ISCTE Business School
Instituto Universitário de Lisboa

An insight study of the state of the Palliative Treatment in Portugal

Artur Pedro Lapa Nunes

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Supervisor:

Gonçalo Amorim (CEng, iMechE)

Invited Lecturer Indeg / ISCTE-IUL

Program Director

MIT Portugal - Innovation & Entrepreneurship Initiative

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Abstract

After cardiac diseases, oncological conditions[1] represent one of the most important causes of death and pain in OECD countries in one hand, and on the other an important financial burden in National Health Systems (NHS). To improve patients' lifetime the traditional approach has focused mostly at the clinical and treatment levels. However, a number of emerging studies have brought to the forefront of the discussion the increasing importance of Palliative Care treatments. In the USA alone, more than 70% cost savings have been achieved in studies focusing on improving the quality of life of the patient and on cost avoidance techniques (R. Sean Morrison, et al., 2008). In spite of this, there is little evidence of the existence of such studies in Portugal.

Accordingly, it would seem highly valuable for the NHS to take notice of what is the state of art in best in class countries and possibly adopt a number of recommendations and best practices with proven results elsewhere.

The specific goals of this thesis are then to be:

1. To develop a case study in order to understand if the best in class Palliative Care techniques are being used in Portugal;

2. To understand what the potential savings could be, in an extremely pronounced downturn of the Portuguese economy, without compromising the quality of the service provided by our NHS.

In an inquiry conducted to 42 health professionals in Portugal, we have validated a number of improvement opportunities in the current Palliative Care practice which, if applied could have considerable economic and social benefits.

Key-words: National Health System; Best Practices; Palliative Care; Cost Reduction;

JEL Classification System:

- M10 - General,
- M48 - Government Policy and Regulation

[1]Oncology is concerned with the diagnosis of any cancer in a person; Therapy (e.g. surgery, chemotherapy, radiotherapy and other modalities); Follow-up of cancer patients after successful treatment; Palliative care of patients with terminal malignancies; Ethical questions surrounding cancer care; Screening efforts of populations, or of the relatives of patients (in types of cancer that are thought to have a hereditary basis, such as breast cancer.

Resumo

Depois das doenças cardíacas as doenças oncológicas representam uma das maiores causas de morte e dor nos países da OCDE, sendo também um dos maiores encargos nos sistemas nacionais de saúde (SNS). Para melhorar a qualidade de vida dos pacientes a medicina em temos tradicionais tem-se focado, principalmente, a nível clínico e nos seus tratamentos. No entanto um número de estudos emergentes veio trazer para discussão o aumento da importância dos cuidados paliativos. Nos Estados Unidos da América foram obtidos mais de 70% de redução de custos em estudos que visaram o aumento da qualidade de vida dos pacientes e técnicas de diminuição de custos (R. Sean Morrison, et al., 2008). Ainda assim há pouca evidência da existência deste tipo de estudos em Portugal.

Em consonância com o já referido seria então bastante valioso para o SNS verificar qual o estado de arte nos países mais desenvolvidos para adotar possíveis recomendações e melhores práticas com resultados comprovados neste domínio.

Os objetivos específicos desta tese são então:

1. Desenvolver um estudo de caso para perceber quais são as melhores práticas em cuidados paliativos a serem usados em Portugal
2. Perceber quais são as potenciais poupanças, numa altura de recessão da economia portuguesa, sem comprometer a qualidade de serviço prestado pelo SNS

Num inquérito elaborado a 42 profissionais da saúde em Portugal, validamos um conjunto de oportunidades de melhoria na atual prática de cuidados paliativos, que se aplicados irão trazer consideráveis benefícios económicos e sociais.

Palavras-Chave: Sistema Nacional de Saúde; Melhores Práticas; Cuidados Paliativos, Redução de custos

Sistema de Classificação JEL:

- M10 - Geral,
- M48 – Politica e regulamentação governamental

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Glossary

OECD – Organization for Economic Co-Operation and Development

IMF – International Monetary Fund

GDP – Gross Domestic Product

EAPC – European Association for Palliative Care

WHO – Word Health Organization

1. Case Study

1.1 Problem Presentation

According with data from Organization for Economic Co-operation and Development (OECD) the world population is aging. The life expectancy of their members' country was in 1960 about 68 years at birth and now it's around 80 years old. People are living in average over more than a decade (12 years).

This is a result of a constant evolution of medicine, treatments and new solutions for the old diseases together with high standards of living and working conditions and also the health-related behaviours according with OECD (OECD, 2010).

In Portugal the increase of the life expectancy is in line with OECD records, from 64 years in 1960 to 80 years in 2010 (16 year life expectancy improvement). However this fantastic evolution of this health indicator brings new and added considerable challenges to the social security and public health systems at large. When we combine this trend with the recent bail out of the Portuguese Government to the International Monetary Fund (IMF), a number of economic reforms are underway to restore the economic confidence, growth and financial stability.

In a time where every expense is a matter of discussion and consideration, the social system as it is has two key challenges along with the continuation of increase in life expectancy of the population:

- Temporal and populational increase of the elderly pensioners: larger basis of pensioners, are depending for longer on the active contributors. Adding to this is the historically high rate of unemployment reaching close to 17,5% (Sic Notícias, 2013), which in turn means less active contributors to state, pension funding;
- Growth of the expenditure in the public health care systems: it's inevitable, more years of life mean that more health care is needed, and the growing population of the elderly makes this expenditure increase. Furthermore the complexity of some diseases and the cost of treatment of this illness is also a burden for the system.

This investigation will focus its approach in the public National Health Care system and how and to what extent the best practices in the field can, if fully exploited, contribute to the reform of the Portuguese social system.

At first, it is important to have an overview of the overheads and cost structures in the Portuguese health system. One important indicator is the total expenditure on health considering the percentage of the Gross Domestic Product (GDP). In Portugal in 1970 the total health expense was 2.4% of the GDP and in 2010 this cost had a growth of 78.0% representing 10.7% of total GDP (OECD, 2012).

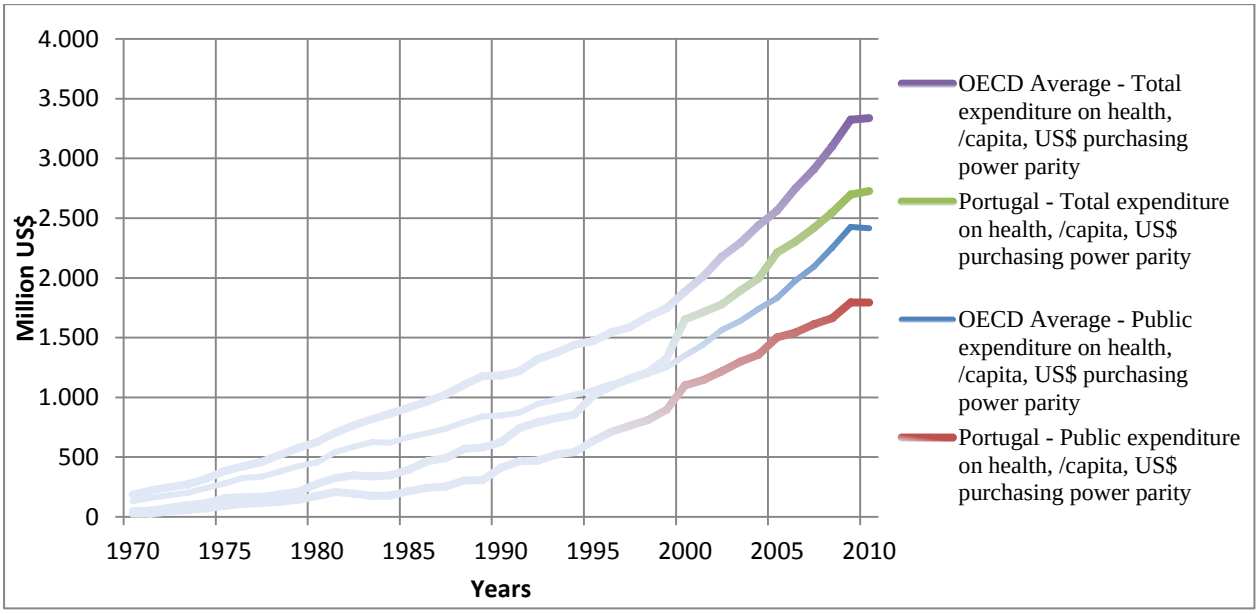


Chart 1 – Evolution of Health Expenditure (Total and Public) of OECD Average and Portugal from 1970 until 2010. **Source:** OECD, 2012.

In chart 1 it's possible to observe the evolution of the health costs related to the Portuguese economy and specially the evolution of the Public contribution for this considerable increase. Especially in the 90's where there was a dramatic increase of US$549 M in public health expenditure. Such increases are generalized across all the decade, but are equally preoccupying in the beginning of the new millennium where, in 5 years (2000-2005) the increase was an extra US $606 M in spending. In the same period the total Portuguese health costs where $748 M and $883 M, respectively, in this case the percentages of public contribution to this general growth were 79% and 69%. (Annex 1)

From 59.0% of Public investment in health in 1970 to 65.8% in 2010 (Annex 2), different governments have made different inputs for this outlay and in consequence of different and often incoherent, short sighted policies, the growth of the total health costs is nowadays *eating up* a considerable chunk of the Portuguese country's GDP. Arguably the question of whether such burden has to be pondered and alternatives explores. This study will try to

identify some alternative routes, namely, via an improvement of the national network of the Palliative Care treatment.

The health care expenditure has been an important issue beyond the Portuguese reality. Indeed, in recent years the formidable technological advances have been many and unprecedented, providing never thought before and new ways of effective treatment to complex and increasing diseases that encompass and aging population with a legitimate search of increasing patterns of quality of life. But such technological wonders and advances in treatment were inexorably encompassed with more costs. In OECD countries the health cost by GDP percentage from 1970 to 2010, more than doubled in 40 years, from 4.75% to 9.73%. (Chart 1)

It's also possible to observe that in the same period the average health cost of the OECD average in 1970 was US$187 M and in 2010 the cost was already over US$3,300 M. This represents an increase of 94% of total health cost. (Chart 1)

Although it's possible to observe a similar trend on the growth of Portugal total expenditure *vis a vis* of the OECD average, however when one looks more attentively this rate of growth has been extraordinarily greater than its OECD country peers. (Chart2) By 1995, Portugal has surpassed the OECD as a % of GDP cost of total health expenditure. And, worst of all, has not stopped increasing topping at 10% of GDP by 2010.

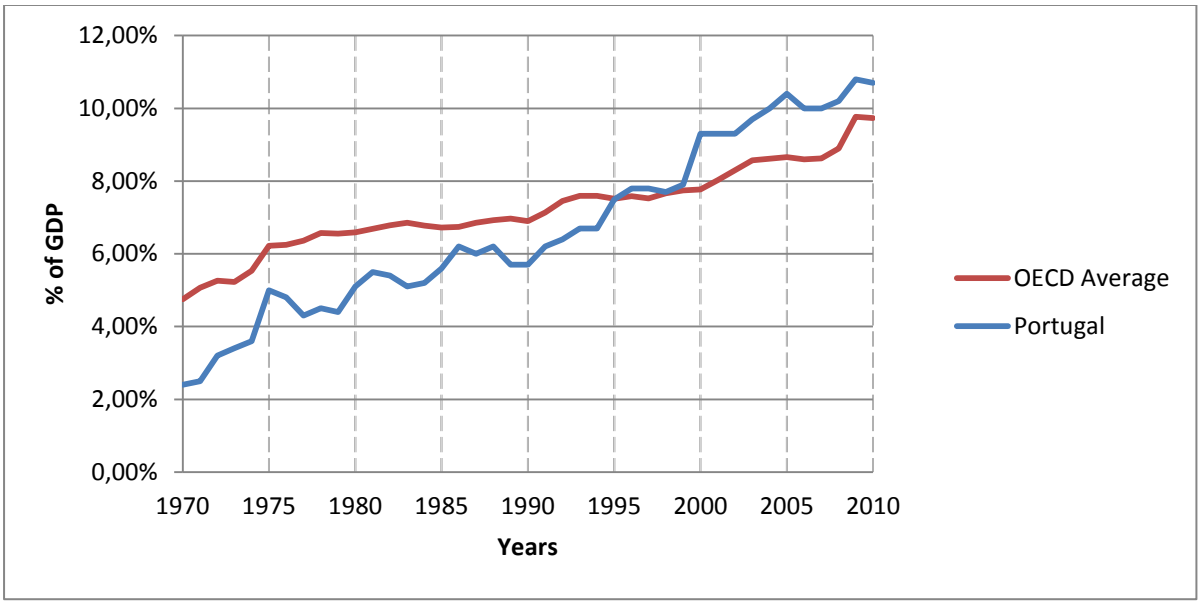


Chart 2 - Comparison between the Portuguese Total Health expenditure, % of GDP from 1970 until 2010 and the OECD average. **Source:** OECD, 2012.

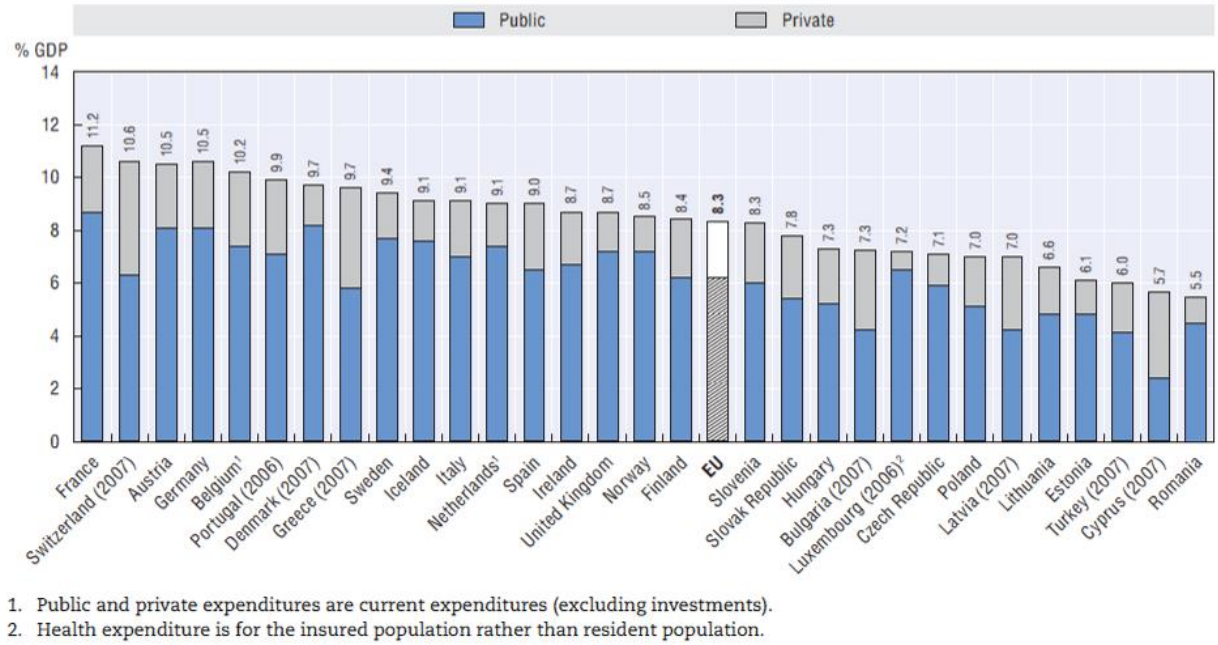
The biggest growth in this period occurred in the 70's where the largest peak of growth was in 1975, with a staggering 28% increase in the expenditure in health in Portugal (Annex 3). In the beginning of the new century there was also a significant increase of this expenditure, again greater than the OECD average.

It is not hard for the untrained eye to see that an explosive mixture has been in the making particularly since the last century years to the present day. In other words, the growth of the Portuguese economy doesn't have the pace of the most advanced OECD countries and therefore the risk of increasing public debt has caused unbalanced macroeconomic budgets.

Since in the 70's the average expenditure of OECD countries was at 4.8% it was to be expected that Portugal had to boost its health expenditure. In spite of that in 2010 the average was only at 9.5%. It's possible to observe a gap of 1.0% to 2.0% from the actual costs of Portugal, representing approximately US$2.000 million/year (OECD, 2012).

Since 1998, Portugal has been spending more in health that the average of OECD countries. How does this extra expenditure can be justified? Is this trend sustainable? What has been driving it? One should also bear in mind that more expenditure does not necessarily convert into higher quality of the service or better standards of life. We will try to look into these issues in further depth in the following sections, presenting some conclusions based on a survey to over 40 health professionals and ultimately proposing some possible recommendations to government officials and public incumbents.

In 2006 the Portuguese expenditure on health care was already 9.9% of GDP and from this around 7.0% was public cost, which puts Portugal as one of top 5 EU countries in the euro zone with the highest investments in this area.



1. Public and private expenditures are current expenditures (excluding investments).
2. Health expenditure is for the insured population rather than resident population.

Chart 3 - Total health expenditure as a share of GDP, 2008. **Source:** OECD Report 2010.

According to World Health Organization (WHO) the increase of the average life expectancy is not being followed by the expected life conditions that are considered to be the minimum standards acceptable for older populations. In spite of the investment done by countries, the results obtained show that this doesn't prove that more costs will result automatically in a better life condition.

Since Portugal is under considerable pressure from the bailout to the IMF and EU, the public resources are being heavily scrutinized as never before. One of the key goals of this study is to better understand what is the current state of affairs and focus on the Palliative Care approach as a possible mitigation route to such unsustainable health costs. Departing from a hypothesis where a relative "immature" process is still in place in Portugal, our inquiry will focus on the observation of the state of art of Palliative Care in Portugal.

Our study builds also a major piece of research in this field. It has been demonstrated that "costs fell by more than 60.0% after Palliative Care consultation for patient who died in the hospital" (Smith, Thomas J. et al.; 2009). If this can be theorized that such cost reductions, ought to be of help, at least to some extent to the Portuguese public health-related expenditure and consequently to the sustainability of the whole NHS.

In the North of Europe and North America Palliative Care is already a mature market, where the practice is well known and established. Plus both private and public sectors are conscious on what to offer to the population (Lopes, Manuel; 2010). For this reason we

advance that it would be of extreme value to benchmark the Portuguese reality against the North American experience and thus assert what economic benefit could be derived from such an exercise.

In a time where there are major concerns about the financial and economic crisis in Europe and elsewhere, social concerns with the effects of the same crisis it's important to project the future, taking into account what are the key decisions that have to be taken today.

2. Study Objectives of the theoretical framework

2.1 Introduction

In order to consider an important overview of the Health care, it's essential to understand the point of view of one of the most important organizations in the world in this field, the World Health Organization (WHO).

"WHO is the directing and coordinating authority for health within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends."(WHO, 2012)

This organization has gained independence and sufficient structure to help in the demand of health information and directives that were needed in order to project the healthcare more effectively.

In one of the most recent studies on population aging WHO has made it's possible to see that developed regions have quickly increased their older populations and until 2025 the projections show that the less developed countries will follow this trend. In 2050 it is estimated that 20% of worldwide population will have 60 years old or more (World Health Organization Europe, 2004) (Chart 4)

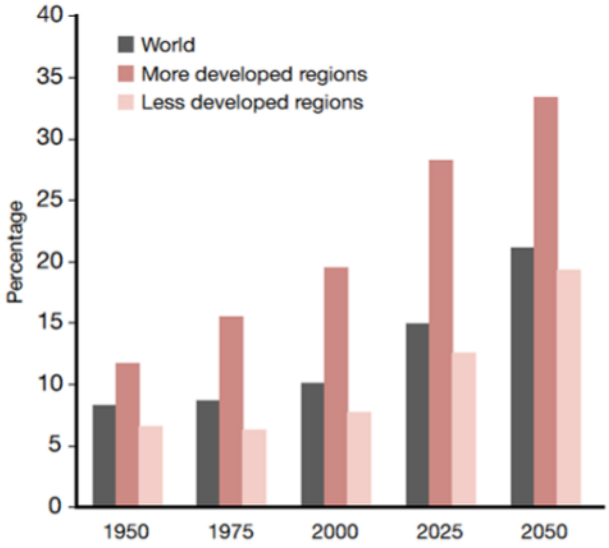


Chart 4 - Population aging: Population aged 60 and over. **Source:** *WHO report, Solid Facts, Palliative Care.*

The consequence of aging population will represent less active population and an increase burden for the social security systems. In accordance with the death causes which recognize that cancer is already the most probable cause of death (Chart 5) WHO states that "policies for Palliative Care need to be developed as part of an innovative global public health policy" where the organization of this type of treatment should be different. (World Health Organization Europe, 2004)

It's expected that Cancer will increase in more than 45% (Chart 5) their effect in the most project deaths, for this reason it's important to consider the outcome of this projections in social, demographic and economical terms.

Firstly it's important to reflect about the social conditions that this projection will impact in people's lives. Cancer is a long-term disease that implies a long time support from everyone around the patients, friends and family, but also the professional help needed, nurses, doctors, psychologists, social assistants, physiotherapists, nutritionists or even volunteers. The long time support refers to the long term assistance, such care is usually taken to mean help with domestic tasks, such as shopping and preparing meals, and assistance with personal care tasks, such as dressing, bathing and nursing care (Adelina Comas-Herrera, 2006).

About demographic status the manifestation of this future outcome will put some limitations about the growing life expectancy[2] and healthy life years[3], some OECD relevant health indicators (OECD, 2010). This will also bring consequences in the birth rate, in long term.

Economically the forecast will bring consequences on the investment that countries will have to improve the quality of life of the older citizens.

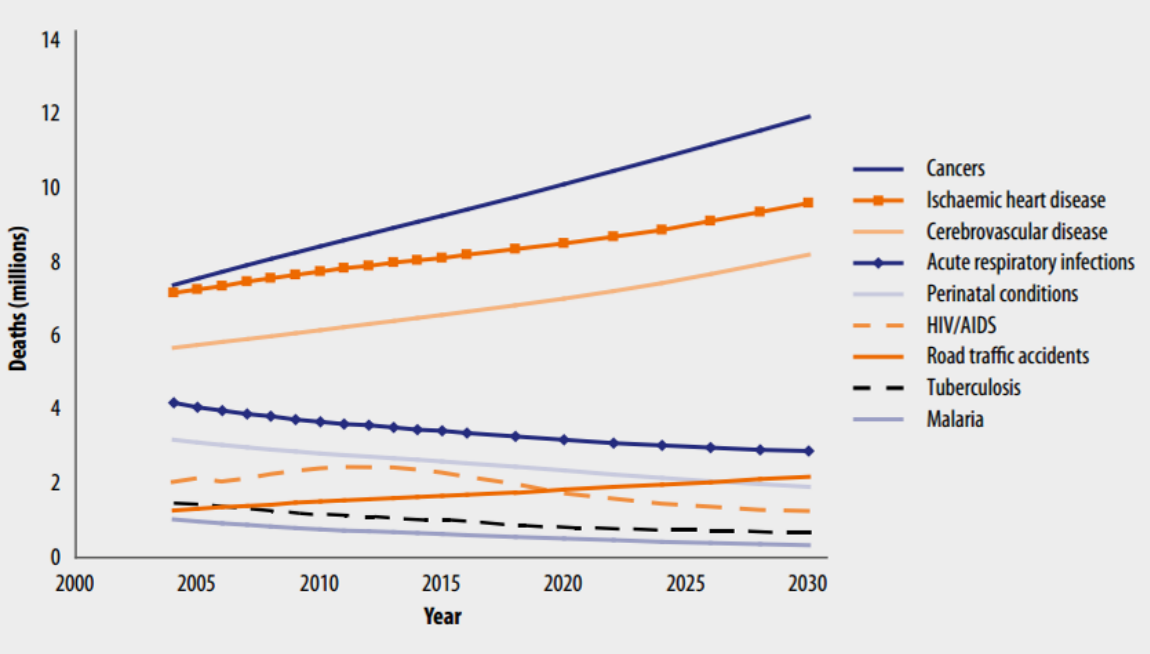


Chart 5 - Projected global deaths for selected causes, 2004-2030. **Source: (World Health Organization, 2008)**

Taking this into account WHO also states that "Whether Palliative Care is specialist or generalist, services need to be integrated into health care delivery systems to be sustainable" (Hall, Sue; Petkova, Hristina; Tsouros, Agis D.; Constatini, Massimo; Higginson, Irene J. WHO Report, 2011)

If indeed WHO's projections are correct, then cancer prevention will have become one of the key drivers in NHS systems. As a complement, it will be equally important to recognize

[2] Life expectancy measures how long, on average, people would live based on a given set of age-specific death rates. (OECD, 2010)

[3] Healthy life years (HLY) at a particular age are the number of years spent free of activity limitation. They are calculated by Eurostat for each EU country using the Sullivan method (Sullivan, 1971) (OECD, 2010)

the relevance to integrate Palliative Care in the present so that in the future the burden of such costs (per person) can be significantly lower. Such a reality will be no different in Portugal.

The WHO health system approach has three goals (Hall, Sue; Petkova, Hristina; Tsouros, Agis D.; Constatini, Massimo; Higginson, Irene J. WHO Report, 2011):

- To improve the health status of the population (both the average level of health and the distribution of health),
- To improve fairness of financing (financial protection and equitable distribution of the burden of funding the system),
- And to improve responsiveness to the non-medical expectations of the population, including two sets of dimensions, respect for people (patient dignity, confidentiality, autonomy and communication) and client orientation (prompt attention, basic amenities, social support and choice.

These three goals should be a priority for every country that wants to have a good involvement of their health systems with their population by providing the best quality service.

Following the vision of this organization health systems also have four functions (Figueras, Mckee, Lessof, Duran, & Menabde, 2008):

- Financing (Revenue collection, fund pooling and purchasing),
- Resource generation (Human resources, technologies and facilities),
- Delivery of personal and population based health services,
- And stewardship (Health policy formulation, regulation and intelligence).

Nevertheless this document refers that the "WHO health system approach is a holistic way of providing health care services" and still this should be seen as the role to follow by all the countries that are members of this organization.

Applying the Palliative Care perspective, by having a continuum of services, is a priority when we speak about sustainability. Controlling and monitoring the patients since the diagnosis phase is a way to prevent unnecessary costs and bad judgment about the patient condition.

Palliative Care isn't a last call resource but a continuous well-being method to all the ones that have chronic diseases and that must be surrounded by trained professionals as well as their family and friends that are one of the main emotional supports for these patients.

That is why WHO promotes a new concept for the Palliative Care method (Figure 1) where the healing process is more dynamic making a mix of the curative actions with palliative ones therefore the transition is easier and starts earlier.

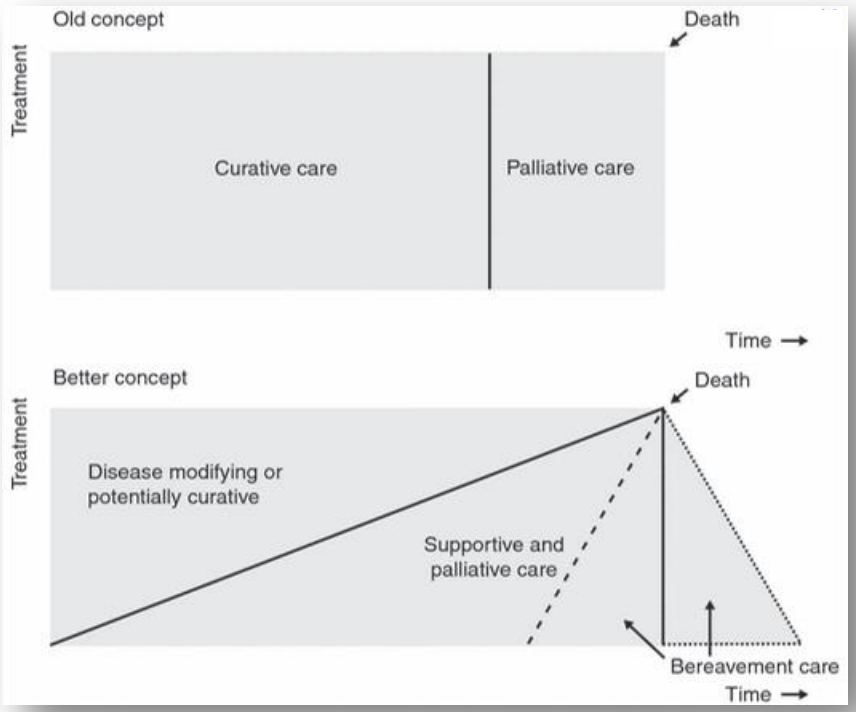
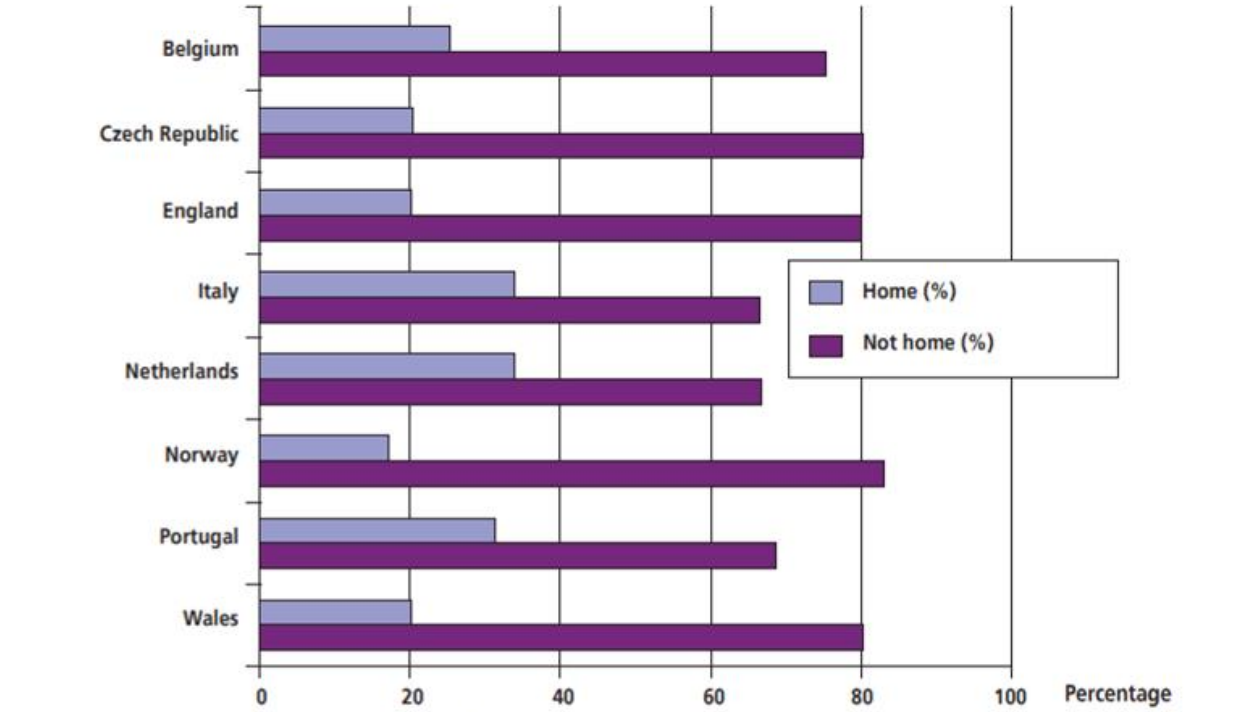


Figure 1 - Old concept versus New concept of Palliative Care.
Source: WHO report, *Solid Facts, Palliative Care*; Adapted from Lynn & Adamson.

One of the situations recognized by overall patients was their motivation to die at home, "75% of respondents would prefer to die at home" (World Health Organization Europe, 2004). This information is very important considering that the percentage of people that die at home started to be the standard measure to understand the evolution of Palliative Care in a certain country. The other reason to consider this a measure of quality is because less time in hospital beds will represent less hospital costs and more availability to emergency situations.

Since the proposition of the Palliative Care has the basis of a continuous treatment will a decreasing level of professional participation, the fundamentals of this concept is to increase the well-being of the patient through a minor intervention of doctors, nurses and drugs as soon as the diagnosis is complete.



Sources: Belgium, Italy and Netherlands: Cohen et al. *(3)*; Czech Republic: *Deaths by place of death, sex and age, 2008 (4)*; England and Wales: *Mortality statistics: deaths registered in 2008. Review of the National Statistician on deaths in England and Wales, 2008 (5)*; Norway: *Deaths of underlying cause of death, by place of death. Per cent. 2008 (6)*; Portugal: *Health statistics 2005 (7).* The sources of data and classification vary slightly from country to country, limiting direct comparison.

Chart 6: Place of death (home versus not home) in eight European countries **Source:** WHO Report: *Palliative Care for older people: Better Practices.*

In Chart 6 it's possible to observe that most of the people that live in the eight countries represented don't die at home, but the desire showed by the patients in dying at home start to pull the attention for this type of information for the decision makers.

The preference of the patients can be viewed in the Figure 2, if it can be a patient choice when it comes to the place where the disease should be treated, the option is preferentially home. It's still very interesting to observe that in special conditions the patients prefer to stay at the hospital like non-solid tumours or in case of availability of inpatient beds.

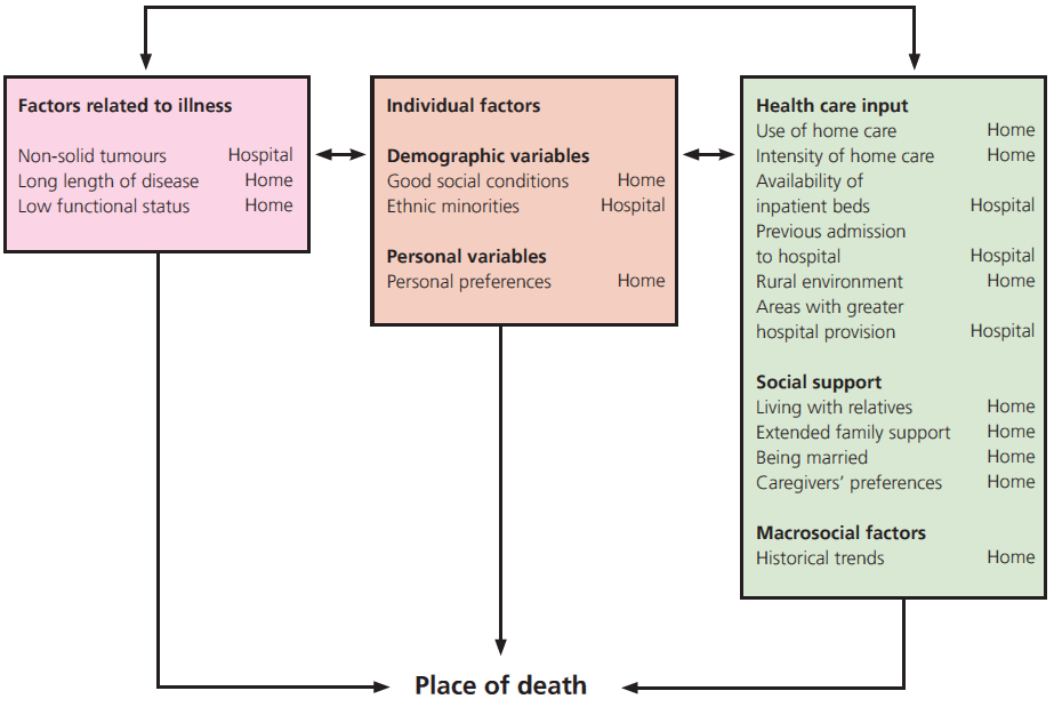
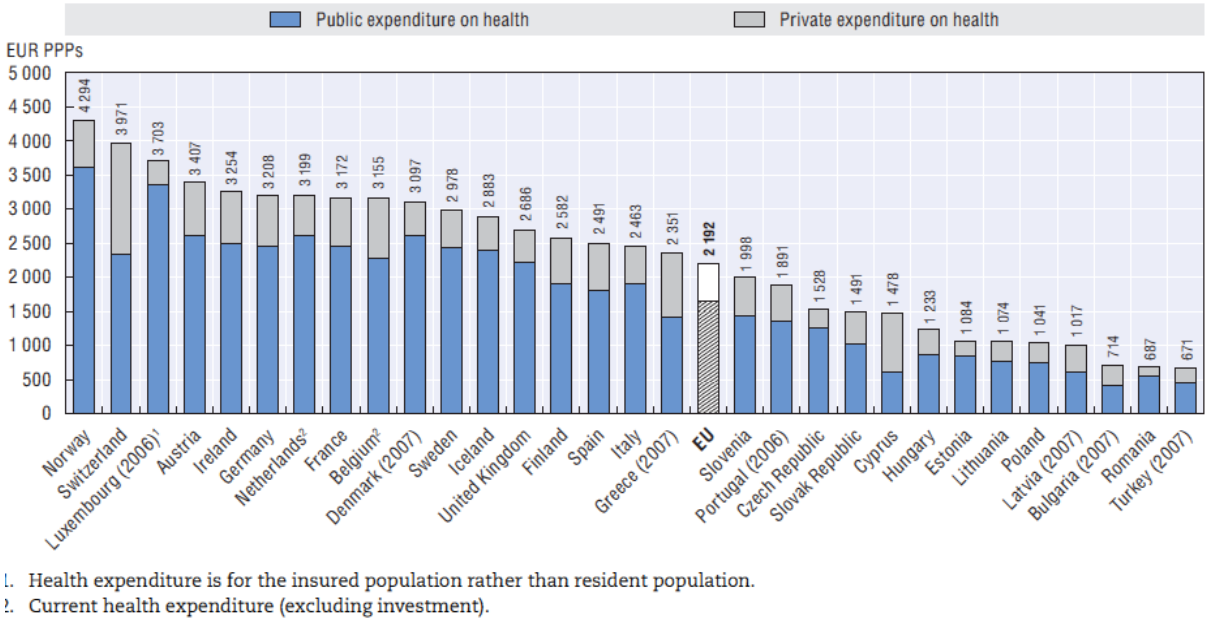


Figure 2 - Factors associated with place of death (home and hospital only).
Source: WHO Report: *Palliative Care for older people: Better Practices.*

This output is very important considering that the majority of answers were that patients prefer to be treated at home, although at this point that isn't happening. For this reason it's important to understand what impact a possible change of paradigm can have in the health expenditure.

2.2 Expenditure in Health

By analyzing the total expenditure it's important to understand how much of this represents the public expenditure and private investment in the area. Considering the data in Chart 7 it can be seen that the average of European Union (EU) is quite lower than the OECD average and that most of the health costs are from the public budget, around 80%.



1. Health expenditure is for the insured population rather than resident population.
2. Current health expenditure (excluding investment).

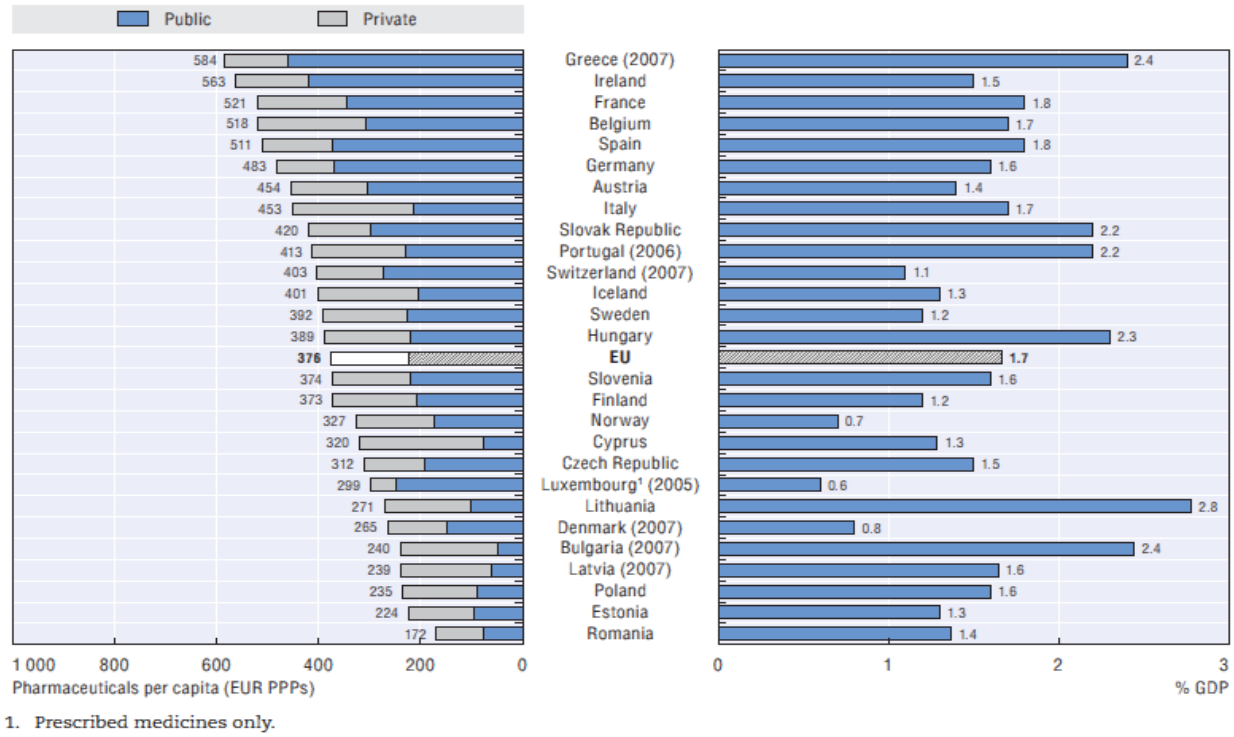
Chart 7: Total Health expenditure per capita, public and private, 2008. **Source:** (OECD, 2010), *Euro in "purchasing power parity"*.

Another important fact in this expenditure *per capita* is to understand the weight of the medicines in this total cost. Analyzing the specific case of Portugal it's interesting to see that total expenditure *per capita* is about €1,891 and from this €413 represent medicines (22.0%) when compared to EU with €2,192 of total and €376 in drugs (17.0%) it's a notable difference (Chart 8).

Even Norway, the country with more total expenditure with €4,294 *per capita* has a smaller value in medicine 327€ *per capita* representing only 8.0% of the total expenditure.

This high expenditure of Portugal in drugs can be also be analyzed when compared by percentage of GDP that reaches 2.2% (Chart 8) when the average of the European Union was 1.7% (in 2008).

Therefore and considering that the health costs in Portugal are very high representing around 11% of GDP (Chart 2), it's not affordable for the Portuguese population to pay this amount of costs specially if we consider the ratio between total health expenditure *per capita* and GDP *per capita* that is around 20% (Chart 9).



1. Prescribed medicines only.

Chart 8: Expenditure on pharmaceuticals per capita and as a share of GDP, 2008. **Source:** OECD Health Data 2010, Eurostat Statistics Database, WHO National Health Accounts

1. 2007. 2. 2006.

Chart 9: Total Health expenditure per capita and GDP per capita, 2008. **Source:** OECD Health Data 2010, Eurostat Statistics Database, WHO National Health Accounts

In Chart 10 it's possible to notice the above the line evolution of the weight of medicines *per capita* of Portugal when compared to the OECD average countries the evolution from 1970 and 2009 was an increase of 94% in Portugal was around 99%. This means that nowadays Portugal is spending more *per capita* in pharmaceuticals than the average of OECD but having a lower GDP *per capita* than the EU average (Chart 9). Such a situation is obviously not sustainable.

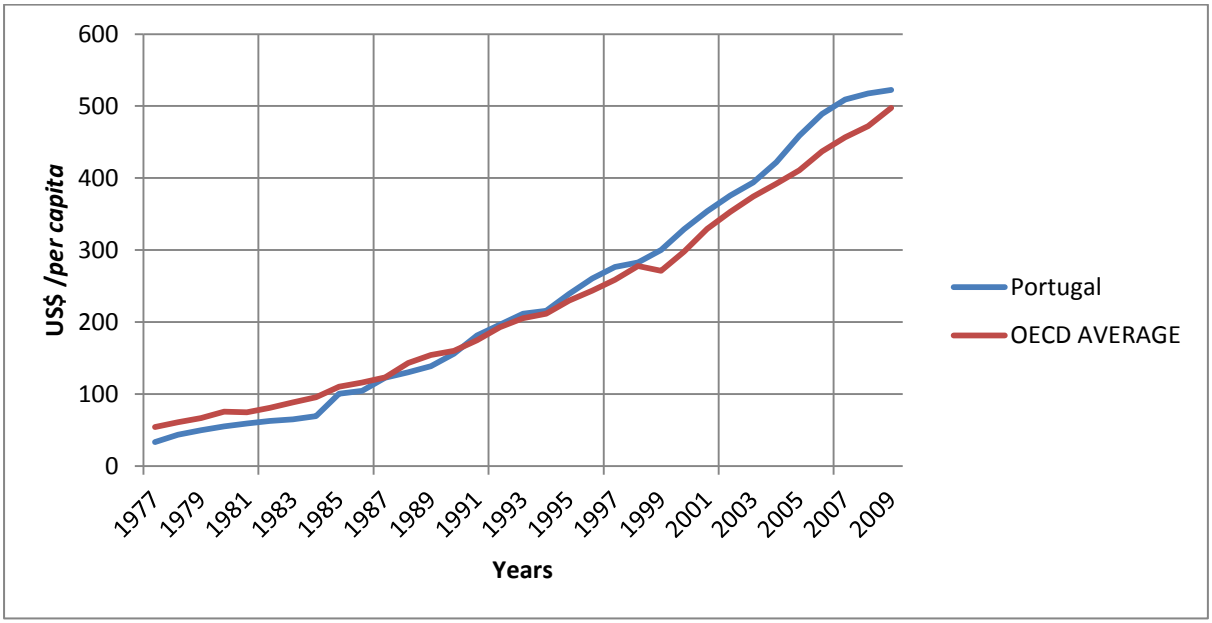
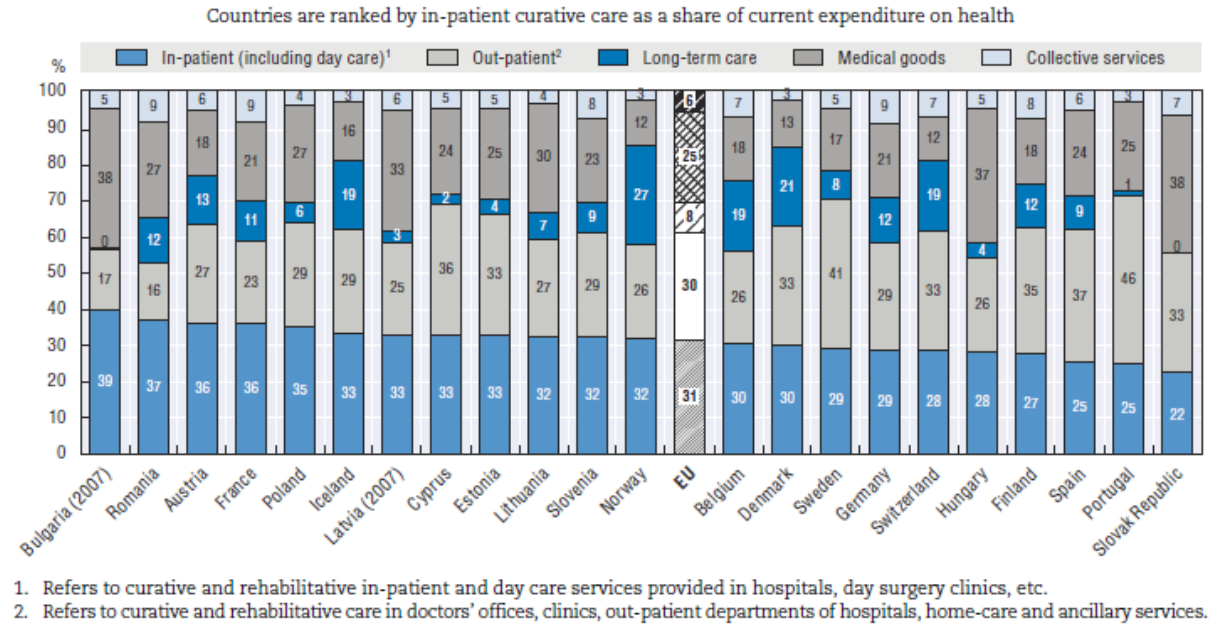


Chart 10: Total expenditure on pharmaceuticals and other medical non-durables, /capita, US$ purchasing power parity, (1977- 2009/ Portugal & OECD Average). **Source:** OECD, 2012.

Presumably, one ought to blame the expenditure in pharmaceuticals which has in turn amplified enormously in this time frame. But more even so since the new millennium where the growth has been nearly exponential.

Even though pharmaceuticals do not account for the total increase in expenditure in health. Other factors have also to be taken into account. Chart 11 helps us better picture such contributions, showing the percentage by function. There are some situations that strike immediately our attention: Bulgaria is the country with most spending by in-patient and medical goods (38%). Another observation is that, on the other hand, Portugal is the country with highest expenditure in out-patient (46%), whereas Norway is the country with greatest expenditure (27%) in Long-Term Care.



1. Refers to curative and rehabilitative in-patient and day care services provided in hospitals, day surgery clinics, etc.
2. Refers to curative and rehabilitative care in doctors' offices, clinics, out-patient departments of hospitals, home-care and ancillary services.

Chart 11: Current Health expenditure by function of health care, 2008 **Source:** *OECD Health Data 2010; Eurostat Statistics Database*.

From such a picture, one can draw a very simple but very striking conclusion: although Norway is the country with the highest investment *per capita* in health, it has at the same time a lower cost *per capita* in pharmaceuticals (than the EU average). Interestingly enough, it is the country with most expenditure in the long-term care. Again, there is a trend here: similarly to (World Health Organization Europe, 2004), an increased portion of long term care will bring considerable savings in curative care, simply put surgeries and pharmaceuticals.

This may also help explain why a significant number of studies were made proving that a good system of long-term care will also represent an investment in Palliative Care, and this type of treatment can reduce until 60% the costs of a hospital (Smith & Cassel, 2009).

There is an obvious question that one ought to draw: should Portugal put more effort in long-term care? More so when, in 2008, long term care only had 1% (Chart 11). It can then be advocated that a greater investment in long term care ought to mean a significant cost reduction in total health cost if applied well, that is according to the gold standard practices.

Palliative Care is "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, thought 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." (Hall, Sue;

Petkova, Hristina; Tsouros, Agis D.; Constatini, Massimo; Higginson, Irene J. WHO Report, 2011)

Although this vision of Palliative Care, the concept of being an universalized activity is still far from what it will represent in the future following the demographic and social evolution, therefore it's important to understand how should this activities be managed, what factors can influence them and if the present approach is the most appropriate one.

With so many technological evolutionary treatments, people expect to die in a comfortable way and as later as possible, but that is not always possible and for that reason the Palliative Care program is a very important subject to handle nowadays.

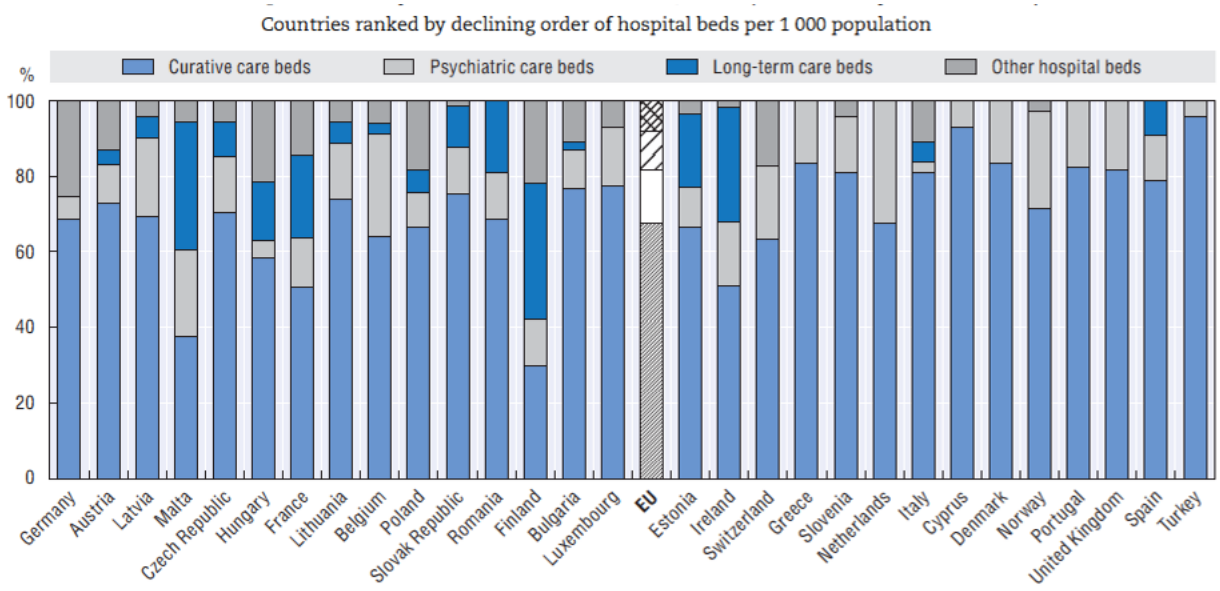


Chart 12: Hospital beds by function of health care, 2008 (or nearest year available) **Source:** OECD Health Data 2010, Eurostat Statistics Database

One other important indicator of health care is the type of hospital bed available since this will determine the priority of which needs will be more urgent to fulfil. In the chart 12 it's possible to observe that in most countries the main concern are the curative care beds, a fact that is easily understandable since this type of bed is the most compulsory one. But we can also see that some countries don't have long-term care beds.

Portugal is one of the countries that have around 80% of Curative care beds and the other 20% are psychiatric beds, which mean that the people that need long-term care requirements or other type of treatments will have to use these two types of beds, greatly hampering the correct health care indispensable for the different variety of patients, such as long term care, for instance. The following pattern becomes to emerge: Portugal has invested negligible

resources in long term and Palliative Care. Also this had a massive repression on the dramatic increase of total health costs. What could explain such an option from a government, decision making process? What is the driving force behind such decisions? In our study we will try to shadow some light into such issues.

2.2.1 Expenditure in the Portuguese Health System

Portugal has around 11 million inhabitants and around 60% of these people live in the big urban centers (Delloite Study, 2011). The population has grown in a 5% rate but the demographic pyramid is being inverted with a higher growth from the older age people than the young one. It is estimated that in 50 years the population above 65 years old will double and the active population will continue to decrease.

This aging of population will bring an increase in health care costs, and from chart 13 it's possible to examine the evolution of the total health expenditure in total numbers. The private costs passed from €4 thousand of million in 2000 to €6 thousand of million in 2008 but the public expense grow from €7.80 thousands of million to €11.20 thousands of million in 2008 which represents a total growth of around €3.4 thousands of million. In other words, almost the double of the €2 thousands of millions of increase in the private sector.

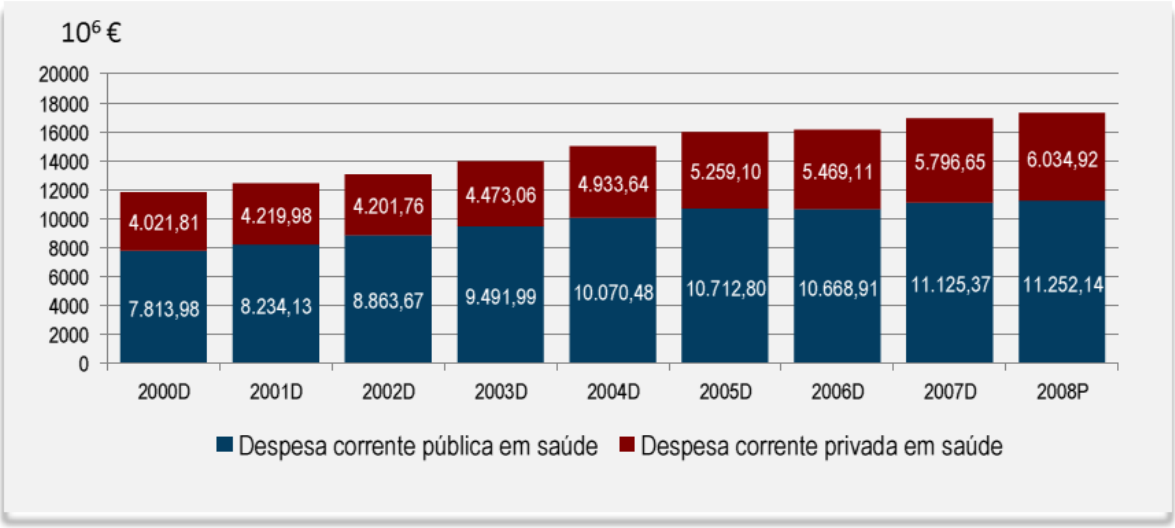


Chart 13: Evolution of the Current Expenditure in Health, Public (In blue) and Private (In red) (2000-2008). **Source:** INE (Instituto Nacional de Estatística/ National Institute of Statistics) 2010.

This data is important to combine with the chart 14 where it's possible to see the distribution of total health expense by the health care agents and where the National Service of Health has more than 50% share. However the total expense of this agent have been decreasing, from 55.9% in average between 2000 and 2005 went to 51.1% of public expense.

From the same data it's also possible to observe that the SNS is decreasing its weight on the total expenses in health, where the expenses with families and other health subsystems are absorbing it with a constant growth. Therefore the families are supporting the increasing costs of healthcare by two ways: directly paying to the health agents and from tax payer pockets.

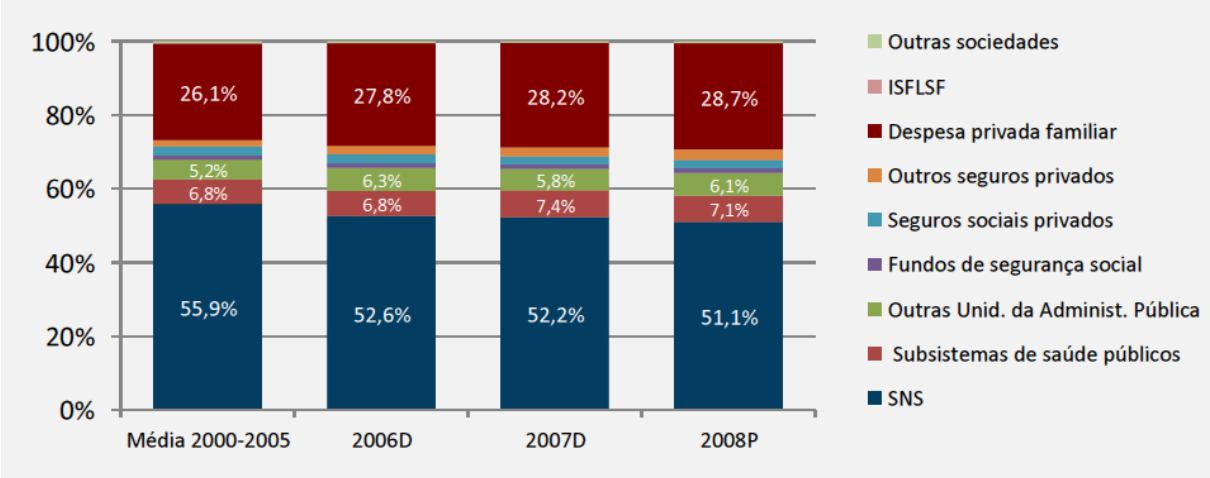


Chart 14: Expense in Health by financial agent (2000-2008) **Source:** INE, 2010 (Despesa Privada Familiar / Family Private Expense – Dark Red), (SNS / NHS – Dark Blue)

One of the major impacts of the familiar private expense is on consumption of drugs, and although there are more and more types of medicines and even generic ones, drugs with the same purpose but with lower costs. This particular expense has been growing a lot in the last years. The size of the medicament industry in Portugal, that is quite big since 2005 the revenues of this sector have grown from around €4 thousand million until around €4.5 thousand million (Chart 15).

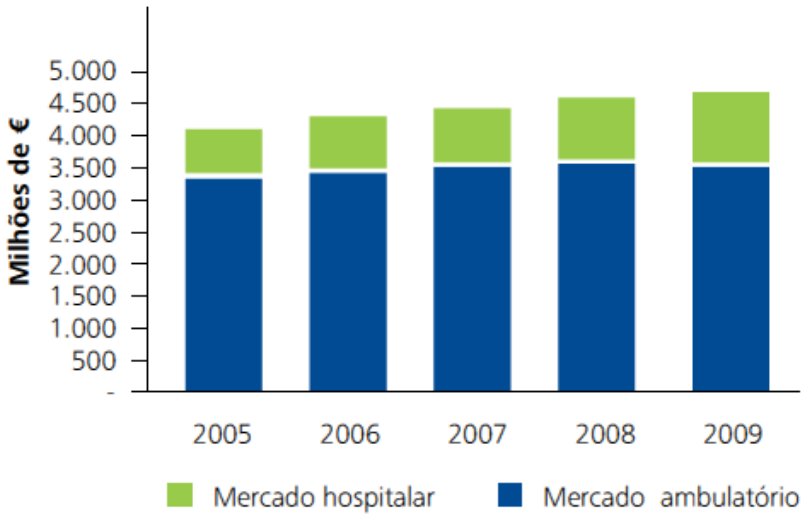


Chart 15: Revenue of drugs in Portugal (Green, Hospital Market) (Blue, Outpatient Market)
Source: (Delloite Study, 2011) Data from APIFARMA (Pharmaceutical Portuguese Association)

From other sources is also possible to observe the impact of this expenditure in the Portuguese Outpatient market with INFARMED, the national authority of the medicine and health products in Portugal. Its reports make it possible to conclude that the generic medicines (generics) are still under 20% of market share of total drugs sold in the Portuguese market. (Annex 3)

Other important aspect of this figure is the fact that the Portuguese NHS represents 45% of the total outpatient market in 2011, and even that it was possible to decrease 19.2% on these costs there was an increase of 9.3% on the Private family expense which means that pharmaceutical margin was not so affected since the overall consumption decreased 3.4%.

According to the OECD the growth in expenses in drugs is as big as or even bigger than the growth in total health expenses. Such a pattern can be observed in a few other counties. But in the case of Portugal the growth of medical expenses between 2008 and 2010 was higher than 4%, whereas the weight of the growth of drugs had a big impact on this (Chart 16).

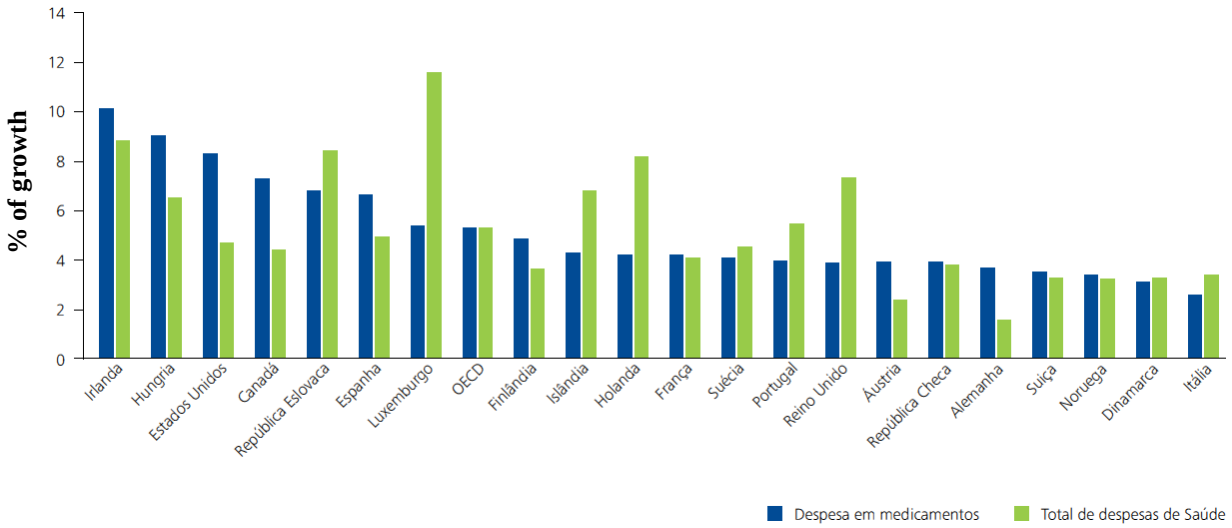


Chart 16: Growth rates of costs in drugs and Health/2008. **Source:** (Delloite Study, 2011) OECD, 2010

(Growth in Drugs expense – Blue / Growth in Total Health Expense – Green)

Taking such facts into consideration and the research topic of our study it's important to understand how the action plan for Palliative Care is going and which will be the impact of this plan, in economical and social figures.

3. Palliative Care

3.1 USA

In North America the Health system is self regulated, supported by the Bismarck System, a system where the insurance companies regulate the market and it's controlled by the private sector (Lopes, et al., 2010). Therefore the Health system analysis is more detailed considering that it's a big market for insurance companies and the decision-makers are influenced by the studies release.

The quality and quantity of these studies are consequently higher than in Europe and considering the proximity of the type of management from North America, it's important to investigate how the actual situation is and which results were found through the research done.

One particular study tried to understand the cost saving associated to the Palliative Care consultation programs, it was analyzed "data from 8 hospitals with established Palliative Care programs for the years 2002 through 2004" (R. Sean Morrison, et al., 2008).

This study had to reflect about two kinds of expenses: “Direct costs are costs that can be directly attributable to medications, procedures, or services. Indirect costs are the general costs of running a hospital that are not directly related to the test or service.”

“This study found that Palliative Care consultation was associated with a reduction in direct hospital costs of almost US$1,700 per admission (US$174 per day) for live discharges and of almost US$5,000 per admission (US$374 per day) for patients who died.”

If we apply the exchange rate for Euro at the time of the study this would represent a reduction of €1.155 per admission (€118 per day) for live discharges and of almost €3.400 per admission (€254 per day) for patients who died, in general this can indicate savings considering the costs of cancer treatments.

In the United States of America (USA) the National Institute of Health (NIH) estimates that the overall costs of cancer in 2007 were US$226.8 thousand million (American Cancer Society, 2012). Therefore the impact of the implementation of Palliative Care can represent a cutback of millions of dollars in the health care budget and at the same time will contribute for a better service through a centralization of the process in the patient well being.

In the same initial research about the influence of palliate care in cost reductions is possible to see that the impact of this process on overall costs. (Chart 17)

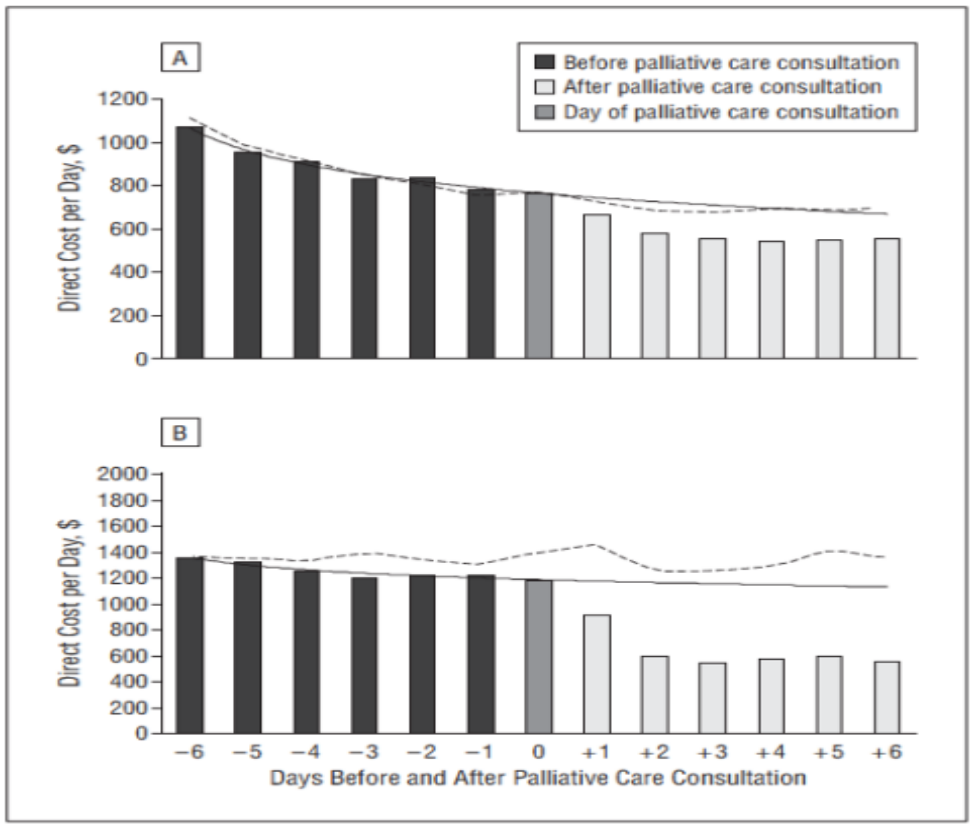


Chart 17 - Mean direct costs per day for Palliative Care patients who were discharged alive. (A) or died (B) before and after Palliative Care consultation. The solid line represents the regression curve of actual costs before Palliative Care consultation (day 0) and estimated costs (days 1-6) assuming that Palliative Care consultation had not occurred. The dashed line represents direct costs per day for usual care patients for the 6 days before and after hospital day 6 (patients with lengths of stay of ≤ 10 days), hospital day 10 (for patients with lengths of stay of 11-20 days), or hospital day 18 (for patients with lengths of stay of > 20 days)

Source: (R. Sean Morrison, et al., 2008)**.**

3.2 Europe

In Europe one of the best School-Hospitals is in Catalonia, where the Palliative Care Research is one of the most important investigations of this Hospital. In one study about cost saving related to Home Palliative Care Treatment (Serra-Prat, Gallo, & Picaza, 2001) the difference was studied between having a standard treatment at the hospital and the home Palliative Care treatment. It was possible to perceive a cost reduction of 71%.

The study compared PADES (Programa d'Atenció Domiciliària i Equips de Suport) patients, the patients that where followed by Palliative Care Teams, with non-PADES, patients that had also chronicle diseases but were not followed by these teams.

Some of the most interesting results of this study were that most of the accompanied patients (84%) didn't go to the hospital in their last month of life while non-PADES only (37%) didn't go and in average the non-PADES represented an increase in costs of around 437€ when compared to PADES. These costs consider the hospital discharges, emergency visits, outpatient visits, PADES visits, number of days in Palliative Care units within nursing homes and only direct costs were considered in the analysis.

A problem raised by this study and that has references in other papers is concerned to the fact that not always home treatment can be applied to the patient, but it's a few percentage considering all the universe of chronic disease therefore this is a real solution for cost avoidance.

The European panorama is quite different from the USA since there are different countries with different financing systems, Bismarck as explain before is supported by the private sector (examples of this policy are Belgium, Germany, France, Holland, Austria and others) but there is also the Beveridge system that depends on the taxes and that is controlled by the public institutions (Denmark, Greece, Spain, Ireland, Italy, Portugal, Sweden, United Kingdom and others are examples of this system) (Lopes, et al., 2010).

3.1.2 The Portuguese situation

The Palliative Care Treatment is a very recent concern for the Portuguese State, only in 2006 was a legislation made for the regulation of this activity. And still there were very different problems in applying the theoretical approach recently legislated.

In Portugal there are difficulties in the health system; lack of a complete information data base, bad strategic planning among other problems found (Delloite Study, 2011). But the chance of improvement is a real and very possible consideration, and slowly there have been signs of evolution.

With the budget limitations applied to the Portuguese Economy considering the help of International Monetary Fund (IMF), European Central Bank (ECB) and European Union (EU) it's very important to investigate the impact in the National Health System (NHS).

In early 2012 the healthcare minister stated that according with three studies to the sector it would be possible to save between 700 and 800 Million € through savings against the waste that exists in hospitals and medical centers (Sol, 2012).

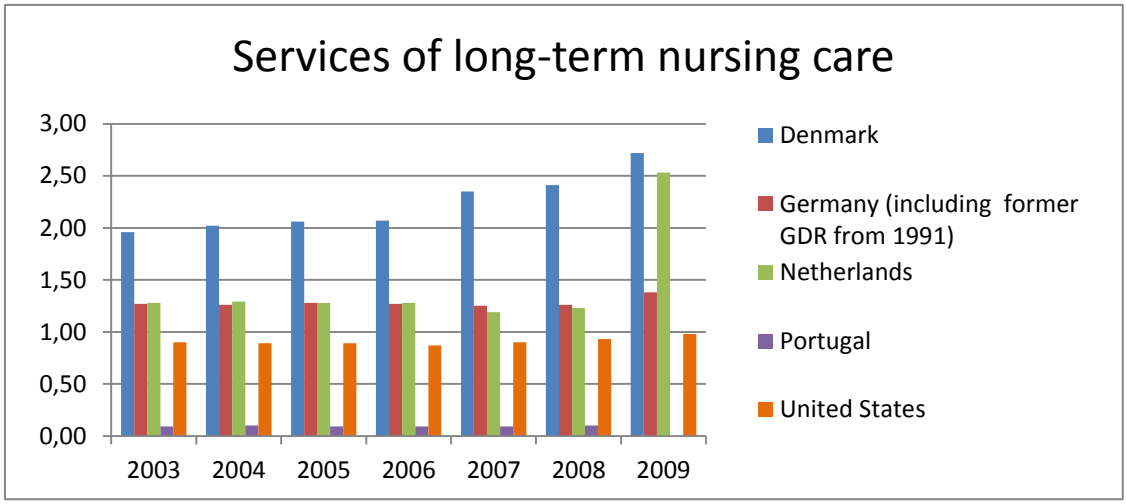


Chart 17: Last data about services of long-term nursing care (Investment by % of GDP).

Source: Data collected in Eurostat (adapted)

In a 2011 report about health in Portugal conducted by Deloitte it is mentioned that it was important to understand how is the national state of affairs on Palliative Care and health in general (Delloite Study, 2011)

Compared with other countries that have a bigger concern of develop the long-term care Portugal didn't invest accordingly in this area of medicine, since the country that invested less was USA but still with a 0.87% of GDP and Portugal the maximum of investment was 0.10% of GDP. In other words the US invests nearly 9 times more than Portugal in long term care (Chart 17). This seems to be one of the chronic problems of underinvestment in Portugal, however without an apparent reason.

Cost of Cancer in Portugal was estimated being 53.3€ *per capita* which means €565 million, this represents 3.91% of the total health expenditure (Araújo, et al., 2009). This study reveals some interesting facts; cancer is the second cause of death in Portugal, in 2005 there were 107,839 deaths and 23,232 (21.50%) were deaths associated to cancer, that is more than 1 in 5 deaths is being caused by cancer related diseases. According to the IMS Health Portugal in 2006 there was an expenditure of €3,284M in drugs (both hospital and outpatient market) this represents about 22.70% of the total health costs (€14,450M - 9.7% of GDP). To ballpark figure the study only considered direct costs; prevention, detection, treatment of cancer and this cost was divided by hospitalization, outpatient care and

pharmacological treatment. According with a mix Delphi panel (that was an expertise group that was interviewed to validate the data since it was not actual, this group was composed by; 9 oncologists, 6 hospital pharmaceutics and 4 hospital administrators) the results were quite similar to the investigation that showed that the biggest expense is in the specific medicaments for cancer treatment, then hospitalization followed by drugs for Palliative Care and last but not the least important the outpatient care.

To understand what these numbers represent in terms of world economic context the study also demonstrates that major economies have a bigger investment than Portugal (3.91%) in cancer cure. United Kingdom (10.60%), Japan (9.30%), Germany (6.60%) or even USA (4.70%) representing some of the larger world economies. And in 2004 this was the investment made in cancer treatment in respect to the total health costs.

One conclusion from the investigation clearly points towards the fact that the expenses in pharmaceutics are growing but also point to the fact that the financial resources are scarce. It is therefore crucial to understand in our study which processes of treatment should be considered in order to yield the greatest benefits for the health of the patients and for sustainability of the Portuguese NHS.

In order to coordinate the newly network RNCCI with the WHO directives and the European Association of Palliative Care (EAPC), a document was drafted with particular objectives for Palliative Care treatment in Portugal: the "*Programa Nacional de Cuidados Paliativos*" (Ministério da Saúde, 2010).

In this document there is an important formalization of how Palliative Care will be structured in Portugal, what kind of teams and levels of intervention will be. In terms of implementation, and considering the purpose of this investigation, it states that according with data from WHO 80% of the patients with cancer that will die would need Palliative Care. In Portugal there is a projection that states that annually around 18,000 people with cancer should need this kind of treatment considering the data from the study above.

Operationally speaking there are some goals that are important to milestone:

- When dealing with the intra hospital teams of Palliative Care support there is the goal of one team for each hospital with more than 250 beds, international recommendations, but the Portuguese goal will be a team per hospital;
- For standard for community teams of Palliative Care support the ratio should be of a team for an area between 140,000 and 200,000 people, however in a short term that won't be possible to do in Portugal unless the population density justifies it;

It's important to mention that there are already 40 teams of integrated continuous care (Equipas de Cuidados Continuados Integrados, ECCI) with specific qualifications in Palliative Care therefore if a need of more teams would be found more personal will have the proper training for this position.

- Standards for places in hospitalization, the ratio for this should be between 80-100 beds per 1 million inhabitants but for the different levels of complexity of the treatments there is a recommendation for different internment localizations with different types of cure answer:
  - Between **20** to **30%** of places in Units of Palliative Care integrated in Hospitals, these are beds for patients of high complexity. In Portugal these places will not be included in the RNCCI.
  - **40** to **60%** in Specific Units of Palliative Care of RNCCI.
  - **20** to **40%** in units of RNCCI but not specific for Palliative Care.

There is a forecast for a period of between 5 to 10 years for the implementation of this scenario, and bearing in mind that the first's years will be intense in increase of qualifications of the whole teams involved.

3.3 Conclusions

In this first stage of the study is possible to understand the relevance of the Palliative Care research nowadays and in the future. For that reason WHO has one vision about which are the better health treatments for the patients. Different nations and insurance companies are also very aware that this investment will bring economic benefits for them and more population/customer satisfaction.

According to different international but also national studies and reports, it's also possible to validate that Portugal has a long to go to be in line with WHO's directives, not to mention the average investment done by other countries that have started long before Portugal with Palliative Care programs.

This network was created in 2006 and since then only the Palliative Care has been one priority in Portugal with a slow implementation pace. But this network is not only about Palliative Care, the concept of Continuous Care focus the idea of inter-sector approach to connect all treatments available to Long Term Care.

Long Term Care is a concept with a common idea: “a well-planned and well-organized set of services and care processes, targeted at the multi-dimensional needs/problems.” (Netherlands Institute of Care and Welfare, 2006).

But the notion of Long varies to some extent from country to country, “in the Netherlands one week home help is considered as called long-term care.” (Netherlands Institute of Care and Welfare, 2006). Therefore it’s important to understand in which basis are the data that will be analyzed and if it will comparable.

4. Problem Recapitulation

The hypothesis proposed with this study is that the investment in Palliative Care will represent significant cost reductions in all Health Cost in Portugal, and demonstrating is one of the main goals of this Master Thesis.

The main objective of this study is to provide a useful insight on what opportunity could arise from the implementation of the “state of art” Palliative Care in Portugal, i.e. cost-saving. Another goal is to assess how the newly review for 2011-2016 fits in the directives of the WHO and best practices in this field (Lopes, et al., 2010).

Another purpose will be to understand which are the most efficient numbers in terms of public expenditure, I.e. operating points, and if these apply to the Portuguese reality, bearing in mind, that different cultural backgrounds may be at play that can influence the data. Anyhow, the idealism of providing excellence health service at the minimum cost should be kept as the major driving force and vision for Palliative Care treatment policies independent of where it is applied to.

The case study will to analyze the problems identified in the “Plano Nacional de Saúde 2011-2016”, a study for Health Care treatment where Palliative Care is included and where are raised some structural and operational problems of the newly created “Rede Nacional de Cuidados Continuados Integrados” (RNCCI) that stands for National Network of Integrated Continuous Care.

4.1 State of Art

4.1.1 USA

One of the most important and recent studies in this field of expertise was made in the USA, Virginia Commonwealth University, where there is a vision of management of Palliative Care Costs (Smith & Cassel, 2009)

One very important fact is that "Palliative Care is rarely profitable by itself compared with other services" and "this is particularly true for patients who are reimbursed on a diagnosis-related group (DRG) system where the hospital receives a lump-sum payment from the insurer to cover the entire cost of care." Because "by the time the patient with pancreas cancer, sepsis, resolved respiratory failure, and dehydration is transferred from the intensive care unit (ICU) to the Palliative Care program, all the funds from the DRG payment have been used."

As mentioned before the American Health system has the private sector as the main booster of the scheme and for that reason the costs and the impact of the measures assumed are more relevant and criticized than in Europe where the Social concern is the top priority.

"To address this issue in hospital cost accounting, we and others have adopted the term *cost avoidance* to show that health care systems or payers can actually save money with Palliative Care even if the unit is not profitable itself." This concept is the one accept worldwide to describe the attempt of reducing costs.

"When a patient is transferred appropriately from the ICU (US$3500/day) to the Palliative Care Unit (PCU) (US$1500/day), the health system saves US$2000 a day. In the analysis of cancer patients who died in the hospital, after an admission of at least five days, total and ancillary service costs were reduced after consultation and transfer, as shown in Fig. 3, and were lower than the reimbursement received. The allocation of resources also dramatically changed."

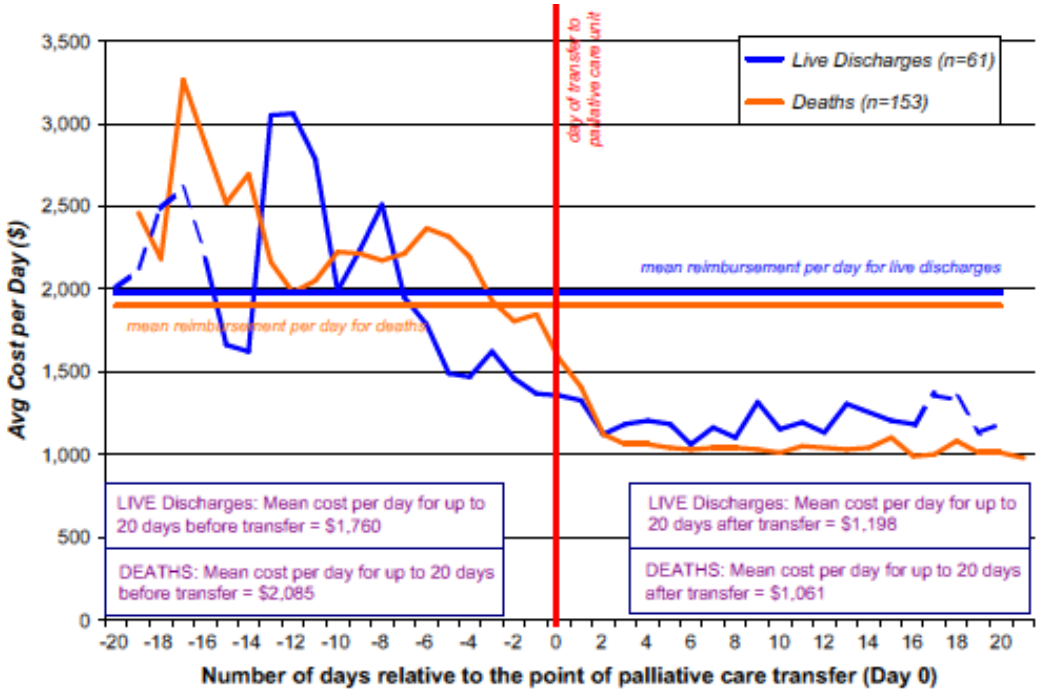


Figure 3 - Representative total cost/day for patients before and after Palliative Care consultation, for patients who died in the hospital (deaths) or were discharged. The vertical line is the day of transfer. The horizontal line is the average reimbursement/day; after transfer, the reimbursement is higher than the cost; so the patient makes a profit for the health system. **Data Source**: VCU Health System, Richmond, Virginia (modified from Naik, 2004). **Source:** (Smith & Cassel, 2009)

"Not counted in this type of analysis are the costs of avoided procedures and tests, such as computerized axial tomography, not done because of the changed medical goals. The impact of such an accounting would depend on whether those tests were profitable to the health system or not. Also not counted is the additional revenue from paying patients who could ''backfill'' the open beds made available by Palliative Care. Health systems with a profit motive may be more interested in filling those beds with insured patients; health systems without a profit motive, such as a health maintenance organization or national health system, may be more interested in appropriate throughput, or the number of patients served with the available facilities."

A second concern is opportunity cost, simply defined as the additional revenue that could be gained if money had been used in a different way. For instance, an ICU bed that is filled with someone who is not getting better may force the hospital into diversion. Oregon Health

& Science University found that when they increased from 47 to 67 ICU beds, emergency room diversion dropped, and they generated US$175,000 more profit a month.

If a Palliative Care program assists in the transfer of 200 ICU patients two days earlier than otherwise would have happened, then the medical staff will have 400 more ICU bed days available.

The reduction of expenditure has to have an objective policy about what to cut and the figure 4 shows us that Pharmacy, Lab, Ancill Treat, and other treatments can reduce by more than 50%.

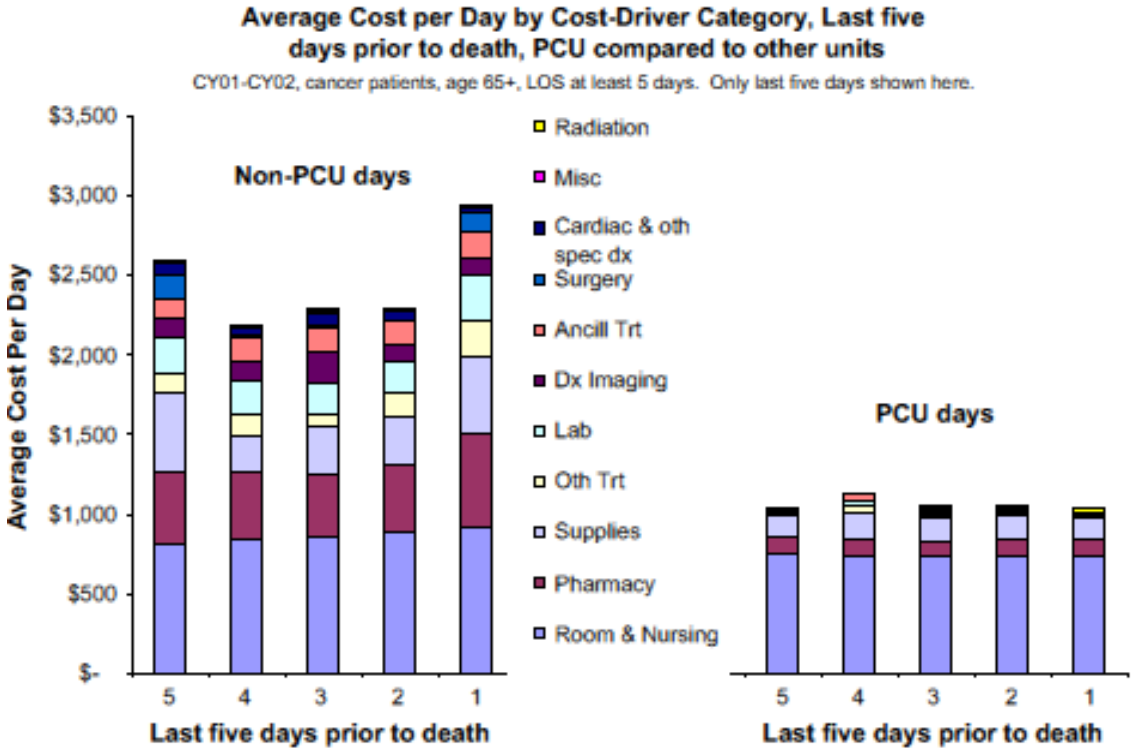


Figure 4 - Changes in the types of costs and actual costs - PCU compared with other units - for patients who died in the hospital.

(Modified from Naik, 2004) **Source:** (Smith & Cassel, 2009)

Whether there is live discharges or hospital deaths the cost reduction are significant with more than 300%, from US$6,974 to US$1,726, and 100%, from US$15,531 to US$7,755, estimated reductions for each case. (Figure 5)

This study has demonstrated a real impact on the management of health budgets that have exponentially increase in the last years.

	Live Discharges			Hospital Deaths		
	Usual Care	Palliative Care	*P*	Usual Care	Palliative Care	*P*
ICU direct costs	$6974	$1726	<0.001	$15,531	$7755	0.045
Died in ICU	NA	NA	NA	18%	4%	<0.001

Modified from Morrison et al., 2008.[5]
NA = not applicable.

Figure 5 - Impact of Palliative Care consultations on place of death and costs of hospitalization. **Source:** (Smith & Cassel, 2009)

4.1.2 Europe

In the European panorama there are two main examples to follow, Catalonia (Spain) and the United Kingdom, of how Palliative Care can be effectively integrated to health care systems.

In Catalonia the health care is accessible and free of charge for all its citizens, physicians, nurses and allied health professionals work together as Palliative Care support teams or units in various settings: hospitals, long-term care centers and the community (Serra-Prat, Gallo, & Picaza, 2001).

This happens through the implementation of the Catalonian WHO Palliative Care Demonstration Project that included some objectives:

- Revising legislation governing the delivery of opioid analgesics;
- Training all health care professionals in basic Palliative Care;
- Developing a model for funding Palliative Care;
- Integrating basic Palliative Care into conventional health care services;
- Implementing specialist Palliative Care services throughout the health care system;
- Developing professional standards; and
- Developing a monitoring and evaluation strategy.

In this context it's important to have a comparative metric that can bring some structural differences between European countries regarding their effort to put in practice the Palliative Care treatment. EAPC developed a metric with "two sets of criteria were used to calculate Palliative Care development: Palliative Care resources, which are weighted at 75% of the total index; and the perceived vitality of the field (critical mass of activists and professionals who increase the likelihood of short- and middle term resource development), which are weighted at 25%. The global index, then, is a synthesis of these two elements." (Policy Department: Economic and Scientific Policy, 2008)

In this way the best of class considered was United Kingdom due to its "quantity of services offered, the high standards expected, and in the research environment." (Policy Department: Economic and Scientific Policy, 2008). The UK had the 100% in the index and it's interesting to see that only 15, out of 26, countries had more than 50% in this analysis. Portugal had only 30%, 22% out of 75% possible and 8% out of 25%. Once again, both meaning that Portugal has still a long way to improve in terms of resources and vitality of the field (Chart 18).

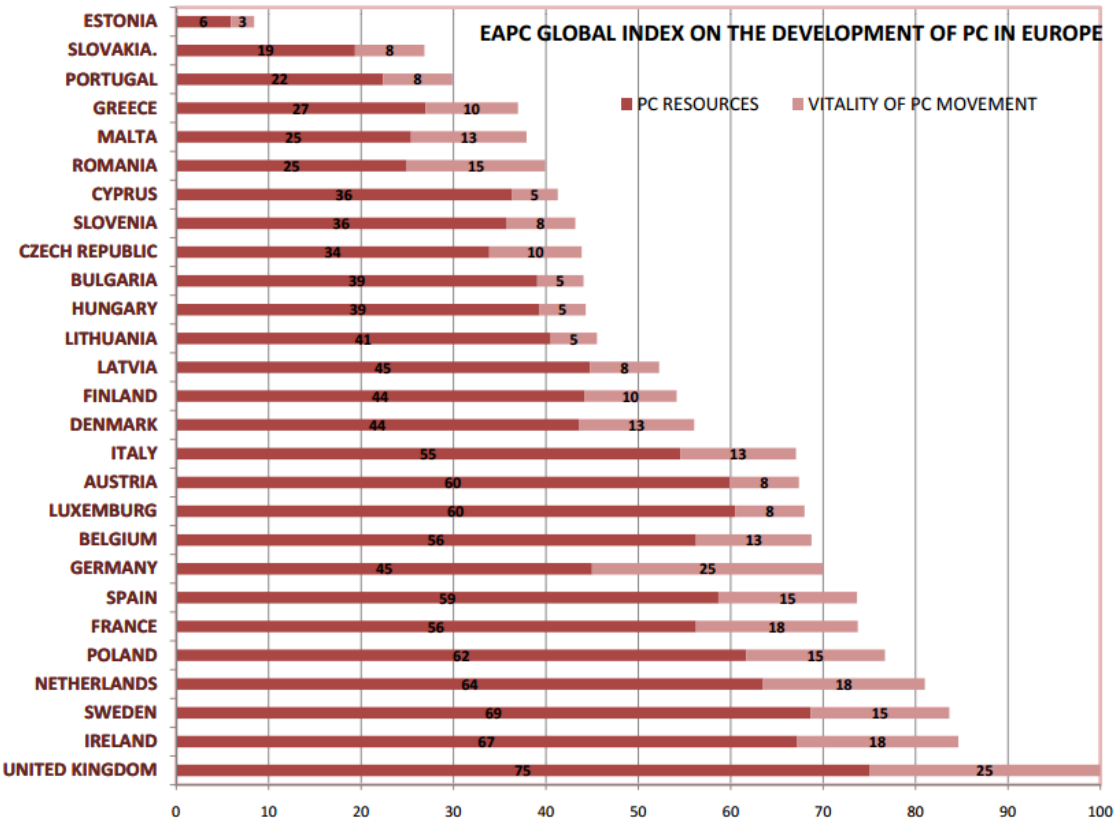


Chart 18 – EAPC Index on the development of Palliative Care in Europe (Results).

Source: (Policy Department: Economic and Scientific Policy, 2008)

This report has gathered 3 options of advice to the European Parliament:

- *Status Quo*: Trust that Palliative Care will develop by encouraging the use of general public health tools already in place in most countries, such as the Patients' Bill of Rights or regulations limiting the waiting time in healthcare centers. If Palliative Care were officially included in healthcare services offered by the National Health Service, no new laws would be necessary.

- General recommendations (but not new legislation) promoted by the European Parliament

In here there are some potential recommendations that should be considered:

- Encourage all countries to devise national plans for Palliative Care and end of life care in close collaboration with professionals and representatives of patients and families and to establish at least one national centre of excellence in the field.
- Promote availability and proper use of opioids when needed (through guidelines)
- Promote integrated healthcare networks which include proper attention to Palliative Care
- Improve information and knowledge systems, including support for research and evaluation in the areas highlighted above, as part of the next EU Framework Program.
- Promote plans for Palliative Care training at both basic and advanced levels of health staff education (particularly in medicine and nursing). Building capacity: skills, knowledge, confidence, networks.
- Encourage countries to facilitate specialist certification / accreditation of physicians and other professionals who work in the Palliative Care field. This could be accomplished through the establishment of academic chairs in countries with strong general Palliative Care infrastructures or perhaps scholarships and international partnerships for countries with less development.
- Promote trained volunteering programs, which are both cost-efficient for the health system and personally rewarding for the volunteer.
- Promote specific programs and measures to provide emotional, social, and financial support to families /relatives of patients at the end of their lives.
- Promote national Palliative Care research as well as a European palliative care research agenda, ensuring specific budget for the field.
- Identify and promulgate best practices in Palliative Care.
- Forge partnerships and collaboration. Commission periodic, detailed studies, in order to update the situation and to carry out self-assessment and benchmarking within and between Member States.

- New legislation (directives) and proactively led actions promoted by the European Parliament, ensuring patient rights and access to proper Palliative Care.

All these measures are very important for the objective of putting in practice the best of Palliative Care in Europe and therefore also in Portugal.

4.1.2.1 The Portuguese Situation

In Portugal the network of Palliative Care started to be built in 2006 with the continuous care network, but this continuous care aims to help all the people with disabilities and not only the persons that have terminal diseases.

In 2006 the APCP (Associação Portuguesa de Cuidados Paliativos / Portuguese Association of Palliative Care) made a document with quality measures for Palliative Care units in total there were defined 32 criteria that focused several points including (Associação Portuguesa de Cuidados Paliativos, 2006):

- **Care to the patient and family:**
    - Need assessment
    - Establishment of therapeutic objectives
    - Care to the patient and family
    - Education of the patient and family
- **Multidisciplinary working teams:**
    - Teamwork system
    - Care and support of the team
    - Continuous formation and investigation
    - Coordination of different levels of units and other support services
- **Quality evaluation and improvement:**
    - Register and documentation systems
    - Monitoring and Information systems
    - Quality Improvement

These set of tools were a theoretical basis to the launch of the network, by promoting a careful planning of Palliative Care Treatment in Portugal.

Even though in 2008 there were only 18 Palliative Care teams in Portugal (Marques, et al., 2009) and from that 5 were created in 2007 and 5 were created in 2008. Other important fact is that from the 18 teams 12 were supported by the NHS.

But the needs identified for Portugal were quite different from the reality found. Through the number of total population and the death patients there was made an estimation of the needs of Palliative Care teams all over Portugal (Capelas, 2007). According to data from the National Statistics Institute of Portugal in 2007 there was already the need of 133 domiciliary Palliative Care teams.

As an example, we present a survey carried out in Portugal in 2009, in which more than 50% of the population either did not know what Palliative Care was, or understood its definition incorrectly (12th Congress of the European Association for Palliative Care, 2011).

Accordingly, new legislation was prepared and in 2013 it was decreed that a new network would be built with focus on Palliative Care.

5. Methodology

In the course of investigation it was possible to interview two professionals in the area to obtain an *in loco* perspective of what is happening in the Palliative Care service in Portugal nowadays.

For the questionnaire it was undertaken a convenience sampling, with the experience in Palliative Care criteria, since it is faster, cheaper and conveniently accessible to the researcher (Hill & Hill, 2000).

To have a quantitative measure a Guttman scale was used, from 1 to 5, in order to acquire a meaningful overview of the opinion of the individuals. (Almeida & Pinto, 1995)

5.1 Empiric Evidence

According to the data collected it will be considered in this investigation two hypotheses:

Hypothesis 1: The current resources in Portuguese NHS being deviated to palliative and continuous care are insufficient, and a preference in patient treatment is directed to pharmaceuticals (prophylactic). NHS resources could be better managed without compromising the overall quality of treatment and life of the patients.

There will be a part of the questionnaire directed to the management professionals of healthcare, especially for the ones with direct responsibility of Palliative Care treatment. These questions will consider the studies that were mentioned previously.

Hypothesis 2: The actual Portuguese human resources in health care are not ready to fully implement the Palliative Care Network and accomplish the goals of the directives set by: "Plano Nacional de Saúde 2011-2016"

In 2008 there were only 18 Palliative Care Teams and most of the teams didn't have more than 5 years of existence, so the cumulative experience of the Portuguese human resources it was limited.

We have designed a questionnaire survey that will attempt to measure (quantitatively) and type of formation (qualitatively) the respondents' opinions and views.

6. Analysis of Results

6.1 Introduction

On the course of this study two key interviews were conducted, one with the president of ANCP, the national association for Palliative Care in Portugal, and the other with a nurse with a postgraduate degree in Palliative Care. These allowed to lay the ground for the qualitative analysis that will be complemented with a quantitative analysis with a questionnaire.

The questionnaire has 26 questions and to which it was possible over a period of 2 months obtain a reply of 42 respondents.

In this chapter we will present and discuss the main results and conclusions from the analysis of the quantitative data developed at the online survey questionnaire. This questionnaire was built with the help and validated by the 2 interviewed professionals previously mentioned.

6.2 Qualitative Analysis

- Exploratory meeting highlights with Mr. Manuel Capelas, the president of ANCP (Associação Nacional de Cuidados Paliativos / National Association for Palliative Care). (Annex 5)

In the vision of Mr. Capelas the National Health System is not going to save money but the total cost per patient can drop between €2,000 to €4,000 per patient per year. There is an estimation of 60,000 patients per year and therefore the savings can represent between €125M to €220M per year that could be channelled for other medical services. Putting these figures in perspective, such savings represent a potential reduction of 2% of the total NHS cost.

Also worth mentioning a study conducted by a community team, in the southern region of Portugal (Algarve), where it was shown that in the last 30 days of life it's possible to save €3,000 per patient. This numbers are coherent with the American studies that found a reduction up to €3,400 per patient.

Between being in a Palliative Care unit in the hospital or at a community center that helps the palliative patients, there is a considerable variation of the expense of the treatment of the patient. The cost per person tends to decrease and also the waiting list of other patient's drops, specially the one's with surgical needs.

- Increase of services through the Network:

The national Network has failed as a supplier of the answers posed by the stakeholders, it lacked pro-activity. The network was in an expectation mode, the government expected that the agents in the sector would contribute more for the development of the needs of Palliative Care in Portugal, which in turn degenerated into an unbalanced situation of the whole system.

Some examples of this contribution for the development could be more private investment in residential houses and in education of the actual human resources available.

- Lack of strategic planning for patient accommodation.

70% of total beds should be outside of the hospitals, it's important that 30% of the total Palliative Care patients be allocated to the hospital facilities according with the conditions of the patients.

- There were a mix of concepts between Palliative Care and Continuous Care:

Palliative Care are more directed to the patients in a terminal phase of the disease with the objective of controlling the dependence but not the cure and the continuous care have the purpose of helping to recover of dependence situations.

- Poor management of the Network by the governmental entities, where the key individuals that were in charge did not possess an adequate experience in the field:

There is a database with reference to the patients and these are listed by arrival order instead of complexity of the disease and priority status. The referral and triage process is also provided late, resulting in all sorts of procedural difficulties. Also, often the patients are also assigned too late which makes the purpose of Palliative Care obsolete, in terms of giving life quality:

- Operational teams on the ground without the adequate training,
- Lack of care with the international standards and guidelines of the services to be provided. No strategic monitoring system in place,
- The structural questions are more relevant than the operational teams that were trying to do as best as they could.

From the beginning of 2013 there will be an official Palliative Care network and therefore it will be separated from the continuous care network that was created in 2004. (National Health Management, 2004).

In this way will be possible to separate which are the real Palliative Care patients from the patients that need continuous assistance.

It will be created a network inside of the NHS that will mainly focus on Palliative Care and people are going to be referenced considering the complexity of their situation. One of its main functions will be to maintain the quality of the Palliative Care services and to understand where are the needs of the population in terms of Palliative Care, where are the patients and what kind of help do they need.

In general there have been some political resistance in Palliative Care training as that takes away some of the control that doctors currently have over the prophylactic method, which is the cultural and "normal code of action". There is the idea that these are minor treatments, there was a misconception because what is important is to have free beds and because that "everyone in the medical field" knows how to do Palliative Care just because they face dying people every day.

Palliative Care avoid that some extra resources are used if the patient is not going to get some advantage with that increase, in terms of quality of life or day of living.

In the S. João Hospital, in Porto (1st in the public Portuguese hospital ranking (Jornalismo Porto Net, 2012)), the changes have been noticeable thanks to the teams that are involved and actively discussing the policies in use and improvement opportunities. However, this is an exception rather than the norm, and the general reality shows there is a chronic lack of training in the field. This is a real obstacle for the professionals that are on the ground, firstly to have the right skills and then to have adequate and clear guidelines and processes in place to make sure they can perfume their jobs properly.

Usually the quality indicator of Palliative Care treatment, to use as a comparison basis, is the number of patients that do chemotherapy in the last 30 days of life. Nevertheless, there is also an equally important indicator which is the number of patients that die at home, naturally under controlled supervision. But it's still a highly controversial practice in Portugal, considering the social and economic situation and even in the rest of the world. To put this in practice the patient needs a lot of attention and assistance, due to his or her terminal condition.

To this end what is crucial is that the patients have the conditions to die with the best possible support that may be available, wherever the place. Unfortunately, because Portugal is so much lagging behind in the process, this means dying at often the less "human" and comfortable place: the hospital.

- Exploratory meeting highlights with Mr. Pedro Soares a nurse that works in IPO (Oncology Portuguese Institute) Lisboa

Pedro Soares is a professional in the health treatment for 15 years. He had several nursing international experiences including Timor-Leste with the Red Cross and in Catalonia when he was taking a post graduation in Palliative Care. Afterwards he also had five months experience in a Palliative Care Team.

Palliative Care is a group model, interaction with other health professionals is very important as well as the family support. This is against the biomedical model where the basis of the treatment is the diagnosis and the technical ideas. Palliative Care has the patient well being as the first main objective to support the plan of action.

In IPO there are about 70% of aged population having Palliative Care. This happens when the patient doesn't go for chemotherapy anymore and this measure is to control the symptoms and help psychologically, emotionally and existentially.

Palliative Care in Pedro's on the field experience has 4 main pillars:

- Control symptomatic (to the physiological level)
- Communication ability
- Team work
- Team involvement

These foundations are the principle to involve professionals and families in a common purpose to a permanent care and articulated effort around the patient.

Nationally speaking there is a platform where the patients have a screening about their condition so they can be allocated to a place where his/her well-being is optimized.

With these two authoritative overviews about the topic, it became clear that the Palliative Care is in its infancy in Portugal. Our study will try get more insights and dive deeper into the matter with a view of better understanding the Palliative Care standard practice in the operational field. With that in mind, we designed and survey questionnaire targeting all types of professionals involved in the field.

6.3 Quantitative analysis

The population of this questionnaire was composed by a total of 38 health institutions related with Palliative Care and with 13 associations of support in the fight against cancer (Annex 6).

An online questionnaire was carried out via Google questionnaire in order to get the maximum answers in a shortest possible period of time, while maximizing the geographical distribution of the sampled population, which covered entirely Portugal.

The inquired sample is characterized by 61.9% women and 38.1% men. Their working location was mainly Lisboa and Porto with 62.5% of cumulative percent from the total sample (Table 1).

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Lisboa	12	28,6	37,5	37,5
	Porto	8	19,0	25,0	62,5
	Açores	1	2,4	3,1	65,6
	Beja	3	7,1	9,4	75,0
	Braga	1	2,4	3,1	78,1
	Évora	2	4,8	6,3	84,4
	Viana do Castelo	2	4,8	6,3	90,6
	Madeira	1	2,4	3,1	93,8
	Castelo Branco	2	4,8	6,3	100,0
	Total	32	76,2	100,0	
Missing	System	10	23,8		
Total		42	100,0		

Table 2 - Working Region from the respondents

About function in Palliative Care 50% were nurses with 31% doctors, other answers had a contribution of psychologists social supporters, physiotherapists, nutritionist, priest and a volunteer. The age average is 38.6 years with a standard deviation of 12.2 years, which means a big diversity in this sample in terms of age (Table 2).

Statistics

Age

N	Valid	42
	Missing	0
Mean		38.60
Std. Deviation		12.210

Table 3 - Age of the respondents

Considering the years of experience the average was 5.19 with a standard deviation of 5.9 years. There are two outliers with much more experience than the average of the sample which it will be taken in consideration for the open questions analysis. (Annex 7)

Unfortunately no one from the sampled population with management functions opted to answer the questionnaire, which features specific questions on the validated challenges of the current state of affairs of Palliative Care administered in Portugal. In itself is a sign, again, of the newness of the matter and lack of empirical and systematic data existing for that purpose.

The first question was about the effort of the agents in healthcare about the development of a Network in Palliative Care. The average response was negative, under 3 in a scale from 1 – Very Bad to 5 – Very good. The government support had an average answer of 2.14, the hospital centres 2.50, the patients associations 2.52, the health professionals associations with 2.40 and other people involved in Palliative Care treatment had an average of 2.57 (Annex 8).

These results can be a little misleading because although the government support had the lowest average result it also had the lowest Std. Deviation figure with 0.89 and the hospital centres had the highest with 1.088 or even the other people involved had a Std. Deviation of 1.085 what means that even this had not so bad results the general opinion is not so certain about the final result.

To understand which was the training of our sample it was asked which type of formation they had and in general terms the answer was positive with the mainly respondents affirmed that attend workshops (25), basic training (24) and conferences (23) other important education was Master degree (22) and also post-graduations (18) although only one person had a PhD what demonstrates a lack of specialized schooling in this field (Annex 9).

The average training hours is 365 considering the 34 valid answers obtained in this question, where the minimum was 2 hours and the maximum 2,000. There is a big dispersion of the quantity of training obtained but is clear that this sample has clearly few hours of training (Annex 10).

About the reimbursement from the employer only 23.8% of the sample had that support, mainly there had to be personal interest and motivation to get new qualifications in Palliative Care. Still the respondents feel that the training that they had changed their professional behaviour with an average of response of 4.37 in a scale from 1 – Low to 5 – Significant.

In a question about the legal aspects, 93% of the respondent's state that they had knowledge about the changes in the Portuguese legislation about the Palliative Care Network (Annex 11).

People consider that the application of Palliative Care techniques can lead to significant cost reduction with 4.26 average responses, (in a scale from 1 – Low to 5 – Significant) that this type of techniques are also valued by the patient with 4.62 average answer, with the same scale, and even can bring economic and social benefits to the patients and society in general with 4.93 average answer, but still again the answer was negative when the question was if Portugal would reach the 30% hospital assistance and 70% extra hospital assistance with a average of 2.79 (Table 3).

		Significant savings	Valuable for the patients family	Social and Economical benefits	Conditions to have the WHO standards
N	Valid	42	42	42	42
	Missing	0	0	0	0
Mean		4.26	4.62	4.93	2.79
Std. Error of Mean		.149	.096	.053	.185
Median		5.00	5.00	5.00	3.00
Std. Deviation		.964	.623	.342	1.200

Table 4 - Several specific believes of the respondents about the Portuguese Palliative Care status

When questioned about the influence of the network of Palliative Care on the perception of the Portuguese society in some pointed out aspects of the daily palliative treatment (Table 4):

- (23A1) Patient, patient family and health professional conflicts had 4.00 average
- (23A2) Lack of Communication had 4.17 average
- (23A3) Barriers to Palliative Care had 4.02 average
- (23A4) Care fragmentation had 3.88 average
- (23A5) Social denial of death had 4.10 average
- (23A6) Feeling of medical failure had 3.69 average
- (23A7) Inadequate training on end of life had 4.10 average
- (23A8) Inertia by technological imperatives had 3.62 average

		23A1	23A2	23A3	23A4	23A5	23A6	23A7	23A8
N	Valid	42	42	42	42	42	42	42	42
	Missing	0	0	0	0	0	0	0	0
Mean		4.00	4.17	4.02	3.88	4.10	3.69	4.10	3.62
Std. Error of Mean		.145	.132	.143	.153	.155	.172	.166	.152
Median		4.00	4.00	4.00	4.00	4.00	4.00	4.00	4.00
Std. Deviation		.937	.853	.924	.993	1.008	1.115	1.078	.987

Table 5 - Predicted influence of the Network in Portuguese society

Therefore is possible to understand that the ability of the health professionals and the new technological advances are not going to be influenced as much as the communication on this subject as well as the social denial of death and the training on the end of life.

Other important aspects obtained through the questionnaire are that:

- 92.9% believe that Palliative Care Treatment should be considered in a earlier stage for the patient well being,
- 75% believe that the investment paradigm is going to change accordingly with the actual needs,
- But about 57.1% does not believe that there will be an increase access to long term beds with the new legislation, against 42.9% that consider that it will.

6.3.1 Questionnaire conclusions

Considering both the hypothesis advanced by our study, we draw the following conclusions:

1. With regards to hypothesis 1[4] it was not possible to achieve any answer on management standards of Palliative Care in Portugal, which can indicate lack of interest in this kind of preliminary studies or even a lack of confidence on the part of key stakeholders in answering it, who may lack detailed, backed-up data as supporting evidence.

It's known that the Portuguese metrics in the area are far from the optimal results and therefore it was extremely important to get some feedback on this.

2. About the hypothesis 2[5] it's not possible to extract a direct cause-consequence effect but it was proven to exist an enormously will to improve. Considering that the most of respondents agree on the benefits of this kind of treatment (with more than 4.5 average in the benefits of Palliative Care) there is still a long way to make since the general opinion is that all the system is not making a sufficient effort (with an average response of 2.5 on the effort of the all stakeholders involved in Palliative Care).

It's also important to know that most of the respondents had awareness of the change in the law and they are quite positive about possible changes in the future regarding the needs of Palliative Care treatment in Portugal.

7. Conclusions

7.1 Main Results

The life expectancy is growing due to health and technological advances, in Portugal this growth corresponds to 16 more years of increasing life expectancy over the past 50 years. Recently Portugal had to call upon a bail out to the IMF in order to assure its responsibilities, this means a starting point several reforms in order to contain the public debt.

Portugal public debt in a long term will be influenced by two main aspects accordingly with the fact of the growth of life expectancy:

[4] The current resources in Portuguese NHS being deviated to palliative and continuous care are insufficient, and a preference in patient treatment is directed to pharmaceuticals

[5] The actual Portuguese human resources in health care are not ready to fully implement the Palliative Care Network and accomplish the goals of the directives set by: "Plano Nacional de Saúde 2011-2016".

- Temporal and populational growth of elderly pensioners,
- And growth of the expenditure in public health care system.

Portugal had a great increase on health costs in the past 40 years and now that is imperative to cut government budgets is also important to know new ways of cost reductions that necessarily don't mean to reduce expenditure by itself.

According with OECD data there was a growth of 78% in the total Portuguese health expenditure, in terms of % of GDP Portugal has overcome the OECD average with a gap of 1% to 2% what can represent around US$2.000 million.

Long term planning is a good way to protect the present and with all the reforms and intervention currently happening in Portugal through IMF counseling. The Health Care system is one of the most relevant topics considering that one of the principal objectives of the Portuguese State is provide Health Care conditions to all the Portuguese population in order to provide social justice.

Palliative Care treatment is recent in Portugal but there are already studies that prove its cost reduction efficiency that can go up to 60%, therefore it would be important to understand what effect there is in Portugal of this possible decrease in expenditure.

WHO studies project that in 2050 around 20% of the population will be with 60 years or over. It's also project that between 2000 and 2030 there will be an increase of over 45% in cancer occurrence. These two realities will increase significantly the burden of health treatments, nevertheless WHO states that health care system must be sustainable therefore finding the best practices and putting them in a good development pace is a must.

The public health expense in Portugal represents around 80% of the total health cost in the country, one of the major contributors for the health expense are the costs with medicines that are also higher than the OECD average. These costs have grown about 99% in the past 30 years.

According with OECD statistics Portugal is the country with more weight in Outpatient cost when compared with the EU countries, these means a considerable double burden for tax payers. Other important fact is the no record of Long Term care beds in Portugal, this will affect people that have other health needs.

In USA there are studies that prove savings in Palliative Care of €1,155 per admission in live discharges and almost €3,400 per admission for patients who died. Other important discovers was that an increase of 20 ICU beds generated a US$175,000 profit a month, thus is important to expend in beds for Palliative Care.

In Europe, in Catalonia it was possible to perceive a cost reduction of 71% with home Palliative Care treatment. For this analysis there were several teams on the group giving support to patients in a terminal stage. However training and investigation is still the priority to start the investment in PCU beds since there are more cultural contrasts in Europe. The UK are in the lead of the state of art of Palliative Care in Europe but only 15 out of 26 countries had more than 50% in the EAPC Development Index of Palliative Care in Europe, an index that tried to measure the quality of this treatment in Europe.

In Portugal there is an underinvestment in Long Term care, though the Palliative Care network is recent but has shown a slow implementation pace considering the objectives initial settled. In 2009 more than 50% of the population didn't know what Palliative Care was, what translates into a lack of awareness in the Portuguese society about this subject.

With an exploratory questionnaire it was possible to confirm some assumptions about the level of qualifications, although there are in fact very qualified persons but in our sample the average was not very high. No one with management influence answered so in this way the conclusions about this can be lack of confidence in answering or even lack of control information that would be very useful to analyze. The respondents admit that at the present the effort on this type of treatment is still far from the maximum potentiality but there is a generalised will to change the current paradigm and also believe in an improvement of the network considering the actual needs of the country.

7.2 Methodology limitations

These was an exploratory study that had the purpose of analyze the insight of the actual Palliative Care treatment in Portugal specially to understand how the best in class practices were being followed, as there was very scarce empirical data of results in practice.

The response rate from managers or someone that has management responsibility in Palliative Care felt very much short of our expectations. Further research should focus on the specific reasons for such a nil response rate, and perhaps recommend change on actionable procedures in order to achieve the goals of minimum standards set by WHO.

8. Recommendations for future proceedings

Future work on this topic should focus on reducing expenditure on oncological and other prophylactic treatments based on expensive and innovative drugs, which do not translate clearly on life improvement condition of the patient, but do have a considerable impact on the burden to the NHS.

In fact there was already a study about the impact of changing the way drugs are distributed by hospitals and health care units in general, stating what should be a rationalization of the medicines and recommendations to choose the "cheapest of the best medicines" instead of the "best of the cheapest drugs" (Conselho Nacional de Ética para as Ciências da Vida, 2012). This motivated a strong opposition from doctors and pharmaceuticals that criticized the fact of the "rationalization of human life". (Rádio Televisão Portuguesa, 2012)

Accordingly with data from the Portuguese National Statistical Institute it's possible to know that in the last five years there were around 105,000 deaths and the National Program of Palliative Care estimates that from that value 60% are related to chronic diseases. If we multiply that value with the €3,000 cost reduction estimation, by the several international studies made in the field and even one in Portugal, the total value saved will be around €200M.

From gross approximations, if we were to save €200M€ on pharmaceuticals, and invest €100M on Palliative Care network, then quality of the patient would be very much increase, while the overall budget reduced.

This can be a starting point for further investigations in the Palliative Care field in Portugal that, from what it was possible to analyse, deserves more attention and action from all the stakeholders that can be direct and indirectly involved in its development.

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10. Annexes

Annex 1 - Public expenditure on health, /capita, US$ purchasing power parity

Source: OECD, 2010

Country /Year	1960	1961	1962	1963	1964	1965	1966	1967	1968	1969	1970	1971	1972	1973	1974	1975	1976	1977	1978	1979	1980
Australia	45			54			66			100		145	153	169	212	316	308	307	335	354	396
Austria	53	57	60	65	69	75	82	93	98	116	124	137	149	170	202	304	345	382	430	478	540
Canada	53					92					205	242	261	276	307	365	405	436	477	519	588
Denmark												301	329	348	415	462	520	546	606	696	783
Estonia																					
Finland	34	37	43	47	55	70	80	96	107	126	134	146	163	185	208	266	293	324	348	391	447
France	43					83					146					289					534
Germany											196	234	269	317	380	454	506	549	614	676	769
Greece											68										272
Hungary																					
Iceland	38	38	42	47	56	59	70	78	110	92	116	150	196	201	278	325	338	385	479	609	664
Ireland	33	34	36	40	45	47	53	63	66	77	95	107	123	144	176	216	224	245	292	346	418
Israel																					
Italy																					
Japan	18	23	27	32	38	45	51	59	69	80	98	103	120	134	168	200	227	248	299	339	386
Korea																					19
Luxembourg																					
Netherlands [1]													190	214	254	299	325	358	399	446	508
New Zealand											169	167	187	208	263	301	299	326	373	412	431
Norway	38	43	48	54	59	63	75	84	93	109	131	150	191	215	245	310	359	413	470	497	567
Poland																					
Portugal											28	33	47	60	72	93	111	118	128	146	178
Slovak Republic																					
Slovenia																					
Spain	9	10	13	14	17	22	26	35	40	51	62	75	93	114	134	164	185	215	238	255	290
Sweden											268	299	317	339	408	478	529	618	678	750	873
Turkey																0		0	0	14	21
United Kingdom	72	75	77	81	86	94	103	113	123	128	138	150	166	186	231	266	288	303	334	366	417
United States	34	36	38	41	43	46	63	88	101	114	128	145	160	180	211	245	275	306	345	390	452
OECD AVERAGE	39	39	43	48	52	63	67	79	90	99	132	161	183	203	245	282	326	338	380	427	455

Country /Year	1981	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000
Australia	432	435	494	592	643	681	706	725	756	791	838	890	933	989	1.057	1.116	1.213	1.295	1.434	1.515
Austria	573	605	636	663	714	778	821	872	936	1.195	1.270	1.365	1.494	1.621	1.659	1.702	1.847	1.969	2.091	2.192
Belgium															1.315	1.413	1.398	1.439	1.527	1.675
Canada	679	771	837	893	951	1.009	1.057	1.124	1.204	1.294	1.397	1.457	1.460	1.476	1.463	1.455	1.508	1.629	1.690	1.772
Chile															192	221	241	273	290	321
Czech Republic										546	522	542	727	766	816	831	832	837	849	887
Denmark	869	955	978	999	1.070	1.090	1.163	1.227	1.248	1.275	1.327	1.386	1.463	1.524	1.542	1.629	1.695	1.750	2.024	2.103
Estonia																			398	403
Finland	510	568	609	646	722	770	837	882	971	1.103	1.220	1.199	1.059	1.032	1.059	1.109	1.166	1.203	1.244	1.321
France					810					1.106	1.180	1.261	1.334	1.373	1.673	1.718	1.773	1.836	1.904	2.020
Germany	871	903	942	1.020	1.096	1.135	1.195	1.296	1.267	1.370		1.617	1.611	1.719	1.853	1.970	1.951	1.989	2.067	2.130
Greece							427	372	452	454	466	531	591	615	657	688	716	720	784	871
Hungary											514	541	549	618	553	537	552	571	586	603
Iceland	781	873	956	926	1.026	1.175	1.340	1.454	1.453	1.441	1.515	1.472	1.500	1.541	1.601	1.644	1.735	1.993	2.264	2.221
Ireland	448	461	466	475	497	494	495	499	524	565	644	713	755	799	863	909	1.029	1.103	1.184	1.323
Israel															968	1.051	1.093	1.042	1.032	1.105
Italy								889	941	1.079	1.166	1.175	1.149	1.126	1.085	1.137	1.226	1.290	1.333	1.497
Japan	439	490	543	568	606	645	700	754	803	866	938	1.006	1.088	1.157	1.279	1.365	1.377	1.403	1.478	1.595
Korea	23	29	37	44	50	52	59	75	97	125	126	141	150	160	185	227	257	278	334	375
Luxembourg															1.764	1.845	1.825	1.925	2.140	2.781
Mexico										120	148	163	173	189	162	153	182	200	225	237
Netherlands [1]	559	608	637	652	681	696	742	774	871	948	1.046	1.167	1.230	1.251	1.276	1.231	1.300	1.318	1.366	1.476
New Zealand	518	541	560	563	534	563	648	729	778	812	859	866	854	924	963	975	1.047	1.117	1.180	1.254
Norway	623	669	732	762	806	930	1.030	1.070	1.079	1.132	1.285	1.375	1.406	1.483	1.567	1.717	1.911	2.086	2.295	2.510
Poland										264	261	278	272	271	297	348	355	362	404	407
Portugal	209	196	178	179	216	245	254	306	309	412	468	473	523	543	636	714	763	812	898	1.102
Slovak Republic																	517	535	537	541
Slovenia															755	805	865	926	986	1.074
Spain	318	351	403	394	401	412	452	541	598	686	737	796	830	840	860	903	941	999	1.045	1.101
Sweden	960	1.040	1.086	1.148	1.146	1.163	1.233	1.282	1.365	1.432	1.393	1.413	1.449	1.449	1.510	1.616	1.619	1.701	1.826	1.941
Switzerland					739	781	832	897	998	1.063	1.174	1.268	1.306	1.348	1.374	1.489	1.564	1.630	1.695	1.786
Turkey				36	35	38	41	59	75	95	106	118	124	119	122	149	179	212	227	272
United Kingdom	471	490	547	571	591	624	673	716	757	802	874	975	1.027	1.086	1.131	1.190	1.195	1.251	1.352	1.446
United States	519	571	623	673	726	787	854	916	1.012	1.124	1.259	1.385	1.505	1.619	1.708	1.779	1.844	1.872	1.946	2.060
OECD AVERAGE	544	586	626	621	669	703	741	794	841	850	874	947	984	1.024	1.061	1.114	1.143	1.199	1.254	1.350

Country /Year	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Australia	1.583	1.712	1.767	1.919	1.993	2.107	2.262	2.342	2.515		
Austria	2.199	2.306	2.403	2.558	2.639	2.828	2.962	3.185	3.320	3.349	
Belgium	1.783	1.876	2.255	2.391	2.463	2.413	2.506	2.763	2.976	3.000	
Canada	1.912	1.996	2.146	2.254	2.421	2.563	2.704	2.823	3.062	3.158	3.245
Chile	351	366	303	318	337	364	414	482	577	579	
Czech Republic	969	1.081	1.201	1.235	1.287	1.351	1.413	1.457	1.720	1.578	
Denmark	2.254	2.425	2.446	2.632	2.740	3.028	3.179	3.434	3.729	3.800	
Estonia	409	448	515	573	638	704	842	1.040	1.043	1.020	
Finland	1.418	1.558	1.678	1.838	1.951	2.070	2.164	2.355	2.459	2.422	2.472
France	2.156	2.327	2.353	2.450	2.597	2.743	2.873	2.877	3.024	3.061	
Germany	2.225	2.327	2.429	2.431	2.577	2.727	2.845	3.037	3.250	3.331	
Greece	1.066	1.140	1.212	1.236	1.414	1.619	1.643	1.797	1.915	1.731	
Hungary	669	782	935	926	1.004	1.054	977	1.022	1.024	1.037	
Iceland	2.302	2.584	2.609	2.707	2.688	2.681	2.788	2.978	2.901	2.662	2.725
Ireland	1.560	1.782	1.944	2.136	2.244	2.415	2.666	2.858	2.841	2.585	
Israel	1.167	1.183	1.080	1.117	1.085	1.121	1.176	1.251	1.254		
Italy	1.663	1.665	1.687	1.802	1.917	2.088	2.120	2.342	2.392	2.359	
Japan	1.689	1.740	1.797	1.895	2.032	2.071	2.207	2.325	2.443		
Korea	504	519	548	597	683	811	918	964	1.084	1.185	1.248
Luxembourg	2.680	3.204	3.060	3.491	3.526	3.921	3.779	3.736	4.021		
Mexico	247	256	278	311	329	353	380	418	445	433	
Netherlands [1]	1.604	1.770	1.895	1.979	2.087	2.800	3.436	3.724	3.907	4.050	4.175
New Zealand	1.306	1.434	1.449	1.572	1.693	1.912	2.016	2.235	2.427	2.515	
Norway	2.727	3.029	3.210	3.406	3.593	3.864	4.107	4.427	4.523	4.607	4.484
Poland	461	521	523	554	594	653	747	891	977	995	
Portugal	1.148	1.220	1.301	1.358	1.504	1.544	1.613	1.664	1.794	1.795	
Slovak Republic	593	650	699	780	848	923	1.082	1.262	1.357	1.351	
Slovenia	1.158	1.250	1.270	1.358	1.424	1.522	1.538	1.785	1.847	1.768	
Spain	1.164	1.244	1.421	1.500	1.601	1.808	1.954	2.157	2.265		
Sweden	2.029	2.200	2.323	2.403	2.405	2.592	2.792	2.980	3.025	3.046	
Switzerland	1.951	2.121	2.204	2.298	2.388	2.514	2.700	3.214	3.366	3.437	
Turkey	288	313	321	370	401	500	570	667			
United Kingdom	1.592	1.741	1.852	2.062	2.206	2.407	2.460	2.593	2.819	2.857	
United States	2.263	2.448	2.623	2.801	2.975	3.200	3.381	3.568	3.780	3.967	
OECD AVERAGE	1.444	1.565	1.639	1.743	1.832	1.978	2.095	2.254	2.427	2.417	3.058

Annex 2 - Public expenditure on health, % total expenditure on health, THE

Source: OECD, 2010

Country /Year	1960	1961	1962	1963	1964	1965	1966	1967	1968	1969	1970	1971	1972	1973	1974	1975	1976	1977	1978	1979	1980
Australia	50,3			50,4			51,1			57,0		62,1	61,4	61,8	62,9	73,6	67,2	61,7	62,5	61,6	62,6
Austria	69,4	66,7	66,9	67,0	66,7	70,3	66,7	67,3	64,1	67,8	63,0	63,8	63,3	63,8	65,2	69,6	69,6	69,8	69,8	68,3	68,8
Belgium																					
Canada	42,6					51,9					69,9	73,0	74,0	73,7	74,6	76,2	77,0	76,7	76,3	75,9	75,6
Chile																					
Czech Republic											96,6					96,9					96,8
Denmark												83,7	84,0	83,8	85,0	85,4	87,0	86,5	86,9	87,8	87,8
Estonia																					
Finland	54,1	54,7	57,0	58,7	60,6	66,0	67,4	71,8	71,7	73,7	73,8	72,7	71,6	73,7	74,7	78,6	78,3	78,8	77,9	78,3	79,0
France	62,4					71,2					75,5					78,0					80,1
Germany											72,8	74,6	75,6	77,0	78,2	79,0	78,9	78,7	78,7	78,5	78,7
Greece											42,6										55,6
Hungary																					
Iceland	66,7	65,4	62,0	62,4	63,6	63,1	65,2	65,9	69,2	64,5	66,2	66,6	81,6	82,1	87,5	87,1	87,0	87,2	89,6	89,5	88,2
Ireland	76,0	76,9	73,3	75,8	81,1	76,2	75,5	75,9	74,2	74,7	81,7	72,5	75,5	79,2	80,0	79,0	78,7	79,5	78,7	82,9	82,0
Japan	60,4	60,2	60,2	60,2	69,8	61,4	60,1	60,4	60,2	59,6	69,8	65,7	67,7	68,8	74,1	72,0	75,1	72,8	76,0	74,3	71,3
Korea																					21,6
Luxembourg											88,9					91,8	91,8	91,4	92,2	92,7	92,8
Mexico																					
Netherlands [1]													68,6	69,2	70,3	71,9	72,0	72,5	72,8	72,4	73,2
New Zealand											80,3	74,9	77,3	74,0	74,0	73,7	74,8	76,3	76,9	84,4	88,0
Norway	77,8	78,1	78,2	79,4	80,3	80,9	85,7	87,3	86,9	88,5	91,6	89,8	95,3	94,5	94,8	96,2	97,4	98,3	92,7	95,3	85,1
Poland																					
Portugal											59,0	59,7	60,0	60,6	62,8	58,9	66,0	70,0	67,1	69,3	64,3
Slovak Republic																					
Slovenia																					
Spain	58,7	53,7	54,0	50,0	48,9	50,8	52,6	61,4	62,0	63,3	65,4	64,6	67,8	76,2	72,5	77,4	73,7	75,6	78,5	79,2	79,9
Sweden											86,0	86,8	86,6	86,1	89,9	90,2	90,2	91,3	91,5	91,7	92,5
Turkey																0,0		0,0	0,0	22,2	29,4
United Kingdom	85,2	85,1	84,6	82,8	82,6	85,8	86,6	87,2	87,0	86,3	87,0	87,0	87,8	87,6	89,7	91,1	91,0	90,0	90,0	89,6	89,4
United States	22,9	23,3	23,0	23,2	22,2	22,1	27,6	35,1	35,8	35,9	36,1	37,0	37,0	37,8	39,4	40,6	40,2	39,7	40,2	40,4	41,0
OECD AVERAGE	**60,5**	**62,7**	**62,1**	**61,0**	**64,0**	**63,6**	**63,9**	**68,0**	**67,9**	**67,1**	**72,6**	**70,9**	**72,7**	**73,5**	**75,0**	**74,6**	**77,6**	**73,5**	**73,6**	**75,5**	**73,2**

Country /Year	1981	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000
Australia	61,2	58,9	62,9	70,7	70,6	69,4	68,9	67,2	66,8	66,2	65,9	65,4	65,0	65,0	65,8	65,2	66,9	66,4	68,4	66,8
Austria	76,0	75,4	76,0	75,6	76,1	76,5	75,9	75,6	73,7	72,9	72,8	73,5	73,8	74,3	73,5	73,2	75,2	75,3	75,7	75,6
Belgium															76,8	78,2	75,4	74,8	74,6	74,6
Canada	75,9	76,3	76,6	76,1	75,5	75,1	75,0	74,9	74,8	74,5	74,6	74,1	72,7	71,9	71,2	70,8	70,1	70,6	70,0	70,4
Chile															48,2	47,2	47,1	48,1	49,9	52,1
Czech Republic					92,2				96,4	97,4	96,8	95,5	94,8	93,9	90,9	90,7	90,3	90,4	90,5	90,3
Denmark	87,7	87,5	86,6	85,9	85,6	84,6	84,4	84,7	84,2	82,7	83,5	83,2	82,7	82,2	82,5	82,4	82,3	82,1	84,0	83,9
Estonia																			77,5	77,2
Finland	79,7	80,0	79,1	78,5	78,6	79,3	79,6	79,4	80,0	80,9	81,1	79,6	76,1	75,5	71,7	71,6	72,1	72,5	71,5	71,3
France					78,5					76,6	76,3	76,6	76,5	76,0	79,7	79,6	79,6	79,5	79,4	79,4
Germany	78,7	78,2	77,3	77,4	77,4	77,6	77,5	77,2	76,0	76,2		80,9	80,3	80,5	81,4	82,0	80,6	79,9	79,8	79,5
Greece							59,9	54,1	55,9	53,7	53,4	54,6	54,5	50,2	52,0	53,0	52,8	52,1	53,4	60,0
Hungary											89,1	88,0	87,4	87,3	84,0	81,6	81,3	74,8	72,4	70,7
Iceland	88,9	89,1	89,5	86,8	87,0	86,5	87,3	87,1	86,5	86,6	86,7	84,8	83,3	83,6	83,9	83,3	82,1	80,4	82,2	81,1
Ireland	82,4	81,8	79,5	77,8	75,8	75,5	72,9	71,1	72,2	71,7	72,9	70,9	73,0	71,7	72,5	71,5	74,9	74,7	75,3	75,1
Israel															67,4	69,0	68,0	64,2	64,3	62,6
Italy								78,5	77,6	79,5	79,3	77,1	75,5	73,5	70,8	70,6	70,8	70,4	70,7	72,5
Japan	71,0	71,0	72,8	72,9	70,7	72,4	73,7	75,2	76,6	77,6	78,3	78,1	79,2	78,6	82,3	82,3	81,2	80,4	80,7	80,8
Korea	21,4	24,1	27,3	30,4	31,5	30,2	30,6	32,8	33,6	38,4	35,7	34,8	35,7	35,0	38,5	41,7	44,4	49,0	50,2	48,6
Luxembourg	92,9	93,0	89,2	89,1	89,2	89,4	93,0	92,9	92,9	93,1	93,0	92,8	92,9	91,7	92,4	92,8	92,5	92,4	89,8	85,1
Mexico										40,4	43,9	43,1	43,2	45,0	42,1	41,4	44,7	46,0	47,8	46,6
Netherlands [1]	73,6	74,3	73,6	73,7	73,3	70,7	71,2	70,6	72,0	71,2	72,8	76,4	77,3	76,4	75,4	69,9	71,2	67,1	65,8	66,4
New Zealand	95,2	88,0	88,6	87,0	87,0	86,3	87,2	85,6	85,8	82,4	82,2	79,0	76,6	77,5	77,2	76,7	77,3	77,0	77,5	78,0
Norway	87,9	87,6	86,6	86,4	85,8	87,0	86,5	85,3	84,2	82,8	84,5	84,8	84,6	84,6	84,2	84,2	81,3	82,2	82,6	82,5
Poland										91,7	75,6	76,4	73,8	72,8	72,9	73,4	72,0	65,4	71,1	70,0
Portugal	64,3	56,2	52,4	51,2	54,6	52,6	51,5	53,7	53,1	65,5	62,8	59,6	63,0	63,4	62,6	65,3	65,7	67,1	67,6	66,6
Slovak Republic																	91,7	91,6	89,6	89,4
Slovenia															77,7	76,2	75,0	75,5	75,7	74,0
Spain	78,7	79,4	84,9	81,9	81,1	79,9	79,7	79,2	78,2	78,7	77,5	77,4	76,6	75,5	72,2	72,4	72,5	72,2	72,0	71,6
Sweden	91,9	91,6	91,5	91,6	90,4	90,2	89,9	89,4	89,6	89,9	88,2	87,2	87,4	87,1	86,6	86,9	85,8	85,8	85,7	84,9
Switzerland					50,3	50,0	49,9	50,4	52,0	52,4	52,8	53,8	54,3	54,2	53,6	54,5	55,0	54,7	55,1	55,4
Turkey				42,2	50,6	42,0	39,5	51,1	58,1	61,0	62,9	67,0	66,4	68,9	70,3	69,2	71,6	71,9	61,1	62,9
United Kingdom	88,9	87,6	87,4	86,9	85,8	85,3	84,3	83,8	83,2	83,6	83,3	84,6	85,1	83,9	83,9	82,9	80,4	80,4	80,6	78,8
United States	40,9	40,2	40,2	39,8	39,6	40,4	40,6	39,2	39,3	39,4	40,9	42,2	43,2	44,6	45,1	45,0	44,8	43,5	43,0	43,0
OECD AVERAGE	**75,6**	**74,7**	**74,8**	**73,1**	**73,4**	**71,5**	**70,9**	**71,3**	**72,6**	**72,9**	**72,8**	**72,9**	**72,7**	**72,3**	**71,5**	**71,4**	**72,0**	**71,5**	**71,6**	**71,4**

Country /Year	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Australia	66,3	66,9	66,1	66,7	66,9	66,6	67,5	67,9	68,5		
Austria	75,1	74,8	74,5	74,7	75,3	75,7	75,8	76,3	76,4	76,2	
Belgium	75,4	73,8	74,5	75,8	75,8	73,6	73,2	74,7	76,1	75,6	
Canada	70,0	69,5	70,2	70,2	70,2	69,8	70,2	70,5	70,9	71,1	70,4
Chile	53,5	54,5	38,8	39,9	40,0	42,1	43,2	44,1	47,7	48,2	
Czech Republic	89,8	90,5	89,8	89,2	87,3	86,7	85,2	82,5	84,0	83,8	
Denmark	84,2	84,5	84,5	84,3	84,5	84,6	84,4	84,7	85,0	85,1	
Estonia	78,6	77,1	77,0	75,5	76,7	73,3	75,6	77,8	75,3	78,9	
Finland	72,0	72,5	74,6	75,0	75,4	74,8	74,4	74,5	75,2	74,5	74,8
France	79,4	79,7	78,9	78,8	78,8	78,7	78,3	76,7	76,9	77,0	
Germany	79,3	79,0	78,5	76,8	76,6	76,5	76,4	76,6	76,9	76,8	
Greece	60,8	58,0	59,8	59,1	60,1	62,0	60,3	59,9	61,7	59,4	
Hungary	69,0	70,2	71,1	69,6	70,0	69,8	67,3	67,1	65,7	64,8	
Iceland	81,0	81,9	81,7	81,2	81,4	82,0	82,5	82,6	82,0	80,4	80,0
Ireland	75,7	76,3	76,7	77,0	75,9	75,1	75,5	75,1	72,0	69,5	
Israel	62,0	63,2	61,7	60,9	59,3	59,8	59,0	59,5	60,5		
Italy	74,6	74,5	74,5	76,0	76,2	76,6	76,6	78,9	79,6	79,6	79,0
Japan	81,4	81,3	80,4	80,8	81,6	79,4	80,4	80,8	80,5		
Korea	54,9	53,7	52,4	52,6	52,9	55,3	55,8	55,9	58,2	58,2	57,3
Luxembourg	84,3	85,5	84,2	84,8	84,9	85,1	84,1	84,1	84,0		
Mexico	44,8	43,9	44,2	45,2	45,0	45,2	45,4	46,9	48,3	47,3	
Netherlands [1]	65,8	65,5	66,5	65,6	65,8	82,4	84,1	84,8	85,4	85,7	85,7
New Zealand	76,4	77,9	78,3	79,6	79,7	80,1	82,4	82,8	83,0	83,2	
Norway	83,6	83,5	83,7	83,6	83,5	83,8	84,1	84,4	84,6	85,5	85,6
Poland	71,9	71,2	69,9	68,6	69,3	69,9	70,4	71,8	71,6	71,7	
Portugal	67,0	68,6	68,7	68,1	68,0	67,0	66,7	65,3	66,5	65,8	
Slovak Republic	89,3	89,1	88,3	73,8	74,4	68,3	66,8	67,8	65,7	64,5	
Slovenia	73,3	73,4	71,6	73,1	72,7	72,3	71,8	73,9	73,2	72,8	
Spain	71,2	71,3	70,3	70,4	70,6	71,3	71,5	72,6	73,6		
Sweden	81,1	81,4	82,0	81,4	81,2	81,1	81,4	81,5	81,5	81,0	
Switzerland	56,9	57,7	58,3	58,4	59,5	59,1	59,1	65,2	65,5	65,2	
Turkey	68,1	70,7	71,9	71,2	67,8	68,3	67,8	73,0			
United Kingdom	79,5	79,6	79,8	81,2	81,7	81,3	81,2	82,5	83,4	83,2	
United States	44,0	43,9	43,8	44,1	44,2	45,0	45,2	46,0	47,3	48,2	
OECD AVERAGE	**71,8**	**71,9**	**71,4**	**71,0**	**71,0**	**71,3**	**71,3**	**72,0**	**72,3**	**71,9**	**76,1**

Annex 3 – Outpatient medical market evolution

Source: Infarmed, 2012

	Mercado Total				Mercado Total de Genéricos						Mercado do Serviço Nacional de Saúde					
	Embalagens	Taxa de Crescimento	Valor a PVP	Taxa de Crescimento	Embalagens	Taxa de Crescimento	Quota de Mercado	Valor a PVP	Taxa de Crescimento	Quota de Mercado	Embalagens	Taxa de Crescimento	Encargos SNS	Taxa de Crescimento	Encargos Utentes	Taxa de Crescimento
2006	241.567.726	-	3.161.767.218	-	23.320.230	-	9,7%	479.098.553	-	15,2%	127.539.760	-	1.422.858.089	-	710.026.365	-
2007	252.699.564	4,6%	3.287.570.234	4,0%	29.501.605	26,5%	11,7%	586.702.495	22,5%	17,8%	129.136.866	1,3%	1.398.013.292	-1,7%	765.849.275	7,9%
2008	251.116.678	-0,6%	3.353.040.217	2,0%	34.231.048	16,0%	13,6%	622.334.310	6,1%	18,6%	131.715.939	2,0%	1.467.354.690	5,0%	767.451.762	0,2%
2009	254.508.442	1,4%	3.321.438.272	-0,9%	40.551.879	18,5%	15,9%	591.038.408	-5,0%	17,8%	137.471.454	4,4%	1.558.976.363	6,2%	723.501.840	-5,7%
2010	245.369.842	-3,6%	3.237.850.618	-2,5%	44.980.048	10,9%	18,3%	617.503.644	4,5%	19,1%	140.060.245	1,9%	1.640.678.917	5,2%	708.660.588	-2,1%
2011	236.951.748	-3,4%	2.942.598.470	-9,1%	51.294.411	14,0%	21,6%	535.142.262	-13,3%	18,2%	139.874.202	-0,1%	1.326.200.964	-19,2%	774.538.491	9,3%
jan-fev 2011	40.637.722	-	500.278.836	-	8.600.148	-	21,2%	99.188.531	-	19,8%	22.256.478	-	208.623.556	-	122.134.483	-
jan-fev 2012	41.726.222	2,7%	461.374.626	-7,8%	10.086.797	17,3%	24,2%	84.449.761	-14,9%	18,3%	23.392.839	5,1%	207.341.589	-0,6%	122.886.953	0,6%
jan-mar 2011	60.943.191	-	756.873.348	-	12.783.822	-	21,0%	146.182.837	-	19,3%	-	-	325.128.708	-	-	-
jan-mar 2012	62.440.719	2,5%	687.613.660	-9,2%	15.113.301	18,2%	24,2%	125.181.599	-14,4%	18,2%	-	-	319.158.418	-1,8%	-	-
	Unidade: Nº Embalagens		Unidade: EUR		Unidade: Nº Embalagens			Unidade: EUR			Unidade: Nº Embalagens		Unidade: EUR		Unidade: EUR	

Annex 4 – Questionnaire done to Health professionals

Instruções

Este questionário faz parte de um caso de estudo de um Mestrado em Gestão do ISCTE-IUL.

O tópico do estudo em questão é o estado atual dos cuidados paliativos em Portugal.

" Os cuidados paliativos são uma parte essencial do controlo do cancro e pode ser fornecido de uma forma relativamente simples e económica. Os cuidados paliativos melhoram a qualidade de vida dos pacientes e famílias que enfrentam uma doença terminal, através de alívio da dor e sintomático, apoio espiritual e psicossocial, de diagnóstico até ao fim da vida e perda." [6]

O inquérito procura esclarecer as oportunidades de melhoria dos cuidados paliativos em Portugal tendo por base o estado de arte Internacional.

O propósito deste questionário tem duas finalidades:

1) Aferir a atual prática de cuidados paliativos na sua instituição / local de trabalho,

2) Identificar oportunidades de melhoria

Por favor preencha o questionário de acordo com:

i. Por si, pela sua experiência e convicções

ii. Pela sua visão dos cuidados paliativos

O questionário inclui 26 questões. Sendo na sua maioria perguntas de resposta fechada.

O tempo resposta ao questionário situa-se nos 10 minutos.

Obrigado pela sua participação.

Artur Nunes

[6] WHO (World Health Organization/ Organização Mundial da Saúde)

1- Informação Pessoal[7]

Género:

Masculino / Feminino

Local de Trabalho:

_____

Qual das seguintes funções melhor descreve a sua ligação com os cuidados paliativos?

- Médico

- Enfermeiro

- Técnico auxiliar de saúde

- Familiar

- Psicólogo

-Assistente social

- Fisioterapeuta

- Outro: :_____

Idade:

_____

Anos de experiência:

_____

Na sua função profissional é responsável pela gestão orçamental em Saúde? *(Exemplo: Centros de Saúde, Hospitais, Departamento Oncológico, Centros de Cuidados Contínuados, entre outros…)

- Sim / - Não

PARTE I

Neste grupo de questões solicita-se que responda se tiver responsabilidade de gestão orçamental em saúde, caso contrário avance para a parte II.

1- Na sua unidade de saúde existe uma unidade de cuidados paliativos implementada?

- Sim / - Não

_____

[7] Esta informação será confidencial e apenas usada para tratamento estatístico

2- Se respondeu afirmativamente à primeira questão, há quanto tempo está em vigor? (Se respondeu negativamente passe para a pergunta 5, por favor)

- Há menos de um ano.

- Entre um a três anos.

- Entre três e cinco anos.

- Há mais de cinco anos.

3- Existem estudos internacionais, nomeadamente nos Estados Unidos da América, que demonstram que os cuidados paliativos podem diminuir até 70% do custo de cada paciente oncológico. Sabendo que em Portugal a integração dos cuidados paliativos ainda é recente, qual foi a redução possível no caso do local que trabalha/gere?

- Residual (até 5%)

- Interessante (entre 5 a 20%)

- Considerável (entre 20 a 40%)

- Outro, por favor especifique

4- Na sua opinião a implementação de cuidados paliativos em vigor na sua unidade de saúde pode ser melhorada?

-Sim / -Não.

5- Se respondeu negativamente à primeira questão, vê vantagens na implementação de cuidados paliativos na unidade que gere/ trabalha?

- Sim / - Não

6- Existem estudos que apontam uma poupança entre €2.000 a €4.000/doente oncológico/ano em condições ótimas no resultado de implementação de cuidados paliativos. Até que ponto lhe parece possível, no caso específico da sua unidade de saúde, atingir estes números? (Classifique de 1 – muito improvável a 5- bastante provável)

7- Qual das seguintes afirmações justifica melhor a sua atitude perante os cuidados paliativos tendo em conta a sua resposta anterior.

- Não, porque ainda não há condições para o fazer, em termos orçamentais e organizacionais.

- Não, porque não é possível devido a falta de qualificação dos recursos humanos existentes.

- Sim, no entanto é um processo que leva o seu tempo.

- Sim e estamos confiantes com os resultados.

- Nenhuma das anteriores.

8- De que modo poderá adotar uma atitude mais pró ativa relativamente aos cuidados paliativos? (Identifique o top 3 do que se aplica no seu caso)

- Mais meios financeiros

- Mais tempo

- Mais formação

- Mais recursos humanos

- Mais sensibilização

- Falta de integração entre serviços

- Facilidade em Prescrever

- Outros

9- Indique quais os fatores mais relevantes, na sua opinião, para um maior investimento na área de cuidados paliativos: (De nada relevante a Muito relevante)

1) Radiação

2)Enfermaria e despesas associadas ao quarto

3)Redução de medicação

4)Cirurgia

5) Outros tratamentos

PARTE II

10- Considera suficiente o esforço das entidades envolvidas no desenvolvimento da Rede de Cuidados Paliativos? (Por favor classifique de 1, fraco, a 5, forte, os seguintes stakeholders)

- Estado

- Centros hospitalares

- Associações de doentes

- Associações de profissionais de saúde.

- Outros stakeholders

11- Já frequentou algum tipo de formação em cuidados paliativos? (Assinale todos os que se aplicam)

- Workshops

- Conferências

- Congressos

- Estágios

- Curso de formação básica

- Mestrado

- Curso de pós-graduação.

- Doutoramento

- Formação específica pelo empregador

-Outro

12- Se respondeu afirmativamente à questão anterior, no total quantas horas de formação frequentou? (Se respondeu negativamente, passe para a pergunta 15)

_____

13- Alguma desta formação foi paga por si?

-Sim / -Não / - Outro_____

14- Por que razão? (Resposta aberta)

15- Sente que a formação alterou o seu comportamento profissional? (Classifique de 1- pouco a 5- muito)

16- Tem conhecimento de que em Agosto deste ano foi aprovada a Rede Nacional de Cuidados Paliativos (Portugal, 2012)?

-Sim / -Não

PARTE III – Estado atual dos Cuidados Paliativos

17- No debate da RTP, "*Prós e Contras*", o tema de dia 8 de Out. 2012 foi sobre os medicamentos inovadores de limitada eficácia e o custo que estes representam para a população portuguesa. Neste debate o Dr. Nuno Miranda, Diretor do Programa Nacional de Prevenção das Doenças Oncológicas, afirmou "*que o último mês de vida deste tipo de pacientes é o mais caro devido a medicação inadequada*" quando se debatia o tratamento de doentes oncológicos. Concorda com esta afirmação? (Classifique de 1 – Discorda a 5- Concorda)

18- Numa altura de grande discussão sobre o orçamento de saúde, sente que os cuidados paliativos poderão resultar em poupanças significativas? (Classifique de 1 – poupanças reduzidas a 5 – poupanças significativas)

19- Esta possível poupança na sua opinião/experiência poderá advir fundamentalmente ao nível de: (Resposta aberta)

20- Considera que os cuidados paliativos são valorizados pelas famílias dos doentes? (Classifique de 1 – Pouco a 5- Muito)

Parte IV – Oportunidade criada pelos Cuidados Paliativos

21- Considera que os Cuidados Paliativos trazem benefícios, económicos e sociais, quer para os pacientes quer para a sociedade civil no geral? (Classifique de 1 – Pouco a 5- Muito)

22- De acordo com estudos efetuados deverá haver uma proporção de 30% assistência hospitalar e 70% assistência extra hospital no caso dos Cuidados Paliativos. Acredita haver condições para que isto se verifique em Portugal? (Classifique de 1 – Pouco a 5- Muito)

23- Através da sua experiência como considera que a Rede Nacional de Cuidados Paliativos poderá influenciar, de uma forma positiva, a visão da sociedade portuguesa nos seguintes aspetos (Gonçalves, 2010): (Classifique de 1 – Pouco a 5- Muito)

- Conflitos doente-família- profissionais

- Comunicação deficiente

- Barreiras e resistências aos cuidados paliativos

- Fragmentação de cuidados

- Negação social da morte

- Sensação de fracasso médico

- Deficiente formação sobre o final da vida

-Inércia por imperativos tecnológicos

24- Um documento da Organização Mundial da Saúde indica que o próprio conceito de cuidados paliativos está a mudar, tornando-se num conceito mais integrante no cuidado dos pacientes desde o início do diagnóstico. Concorda com essa integração numa fase inicial ainda que haja a possibilidade de cura?

-Sim / - Não

25- Comparado com a média da União Europeia Portugal é um dos países que menos investe em cuidados de longo prazo (dados da OCDE, 2012), considera que esta situação tem tendência a mudar de acordo com as necessidades existentes?

-Sim / -Não

26- Em termos de camas para tratamentos de longo prazo Portugal é um dos países com menor acesso (dados da OCDE, 2012), considera que este paradigma irá mudar com a nova legislação?

-Sim / -Não

Annex 5 – Mr. Manuel Capelas biographic information

Manuel Luís Vila Capelas is an Associate Professor at the Catholic University. Published 10 articles in journals and 17 papers in proceedings events, has published two book chapters. Has 88 items of technical production. Participated in 8 events abroad and 32 in Portugal. Works in Health Sciences in his professional activities and interacted with 30 colleagues in co-authorship of scientific papers.

Graus Académicos (Academic Degrees)

2004-2006 Mestrado / Master degree

Master in Palliative Care (2 years) in Universidade de Lisboa, Portugal.

2002-2003 Licenciatura / Licentiate degree

Graduation in Nursing – Complementary course of training (1 years) in Escola Superior de Enfermagem S. Francisco das Misericórdias, Portugal.

1987-1989 Bacharelato / Bachelor degree

Barchelor in Nursing (4 years) in Escola Superior de Enfermagem S. Francisco das Misericórdias, Portugal.

Annex 6 – Contacted entities

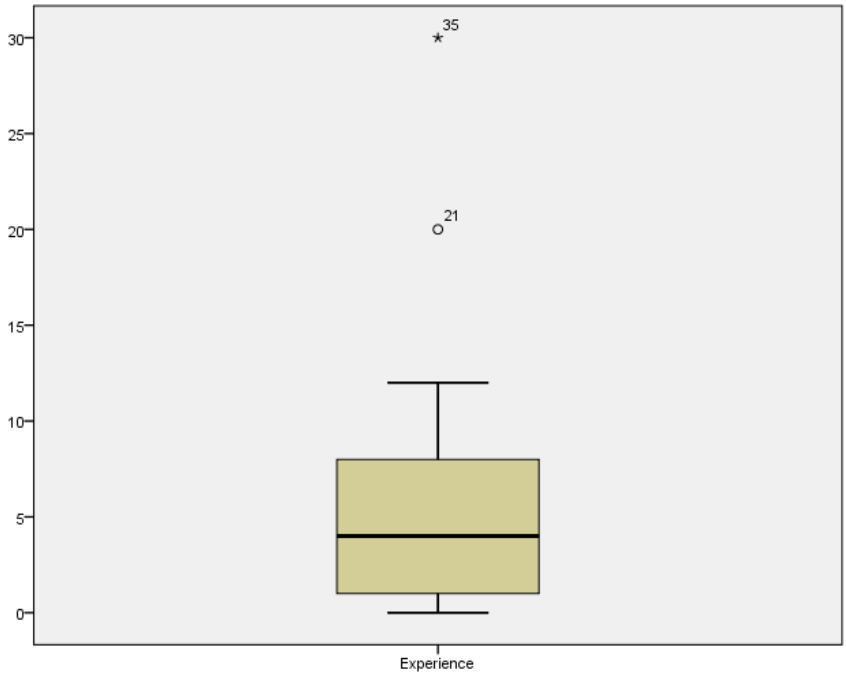
Equipa de Cuidados Continuados do Centro de Saúde Odivelas
Sociedade Portuguesa de Enfermagem Oncológica
Ordem dos Piscólogos Portugueses
Associação Portuguesa de Medicina Geral e Familiar
Unidade da Santa Casa da Misericórdia de Azeitão
Unidade de Assistência Domiciliária do IPO de Lisboa Francisco Gentil, E.P.E.
Serviço de Medicina Paliativa do Hospital do Fundão (Centro Hospitalar da Cova da Beira, EPE)
Serviço de Cuidados Paliativos do IPO do Porto, E.P.E.
Unidade de Cuidados Paliativos S. Bento de Menni, IHSCJ, Casa de Saúde da Idanha
Serviço de Cuidados Paliativos do IPO de Coimbra-FG, E.P.E.
Unidade de Cuidados Paliativos do Hospital da Luz
Equipa Intrahospitalar de Suporte em Cuidados Paliativos do Hospital de Santa Maria
Unidade de Cuidados Paliativos do Hospital do Mar
Equipa Intrahospitalar de Suporte em Cuidados Paliativos do Hospital de Elvas
Unidade de Cuidados Paliativos do Hospital do Litoral Alentejano, EPE - Santiago do Cacém
Unidade de Cuidados Paliativos da Rede (UCP-R) no IPO-Porto
Centro Hospitalar de Lisboa Zona Central, EPE
Equipa Comunitária de Suporte em Cuidados Paliativos do Algarve
ECCI de Albufeira
ECCI de Alcoutim
ECCI de Aljezur
ECCI de Faro
ECCI de Lagoa
ECCI de Loulé
ECCI de Monchique
ECCI de Olhão
ECCI de Portimão
ECCI de S. Brás de Alportel
ECCI de Silves
ECCI de Tavira
ECCI de Vila do Bispo
ECCI de Vila Real de St.º António/ Castro Marim
Serviço de Cuidados Paliativos do Hospital de São João
Equipa Intra-Hospitalar de Suporte em Cuidados Paliativos do IPOLFG, EPE
Equipa Intra-Hospitalar de Suporte em Cuidados Paliativos do Hospital Reynaldo dos Santos, V. F. de Xira
Equipa de Suporte em Cuidados Paliativos da Unidade Local de Saúde Matosinhos
Equipa Comunitária de Suporte em Cuidados Paliativos Beja +

Equipa Intra-Hospitalar de Cuidados Paliativos do H. G. S. António (Porto)
Unidade Domiciliaria de Cuidados Paliativos –Planalto Mirandês
Acreditar – Núcleo Regional Sul
Acreditar – Núcleo Regional Centro
Acreditar – Núcleo Regional Norte
Acreditar - Núcleo Regional da Madeira
Liga Portuguesa contra o Cancro
Núcleo Regional dos Açores
Núcleo Regional do Centro
Núcleo Regional da Madeira
Núcleo Regional do Norte
Núcleo Regional do Sul
Serviços Centrais (Sede Nacional)
Portal de Informação Português de Oncologia Pediátrica

Annex 7 – Analysis to the experience years of the sample

Descriptives

			Statistic	Std. Error
Experience	Mean		5.19	.911
	95% Confidence Interval for Mean	Lower Bound	3.35	
		Upper Bound	7.03	
	5% Trimmed Mean		4.41	
	Median		4.00	
	Variance		34.841	
	Std. Deviation		5.903	
	Minimum		0	
	Maximum		30	
	Range		30	
	Interquartile Range		7	
	Skewness		2.274	.365
	Kurtosis		7.068	.717



Quartile representation of the experience of the respondents.

Annex 8 – Analysis of the effort perceived in Palliative Care

Statistics

		Government	Hospital Centers	Patient Associations	Health Professional Associations	Other Stakeholders
N	Valid	42	42	42	42	42
	Missing	0	0	0	0	0
Mean		2.14	2.50	2.52	2.40	2.57
Median		2.00	2.00	3.00	2.50	3.00
Std. Deviation		.899	1.088	.969	1.037	1.085
Minimum		1	1	1	1	1
Maximum		4	5	5	5	5

Annex 9 – Type of training obtained in Palliative Care

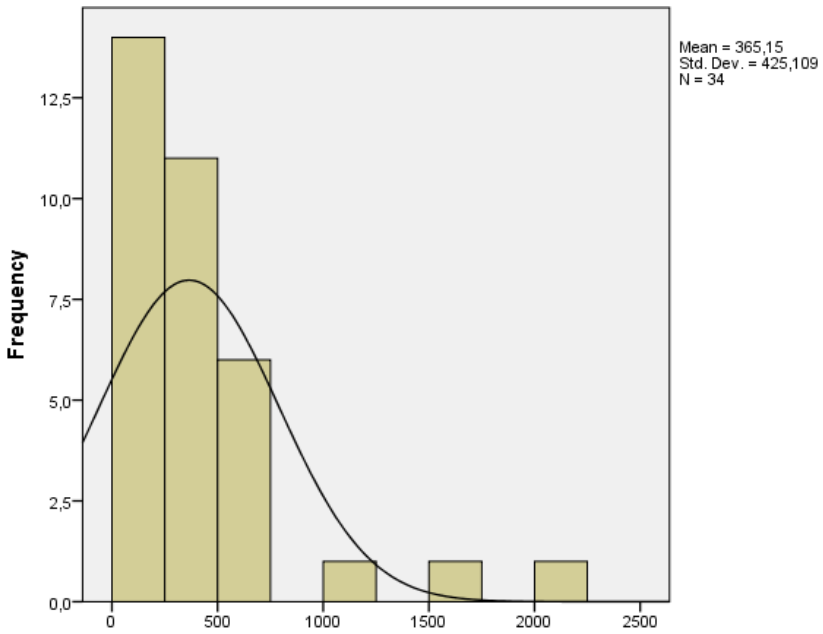
		Responses		Percent of Cases
		N	Percent	
$A11_total[a]	Workshops	25	15,0%	59,5%
	Conferências	23	13,8%	54,8%
	Congressos	26	15,6%	61,9%
	Estágios	21	12,6%	50,0%
	Curso de Formação Básica	23	13,8%	54,8%
	Mestrado	22	13,2%	52,4%
	Curso de Pós-graduação	18	10,8%	42,9%
	Doutoramento	1	0,6%	2,4%
	Formação específica pelo empregador	6	3,6%	14,3%
	Outro	2	1,2%	4,8%
Total		167	100,0%	397,6%

a. Group

Annex 10 – Training hours in Palliative Care Formation

Statistics

N	Valid	34
	Missing	8
Mean		365.15
Median		300.00
Std. Deviation		425.109
Minimum		2
Maximum		2,000
Percentiles	25	41.75
	50	300.00
	75	500.00



Total hours in Palliative Care Training.

Annex 11 – Awareness of the legal changes in the Palliative Care Network

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	39	92,9	92,9	92,9
	No	3	7,1	7,1	100,0
	Total	42	100,0	100,0	