Let’s talk about this patients.....
Suport a Programes de 52 països
Suport al D Salut, ICS, Caixa, altres
Càtedra UVIC/ICO/CCOMS de Cures Pal·liatives
Chair UVIC/ICO/WHOCC of Palliative Care
Atenció pal·liativa de persones amb malalties avançades i llurs famílies a la comunitat
Palliative Approach for persons with advanced chronic conditions and their families in the community
Program for the comprehensive psychosocial and spiritual care of patients with advanced conditions and their families

La Caixa Foundation & WHOCC Barcelona
## Conceptual transitions in Palliative Care in the XXI century

<table>
<thead>
<tr>
<th>FROM</th>
<th>Change TO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Terminal disease</td>
<td>Advanced progressive chronic disease</td>
</tr>
<tr>
<td>Prognosis of weeks or months</td>
<td>“Limited life prognosis”</td>
</tr>
<tr>
<td>Cancer</td>
<td>All chronic progressive diseases and conditions</td>
</tr>
<tr>
<td>Disease</td>
<td>Condition (multi-pathology, frailty, dependency, .)</td>
</tr>
<tr>
<td>Progressive course</td>
<td>Frequent crises of needs and demands</td>
</tr>
<tr>
<td>Mortality</td>
<td>Prevalence</td>
</tr>
<tr>
<td>Dichotomy curative - palliative</td>
<td>Synchronic, shared, combined care</td>
</tr>
<tr>
<td>Specific OR palliative treatment</td>
<td>Specific AND palliative treatment needed</td>
</tr>
<tr>
<td>Prognosis as criteria intervention</td>
<td>Complexity as criteria</td>
</tr>
<tr>
<td>Rigid one-directional intervention</td>
<td>Flexible intervention</td>
</tr>
<tr>
<td>Passive role of patients</td>
<td>Advance care planning / Autonomy</td>
</tr>
<tr>
<td>Reactive to crisis</td>
<td>Preventive of crisis / Case management</td>
</tr>
<tr>
<td>Palliative care services</td>
<td>+ Palliative care <em>approach</em> everywhere</td>
</tr>
<tr>
<td>Specialist services</td>
<td>+ Actions in all settings of health care</td>
</tr>
<tr>
<td>Institutional approach</td>
<td>Community approach</td>
</tr>
<tr>
<td>Fragmented care</td>
<td>Integrated care</td>
</tr>
</tbody>
</table>

Gómez-Batiste X et al, Current Opinion in Supportive Palliative Care, 2012
Gómez-Batiste X et al, BMJ SPCare, 2012
Gómez-Batiste X et al, Medicina Clínica, 2013
The Catalonia WHO Demonstration Project on Palliative Care implementation: results at 20 years and challenges

X Gómez-Batiste MD, PhD
The ‘Qualy’ End of Life Care Observatory
WHO Collaborating Centre for Public Health Palliative Care Programmes
Chair of Palliative Care. University of Vic
Institut Català d’Oncologia

2012
Catalonia 2012

- 7,300,000 inhabitants (4.5 in Metropolitan Barcelona)
- > 65 years: 17%
- 60,000 people with dementia
- 130,000 elderly with pluripatatology and dependency
- Mortality rate: 9 / 1,000
- Life expectancy: 82
Catalonia: Mortality / prevalence

Mortality
• Global: 60,000
• Cancer: 16,000
• Noncancer chronic: 29,000
• Total chronic conditions: 45,000
• Cancer / noncancer

Prevalence of terminal patients (*):
• Cancer: 4,000 (mean survl 3 months)
• Other conditions: 18,000 (mean sl 9 months)
• Total: 22,000

(*) Previous Estimation based in McNamara, 2006
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
Institut Català d’Oncologia

Care Resources 2009 (Total: 236)

HSTs: 49

Outps: 50

PADES: 74

PCUs: 60

Other: 10
<table>
<thead>
<tr>
<th>DIRECT</th>
<th>PC Services</th>
<th>Acute: 32</th>
<th>Non Acute: 27</th>
<th>Total: 59</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatients</td>
<td>CExt EIAIA: 22</td>
<td>CExt convenc: 28</td>
<td>Total: 50</td>
<td></td>
</tr>
<tr>
<td>Hospital Support Teams</td>
<td>38</td>
<td>Total: 38</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Support Teams</td>
<td>74</td>
<td>Total: 74</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psicosocial Support Teams</td>
<td>5</td>
<td>Total: 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>231</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| INDIRECT                           | Planning Research Knowledge Training | Dpment of Health - PDSS Catalan Institute of Oncology – Training & Research Dpments The ‘Qualy’ Observatory/WHOCC | 5 |
| TOTAL SPECIFIC RESOURCES PC       | **236**     |            |              |
Catalonia 2010

- Coverage (geographic): 100%
- 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
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.

- 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)
- Effectiveness (Gomez-Batiste et al, J Pain Symptom Manage 2010)
- Satisfaction of patients and their relatives (Survey CatSalut, 2008)

**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, bereavement
- Professionals: low income, support, and academic recognition
- Financing model and complexity
- Research and evidence
New perspectives, new challenges:
• Palliative approach / chronicity
• Care of essential needs
• Psychosocial spiritual care
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 Espaullella,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 of the chronic diseases. Early identification of such patients in need of PC becomes important. In this feature article we describe the development of the NECPAL (NECtality Palliative Programme) tool. The focus is on PC in patients in need of PC. The NECPAL tool is an extension of the NECPAL tool developed by the NECPAL Programme. The tool is designed to assess the prevalence of chronic conditions in the population and identify patients with chronic conditions who may benefit from PC. The tool is designed to improve PC in patients with chronic conditions, and to identify patients with chronic conditions who may benefit from PC. The tool is designed to improve PC in patients with chronic conditions, and to identify patients with chronic conditions who may benefit from PC.

Gómez-Batiste X, et al. BMJ Supportive & Palliative Care 2012;0:1–9. doi:10.1136/bmjjspcare-2012-000211

The concept is that PC measures need to be applied in all settings of healthcare systems (HCS). The population-based...
The NECPAL / MACA WHOCC & Dep of Health Program: components

- **Research**
  - Construction and validation of tool
  - Prevalence study
  - Prognostic cohort study
- **Implementation (WHOCC & Department of Health)**
  - Territories
  - Settings
- **Tools:** Identification, How to, District approach
- **Research:** Evaluation of the impact of implementation
- **Setting up Public Health Policy:** coverage
Building the NECPAL Tool
Three triggers for Supportive/ Palliative Care - to identify these patients we can use any of the following methods:

1. The surprise question, "Would you be surprised if this patient were to die in the next 6-12 months" - an intuitive question integrating co-morbidity, social and other factors.

2. Choice/ Need - The patient with advanced disease makes a choice for comfort care only, not ‘curative’ treatment, or is in special need of supportive/palliative care.

3. Clinical indicators - Specific indicators of advanced disease for each of the three main end of life patient groups - cancer, organ failure, elderly frailty dementia (see over)
<table>
<thead>
<tr>
<th>Surprise question</th>
<th>Would you be surprised if this patient dies within 1 year?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need, demand and choice</td>
<td>Any request to limit the treatments or palliative care from patient, family, or team members?</td>
</tr>
<tr>
<td><strong>General clinical indicators</strong> (severe, progressive, sustained, not related to intercurrent process)</td>
<td>Nutritional decline</td>
</tr>
<tr>
<td><strong>Combined Severity AND Progression</strong></td>
<td>Functional decline</td>
</tr>
<tr>
<td></td>
<td>Severe psychological adjustment difficulties</td>
</tr>
<tr>
<td>Co-morbidity</td>
<td>- 3 + chronic diseases</td>
</tr>
<tr>
<td></td>
<td>- Geriatric syndromes</td>
</tr>
<tr>
<td></td>
<td>- Severe complications</td>
</tr>
<tr>
<td>Use of resources</td>
<td>- &gt;3 urgent admissions in 6 months</td>
</tr>
<tr>
<td>Specific indicators</td>
<td>Cancer, COPD, Heart, Hepatic or Renal Failure, Neurological, Stroke, Dementia, AIDS, other</td>
</tr>
</tbody>
</table>

**The NECPAL-WHOCC Tool**

(*) In red, the differences with PIG/SPCIT
The prevalence study

Palliative Medicine

Prevalence and characteristics of patients with advanced chronic diseases and conditions in need of palliative care in the general population: a cross-sectional study
0. Total population registered
   • “Chronic lists” (Patients with Chronic conditions)
     • “Advanced chronic patient’s” list (“Level 1”)

3. Surprise question negative (“SQ +” or “Level 2”)
   +/-

4. Other + parameter (“NECPAL +” or “Level 3”)

**Procedure of recruitment of patients** (Doctor & Nurse in every setting)
Random populational sample of Primary Care Services
<table>
<thead>
<tr>
<th>Description</th>
<th>n (% Total Pop)</th>
<th>n (% Pop ≥65)</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Advanced chronic” list (Level 1)</td>
<td>1064 (2.06%)</td>
<td>972 (10.91%)</td>
</tr>
<tr>
<td>SQ- (Surprise Question «negative» / Level 2)</td>
<td>750 (1.45%)</td>
<td>687 (7.71%)</td>
</tr>
<tr>
<td>SQ- + 1 additional criteria / Level 3 (NECPAL +)</td>
<td>684 (1.33%)</td>
<td>623 (7.00%)</td>
</tr>
</tbody>
</table>

N & % of recruited / level / population
Main characteristics

- Age (mean): 82
- Female 65%
- Frailty + Multimorbidity 32% +/- dementia 23% = 55%
- Cancer & Individual Organ failures: 45%
- Cancer/noncancer: 1/7
- Home: 65%
- Nursing home: 22%
<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>

TABLE 3: Characteristics of SQ+ patients by disease / condition

Homes 75a amb càncer y insufic. orgàniques a Hospital y CSS

Dones > 85a amb demència y fragilitat severa en residències / domicili
Prevalence x settings

<table>
<thead>
<tr>
<th>Setting</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>20-25</td>
</tr>
<tr>
<td>District General Hospital</td>
<td>38%</td>
</tr>
<tr>
<td>University Hospital HUB</td>
<td>39%</td>
</tr>
<tr>
<td>Internal Medicine HUB</td>
<td>47%</td>
</tr>
<tr>
<td>ICU HUB</td>
<td>30%</td>
</tr>
<tr>
<td>Nursing homes</td>
<td>40-70%</td>
</tr>
</tbody>
</table>
The cohort study

1,064 patients included
Estimation of Survival of NECPAL +

Cohort study at 1 year:

- 1,064 patients included
- Estimation of survival
  - Mean: 16-18 months
  - Median: 16
- Mortality at 1 year: 40%

Regression analysis will identify individual factors
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
District 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 & integrated care

Good care for noncomplex

Specialist Services
- Estratification, identification and registry
- Criteria intervention
- Continuing / emergency care / Coordination
- Information system
- Training / incentives

+ General Measures in conventional services

+ Evaluation & Quality improvement
+ Leadership
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: rols
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
Benefits & risks: Ethical approach

- 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
- Dichotomistic perspective
- Reducing curative opportunities
- Impact on patients and families
- Misuse to reduce resources
New perspectives, new challenges:
• Care of essential needs
The clinical / individual perspective
Model of needs

**Vol. 24 No. 2 August 2002**

A Model to Guide Patient and Family Care

**Model of needs**

- **Disease Management**
  - Primary diagnosis, prognosis, evidence
  - Secondary diagnoses (e.g., elements, psychiatric diagnosis, substance use, trauma)
  - Comorbidities (e.g., depression, anxiety, organ failure)
  - Adverse events (e.g., side effects, toxicity)

- **Physical**
  - Pain and other symptoms
  - Level of consciousness, cognition
  - Function, safety, skin:
    - Motor (e.g., mobility, swallowing, excretion)
    - Sensory (e.g., hearing, sight, smell, taste, touch)
    - Physiologic (e.g., breathing, circulation)

- **Psychological**
  - Personality, strengths, behaviour, motivation
  - Depression, anxiety
  - Emotions (e.g., anger, distress, hopelessness, loneliness)
  - Fear (e.g., abandonment, burden, death)
  - Control, dignity, independence

- **Social**
  - Cultural values, beliefs, practices
  - Relationships, roles with family
  - Community
  - Isolation, abandonment, reconciliation
  - Safe, comforting environment
  - Privacy, intimacy
  - Routine, rituals, recreation, vocation
  - Financial resources, expenses
  - Legal (e.g., power of attorney, advance directives, test or testamentary, beneficiaries)
  - Family, personal, legal, religious, cultural

- **Patient and Family Characteristics**
  - Demographics (e.g., age, gender, race, contact information)
  - Culture (e.g., ethnicity, language, subculture)
  - Personal values, beliefs, practices
  - Strengths
  - Developmental stage, education, literacy
  - Disabilities

- **Practical**
  - Activities of daily living (e.g., personal care, household activities, see detailed listing on page 91)
  - Dependents, pets
  - Telephone access, transportation

- **Spiritual**
  - Meaning, value
  - Existential, transcendental
  - Values, beliefs, practices, affiliations
  - Symbols, icons

**Loss, Grief**
- Loss (e.g., acute, chronic, anticipatory)
- Bereavement planning
- Mourning

**End of Life Care/Death Management**
- Life closure (e.g., completing business, closing relationships, saying goodbyes)
- Care giving (e.g., money, organs, thoughts)
- Legacy creation
- Preparation for expected death
- Anticipation and management of physical changes in the last hours of life
- Rituals, rituals
- Pronouncement, certification
- Perinatal care of family, handling of the body
- Funeral, memorial services, vaccinations

**Other common symptoms include, but are not limited to**
- Cardio-respiratory: shortness of breath, cough, edema, cardiac, opiate, agonal breathing patterns
- Gastrointestinal: nausea, vomiting, constipation, obstruction, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia
- Oral conditions: dry mouth, mucositis
- General: agitation, anorexia, fatigue, weakness, bleeding, delirium, confusion, fever/chills, infection, nausea, pneumonia, myelosuppression, odor, petechiae, sweats, syncope, vertigo

*Fig. 2: Issues common to illness and bereavement.*

**Ferris, 2002**
Trajectories & workload

GP's workload - Average 20 deaths/GP/yr (approximate proportions)

- Cancer: 1/4
- Frailty / Dementia: 1/3
- Organ Failure: 1/3
- Sudden Death: 1/12

"Cancer" Trajectory, Diagnosis to Death
- Onset of incurable cancer
- Time: Often a few years, but decline usually seems ~2 months

Organ System Failure Trajectory
- Begins to use hospital often, self-care becomes difficult
- Time: ~2-5 years, but death usually seems "sudden"

Frailty / Dementia Trajectory
- Onset could be deficits in ADL, speech, ambulation
- Time: ~ quite variable - up to 6-8 years

Source: GSF NHS
Figure 2: Physical, social, psychology and spiritual wellbeing in the last year of life

Trajectories
- Physical
- Social
- Psychological
- Spiritual

Wellbeing vs. Distress

acute exacerbations

Palliative phase

Death

Disabilities at the last year of life

The care of essential needs

Needs of patients with advanced conditions

Essential:
• Dignity
• Spirituality
• Love & tenderness
• Autonomy
• Hope

Basic:
• ADL
• IADL
• Security…
• Privacy…
ESSENTIAL NEEDS
Spirituality, Dignity, Autonomy, Hope, Family & Relations

BASIC NEEDS
ADLs, IADLs, Comfort, Relations, Safety

CONTEXT
Patient: Relational, Social, Family, Economic Resources

CONTEXT
Institutional: Values, Culture, Policies, Team, Organization
Atmosphere
Components of the Model

Values, attitudes, behaviours:
- Hospitality
- Empathy
- Compassion
- Commitment
- Congruence
- Presence
- Confidence
- Honesty

Abilities to respond to essential needs:
- Dignity
- Spirituality
- Family and key relations
- Hope
- Autonomy

Abilities regarding basic healthcare:
- Clinical: Symptoms & Disease management
- Communication & Counselling
- Ethics & Advance Care Planning
- Continuity & Case management

Best personal behaviour & good manners

MODEL OF ESSENTIAL ABILITIES/SKILLS FOR HEALTH-CARE PROFESSIONALS
<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>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.</td>
<td>Start gradually, gently and slowly to explore dimensions, with open questions</td>
</tr>
<tr>
<td>3.</td>
<td>Establish a common language, understanding, goal-orientation, confidence relationship</td>
</tr>
<tr>
<td>4.</td>
<td>Explore the information, experience, meaning &amp; adjustment to disease</td>
</tr>
<tr>
<td>5.</td>
<td>Explore &amp; promote life review, identify goals, meaning, values, beliefs, legacy, previous crises and experiences</td>
</tr>
<tr>
<td>6.</td>
<td>Explore &amp; promote the quality of family and social relationships</td>
</tr>
<tr>
<td>7.</td>
<td>Explore &amp; promote reflection on unfinished business, relations, forgiveness, guilt</td>
</tr>
<tr>
<td>8.</td>
<td>Explore &amp; promote religious expressions and practice</td>
</tr>
<tr>
<td>9.</td>
<td>Review and readjust goals, language, and expectations to prevent misunderstandings &amp; to promote hope</td>
</tr>
<tr>
<td>10.</td>
<td>Prevent crises and explore scenarios of decision-making choices</td>
</tr>
<tr>
<td>11.</td>
<td>Offer and guarantee support and accessibility</td>
</tr>
<tr>
<td></td>
<td>Question</td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------------------</td>
</tr>
<tr>
<td>1.</td>
<td>&quot;How do you feel?&quot;</td>
</tr>
<tr>
<td>2.</td>
<td>&quot;How do you see the current status of your condition?&quot;</td>
</tr>
<tr>
<td>3.</td>
<td>&quot;What are you worried about?&quot;</td>
</tr>
<tr>
<td>4.</td>
<td>&quot;How do you think things can go in the future?&quot;</td>
</tr>
<tr>
<td>5.</td>
<td>&quot;What helps you to cope with this situation?&quot;</td>
</tr>
<tr>
<td>6.</td>
<td>&quot;What would you like us to do for you?&quot;</td>
</tr>
</tbody>
</table>

**Key questions**
New perspectives, new challenges:
• Psychosocial spiritual care
Improving psychosocial & spiritual care

The La Caixa Program at 4 years
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.S.C. (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.
Main goal:

improve the quality of comprehensive care of patients with advanced chronic conditions and their families

Mission

Develop the emotional social and spiritual care

Vision

Improvement of psychosocial spiritual care in all settings

Values

Care of essential needs of vulnerable persons, respect, dignity, compassion, humanism
Additional aims:

1. Generate experience and evidence
2. Develop innovative models of care and organisation
3. Disseminate knowledge
4. Commitment to evaluation
5. Mid term sustainability
Programa La Caixa/CCOMS per a l’atenció integral de persones amb malalties avançades i famílies

29 EAPs teams
125 full time professionals

> 45.000 Patients
> 55.000 relatives

140 ECPs receptors

6 milion Euros / year
Some details

29 Psychosocial Care Teams (PCT) from “la Caixa” Foundation
Scope: 17 Autonomous Communities

133 multidisciplinary professionals:

Professional profiles:
- 58% Psychologists
- 22% Social workers
- 20% Doctors + Nurses

Scope of attention:
- 55 hospitals/sanitary centers
- 62 home care teams
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>

**Consolidation Model**

![Bar chart showing number of patients and family members over the years.](chart.png)
Other Results:
Efectiveness
Satisfaction:
Families
Stakeholders
Quality / organizational audit
Pacientes

Estado de ánimo (escala numérico verbal 0 a 10)

(*) Estadísticamente Significativo
Pacientes

Evolución de la ansiedad (ENV 0-10)

* Estadísticamente Significativo
Pacientes

Malestar (ENV 0 a 10)

(*) Estadísticamente significativo
Conclusiones: efectividad en pacientes

- Mejora significativa de estado de ánimo, ansiedad, malestar, adaptación emocional y sufrimiento
- Mejora significativa de parámetros referidos a espiritualidad (Paz/perdón, sentido)
- Predominio de mejora entre 1ª y 2ª evaluación (= que en evaluaciones de SCP) y mantenimiento posterior
Conclusiones: efectividad en familiares

- Mejora significativa de malestar, ansiedad, depresión e insomnio
- Predominio de mejora entre 1ª y 2ª evaluación (= que en estudios efectividad en el SCP) y mantenimiento posterior
Encuesta Equipos Receptores

<table>
<thead>
<tr>
<th>Atención</th>
<th>Impacto en receptores</th>
<th>Formación</th>
<th>Satisfacción EAPS - Programa</th>
<th>Eficacia - Eficiencia</th>
<th>Evolución EAPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>4,45</td>
<td>4,05</td>
<td>4,18</td>
<td>4,63</td>
<td>4,51</td>
<td>4,49</td>
</tr>
</tbody>
</table>
Evaluación de grupos de interés
“Stakeholders”

Realizada por:
Fundación Avedis-Donabedian
### Grupos de interés

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Profesionales del EAPS: Psicólogos, Trabajadores Sociales, Enfermeras, Voluntarios Médicos (nº de casos)</td>
</tr>
<tr>
<td>2.</td>
<td>Directores / Coordinadores de los EAPS (nº de casos)</td>
</tr>
<tr>
<td>3.</td>
<td>Gestores de los EAPS de los equipos a los que da soporte el EAPS: Equipos Receptores (nº de casos)</td>
</tr>
<tr>
<td>4.</td>
<td>Profesionales de los equipos (nº de casos)</td>
</tr>
<tr>
<td>5.</td>
<td>Gerentes de Equipos Receptores (nº de casos)</td>
</tr>
<tr>
<td>6.</td>
<td>Responsables de Comunidad Autónoma (nº de casos)</td>
</tr>
<tr>
<td>7.</td>
<td>Expertos Nacionales e Internacionales (nº de casos)</td>
</tr>
<tr>
<td>8.</td>
<td>Colegios Profesionales (nº de casos)</td>
</tr>
</tbody>
</table>
### Área relevante: Satisfacción global

<table>
<thead>
<tr>
<th>Código</th>
<th>Pregunta</th>
<th>Grupo de interés</th>
<th>p valor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1 EAPS (89)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 DIR. EAPS (18)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 GER. EAPS (12)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 EQ. RECPT (111)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5 GER. E.R. (33)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 RESP. C.A. (14)</td>
<td></td>
</tr>
<tr>
<td>5.1.1</td>
<td>Valore su satisfacción con el desarrollo del Programa</td>
<td>7,87 (1,44)</td>
<td>0,01</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7,94 (0,8)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>8,42 (1,24)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>8,22 (1,89)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>8,27 (1,35)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>7,07 (1,38)</td>
<td></td>
</tr>
</tbody>
</table>

Grupos de interés: satisfacción percibida
Other evaluations

- Survey satisfaction patients
- Survey satisfaction families
- Qualitative analysis clinical charts
- Sequential pre-post effectiveness
- External audit administrative

Ongoing research
- Randomised trial effectiveness & efficiency
- Survey satisfaction families
- Qualitative analysis clinical charts
- Sequential pre-post effectiveness
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-high income countries, more than 75\% 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
EDITORIAL

Innovaciones conceptuales e iniciativas de mejora en la atención paliativa del siglo XXI

Conceptual innovations and initiatives to improve palliative care in the XXI century

Xavier Gómez-Batiste*, Carles Blay, Jordi Roca y M. Dulce Fontanals

Cátedra ICO/UVIC de Cuidados Paliativos, Observatorio Qualy/Centro Colaborador de la OMS para Programas Públicos de Cuidados Paliativos, Instituto Catalán de Oncología-Universidad de Vic, Barcelona, España

Transiciones conceptuales en la atención paliativa en el siglo XXI

Los Cuidados Paliativos nacieron el Reino Unido en los Hospices de los 60, y propusieron un modelo de atención y organización, servicios, y programas públicos de cuidados paliativos que se adaptaron a las características culturales y de cada sistema de salud. Aún así, en la mayoría de los países están todavía centrados en atender a enfermos de cáncer, en fases muy avanzadas, durante pocos meses, en servicios específicos, con criterios de acceso frecuentemente basados en el pronóstico, y modelos de intervención «dicitómicos», con escasa interacción entre servicios, y modelos de organización basados en intervenciones urgentes, muy fragmentados y generalmente «reactivos» a las crisis de necesidades.

La perspectiva epidemiológica: la mortalidad

Se han producido avances en la perspectiva epidemiológica al identificar las causas de mortalidad por enfermedades crónicas evolutivas que podrían requerir intervenciones paliativas, y que explican el 75% de la misma en nuestro país1, con una proporción cáncer/no-cáncer de 1/2, además de un cambio de perspectiva pronóstica, desde la «enfermedad o paciente terminal» hacia «personas con enfermedades crónicas avanzadas y pronóstico de vida limitado»2, un término mucho más amplio, así como el concepto de «trayectoria» evolutiva en crisis1.

Los modelos de identificación de personas con necesidades paliativas en la comunidad

Durante años, la principal dificultad para la atención paliativa precoz y adecuada de pacientes no-cáncer en servicios de salud consistió en la falta de instrumentos que identifiquen a los pacientes con necesidades paliativas. El desarrollo del Gold Standards Framework (GSF/FIG)3 y el Scottish Palliative Care Indicator Tool (SPCIT) en el Reino Unido propusieron instrumentos sencillos y aplicables, de los que actualmente disponemos de una adaptación a nuestro entorno con el instrumento NECPAL-CCOMS2.

Una nueva perspectiva epidemiológica: la prevalencia

La existencia de un instrumento que identifica a pacientes con enfermedades crónicas y necesidades de atención
Clusters of complex chronic patients and their screening methodology (tools or individual parameters)

"Target": 2% of population

Use / consumption / cost / emergencies

Poli-pharmacy

Clinical Complexity / severity

Co-morbidity

Dependency

+ Advanced with limited life prognosis (NECPAL)
Models of palliative interventions in chronic care

**“Planned”**
- Mostly non-cancer 85 / 15%
- Mostly community services
- Early
- Length survival 12-14 months
- Preventive / Programmed
- Community identification tool
- Advance care planning
- Case management
- Integrated care

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

XGB et al, Current Opinion in SPCare2012
Palliative approach: the “soul” of Chronic Care Programmes
Organic Law 6/2006 of the 19th July, on the Reform of the Statute of Autonomy of Catalonia

ARTICLE 20. THE RIGHT TO UNDERGO THE PROCESS OF DEATH WITH DIGNITY

1. Each individual has the right to receive appropriate treatment of pain and complete palliative attention and to undergo the process of death with dignity.

2. Each individual has the right to express his or her will in advance in order to record instructions regarding any medical treatment or intervention that he or she may undergo. These instructions must be respected especially by medical staff, in accordance with the terms established by the law, if the individual is not able to express his or her wishes personally.
Palliative care as a Human Right and Public Health perspective the way to achieve it
Thank you!!!!!!

Xgomez@iconcologia.net

http://ico.gencat.cat
http://uvic.cat/mastersuniversitaris
http://mon.uvic.cat/catedra-atencion-cuidados-paliativos