,** which was founded in 1995 developed in 2010, *a Pediatric Palliative Home Care Service* for children with life-limiting conditions, their family members and significant others (i.e. peers and schoolmates) who are supported throughout the illness and after the death of a child. The interdisciplinary team of trained professionals collaborates with several Pediatric units of public Pediatric hospital and private clinics in Athens and collaborates with the grief counsellors of Merimna’s Childhood and Family Bereavement Support Center, which operates since 1998.

4. The **Outpatient Pain Clinic** of the A’ Anesthesiology Clinic, Aretaieion University Hospital, was established in 1998 and it provides holistic pain management to patients with life threatening illnesses. The study includes an extensive reference to this clinic because it is different from the other pain clinics in Greece, as it has expanded its work with the support of volunteer health professionals and manages apart from the somatic the “holistic” pain, supporting hundreds of patients every year.

   “The NGO “Nosilia” which provides home care since 2001, in 2017-2018 in cooperation with the cancer patients’ association “KEFI”, established an interdisciplinary team of health professionals and provided palliative home care to a number of patients. Nevertheless, due to lack of funding it has temporarily disrupted the operation of the Palliative Care program.

Table 9. Provider profiles

[For the information on the table responsible are the providers, while for the classification responsible is the National Committee]

PROVIDER PROFILES						
	Name of program and explanation of ownership	**Establishment date**	**Geographical coverage area**	**Types of services provided**	**List of staff by discipline (numbers and FTE's)**	**Number of admissions in 2017 by diagnosis**
1	**Palliative Care Unit "Jenny Karezi"** School of Medicine, National and Kapodistrian University of Athens, Aretaieion Hospital	1992	Athens, Attica & regions across Greece	Consultations every day, 24hours on call Other services: Outpatient clinic, reflexology, relaxation, psychological support for patients and for families, psychotherapy, bereavement support, physiotherapy; Educational Programs; Clinical Research	Full time employees: Physicians: 2 Nurses: 1 Social workers: 1 Psychologists: 2 Pharmacists: 1 Therapists: 2 Administrative: 1 Volunteers: 8 1 physician, 1 dietician, 1 social worker, 1 psychiatrist, 2 nurses, 1 occupational therapist, 1 physiotherapist	Total: 445 (new cases 398) Cancer, total: 264 (231 new cases) Motor neuron disease: 4 (2 new cases) Cardiac Respiratory Other: Total 177 (165 new cases): Auto immune diseases, neurologic, Alzheimer & dementia, kidney failure, aids etc

2	**"Galillee" Palliative Care Unit** Non-Profit Ecclesiastical Organization with a legal status of a private organization under the auspices of the Holy Diocese of Mesogaia and Lavreotiki	March 1st 2010	The area of the Diocese of Mesogaia and Lavreotiki, that is the East and South Attica region	Inpatient: 9 beds Day Care (& number of beds): No beds, only activities Home care: One team Consultations Other services: Bereavement	Physicians: 3 Nurses: 15 Nurse aides: 2 Social workers: 3 Psychologists 1 Therapists: 1 Administrative: 7 Volunteers: 150 Other cleaning employees: 4 Art therapist: 1	New cases per year Cancer: 122 Motor neuron disease 15
3	**"Merimna" Society for the Care of Children and Families in Illness and Death** Civil, non-profit organization	1995 foundation of the organization The Pediatric Palliative Home Care Service (PPHCS) began its operation in January 2010	Athens & Piraeus, Attiki	Home care (1 team) Consultations to pediatricians and other professionals (nurses, psychologist, social workers, physiotherapist, teachers, et.al.) in pediatric hospitals and the local community Other services: Joint collaboration projects with pediatric units in Hospitals; Educational Programs	Physicians: 2 pediatricians (part time 50%) Nurses: 2 nurses (full time) Social workers: 1 social worker (volunteer 40%) Psychologists: 1 psychologist (part time 50%)Administrative: 1 secretary (part time 50%) Volunteers: 6 volunteers for the practical needs of families	12 children with motor neuron disease 5 children with neurodegenerativ e conditions 4 children with cancer 1 child with metabolic disease 1 child with syndrome
4	**Pain Clinic** A' Anesthesiology Clinic, Aretaieion University Hospital, Athens	1998	Greece	Inpatient (& number of beds): no beds for inpatients at the Pain Clinic; Pain relief and PC service is provided to inpatients of the hospital and other Hospital departments:	Physicians: 1 (full time, hospital's personnel), 1 (part-time 30%, hospital's personnel) 4 volunteers (20%) Nurses: 1 (full time, hospital's	Outpatients visits in 2018: 1756 individuals, 40% of whom are cancer patients. Integrated

			120 inpatients/year, 5-7 beds/month Day Care (& number of beds): no Day Care bed belonging to the Pain Clinic; Pain relief and PC service is provided to outpatients as they can be hosted for day care at other departments of Aretaieion hospital; Pain relief and PC services are provided to day care patients of other Hospitals' departments ; 105 day care center patients and up to 5 beds/month. Home care: yes, more than 2 teams Consultations: yes Other services: yes, nationally recognized undergraduate and post graduate training of physicians and other health care providers. Also, Master of science on the aforementioned topics	personnel), 3 volunteers (part time 20%) Nurse aides: 2 hospital's personnel (1 full time and 1 part time 20%) Social workers: 2 volunteers (part time 20%) Psychologists: 6 volunteers (part time 20%) Pharmacists: 2 (part time 25%) Therapists: 4 volunteers (part time 20%) Administrative personnel: 1 (part time 25%), 1 volunteer Volunteers from different disciplines are called upon demand – nutritionist, ozonotherapist, dentist, reflexologist, shiatsu, priest. Each individual 10%) Others: residents and fellows of various disciplines	Palliative Care is provided as we support the early inclusion of Palliative Care in the course of the disease 25 outpatient visits in 2018

	“Nosilia” Non-profit organization providing home care services	2001 foundation of the organization The palliative home care program ‘Stirizoume’, operated from Nov 2017 – June 2018 in partnership with the cancer patients’ Association “KEFI”	Wider area of the municipality of Athens	Home care: 1 team Consultations	1 Physician, 180 hours 1 Nurse, 360 hours 1 Nurse aide, 2080 hours 1 Social worker, 360 hours 1 Psychologist, 360 hours Pharmacists Therapists 1 Administrative, 2080 hours 1 Administrative, 1040 hours Volunteers- Physicians 1 Physician, 260 hours 1 Physician, 130 hours 1 Physician, 130 hours 1 Physician, 70 hours Volunteers- Nurses 1 Nurse, 780 hours Volunteers- Psychologist 1 Psychologist, 130 hours	Admissions in 2017 Cancer: 22 Motor neuron disease, cardiac respiratory and other chronic diseases: 48 (+53 patients since 2016)

Palliative Care services are provided to patients free of charge. Most of the organizations in the list have an interdisciplinary team of paid and/or volunteer professionals and offer services to patients with cancer, neurological diseases, and other life-threatening or life-limiting conditions. All of them are located in the large area of Attiki.

In view of the limited number of the available specialized Palliative Care Services, patients with life limiting illnesses are cared for with a focus solely on pain and other symptom management, as well as at the end of life. This care is provided by oncologists or anesthesiologists, at the approximately 40 oncology departments, or 57 pain clinics of public hospitals. A few pain clinics also offer some "*general*" Palliative Care services, mainly on an outpatient basis including psychological and rehabilitation services.

However, "Pain Clinics or Pain Centers" are internationally recognized as structures with a purpose **distinct** to that of Palliative Care Units. The primary aim of pain clinics or centers, as it is also stated in the relevant national institutional framework for their operation, is "specialized diagnosis of the cause and management of pain". Pain management constitutes an important part of Palliative Care, but it does not correspond to the total of the philosophy and services provided, which comprise organic symptoms, psychosocial and spiritual problems. According to international standards, there are significant differences between pain clinics and Palliative Care units. Indicatively, some of these are:

1. The patient target group each of them is addressed to differs, as the concept of a life-threatening disease to be handled by Palliative Care services is not necessary the same at pain clinics treating the pain including that of patients with non-malignant diseases[5].

2. Palliative Care by definition involves different medical specialties working together in hospices or at home or in hospitals where patients can be treated on a 24 hours basis. Pain clinics, on the other hand, operate as medical centers *stricto sensu* and they can employ health professionals other than the medical staff in its handling of 'holistic' pain.

3. Palliative Care is internationally recognized as an independent specialization and does not come under the administration of another medical specialty. Pain clinics, on the other hand, in Greece usually belong to the Anesthesiology departments.

In Greece pain clinics focus on the handling of pain, in accordance to their institutional framework as well as their recruitment and staffing. Nevertheless, as mentioned above, this Feasibility Study makes special reference to the pain clinic of the A' Anesthesiology Clinic in Aretaieio Hospital, in which the

[5] For relevant information, see the following web addresses:
1. www.england.nhs.uk/wp-content/uploads/2013/06/d08-spec-service-pain-mgt.pdf
2. www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts
3. www.painmed.org for the American Academy of Pain
4. aahpm.org for the AMERICAN Academy of Hospice and Palliative Medicine
5. www.painaustralia.org.au
6. www.palliativecare.org.au

care of “holistic pain” has been expanded with the support of volunteers, so as to include General Palliative Care services.

Moreover, in addition to pain clinics, there are other structures and teams, specialized in providing multidisciplinary care to patients with chronic diseases.

In the field of mental health, and particularly in the care of patients with dementia and Alzheimer's disease, many structures and programs have been established which are financially supported by the government and regulated by the Law on Mental Health Care. These patients, along with others suffering from several psychiatric disorders, are cared for throughout the country in 18 "hospices, 1 short-term inpatient Unit, 13-day centers, and at home through the support of two home care teams.

Concerning the rehabilitation of the disabled persons, there is an important NGO named ELEPAP which provides psychosocial support, diagnosis, health care, therapeutic and educational services for physically disabled infants, children, adolescents and adults in 6 rehabilitation centers nationwide.

Additionally, the public Spiliopouleio Hospital, “Saint Elena”, provides care to terminally ill cancer patients.

With regard to the needs of children and adolescents with a chronic and/or life-threatening illness, there are several NGOs and societies that provide through the public or private sectors, various types of services. These services include mostly psychological, practical and economical support offered by psychologists, social workers and volunteers. In addition, a few organizations provide care at home, thanks to the services offered by nurses and doctors, mostly on voluntary basis. Pain centers or pain units exist in large public Pediatric hospitals and are operated by anesthesiologists and nurses, lacking an interdisciplinary approach and Palliative Care orientation. As already stated, the only organization in Greece that operates, a Pediatric Palliative Home Care Service (PPHCS) since 2010 is “Merimna”. "Merimna" supports children in need of Palliative Care via an interdisciplinary team of professionals (pediatricians, nurses, psychologist and social worker) who provide a) medical and nursing care to alleviate the child’s symptoms, b) psychosocial support for the ill child and family members, c) counselling and guidance to schools to facilitate the child’s integrate and support affected peers and teachers, and d) bereavement support for family members after the child’s death.

Beds specifically allocated to inpatients for palliative care, in the public sector, do not exist officially. However, dated information from a European Association for Palliative Care study conducted in 2005 estimated that, there were beds available for terminal care within public hospital oncology departments, which does not imply that Palliative Care services for families by a trained interdisciplinary team of professionals.

Hospices are not well developed since it was only in 2003 (Law 3106/2003 on the reorganization of the national social care system) that the legislative framework for their establishment was set and in 2007 a ministerial degree (DY8/B/oik.89126/1-2-2007 (B 1534) determined the prerequisites for building and organizing hospices. However, at the time of writing (2018), the plan to establish such public hospices had not yet been implemented and the process was incomplete. There is only **one 9-**

bed hospice in the major Athens area, allocated to cancer and patients with motor neuron disease, operated by "GALILEE" Palliative Care Unit.

The lack of activity on the part of the official government to raise awareness in a systematic way about Palliative Care is partially filled by the University, the Greek Society for Pediatric Palliative Care, the Hellenic Association of Pain Control and Palliative Care (HAPCPC), the Hellenic Society of Pain Management and Palliative Care-PARH.SY.A and various NGOs. The objectives of these Panhellenic Associations and NGOs include raising the public and patients' awareness; providing training for health professionals and volunteers developing activities to improve the quality of patients' lives through pain and other symptoms' relief and occasionally offering psychological support to the terminally ill, their relatives and carers.

4.3 Policy - References to PC in relevant National Action Plans

In order to get a better insight into the Greek national policy for Palliative Care, we also looked at the National Action Plans (NAPs) for health issues and different diseases because they provide a blueprint for the government, different institutions and civil society to coordinate action and track results. More specifically, we examined existing NAPs on the most relevant to PC issues namely the NAPs for Alzheimer-Dementia, Public Health, Cancer, Cardiovascular diseases, HIV-AIDS and rare diseases.

The aim of our research was to identify therein references to and provisions for Palliative Care services. Thus, in what follows we have also included not only references to Palliative Care as such but any reference to services such as home care or hospices which involve Palliative Care services.

Two important notes: Firstly, with the exception of the National Action for Alzheimer-Dementia all the other NAPs are outdated but their duration is mentioned below. Secondly, given the existing disagreement over the translation in Greek of the term Palliative Care, namely Anakoufistiki or/and Parigor(it)iki, when the word "Palliative" is used, a note follows clarifying which Greek term is used every time.

a. National Action Plan for Alzheimer-Dementia 2015-2020

The National Action Plan on Alzheimer-Dementia includes concrete references to Palliative Care Services. More specifically:

Action 4 refers to the gradual development of *Day Care Centers* for people with dementia spatially distributed in cities throughout Greece, and the strengthening of the existing Day Care Centers. Furthermore, it refers to the establishment of multidisciplinary teams in the Day Care Centers which will include psychologists, nurses, occupational therapists and social workers.

Action 5 refers to the establishment and operation of an adequate network of *certified Nursing Homes for the Elderly* to cover residence and accommodation needs of people with dementia.

Action 6 refers to *End of life Institutions* and aims to create structures of Palliative Care for the terminally ill (Hospices). It also suggests that the use and adaptation of the existing structures (e.g. old hospital buildings) can be a practical solution for the necessary infrastructure.

Action 7 refers to *Decentralized Care - Care at Home* for people with dementia who are unable to move from their home because of serious mobility problems, the advanced stage of the disease or the caregiver's moving weakness. It includes care services in different fields of care, medical, nursing and social, in order to facilitate everyday life and ultimately improve the quality of life of people with dementia and their caregivers. The palliative home care services should be staffed by social workers, health visitors, nurses etc. specialized in care for people with dementia across the whole spectrum of the disease's process and interconnect the homes of people with dementia with Primary Care services.

It is noted that in this National Action Plan we find only the term "**anakoufistiki**" translating the English term "palliative care".

Additionally, in December 2014, it was established by law the National Observatory for Dementia and Alzheimer's disease as a public independent institution of the Ministry of Health. The aim of the Observatory is to support the country's policy to tackle the disease and protect the rights of patients and their families.

b. National Action Plan for Public Health 2008-2012

Clearly this is an outdated National Action Plan. Nevertheless, under the fifth axis with the title *Management and care of patient disease and his family* (p.319) **Action 3** refers to the establishment of Pain Clinics, **Action 4** to the establishment of Home Care Services, **Action 5** to the establishment of Palliative Care Units [both terms are used here "anakoufistiki" and "parigoritiki" separated by a hyphen (-)] and **Action 6** refers to the establishment and operation of Nursing and Palliative Care Hospices for final Stage Patients [the term **anakoufistiki** is used].

c. National Action Plan for Cancer 2011-2015

This National Action Plan is also outdated but a new Action Plan for cancer is currently under development. Nevertheless, a close examination of this Plan reveals references to Palliative Care Services.

In **section 5** *Deficiencies of the Health System* (p. 10) it is stated: "Significant weakness of Palliative Medicine (including home care), despite the diligent but fragmented efforts [both terms are used here, first parigoritiki and then anakoufistiki separated by a hyphen (-)]

Furthermore in p.18 we find the following:

Action 1: Development of the institutional framework for home care and the operation of hospices for end-stage patients

Action 2: Advisory and palliative support (both parigoritiki - anakoufistiki are used)

Action 3: Development of final-stage hospices

d. <u>National Action Plan for HIV-AIDS 2008-2012</u>

There is no reference to Palliative Care services. However, there is reference to *Home Care* and more specifically *to* "Activation of the Home Care Institution" (Action 2, p. 58)

It should be noted that a new National Action Plan for HIV-AIDS is also currently under development.

e. <u>National Action Plan for Rare Diseases, 2008-2012</u>

There is no reference to Palliative Care services as such. Nevertheless, we find several relevant references. In response to the special needs of the people suffering from a rare disease and their families, the establishment of new structures (hospices) to support them is mentioned (p. 20). More specifically in p. 34, a reference is made to (a) the development of flexible and alternative therapeutic interventions such as home care, and (b) the development of respite care services - hospices which will relieve families caring for a family member.

f. <u>National Action Plan for cardiovascular diseases 2008-2012</u>

There is no reference to palliative care.

Inclusion of Palliative Care in each of these relevant national strategies is a priority area for Palliative Care policy development in the country as recommended later in the report. Beyond inclusion in these major reports it is also essential that the activities in these national plans are acted upon, which may require budget and monitoring on the part of the Palliative Care community in Greece.

4.4 Overview of the Legal Framework on Palliative Care

The legislation on Palliative Care in Greece is essentially limited to the following:

- Article 17 of the Law 3106/2003 (A’ 30), prepared by the Department of Family Protection of the Ministry of Health.

- Article 29 of the Law 3418/2005 (A’ 287), which provides for the obligation of the physician who treats any person suffering from an incurable disease at the terminal stage to provide Palliative Care and to cooperate with the relatives of the patients in order to alleviate the psychosomatic pain of the patient.

Furthermore, Inter-ministerial Decision 8/B/89126 (Government Gazette 1534/B/17.08.2007), describes the conditions and specifications for the development of Palliative Care Services (Home Care, Day Center and Hospices) under the name of HO.NC.PC. (Hospices for Nursing Care and Palliative Care). **<u>This Ministerial Decision has never been used in practice</u>** for the development of Palliative Care Hospices, possibly due to the excessive demands on building infrastructure and staff. New conditions and specifications for the establishment and operation of "Care Centers for Rehabilitation of Patients with Cancer" were determined with the Ministerial Decision 121/30-10-2008 (B 2277), which however, have never operated as hospices for patients.

It should also be noted that in 2012, Welfare Management was transferred from the Ministry of Health to the Ministry of Labour. All Institutions of Health-Welfare under the name of "Hospice" such as Boarding Houses, Elderly Care Units - Nursing Homes, Rehabilitation Centers etc. were transferred to the Ministry of Labour. The Department of Mental Health constitutes an exception as it remained under the supervision of the Ministry of Health, which is responsible for dementia and Alzheimer's disease, and relevant "Hospices" and "Boarding Houses".

The aforementioned separation of the Health Services (Ministry of Health) and Welfare (Ministry of Labour) in 2012 led to an absence of focal points at the Ministries for the development of a Palliative Care Service. The undertaking of the responsibility for the implementation of Law 2003 by the Ministry of Labour resulted in the lack of a competent department which can oversee the development of a Palliative Care Hospice with complex nursing care and opioid administration. On the other hand, the Ministry of Health recognizes that it constitutes in fact the "competent body", but does not have the appropriate legal framework to assume this responsibility.

Contrary to the weak institutional framework for palliative care, there is an elaborate institutional framework for **Mental Health** with laws, presidential decrees and ministerial decisions. Since at least 1999, Mental Health Management (as opposed to the management of other diseases) in Greece has been monitored and funded by the Department of Mental Health in the Ministry of Health.

Relevant Mental Health legislation and regulatory framework

i. Law 2716/1999, Government Gazette 96 / A / 17.05.1999.
ii. The 2014 Ministry of Health Circular for funding NGOs which includes: Conditions of funding, categories of visits, actions in the community, telephone sessions, rehabilitation centers, mobile units, relevant forms etc. All of this could also be applicable for the PC teams.
iii. Law 4213/2013 Government Gazette 1426 / B / 12.06.2013, article 27 for supervision of the economics of mental health.
iv. The joint Ministerial Decision Α3α/οικ.876/16.5.2000 on «Determination of the organization and operation of Psychiatric Rehabilitation Units (Shelters, Hospices) and the protected apartment living programs, of article 9, Law 2716/1999».
v. The joint Ministerial Decision (Government Gazette 1157/B/29.03.2018): Modification and update of Decision Α3α/οικ.876/16.5.2000 (Β΄ 661) on «Determination of the organization and operation of Psychiatric Rehabilitation Units (Shelters, Hospices) and the protected apartment living programs, of article 9, Law 2716/1999».

vi. National Action Plan on Dementia and Alzheimer's Disease: www.alzheimer-drasi.gr/images/doc/ethniko_sxedio_drasis.pdf
vii. National Observatory on Dementia and Alzheimer's Disease: Law 4316 Government Gazette A 270 / 24-12-2014 «Establishment of an observatory for dementia, improvement of perinatal care, issues of competence of the Ministry of Health and other provisions» https://alzheimerathens.gr/ethniko- paratiritirio.

Recently, funding has been approved for the establishment of eight home care services all over Greece and two "end-of-life" hospices, one in Thessaloniki and another in Kalamata.

Although the above legislation describes mental health structures, it may provide precedent for the development of legislation on Palliative Care structures as they involve the following characteristics:

1. **Structures - Services** (Home Care, Day Centers, Hospices)

2. **Population** (Alzheimer and dementia patients are included in the Palliative Care)

3. **Staff** (Interdisciplinary team with physicians, nurses, social workers, psychologists, and other mental health professionals). Palliative Care staff members should be specified and include professionals specializing in palliative care, as well as oncologists, general practitioners, pulmonologists, nurses and mental health professionals who have been trained in the palliative care.

4. **Chief Authority** (Department of Mental Health at the Ministry of Health)

5. **National Strategic Plan for Dementia**

6. **National Observatory and Funding** (compensation for team visits and not just for a doctor, daily subsistence for the hospice, etc.)

Other Laws Relating to Palliative Care:

1. **Law on drugs causing addiction** (Laws): Law 4139 Gazette 74 / A / 20.03.2013

2. **Law for Primary Health Care**: N.4486 Government Gazette 115 / A 07.08.2017

It should be underlined that in all the above Palliative Care is translated in Greek as "Anakoufistiki Frontida). In all other cases, such as the Code of Medical Ethics and Code of Nursing Ethics, presidential decrees or ministerial decisions, where parigori(ti)ki Frontida is mentioned, it does not concern structures or services or specializations of the Integrated Interdisciplinary Care called "Palliative Care" but they refer to sectors, or interventions of different disciplines (e.g. parigori(ti)ki radiotherapy, parigori(ti)ki palliative physiotherapy etc).

Taking into account the levels of the health care system (primary, secondary etc.) and the welfare system, in which Palliative Care services can be included, the following laws and regulations should be taken into consideration for the future development of the institutional framework for palliative care:

1. **Home care**

i. Law 4272/2014 article 35
ii. Law 3235 GG 53 / A / 18.02.2004
iii. Law 4238 Government Gazette 38 / A / 17.02.2014
iv. Law 4486 Government Gazette 115 / A 07.08.2017
v. The pilot home care program for secondary and tertiary hospitals of the Department of Primary Care of the Ministry of Health
vi. The "House Help" program of municipalities
vii. Additional provisions of the Ministry of the Environment for waste management and KELPNO (Hellenic Center for Disease Control and Prevention) for infection management.

2. **Day Care Centers**

Similar structures are the Elderly Care Centers which are under the jurisdiction of the Ministry of Labour:

i. Law 2345/1995, Government Gazette 213 / A / 12.10.1995, "Organized services for provision of protection from social welfare institutions and other regulations"
ii. Law 4052, Government Gazette 41 / A / 01.03.2012

3. **Secondary and Tertiary Health Care in Hospitals**

i. **Pain clinics**, which now, due to staffing and orientation (they are clinics working with anesthesiologists who treat pain caused by benign and malignant diseases) can be considered part of "general palliative care" as defined above (p. 8).
ii. The Ministerial Decision Υ4α/οικ.1620 12/07/15-102008 (Β' 150), "Institutional framework for the organization and operation of Chronic Pain treatment". Corresponding structures of intra-hospital clinics in the field of Mental Health are the "Memory Clinics" operated by neurologists.

In-hospital councils or groups:

Oncological Councils Law 4052 Government Gazette A 41 / 01.03.2012 article 135.

Nutrition Support Groups and Oncology Councils Law 4316 Government Gazette A 270 / 24-12-2014 Article 6.

Respective Palliative Care groups could be created in hospitals with decisions of the Boards (provided that these decisions are published at the Government Gazette as mentioned above). This does not require interventions in the act of establishment of the hospitals, new mass recruitment, etc.

4. **Free-standing Hospice-Inpatient Unit or facility**

For these structures reference is made only to the inter-ministerial decision regarding Hospices for Nursing Care and Palliative Care 8 / B / house 89126 Government Gazette 1534 / B / 17.08.2007.

4.5 Essential Palliative Medicine Availability

The following medicines are currently available in Greece:

Table 10. Palliative medicine available in Greece

Non-opioids and NSAIMs	
Acetylsalicylic acid	Suppository: 50 mg Tablet: 80 mg; 100 mg; 160 mg; 325 mg; 500 mg
Ibuprofen	Oral liquid: 100 mg/5 mL; 200 mg/5 mL Suppository: 500 mg Tablet: 200 mg; 400 mg; 600 mg
Paracetamol	Oral liquid: 120 mg/5 mL Suppository: 200 mg; 600 mg Tablet: 500 mg; 1000 mg Injection: 1000 mg; plus (IM): 600 mg + 20 mg lidocaine
Opioid analgesics	
Codeine	Tablet: 10mg, 30 mg (phosphate) + paracetamol
Tramadol	Injection: 100 mg/ 2mL; 100 mg/ml Caps: 50 mg; 100 mg; 150 mg; 200 mg (Immediate Release) Tablets: 50 mg; 100 mg; 150 mg; 200 mg (Retard) Oral liquid: 100 mg/mL
Buprenorphine	Transdermal patch: 35 micrograms/hr; 52.5 micrograms/hr; 70 micrograms/hr
Oxycodone	Tablet: 5 mg + 325 mg paracetamol
Fentanyl	Transdermal patch: 12 micrograms/hr; 25 micrograms/hr; 50 micrograms/hr; 75 micrograms/hr; 100 micrograms/hr Oral transmucosal lozenge: 200 micrograms/hr; 400 micrograms/hr; 600 micrograms/hr; 800 micrograms/hr Sublingual tablets: 100 micrograms/hr; 200 micrograms/hr; 300 micrograms/hr; 400 micrograms/hr; 600 micrograms/hr; 800 micrograms/hr Sublingual tablets: 67 micrograms/hr; 133 micrograms/hr; 267 micrograms/hr; 400 micrograms/hr; 533 micrograms/hr; 800 micrograms/hr Nasal spray: 100 micrograms/hr; 400 micrograms/hr

Morphine	Oral: Hydrochloride water soluble powder in various concentrations (1 mg/mL; 2 mg/mL; 5 mg/mL; 10 mg/mL) Injection: 10 mg (morphine hydrochloride or morphine sulfate in 1-mL ampoule
Methadone	Only for the management of drug rehabilitation
Medicines for other common symptoms in palliative care	
Amitriptyline	Tablet: 10 mg; 25 mg
Dexamethasone	Injection: 4mg/mL in 1-mL ampoule Oral liquid: 2mg/5 mL Tablet: 2 mg
Diazepam	Injection: 5mg/mL Rectal solution: 5 mg Tablet: 2 mg; 5 mg; 10 mg
Fluoxetine	Solid oral dosage form: 20 mg
Haloperidol	Injection: 5mg in 1-mL ampoule; 50 mg/mL Oral liquid: 2mg/ mL Solid oral dosage form: 1 mg; 5 mg; 10 mg
Hyoscine Butylbromide	Injection: 20 mg/ mL Suppository: 7.5 mg; 10 mg Tablet: 10 mg
Lactulose	Oral liquid: 3.1-3.7 g/5 mL
Loperamide	Solid oral dosage form: 2mg
Metoclopramide	Injection: 5mg (hydrochloride)/ mL in 2-mL ampoule Oral liquid: 5 mg/5 mL Solid oral form: 10 mg (hydrochloride) Nasal spray: 10 mg/dose; 20 mg/dose
Midazolam	Injection: 15 mg/3 mL; 50 mg/ 10mL
Ondansetron/Granisetron	Injection: 2mg base/ mL in 2-mL ampoule (as hydrochloride) Oral liquid: 4 mg/5 mL Solid oral dosage form: Eq 4 mg base; Eq 8 mg base Ondansetron transdermal patch: 3.1 mg/24 hrs/week

To conclude, we compared the list of the national essential medicines available in Greece in order to identify specific medicines that are on the WHO model list of essential medicines pain and Palliative Care section but are not on the national list. All the medicines were available with the exception of Cyclizine and Hyoscine hydrobromide (see appendix E). Methadone is registered but is only approved for treatment of opioid use disorder and not for pain management. More importantly, morphine is only available in injectable form and in oral solution from powder. Morphine tablets also need to be made available.

4.6 Education & Research

4.6.1 Overview

The European Association for Palliative Care, has identified three levels of education for the delivery of adult palliative care[6] and of children[7].

Levels	Description
Basic Palliative Care	A way to integrate Palliative Care methods and procedures in settings not specialized in palliative care. Should be made available to general practitioners and staff in general hospitals, as well as to nursing services and nursing home staff. May be taught through undergraduate learning or through continuing professional development.
General Palliative Care	Provided by primary care professionals and specialists treating patients with life-threatening diseases who have good basic Palliative Care skills and knowledge. Should be made available to professionals who are involved more frequently in palliative care, such as oncologists, but do not provide Palliative Care as the main focus of their work. Depending on discipline, it may be taught at an undergraduate or postgraduate level or through continuing professional development.
Specialist Palliative Care	Provided in services whose main activity is the provision of palliative care. These services generally care for patients with complex and difficult needs and therefore require a higher level of education, staff and other resources. Usually taught at a postgraduate level and reinforced through continuing professional development.

Whilst education programs vary throughout Europe and across the world, there are key principles that should underpin every training in adult and in pediatric palliative care. Thanks to the work of two task forces on Education in Palliative Care, the European Association for Palliative Care (EAPC) has issued two key documents outlining specific core components that must be included in every educational program on adult or pediatric Palliative Care (Gamondi *et al*., 2013; Downing *et al*., 2014). For each of the above levels, EAPC identified the required level of knowledge, skills, capacity for interdisciplinary thinking, and ability for self-awareness and reflective practice. These guidelines need to help those designing educational programs to meet the needs of distinct levels of practice in palliative care.

[6] Gamondi C, Larkin P, Payne S. Core competencies in palliative care: An EAPC white paper on Palliative Care education – part 1. *European J Palliative Care.* 2013; 20(2):86-90.

[7] Downing J, Ling J, Benini F, Payne S, & Papadatou D. A summary of the EAPC white paper on core competencies for education in paediatric palliative care. *European J Palliative Care.* 2014; 21(5):245-249.

4.6.2 Palliative Care Education in Greece

Undergraduate and graduate education at academic settings for students in health care and mental health care is provided by the following educational institutions:

Educational Institution	Name
Medical Depts or Schools (7)	i. National and Kapodistrian University of Athens ii. Aristoteleio University of Thessaloniki iii. University of Crete iv. University of Ioannina v. University of Patras vi. Democriteion University of Thrace vii. University of Thessalia
Nursing Depts (3)	i. National and Kapodistrian University of Athens ii. University of Peloponnese iii. University of West Attica
Nursing Depts in Technological Educational Institutes (TEIs) (7)	i. TEI of Thessaloniki ii. TEI of Lamia iii. TEI of Larissa iv. TEI of Patras v. TEI of Crete vi. TEI of Sterea Ellada vii. TEI of Didimoticho
Psychology Depts (5)	i. National and Kapodistrian University of Athens ii. Panteion University iii. University of Crete iv. Aristoteleio University of Thessaloniki v. University of Ioannina
Social Work Depts (2)	i. Democriteion University of Thrace ii. University of West Attica
Social Work Depts in Technological Educational Institutes (TEIs) (2)	i. TEI of Crete ii. TEI of Patras

According to the available data that was collected from all the academic institutions "palliative care" is almost totally absent from the undergraduate educational programs of all Schools of Medicine (with the exception of two electives) and are integrated in all the University educational programs of Nursing. Three post-graduate programs in Palliative Care are available for those interested to specialize. Below is a description of the existing courses and educational programs on Palliative Care in Greece (for more information about the university programs see Appendix F).

Undergraduate Courses

- In **Medical Schools,** "Palliative Care" is an elective course only at the National and Kapodistrian University of Athens. Reference to Palliative Care is made in two other courses on *Pain Relief* (University of Athens), and *Oncology and Ethics* (University of Patras).

- In **Nursing Departments** "Palliative Care" is a compulsory course at the National and Kapodistrian University of Athens and is taught to approximately 220 students per year who also visit, in small groups, "GALILEE" and "Merimna" so as to become acquainted with the implementation of such services in adult and childhood populations. A compulsory course on Palliative Care is also taught at the University of West Attica, and an elective course at the TEI of Nursing, in Heraklion and Larissa. In the other departments of Nursing (e.g. TEI of Patras, Ioannina, Didimoticho, Thessaloniki and Sterea Ellada), the Palliative Care approach is mentioned in various courses (e.g. gerontological nursing).

- In **Psychology Departments**, Palliative Care is not offered as a course, but related topics are included in compulsory courses (National and Kapodistrian University of Athens, University of Ioannina) and elective courses on health psychology (University of Ioannina, University of Crete, Panteion University)

- In **Social Work Departments**, Palliative Care is not offered as compulsory or elective course. Nevertheless, topics of Palliative Care for adults and children, family bereavement and interdisciplinary cooperation are included in compulsory courses (University of West Attica, TEI of Crete) and optional courses (Democritus University of Thrace, University of West Attica)

Palliative Care is **not** taught at any department of **Pharmacology** and of **Physiotherapy** in Greece.

Postgraduate Programs on Palliative Care and Courses

There are three postgraduate programs on Palliative Care:

1. *"Organization and Management of Palliative and Supportive Care" (*120 ECTS).
   It is offered by the Medical and Nursing Departments of the National and Kapodistrian University of Athens and is addressed to post-graduate students from a variety of disciplines.

2. *"Oncology Nursing and Palliative Care"* (120 ECTS), offered by the Nursing Department of the National and Kapodistrian University of Athens and is addressed to nurses.

3. *"Supportive and Palliative Care of Patients with Cancer"* (30-60 ECTS) offered by the Nursing Dept. of the University of West Attica.

Furthermore, at a graduate level, Palliative Care is mentioned in various courses in the schools of Medicine and Nursing (National and Kapodistrian University of Athens & Nursing Dept. TEI of Larissa) as well as in the department of Social Work (TEI of Crete).

It should be noted that education on *Pediatric Palliative Care* is limited to few hours at both undergraduate and postgraduate levels, with the exception of the aforementioned interdisciplinary postgraduate program (offered by the Medical School and the Nursing School of EKPA). Courses on Pediatric Nursing at an undergraduate and postgraduate level include certain hours on pediatric Palliative Care in some departments (National and Kapodistrian University of Athens & University of Peloponnese).

Finally, at an undergraduate level, Palliative Care and Pediatric Palliative Care courses or topics are mainly theoretical, while clinical practice is limited (13 hours) due to very few available Palliative Care services for adults and children. At postgraduate level, a special effort is made to ensure a 150-hour clinical experience in existing services.

In summary, Palliative Care is rarely addressed in the undergraduate studies of health and mental health students, while the content of teaching remains to be explored. Worth mentioning are the nursing departments which have pioneered in Palliative Care education, and have been instrumental in developing post-graduate programs, independently or in collaboration with a medical school.

Training and Clinical Practice Provided by NGOs

Various NGOs that provide Palliative Care services, offer continuing education programs on Palliative Care for adults or children for professionals and volunteers. Following is a brief description of the training programs (both theoretical and clinical practice) on palliative care, organized by NGOs.

Merimna organizes and provides the following educational activities:

i. *Training programs in pediatric palliative care*. It comprises 3 modules (200 hours in total) and is addressed to pediatricians, nurses, social workers, psychologists, physiotherapists and special education teachers.

ii. *Training for volunteers*. So far there are 6 trainings for 6 groups of volunteers who are involved in the pediatric palliative home care service and fundraising activities for "Merimna".

iii. *Lectures and seminars* on the pediatric Palliative Care approach and Merimna's services. They are addressed to undergraduate nursing students and graduate students in Palliative Care of the National and Kapodistrian University of Athens and the University of Peloponnese (academic level), to the staff/professionals of pediatric clinics, PICU, NICU, Oncology units in public and private hospitals (clinical level), and to community services (i.e. special schools, rehabilitation centers).

iv. *Panhellenic Symposia on Pediatric Palliative Care.* In collaboration with the Greek Society for Pediatric Palliative Care, Merimna organized and hosted 3 Panhelenic Symposia (2009, 2011, 2016) that were well-attended and included as speakers national and international leaders in the field of pediatric palliative (e.g. Sister Francis Dominica, Myra Bluebod-Langner, Ann Goldman, Renee McCullock).

v. *Transformational leadership in Palliative Care Nursing*. In collaboration with "GALILEE" and the Department of Nursing of the National and Kapodistrian University of Athens, and the "Hospice Casa Sperantei" of Brasov Romania, “Merimna” provides a one-year training program.

vi. *Training in Palliative Care for health care professionals working in the public sector*. Invited –by the 2nd Regional Health Authority of the Ministry of Health, “Merimna” in collaboration with “GALILEE” and the Department of Nursing of the National and Kapodistrian University of Athens, provided 80hrs of training to 25 health care professionals working in public hospitals.

GALILEE organizes and provides the following educational activities:

i. *Annual seminars on "Basic Principles of Palliative Care*" (40 hrs). Participants include doctors, nurses, social workers, pharmacists, physiotherapists, theologians, priests, art psychotherapists, administrative personnel etc. So far 266 professionals have been trained in 10 consecutive yearly seminars. Training topics included: Introduction to palliative care, structures in Greece, holistic evaluation in palliative care, pain and suffering, basic principles in pain management, managing symptoms in palliative care, group dynamics, communication skills in palliative care, grief and bereavement, ethical dilemmas, the Ontario cancer care model, volunteers in a team of palliative care, Palliative Care unit management, spiritual care etc.

ii. *Clinical practice* (1-2 weeks) for students attending the postgraduate programs on Palliative Care. So far 49 professionals have received 4.880 hours of training.

iii. *Training program for volunteers* (40hrs). So far, 180 volunteers have been trained through 6 annual thematic packages including also experiential learning.

iv. *Training in Palliative Care for health care professionals working in the public sector.* “GALILEE” in cooperation with Merimna, and the Department of Nursing of the National and Kapodistrian University of Athens, following the invitation of the 2nd Regional Health Authority, have provided 80hrs of training to 25 health professionals working in public hospitals.

v. *Transformational leadership in Palliative Care Nursing*. In collaboration with "Merimna" and the Dept. of Nursing of the National and Kapodistrian University of Athens, and the "Hospice Casa Sperantei" of Brasov Romania, GALILEE offers a one-year training.

Furthermore, the three scientific societies of Palliative Care in Greece, implement important programs of education and capacity building for health professionals on relevant topics. Below follows a short description of their work.

Hellenic Association for Pain Control and Palliative Care (HAPCPC) organizes and provides the following educational activities:

i. *Seminars on Palliative and Supportive Care (30 hours). 1 annually with 20 participants (physicians, nurses, psychologists, social workers etc).*

ii. *Organization of 2-3/year scientific meetings in collaboration with Nursing Associations and Oncology Associations.*

Hellenic Society of Pain Control and Palliative Care - PARH.SY.A organizes and provides the following educational activities:

i. *Three seminars per year* are addressed to 50-80 health care professionals (i.e. doctors, nurses, psychologists, physiotherapists, auxiliary therapists).

ii. *18 congresses and seminars* have been organized over the years, including 4 World Congresses. These are focused on Therapy of Chronic Pain and Palliative Care. Trainers and invited speakers included experts in the field such as Robert Twycross, Irene Higgingson, Ludjack Stein Kaasa, Sebastiano Mercadante, Snezana Bosnjack, Kriss Vissers.

The **Greek Society for Pediatric Palliative Care** organizes the following activities:

i. Training seminars on Clinical Pediatric Palliative Care (6-7 hours each), addressed to health professionals (doctors, nurses, psychologists, social workers, physiotherapists, special educators etc). The first seminar was organized in 2018, at the General Ongology Hospital "Agioi Anargyroi" at Kifisia.

ii. The Society, in cooperation with Merimna has co-organised the two Panhellenic Symposia of Pediatric Palliative Care (2011, 2016).

4.6.3 Research

Research is conducted (a) in the *academic setting* through the completion of post graduate programs (M.Sc. and Ph.D.), as well as through the studies of professors who specialize in palliative care, and (b) in the *community*, through some NGOs that provide Palliative Care services in Greece.

Research at an academic setting

Since the development of the MSc: "Organization and Management in Palliative and Supportive care of chronically ill", of the Medical School in collaboration with the Department of Nursing (National and Kapodistrian University of Athens), several students have completed their dissertation (Master level) on adult or pediatric Palliative Care topics. Most often these involve a systematic review of the literature and/or research on a related topic.

More specifically, a total of 71 theses have been completed and they can be classified in the following subjects. (Numbers in brackets indicate the number of theses belonging in each category). The majority have been published in international scientific journals.

- Physical and psychological symptoms in cancer patients (29)
- Physical and psychological symptoms in patients with non-malignant, life-threatening or not diseases (e.g. kidney failure, stroke, Alzheimer disease, multiple sclerosis, Hansen disease, AIDS, osteoarthritis) (11)
- Psychological distress of caregivers (14)
- Psychological distress, satisfaction, burden, post trauma, resilience of health care professionals (12)
- Grief and bereavement for children and for adults (3)
- Pediatric Palliative Care (2)

Palliative Care studies conducted in the context of a Ph.D. have focused mostly on the quality of life of patients with a life-threatening illness, the needs of family members, and the responses of health care professionals to the care of patients with a life-threatening illness. Professors specializing in Palliative Care in the Nursing and Medical Departments have also conducted studies on various topics, which have been published in peer-reviewed journals. A brief indication of some topics comprises:

- The training of nurses in assessing and managing pain in patients with cancer
- Training in pediatric palliative for a multidisciplinary team of health care professionals
- Pain and symptom management for patients in need of Palliative Care
- Palliative Care needs of Greek patients with a life-threatening illness
- Needs for supportive care among cancer patients who receive chemotherapy
- Exploring the knowledge and attitudes towards Palliative Care among nursing students
- The grief of nurses and physicians who care for children who die
- The psychometric properties of various scales used in palliative care

Scientific studies regarding palliative care, were conducted in the Pain Relief and Palliative Care Unit “Jenny Karezi”, School of Medicine of the National and Kapodistrian University of Athens. They have been published in international peer reviewed scientific journals with the following topics:

- Psychometric properties of research instruments (physical and psychological symptoms) (24)
- Pain treatment in Palliative Care (22)
- Clinical pharmacology in Palliative Care (7)
- The needs and the comprehensive treatment of physical and psychological symptoms of patients with life threatening diseases (86)
- Quality of life in cancer patients (6)
- Caregivers of patients with cancer and their psychological state (7)
- Death issues-grief and bereavement (10)
- Spirituality and religiosity (3)

- Ethical and moral issues in Palliative Care (9)
- Research regarding Palliative Care status in Greece (4)

Research in the community, through NGOs

The Palliative Care teams of "GALILEE" and “Merimna” have undertaken research projects in an attempt to better understand the needs of the families they serve and explore the satisfaction with the provided palliative home care services.

For example, the “GALILEE” team conducted a survey with cancer patients treated in the “Saint Savas” Hospital to assess the patients’ problems and needs regarding palliative care. In another study the team explored the symptom burden at the time of admission at GALILEE’s home care program, and two months later, recording a statistically significant decrease in depression and improvement in overall sense of well-being. Finally, another study on caregiver satisfaction showed increased levels of satisfaction at 2 or 3 weeks after the patient's death, which correlated with the patient's functional status.

“Merimna”’s team conducted a qualitative study with parents whose child died in the hospital and parents whose child died at home and explored the factors that affected the decision-making process regarding the location of the child’s care at the end of life, and death.

4.7 Implementation

Today there is no legal framework for hospice and Palliative Care units in Greece. Patients who need to receive Palliative Care services can address either to non-governmental organizations & patients associations, or to providers whose primary health services are not related directly to palliative care.

The first category providers (specialist PC) are described analytically in section 4.2. The second category consists of the following providers:

- *Public clinics,* within public hospitals, which provide inpatient hospice services and Greek National Organization for the Provision of Health Services (EOPYY) reimburses 34,6€ per day per patient (same as any daily hospitalization).
- *Private rehabilitation centers*, which EOPYY reimburses for 150€ per day per patient (for inpatient services) or 75€ (for outpatient services).
- *Small general private clinics,* which provide mainly geriatric services and they are reimbursed from EOPYY for 34,6€ per day per patient.
- *Chronic disease private* (usually non profitable) *institutions*, which mainly take care of inpatients and EOPYY reimburses for 34,6€ per day per patient.

According to the categories proposed at the present Feasibility Study, reimbursement for Palliative Care services in Greece, should be as following:

Palliative Care type	Proposed Reimbursement
Inpatient care	Bundled payment
Outpatient care	Payment per capitation
Home based care	P4P – Pay for Performance

As noted above three specialised Palliative Care programs operate in Athens, one by “Jenny Karezi”, the Palliative Care Unit of the Medical School of EKPA, the second by GALILEEE and the third one by MERIMNA. Additionally, there is the General Palliative Care program of the pain clinic of the A’ Anesthesiology Clinic, Aretaieio University Hospital and a home PC program under development of the NGOs NOSILEIA and KEFI. In addition, there are 40 oncology clinics and 56 public hospital pain management services some of which provide General Palliative Care services (see section 4.2). Also, the National Action Plan for Alzheimer’s Disease calls for strengthening existing services and the establishment of new services to deliver hospice and Palliative Care services for people living with dementia.

There are **no agreed** National Standards for what is an ‘approved’ Palliative Care service at present, so it is difficult to determine the degree and quality of Palliative Care implementation in the country. Standards should be consistent with the guidance from the European Association for Palliative Care. A call for the establishment of approved national operating standards is included in this report. Standards should also differentiate between the provision of **"Basic" “General” and "*Specialized*"** or **"*Specialist*"** palliative care. International experience demonstrates that the majority of patients needing Palliative Care should be able to be cared for by their primary care clinicians if they have at least basic training in ***Palliative Care approach***.

National standards for providers of Palliative Care usually at minimum address the following areas:

- Definition, history, and philosophy of Palliative Care provision
- Access to Palliative Care including admission requirements
- The scope of palliative care: PC has an active role from the diagnosis of an illness to the support of a family for bereavement after the death of the patient
- The required and optional members of the interdisciplinary team including their roles, scope of practice, required education and training
- The interdisciplinary plan of care development and updating process
- The Medical & Nursing Records
- Safety and infection control
- Medication, equipment, & consumable medical supplies
- Settings of care
- Nutritional management
- Governance and leadership
- Quality Assessment and Performance Improvement
- Ethical Issues

- Financial and human resource management
- Staff and provider support and supervision
- Bereavement support
- Pediatric Palliative Care provision

Beyond program operational standards there is also a need for the development of clinical guidelines and protocols to guide the provision of actual Palliative Care to the patients and families.

4.8 The Role of Non-Governmental Organizations & Patients' Associations

Non-Governmental Organizations play an important role in raising awareness, advocating and promoting the development of Palliative Care in Greece, as well as providing Palliative Care services to people in need.

We presented above the most active NGOs providers of Palliative Care services namely **MERIMNA, GALILEE** and **NOSILIA-KEFI** (their capacity, geographic coverage, type of services etc.).

Apart from the above NGOs there are other important associations in this field, operating under the legal form of Somateio, such as **the Hellenic Society of Pain Management and Palliative Care - PARH.SY.A., the Hellenic Association of Pain Control and Palliative Care (HAPCPC)** and **the Greek Society for Pediatric Palliative Care**.

PARH.SY.A. was founded in November 1997 by a group of anesthesiologists with an expertise in pain management and palliative care. It seeks to promote in Greece the implementation of a holistic approach in caring for patients with chronic pain and patients at the terminal stage. Among its 450 members, there are doctors who operate on a voluntary basis the pain centers throughout the country. PARHY.SY.A is also a collective member of the EAPC, ECEPT, EuLAP, WIP, and WHPCA. The Society builds the capacity of its members by providing ongoing training in Palliative Care in hospitals all over Greece. It participates in awareness raising activities including TV campaigns, World Hospice and Palliative Care Day events, seminars, conferences, website and publishing of the journal *Parigoriki Frontida* since 2006. Also, it conducts research in the field of Palliative Care including the development of a National Registry for Neuropathic Pain and publication of guidelines for Management of Neuropathic Pain.

The Hellenic Association of Pain Control and Palliative Care was founded in 1997 by a team of multidisciplinary health care professionals with expertise in pain relief and palliative care. It promotes education and training in Palliative Care and is also a collective member of the EAPC.

The Greek Society for Pediatric Palliative Care was founded in 2009 with the aim: 1) to promote the provision of pediatric Palliative Care to children and adolescents facing a life-threatening or life-limiting illness and their families; 2) to inform and train health professionals on Pediatric Palliative Care and 3) to provide information and raise the awareness of the society on the issues of Pediatric Palliative Care. It is also a collective member of the EAPC.

These societies train professionals organize symposia and participate at international and European fora.

Furthermore, there are several **patients' associations** and support groups in Greece for most diseases. The majority are voluntary and cover their operational costs through subscription fees and donations from pharmaceutical companies and other private donors. A few of them receive funding from the state and offer a wide range of services to their members.

During the course and for the purposes of this study, we contacted, where possible, the federations and confederations of patients' associations for most of the diagnostic groups that require Palliative Care and some associations representing large numbers of patients. More specifically, we contacted **the National Confederation of People with Disabilities** (with 600-700 members primary associations across Greece), the **Hellenic Federation of Nephrology Patient Associations** (with 42 members primary associations and 11.000 patients members), the **Hellenic Federation of Diabetes Patient Associations** (including 25 primary associations and 27.000 patients), the **Association of Cancer Patients of Macedonia and Thrace** (7.000 members), the **Association of Cancer Patients "KEFI of Athens",** the **Association against Rheumatoid Diseases** (750-800 members patients), the **Association for Multiple Sclerosis** (7.000 members across Greece), the **Hellenic Cystic Fibrosis Association** (500 members), the **Greek Association of Alzheimer Disease and Relative Disorders** (Alzheimer Hellas), and the **Association of People Living with HIV - Positive Voice.**

A short questionnaire was prepared and filled in over the phone - in most of the cases it was necessary to clarify the content of the term "palliative care" for the representative of the association to be able to answer some of the questions (see the questionnaire in appendix J). More specifically, the questionnaire included questions about the target group and the number of beneficiaries per year, the provided services, the specialties of the professionals supporting their members, how these organizations understand the concept Palliative Care, whether they are interested in promoting awareness about it, and whether they are interested in providing Palliative Care services to their beneficiaries in the future.

The main results of our research follow below:

Given that the institutional framework for Alzheimer/dementia in Greece is quite elaborate, it is not surprising that the two biggest Alzheimer associations in Athens and Thessaloniki, are familiar with the term and the services involved in palliative care. Furthermore, these organizations are well established, they provide certain services to their patients, as they run day care centers and home care programs which involve multidisciplinary teams (e.g. the Athens organization operates 4 day care centers, and their home-care teams realize approximately 3.000 visits/year in Athens). Their teams of professionals include doctors, psychologists, logotherapists, social workers, physiotherapists and volunteers etc. Additionally, they are willing to engage more actively in raising awareness and supporting their members. Smaller Alzheimer associations across Greece with less resources, as it was explained, might not be able to define the term "palliative care" but they are definitely open to learn

about it, raise awareness about these services and even actively engage in the provision of Palliative Care services.

Concerning the rest of the patients' associations there is a lack of knowledge and confusion regarding the services involved in palliative care. For example, 5/10 did not know what Palliative Care is, 3/10 answered that Palliative Care is "end-of-life-care". Nevertheless, after we explained to them what kind of services are involved, all organizations confirmed that their target groups are in dire need of that type of services. Additionally, they showed a strong interest to further learn about Palliative Care and contribute in raising awareness, promoting these services and even engaging actively in the provision of Palliative Care services.

Palliative Care Services for refugees

Currently, the **Doctors Without Borders (MSF)**, the **Doctors of the World** and **K.E.EL.P.N.O.** (The National Center for the Prevention and Control of Diseases) are the three main bodies that provide health care services to refugees and migrants, currently living in Greek camps. According to Apostolos Veizis, Programs Director of the Greek branch of MSF, over the last few years, the organization has come across refugees with cancer in need of palliative care. MSF referred them to pain management services. It should be noted that MSF (the international organization) has expertise in palliative care; however, in order for it to become operational in the Greek context, a decision should be taken at the organizational level, the necessary resources (human and financial) should be ensured and a comprehensive and clear regulatory framework should be established. To conclude, even though the Doctors without Borders, the Doctors of the World, and the K.E.EL.P.N.O. staff members could in principle join Palliative Care providers in Greece, a strategic decision-making process and a comprehensive plan are required for Palliative Care needs of refugees and migrants to be met with competence.

5. The Need for Palliative Care Services in Greece

This assessment of need for Palliative Care is based on two major studies on the need for Palliative Care that have recently been published. The actual need for Palliative Care in Greece is not known, however the calculations from these studies can serve as reasonable estimates of the need for planning purposes. In addition, estimates of need by region in Greece are needed.

5.1 Overall Country Need

Based on the international assessment methods the annual need for Palliative Care both before and at the end of life in Greece is as high as 135,000 patients and their families. Non-decedents are those experiencing serious health related suffering that are likely to live more than one year.

Table 11. Need for PC in Greece – Lancet results

Decedents	62,000
Non-decedents	73,000
Total	**135,000**

Table 12. Need for PC in Greece – Atlas results

Adults	Cancer	26,321
	CVD	20,686
	COPD	4,452
	Other progressive illness	5,401
Children		3,219
Total at EOL		**60,079**
Total at EOL & before EOL		**120,157**

Table 13. Comparison of Atlas & Lancet results

	Atlas	**Lancet**
Adults Decedents	56,860	
Child Decedent	3,219	
Total decedents	**60,079**	**62,000**
Adult non-decedent	56,860	
Child non-decedent	3,219	
Total non-decedents	**60,079**	**73,000**
Grand Total	**120,157**	**135,000**

Table 14. Breakdown of major diagnostic groups needing palliative care

Diagnosis	**Decedents**	**Non-decedents**	**Totals (%)**
All Cancers	25,437	23,939	49,376 (36.7)
Dementias	7,864	28,198	36,062 (26.8)
CVD	12,442	11,862	24,304 (18)
Other	8,743	8,772	17,515 (13)
Lung	5,078	0	5,078 (3.8)
Heart	2,292	0	2,292 (1.7)
Total	**61,856**	**72,771**	**134,627**

Note: Based on Lancet Commission Results, see **Appendix C** for a complete breakdown

5.2 Need for Palliative Home-based and Outpatient Care

The great majority of patients needing Palliative Care in Greece can best be served by delivering home based palliative care. In countries where Palliative Care is well developed including the UK, the USA, Australia, and many EU countries, provision of home care allows patients to avoid unnecessary hospitalization and associated costs. Most people prefer to be in the place they call home when ill rather than in an institution. Palliative Care makes this possible by providing access to Palliative Care providers 24 hours a day, 7 days a week, who support family care givers providing over 90% of direct care.

Palliative Care professionals develop a plan of care for the patient and teach family members to provide basic nursing care to their loved one so as to maintain the patient at home, free from pain and unnecessary suffering. Short term inpatient care may be needed for some patients for severe symptom management and stabilization.

To determine the number of patients that need Palliative Care at home we calculate an average daily census based on an expected mean length of service. In a perfect world where every person in need of Palliative Care received an average of **70 days (**with some patients receiving care for one day and others being cared for many months) the calculations would look as follows:

- 62,000 decedents times 70 days = 4,340,000 days divided by 365 days = 11,890 patients per day or average daily census (ADC)

In addition, non-decedents would need a lesser degree of home and outpatient care. If we use the assumption that these patients would need 25% of the care that decedents receive this would add an additional

- 73,000 non-decedents times 25% =18,250*70=1,277,500/365 = 3,500 additional ADC
- 11,890 + 3,500 = approximately 15,000 ADC for home and outpatient care patients

5.3 Inpatient Bed Need for Palliative Care

To estimate the need for **inpatient palliative** or **hospice care beds** we can again use the average daily census and apply a percentage to the number of patients needing inpatient care on a given day. In the United States the percentage is 2.5% of hospice days; however, this does not account for other non-hospice Palliative Care patients and use of hospitals in Greece. Therefore, an estimate of 3.5% will be used to calculate the average daily census for decedents of 15,000 which accounts for a need of **525 beds**.

Another method used by the WHO Collaborating Center in Catalonia, Spain, to estimate bed need is *5 beds per 100,000* population (107.68). Using this method results in a projection of **538 beds** in Greece. Given the fact that the majority of patients die at home and continue to desire home as the site of care, inpatient Palliative Care should NOT be over-emphasized. For planning purposes, need for

occupancy turn over and growth in the population, it would be safe to estimate approximately **500 beds for the country**. It will be necessary to determine which regional hospitals should have inpatient Palliative Care beds and what additional inpatient hospice beds might be feasible.

5.4 Health Workforce Need

The current population of Greece is about 10.8 million people. Using a population approach, we can also project the need for palliative home care services and hospice and Palliative Care inpatient beds/units. To provide home based and inpatient care to a population of approximately 15,000 patients per day will require some reallocation of health professional resources for both the urban and rural areas.

There are two methods to use to calculate the **staffing needs** for home-based care and inpatient care. One is based on the projected *average daily census* and the second is an *epidemiological population-based approach* proposed by professor Gomez-Batiste[8].

Using the *average daily census* (ADC), for home-based care, we use a ratio of one full time equivalent (FTE) nurse for every 10 patients on daily service and for physicians we use one FTE for every 30 patients on service. In addition, other staff are needed for the clinical services including social workers, psychologists, social assistants/volunteers, therapists, and drivers. It is estimated that 2 FTE of other clinical specialists, is needed for every 30 patients on service, including one full time social worker for each Palliative Care team.

In addition, **volunteers** could be used to supplement the staffing and to improve quality of caring. Approximately 25% of families may use a volunteer for at least 2 hours a week.

- If 3,750 patients (25% of 15,000) receive 2 hours a week of care X 52 weeks = 380,000 hours of volunteer assistance per year. If each volunteer worked 8 hours/week about 50,000 volunteers would be needed eventually. There are some legal risks (see above) and a lack of volunteerism history and legislation in Greece that may make this difficult to achieve.

If we have an ADC of 15,000 patients, using the above assumptions, we can project that FTE's for **palliative home care 1,500** nurses will be required, **500 physicians,** and **1000 other clinical support staff.**

For inpatient care we will use the population-based assumptions below for each 10 beds. Inpatient nursing is 50% professional nurses and 50% nursing assistants.

[8] Gomez-Batiste G, et al. (2017). Comprehensive and integrated Palliative Care for people with advanced chronic conditions: An update from several European initiatives and recommendations for policy. *J Pain and Symptom Mgmt*; 53(3):509-517.

Table 15. Inpatient staffing ratios[9]

For inpatient care per 10 beds	**For home care per 30 ADC**
1.5 MD's	1 MD
12 nurses	3 nurses
4 other clinical staff	2 other clinical staff

Table 16. Clinical staffing needed

For home-based care	**For inpatient care (for 500 beds) ***	**Total Clinical Staff**
500 physicians 1,500 nurses 1,000 other clinical staff (including social workers, psychologists, physiotherapist, etc) **3,000 Total**	75 physicians 600 nurses (includes 50% nursing assistants) 200 other clinical staff **875 Total** *These staff are already allocated in the health care system since these are existing patients	575 physicians 2,100 nurses (includes nursing assistants) 1,200 other clinical staff (including social workers, psychologists etc) **3,875 Total**

Cancer patients will require about 37% of these resources.

This projection does not include **administrative staff**. If we use an estimate of 20% additional administrative staff, we would add about another 775 or **a total of 4,650 staff**. Palliative Care teams generally work well with caseloads up to 50 patients. Additional teams can be formed under one administrative authority for a given geographic area, as scale up continues. To care for a daily census of 15,000 patients would eventually require approximately 300 such teams to serve the country, each with about 16 full time staff.

It is important to understand that these are estimates of the current need in a perfect world where everyone gets palliative care. In no country is the full need for Palliative Care being met. In the 45 years that Palliative Care has been developing in the USA only about 75% of the current need is being met. In Greece it will likely to take decades to meet the majority of the need for Palliative Care and planning must take this into account.

[9] White paper on standards and norms for hospice and Palliative Care in Europe: Part 2. European Journal of Palliative Care 2010;17(1):22

6. Gap Analysis – Unmet Need

Based on a survey of existing hospice and Palliative Care providers in Greece, we have estimated that the current capacity to deliver specialized Palliative Care is approximately **600 patients per year.** Using the Lancet Commission estimate this represents just under 1% of the need for Palliative Care just for decedents (62,000) and even less if we count the total need for decedents and non-decedents (135,000). This estimate does not include services provided in the pain clinics and other centers but even if those were included the number would certainly be less than 10%. The number of people currently unable to receive Palliative Care is only part of the picture. Many additional gaps exist based on interviews with Palliative Care experts and patients and families. There continue to be gaps in policy, education, and medicine availability as well as financial and human resources.

6.1 The Voice of Patients and Families

The son of a 64-year-old woman with glioblastoma at GALILEE Hospice says: "*She paid for 35 years; now I have to rely on the church in her hour of need*".

A woman in her early 50's with gastric cancer reported that her diagnosis was delayed for 6 months. She was forced to discharge from the public hospital and has been getting home care and short-term inpatient care at GALILEE "*It's wonderful, words cannot express, I am very lucky that I am here. Talking helps… everyone here is special; their love and kindness give me strength*".

A 54-year-old woman with metastatic breast cancer diagnosed in 2015 cared for at the pain clinic " *Big help, more mobile now… it helps me get through… they explain everything in simple terms, how to get through…Wish I was not sick but they help cure my symptoms*".

The bereaved mother of a child with Spinal Muscular Atrophy type 1 said "*It is not an obligation for them to provide home visits…they were there when she had a need and provide answers to our questions…At Merimna they helped us without judging us day and night*."

6.2 Key Informants

Several experts in Palliative Care were interviewed to gain insight into both the unmet need for Palliative Care and for recommendations on the way forward. Their comments are summarized below:

Dr. Aliki Tserkezoglou, Director of GALILEE Hospice - originally trained as an OB/GYN, specialized in gynecology oncology, then she was trained in Palliative Care at Cardiff University in 2011 and at the European Academy of Palliative Care EUPCA) in 2015. While GALILEE has a nine-bed inpatient unit they focus mainly on home care. The home care team is based at their unit and is serving 82 patients at present. They have cared for over 890 patients with an average length of service of 67 days and 67% home deaths. Additionally, 120 patients received PC services at the hospice during the first year

of its operation. They operate a 24-hour 7 day a week phone access line for home patients. There is a large classroom space for training, and they teach a 40-hour basic course on palliative care. Nurses from the University of Athens have a compulsory rotation at GALILEE for 1-2 weeks after the basic training. Furthermore, the unit organizes seminars on Palliative Care for volunteers. Opioids for pain management are available in the hospice and they are prescribed by the doctors. The entire operation of GALILEE is funded by the Greek Orthodox Church and its donors. Dr. Tserkezoglou perceives public awareness of Palliative Care to be very low.

Dr. Elisabeth Patiraki, Professor, Department of Nursing, University of Athens – Dr. Patiraki is a nurse with a PhD in pain assessment. She has attended training seminars at Casa Sperantei hospice in Romania and St. Christopher's Hospice in the UK. She teaches the course of Palliative Care at the undergraduate level, in two postgraduate programs and in a yearly training program on basic principles of Palliative Care in GALILEE. Although she trains nurses for many years using the ELNEC model (end of life nursing education consortium) in undergraduate level and two postgraduate programmes, she believes that it is essential that physicians be taught Palliative Care and is concerned about the lack of model physician leadership in Greece. Her view is that Palliative Care has not been a priority of the government and medical establishment. The state should initiate Palliative Care in hospitals but there has been much resistance. Support for Palliative Care is needed from respected leaders, a new law on Palliative Care is needed, and a payment mechanism to encourage growth.

Dr. Athina Vadalouka, President, the Hellenic Society of Pain Management and Palliative Care - PARH.SY.A. – Dr. Vadalouka has been promoting pain relief and Palliative Care in Greece since the 1980's. Her society cooperates with many pain clinics in Greece and has hosted a number of international conferences in Greece. PARH.SY.A's collaborators have developed clinical guidelines for pain management and provide ongoing training on this subject. Dr. Vadalouka would like to see the addition of buprenorphine, sustained release morphine, and methadone for cancer pain. She thinks that oncologists do not understand the need for Palliative Care and the need for increased home care support.

Dr. Ioannis Konstantinidis, specialist pathologist, Coordinator-Director of the Department of Pathology in "Pammakaristos" state Hospital, Head of the home Palliative Care program "Stirizoume", operated by the NGO "Nosilia" and the patients' association "KEFI". – Dr. Konstantinidis has received Palliative Care training in Cyprus. He is concerned particularly with the provision of home care and support to the elderly population, those with frailty, dementia, stroke, neurological disease, and limited mobility. He also believes in the benefits of home Palliative Care and for this reason he thinks that family doctors should be trained in the provision of Palliative Care services. The program "Stirizoume" which was realized by "Nosileia" and "KEFI" provided Palliative Care to over 100 of these patients through an interdisciplinary team which included psychologists, doctors, nurses and social workers (The program was suspended temporarily due to lack of funding).

Dr. Ioanna Siafaka, professor of Anesthesiology & Pain Therapy at the Medical School of the National and Kapodistrian University of Athens. Mrs. Siafaka trained in pain treatment and Palliative Care in London at Guys & St. Thomas, in Scotland at various hospitals, and at St Colubas Hospice. Furthermore, Professor Siafaka is the director of the Pain Clinic of Aretaieio University Hospital, which

includes the following services: day care, pain and symptom management, reflexology, bereavement support, 24 hour on-call, and medication management. The pain clinic gets many referrals from hospitals and co-manage with primary care physicians. Professor Siafaka is also the Vice President of PARH.SY.A and contributes to their educational courses, practicum and lectures. Professor Siafaka has authored one book, 28 book chapters, and has more than 100 publications including 50 abstracts in international journals and 47 full journal publications. She also participates in research in psychosocial oncology, nutrition and pharmacology.

6.3 Gaps in Children's Palliative Care

An exploratory study was conducted during the early 1990's with funding from the European Commission – "Europe Against Cancer Program". The study purpose was to explore the experiences and needs of families at the end of a child's life, by comparing families whose child died at home and those whose child in the hospital[10]. These families lived in various parts of Greece, but the child was treated for cancer at the Pediatric Oncology Unit at the Children's Hospital "A. & P. Kyriakou" in Athens. Their decision between home or hospital as the site of dying, was affected mostly by the child's preference and parents' desire to respond in a most appropriate way. Without access to Palliative Care services, families who cared alone for their child at home were satisfied with their decision, but experienced increased anxiety as the end was approaching and expected more support from health care professionals, particularly physicians.

Following this study, a Training Program of 700 hours on "Pediatric Palliative Home Care" was offered by the Nursing Department of the National and Kapodistrian University of Athens, for the duration of one year. It was again funded by the European Union and was addressed to 20 health care professionals who worked in the two largest pediatric hospitals of Athens, as well as mental health professionals who provide services in the community. Danai Papadatou who was the principal coordinator of the project, met with officials at the Ministry of Health in order to promote the development of a pediatric palliative home care program that would be based at the Children's Hospital "Aglaia Kyriakou". The proposal was rejected with the excuse that "*these children would anyway die*". This led to the foundation of "Merimna" a civil non-profit organization for the care of children facing illness and death, in 1995.

[10] Papadatou, D., Yfantopoulos, J. & Kosmides, H. (1996). Child dying at home or in hospital: Experiences of Greek mothers. Death Studies, 20, 3, 215-236.

7. Scaling up Palliative Care in Greece

It is clear that given the size of the unmet need for Palliative Care in Greece and the continuing financial limitations due to the economic situation, it will be needed many years to bridge this gap and scale up Palliative Care in the country. The National Committee will consider a number of strategies for scale up that address geographic distribution, inclusion of different diagnostic groups, criteria for identifying patients and initiating care.

Creation of a comprehensive national strategy for scaling up Palliative Care in Greece is an essential next step to ensure that Palliative Care is available for all who need it in Greece.

8. Recommendations

The recommendations in this report follow the WHO public health model for palliative care, which centers on five main areas:

1. Policy and legislation
2. Medicine
3. Education
4. Implementation
5. Research

8.1 Policy and Legislation

Palliative Care must be defined in law and included in all appropriate major health policy document and plans in the country.

Problem 1:
There is no functional legislative framework for the provision of Palliative Care to children, teenagers and adults in the country. The existing framework considers as a precondition for the development of external structures (home care and day care) the creation of a hospice with which these will be connected. Additionally, the standards for the establishment of a hospice are unjustifiably high and extremely expensive. Therefore, there is no possibility for the development of independent, flexible and affordable home care and day care services.

Recommendations:

i. Development of a legislative framework that ensures access to **specialized Palliative Care services** for children, adolescents and adults. This legislative framework should separate the needs of Palliative Care for adults from those for minors and their families and should also provide specific services for teenagers. Additionally, there should be operational interconnection with the existing

primary health care and hospital care services. It would also be important to examine the expansion of the existing legal frameworks such as the latest law for Primary Health Care (Law 4486, Gazette 115/A 07.08.2017) so as to promote the use of primary health care structures after the appropriate preparatory training of health professionals and the cooperation with the local government.

ii. Financing NGO-provided Palliative Care services to the community at least in part from the state budget or an annual fundraiser for the promotion of Palliative Care in the country.

Problem 2:

Lack of regulations for the provision of Palliative Care in public institutions. Currently there are no agreed regulations and procedures for the formal approval of Palliative Care services within public structures.

Recommendation:

i. Development of regulations and procedures for the organization and operation of:
   - Outpatient and day care centers with comprehensive Palliative Care services.
   - Palliative Care units with beds in hospitals.
   - Palliative Care consultation teams within the hospitals, with the participation of clinicians with special training in palliative care.

Problem 3:

There are no National Standards for Operation of Palliative Care Services and clinical guidelines for the provision of palliative care.

Recommendation:

i. Formation of a sub-committee of the Ministry of Health National Palliative Care Committee to draft standards for Palliative Care program operation and clinical guidelines.

Problem 4:

NGOs providing home-based Palliative Care (and / or hospices) are not licensed as there is no relevant legislative and regulatory framework.

Recommendation:

i. Establish a license for the provision of Palliative Care through the operation of:
   - Palliative Home care services
   - Hospices independent of Hospitals - but in cooperation with them through contracts
   - Palliative Care Day Care structures

   After their establishment, these services will be connected with Primary Health Care services and hospitals and they will constitute part of the unified Palliative Care services within the national health system.

Problem 5:
The provisions for volunteering are incomplete, so NGOs using volunteers are left exposed to a possible labor inspection.

Recommendation:
i. Establishment of an institutional and legislative framework for the provision of volunteer services in Greece.

Problem 6:
Given the current legal framework (i.e. Oviedo Convention art 9, Code of medical Conduct art. 29, penal Code articles 299, 300, 306, 307, 311,312) there is no specific provision that would enable patients to express their DNAR order in a way that it would be binding and non-penalizing. Moreover, there is no legal framework for issues related to advanced care planning, such as mental capacity for decision making, living will in relation to health care issues, surrogate decision making, futile treatment, terminal sedation etc.

Recommendation:
i. Issues related to frequent bioethical dilemmas in palliative care, that is breaking the bad news, assessing patients' and families' wishes for care, especially at the end of life and procedures that safeguard ease of suffering, patient autonomy and self-respect should be highlighted, discussed and appropriately handled.

8.2 Medicine

All medicines on the WHO model list of essential medicines for pain relief and Palliative Care should be available, accessible and affordable.

Problem 7:
The process of accessing opioids and their use at home is time consuming and demanding.
The prescription of opioids for outpatient use requires special authorization from the Region and frequent renewal. However, it cannot always be predicted when the patient will need opioids in order to start the procedure early. In addition, while we have access to specific opioids such as morphine (injection and immediate release oral solution from powder) and fentanyl, unfortunately other medicines widely used abroad, are not used in Greece such as slow release morphine and methadone which is only used for drug rehabilitation.

Recommendations:
i. Simplification of the procedure for writing prescriptions.
ii. Improvement of access to necessary medicines widely used for patients in need of palliative care. Working with the National Organization for Medicines (EOF) to ensure access to specific drugs necessary for child / adolescent / adult palliative care, including all pain and Palliative Care medicines listed in the WHO model list of essential medicines.

iii. Importation of morphine tablets (immediate and slow release); bigger quantities of morphine (powder, injection); to ensure there are no stock outs.

Problem 8:
NGOs providing palliative home care and hospice care do not have a prescription license as a provider.

Recommendation
i. Authorization for licensed NGOs to prescribe for home care service patients.

8.3 Education

All health care professionals should receive basic education on Palliative Care including those in medical, nursing, and other schools on social and mental health sciences and there should be provision for continuing education for practicing health care professionals.

Problem 9:
Inadequate knowledge about Palliative Care of physicians/pediatricians (and neurologists in particular) and other health and education professionals (physiotherapists, speech therapists, psychologists, social workers, pharmacists, special pedagogues).

Recommendations:
i. Establishment of a compulsory course on Palliative Care for adults and children in all undergraduate programs for students of health and mental health disciplines.
ii. Introduction of "Palliative Care for Children, Adolescents and Adults" as a compulsory course in all postgraduate programs for physicians, nurses, psychologists, social workers, physiotherapists and special educators.
iii. Introduction of a sub-specialization in Pediatric Palliative Care in the existing Interdepartmental Postgraduate Study Program of the Medical School and the Nursing Department of the National and Kapodistrian University of Athens.
iv. Training of all hospital health professionals working in departments hospitalizing or attending patients with life-threatening illnesses, on the basic principles of Palliative Care (basic Palliative Care or general palliative care). Furthermore, Palliative Care should be included in many medical and nursing specialties.

Problem 10:
Social Security Funds. Doctors in the Centers for the Assessment and Certification of Disability (KEPA) are not trained and they do not know about Palliative Care and the special needs of children, adolescents and adults with life-threatening diseases.

Recommendations:
i. Training the doctors of KEPA in palliative care.
ii. Simplification of relevant documents and procedures.

iii. Re-evaluation of the documents required for some patients with end-stage illnesses (e.g. why a 2-year child suffering from a neurodegenerative a condition that affects brain development by definition needs to be examined in order to identify a severe mental retardation).
iv. Staffing of KEPA with health professionals with knowledge in Palliative Care and illnesses that fall within its scope.

Problem 11:
The public is not aware of what Palliative Care can offer and views suffering as inevitable.

Recommendations:

i. Careful development of a national strategy to raise awareness of what hospice and Palliative Care can do for seriously ill patients and their families, without creating expectations that cannot be fulfilled. Patients' representatives (particularly patients suffering from life threatening diseases) should participate in the development of the national strategy as key partners.

8.4 Implementation

Palliative Care programs should be implemented throughout the country according to national standards and should include Palliative Care services.

Problem 12:
Lack of access to Palliative Care services in the big hospitals of the country.

Recommendations:

i. Development in all public pediatric and adult hospitals of a Palliative Care section with inpatient and outpatient services corresponding with community need, according to international and national standards.
ii. Establishment of an "Interdisciplinary Palliative Care Group" (IPCG) in every major hospital of the country covering the needs of smaller health services in their regions.
iii. Calling on hospitals boards to establish "Interdisciplinary Palliative Care Groups" (IPCG) at every major hospital in the country (Athens, Thessaloniki, Patras, Crete, Ioannina, Larissa), which will provide consultation to health professionals providing Palliative Care to children and adolescents with life-threatening illness as well as to staff of the intensive care units. The remaining pediatric, general hospitals and maternity hospitals could be connected with the specific groups (IPCGs) in their region so as to meet their needs.
iv. The training, organization and supervision of these interdisciplinary advisory groups should be governed by agreed standards of operation for Palliative Care services with support from NGOs that have already experience in palliative care, the National and Kapodistrian University of Athens or other universities in the country interested in developing postgraduate programs in adult Palliative Care and child and adolescent palliative care.

Problem 13:

Limited number of patients (adults and children) who have access and benefit from existing Palliative Care services provided by specialized and recognized NGOs. There are long waiting lists and Palliative Care providers cannot meet the needs due to limited resources.

Recommendations:

i. Extending the existing Palliative Home Care provided by recognized NGOs to the wider region of Attica and Thessaloniki after securing funding.
ii. Operation of a Palliative Day Care Center for adults, children and their families. Day Care Centers make it easier for families to leave home and socialize as they allow both the patient and his family members to benefit from both clinical care, psychological support and other services provided either on an individual basis or in a group (parents and children groups).
iii. Operation of Palliative Care Hospices, according to national and European standards and specifications.
iv. Respite care centers for children and separately for adolescents and adults should be established and operate according to the national and European standards for Palliative Care.
v. Cooperation between different Palliative Care services and the Local Health Units (TOMY) is necessary in order to raise awareness about patients' needs.

Problem 14:

There are no structures or transition processes to provide Palliative Care to teenagers and young adults who until recently were users of Pediatric care services. They need services and structures staffed with specialized health professionals able to address the needs of the patients of this age group.

Recommendation:

i. Provision of special care for young people aged over 16 who are obliged to be admitted to adult units unprepared to support them. Their psychosocial needs may correspond to those of adolescents / young adults, but as their physique is often more similar to that of children, their organic needs require pediatric knowledge, and doctors for adults do not possess that knowledge.

Problem 15:

Failure to inform families about the existence of Palliative Care services, and referral to existing services takes a long time, which influences the effectiveness of the clinical and psychosocial interventions.

Recommendations:

i. Educating and raising the awareness of healthcare professionals in providing Palliative Care (by organizations with a long experience in providing services).
ii. Establishment of an electronic platform for Palliative Care in Greece including detailed information about the existing Palliative Care providers and services. The platform will include an application that will facilitate the communication among Palliative Care structures and services and the early referral of patients in need of Palliative Care to Palliative Care services or related

hospices and Day Care Centers. A link to the platform should be available on the websites of relevant organizations.

Problem 16:
Insufficient knowledge and psychosocial support for children, teenagers and adults in need of Palliative Care and their families by public and private hospitals.

Recommendation:
i. Raising the awareness of all public hospitals, mental health professionals (psychologists, psychiatrists and social workers) on the specific psychological needs of families with a member in need of palliative care, so as to be able to provide appropriate psychosocial support to these patients / families from the onset of diagnosis of a life-threatening illness.

Problem 17:
Insufficient funding for equipment necessary for child / adult Palliative Care at home (e.g. ventilators, special mattresses, beds, stroller, extra physiotherapy etc.). The available funds cover a small percentage of the cost of equipment and special treatments needed by families receiving palliative homecare. Additionally, even the small amount covered by public insurance is only available with very long delays, resulting in a huge financial burden on the families.

Recommendations:
i. Timely cover of a higher percentage of costs for equipment and treatment needed by patients.
ii. Covered costs by Public Insurance of equipment used by patients to be returned after the completion of their treatment, so as to be used by other patients.

8.5 Research

Research is essential for the growth, development and acceptance of Palliative Care in any country. Policy makers and political leaders need evidence of the value of Palliative Care and to understand its impact on the health care system.

Problem 18:
Lack of evidence on models of care in the Greek context and lack of evidence on outcomes and impact of Palliative Care in Greece. While Palliative Care should meet European standards for operation there is room for exploration of how culturally appropriate models of Palliative Care can be developed in Greece. Likewise, measurement of Palliative Care outcomes is needed.

Recommendation:
i. Monitoring and evaluation of Palliative Care services should be instituted from the initiation of services using validated instruments. Research models should be utilized to formally study the outcomes and impact of palliative care. Results should be published in peer reviewed journals and used in advocacy and communications.

Problem 19:

Lack of a National Record of illnesses that threaten the life of a child or adult and failure to monitor the continuity of care of these patients.

The only available data at national level are the number and cause of deaths in children / adults, which often does not specify the underlying disease, but the final symptom that caused death. This practice does not allow a valid identification of the number of patients diagnosed with a serious and life-threatening illness requiring palliative care, nor the statistical determination of other parameters that affect such care (e.g. services involved in care, duration of illness etc.).

Recommendations:

i. Establishment of a National Archive recording all patients suffering from a serious and life-threatening illness including analytical data on the diseases and the needs of the patients.
ii. Correct completion and further use of the Death Certificate, updating the National Record and extracting valid statistical data and possibly adding information (e.g. use or not of Palliative Care services). This will allow a valid identification of the number of adults and children suffering from serious and life-threatening diseases and will therefore allow a more appropriate and long-term planning for the development of regional Palliative Care facilities.
iii. Creation of a single electronic patient file based on social security numbers (AMKA and AMA), so that diagnoses are recorded as well as the history of examinations and hospitalizations of each insured person.
iv. Expansion of existing data bases for specific diseases (e.g. the record for cancer in Crete).

9. Conclusions and Next steps

Palliative Care has a long history in Greece, yet it has not developed in line with other high-income countries in the European Union. At present there are three programs delivering Specialized Palliative Care in the country serving about 600 patients per year. In addition, there are 40 oncology and 57 pain clinics in hospitals some of which offer General Palliative Care services. Finally, there is one program of Specialized Palliative Home Care under development.

In this report, the need for Palliative Care has been estimated at 120,000 to 135,000 patients and their families per year. This translates to approximately 15,000 patients per day. Over 95% of them could receive care in their home setting and only about 3.5% in inpatient facilities at any given time. A projection of 500 inpatient beds for Palliative Care has been made. To meet the entire current need would require about 300 home care teams each serving 50 patients per day and would likely take decades to achieve.

Approximately 37% of the need for Palliative Care in Greece is for cancer patients and 63% for other conditions such as cardiovascular disease, chronic obstructive pulmonary disease, drug resistant TB, HIV, diabetes, cirrhosis, kidney disease, dementias, and other complex chronic conditions. Moreover, Palliative Care services need elderly adult patients as well as infants/newborns and children suffering from congenital or chronic life-threatening diseases.

It is important to understand that these are estimates of the current need in a perfect world where everyone gets palliative care. In no country is the full need for Palliative Care being met. For example, in the 45 years that Palliative Care has been developing in the USA only about 75% of the current need is met. In Greece it will likely take many years to meet the majority of the need for Palliative Care and planning must take this into account.

The gap between the need for and capacity to delivery Palliative Care in Greece is very wide. The need for decedents alone is about 62,000 people annually. Current capacity to deliver Palliative Care is less than 4% of the decedent need and less than 2% of the total need. While hospice and Palliative Care is primarily an outpatient and home-based care service, there is some need for inpatient care, usually for brief periods for severe symptom management. At present, the total need for inpatient Palliative Care beds is estimated at 500 beds while only 9 dedicated hospice inpatient beds are currently available. This represents less than 0.5 % of the ultimate need.

In order to close the gap in access to Palliative Care in Greece it will require overcoming some significant barriers including changing existing laws that have not been implemented and interfere with correct Palliative Care development; educating a workforce of over 4,000 health professionals and many currently practicing prescribers; changing some current health budget flows to invest more in palliative home-based care; clarifying regulations on controlled substance prescribing and monitoring; creating a registry of patients receiving palliative care; developing standards of Palliative Care operation and clinical guidelines for provision of care for adults and children; including primary care providers in Palliative Care delivery and implementing new Palliative Care interdisciplinary teams

throughout the country for both adults and children and clinical guidelines for the provision of these services.

This report is an attempt to examine the current status of Palliative Care in Greece and to explore the feasibility of bridging the gap in lack of access to palliative care. It identifies 19 major problems to be addressed and offers 40 recommendations to improve the provision of Palliative Care in Greece. Much more work is needed to do the extensive planning that is needed to accomplish this task.

With the support of the Ministry of Health, the Stavros Niarchos Foundation, and all the organizations in the country interested in, supporting, and providing services, improving the provision of Palliative Care in Greece has a good prospect of succeeding. To succeed will require continuing political support, good will within the Palliative Care community, external expert assistance, extensive planning, and generous financial support for implementation.

Next steps

For upgraded access to Palliative Care services in Greece it is necessary to develop and implement an integrated national strategy. As mentioned at the beginning of this Study for this purpose the project to further develop Palliative Care in Greece consists of three phases:

- This first phase has been completed with the development of this Feasibility Study which examines the current situation and makes a series of recommendations on how to proceed. This Study was prepared by the National Committee for the Development and Implementation of a National Palliative Care Strategy in Greece, which was established for this purpose.

- The second phase of this project is envisioned to develop a comprehensive five-year National Strategy for Palliative Care Implementation in Greece (2020-2025). The National Strategy will be developed by the National Committee and it will be submitted for MoH approval.

- The third phase (2020 – onward) will include the work to carry out implementation of the National Strategy.

The National Strategy for the Implementation of Palliative Care for adults and children in Greece will be an approximately 150-page long document to include at least the following:

1. Executive summary
2. Methodology
3. Main Chapters
   i. Introduction and summary of identified needs, resources, & barriers
   ii. Analysis of the legal and regulatory environment and specific recommendations on changes required
   iii. Public health recommendations

- Policy
- Medicine availability
- Education and Training
- Implementation of services
- Research

iv. Establishing Palliative Care as a specialization in health care
v. Development of national standards for Palliative Care providers
vi. Development of clinical guidelines for provision of care
vii. The Palliative Care workforce
viii. Public engagement
ix. Support for carers and families
x. End of life care
xi. Measurement, outcomes, indicators, and research
xii. Timelines and targets
xiii. Conclusions

4. References and Appendices
5. Recommendations for next steps in phase three of the consultation

Appendix A. National Committee for the Development & Implementation of a Palliative Care Strategy in Greece (setup decision Α1β/Γ. Π. οικ 58099, 25/07/2018)

No	Name - Surname	Title	Organization
1	Dr. Olga Iordanidou	Chair, Chief Executive, 2nd Regional Health Authority of Piraeus & Aegean Islands	Ministry of Health
2	Prof. Chara Spiliopoulou	Dean of the Medical School, National and Kapodistrian University of Athens	National and Kapodistrian University of Athens
3	Prof. Kyriaki Mystakidou	Professor of Palliative Care, Medical School, National and Kapodistrian University of Athens	Scientific Director, Palliative Care Unit "Jenny Karezi"
4	Prof. Danai Papadatou	Professor of Clinical Psychology, Nursing Dept., National and Kapodistrian University of Athens	President of Board of Directors, “Merimna”
5	Prof. Elisabeth Patiraki	Professor & Vice Chair of Nursing Dept., School of Health Sciences, National and Kapodistrian University of Athens	Nursing Department, National and Kapodistrian University of Athens
6	Prof. Ioanna Siafaka	Professor of Anesthesia and Pain Therapy, Medical School, National and Kapodistrian University of Athens	Head, Pain Clinic (Aretaieio Hospital)
7	Dr. Ioannis Konstantinidis	Coordinator-Director, Department of Pathology, “Pammakaristos” General Hospital	President, NOSILIA
8	Dr. Aliki Tserkezoglou	Gynecologist Oncologist	Director, GALILEE
9	Mrs. Zoe Grammatoglou	President	President of KEFI
10	Mrs. Stavroula Katsikarou	Director of the Department for the Development of Health Care Units	Ministry of Health
11	Mr. Mavroeidis Christofilopoulos	Head of Budget & Budgetary Reporting	Ministry of Health
12	Mrs. Christina Tzortzi	Head of Department for Primary Health Care	Ministry of Health
13	Dr. Spyros Goulas	Department of Operational Planning and Programming, Strategic Planning Division	EOPYY
14	Dr. Theodoros Paschalis	Department of Quality Assurance and Effectiveness, Strategic Planning Division	EOPYY
15	Mrs. Evaggelia Skyllakou	Lawyer, senior investigator	The Greek Ombudsman, Directorate of Health and Social Security

Appendix B. Detailed Breakdown of Need for Palliative Care in Greece from Global Atlas

Disease categories/groups requiring palliative care at the end of life	Total Deaths from diseases requiring palliative care at the end of life Numeric (A)	Pain Prevalence at the end of life (%): B	Patients in need of palliative care at the end of life Numeric: C=AxB
CANCER			
Adults	31,334	84%	26,321
Children	74	80%	59
Total Cancer	31,408		26,380
HIV/AIDS			
Children	0	80%	0
Adults	43	55%	24
Total HIV/AIDS	43		24
PROGRESSIVE NON-MALIGNANT DISEASES			
Adults			
Alzheimer's disease & other dementias	2,085	47%	980
Cardiovascular diseases (excluding sudden deaths)	30,875	67%	20,686
Chronic obstructive pulmonary diseases	6,645	67%	4,452
Cirrhosis of the liver	882	34%	300
Diabetes mellitus	1,769	64%	1,132
Multiple sclerosis	119	43%	51
Kidney diseases	3,338	50%	1,669
Parkinson's disease	1,469	82%	1,205
Rheumatoid arthritis	44	89%	39
Drug-resistant tuberculosis	1	90%	1
Total PROGRESSIVE NON-MALIGNANT DISEASES	47,227		30,515
PROGRESSIVE NON-MALIGNANT DISEASES			
Children			
Cardiovascular diseases (excluding sudden deaths)	15	67%	10
Cirrhosis of the liver	33	67%	22
Congenital Anomalies (excluding 50% heart anomalies)	121	67%	81
Endocrine, blood, immune disorders	623	67%	417
Meningitis	24	67%	16
Kidney diseases	0	67%	0
Protein energy malnutrition	3,833	67%	2,568
Neurological conditions (excluding epilepsy)	24	67%	16
Neonatal conditions (see formula for excluded conditions)	43	67%	29
Total PROGRESSIVE NON-MALIGNANT DISEASES	4,716		3,160
Total Adults at EOL	78,604		56,860
Total Children at EOL	4,790		3,219
Total Adults & Children at EOL	83,394		60,079
TOTAL NEED BEFORE AND AT THE END OF LIFE Adults			113,719
TOTAL NEED BEFORE AND AT THE END OF LIFE Children			6,438
TOTAL NEED BEFORE AND AT THE END OF LIFE			120,157

Appendix C. Diagnostic Condition Breakdown based on Lancet Commission results

Conditions that generate a need for Palliative Care (with ICD-10 numbers)	Decedents in need of Palliative Care in 2015	Non-decedents in need of Palliative Care in 2015	Total patients in need of Palliative Care in 2015
C00-97: Malignant neoplasms (except C91-95)	25,437	23,939	49,376
F00-04: Dementia	7,864	28,198	36,062
I60-69: Cerebrovascular disease	12,442	11,862	24,304
J40-47; J60-70; J80-84; J95-99: Chronic lower respiratory dz; lung dz due to external agents; interstitial lung dz; other dz of resp system	5,078	0	5,078
B20-24: HIV disease	256	3,821	4,077
G20-26; G30-32; G35-37; G40-41; G80-83 Extrapyramidal & mvt disorders; other degen dz of CNS; Demyelinating dz of CNS; Epilepsy; Cerebral palsy & other paralytic syndromes	695	2,654	3,349
S00-99; T00-98; V01-Y98: Injury, poisoning, external causes	983	1,965	2,948
I05-09; I25; I42 & I50: Chronic rheumatic heart diseases; Cardiomyopathy & Heart failure	2,292	0	2,292
I25: Chronic ischemic heart disease	1,522	0	1,522
C91-95: Leukemia	1,408	0	1,408
K70-77: Diseases of liver	1,301	0	1,301
I70: Atherosclerosis	1,224	0	1,224
M00-97: Musculoskeletal disorders	737	147	884
N17-19: Renal failure	858	0	858
Q00-99: Congenital malformations	174	174	348
P07; P10-15: Low birth weight & prematurity; Birth trauma	135	0	135
A15-19: Drug-sensitive TB	72	0	72
G00-09: Inflammatory disease of CNS	28	1	29
A15-19: M/XDR TB	11	6	17
Protein-Energy Malnutrition	3	0	3
A96,98,99: Hemorrhagic fevers	1	1	2
TOTAL	**62,521**	**72,768**	**135,289**

Appendix D. WHO Definitions of Palliative Care and Palliative Care for Adults & Children

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

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 Pediatric 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 centers and even in children's homes.

Appendix E. WHO Model List for Essential Medicines for Pain and Palliative Care

2. MEDICINES FOR PAIN AND PALLIATIVE CARE	
2.1 Non-opioids and non-steroidal anti-inflammatory medicines (NSAIMs)	
acetylsalicylic acid	**Suppository:** 50 mg to 150 mg. **Tablet:** 100 mg to 500 mg.
ibuprofen **a**	**Oral liquid:** 200 mg/5 mL. **Tablet:** 200 mg; 400 mg; 600 mg. **a** Not in children less than 3 months.
paracetamol*	**Oral liquid:** 120 mg/5 mL; 125 mg/5 mL. **Suppository:** 100 mg. **Tablet:** 100 mg to 500 mg. * Not recommended for anti-inflammatory use due to lack of proven benefit to that effect.
2.2 Opioid analgesics	
codeine	**Tablet:** 30 mg (phosphate).
fentanyl*	**Transdermal patch:** 12 micrograms/hr; 25 micrograms/hr; 50 micrograms/hr; 75 micrograms/hr; 100 micrograms/hr *for the management of cancer pain
□ morphine*	**Granules (slow-release; to mix with water):** 20 mg –200 mg (morphine sulfate). **Injection:** 10 mg (morphine hydrochloride **or** morphine sulfate) in 1- mL ampoule. **Oral liquid:** 10 mg (morphine hydrochloride **or** morphine sulfate)/5 mL. **Tablet (slow release):** 10 mg–200mg (morphine hydrochloride **or** morphine sulfate). **Tablet (immediate release):** 10 mg (morphine sulfate). *Alternatives limited to hydromorphone and oxycodone

Complementary list	
*methadone**	***Tablet:*** *5 mg; 10 mg (as hydrochloride)* ***Oral liquid:*** *5mg/ 5mL; 10mg/ 5mL (as hydrochloride)* ***Concentrate for oral liquid:*** *5 mg/ mL; 10mg/ mL (as hydrochloride)* **For the management of cancer pain.*
2.3 Medicines for other common symptoms in palliative care	
amitriptyline	**Tablet:** 10 mg; 25 mg; 75 mg.
cyclizine **[c]**	**Injection:** 50 mg/ mL. **Tablet:** 50 mg.
dexamethasone	**Injection:** 4 mg/ mL in 1- mL ampoule (as disodium phosphate salt). **Oral liquid:** 2 mg/5 mL. **Tablet:** 2 mg **[c]**; 4 mg.
diazepam	**Injection:** 5 mg/ mL. **Oral liquid:** 2 mg/5 mL. **Rectal solution:** 2.5 mg; 5 mg; 10 mg. **Tablet:** 5 mg; 10 mg.
docusate sodium	**Capsule:** 100 mg. **Oral liquid:** 50 mg/5 mL.
fluoxetine **a**	**Solid oral dosage form:** 20 mg (as hydrochloride). **a** >8 years.
haloperidol	**Injection:** 5 mg in 1- mL ampoule. **Oral liquid:** 2 mg/ mL. **Solid oral dosage form:** 0.5 mg; 2mg; 5 mg.
hyoscine butylbromide	**Injection:** 20 mg/ mL.
hyoscine hydrobromide **[c]**	**Injection:** 400 micrograms/ mL; 600 micrograms/ mL. **Transdermal patches:** 1 mg/72 hours.
lactulose **[c]**	**Oral liquid:** 3.1–3.7 g/5 mL.
loperamide	**Solid oral dosage form:** 2 mg.
metoclopramide	**Injection:** 5 mg (hydrochloride)/mL in 2-mL ampoule. **Oral liquid:** 5 mg/5 mL. **Solid oral form:** 10 mg (hydrochloride).
midazolam	**Injection:** 1 mg/ mL; 5 mg/ mL. **Solid oral dosage form:** 7.5 mg; 15 mg. **Oral liquid:** 2mg/ mL **[c]**.

ondansetron [c] a	**Injection:** 2 mg base/ mL in 2- mL ampoule (as hydrochloride). **Oral liquid:** 4 mg base/5 mL. **Solid oral dosage form:** Eq 4 mg base; Eq 8 mg base. a >1 month.
senna	**Oral liquid:** 7.5 mg/5 mL.

Appendix F. Palliative Care in Higher Education: Programs/Courses

DEPARTMENTS OF MEDICINE				
DEPARTMENT - UNIVERSITY	**COURSE / PROGRAM TITLE**	**HOURS**	**LECTURER(S)**	**BIBLIOGRAPHY**
School of Medicine National & Kapodistrian University of Athens	Treatment of benign and malignant pain - palliative and symptomatic care (Parigoriki) UNDERGRADUATE ELECTIVE	30	I. Siafaka, H. Staikou	Selected journal articles
	Holistic care of chronically ill patients UNDERGRATE ELECTIVE	26	K. Mystakidou	Selected journal articles [indicatively: Cherny N. et al. (2015). Oxford Textbook of Palliative Medicine, Oxford University Presss; Walsh D., et al (2009), Palliative Medicine, Elsevier Pub.)
	Pain treatment in the framework of supportive care for the terminally ill patient (PC - Parigoriki) POSTGRADUATE ELECTIVE	15	I. Siafaka, A. Vadalouka	Selected journal articles
	Neoplastic disease: Research and clinicopathologoanatomic approach in the framework of personalized medicine	8	K. Mystakidou	Selected journal articles [indicatively: Cherny N. et al. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press
Dept of Medicine University of Patras	Oncology (terminal stage patients/PC for Adults) UNDERGRADUATE REQUIRED	2	H. Kalofonos	Casciato D. A., Territo M C., Clinical Oncology, K & N Litsas OE
	Bioethics (Palliative Care for Adults) UNDERGRADUATE REQUIRED	4	H. Kalofonos A. Liourdi	Notes for the course prepared by the professor

Dept of Medicine University of Crete	Compassion in Clinical Care	14	C. Lionis	Shea S., Wyanyard R., Lionis C., eds. (2014) Providing compassionate healthcare: challenges in policy and practice, Routledge. Other selected journal articles.
School of Medicine National & Kapodistrian University of Athens	MSc in Neoplastic disease: clinicopathological approach and research, 120 ECTs POSTGRADUATE REQUIRED	8	K.Mystakidou	Selected journal articles and other scientific publications [indicatively: Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press]
Dept of Nursing School of Medicine National & Kapodistrian University of Athens	MSc in Organization and management of palliative and supportive care for chronically ill patients (OMPSC) [Anakoufistiki] 120 ECTs		K, Mystakidou E. Patiraki	
	Philosophy and Principles of Palliative Care-Epidemiology of chronic diseases/OMPSC POSTGRADUATE REQUIRED	30	K. Mystakidou	Selected journal articles and other scientific publications [indicatively: Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; D. Walsh *et al*. (2009), Palliative Medicine, Elsevier Publ.
	Relief and Prevention of Chronic Pain-Clinical Pharmacology/OMPSC POSTGRADUATE REQUIRED	30	K. Mystakidou E. Patiraki	Selected journal articles and other scientific publications [indicatively: Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; D. Walsh *et al*. (2009), Palliative Medicine, Elsevier Publ.
	Interdisciplinary approach in Palliative Care /OMPSC POSTGRADUATE REQUIRED	20	K. Mystakidou E. Patiraki	Selected journal articles and other scientific publications [indicatively: Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; D. Walsh *et al*. (2009), Palliative Medicine, Elsevier Publ.

Dept of Nursing School of Medicine National & Kapodistrian University of Athens	Biostatistic/OMPSC POSTGRADUATE REQUIRED	20	V. Kouloulias	Trichopoulos D., *et al*. (2001). Biostatistics. Pub. Parisianos; Various scientific journal articles
	Holistic assessment and treatment of symptoms/OMPSC POSTGRADUATE REQUIRED	40	K. Mystakidou	Selected journal articles and other scientific publications [indicatively: Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; D. Walsh *et al*. (2009), Palliative Medicine, Elsevier Publ Mystakidou K. (2005). Holistic Care for patients with chronic and advanced diseases. Pain Relief and Palliative Care Unit]
	Psychosocial and spiritual support of patients and their families-Intercultural support/OMPSC POSTGRADUATE REQUIRED	20	K. Mystakidou	Selected journal articles and other scientific publications [indicatively: Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; D. Walsh *et al*. (2009), Palliative Medicine, Elsevier Publ.
	Holistic assessment of patients with chronic non-malignant diseases/OMPSC POSTGRADUATE REQUIRED	30	K. Mystakidou	Selected journal articles and other scientific publications [indicatively: Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; D. Walsh *et al*. (2009), Palliative Medicine, Elsevier Publ.
	Disease, Death, Mourning/OMPSC POSTGRADUATE REQUIRED	20	D. Papadatou	Hennezel, Marie, *Μύχιος Θάνατος, Synergie Publications,* 2011; Neimeyer, R., *Lessons of Loss: A Guide to Coping,* Kritiki Publications, 2006; Various journal articles
	Pediatric Palliative care/OMPSC POSTGRADUATE REQUIRED	30	D. Papadatou	Various journal articles

Dept of Nursing School of Medicine National & Kapodistrian University of Athens	Improving the quality of Palliative Care/OMPSC POSTGRADUATE REQUIRED	20	E. Patiraki	Ferrell, B., R., Coyle N., Textbook of Palliative Nursing, Oxford University Press, New York, 2006; Kinghorn, S., Gamlin R., Palliative Nursing Care - Ensuring Hope and Quality of Life, Vita Publications, 2004; Student, Johann-Christoph, *Palliative Care: wahrnehmen - verstehen - schützen,* Stuttgart, Thieme, 2007
	Emergencies in Palliative Care /OMPSC POSTGRADUATE REQUIRED	20	K. Mystakidou	Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; D. Walsh *et al*. (2009), Palliative Medicine, Elsevier Pub; Various scientific journal articles
	Organization and management of Palliative Care structures /OMPSC POSTGRADUATE REQUIRED	30	E. Patiraki S. Katsaragakis	Ferrell, B., R. , Coyle N., Textbook of Palliative Nursing, Oxford University Press, New York, 2006; Kinghorn, S., Gamlin R., Palliative Nursing Care - Ensuring Hope and Quality of Life, Vita Publications, 2004; Student, Johann-Christoph, *Palliative Care: wahrnehmen - verstehen - schützen,* Stuttgart, Thieme, 2007
	Preparatory Grief. Ethical dilemmas-Legislature OMPSC POSTGRADUATE REQUIRED	20	K. Mystakidou	Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; Mitrosyli M. (2009). Health Law. Papazisis Pub; Various scientific journal articles
	Two of the following elective courses /OMPSC			

	Communication and interpersonal relations (12hrs PC for Adults, 4hrs interdisciplinary cooperation) POSTGRADUATE ELECTIVE	16	D. Papadatou	Gawande, A., *We the mortals,* Crete University Press, 2016; Zimbardo, P., *The Lucifer Effect,* University Studio Press, 2008; Selected journal articles
	Comorbidities and Palliative Care in geriatric patients/OMPSC POSTGRADUATE ELECTIVE	20	K. Mystakidou E. Patiraki	Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; D. Walsh *et al*. (2009), Palliative Medicine, Elsevier Pub; Various scientific journal articles
	Complementary Palliative Care therapies for chronically ill patients/OMPSC POSTGRADUATE ELECTIVE	30	E. Eytychidou A. Mantoudi	Synovitz L.B. & Larson K.L. (2013), Complementary and alternative medicine for health care professionals. Jones & Barlett Learning. Various scientific journal articles
	Education for educators/OMPSC POSTGRADUATE ELECTIVE	20	K. Mystakidou E. Patiraki	Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; D. Walsh *et al*. (2009), Palliative Medicine, Elsevier Pub; Various scientific journal articles
	Cost-effectiveness of Palliative Care/OMPSC POSTGRADUATE ELECTIVE	20	K. Mystakidou E. Patiraki S. Katsaragakis	Cherny N., *et al*. (2015). Oxford Textbook of Palliative Medicine, Oxford University Press; D. Walsh *et al*. (2009), Palliative Medicine, Elsevier Pub; Various scientific journal articles
	Writing techniques of scientific studies/OMPSC POSTGRADUATE ELECTIVE	20	M. Giannakopoulou	Boaz A, Ashby D. Fit for purpose? Assessing research quality for evidence-based policy & practice. London: ESRC UK Center for Evidence Based Policy and Practice, 2003; Greenhalgh T. How to Read a Paper: The

				Basics of Evidence-Based Medicine (HOW-How To). BMJ Books 4th ed. Wiley-Blackwell, 2011; Various scientific journal articles
	Research methodology/OMPSC POSTGRADUATE ELECTIVE	30	Ch. Lemonidou	Various scientific journal articles

DEPARTMENTS OF NURSING				
DEPARTMENT - UNIVERSITY	**COURSE / PROGRAM TITLE**	**HOURS**	**LECTURER**	**BIBLIOGRAPHY**
Dept of Nursing National & Kapodistrian University of Athens	Palliative Care UNDERGRADUATE REQUIRED	26	E. Patiraki, D. Papadatou, S. Katsaragakis	Becker, R., *Fundamental Aspects of Palliative Care Nursing,* 2nd Ed., Quay Books, Division, London, England, 2010, Medicine, Elsevier Pub; Selected journal articles
	Psychology in the Health Sector UNDERGRADUATE REQUIRED	20	D. Papadatou, A. Pashali	Papadatou, D., & Anagnostopoulos, F., Health *Psychology* Papazisis Publ., 2012
	Nursing problems of children with chronic diseases UNDERGRADUATE ELECTIVE	52	V. Matziou	Matziou, V., Nursing Care of Children with Chronic Diseases, Lagos Publ., Athens, 2007
	Pediatric Palliative care POSTGRADUATE REQUIRED	30	D. Papadatou	Various journal articles

	Disease, Death, Mourning POSTGRADUATE REQUIRED	20	D. Papadatou	Hennezel, M., *Μύχιος Θάνατος,* Synergie Publications, 2011; Neimeyer, R., *Lessons of Loss: A Guide to Coping,* Kritiki Publications, 2006; Various journal articles
	1.Palliative Nursing Care of Children & Adolescents ELECTIVE 2. Nursing Problems of Children & Adolescents with Cancer REQUIRED 3. Pediatric Pain Management REQUIRED **In the framework of the Postgraduate Program in Applied Clinical Nursing in Children**	12 20 10	V. Matziou	Matziou, V., Nursing Care of Children with Chronic Diseases, Lagos Publ, Athens, 2007
Dept of Nursing National & Kapodistrian University of Athens	**MA in Advanced Palliative Care and Mental Health of Adults & Children** **Oncology Nursing & Palliative Care** **Compulsory Courses 600hrs, 30 ECTs** — **Hrs** Cancer as a Chronic Illness: Supportive & Palliative Care — 28 Clinical Leadership & Resource Management in Cancer Nursing & Palliative Care — 20 Evidence Based & Applied Research in Chronically Ill Patients Care — 16 Palliative Care for Patients — 16	TOTAL= 120 ECTs 30 ECTs for palliative care 130 hrs	E. Patiraki, D. Papadatou, S. Katsaragakis, I. Kaklamanos, A. Stamatakis, B. Matziou	Ferrell B., R., Coyle N, Paice, J., *Oxford Textbook of Palliative Nursing*, Oxford University Press Inc, New York , 2015; Yarbro, C., H., Wujcik D., Gobel, B. *Cancer Nursing: Principles and Practice*, Jones & Bartlett Publishers, 2018; Related articles

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School of Health Sciences & Welfare

University of West Attica</td>
<td>Oncological Palliative Nursing
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<td>Ourania Govina</td>
<td>Corner J., Bailey C. (eds) Cancer Nursing: Care in Context, Blackwell Science Ltd.: Oxford, 2001</td>
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<td>Supportive & Palliative Care of Oncological Patients
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<td>Corner J., Bailey C. (eds) Cancer Nursing: Care in Context, Blackwell Science Ltd.: Oxford, 2001</td>
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<td rowspan="2">Dept of Nursing
Faculty of Human Movement & Quality of Life Sciences

University of Peloponnese</td>
<td>Pediatric Nursing
UNDERGRADUATE REQUIRED</td>
<td>3</td>
<td>Panteleimon Perdikaris</td>
<td>Matziou, V., Pediatric Palliative Care - Basic Principles in Pediatric Care, Publishing House: Lagos D. Athens, 2013</td>
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<td>Organization of Health Services (the organization of hospices for end-of-life-care)</td>
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<td>Panagiotis Prezerakos</td>
<td>Liaropoulos L., Organization of Health Services and Systems, Iatrikes Ekdoseis VITA, Athens, 2007 (Greek)</td>
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Dept of Nursing School of Health & Welfare Services Technological Educational Institute (TEI) of Crete	Nursing Oncology & Palliative Care UNDERGRADUATE REQUIRED	4	Theoharis Konstantinidis	Corner J., Bailey C. (eds) *Cancer Nursing: Care in Context,* Blackwell Science Ltd.: Oxford, 2001
Dept of Nursing School of Health & Caring Professions Technological Educational Institute (TEI) of Western Greece	Gerontology Nursing UNDERGRADUATE REQUIRED	6	N. Stefanopoulos	Redfern, S., Ross F., *Nursing Older People,* Churchill Livingstone, London, 2001
Dept of Nursing School of Health & Welfare Professions Technological Educational Institute (TEI) of Thessaly	Nursing Care of Chronic Sufferers / PC [Parigoritiki] (9hrs PC for adults, 2hrs PPC, 2hrs family bereavement, 9 interdisciplinary cooperation) UNDERGRADUATE ELECTIVE	22		Ferrell, B. R. , Coyle N., Textbook of Palliative Nursing, Oxford University Press, New York, 2006; Kinghorn, S., Gamlin R., Palliative Nursing Care - Ensuring Hope and Quality of Life, Vita Publications, 2004; Student, Johann-Christoph, *Palliative Care: wahrnehmen - verstehen - schützen,* Stuttgart, Thieme, 2007
Dept of Nursing School of Health & Welfare Professions Technological Educational Institute (TEI) of Thessaly	Grief & Bereavement (5hrs PC for adults, 5 hrs PC for children, 20hrs Grief & bereavement) POSTGRADUATE ELECTIVE	30	D. Papadatou, T. Bellali	Hennezel, M., *Μύχιος Θάνατος, Synergie Publications,* 2011; Neimeyer, R., *Lessons of Loss: A Guide to Coping,* Kritiki Publications, 2006; Various journal articles

DEPARTMENTS OF PSYCHOLOGY				
DEPARTMENT - UNIVERSITY	**COURSE / PROGRAM TITLE**	**HOURS**	**LECTURER**	**BIBLIOGRAPHY**
Dept of Psychology School of Philosophy National & Kapodistrian University of Athens	Health Psychology: Clinical Interventions (incl Palliative Care for Children - Anakoufistiki) UNDERGRADUATE ELECTIVE	13	Maria Loumakou	Loumakou, M., Mprouskeli, V., *Child and Life Events*, Athens, Gutenberg Publ., 2010
	Special Topics in Health Psychology UNDERGRADUATE ELECTIVE	14	Maria Loumakou	Bor, R., Sheila, G., Riva, M., Evans, A., *Councelling in the Health Sector,* Pedio Publ., 2017
Dept of Psychology Panteion University	Introduction to Health Psychology (incl Palliative Care-Anakoufistiki)	5	Fotios Anagnostopoulo s	DiMatteo R. M., Martin R. Leslie, *Health Psychology*, Pedio Publ. 2011
Dept of Psychology School of Social Sciences University of Crete	Health Psychology: Clinical Interventions (incl Palliative Care for Children [Anakoufistiki] UNDERGRADUATE ELECTIVE	8	Evangelos Karadimas	Karadimas, V., *Health Psychology*, Tipothito - Dardanos Publ., 2005
Dept of Psychology Faculty of Philosophy, Pedagogy & Psychology University of Ioannina	Social and Cognitive approaches in the psychology of health UNDERGRADUATE REQUIRED	15	Anna Kaltsouda	DiMatteo M.R. & Martin L.E., Health Psychology, Pedio Publ. 2011
Dept of Psychology Faculty of Philosophy, Pedagogy & Psychology University of Ioannina	Health Education I UNDERGRADUATE ELECTIVE	12	Professor from another school or Dept or a doctoral student	Kourmousi, N. (a) Προγράμματα προαγωγής ψυχικής υγείας στην Α΄θμια Εκπαίδευση & (b) Βήματα για τη ζωή, Εκδόσεις: Α. Σοκόλη & ΣΙΑ ΕΕ

DEPARTMENTS OF SOCIAL WORK				
DEPARTMENT - UNIVERSITY	**COURSE / PROGRAM TITLE**	**HOURS**	**LECTURER**	**BIBLIOGRAPHY**
Dept of Social Management & Political Science School of Social, Political & Economic Sciences Democritus University of Thrace	Social Work in the health sector (PC) UNDERGRADUATE ELECTIVE	10	Vassilis Karagkounis	Karagkounis, V., Social Work in Health Sector: Concepts, methods and practices in the hospital and the community, Topos Publ., 2018
Dept of Social Work University of West Attica	Social Work with Children and Adolescents UNDERGRADUATE REQUIRED	9	Ch. Asimopoulos	Kontopoulou, M. Child and Psychosocial difficulties, Gutenberg Publ.
Dept of Social Work University of West Attica	Social Work in Health Care UNDERGRADUATE ELECTIVE	9	E. Mavrogeni	Karagounis, B. Social Work in health care, Topos Publ.
Dept of Social Work University of West Attica	Psychotherapeutic approaches in social work UNDERGRADUATE REQUIRED	4	Ioannis Dritsas	Magriplis, D. (ed) Aspects of the Cultural Phenomenon (Scientific Journal: God, Human Being, Society), Charpandidis Publ.
Dept of Social Work School of Health & Welfare Services Technological Educational Institute (TEI) of Crete	Social work and management of health and mental health problems POSTGRADUATE REQUIRED	9	Maria Papadaki	Not specified

Dept of Social Work School of Health & Welfare Services Technological Educational Institute (TEI) of Crete	Social Work and Health Care UNDERGRADUATE ELECTIVE	9	Maria Papadaki	Karagounis, V. "Social Work in Health Care: Approaches, methods and practices in the hospital and community; Papagiannis, A., Talking to the sick person; Iakovidis, A. & Iakovidis, V., Mental effects of cancer

Appendix G. Indicative Titles of Doctoral Dissertations on Palliative Care at the School of Health Sciences, Department of Nursing, National and Kapodistrian University of Athens

Timbalexi-Margaritidou (1991). Nurses’ ethical and deontological attitudes towards AIDS patients.

Patiraki-Kourbani, E. (1995). Nursing assessment of pain in patients with cancer.

Kyritsi-Koukoulari, E. (1996). Self-image in children with cancer who experience physical changes.

Gika, M. (1998). The dilemma of euthanasia in nursing care.

Patistea, E. (1999). Parental strategies in coping with childhood leukemia.

Sarris, M. (1999). The exploration of quality of life in patients subjected to renal transplantation.

Samoutis, A. (2001). The quality of life study of patients with medium and severe psoriasis and the economic impact of the disease in Greece.

Aggelopoulou, Z. (2002). Assessment of anxiety, depression and quality of life of patients with heart failure.

Papageorgiou, D. (2002). The impact of neurotoxicity on patients with cancer undergoing chemotherapy.

Papazoglou, I. (2003). Family support as provided by health care professionals at the end of life and death of a patient.

Bellali, T. (2003). The study of parental grief following the donation of their child’s organs.

Lavdaniti, M. (2003). Fatigue in women with breast cancer undergoing radiotherapy.

Servitzoglou, M. (2004). The quality of life of adolescents and young adults cured by childhood cancer.

Katsaragakis, S. (2005). Quality of life of patients with lung cancer.

Lamprinou, A. (2005). Evaluation of nursing education in Greece and Cyprus regarding the care of the elderly.

Papastavrou, E. (2005). The family’s burden of caring for a patient with Alzheimer’s Disease and related dementias.

Katsoulas, Th. (2006). Quality of life changes in patients with chronic obstructive pulmonary disease after hospitalization due to acute exacerbation.

Mynasidou, E. (2006). Exploration of the quality of life of patients with chronic diseases.

Perdikaris, P. (2007). Fatigue in pediatric patients with cancer.

Vouzavali, F. (2008). The phenomenological exploration of the therapeutic relationship between nurses and patients with a life-threatening illness.

Dimoni, Ch. (2008). The effect of symptoms and drug side effects on the HIV/AIDS patients' perceptions and compliance to antiretroviral therapy.

Adamakidou, Th. (2009). Cancer patients' self-assessment vs nurses' assessment of quality of life at home.

Govina, O. (2009). The burden of family members caring for patients with advanced cancer.

Zois, K. (2010). Investigation of parents' support needs, whose children are subjected to hematopoietic stem cell transplantation.

Moraiti, A. (2011). The lived experience of parents who raise a child with Duchenne Muscular Dystrophy.

Kouli, E. (2013). Socioeconomic and qualitative evaluation of home care in patients with malignant neoplasms.

Tsaroucha, S. (2014). Factors affecting the hope of patients who undergone hematopoietic stem cell transplantation prospectively.

Vlachioti, E. (2014). Assessment of the quality of life in children and adolescents with cancer during and post treatment.

Kollia, Z. (2014). The impact of the education on the self-care of patients with heart failure.

Moisiadou, E. (2014). Self-assessment of psychopathology, self-esteem, and coping in patients with chronic renal failure on hemodialysis.

Psychogyiou, A. (2018). Supportive care needs of women with advanced breast cancer undergoing chemotherapy at day care setting.

APPENDIX H. Selected publications of members of the National Committee on issues of Palliative Care, Bereavement and Symptom Management

Books and Chapters in Books

Greek References

Patiraki-Kourmpani E. & Katsaragakis S. (2019). Eds. of the Greek edition, Fundamental Aspects of Palliative Care Nursing- Substantiated Knowledge and Practice, Athens: Broken Hill Publishers LTD

[Πατηράκη-Κουρμπάνη Ε. & Κατσαραγάκης Σ. (2019). Επιμέλεια ελληνικής έκδοσης: Becker R. Θεμελιώδεις διαστάσεις της Ανακουφιστικής Φροντίδας στη Νοσηλευτική. Τεκμηριωμένη γνώση και πρακτική. Αθήνα: Broken Hill Publishers LTD]

English References

Mystakidou K, Parpa E, Tsilika E. Sleep Disorders. In: Oxford Textbook of Palliative Medicine. (6th Ed.).

Cherny N., Fallon M., Kaasa M., Portenoy R., Currow DC. (eds). Oxford University Press, UK, 2019; (to be published)

Papadatou, D. (2019). Careproviders' response to the death of a child. In A. Oxford Textbook of Palliative Care for Children, 3rd Edition, edited by R. Hain, A. Rapoport, M. Meiring, A. Goldman UK: Oxford University Press (in press)

Papadatou, D. (2018). Pediatric Palliative Care team: Coping with suffering and cultivating team support. In M. Muckaden (Ed.). Paediatric Palliative Care (pp. 189-204). Children's Palliative Care, Maharashira, India.

Appendix I. Schedule of meetings

1st Meeting. Athens, 21st May 2018, Stavros Niarchos Foundation Offices

PART A - GETTING TO KNOW EACH OTHER

Chair: Dr. Stephen Connor, Executive Director of the WHPCA (***through teleconference)***

[Working language in this section: English]

15.00 - 15.30	Introductions [2-3' for the members of the Committee to introduce themselves and their work related to Palliative Care in Greece]
15.30 - 15.50	Presentation on the scope and the process of the work of the National Committee for the Development & Implementation of a Palliative Care Strategy in Greece **Dr. Stephen Connor, Executive Director of the WHPCA**
15.50 - 16.00	Q & A
16.00 - 16.10	Progress of the work done so far [Dr. Stephen Connor]

PART B - GETTING TO KNOW PALLIATIVE CARE IN GREECE

Chair: Dr. Olga Iordanidou, Chief Executive 2nd Regional Health Authority of Piraeus & Aegean Islands, Ministry of Health and Social Solidarity

[Working language in this section: Greek]

16.10 - 17.00	The challenges which members of the Committee face in their work in Palliative Care
17.00 - 17.10	Closure: The way forward Setting the date of the next meeting **Dr. Eugenia Vathakou, Coordinator**

2nd Meeting. Athens, 10th July 2018, Stavros Niarchos Foundation Offices

Principal Investigator: Dr. Stephen Connor (via zoom)
Chair: Dr. Olga Iordanidou
Coordinator: Dr. Eugenia Vathakou

15.00 - 15.10	Setting the ground (introduction in English)
15.10 - 16.40	Challenges and recommendations (discussion in Greek) • *Terminology in use* • *Registry & estimation of current numbers served* • *Legislative framework* • *Clinical level* • *Social Security Funds* • *Education* • *New services to be provided by law*
16.40 - 17.20	Initial estimates of the need for Palliative Care in Greece, Dr. Stephen Connor
17.20 - 17.30	Closure: The way forward Setting the date of the next meeting

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3nd Meeting. Athens, 26th September 2018, Stavros Niarchos Foundation Offices

Principal Investigator: Dr. Stephen Connor (via zoom)
Chair: Dr. Olga Iordanidou
Coordinator: Dr. Eugenia Vathakou

15.00 - 15.10	Setting the ground Approval of the minutes of the previous meeting
15.10 - 16.00	Review of the Feasibility Study
16.00 - 16.30	Terms of Reference of the Sub-Committees
16.30 - 17.00	Operational Plan: what should be included
17.00 - 17.30	Discussion on the name Issue
17.30 - 17.45	Closure: The way forward Setting the date of the next meeting

4th Meeting. Athens, 16th October 2018, Stavros Niarchos Foundation Offices

Principal Investigator: Dr. Stephen Connor (via zoom)
Chair: Dr. Olga Iordanidou
Coordinator: Dr. Eugenia Vathakou

Main topic of the meeting: Review of the Feasibility Study

5th Meeting. Athens, 29th October 2018, Stavros Niarchos Foundation Offices

Principal Investigator: Dr. Stephen Connor (via zoom)
Chair: Dr. Olga Iordanidou
Coordinator: Dr. Eugenia Vathakou

Main topic of the meeting: Review of the Feasibility Study

Appendix J. Information collection form for education courses/programs on palliative care/with Palliative Care content

In the framework of the works of the National Committee on Palliative Care (PC), we would like to invite you to complete the form with information about the courses in which PC for adults/children is taught in your institution at undergraduate or/and postgraduate level. Please complete a separate form for each course in which PC is taught (fully or partly).

INSTITUTION: ____

SCHOOL & DEPARTMENT: ____

TTILE OF THE COURSE ____

☐ **COURSE OF UNDERGRADUATE PROGRAM**

☐ **COURSE OF POSTGRADUATE PROGRAM**

☐ **COMPULSORY** ☐ **ELECTIVE**

ECTS: ____________________ **SEMESTER:** _______________

TOTAL NUMBER OF COURSE TEACHING HOURS ___________________

TEACHING HOURS focusing on the following topics

Palliative Care for Adults _______________ hours

Palliative Care for Children _______________ hours

Family Bereavement _______________ hours

Multidisciplinary Cooperation _______________ hours

LECTURER: ____

RESOURCE: ____

Author _______________________ **Publishing house** ________________________

Thank you very much!

Appendix K. Information collection form (for use with NGOs)

In the framework of the works of the National Committee for the development and implementation of a Strategy for Palliative Care[11] in Greece, we collect information for the Feasibility Study that we prepare, and we would like to invite you to answer the following questions.

NAME SURNAME: ____

ORGANISATION:____

POSITION: ____

SERVICES PROVIDED: ____

____

____

NUMBER OF BENEFICIARIES/YEAR: ____

HOW DO YOU UNDERSTAND THE CONCEPT OF PALLIATIVE CARE?

____

____

(If the representative does not know (at all or sufficiently) the term PC clarifications are provided)

DOES YOUR ORGANISATION PROVIDE PC SERVICES?

☐ **YES** ☐ **NO**

IF YES, WHAT ARE THESE SERVICES? ____

____

[11] During the interviews we used both terms Anakoufistiki and Parigoriki to translate the term Palliative Care. At the end of the interview we asked our interviewees which term should be used for the translation of the English term Palliative Care in the Greek language: Anakoufistiki or Parigoriki.

WHO IS INVOLVED IN THE PROVISION OF PC IN YOUR ORGANISATION FROM THE FOLLOWING SPECIALISATIONS

☐ **DOCTOR** ☐ **NURSE** ☐ **SOCIAL WORKER** ☐ **PRIEST**

☐ **PSYCHOLOGIST** ☐ **PSYSIOTHERAPIST** ☐ **VOLUNTEER** ☐ **OTHER**

IF PC SERVICES ARE NOT CURRENTLY PROVIDED TO YOUR BENEFICIARIES WOULD YOU BE INTERESTED IN PROVIDING THEM THESE SERVICES IN THE FUTURE?

☐ **YES** ☐ **NO** ☐ **I DO NOT KNOW**

PLEASE EXPLAIN YOUR ANSWER ____

____

____

WOULD YOU BE INTERESTED IN PROMOTING PC SERVICES IN GREECE (i.e. promotion of PC services in the relevant National Action Plan or when these services are developed to refer patients to them?)

☐ **YES** ☐ **NO** ☐ **I DO NOT KNOW**

WHICH TERM WOULD YOU CHOOSE FOR THE TRANSLATION OF THE ENGLISH TERM PALLIATIVE CARE IN THE GREEK LANGUAGE: ANAKOUFISTIKI OR PARIGORIKI AND WHY?

Thank you!

References

Downing, J., Ling, J., Benini, F., Payne, S. & Papadatou, D. (2014). A summary of the EAPC White Paper on core competencies for education in Pediatric palliative care. *European Journal of Palliative Care*, *21 (5),* 245-249.

Economou, C., Kaitelidou, D., Karanikolos, M. & Maresso, A. (2017). Greece - Health Systems in Transition, 19 (5), http://www.euro.who.int/__data/assets/pdf_file/0006/373695/hit-greece-eng.pdf

Gamondi, C., Larkin, P. & Payne, S. (2013). Core competencies in palliative care: an EAPC White Paper on Palliative Care education – part 1. European Journal of Palliative Care, 20(2), 86-91.

Global Atlas of Palliative Care at the End of Life. World Health Organization & Worldwide Palliative Care Alliance. Connor, S. & Sepulveda, C. (eds.) (2014).

Gomez-Batiste, G. *et al*. (2017). Comprehensive and integrated Palliative Care for people with advanced chronic conditions: An update from several European initiatives and recommendations for policy. J Pain and Symptom Mgmt, 53(3), 509-517.

Kateilidou, D., Mladovsky, P., Leone, T., Kouli, E. & Siskou, O. (2012). Understanding the oversupply of physicians in Greece: the role of human resources planning, financing policy, and physician power, Int J Health Serv., 42(4), 719-38.

Knaul F, Farmer P, Krakauer E, de Lima L, Bhadelia A, Xiaoxiao JK, Arreola-Ornelas H, Dantes OG, Rodriquez NM, Alleyne G, Connor, S, Hunter D, Lohman D, Radbruch L, Saenz R, Atun R, Foley K, Frenk J, Jamison D, & Rajagopal MR. (2017). Alleviating the Access Abyss in Palliative Care and Pain Relief: an imperative of universal health coverage: Report of the Lancet Commission on Global Access to Palliative Care and Pain Control. Lancet http://www.thelancet.com/commissions/palliative-care

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NM, Alleyne G., Connor, S., Hunter, D., Lohman, D., Radbruch, L., Saenz, R., Atun, R., Foley, K., Frenk, J., Jamison, D., & Rajagopal, M.R. (2017). Alleviating the Access Abyss in Palliative Care and Pain Relief: an imperative of universal health coverage: Report of the Lancet Commission on Global Access to Palliative Care and Pain Control. Lancet http://www.thelancet.com/commissions/palliative-care

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Radbruch L., Leget C., Bahr O. *et al*. (2016). Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care. Palliative Medicine, 30(2), 104-116.

Souliotis K., Golna C., Tountas Y. & Siskou O. (2016). Informal payments in the Greek health sector amid the financial crisis: old habits die last.., The European Journal of Health Economics, 17(2), February.

Stjernswärd J., Foley K.M. & Ferris F.D. (2007). The public health strategy for palliative care, J Pain Symptom Manage, 33(5), May, 486-93.