International Palliative Care and Hospice Congress Istambul 9-11 March 2018

Building Palliative Care In Europe

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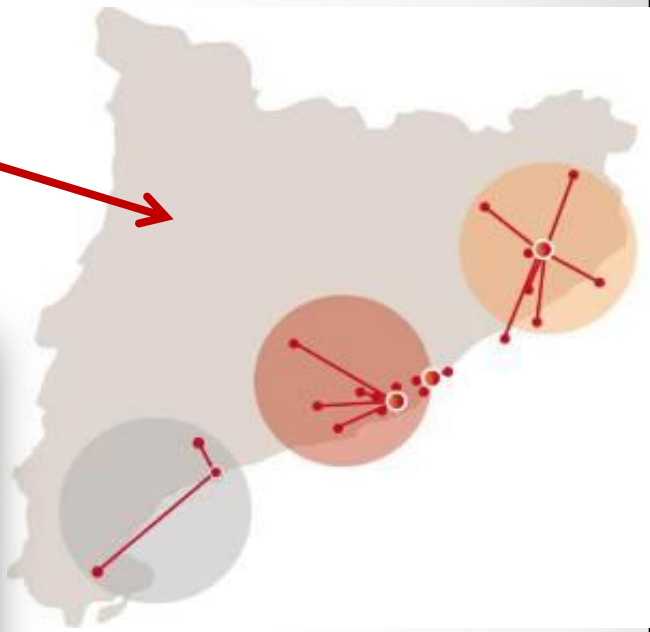
UNIVERSITAT DE BARCELONA

Generalitat de Catalunya
Departament de Salut

ICO Institut Català d'Oncologia

Institut Català d'Oncologia

3 cancer centres
16 regional units
2.5 millions
50% population



ICO- Girona
Blanes / Calella / Figueres / Olot / Palamós / Salt / Vic

ICO - Badalona
Sta. Coloma de Gramenet / Mataró / Badalona

ICO Hospitalet - Barcelona
Igualada / Martorell / Sant Boi de Llobregat / Sant Joan Despí / Sant Pere de Ribes / Viladecans / Vilafranca del Penedès

During my presentation:

1. **Differences - historical backgrounds,**
   - socioeconomic – political context
   - cultural beliefs
   - Values

2. **Context and situation for Palliative services**
   - Human resources
   - Geographical differences

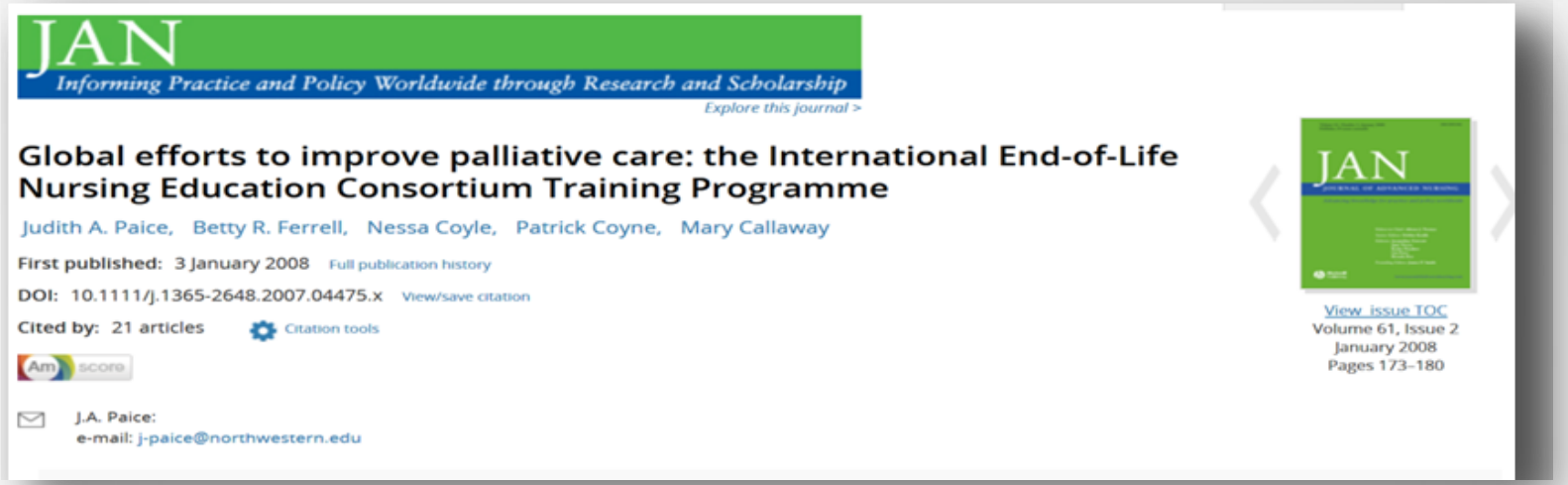
1. **Educational needs for professionals involved in Palliative care**

Palliative care:

- *"**PC means patient and family-centered** care that optimizes quality of life by anticipating, preventing, and treating suffering.*
- *Throughout the **continuum of illness addressing physical, intellectual, emotional, social, and spiritual needs** and to facilitate patient autonomy, access to information, and choice".*

Ferrell et al. ASCO congress 2016

1. General context of cancer world-wide:



JAN
Informing Practice and Policy Worldwide through Research and Scholarship
Explore this journal >

Global efforts to improve palliative care: the International End-of-Life Nursing Education Consortium Training Programme

Judith A. Paice, Betty R. Ferrell, Nessa Coyle, Patrick Coyne, Mary Callaway

First published: 3 January 2008 Full publication history

DOI: 10.1111/j.1365-2648.2007.04475.x View/save citation

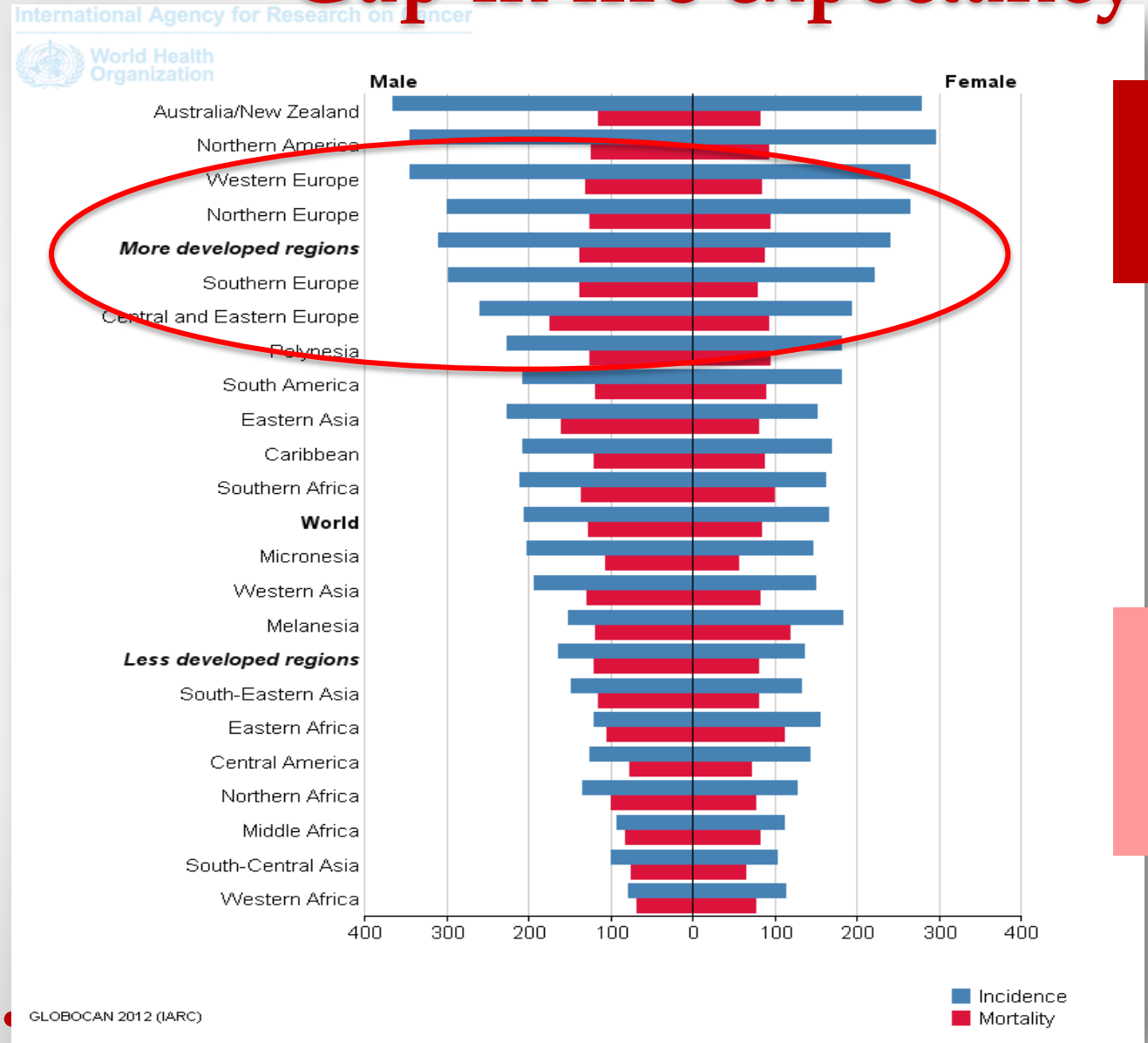
Cited by: 21 articles Citation tools

J.A. Paice:
e-mail: j-paice@northwestern.edu

View issue TOC
Volume 61, Issue 2
January 2008
Pages 173–180

- **Paice J et al.**, publication in 2008,
  - global efforts in the world have been done regarding cancer pts.
- **>50 million people die form cancer each year world -**many *without access to adequate pain control or palliative care!!.*

Gap in life expectancy



High incidence.
80% non advanced stage
Many survivors

80% advanced stage at initial
Lack of data – cancer underappreciated
High mortality

European context:

Population 484.590.000
11.4% population are minorities
187 minorities = 42 millions

June 1993 - Copenhagen European Council
democracy, law for ….
combat discrimination based on sex, racial or ethnic origin, religion, disability, age or sexual orientation - Romany population

Fernández-Ortega et al. **Educational Challenges: Some strategies to provide better cancer care in underserved populations**. EONS 2016 www.cancernurses.eu/magazine

30 countries & 26 languages. Most spoken: German or "Bad English"

European context - disparities

At this MOMENT:
25 millions persons live with cancer around the world.

WHO. 2014

- **Disparities** in the developed world **&** in **Europe.**
- Multiple dimensions of inequalities
  - in cancer prevalence and prevention,
  - due **race, socioeconomic status, education level, geographical location, and immigration status.**

European disparities in cancer

- **Diversity;** cultural, demographical and socio-political characteristics
  - ***How cancer patients needs are covered and how have been addresses the cancer policies into this countries?***
- **Minorities – migration from out Europe.** Refugees Middle East: Sirian, Afganistan, Chad, Eritrea
  - ***How to integrate or rejected from National Health coverage***
  - **Ex:** incidence **cervical cancer -** Eastern Europe rising, in contrast to the reduction in most countries of Western Europe.
  - **Garner 2003,** explains disparities in morbidity, mortality, survival, access for clinical trials, stage of diagnosis and in ***access to screening.***

WPCA, Global Atlas for PC, 2014

Disparity on screening:

Psycho-Oncology
Psycho-Oncology **22**: 2664–2675 (2013)
Published online 3 July 2013 in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/pon.3344

2013: **Eastern European immigrants** - underu
Breast cancer screening - Insufficient knowledg

Review

Breast cancer screening utilization among Eastern European immigrant women worldwide: a systematic literature review and a focus on psychosocial barriers

Valentina A. Andreeva[1]* and Pallav Pokhrel[2]
[1]*UREN, University of Paris, Bobigny 93017, France*
[2]*Cancer Prevention and Control Program, University of Hawaii Cancer Center, Honolulu, HI, USA*

**Correspondence to: Valentina A. Andreeva, UREN, University of Paris, 74 rue Marcel Cachin, Bobigny 93017, France. E-mail: v.andreeva@uren.smbh.univ-paris13.fr*

Abstract

Objective: Many countries host growing Eastern European immigrant communities whose breast cancer preventive behaviors are largely unknown. Thus, we aimed to synthesize current evidence regarding secondary prevention via breast cancer screening utilized by that population.

Methods: All observational, general population studies on breast cancer screening with Eastern European immigrant women and without any country, language, or age restrictions were identified. Screening modalities included breast self-examination, clinical breast examination, and mammography.

Results: The selected 30 studies were published between 1996 and 2013 and came from Australia, Canada, Denmark, Germany, Israel, the Netherlands, Spain, Switzerland, the UK, and the USA. The reported prevalence of monthly breast self-examination was 0–48%; for yearly clinical breast examination 27–54%; and for biennial mammography 0–71%. The substantial methodologic heterogeneity prevented a meta-analysis. Nonetheless, irrespective of host country, healthcare access, or educational level, the findings consistently indicated that Eastern European immigrant women underutilize breast cancer screening largely because of insufficient knowledge about early detection and an external locus of control regarding decision making in health matters.

Conclusions: This is a vulnerable population for whom the implementation of culturally tailored breast cancer screening programs is needed. As with other underscreened immigrant/minority groups, Eastern European women's inadequate engagement in prevention is troublesome as it points to susceptibility not only to cancer but also to other serious conditions for which personal action and responsibility are critical.

Received: 8 November 2012
Revised: 28 May 2013

People in poorer inner-city neighborhoods are being screened at much lower rates than people in the richer suburbs. UK- Sw- Fr…

European context, summary:

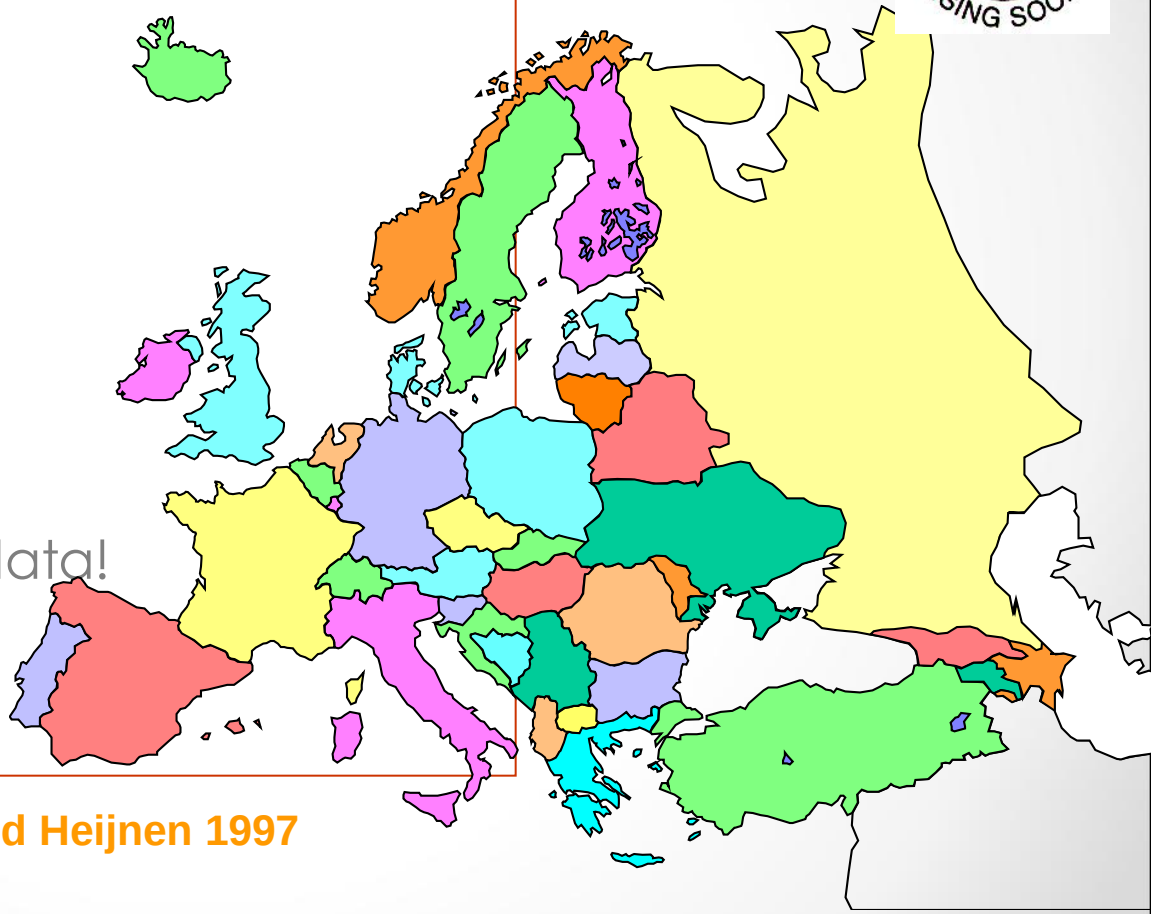
1. **Economical crisis -** greater impact on cancer patients, females, elders and survivorships
   - **High risk to** involution in human and health rights. Affecting male & female equity. Partial, worst & less payed works

2. **Subpopulations - each country or region** to optimize cancer care.
   - **Local patients organizations**, to help families, immigrants and some services as pharmacies or help for caregivers. NGO's advocacy on patient's rights

3. **Solutions** focus in **education and training of professionals** in cancer care, fellowships, grants, direct support of conferences & educational materials….
   - Scientific societies role: EAPC- EONS- MASCC

Nursing rate in Europe:

- Finlandia 1862 (**x 100.000 Hab.)**
- Noruega 1000
- Alemania 840
- Islandia 810
- Bélgica 800
- Austria 569
- Francia 536
- Spain..... 480
- Portugal 450
- Others: No data!



Salvage and Heijnen 1997

Cancer nurses & Oncologist shortage

Shortage of trained professionals – due to financial constrains but, also to lack of scientific and epidemiological background

Ageing professionals-Western Europe. Doctors 30% >55y. Nurses 41-45years. ICN 2007

WHO reported in **2004 nurses-ratio** differences across countries:

- Finland 1200 nurses/ 100,000 population / 500 in Spain or Portugal.
- Uganda or Liberia 10 nurses.
- Regions with the highest ratio is 10 times that of the lowest ratios. Regional different levels coexisting within a country

Factors pushing nurses to leave source countries – low pay, poor career prospects, political instability and social violence. Luxemburg, France- Switzerland, Portugal – Switzerland, Spanish nurses in …. all European countries!

Shared language, common educational curriculum, postcolonial ties: Indian and Pakistan nurses in UK, African in Italy, Latinos in Spain or Subsaharian in France.

Today: nurses rate in Spain 508

SANIDAD Desigualdades entre CCAA

España necesita unas 142.000 enfermeras para alcanzar a Europa

- En nuestro país hay 508 enfermeros por cada 100.000 habitantes
- La media europea es de 811 profesionales por cada 100.000 habitantes
- Hay grandes desigualdades territoriales en el número de profesionales contratados

Una enfermera realiza una medición de niveles de glucosa en sangre. | MATÍAS COSTA

Noticias Relacion

Así reacciona una enfermera a paciente

Sanidad cesa a enfermeras po

Conselleria no permite enferme crónicos en los colegios

Guerra abierta por la prescripc Enfermería

'Es habitual que entren extraño quirófano durante la operación

Más leídas

Un premio con 'padre' españ

Las pioneras del 'corta y peg premio Princesa de Asturias Investigación Científica

La vacuna contra la meningit adquirirse en farmacias

El tabaco es la principal caus una decena de tumores

'Muchos votos son irracional

La familia pakistaní que guar secreto sobre el cerebro hu

Una infección que puede ter ingreso involuntario

European mean rate: 811

2. European Palliative care situation:

…

1st edition - 2006
Atlas of Palliative Care in Europe

Centeno et al. EAPC task force

Systematic review 300 articles, in 10 year period up to 2005. Databases – PUBMED and CINHAL.

- A peer-review process
  1. to witness the **progress and changes** in palliative care in each country.
  2. + Summary of **the references**
  3. Identification of **key people** who reported on the development of palliative care in those countries.

Authors: Spain- UK- Romania
Centeno C, Lynch T –Int Hospice & palliative care, Donea O Romania & Clark D.

Map 1. Key map

53

COUNTRIES WITH RESPONSE TO QUESTIONNAIRE

AL Albania
AD Andorra
AM Armenia

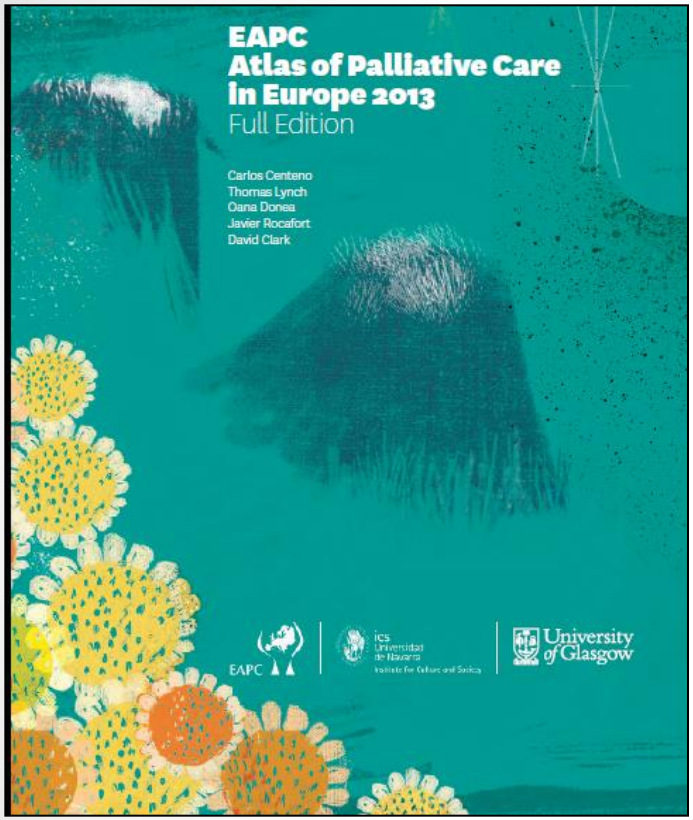
Albania	Czech Republic	Israel	Norway	Spain
Andorra	Denmark	Italy	Poland	Sweden
Armenia	Estonia	Kazakhstan	Portugal	Switzerland
Austria	Finland	Kyrgyzstan	Republic of Moldova	Tajikistan
Azerbaijan	France	Latvia	Republic of Macedonia	Turkey
Belarus	Georgia	Lithuania	Romania	Turkmenistan
Belgium	Germany	Luxembourg	Russian Federation	Ukraine
Bosnia Herzegovina	Greece	Malta	San Marino	United Kingdom
Bulgaria	Hungary	Monaco	Serbia	Uzbekistan
Croatia	Iceland	Montenegro	Slovakia	
Cyprus	Ireland	Netherlands	Slovenia	

GB United Kingdom

ATLANTES Program | ICS - University of Navarra

Centeno C et al. Atlas of Palliative Care in Europe 2013. EAPC

Palliative care situation



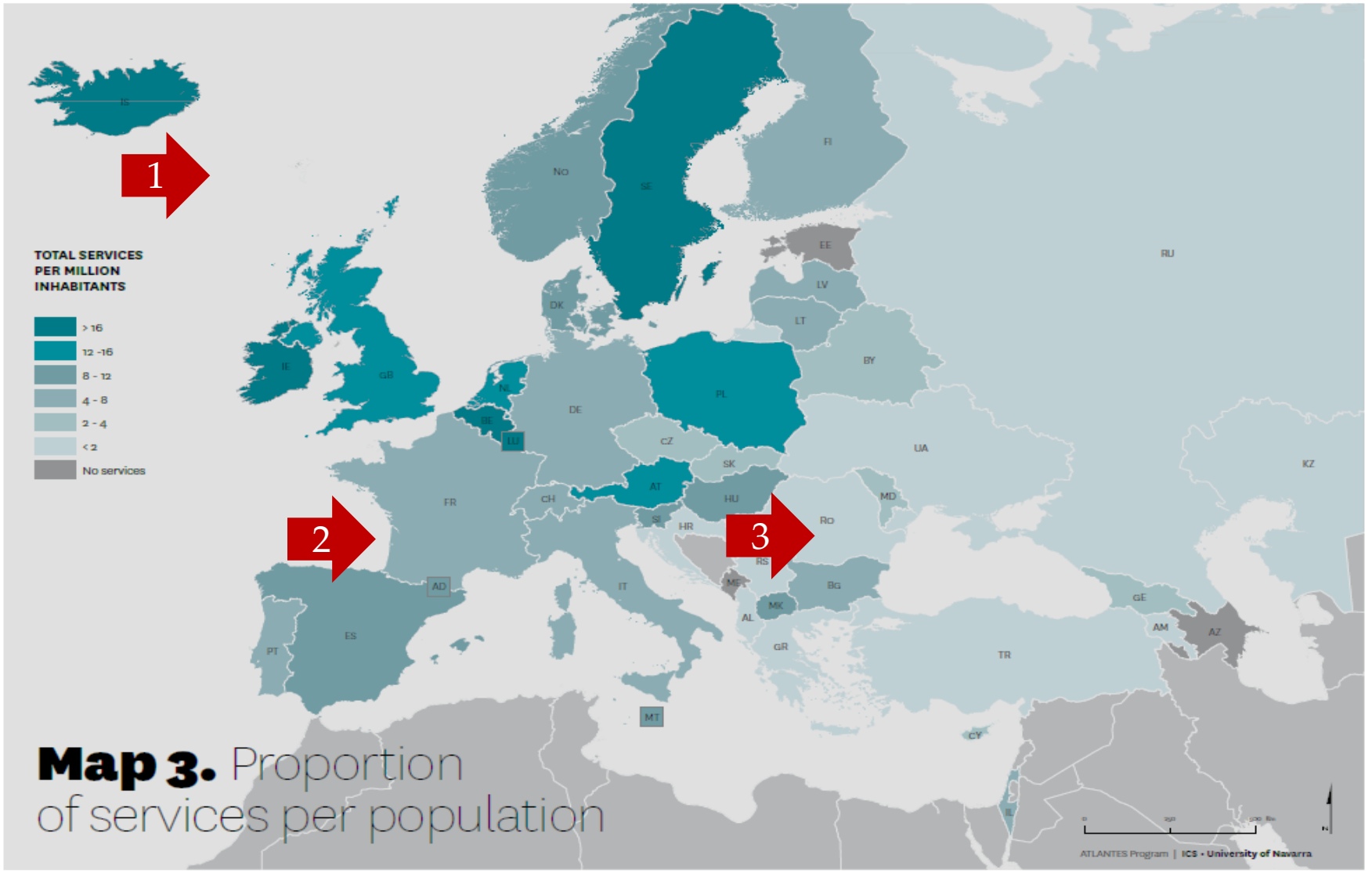
Centeno C et al. Atlas of Palliative Care in Europe 2013. EAPC

Bulgaria and Romania, as other Eastern European countries

- *The EAPC atlas shows that Romania ranked 26th out of 28 European countries in terms of palliative care resources in 2013.*

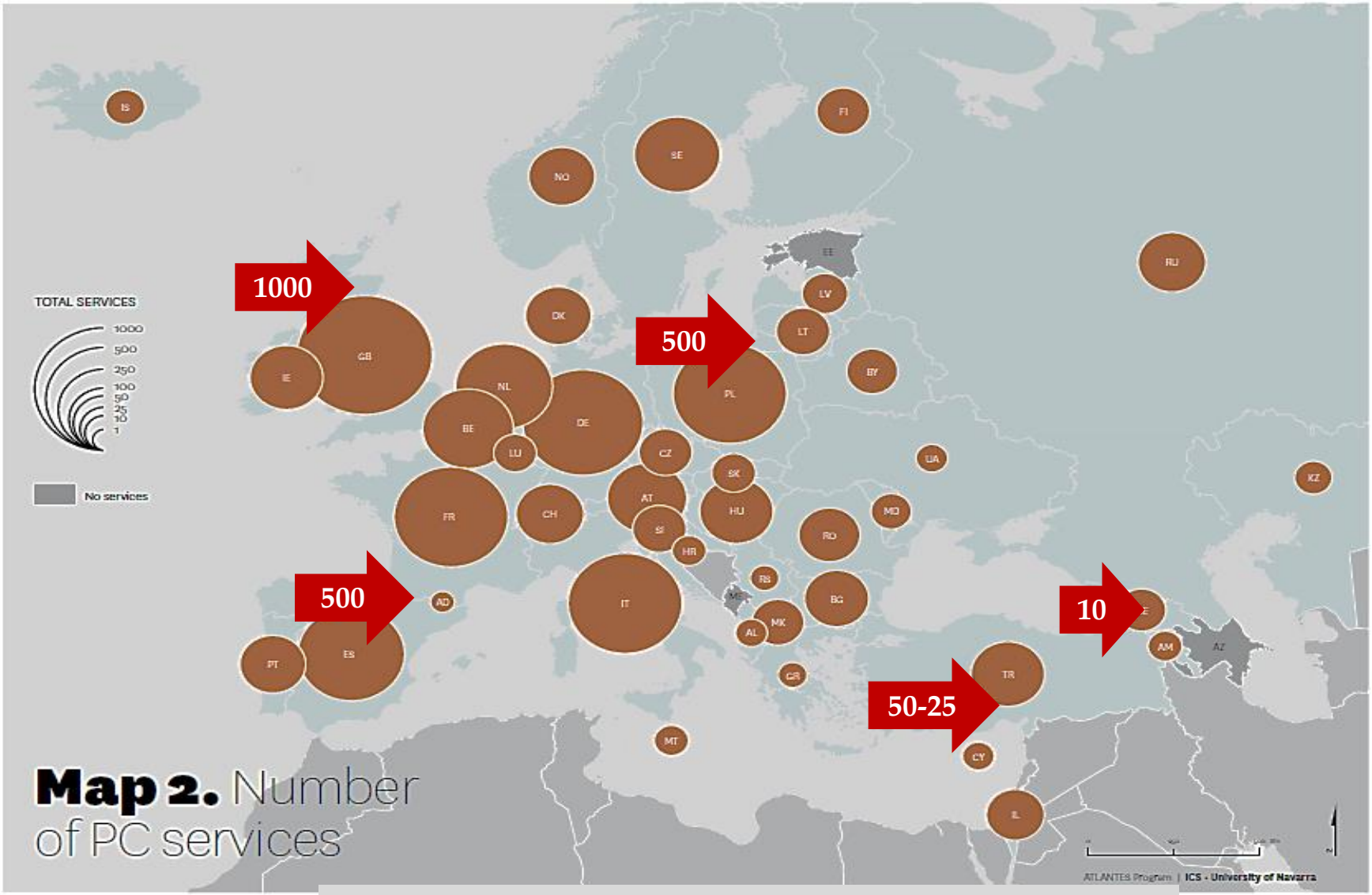
- **Why is the end-of-life experience still not Better in Europe?**.
- Quality of Death Index ranked Ukraine, Romania and Bulgaria among the 20 worst performing countries in the world.

Proportion per population



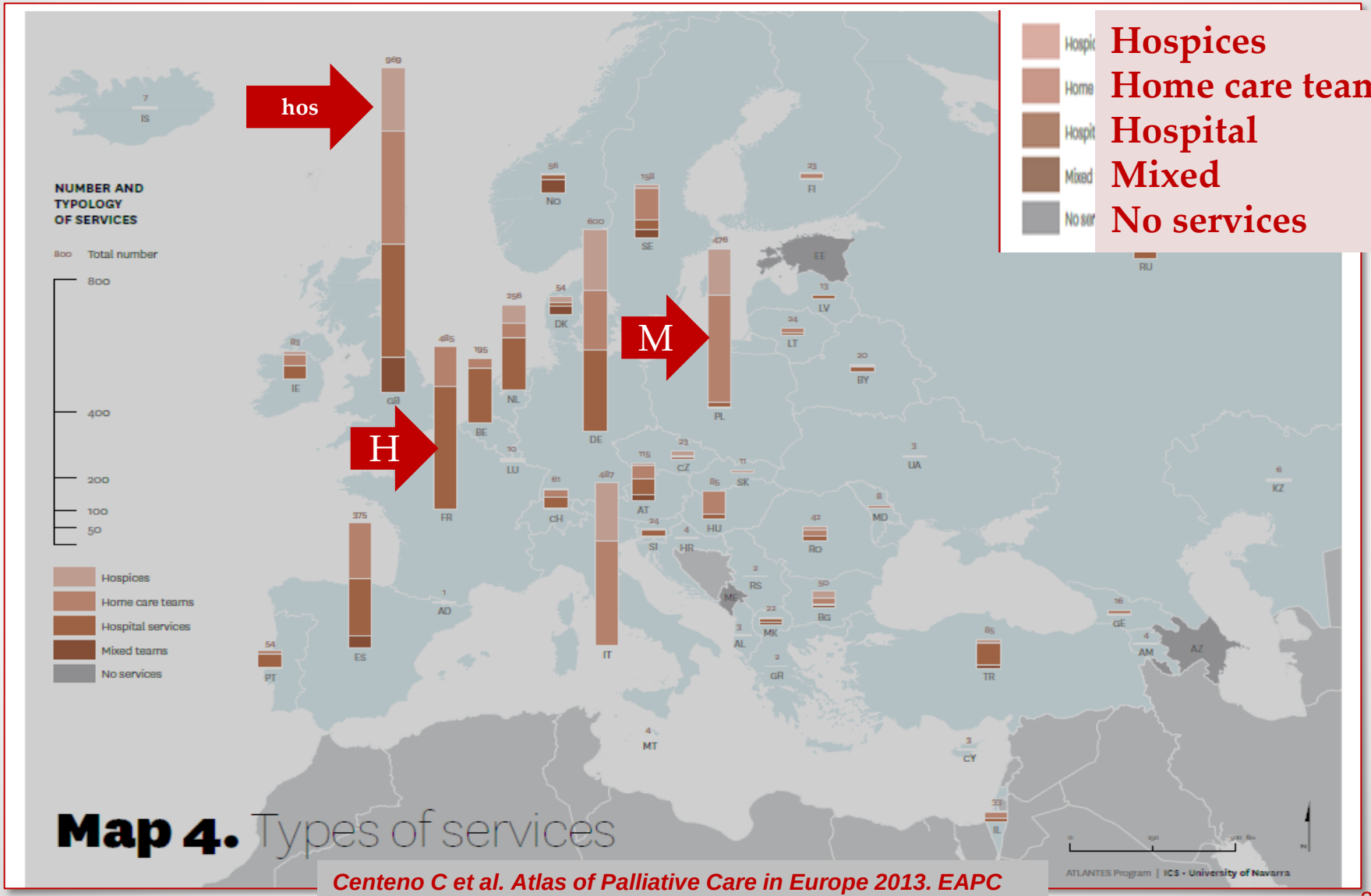
Centeno C et al. Atlas of Palliative Care in Europe 2013. EAPC

Palliative:



Centeno C et al. Atlas of Palliative Care in Europe 2013. EAPC

Types of services



Centeno C et al. Atlas of Palliative Care in Europe 2013. EAPC

Care at home – at Hospitals?

DOI: 10.1590/1516-3180.20161341T2

Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers

This is the abstract of a Cochrane Review published in the Cochrane Database of Systematic Reviews (CDSR) 2013, issue 6, art. nº CD007760. DOI: 10.1002/14651858.CD007760.pub2. For full text and details about the authors, see reference 1.

Barbara Gomes, Natalia Calanzani, Vito Curiale, Paul McCrone P, Irene J. Higginson, Maja de Brito

The independent commentary was written by Mauricio de Miranda Ventura

ABSTRACT

BACKGROUND: Extensive evidence shows that well over 50% of people prefer to be cared for and to die at home provided circumstances allow choice. Despite best efforts and policies, one-third or less of all deaths take place at home in many countries of the world.

OBJECTIVES: 1. to quantify the effect of home palliative care services

significant beneficial effects of home palliative care services compared to usual care on reducing symptom burden for patients (three trials, two of high quality, and one CBA with 2107 participants) and of no effect on caregiver grief (three RCTs, two of high quality, and one CBA with 2113 caregivers). Evidence on cost-effectiveness (six studies) is inconclusive.

AUTHORS' CONCLUSIONS: The results provide clear and reliable evidence that home palliative care increases the chance of dying at home and reduces symptom burden in particular for patients with cancer, without impacting on caregiver grief. This justifies providing home palliative care for patients who wish to die at home. More work is needed to study cost-effectiveness especially for people with non-malignant conditions, assessing place of death and appropriate outcomes that are sensitive to change and valid in these populations, and to compare different models of home palliative care, in powered studies.

The full text of this review is a[illegible] onlinelibrary.wiley.com/doi/10.1

2013

Many countries
>50% prefer at home
Only 30% or less ...
die at home

REFERENC

1 [illegible]N, Cu[illegible]ness of home pal[illegible] advanced illness and their caregivers. Cochrane Database Syst Rev. 2013;(6):CD007760.

OMMENTS

The relevance of this study stems from the fact that aging of popula-

Quality of death

1. Palliative&health care enviroment

2. Human resources in Palliative C.

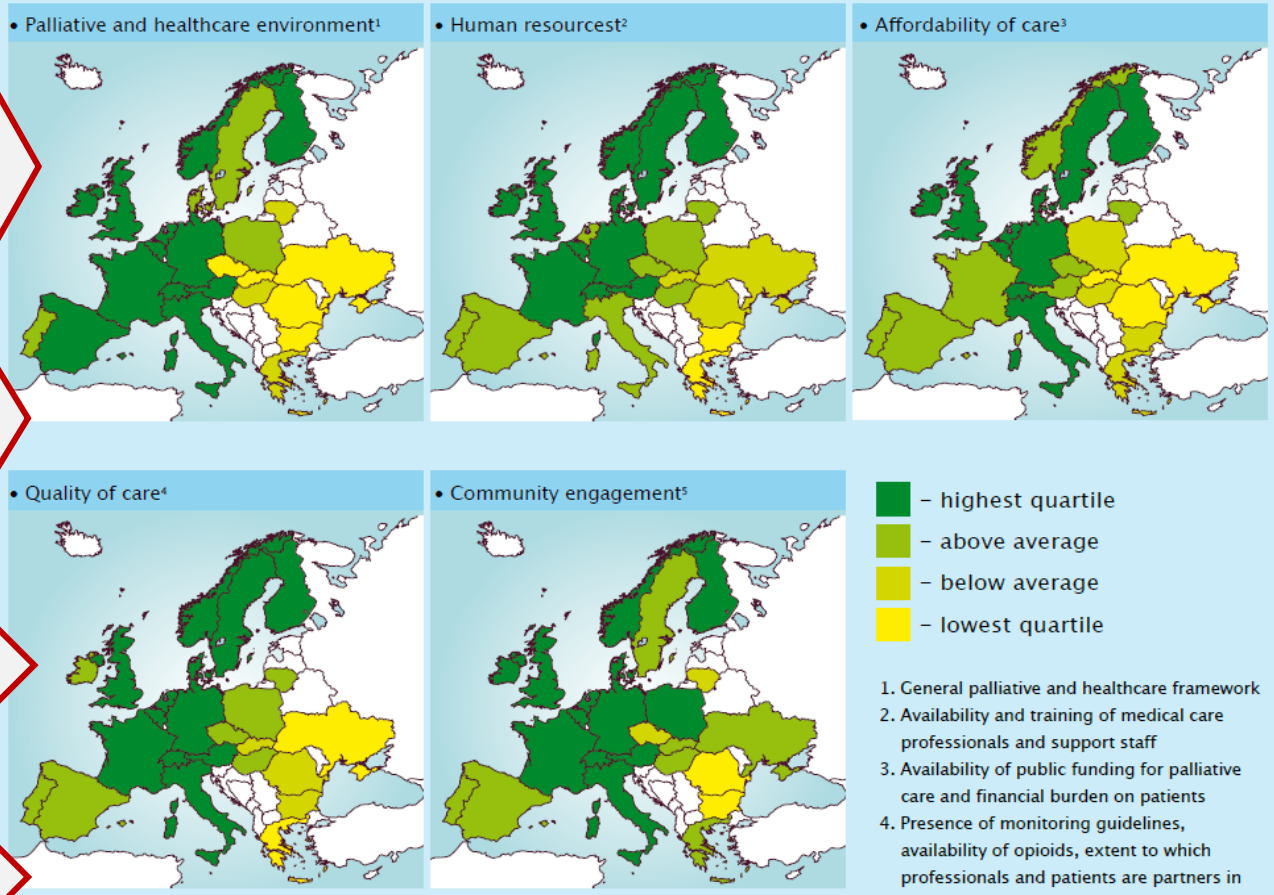
3. Affordability of care

4. Quality of care

5. Comunity engagement

Quality of death across Europe

The Economist Intelligence Unit ranked countries across the world according to the availability, affordability and quality of palliative care available to adults. Countries were scored according to 20 indicators, in five categories. These maps show the global quartile rankings for European countries



1. General palliative and healthcare framework
2. Availability and training of medical care professionals and support staff
3. Availability of public funding for palliative care and financial burden on patients
4. Presence of monitoring guidelines, availability of opioids, extent to which professionals and patients are partners in care
5. Availability of volunteers and public awareness of palliative care

Source: The 2015 Quality of Death Index (2015) The Economist Intelligence Unit Ltd

Quality of death

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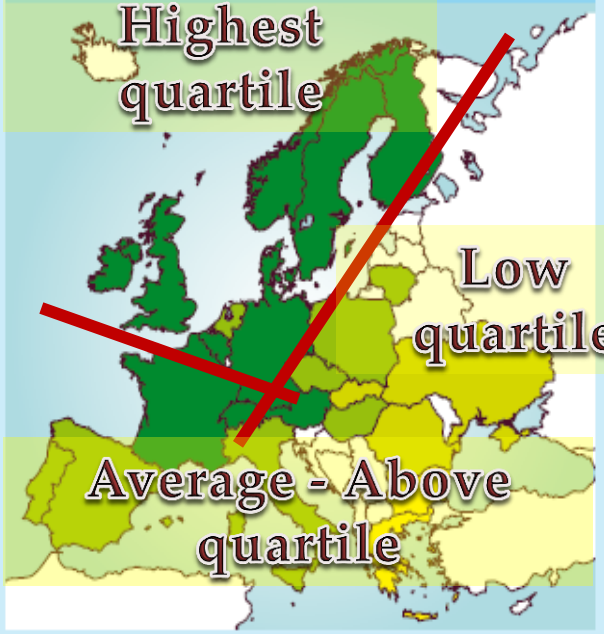
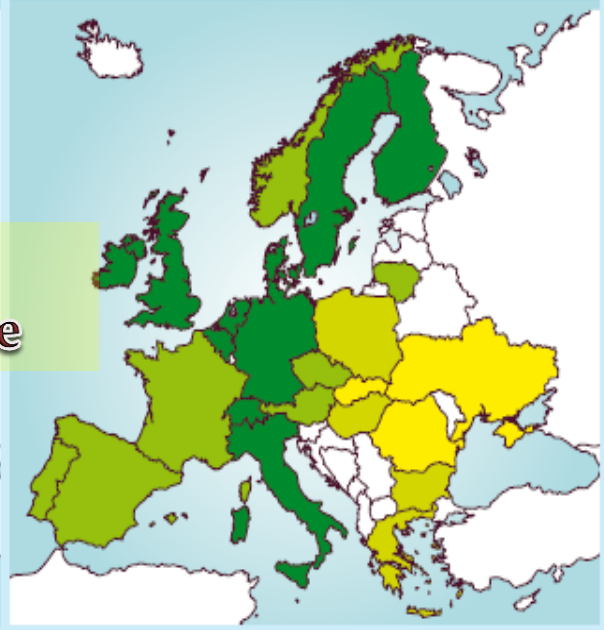
The Economist Intelligence Unit ranked countries across the world according to the availability, affordability and quality of palliative care available to adults. Countries were scored according to 20 indicators, in five categories. These maps show the global quartile rankings for European countries

- Palliative and healthcare environment[1]

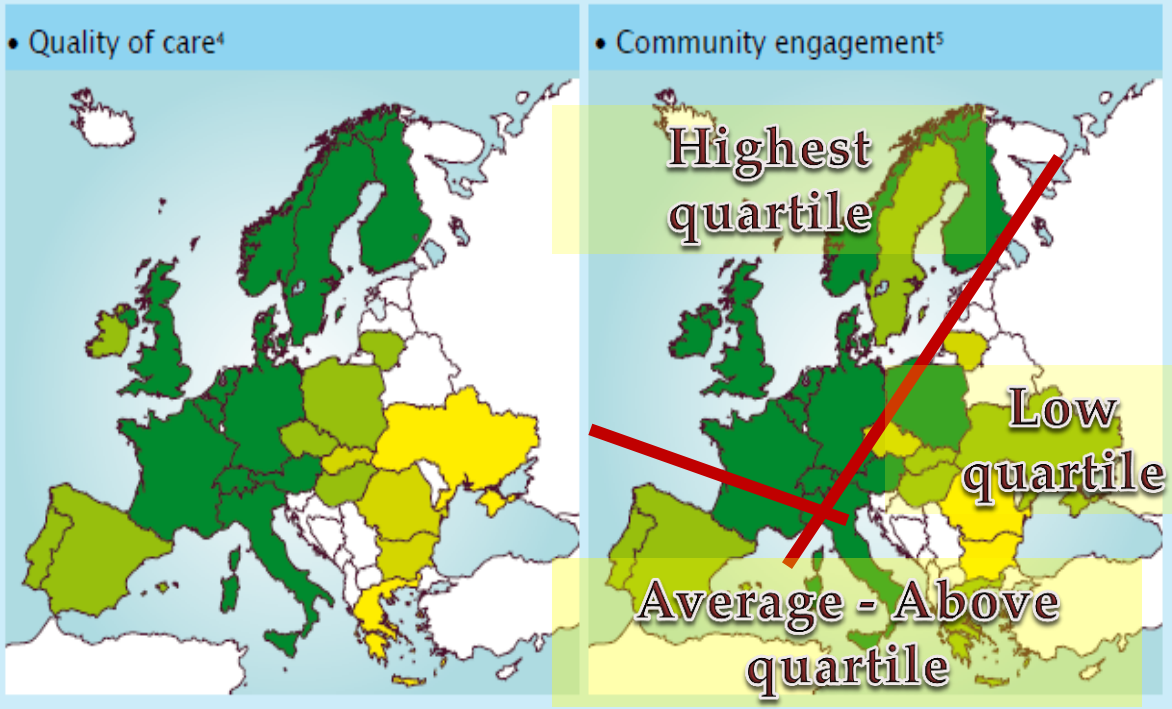
- Human resourcest[2]



- Affordability of care[3]



Quality of death



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Source: The 2015 Quality of Death Index (2015) The Economist Intelligence Unit Ltd

- Quality of Death Index ranked Ukraine, Romania and Bulgaria among the 20 worst performing countries in the world.

Why is the end-of-life experience still not Better in Europe?.

- Economic and political can affect on decreasing quality of death and life..

5 indicators:

1. **Pain control - first indicator**
   - still not central to decision making in oncology & in our hospitals,
   - In acute and long-term centers, pain is not registered in a protocol manner
   - many medical and nurses professionals are not involved in the correct use of analgesia
2. **Education in Palliative for nurses and medical staff**
3. **Nurses specialist's in cancer care & palliative care**
4. **Grief and mourning attention to family members**
5. **Involvement in research**

UK- Missing out on palliative care


Analysis

Survey reveals sharp contrasts in quality of palliative care

Alarming analysis leads to call for a comprehensive discussion on access to services, writes Nick Triggle

Data sources across UK: National Sourvey of Bereaved People in England

1/5 do not recieve Palliative care

- **Cancer patient services** better than other conditions –vascular, respiratory, demencia
- Less cost +less emergencies admissions

- The oldest >85 years, less access to care than younger- Only 16% palliative
- Ethnic groups report poorer care
- Deprived areas less likely to have support at home
- Having spouse or partner batter pain control
- Palliative specialist only in 1/5 hospitals- Royal College Physicians

Nick Triggle in Cancer Nursing Practice. 2015(14)4:8 - about Dixon et al. 2015

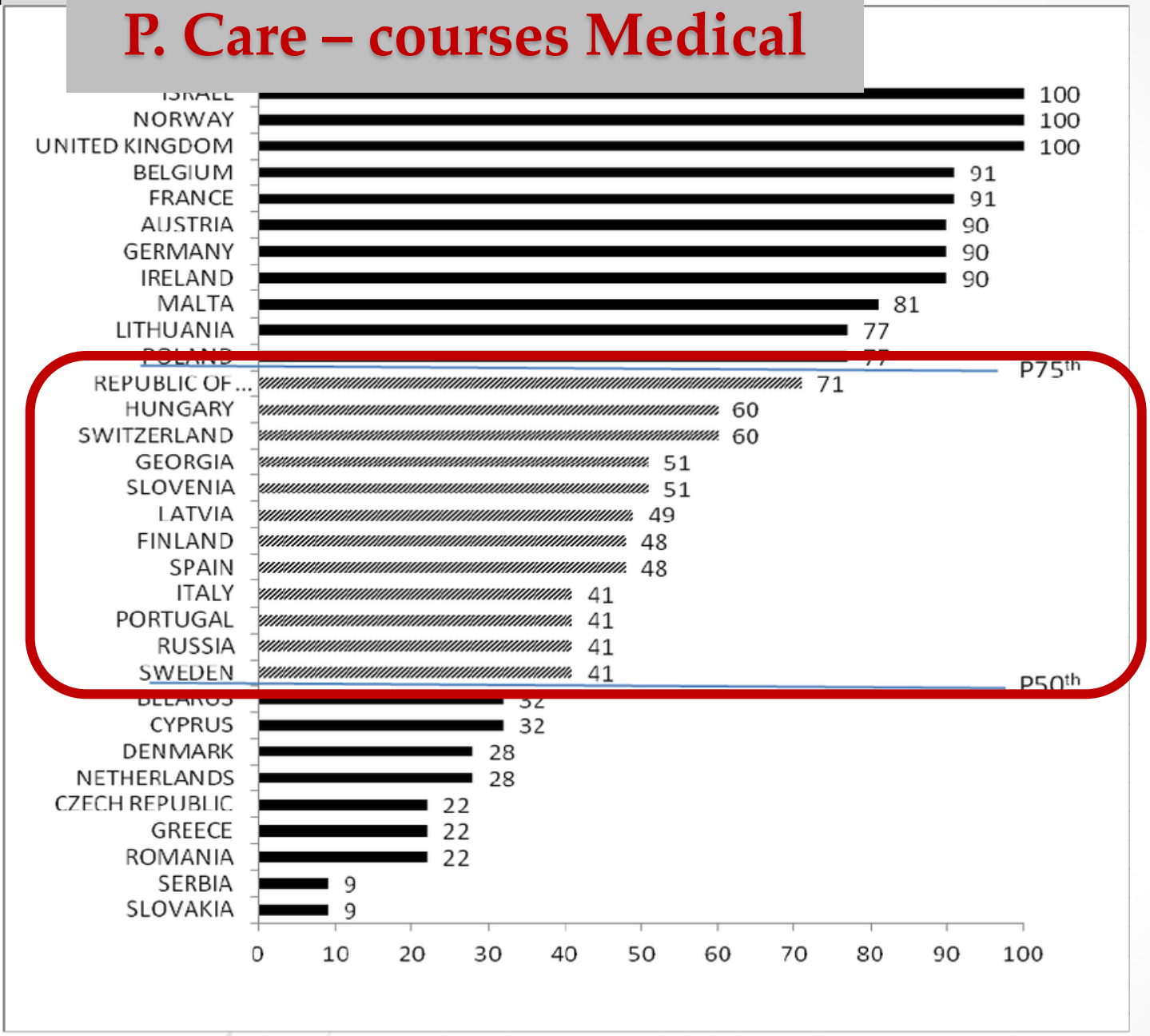
2nd Indicator: Professional's education and training

EONS project ReCAN, Wells M. and the working group that met last November 2016.

- **Aim:** to investigate whether there is a relationship between **cancer nurse education** and training and patient experiences & outcomes.

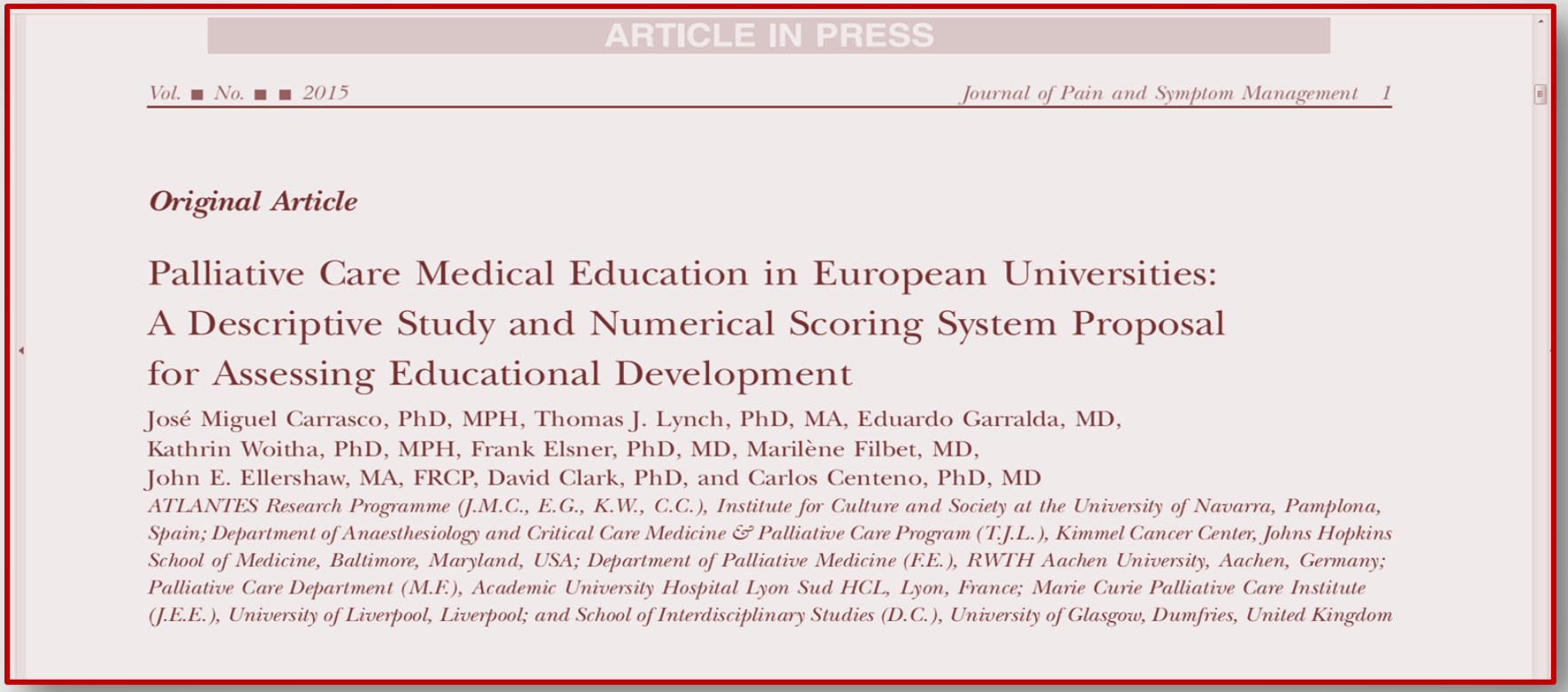
Training in aging-chronicity, wills, autonomy, clinical evidence-based.

P. Care – courses Medical



Note: Countries with the same score have been ordered alphabetically. Countries without PC courses in undergraduate medical curricula or teachers of the discipline: Albania, Andorra,

Medical Education Euroepan Universities



ARTICLE IN PRESS

Original Article

Palliative Care Medical Education in European Universities: A Descriptive Study and Numerical Scoring System Proposal for Assessing Educational Development

José Miguel Carrasco, PhD, MPH, Thomas J. Lynch, PhD, MA, Eduardo Garralda, MD, Kathrin Woitha, PhD, MPH, Frank Elsner, PhD, MD, Marilène Filbet, MD, John E. Ellershaw, MA, FRCP, David Clark, PhD, and Carlos Centeno, PhD, MD

ATLANTES Research Programme (J.M.C., E.G., K.W., C.C.), Institute for Culture and Society at the University of Navarra, Pamplona, Spain; Department of Anaesthesiology and Critical Care Medicine & Palliative Care Program (T.J.L.), Kimmel Cancer Center, Johns Hopkins School of Medicine, Baltimore, Maryland, USA; Department of Palliative Medicine (F.E.), RWTH Aachen University, Aachen, Germany; Palliative Care Department (M.F.), Academic University Hospital Lyon Sud HCL, Lyon, France; Marie Curie Palliative Care Institute (J.E.E.), University of Liverpool, Liverpool; and School of Interdisciplinary Studies (D.C.), University of Glasgow, Dumfries, United Kingdom

Lacasta MA in 2016. Of 261 palliative care teams, they responded 78 that they provided care to relatives in the Palliative unit and type of psychological care was questioned also

3rd: Palliative CN'sNurses

Palliative CN's nurses interventions 4 core categories:

1. **Teaching, Guidance, and Counselling**: Activities to provide information and materials, encourage action and responsibility for self-care and coping, and assist the individual/family/community to make decisions&solve problems.

2. **Treatments and Procedures**: Activities such as wound care, specimen collection, resistive exercises, and medication prescriptions that are designed to prevent, decrease, or alleviate signs and symptoms of the individual, family or community.

3. **Case Management**: Activities as coordination, advocacy, and referral that facilitate service delivery, improve communication among health and human service providers, promote assertiveness, and guide the individual, family or community toward use of appropriate resources.

4. **Surveillance**: Activities such as detection, measurement, critical analysis, and monitoring intended to identify the individual/family/community's status in relation to a given condition or phenomenon.

Education in Palliative care. Situation in SPAIN

Study done Sept-October 2015,

- to identify which University Faculties and nursing schools in the country offer specific training in palliative care at undergraduate, master and doctoral degree. Compare with 2010/2011

- **Results** 101 schools and faculties enrolled in the National register,
- 48.51% of the centers specific training in palliative care in their curricula, either exclusively or shared with other
- In the curricula, 35 were specific for palliative care content,
- two thirds of which are compulsory
- the rest are optional
- 36.3% of subjects share the credits with contents as geriatrics, critical care or chronicity
- 63.6% are delivered only competencies in palliative care.

Education in Palliative care. Situation in SPAIN - 2

3 to 6 ECTS (European Credit Transfer System) in English equivalent to 25-30 hours of work per credit).

Study done Sept-October 2015

Not uniform

Less 20%

- During 3rd and 4th year of studies 85.71%
- In some Autonomous Communities–there is no Palliative content in nursing curricula
- Some Universities Huelva, Andalusia or Catalonia approaches done in multidisciplinary perspective. Exact diversity in Greece, Italy France, Cyprus or Malta

Psychological competencies CN's Palliative

Table 1. *Mean confidence scores by competency at pre-program and post-program (where 1 = not at all confident and 10 = very confident)*

Competency	Pre-program	Post-program
Knowledge of Psychological Theories of Adjustment and Loss		
1a. Knowledge of mood and adjustment difficulties.	4.9	8.1
1b. Knowledge of vulnerability to mood and adjustment difficulties.	4.9	8.0
1c. Knowledge of distress and coping.	5.2	8.4
Assessment of Psychological Wellbeing		
2a. Assess general psychological well being.	6.3	8.9
2b. Assess the impact of cancer of daily living.	6.3	8.4
2c. Screen for psychological distress using tools.	4.8	7.4
2d. Elicit worries and other concerns.	5.9	8.7
Psychological Interventions		
3a. Give information including breaking bad news.	7.1	8.9
3b. 'Hold' distress through periods of crisis and adjustment.	5.2	8.0
3c. Use psycho-education to support coping strategies of patients and carers.	4.5	7.9
3d. Use psycho-educational approaches to deal with specific symptoms.	4.7	7.6
3e. Offer advice about interventions to enhance self-care and control.	5.3	8.0
3f. Use psychological techniques based on training and experience.	4.3	7.9
3g. Refer appropriately to psychological/psychiatric specialist services.	6.5	8.9
Supervision		
4. Ability to access and use appropriate case work supervision and training.	5.8	8.9

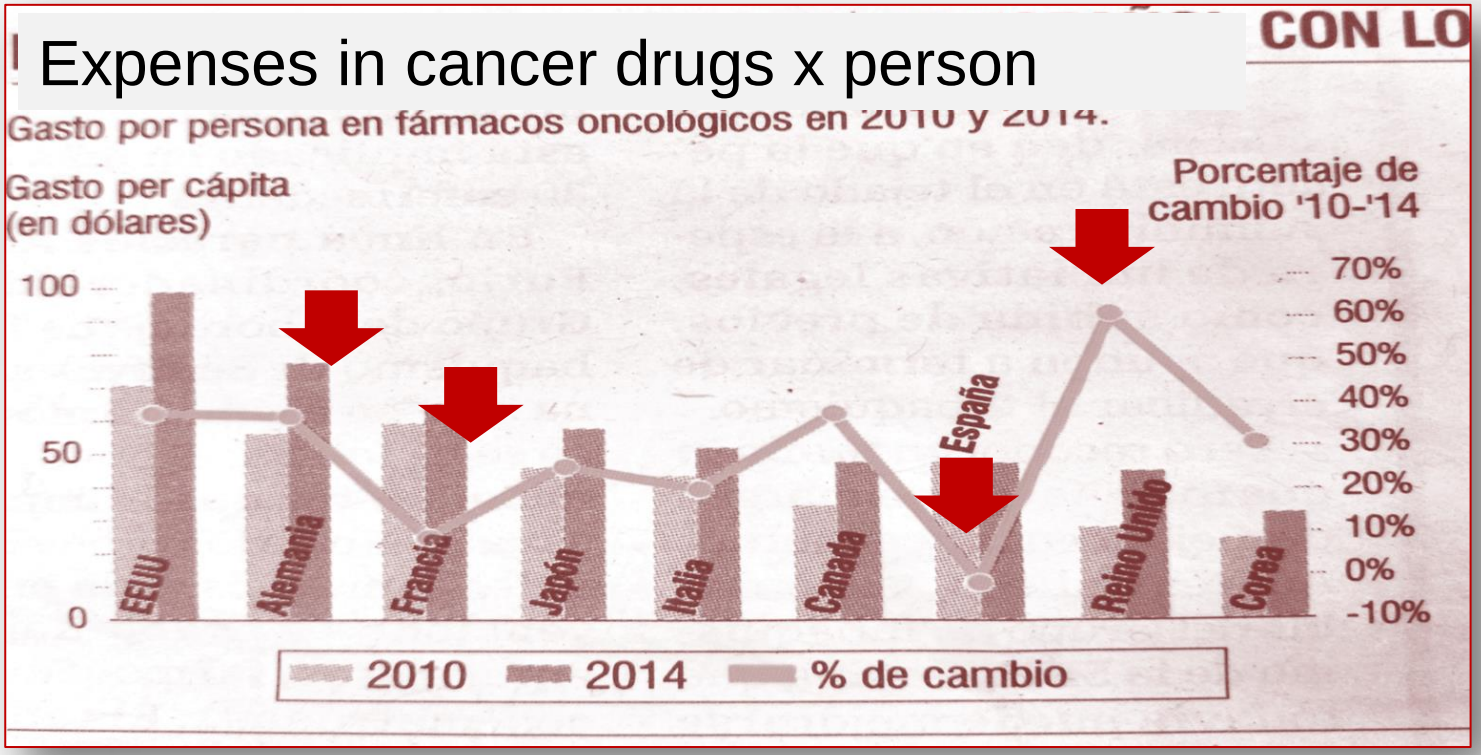
Indicator 4th Bereavement care&grief

- **Lacasta MA in 2016: Of 261 palliative care teams, they responded 78%** that they provided care to relatives in the Palliative unit and type of Bereavement care was:
  - few would provide follow-up after death
  - many only given to people who are at high risk of developing a complicated grief, or people without sufficient resources.
  - majority of units of CP have psychological service and standardized this measures after death occur.
- **How nurses responde to loss**? How is the experience of "Cumulative Grief"
- **Types of Organizational Support for professionals –** orientation to new nurses, home care staff

Indicator 5th: Participating in C.T - Research

- **enrollments in clinical trials for palliative patients:**
- Last ASCO congress, reported by **Betty R. Ferrell**
  - Cancer clinical trials are vital and patients should have the opportunity to participate in clinical trials.
  - Palliative patients may have benefit from the symptoms control, symptoms management & supportive in palliative care.
- This question has been not addressed often but it is now on the table

Expenditure medications...2010-2014



- Europe- common **National Health Systems** coverage
- Most of cancer Chemotherapy drugs are **hospital dispensed**, but most of the **supportive medications are payed by patients**. Copay systems
- Getting **funds from public & private** to improve palliative services

Final message:

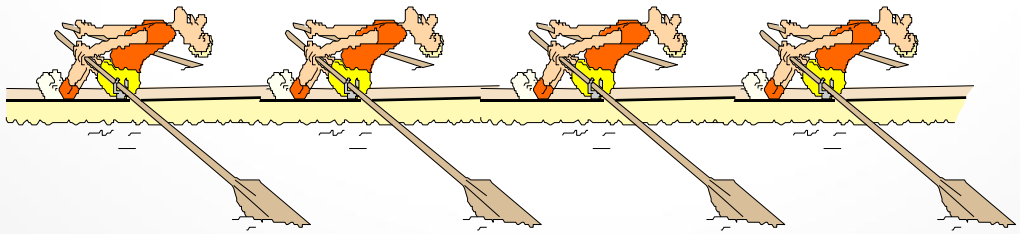
1. **Context in Europe is diverse** - inequalities. Patient and family needs are also divers and they have to be sensitively and culturally handled.

2. Patient **decision-making** could be increased if professionals is better educated and society are more sensitive

3. Healthcare **professionals**' medical and nurses **education and training** should be contemplate at pre and post-graduated level

4. **Indicators of Quality-** are **number of** services and type, but also pain-professional education, bereavement care, and research in Palliative

5. **Clinical Nurses CN's are ideally placed, and should lead** palliative care process and advance cancer patient follow -up



Thanks !

Teşekkürler !

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