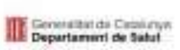
Let’s talk about this patients…..

OBSERVATORI

QUALY / CCOMS-ICO

"Promovent Qualitat en L'Atenció Pal·liativa"



WHO COLLABORATING CENTRE PUBLIC HEALTH PALLIATIVE CARE PROGRAMMES

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

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

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 / Barcelona

7.3 milion habitants

Catalonia 2012

- 7.300.000 inhabitants (4.5 in Metropolitan Barcelona)
- > 65 years: 17%
- 60.000 people with dementia
- 130.000 elderly with pluripatology 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**

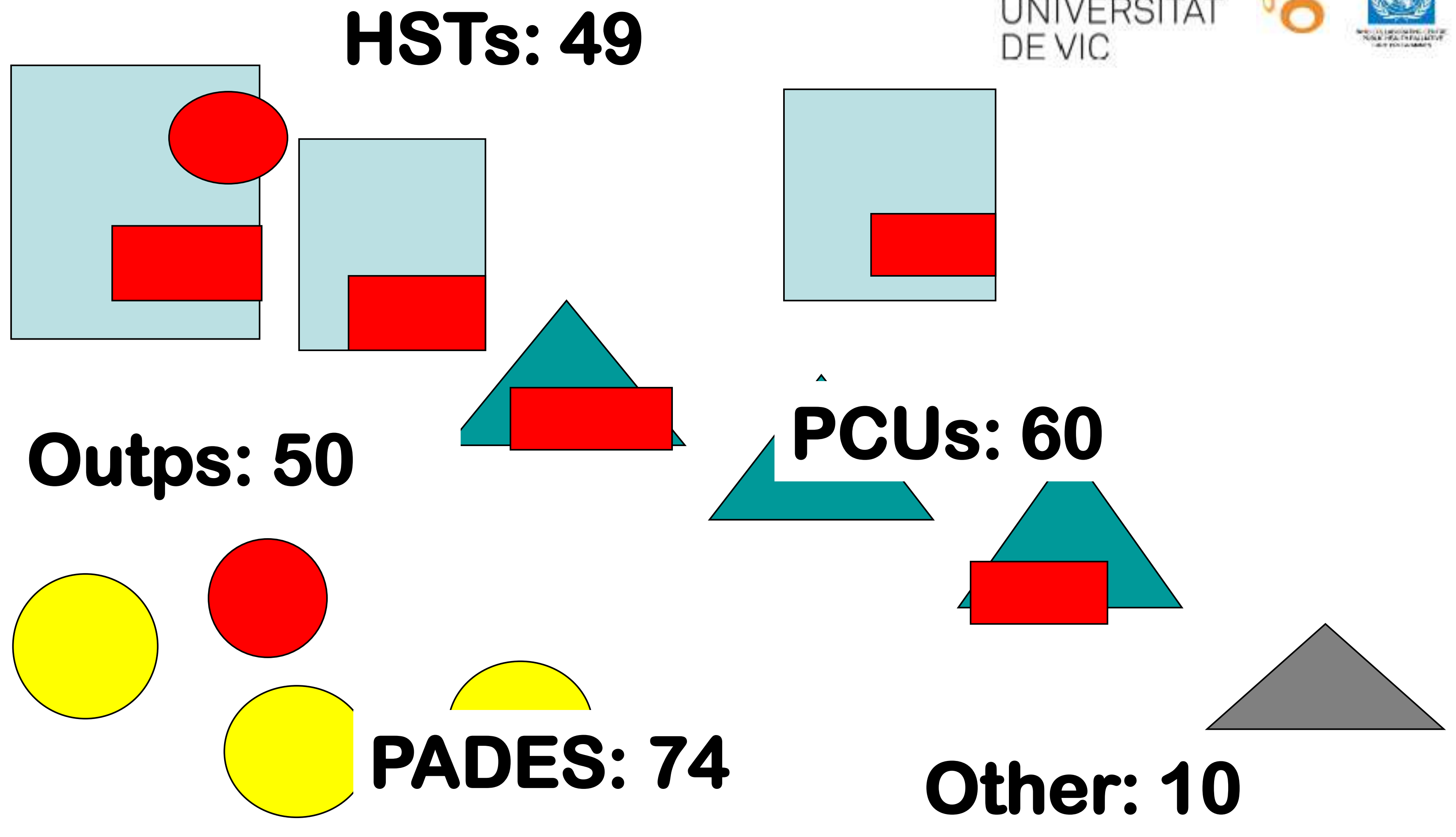
(*) Previous Estimation based in McNamara, 2006

Vol. 43 No. 4 April 2012 *Journal of Pain and Symptom Management* 783

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



Care Resources 2009 (Total: 236)

Resources CP Cat 2009

DIRECT			
	PC Services	Acute: 32 Non Acute: 27	Total: 59
	Outpatients	CExt EIAIA: 22 CExt convenc: 28	Total: 50
	Hospital Support Teams	38	Total: 38
	Home Support Teams	74	Total: 74
	Psicosocial Support Teams	5	Total: 5
	Other	5	5
		TOTAL	231
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

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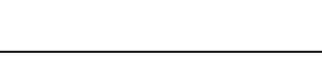
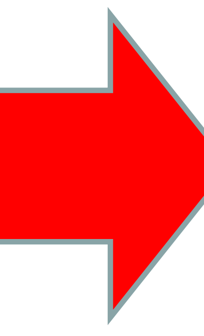


- Quantitative / 5 years (Gómez-Batiste X et al, JPSM)
- External evaluation of indicators (Suñol et al, 2008)
- SWOT nominal group of health-care professionals (Gomez-Batiste X et al, 2007)
- Focal group of relatives (Brugulat et al, 2008)
- Benchmark process (2008) (Gomez-Batiste et al, 2010)
- Efficiency (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 Espaulella,[4] Jose Espinosa,[1] Montserrat Figuerola,[1] Carles Constante[6]

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

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Accepted 19 November 2012

ABSTRACT

Institut Català d'Oncologia

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, Disctrict approach
- Research: Evaluation of the impact of implementation
- Setting up Public Health Policy: coverage

Building the NECPAL Tool

Med Clin (Barc). 2013;140(6):241–245

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MEDICINA CLINICA

www.elsevier.es/medicinaclinica

Original

Identificación de personas con enfermedades crónicas avanzadas y necesidad de atención paliativa en servicios sanitarios y sociales: elaboración del instrumento NECPAL CCOMS-ICO©

Xavier Gómez-Batiste [a,*], Marisa Martínez-Muñoz [a], Carles Blay [b], Jordi Amblàs [c,d], Laura Vila [b] y Xavier Costa [e]

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[c] Hospital de la Santa Creu, Vic, Barcelona, España
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Supportive and Palliative Care Indicators Tool (SPICT)

Use the SPICT to identify people with one or more advanced, progressive, incurable conditions; or at risk of dying of a sudden, acute deterioration for assessment and care planning.

1. Look for two or more general clinical indicators of deteriorating health

- Performance status poor (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- A new event or diagnosis that is likely to reduce life expectancy to less than a year.
- Lives in a nursing care home or NHS continuing care unit, or needs care at home.

2. Now look for clinical indicators of advanced conditions

Advanced heart/ vascular disease

- NYHA Class III/IV heart failure, or extensive coronary artery disease:
  - breathless or chest pain at rest or on minimal exertion.
- Severe, inoperable peripheral vascular disease.

Advanced respiratory disease

- Severe chronic obstructive pulmonary disease (FEV1<30%) or severe pulmonary fibrosis
  - breathless at rest or on minimal exertion between exacerbations.
- Meets criteria for long term oxygen therapy (PaO2 < 7.3 kPa).
- Has needed ventilation for respiratory failure.

Advanced kidney disease

- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min).
- Kidney failure as a recent complication of another condition or treatment.
- Stopping dialysis.

Advanced liver disease

- Advanced cirrhosis with one or more complications in past year:
  - diuretic resistant ascites
  - hepatic encephalopathy
  - hepatorenal syndrome
  - bacterial peritonitis
  - recurrent variceal bleeds
- Serum albumin < 25g/l, INR prolonged (INR > 2).
- Liver transplant is contraindicated.

Advanced cancer

- Functional ability deteriorating due to progressive metastatic cancer.
- Too frail for oncology treatment due to advanced multimorbidity or advanced cancer.

Advanced neurological disease

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/or progressive dysphagia.
- Recurrent aspiration pneumonia; breathless or respiratory failure.

Advanced dementia/ frailty

- Unable to dress, walk or eat without help.
- Eating less; difficulty maintaining nutrition.
- Urinary and faecal incontinence.
- Progressive weakness, fatigue, inactivity.
- Unable to communicate meaningfully; little social interaction.
- Fractured femur; falls.
- Recurrent febrile episodes or infections; aspiration pneumonia.

3. Ask

Would it be a surprise if this patient died in the next 6-12 months?	No

4. Assess and plan

- Assess the patient & family for unmet needs.
- Review treatment / care plan, and medication.
- Discuss and agree care goals with the patient & family.
- Consider specialist palliative care referral if symptoms are complex or poorly controlled.
- Consider using GP register to coordinate care in the community.
- Handover: care plan, agreed levels of intervention, CPR status.

SPICT, March 2012

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 frail/ dementia (see over)

General Predictors of End Stage Illness

- **Multiple co-morbidities**
- Weight loss - Greater than 10% weight loss over 6 months
- General physical decline
- Serum Albumin < 25 g/l
- Reducing performance status / Karnofsky score (KPS) < 50%. Dependence in most activities of daily living (ADL's)

1. Cancer Patients

Cancer

Any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from diagnosis e.g. lung cancer. 'The single most important predictive factor in cancer is performance status and functional ability' – if patients are spending more than 50% of their time in bed/lying down, prognosis likely to be about 3 months or less

2. Organ Failure Patients

2.1 Heart Disease - CHF

At least two of the indicators below -
- CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
- Patient thought to be in the last year of life by the care team - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

2.2 Chronic Obstructive Pulmonary Disease – COPD

- Disease assessed to be severe e.g. (FEV1 <30% predicted – with here caveats about quality of testing)
- Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)
- Fulfils Long Term Oxygen Therapy Criteria
- MRC grade 4/5 – shortness of breath after 100 meters on the level or confined to house through breathlessness
- Signs and symptoms of Right heart failure
- Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression

2.3 Renal Disease

- Patients with stage 5 kidney disease who are not seeking or are discontinuing dialysis or renal transplant. This may be from choice or because they are too frail or have too many co-morbid conditions.
- Patients with stage 4 or 5 chronic kidney disease whose condition is deteriorating and for whom the one year 'surprise question' is applicable ie overall you would not be surprised if they were to die in the next year?
- Clinical indicators:
  - CKD stage 5 (eGFR <15 ml/min)
  - Symptomatic renal failure (anorexia, nausea, pruritus, reduced functional status, intractable fluid overload)

2.4 Neurological Disease - a) Motor Neurone Disease

MND patients should be included from diagnosis, as it is a rapidly progressing condition
Indicators of rapid deterioration include:
- Evidence of disturbed sleep related to respiratory muscle weakness in addition to signs of dyspnoea at rest
- Barely intelligible speech
- Difficulty swallowing
- Poor nutritional status
- Needing assistance with ADL's
- Medical complications eg pneumonia, sepsis
- A short interval between onset of symptoms and diagnosis
- A low vital capacity (below 70% of predicted using standard spirometry)

Surprise question	Would you be surprised if this patient dies within 1 year?	
Need, demand and choice	Any request to limit the treatments or palliative care from patient, family, or team members?	
• General clinical indicators (severe, progressive, sustained, not related to intercurrent process) • Combined Severity AND Progression	Nutritional decline	Weight / albumin
	Functional decline	KPS or Barthel
	Severe psychological adjustment difficulties	Numerical Verbal Scale / HADS test.
Co-morbidity	- 3 + chronic diseases - Geriatric syndromes - Severe complications	- Charlson test - Pressure ulcers, Severe frailty, infections, disphagia, delirium, falls
Use of resources	- >3 urgent admissions in 6 months	Or increase in need / demand of care
Specific indicators	Cancer, COPD, Heart, Hepatic or Renal Failure, Neurological, Stroke, Dementia, AIDS, other	

The NECPAL-WHOCC Tool

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

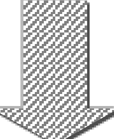
The prevalence study

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

	n (% Total Pop)	n (% Pop ≥65)
"Advanced chronic" list (Level 1)	1064 (2.06%)	972 (10.91%)
SQ- (Surprise Question «negative» / Level 2)	750 (1.45%)	687 (7.71%)
SQ- + 1 additional criteria / Level 3 (NECPAL +)	684 (1.33%)	623 (7.00%)

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%

	Cancer	Organ failure	Dementia	Advanced frailty	P- value
Age Mean (SD)	73.3 (13.9)	76.0 (14.0)	85.5 (6.5)	87.0 (6.8)	<0.001
Male N (%)	58 (57.43)	138 (54.12)	37 (19.89)	84 (29.47)	< 0.001
Female N (%)	43 (42.57)	117 (45.88)	149 (80.11)	201 (70.53)	

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

- GP: 20-25
- District GeneralHospital : 38%
- University Hospital HUB: 39%
- Internal Medicine HUB: 47%
- ICU HUB: 30%
- Nursing homes: 40-70%

The cohort study

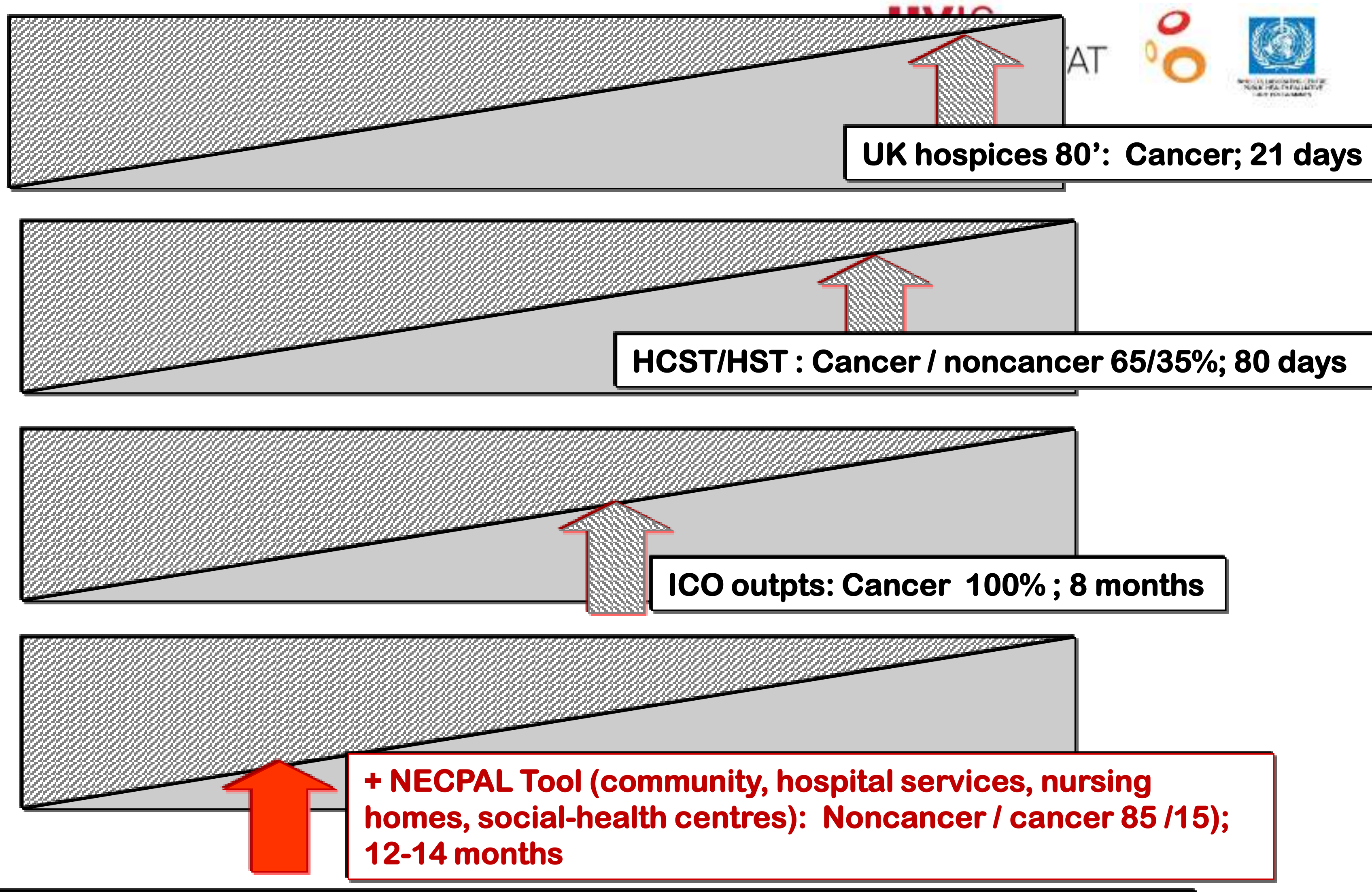
1.064 patients included

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

Specialist Services

Joint policies & shared & integrated care

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

Good care for noncomplex

+ 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 responsable, 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 accesibility, 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
- Dichotomic 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

DISEASE MANAGEMENT
- Primary diagnosis, prognosis, evidence
- Secondary diagnoses (e.g., dementia, psychiatric diagnoses, substance use, trauma)
- Co-morbidities (e.g., delirium, seizures, organ failure)
- Adverse events (e.g., side effects, toxicity)
- Allergies

PHYSICAL
- Pain and other symptoms *
- Level of consciousness, cognition
- Function, safety, aids:
  - Motor (e.g., mobility, swallowing, excretion)
  - Senses (e.g., hearing, sight, smell, taste, touch)
  - Physiologic (e.g., breathing, circulation)
  - Sexual
- Fluids, nutrition
- Wounds
- Habits (e.g., alcohol, smoking)

PSYCHOLOGICAL
- Personality, strengths, behaviour, motivation
- Depression, anxiety
- Emotions (e.g., anger, distress, hopelessness, loneliness)
- Fears (e.g., abandonment, burden, death)
- Control, dignity, independence
- Conflict, guilt, stress, coping responses
- Self-image, self-esteem

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

PATIENT AND FAMILY

Characteristics
- Demographics (e.g., age, gender, race, contact information)
- Culture (e.g., ethnicity, language, cuisine)
- Personal values, beliefs, practices, strengths
- Developmental state, education, literacy
- Disabilities

SOCIAL
- Cultural values, beliefs, practices
- Relationships, roles with family, friends, community
- Isolation, abandonment, reconciliation
- Safe, comforting environment
- Privacy, intimacy
- Routines, rituals, recreation, vocation
- Financial resources, expenses
- Legal (e.g., powers of attorney for business, for healthcare, advance directives, last will/ testament, beneficiaries)
- Family caregiver protection
- Guardianship, custody issues

END OF LIFE CARE/ DEATH MANAGEMENT
- Life closure (e.g., completing business, closing relationships, saying goodbye)
- Gift giving (e.g., things, money, organs, thoughts)
- Legacy creation
- Preparation for expected death
- Anticipation and management of physiological changes in the last hours of life
- Rites, rituals
- Pronouncement, certification
- Perideath care of family, handling of the body
- Funerals, memorial services, celebrations

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
- Spiritual advisors, rites, rituals
- Symbols, icons

* Other common symptoms include, but are not limited to:
Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns
Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia
Oral conditions: dry mouth, mucositis
Skin conditions: dry skin, nodules, pruritus, rashes
General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, 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)

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

"Cancer" Trajectory, Diagnosis to Death

Function: High – Low. Cancer → Death

Onset of incurable cancer → Time – Often a few years, but decline usually seems <2 months

Organ System Failure Trajectory

(mostly heart and lung failure)

Function: High – Low. Death

Begin to use hospital often, self-care becomes difficult → Time ~ 2-5 years, but death usually seems "sudden"

Frailty / Dementia Trajectory

Function: High – Low. Death

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

Wellbeing

Heart Failure

Trajectories
- Physical
- Social
- Psychological
- Spiritual

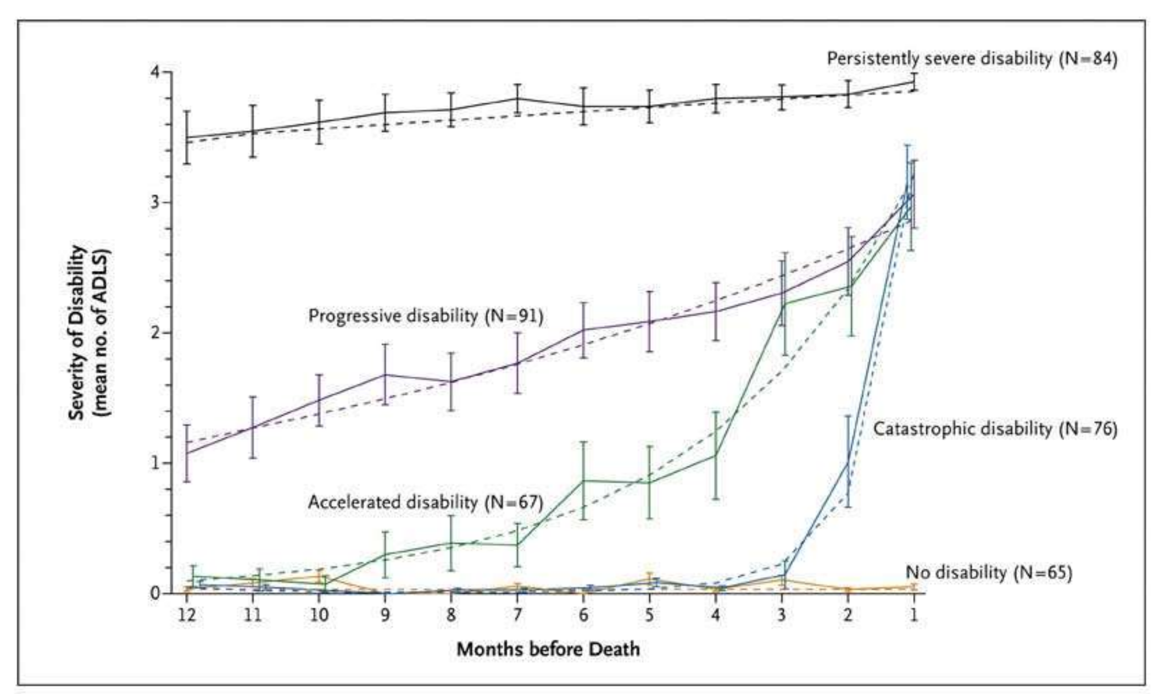
Distress

acute exacerbations

← Palliative phase → Death

Murray, S. A et al. BMJ 2008;336:958-959

...bilities at the last year of life



Gill, Thomas M, Gahbauer, Evelyne A; Han, Ling; et al. The New England Journal of Medicine 362. 13 (Apr 1, 2010): 1173-80.

The care of essential needs

Maté-Méndez J, González-Barboteo J, Calsina-Berna A, Mateo-Ortega D, Codorniu-Zamora N, Limonero-García JT, Trelis-Navarro J, Serrano-Bermúdez G, and Gómez-Batiste X. ***The Institut Català d'Oncologia (ICO) model of palliative care: An integrated and comprehensive framework to address essential needs of patients with advanced cancer.*** Journal of Palliative Care 2013, in press. Accepted August 2013.

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

Basic:
- ADL
- IADL
- Security…
- Privacy…

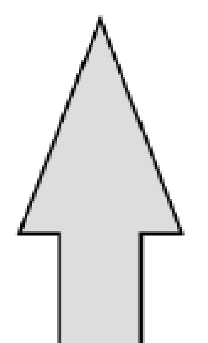
Needs of patients with advanced conditions

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



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

ETHICAL COMMITMENT

MODEL OF ESSENTIAL ABILITIES/SKILLS FOR HEALTH-CARE PROFESSIONALS

Components of the Model

Steps for excellent care

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
2.	Start gradually, gently and slowly to explore dimensions, with open questions
3.	Establish a common language, understanding, goal-orientation, confidence relationship
4.	Explore the information, experience, meaning & adjustment to disease
5.	Explore & promote life review, identify goals, meaning, values, beliefs, legacy, previous crises and experiences
6.	Explore & promote the quality of family and social relationships
7.	Explore & promote reflection on unfinished business, relations, forgiveness, guilt
8.	Explore & promote religious expressions and practice
9.	Review and readjust goals, language, and expectations to prevent misunderstandings & to promote hope
10.	Prevent crises and explore scenarios of decision-making choices
11.	Offer and guarantee support and accessibility

1.	*"How do you feel?"*
2.	*"How do you see the current status of your condition?"*
3.	*"What are you worried about?"*
4.	*"How do you think things can go in the future?"*
5.	*"What helps you to cope with this situation?"*
6.	*"What would you like us to do for you?"*

Key questions

New perspectives, new challenges:

- **Psychosocial spiritual care**

Improving psychosocial & spiritual care

The La Caixa Program at 4 years

Palliative and Supportive Care (2011), **9**, 239–249.
© Cambridge University Press, 2011 1478-9515/11 $20.00
doi:10.1017/S1478951511000198

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

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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.

Programa para la atención integral

a personas con enfermedades avanzadas

Main goal:

improve the quality of comprehensive care of patiens witth advanced chornic conditions and tehir families

Mission

Develop the emotional social and spiritual care

Vision

Improvement of psychosocial spiritual care in all settings

Values

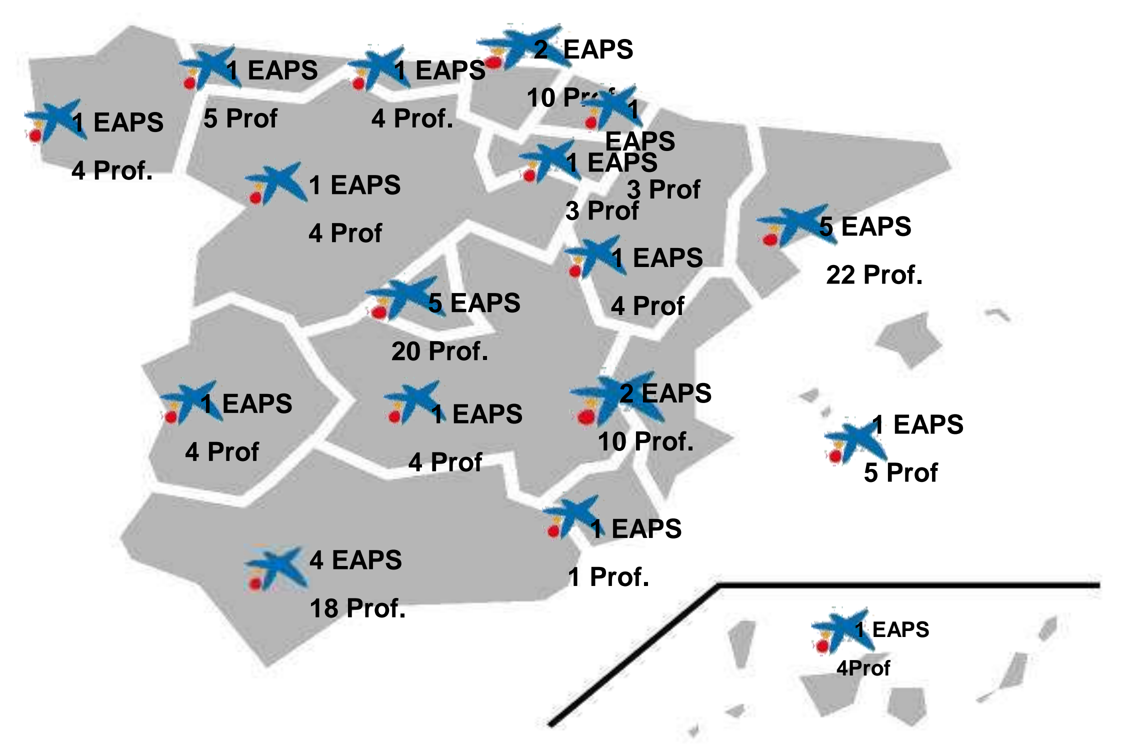
Care of esential needs of vulnerable persons, respect, dignity, compassion, humanism

Dirección científica:

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

1 PCT
1 PCT
1 PCT
2 PCT
1 PCT
1 PCT
1 PTC
1 PCT
5 PCT
1 ICT
4 PCT
1 PCT
2 PCT
1 PCT
1 PCT
1 PCT
4 PCT
1PCT

133 multidisciplinary professionals:

Professional profiles:

58% Psychologists
22% Social workers
20% Doctors + Nurses

Scope of attention:

- 55 hospitals/sanitary centers
- 62 home care teams

Health teams poll

Attention	Satisfaction	Support team	Relationship PCT - Sanitay Teams	Coordination	Communication
4,63	4,64	4,44	4,68	4,58	4,13

85 teams sanitary teams **interviewed**
Average **Rating: 4.51** out of **5**

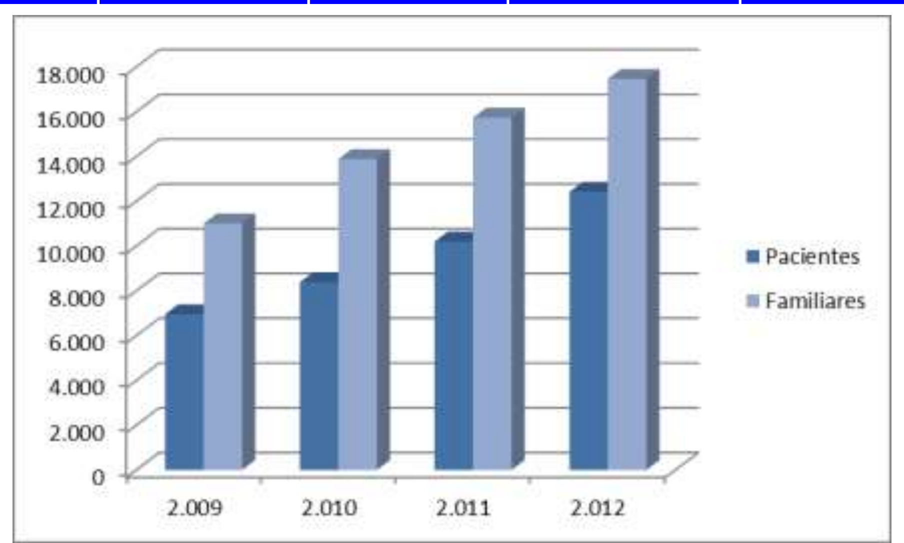
Results: January 2013

Programa per a l'atenció integral de persones
amb malalties avançades i els seus familiars
Obra Social "la Caixa"
Programa para la atención integral de personas
con enfermedades avanzadas y sus familiares

Consolidation Model

Care delivery details: more than **40,000 patients** and more than **65,000 relatives**

	2009	2010	2011	2012	2013	TOTAL
Patients	6.957	8.385	10.203	**12.422**	**6.070**	**44.037**
Family Members	11.011	13.885	15.738	**17.468**	**7.784**	**65.886**



Obra Social "la Caixa"

Institut Català d'Oncologia

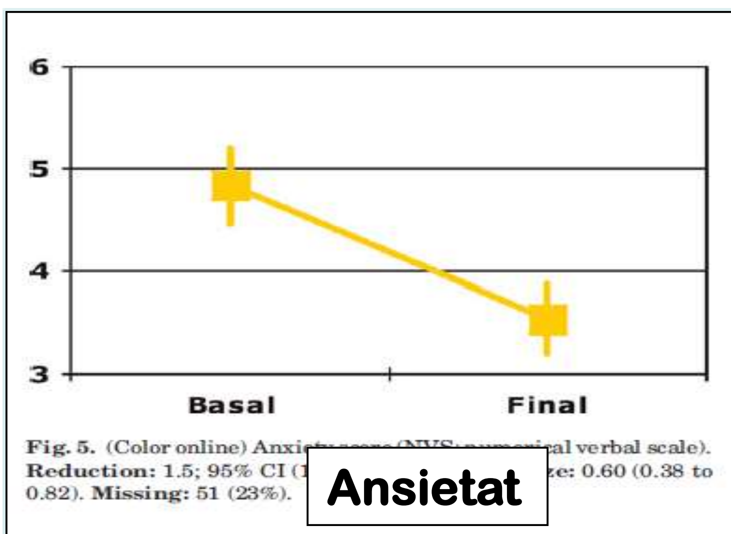


Fig. 5. (Color online) Anxi... (NVS: numerical verbal scale). Reduction: 1.5; 95% CI (1... ...ze: 0.60 (0.38 to 0.82). Missing: 51 (23%).

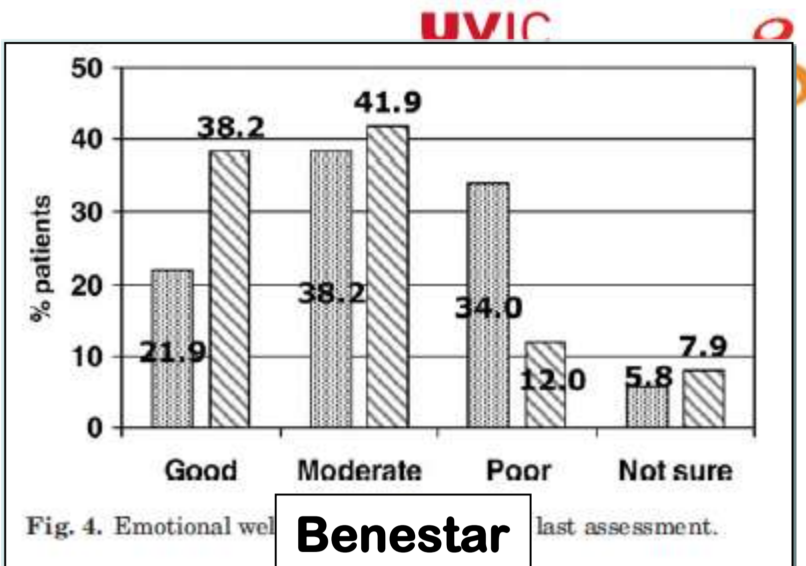


Fig. 4. Emotional wel... last assessment.

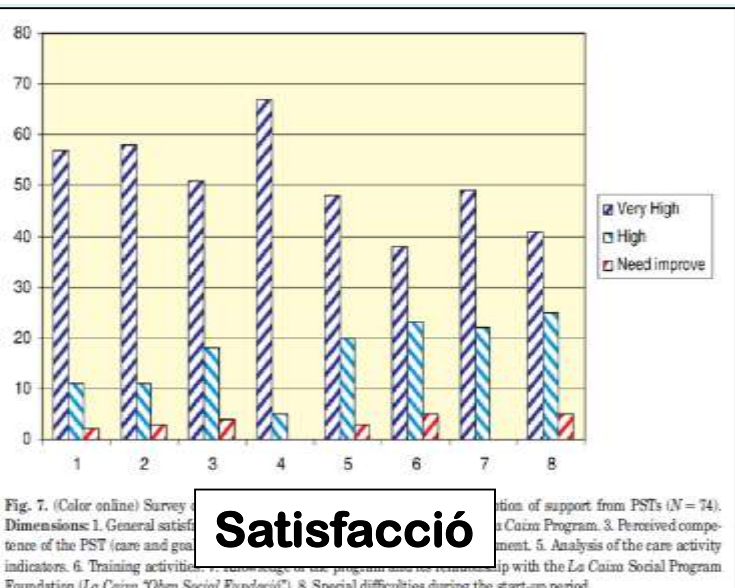


Fig. 7. (Color online) Survey ... tion of support from PSTs (N = 74). Dimensions: 1. General satisf... La Caixa Program. 3. Perceived competence of the PST (care and goa... ment. 5. Analysis of the care activity indicators. 6. Training activitie... ip with the La Caixa Social Program Foundation (La Caixa "Obra Social Fundació"). 8. Special difficulties during the start-up period.

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

Atención	Impacto en receptores	Formación	Satisfacción EAPS - Programa	Eficacia - Eficiencia	Evolución EAPS
4,45	4,05	4,18	4,63	4,51	4,49

Evaluación de grupos de interés

"Stakeholders"

Realizada por:
Fundación Avedis-Donabedian

GRUPOS DE INTERÉS							
1. Profesionales del EAPS: Psicólogos Trabajadores Sociales Enfermeras Voluntarios Médicos (nº de casos)	2. Directores / Coordinadores de los EAPS (nº de casos)	3. Gestores de los EAPS ((nº de casos)	4. Profesionales de los equipos a los que da soporte el EAPS: Equipos Receptores (nº de casos)	5. Gerentes de Equipos Receptores (nº de casos)	6. Responsables de Comunidad Autónoma (nº de casos)	7. Expertos Nacionales e Inter-Nacionales (nº de casos)	8. Colegios Profesionales (nº de casos)

Grupos de interés

DIMENSIÓN 5. SATISFACCIÓN PERCIBIDA

Área relevante: Satisfacción global

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

Grupos de interés: satisfacción percibida

Other evaluations

- Survey satisfaction patients
- Survey satisfaction families
- Qualitative analysis clinical charts
- Sequential pre-post efectiveness
- External audit administative

Ongoing research

•Randomised trial effectiveness & efficencySurvey satisfaction families

•Qualitative analysis clinical charts

•Sequential pre-post efectiveness

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[a,b], Marisa Martínez-Muñoz[a,b], Carles Blay[b,c], Jose Espinosa[a,b], Joan C. Contel[c], and Albert Ledesma[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

Med Paliat. 2012;19(3):85–86

Medicina Paliativa

www.elsevier.es/medicinapaliativa

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 «dicotómicos», 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 país[1], 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 crisis[3].

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 identificasen a los pacientes con necesidades paliativas. El desarrollo del *Gold Standards Framework* (GSF/PIG)[4] 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-CCOMS[5].

Una nueva perspectiva epidemiológica: la prevalencia

La existencia de un instrumento que identifica a pacientes con enfermedades crónicas y necesidades de atención

* Autor para correspondencia.
Correos electrónicos: Xgomez.whocc@iconcologia.net, Xavier.gomez@uvic.cat (X. Gómez-Batiste).

+ Advanced with limited life prognosis (NECPAL)

Use / consumption / cost / emergencies

Co-morbidity

"Target ": 2% of population

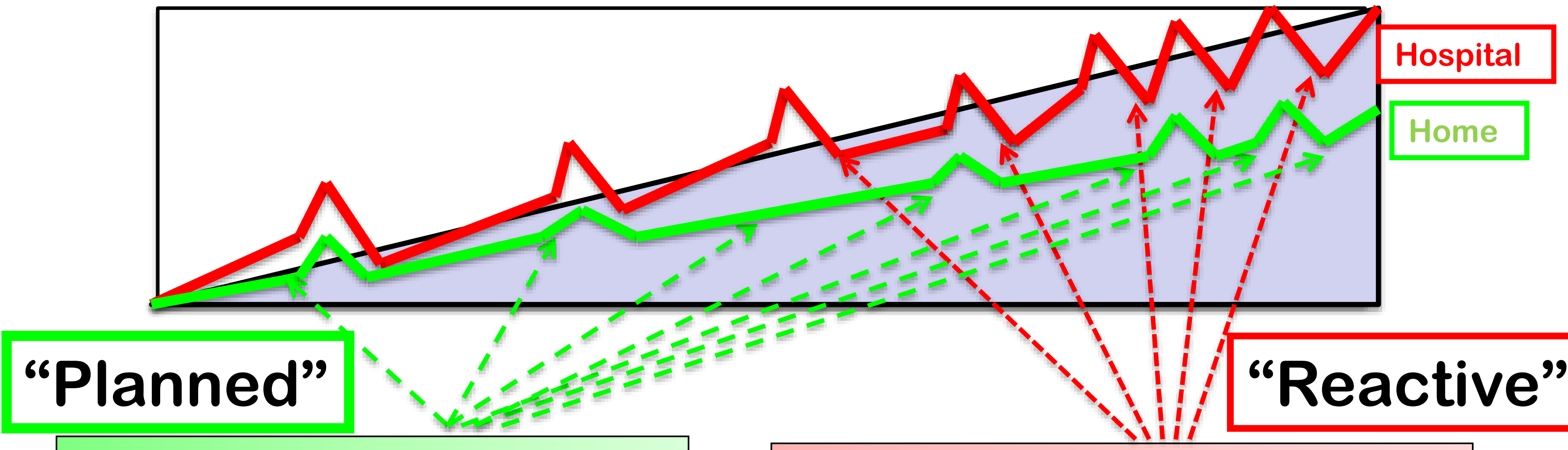
Poli-pharmacy

Dependency

Clinical Complexity /severity

Clusters of complex chronic patients and their screening methodology (tools or individual parameters)

Models of palliative interventions in chronic care



- 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

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

XGB et al, Current Opinion in SPCare2012

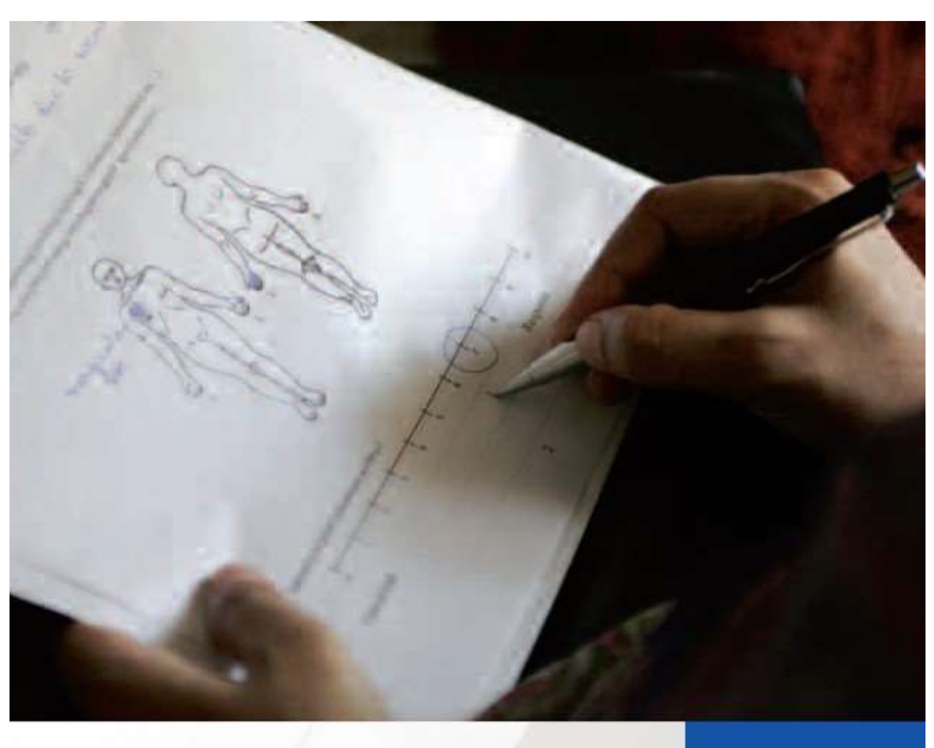
Pal.liative approach: the “soul” of Chronic Care Programmes

The Parliament of Catalonia

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

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