Let’s talk about these persons
Prof Xavier Gómez-Batiste, MD, PhD

**Director**
- Qualy/WHO Collaborating Center for Palliative Care Palliative Care Programs. Catalan Institute of Oncology. Barcelona.
- Chair of Palliative Care, University of Vic
- Program for the Psychosocial and Spiritual Care of people with advanced chronic conditions and their families. La Caixa Foundation

**Chairperson**
- Former Medical Officer for Palliative and Longterm care. WHO HQ. Geneva
- Academic
- Research
- Consultation

Research:
- Epidemiology
- Effectiveness
- Services/program’s
• Palliative care as a Public Health issue and National Palliative Care Programs
• Developing palliative care programs in Spain: Extremadura and Catalonia
• Catalonia WHO Demonstration Project for Palliative Care implementation results at 20/25 years
• Qualitative evaluation: strengths, weaknesses, areas of improvement, and challenges
• Conceptual transitions and new definitions of palliative care at the XXI century
• Extending palliative approach for all patients in all settings: the MACA/NECPAL Program at the DoH
• Improving psychosocial and spiritual care: The Spanish La Caixa Foundation Program
• The next steps: community palliative care, society involvement, compassionate communities
• The Palliative Care Resolution and Initiative at the WHO HQ
• Interaction chronic/palliative care
• The areas of cooperation

Proposed outline
### Challenges

- How to extend palliative care
  - All patients: Targets?
  - All chronic conditions
  - All dimensions: multidimensional
  - Timely: 1st transition
  - All health and social settings
  - All countries
- Role of specialized services?
- Society involvement
- Sustainability

### Requisites: leadership!!!!

#### Policies
- Population approach
- District approach
- Community approach

#### Model of Care:
- Person-centred
- Comprehensive
- Essential needs

#### Model Organization:
- All settings
- Integrated
- Demographic scenarios
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Conceptual transitions in Palliative Care XXIc
XGB et al, BMJ SPC 2012
Special Article

The Public Health Strategy for Palliative Care

Jan Stjernswärd, MD, PhD, FRCP (Edin), Kathleen M. Foley, MD, and Frank D. Ferris, MD
Spain:
- Universal Health Care Coverage
- Free Access
- Public Health Primary Care System
- National EoL Strategy
- 17 Regional departments of Health

Extremadura:
- 1 milion
- Public Provision
- Rural
- Sparsely populated

Catalonia:
- 7.3 milion
- Urban/metropolitan/rural
- Sociohealth system
- Public funding
- Mixed provision
Existing Palliative Care has shown effectiveness and efficiency

- Improves symptoms
- Reduces suffering
- Reduces complex bereavement
- Increases satisfaction
- Reduces suffering

- Added values:
  - Comprehensive
  - Patients and families
  - Essential needs
  - Interdisciplinarity
  - Dignity
  - Ethics
  - Humanism

- Reduce use of hospital beds
- Reduce admissions and length of stay in hospital
- Reduce emergencies
- Cost of Palliative care beds 50% of conventional
  - Increases home care
  - Cost of health care 70% in the last 6 months
  - Cost of hospitals is 70% of the cost of End of life care
Special Article

The Catalonia World Health Organization Demonstration Project for Palliative Care Implementation: Quantitative and Qualitative Results at 20 Years

Xavier Gómez-Batiste, MD, PhD, Carmen Caja, RN, Jose Espinosa, MD, Ingrid Bullich, RN, Marisa Martínez-Muñoz, RN, Josep Porta-Sales, MD, PhD, Jordi Trelis, MD, Joaquim Esperalba, MD, MBA, and Jan Stjernsward, MD, PhD

The "Qualy" Observatory/WHO Collaborating Center for Palliative Care Public Health Programs (X.G.-B., J.E.R., M.M.-M., J.S.), Palliative Care Service (J.P.-S., J.T.), Catalan Institute of Oncology; and Catalan Department of Health (C.C., I.B., J.E.), Government of Catalonia, Barcelona, Spain
Catalonia 2014

- Coverage (geographic): 95%
- Coverage cancer: 73%
- Coverage non cancer: 40-56% (*)
- Proportion cancer/noncancer: 50%
- Nº Dispositives: 236
- Beds/milion: 101.6
- Full time doctors: 220 (30 / milion)

(*) McNamara, 2006
<table>
<thead>
<tr>
<th>Type of service</th>
<th>2010</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Care Support Teams (HCSTs) (*) (**)</td>
<td>72</td>
<td>73</td>
</tr>
<tr>
<td>Hospital Support or Consultation Teams (HST)</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td>Specific Support Teams to Nursing homes (STNH)</td>
<td>-</td>
<td>20</td>
</tr>
<tr>
<td>Psychosocial Support Teams (PSSTs)</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Palliative Care Units (PCU) in Intermediate Care Centers (*** )</td>
<td>28 PCU</td>
<td>28 PCU</td>
</tr>
<tr>
<td></td>
<td>383 Beds</td>
<td>383 Beds</td>
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<tr>
<td>Palliative Care Units in Nursing Homes</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>319 beds</td>
<td>358 beds</td>
</tr>
<tr>
<td>Palliative Care Units in acute hospital</td>
<td>5 PCU</td>
<td>5 PCU</td>
</tr>
<tr>
<td></td>
<td>40 Beds</td>
<td>40 Beds</td>
</tr>
<tr>
<td>PC Outpatient Clinics</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Private services</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>239 + 4 = 243</strong></td>
<td><strong>264 + 6 = 270 (+ 27)</strong></td>
</tr>
</tbody>
</table>

Institut Català d’Oncologia
Catalonia
WHO DP 1990-2015: resources (XGB et al, JPSM in press 2016)
Specific Resources / Settings

Acute Hospitals

Mid term and long term, RHB, (Sociohealth Centers)

Support teams to Nursing Homes: 20

Nursing homes

Primary care centers
Community / home

Units: 60
Support teams: Home 73
Hospital: 49
Outp’s / Day care
Psychosocial support teams: 9
Comprehensive system in small districts (20-50,000 hab)

Basic team intervening in every place, mixed cancer @ geriatrics, conventional beds

Comprehensive district system (16 sectors of 100-150,000 hab): integrated

PC Unit at the CSS, Support teams to Hospital, Home, and residences

Complex metropolitan systems: all levels (300-500,000 hab): levels, coordination, teaching and reference units

District organizational models
Sectorised Palliative Care Planning

**Context / Needs:**
- Demography
- Resources
- Type patients: cancer, geriatrics, aids, other
- Complexity
- Mortality / Prevalence
- Qualitative assessment (SWOT)

**Direct coverage for complex**
- Joint policies & shared care

**Coverage for all**

**Specialist Services**
- Estratification, identification and registry of target pats.
- Criteria intervention
- Continuing / emergency care / Coordination
- Information system
- Training / incentives

**+ Evaluation & Quality improvement**

**+ Palliative approach in all settings**

**+ Leadership**
Weak Points

- Low coverage noncancer, inequity variability, sectors and services (specific and conventional)
- Difficulties in access and continuing care (7/24)
- Late intervention
- Evaluation
- Psychosocial, espiritual, bereavement
- Volunteers
- Professionals: low income, support, and academic recognition
- Financing model and complexity
- Research and evidence

Quantitative / 5 years (Gómez-Batiste X et al, JPSM)
External evaluation of indicators (Suñol et al, 2008)
SWOT nominal group of health-care professionals (Gomez-Batiste X et al, 2007)
Focal group of relatives (Brugulat et al, 2008)
Efficiency (Serra-Prat et al 2002 & Gomez-Batiste et al 2006)
Cost / savings (Paz-Ruiz, Gomez-Batiste et al 2009)
Effectiveness (Gomez-Batiste et al, J Pain Symptom Manage 2010)
Satisfaction of patients and their relatives (Survey CatSalut, 2008)
New perspectives, new challenges:
• Palliative approach / chronicity
• Care of essential needs
• Psychosocial spiritual care
<table>
<thead>
<tr>
<th>Dimension</th>
<th>Action</th>
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<tbody>
<tr>
<td><strong>Policy / Public Health:</strong></td>
<td>- Development and validation of the <strong>NECPAL-CCOMS tool</strong> to identify individuals in need of palliative care</td>
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<td>- Interaction</td>
<td>- Development and validation of the <strong>ENP tool</strong> for psychosocial and spiritual needs</td>
</tr>
<tr>
<td>- Alignment with the WHO</td>
<td>- Determination of prevalence of individuals with palliative care needs and limited life prognosis in the population</td>
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<tr>
<td>Resolution of Palliative Care, people-centered</td>
<td>- MACA/NECPAL Program for early identification, registry and palliative approach/care of individuals with palliative care needs in</td>
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<tr>
<td>and integrated care initiatives</td>
<td>the community (primary care and nursing homes) from the Department of Health</td>
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<tr>
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<td>- Integrated care in districts</td>
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<td>- Codification and registry (Complex/Advanced Chronic) of the joint information system</td>
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<td><strong>New specific services /organizational changes</strong></td>
<td>- Psychosocial Support Teams</td>
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<td>- PC Support Teams in Nursing Homes</td>
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<td>- Primary Care Support for Nursing Homes (Geriatr-ICS Program)</td>
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<td>- Case management nurses in primary care services</td>
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<td><strong>Essential needs of patients</strong></td>
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<td><strong>Model of care</strong></td>
<td>- Spiritual care development</td>
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<td>- Comprehensive / Integrated model of care and intervention in individuals with advanced chronic conditions</td>
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<tr>
<td><strong>Training</strong></td>
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<td>- Chair of Palliative Care at the International University of Catalonia</td>
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<td></td>
<td>- Advance care planning (SCP)</td>
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<td>- Psychosocial/spiritual postgraduate course</td>
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<td>- Palliative care in the chronic care model</td>
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<td><strong>Research</strong></td>
<td>- 8 palliative care related PhD projects</td>
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<td>- Research group at the Catalan Institute of Oncology</td>
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**Conceptual transitions in Palliative Care XXIc**

XGB et al, BMJ SPC 2012
**Palliative approach and care in the evolution of patients with advanced chronic conditions**

1st transition

Building the epidemiology, clinical care, ethics and organization for the 1st transition

- Prevalence 1.0-1.5%
- Identified by tool
- Living in the community or nursing homes
- Frailty, multimorbidity, organ failures, dementia, cancer
- Prognostic: limited life prognosis (median survival around 2 years)
- Progressive impairment and loss
- Complex clinical decision-making combining curative/palliative
- More focus on
  - Advance care planning
  - Essential needs (spirituality, dignity, relations, hope, autonomy)
  - Psychosocial aspects (emotional, loss, family)
  - Bereavement
- Organizational: all services involved
Components to define target patients

Life prognosis:
- Limited
- Years, months, weeks

Interventions: “palliative approach” or “palliative care”: basic or complex
- Assessment
- Symptom control
- Emotional support
- Care of essential needs
- Ethical dilemmas
- Advance care Planning
- Case management, integrated and continuing care

Chronic, serious, life-threatening, illness or condition, mostly:
- Advanced
- Progressive
- Frequent crisis of needs
- High need and demand

Palliative needs of patient and family:
- Basic or complex
- Multidimensional
- Suffering
- Essential

“Palliative Cluster”

(Disease – specific interventions have mostly a progressively limited impact in modifying the course of disease, prognosis, and quality of life)
Terms considered most appropriate to describe the initiative

“Comprehensive, person-centred and integrated palliative approach and care for persons with complex advanced chronic conditions in all settings”
A Method for Defining and Estimating the Palliative Care Population

Beverley McNamara, PhD, Lorna K. Rosenwax, PhD, and C. D'Arcy J. Holman, MBBS, PhD


ded in mortality
Identification and palliative care approach of patients with advanced chronic diseases and limited life prognosis in health care services: the NECPAL/MACA Project in Catalonia

The ‘Qualy’ Observatory
WHO Collaborating Centre for Public Health Palliative Care Programmes
Chair of Palliative Care. University of Vic
&
Catalan Department of Health
Identifying patients with chronic conditions in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rates in Catalonia

Xavier Gómez-Batiste,1,2 Marisa Martínez-Muñoz,1,2 Carles Blay,2,3 Jordi Amblàs,4 Laura Vila,3 Xavier Costa,3 Alicia Villanueva,5 Joan Espauellà,4 Jose Espinosa,1 Montserrat Figuerola,1 Carles Constante6

ABSTRACT
Palliative care (PC) has focused on patients with cancer within specialist services. However, around 75% of the population in middle and high-income countries die of one chronic advanced disease. Early identification of such patients in need of PC becomes critical. In this feature article we describe the initial NECPAL (Necesitats Palliative i PC) Programme, which focuses on development of the NECPAL tool to identify patients in need of PC in the region. The NECPAL prevalence study, which aims to determine the prevalence of advanced chronic illness within the population and all socio-demographic groups of Catalonia, and thus implement the NECPAL Programme in the region, was presented during the NECPAL meeting. The main differences from the British reference tools on which NECPAL are based are highlighted. The preliminary results of the prevalence study show that 1.45% of the population and 7.71% of the population over 65 are in need of advanced PC palliative care. The tool is designed to assist with the development of advanced PC palliative care services and to facilitate the implementation of the NECPAL Programme in the region. The tool is supported by a website that provides educational material on PC palliative care and includes an interactive tool for the development of PC palliative care services. The tool is expected to be useful for healthcare professionals and policy makers in the development of PC palliative care services.
### The NECPAL-ICO-CCOMS © Tool

<table>
<thead>
<tr>
<th>Classification:</th>
<th>Codification and Registry</th>
</tr>
</thead>
</table>
| **Surprise Question (PS)** | **SQ + (I would not be surprised)**  
**SQ - (I would be surprised)** |
| **NECPAL Parameters** | **NECPAL + (die 1+ a 13+)**  
**NECPAL - (No parameters)** |

#### PATIENT: ________________________________  
HC: ________________________________  
DATE: ____/____/____  
SERVICE: ________________________________  
RESPONSIBLE(S): ________________________________

<table>
<thead>
<tr>
<th>Surprise Question (to/among professionals)</th>
<th>Would you be surprised if this patient dies within the next year?</th>
</tr>
</thead>
</table>
| **Demand** or **Need**                     | - Demand: Have the patient, the family or the team requested in implicit or explicit manner, palliative care or limitation of therapeutic effort?  
- Need: identified by healthcare professionals from the team |
| **General Clinical Indicators:** In the last 6 months | - Nutritional Decline  
- Functional Decline  
- Cognitive Decline |
| **Severe Dependence** | - Karnofsky < 50 or Barthel < 20 |
| **Geriatric Syndromes** | - Falls  
- Pressure Ulcers  
- Dysphagia  
- Delirium  
- Recurrent infections |
| **Persistent symptoms** | - Pain, weakness, anorexia, dyspnoea, digestive...  
- ≥ 2 symptoms (ESAS) persistent or refractory |
| **Psychosocial aspects** | - Distress and/or Severe adaptive disorder  
- Detection of severe emotional distress > 9 |
| **Multi morbidity** | - ≥ 2 advanced chronic diseases or conditions (from the list of specific indicators)  
- Social and family assessment |
| **Use of resources** | - Evaluate Demand/Intensity of Interventions  
- ≥ 2 urgent or non-planned admittances in last 6 months  
- Increase Demand/Intensity of interventions (homecare, nurse interventions, etc) |
| **Specific indicators** | - Cancer, COPD, CHD, Liver, Renal, CVA, Dementia, Neurodegenerative diseases, AIDS, other advanced  
- To be developed as annexes  
- Criteria of severity and progression |

[Image of form]
Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: A cross-sectional study

Xavier Gómez-Batiste¹,², Marisa Martínez-Muñoz¹,², Carles Blay²,³, Jordi Amblàs⁴, Laura Vila⁵, Xavier Costa⁵, Joan Espaulella⁴, Jose Espinosa¹,², Carles Constante⁶ and Geoffrey K Mitchell⁷

Abstract
Background: Of deaths in high-income countries, 75% are caused by progressive advanced chronic conditions. Palliative care needs to be extended from terminal cancer to these patients. However, direct measurement of the prevalence of people in need of palliative care in the population has not been attempted.

Aim: Determine, by direct measurement, the prevalence of people in need of palliative care among advanced chronically ill patients in a whole geographic population.

Design: Cross-sectional, population-based study. Main outcome measure: prevalence of advanced chronically ill patients in need of palliative care according to the NECPAL CCMS-ICO® tool. NECPAL+ patients were considered as in need of palliative care.

Setting/participants: County of Osona, Catalonia, Spain (156,807 inhabitants, 21.4% > 65 years). Three randomly selected primary care centres (51,595 inhabitants, 32.9% of County’s population) and one district general hospital, one social-health centre and four nursing homes serving the patients. Subjects were all patients attending participating settings between November 2010 and October 2011.

Results: A total of 785 patients (1.5% of study population) were NECPAL+: mean age = 81.4 years; 61.4% female. Main disease/condition: 31.3% advanced frailty, 23.4% dementia, 12.9% cancer (ratio of cancer/non-cancer = 1/7), 66.8% living at home and 19.7% in nursing home; only 15.5% previously identified as requiring palliative care; general clinical indicators of severity and progression present in 94% of cases.

Conclusions: Direct measurement of prevalence of palliative care needs on a population basis is feasible. Early identification and prevalence determination of these patients is likely to be the cornerstone of palliative care public health policies.

Populational Prevalence approach
• Population: 1-1.5%
• General Practitioner: 20-25
• District General Hospital: 38%
• University Hospital: 39%
• Internal Medicine: 47%
• ICU HUB: 30%
• Nursing homes: 40-70%

Prevalence x settings
### TABLE 3: Characteristics of SQ+ patients by disease / condition

<table>
<thead>
<tr>
<th></th>
<th>Cancer</th>
<th>Organ failure</th>
<th>Dementia</th>
<th>Advanced frailty</th>
<th>P- value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age Mean (SD)</strong></td>
<td>73.3 (13.9)</td>
<td>76.0 (14.0)</td>
<td>85.5 (6.5)</td>
<td>87.0 (6.8)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Male N (%)</strong></td>
<td>58 (57.43)</td>
<td>138 (54.12)</td>
<td>37 (19.89)</td>
<td>84 (29.47)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Female N (%)</strong></td>
<td>43 (42.57)</td>
<td>117 (45.88)</td>
<td>149 (80.11)</td>
<td>201 (70.53)</td>
<td></td>
</tr>
</tbody>
</table>

**Who need palliative care in the general population?**
**Total prevalence: 1-1.5%**

- **Male 75y**
  - cancer & organ failures

- **Females > 85y**
  - Severe frailty, multimorbidity & dementia
UK hospices 80’: Cancer; 21 days

HCST/HST: Cancer / noncancer 65/35%; 80 days

ICO outpts: Cancer 100%; 8 months

+ NECPAL Tool (community, hospital services, nursing homes, social-health centres): Noncancer / cancer 85 /15); 12-14 months

Earlier detection, proportion cancer /noncancer; time of intervention/survival and place & type of service of Patients with Palliative Care Needs

HCST: Home Care Support Team; HST: Hospital Support Team; ICO Outpts: Palliative Care Outpatient Clinic at the Catalan Institute of Oncology; + NECPAL Tool: patients identified by the NECPAL tool
The Palliative & Chronic care Program at the Catalan Department of Health

In Primary care services:
- Identificacion and registry
- Improved model of care
- Integrated care
- Shared information system

Added:
- Training
- ACP model and training
Evolution of complex & advanced patients identification from 2012 to 2015’set

- 2% of the total Catalanian population
- 40% of the target of complexity identified in 3 years

- MACA: Patients with advanced chronic conditions
- PCC: Patients with complex chronic conditions

SOURCE: HC3, 2015
Patient’s procedures

1. Identify, codify, register
2. Assess needs of patient and careers
3. Identify values, goals and preferences (ACP)
4. Review diseases and conditions
5. Review pharmacologic treatment
6. Build up a Therapeutic plan
7. Design a responsible, continuing and emergency care (Case Management)
8. Coordinate with other services: roles
<table>
<thead>
<tr>
<th>Action</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Multidimensional assessment: symptoms, emotional, essential-spiritual, adjustment, resources, context</td>
<td>Use validated tools</td>
</tr>
</tbody>
</table>
| 2. Explore worries, fears, values and preferences of patients and families | - Start Advance care planning  
- Shared decision making  
- Start discussion about the future |
| 3. Review state of diseases and conditions                            | - Stage, Prognosis, Possible complications  
- Therapeutic Aims  
- Recommendations to prevent / respond to crisis |
| 4. Review treatment                                                   | - Update aims  
- Adequacy  
- De-prescribing if needed  
- Conciliation between all services |
| 5. Identify, assess, and care primary career                          | - Assessment  
- Education and support  
- Empowerment |
| 6. Involve the team                                                   | - Assessment  
- Plan  
- Definition of roles |
| 7. Define, agree and start a Comprehensive Multidimensional Therapeutic Plan | - Respecting the preferences of patients  
- Addressing all the needs identified  
- Use the square of care model  
- Involving all team(s) |
| 8. Organize care with all services involved, with special emphasis in the role of specialized Palliative Care Services | - Case management  
- Shared care and decision making  
- Therapeutic pathways across settings  
- Look care and setting transitions  
- Therapeutic Conciliation between services |
| 9. Register and share key information with all involved services      | - In clinical charts  
- In shared information  
- In anticipatory care planning booklet  
- In reports of multi-disciplinary team meetings |
| 10. Evaluate / monitor outcomes                                       | - Using validated tools  
- Frequent review and update  
- After death clinical audit |
Improving palliative care in Health and Social services

1. Identify and register patients in need of palliative care approach
2. Training, policies and protocols of professionals in most prevalent situations
3. Multidisciplinary team approach
4. Identify primary career and family needs and choices
5. Improve accessibility, home care, intensity of care, etc
6. Case management, preventive approach, continuing care, coordination and integrated policies, district approach
<table>
<thead>
<tr>
<th>Actions to Improve Palliative Approach in Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establish and document a formal policy for palliative approach</td>
</tr>
<tr>
<td>Determine the prevalence and identify patients in need</td>
</tr>
<tr>
<td>Establish protocols, registers, and tools to assess patients’ needs and respond to most common situations</td>
</tr>
<tr>
<td>Train professionals and insert palliative care training and review in the conventional training process (sessions, etc)</td>
</tr>
<tr>
<td>Identify the primary carers of patients and give support and care, including bereavement</td>
</tr>
<tr>
<td>Increase team approach</td>
</tr>
<tr>
<td>In services with high prevalences: devote specific times and professionals with Advanced training to attend palliative care patients (Basic Palliative Care)</td>
</tr>
<tr>
<td>Increase the offer and intensity of care for identified persons focused in quality of life</td>
</tr>
<tr>
<td>Integrated care: Establish links, joint information system, criteria intervention and access to Palliative Care Specialized services and all services in the area</td>
</tr>
<tr>
<td>Address the ethical challenges of early identification</td>
</tr>
</tbody>
</table>

**10 actions to improve palliative approach in services**

X Gómez-Batiste, S Murray, S Connor, 2016
District Palliative Care Planning

Context / Needs:
- Demography
- Resources
- Type patients: cancer, geriatrics, aids, other
- Complexity
- Mortality / Prevalence
- Qualitative assessment (SWOT)

Direct coverage for complex
- Estratification, identification and registry
- Criteria intervention
- Continuing / emergency care / Coordination
- Information system
- Training / incentives

Joint policies & shared & integrated care

Good care for noncomplex

+ Evaluation & Quality improvement
+ Leadership

+ General Measures in conventional services

Specialist Services

Institut Català d’Oncologia
• Establish a formal national or regional policy with participation of patients and all stakeholders (professionals, managers, policymakers, funders)
• Determine (or estimate) the populational and setting-specific mortality and prevalence and needs assessment
• Elaborate, agree and validate an adapted tool for the identification
• Establish protocols to identify this patients in services
• Establish protocols to assure good comprehensive person-centered care for the identified patients
• Identify the specific training needs, train professionals and insert palliative care training in all settings
• Promote organisational changes in primary care, Palliative Care Specialised, Conventional services and integrated care across all settings in districts
• Identify and address the specific ethical challenges
• Insert palliative approach in all policies for chronic conditions (cancer, geriatrics, dementia, other,...)
• Establish and monitorise indicators and standards of care and implementation plans and generate research evidence

10 actions for establishing a national/regional policy for comprehensive and integrated palliative approach X Gómez-Batiste, S Murray, S Connor, 2016
Ethical approach: Benefits & risks

- Starting Systematic process: Needs assessment, Advance Care Planning, Review of Condition and treatment, Family involvement, Case management, Continuing care, etc
- Patient’s involvement/ACP
- Starting palliative perspective
- Adequation vs limitation of resources
- Increasing home care

- Estigma
- Abandonment
- Dichotomic perspective
- Reducing curative opportunities
- Impact on patients and families
- Misuse to reduce cost

X Gómez-Batiste et al, J of Palliat Care 2016, in press
Prognostic approach

X Gómez-Batiste et al, Palliat Med, 2016, 2nd review
A Calsina et al, J of PM, sended
FIGURE 4: Models of palliative interventions in chronic advanced palliative care

Current model: “Late, Reactive and Fragmented”

Proposed model “Early, Preventive and Integrated”

- Mostly cancer 70 /30%
- Mostly in palliative care services
- Late
- Median length survival 2-3 months
- Late Identification in Pal Care services
- Reactive / after crisis / Post acute
- Emergencies
- Fragmented care

- Mostly non-cancer 85 / 15%
- Mostly in community services
- Early
- Median length survival 24 months
- Preventive / Planned
- Timely identification in the Community
- Advance care planning
- Case management
- Integrated care
Adapting palliative care services

- From passive, late, one-directional dychotomic intervention based in prognosis
- to timely, flexible, cooperative, shared, based in complexity
- From cancer to all
- Training:
  - Clinical
  - Ethical
  - Organizational / managerial
- From service to population
- From own to all services’ approach
- Resistances and barriers

Change of perspective!!!!
Adapting palliative care national / regional programs

- New epidemiology: from mortality to prevalence
- New perspective: from services to population
- New organization:
  - integrated care, networks, sectors
  - All services

Change of perspective!!!!

New opportunity to reform

From WHO Resolution to Revolution
New perspectives, new challenges:
• Care of essential needs
Model of personal & profesional competencies for palliative care provision

**Values and behaviours:** hospitality, empathy, compassion, commitment, presence, honesty, congruence,..

**Care of essential needs:** Spirituality, dignity, autonomy, relations, hope,..

**Clinical care:** assessment, symptoms, medicines,..

**Communication / Emotional / Counselling**

**Ethics / Advance Care Planning**

**Continuity / Case Management / Integrated care**

**4 Basic Care Competences**

**Personal values:** Education and respect

**Organizational Context:** Values / Leadership / Team approach / Networking

**Social values & Policy context:** Human rights, Universal Health Coverage, Access, Equity, Quality

<table>
<thead>
<tr>
<th>Steps for excellent care</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Create a context of application of basic personal behavior and basic care competence: privacy, safety, comfort, symptom control, communication, active listening, counseling, ethical decision-making, advance-care planning, case management and continuity.</td>
</tr>
<tr>
<td>2. Start gradually, gently and slowly to explore dimensions, with open questions.</td>
</tr>
<tr>
<td>3. Establish a common language, understanding, goal-orientation, confidence relationship.</td>
</tr>
<tr>
<td>4. Explore the information, experience, meaning &amp; adjustment to disease.</td>
</tr>
<tr>
<td>5. Explore &amp; promote life review, identify goals, meaning, values, beliefs, legacy, previous crises and experiences.</td>
</tr>
<tr>
<td>6. Explore &amp; promote the quality of family and social relationships.</td>
</tr>
<tr>
<td>7. Explore &amp; promote reflection on unfinished business, relations, forgiveness, guilt.</td>
</tr>
<tr>
<td>8. Explore &amp; promote religious expressions and practice.</td>
</tr>
<tr>
<td>9. Review and readjust goals, language, and expectations to prevent misunderstandings &amp; to promote hope.</td>
</tr>
<tr>
<td>10. Prevent crises and explore scenarios of decision-making choices.</td>
</tr>
<tr>
<td>11. Offer and guarantee support and accessibility.</td>
</tr>
</tbody>
</table>
New perspectives, new challenges:
• Psychosocial spiritual care
Program for the comprehensive psychosocial and spiritual care of patients with advanced conditions and their families

La Caixa Foundation & WHOCC Barcelona
What we do

**Emotional and social care**
- Providing psychological and social care measures to help patients and their families face the illness.

**Spirituality**
- Includes spiritual aspects that enable patients and their families to face the final process in complete respect for individual beliefs and convictions.

**Grieving**
- Care for all those involved in the loss of a loved one that require or request support.

**Volunteers**
- By providing personal support, volunteers provide a response to the social needs of patients and their families.

**Proffesional Support**
- Specific support for healthcare workers in subjects such as communication in difficult situations and stress management.
How we do it, and with whom

Structure

42 Psychosocial Care Teams (EAPS) distributed around the 17 autonomous communities.

200 multidisciplinary professionals (psychologists, social workers and nurses)

511 volunteers

Sphere of action

126 hospitals

109 home care teams/ hospitals

Concept of Psychosocial support teams giving support to existing services
ORIGINAl ARTICLES

The "La Caixa" Foundation and WHO Collaborating Center Spanish National Program for enhancing psychosocial and spiritual palliative care for patients with advanced diseases, and their families: Preliminary findings

XAVIER GÓMEZ-BATISTE, M.D., Ph.D., 1 MONTSE BUISAN, B.Sc. (Psyc.), 2 M. PAU GONZÁLEZ, B.Sc. (Psyc.), 1 DAVID VELASCO, B.Sc. (Psyc.), 2 VERÓNICA DE PASCUAL, L.L.B., 2 JOSE ESPINOSA, M.D., 1 ANNA NOVELLAS, B.A. (Sociol.), 1 MARISA MARTÍNEZ-MUÑOZ, R.N., 1 MARC SIMÓN, M.B.A., 2 CANDELA CALLE, M.D., 3 JAUME LANASPA, M.B.A., 2 AND WILLIAM BREITBART, M.D.
Care delivery details: more than **40,000 patients** and more than **65,000 relatives**

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>6.957</td>
<td>8.385</td>
<td>10.203</td>
<td>12.422</td>
<td>6.070</td>
<td>44.037</td>
</tr>
<tr>
<td>Family Members</td>
<td>11.011</td>
<td>13.885</td>
<td>15.738</td>
<td>17.468</td>
<td>7.784</td>
<td>65.886</td>
</tr>
</tbody>
</table>

>200,000 persons cared

8.5 milion Euros / year
Other Results:
Efectiveness
Satisfaction:
Families
Stakeholders
Quality / organizational audit
Interaction
Chronic
&
Palliative Care
Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach

Xavier Gómez-Batiste\textsuperscript{a,b}, Marisa Martínez-Muñoz\textsuperscript{a,b}, Carles Blay\textsuperscript{b,c}, Jose Espinosa\textsuperscript{a,b}, Joan C. Contel\textsuperscript{c}, and Albert Ledesma\textsuperscript{c}

Purpose of review
We describe conceptual innovations in palliative care epidemiology and the methods to identify patients in need of palliative care, in all settings. In middle- and high-income countries, more than 7.5\% of the population will die from chronic progressive diseases. Around 1.2–1.4\% of such populations suffer from chronic advanced conditions, with limited life expectancy. Clinical status deteriorates progressively with frequent crises of needs, high social impact, and high use of costly healthcare resources.

Recent findings
The innovative concept of patients with advanced chronic diseases and limited life prognosis has been addressed recently, and several methods to identify them have been developed.

Summary
The challenges are to promote early and shared interventions, extended to all patients in need, in all settings of the social care and healthcare systems; to design and develop Palliative Care Programmes with a Public Health perspective. The first action is to identify, using the appropriate tools early in the clinical evolution of the disease, all patients in need of palliative care in all settings of care, especially in primary care services, nursing homes, and healthcare services responsible for care provision for these patients; to promote appropriate care in patients with advanced diseases with prognosis of poor survival.

Keywords
advanced chronic patients, chronic care, planning, policy, stratification
**Models of palliative interventions in chronic care:**
from late, institutional, reactive and fragmented to early, community, preventive and integrated

- Mostly cancer 70 /30%
- Mostly in palliative care services
- Late
- Median length survival 2-3 months
- Identification in Pall Care services
- Reactive / after crisis
- Post acute
- Emergencies
- Fragmented care

- Mostly non-cancer 85 / 15%
- Identification mostly community services
- Early
- Median length survival 24 months
- Preventive / Programmed
- Advance care planning
- Case management
- Integrated care

XGB et al, 2012
Adapting the clinical, ethical & organizational perspectives of palliative approach & palliative care to the evolution of persons with advanced chronic conditions

**Longterm Chronic Complex Condition**
- Disease-centered
- Survival, sec/tert prevention
- Build confidence
- Shared Decission-making
- Common language
- Advance directives
- Disease / Care management
- RHB
- Primary & secondary specialist care

**Advance d chronic disease / condition**
- Condition & QoL
- Multidimensional assessment
- Advance Care Planning
- Values & Preferences &Scenarios
- Crisis prevention
- Gradual palliative care approach
- Gradual essential needs
- RHB
- Case management & Integrated care
- Primary care & secondary & occasional palliative care

**Terminal condition**

**Time line:**
--- 2-5 years --- 2 years --- 6 months

**“Complex Chronic condition”**
- QoL
- Review & Adjust frequently
- Essential needs
- Sedation
- Elarging / shortening life
- Nutrition/hydration
- Bereavement
- Primary & palliative care (if needed) shared care

**“End of life or terminal”**
FIGURE 8: Place of identification, types of patients, and median survival of patients with palliative care needs identified in the community.

Specialist Pall care services; Cancer / non-cancer 65/35%; 1-3 months.

Community, hospital services, nursing homes, social-health centres): Non-cancer / cancer 85/15; 24 months.
Palliative care approach: the “soul” of Chronic Care Programmes
WHO INITIATIVE FOR PALLIATIVE CARE: STRATEGY AND ACTION PLAN
(1) to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to **integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes**;

(3) to develop and strengthen, where appropriate, evidence-based guidelines **on the integration of palliative care into national health systems, across disease groups and levels of care, that adequately address ethical issues related to the provision of comprehensive palliative, such as equitable access, person-centred and respectful care, and community involvement, and to inform education in pain and symptom management and psychosocial support**
Global Atlas of Palliative Care at the End of Life

• 57 million deaths / 38 million of diseases requiring palliative care
• 60-80% of mortality in most countries
• 60-70% in need of palliative care
• Around 1% of population (73 million) in need
• 27 million persons die every year with palliative care needs (66% adults > 60, 10% children)
• 27x3 = 81 million persons affected (family careers)
• > 50 millions prevalent
• 78% in low-middle income countries
• 86% non-communicable diseases
• Causes vary in regions: HIV/AIDS in Africa, multi-morbidity in Europe
• < 20% of people with pain have access to essential pain drugs as opioids

Epidemiology of palliative care needs (Source: Global Atlas)
<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
<th>N (%)</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>No known activity</td>
<td>75 (32.0)</td>
<td>No services: 42.0%</td>
</tr>
<tr>
<td>Group 2</td>
<td>Capacity building pioneers with no services</td>
<td>23 (10.0)</td>
<td></td>
</tr>
<tr>
<td>Group 3</td>
<td>3a Isolated provision</td>
<td>74 (31.6)</td>
<td>Isolated: 31.6%</td>
</tr>
<tr>
<td></td>
<td>3b Generalized provision</td>
<td>17 (7.3)</td>
<td>Generalized Provision: 26.6% (Inserted 19.3%) (Fully integrated 8.6%)</td>
</tr>
<tr>
<td>Group 4</td>
<td>4a Preliminary insertion in the mainstream</td>
<td>25 (10.7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4b Full integration into the mainstream</td>
<td>20 (8.6)</td>
<td></td>
</tr>
</tbody>
</table>

Countries by level of Palliative Care development (Source: Global Atlas)
Vision: main objectives at long-term

• All Member States having Palliative care fully integrated in their National Health Services
• Palliative Care and essential drugs available, accessible to all in all settings of care
• Palliative care applied as a human right
• Low income countries
• Countries without any implementation
• Access to essential medicines
• Model of care: essential needs (spirituality) and ethics (advance care planning)
• Primary and community perspective
• Early Palliative care for persons with long-term/chronic conditions
• Integrated / comprehensive models of organization
• Leadership: Clinical, organizational & policy

Special areas of interest
WHO DEMONSTRATION PROJECTS

Aims:
• Generate experience and evidence
• Innovation
• Involve different actors
• Recognise experiences

Settings:
• Low-middle income countries
• Regions: Africa, Asia, Latin america
• Different target patients
• Different settings: community, nursing homes, districts, …

Methods:
• Of priority issues
• Clear aims
• WHO and Public Health principles
• Clear leadership
• Institutional commitment
• Clear methodology
• Commitment to evaluation
• Commitment to publish results
• Share experience
• Benchmark

Organization:
• WHO and WHOCC leadership
• Common website
• Regular Evaluation
WHO proposal for Palliative care & approach

All patients
All conditions
   All time
   All needs
All professionals
All settings
All countries
1) Organizing Palliative care at WHO HQ and regions with all clusters and involvement of WHOCCs
2) Information sent & training offered to Focal points, WHO CRs, Ministries
3) Consensus WHO – Drug control agencies
4) Consensus main stakeholders: Professional leaders and organizations, NGOs, partners
5) Build and disseminate the knowledge for capacity building: Guidelines, manuals and tools
6) Build and implement the methods for training
7) Start implementation in country’ support initiatives and demonstration projects
8) Define evaluation plan: methodology and indicators (Globally and at a National level)
9) Funding, Marketing, and Dissemination

Operational objectives to start 2015-2016
1. High degree of internal and external consensus with WHO leadership and innovation
2. Significant increase of Countries with Palliative Care Plans and Essential Drugs available, and demands for Technical Assistance
3. Guidelines, Manuals, Tools and Training activities available and disseminated
4. Country National Programs going on
5. Countries developed access to essential drugs
6. Demonstration Projects going on
7. WHOCCS Global network
8. Acquired Experience and Evidence
9. Innovative Perspectives of Palliative Care
10. Stable funding and support
Palliative care: basic human right indicator of degree of respect for human dignity. All countries
Palliative care: the soul of the health care system
You all matter for WHO