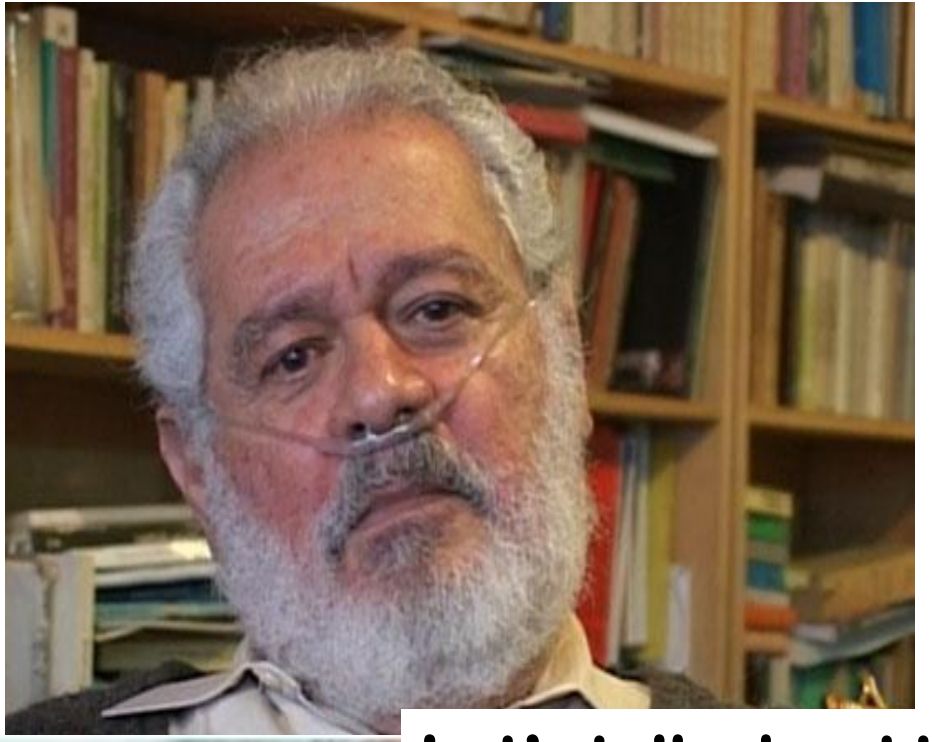
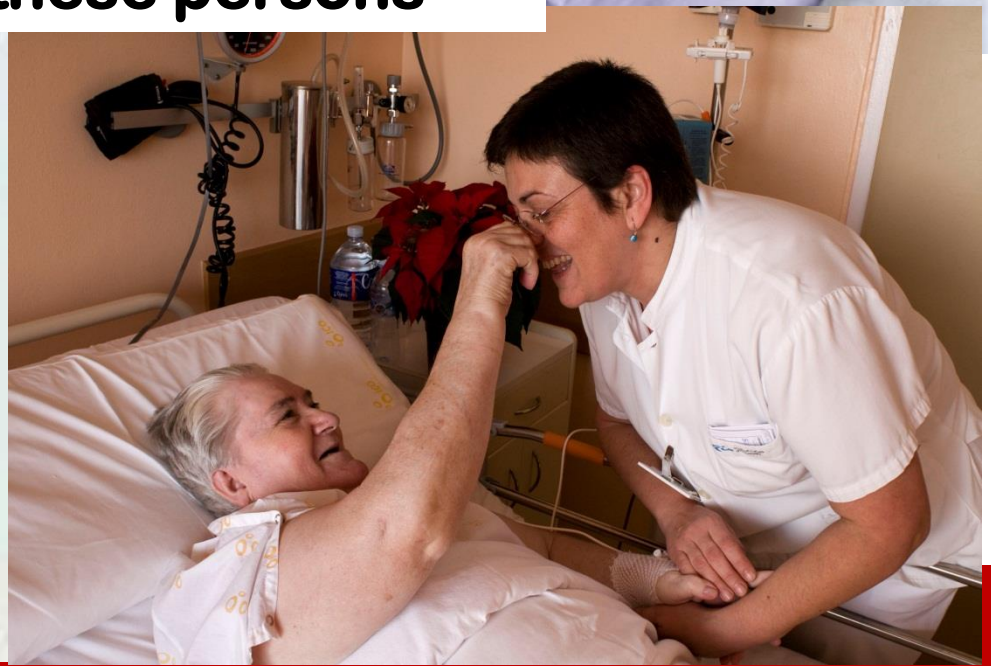


Let's talk about these persons



Prof Xavier Gómez-Batiste, MD, PhD

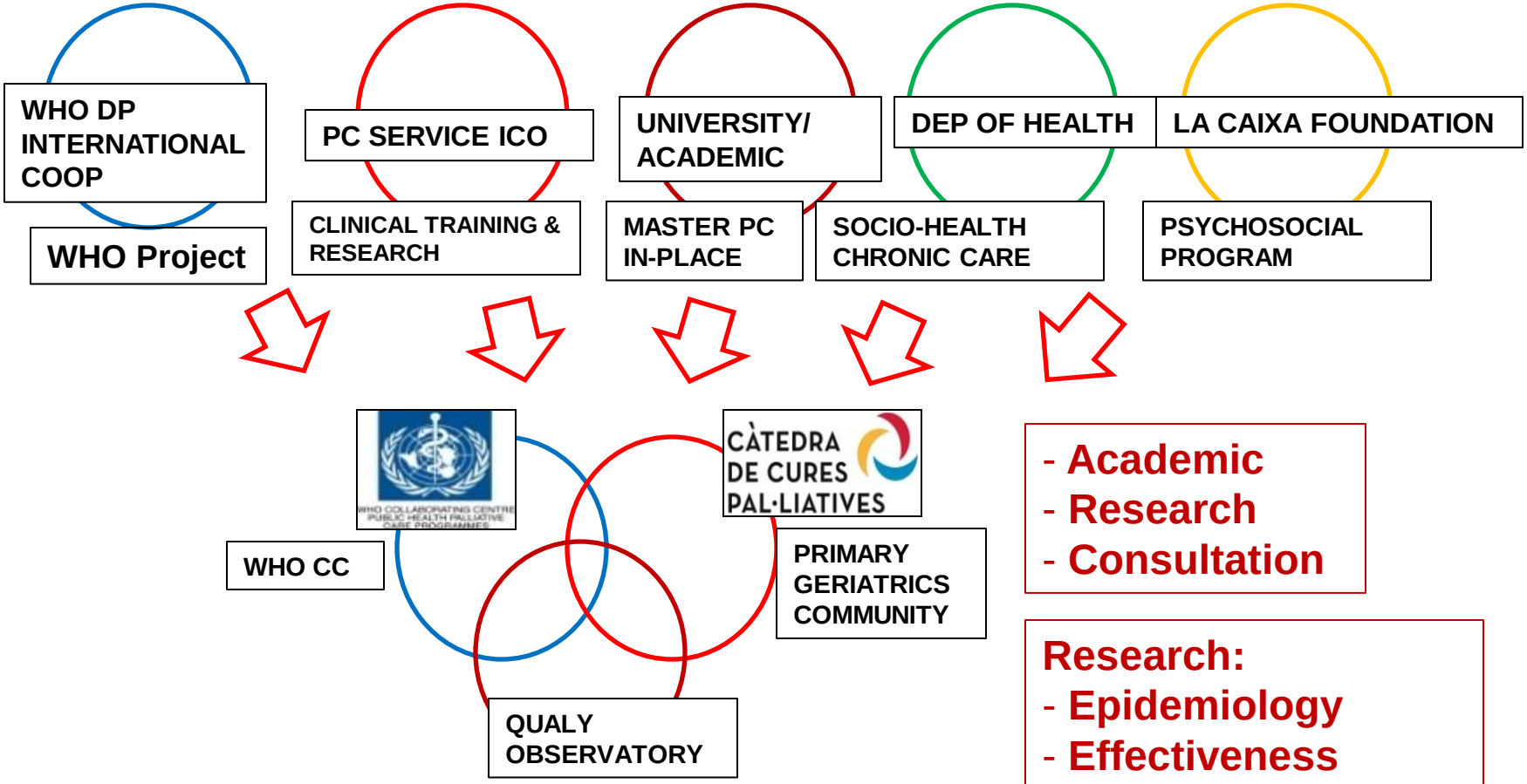
Director

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

Chairperson

- **Standing advisory committee for the prevention and care of people with chronic conditions. Department of Health. Government of Catalonia.**

Former Medical Officer for Palliative and Longterm care. WHO HQ. Geneva


WHO DP INTERNATIONAL COOP
WHO Project
PC SERVICE ICO
CLINICAL TRAINING & RESEARCH
UNIVERSITY/ ACADEMIC
MASTER PC IN-PLACE
DEP OF HEALTH
SOCIO-HEALTH CHRONIC CARE
LA CAIXA FOUNDATION
PSYCHOSOCIAL PROGRAM
WHO CC
CÀTEDRA DE CURES PAL·LIATIVES
PRIMARY GERIATRICS COMMUNITY
QUALY OBSERVATORY
- 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, compassive communities
- The Palliative Care Resolution and Initiative at the WHO HQ
- Interaction chronic/palliative care
- The areas of cooperation

Proposed outline

Challenges/Requisites of Public Health Palliative Care

Challenges

- How to extend palliative care
  - All patients: Targets?
  - All chronic conditions
  - All dimensions: mulidimensional
  - Timely: 1st transition
  - All health and social settings
  - All countries
- Rol 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

	FROM	Change TO
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	Cancer	All chronic progressive diseases and conditions
	Disease	Condition (multi-pathology, frailty, dependency, .)
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	Specialist services	+ Actions in all settings
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	Services' approach	Population & District
	Individual service	District approach

Conceptual transitions in Palliative Care XXIc
XGB et al, BMJ SPC 2012

486 Journal of Pain and Symptom Management Vol. 33 No. 5 May 2007

Special Article

The Public Health Strategy for Palliative Care

Jan Stjernswärd, MD, PhD, FRCP (Edin), Kathleen M. Foley, MD, and Frank D. Ferris, MD

UVIC UNIVERSITAT DE VIC

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Policy

- Palliative care part of national health plan, policies, related regulations
- Funding / service delivery models support palliative care delivery
- Essential medicines

(Policy makers, regulators, WHO, NGOs)

Drug Availability

- Opioids, essential medicines
- Importation quota
- Cost
- Prescribing
- Distribution
- Dispensing
- Administration

(Pharmacists, drug regulators, law enforcement agents)

Implementation

- Opinion leaders
- Trained manpower
- Strategic & business plans – resources, infrastructure
- Standards, guidelines measures

(Community & clinical leaders, administrators)

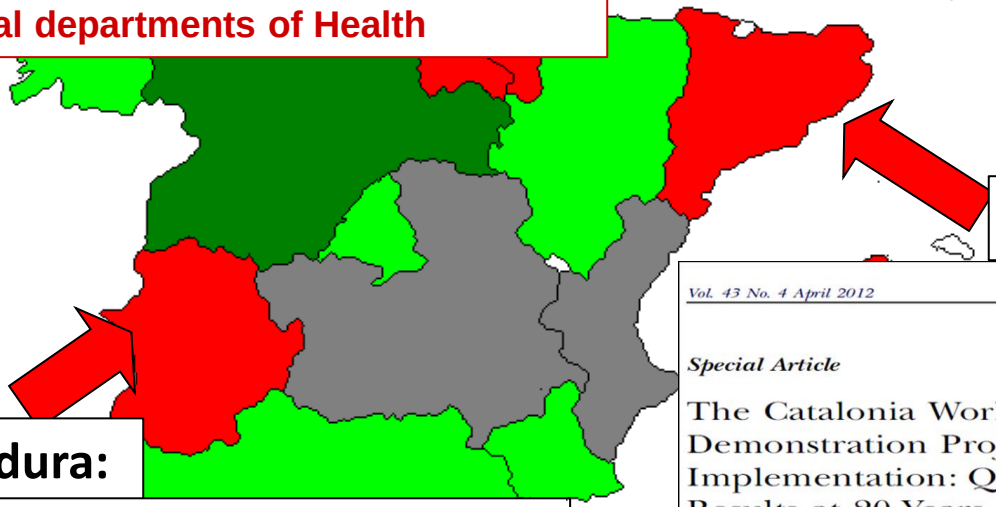
Education

- Media & public advocacy
- Curricula, courses – professionals, trainees
- Expert training
- Family caregiver training & support

(Media & public, healthcare providers & trainees, palliative care experts, family caregivers)

Spain:

- **Universal Health Care Coverage**
- **Free Access**
- **Public Health Primary Care System**
- **National EoL Strategy**
- **17 Regional departments of Health**



Catalonia

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

Extremadura:

Vol. 33 No. 5 May 2007 Journal of Pain and Symptom Management 591

Special Article

Regional Palliative Care Program in Extremadura: An Effective Public Health Care Model in a Sparsely Populated Region

Emilio Herrera, MD, Javier Rocafort, MD, Liliana De Lima, MHA, Eduardo Bruera, MD, Francisco García-Peña, MD, and Guillermo Fernández-Vara, MD

Catalonia: 7.3 milion

- **Urban/metropolitan/rural**
- **Sociohealth system**
- **Public funding**
- **Mixed provision**

Extremadura:

- **1 milion**
- **Public Provision**
- **Rural**
- **Sparsely populated**

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
- Interdiscilpinary
- 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

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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)

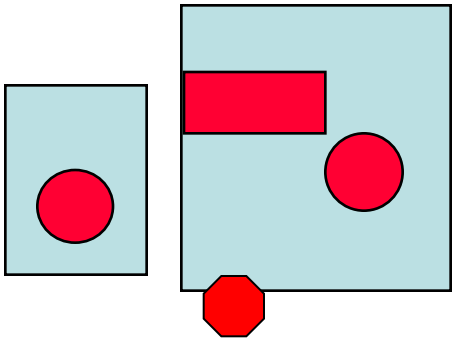
(*) McNamara, 2006

	Type of service	*2010*	*2015*
Specialized care services	Home Care Support Teams (HCSTs)(*) (**)	72	73
	Hospital Support or Consultation Teams (HST)	49	49
	Specific Support Teams to Nursing homes (STNH)	-	20
	Psychosocial Support Teams (PSSTs)	6	9
	Palliative Care Units (PCU)in Intermediate Care Centers (***)	28 PCU 383 Beds	28 PCU 383 Beds
	Palliative Care Units in Nursing Homes	27 319 beds	27 358 beds
	Palliative Care Units in acute hospital	5 PCU 40 Beds	5 PCU 40 Beds
	PC Outpatient Clinics	50	50
	Private services	2	3
Other specific structures (academic or managerial)	Teams at the Dept. of Health	1	1
	Education and training units	1 (ICO)(****)	1 (ICO)
	Clinical research team	1 (ICO)	1 (ICO)
	Chairs of Palliative Care	0	2 (University of Vic and International University of Catalonia)
	Observatory/WHOCC	1 (ICO)	1 (ICO)
Total	Specialized services (care + other)	239 + 4 = 243	264 + 6 = 270 (+ 27)

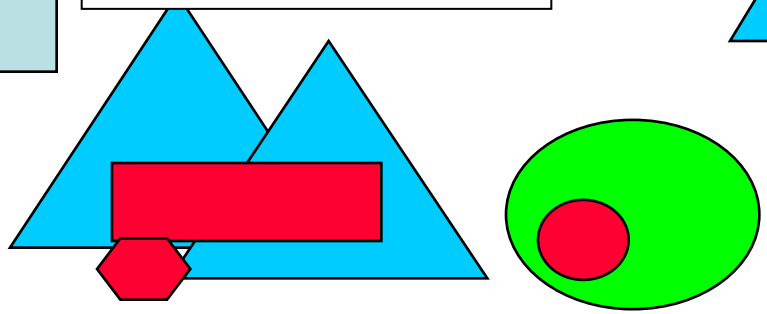
Catalonia WHO DP 1990-2015: resources (XGB et al, JPSM in press 2016)

Specific Resources / Settings

Acute Hospitals

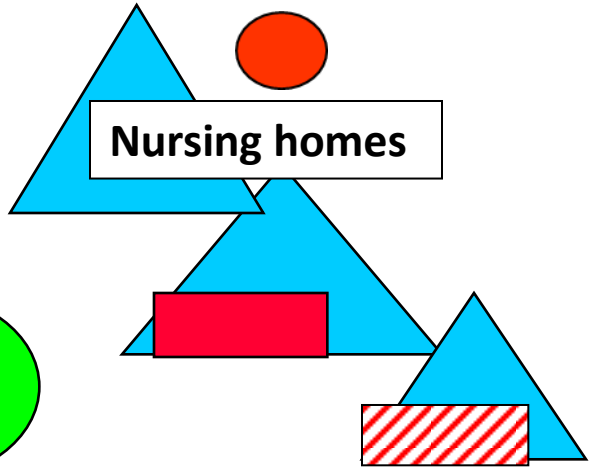


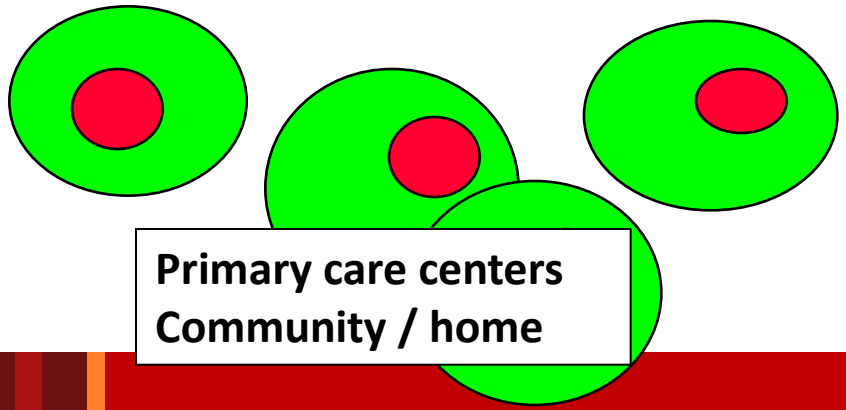
Mid term and long term, RHB, (Sociohealth Centers)



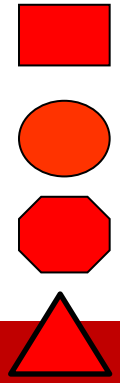
Support teams to Nursing Homes: 20

Nursing homes



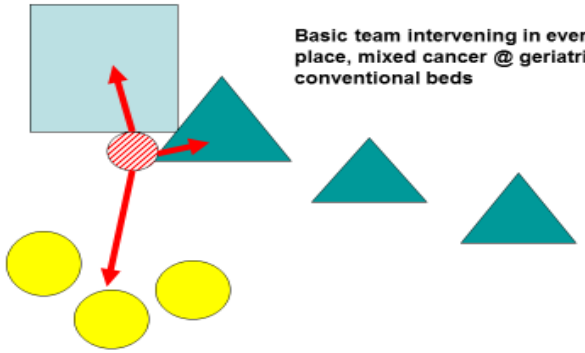


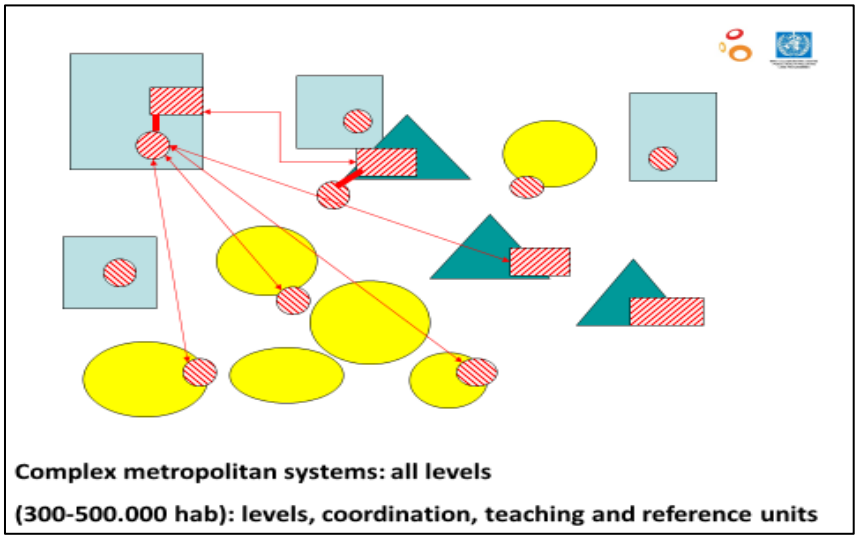
Primary care centers
Community / home



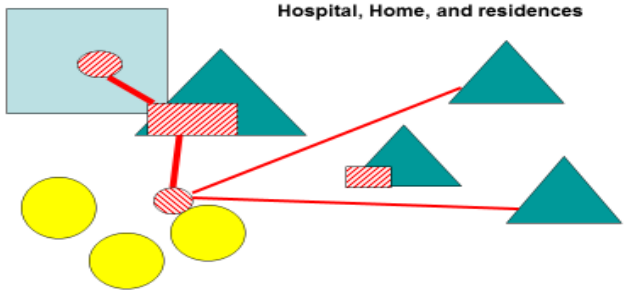
Units: 60
Support teams: Home 73
Hospital: 49
Outp's / Day care
Psychosocial support teams: 9

Comprehensive system in small districts (20-50.000 hab)





Comprehensive district system
(16 sectors of 100-150.000 hab): integrated



District organizational models

Sectorised Palliative Care Planning

Context / Needs:

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

Specialist Services

Direct coverage for complex

Joint policies & shared care

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

Coverage for all

+ Palliative approach in all settings

+ Evaluation & Quality improvement

+ Leadership

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,

UVIC UNIVERSITAT DE VIC

WHO COLLABORATING CENTRE PUBLIC HEALTH PALLIATIVE CARE PROGRAMMES

- 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)
- 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)

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
- Volonteers
- Professionals: low income, support, and academic recognition
- Financing model and complexity
- Research and evidence

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New perspectives, new challenges:

- **Palliative approach / chronicity**
- **Care of essential needs**
- **Psychosocial spiritual care**

Dimension	Action
Policy / Public Health: - Interaction chronic/palliative care - Alignment with the WHO Resolution of Palliative Care, people-centered and integrated care initiatives	- Development and validation of the ***NECPAL-CCOMS tool*** to identify individuals in need of palliative care - Development and validation of the ***ENP tool*** for psychosocial and spiritual needs[1] - Determination of prevalence of individuals with palliative care needs and limited life prognosis in the population - MACA/NECPAL Program for early identification, registry and palliative approach/care of individuals with palliative care needs in the community (primary care and nursing homes) from the Department of Health - Integrated care in districts - Codification and registry (Complex/Advanced Chronic) of the joint information system
New specific services /organizational changes	- Psychosocial Support Teams - PC Support Teams in Nursing Homes - Primary Care Support for Nursing Homes (Geriatr-ICS Program) - Case management nurses in primary care services
Model of care	- Essential needs of patients - Spiritual care development - Comprehensive / integrated model of care and intervention in individuals with advanced chronic conditions
Training	- Chair of Palliative Care at the University of Vic - Chair of Palliative Care at the International University of Catalonia - Advance care planning (SCP) - Psychosocial /spiritual postgraduate course - Palliative care in the chronic care model
Research	- 8 palliative care related PhD projects - Research group at the Catalan Institute of Oncology

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	Cancer	All chronic progressive diseases and conditions
	Disease	Condition (multi-pathology, frailty, dependency, .)
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	Specialist services	+ Actions in all settings
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	Services' approach	Population & District
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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

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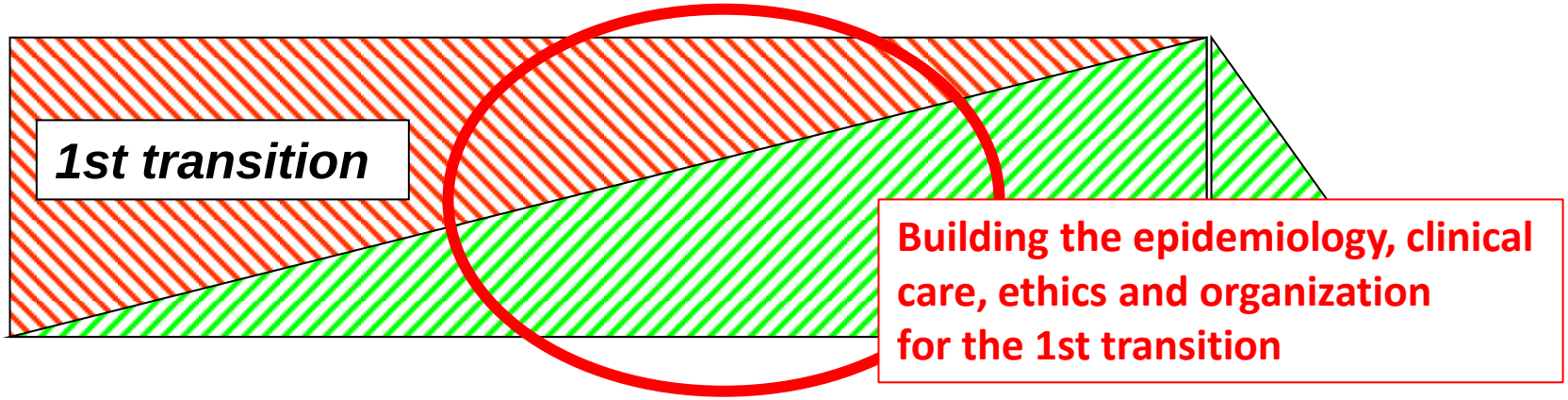
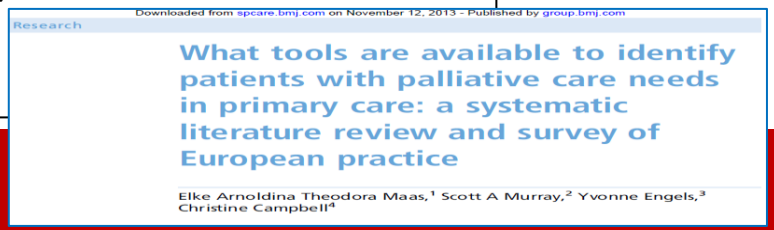


Building the epidemiology, clinical care, ethics and organization for the 1st transition

- **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 decission-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**



Research

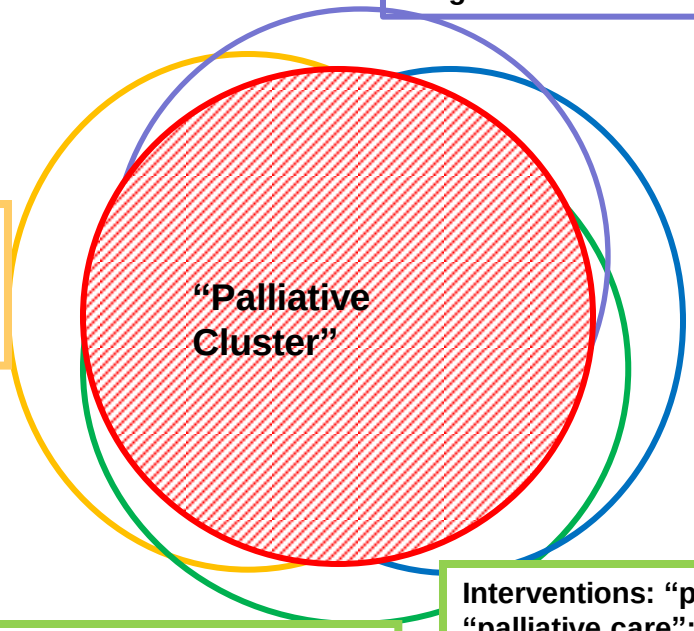
What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice

Elke Arnoldina Theodora Maas,[1] Scott A Murray,[2] Yvonne Engels,[3] Christine Campbell[4]

Components to define target patients

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

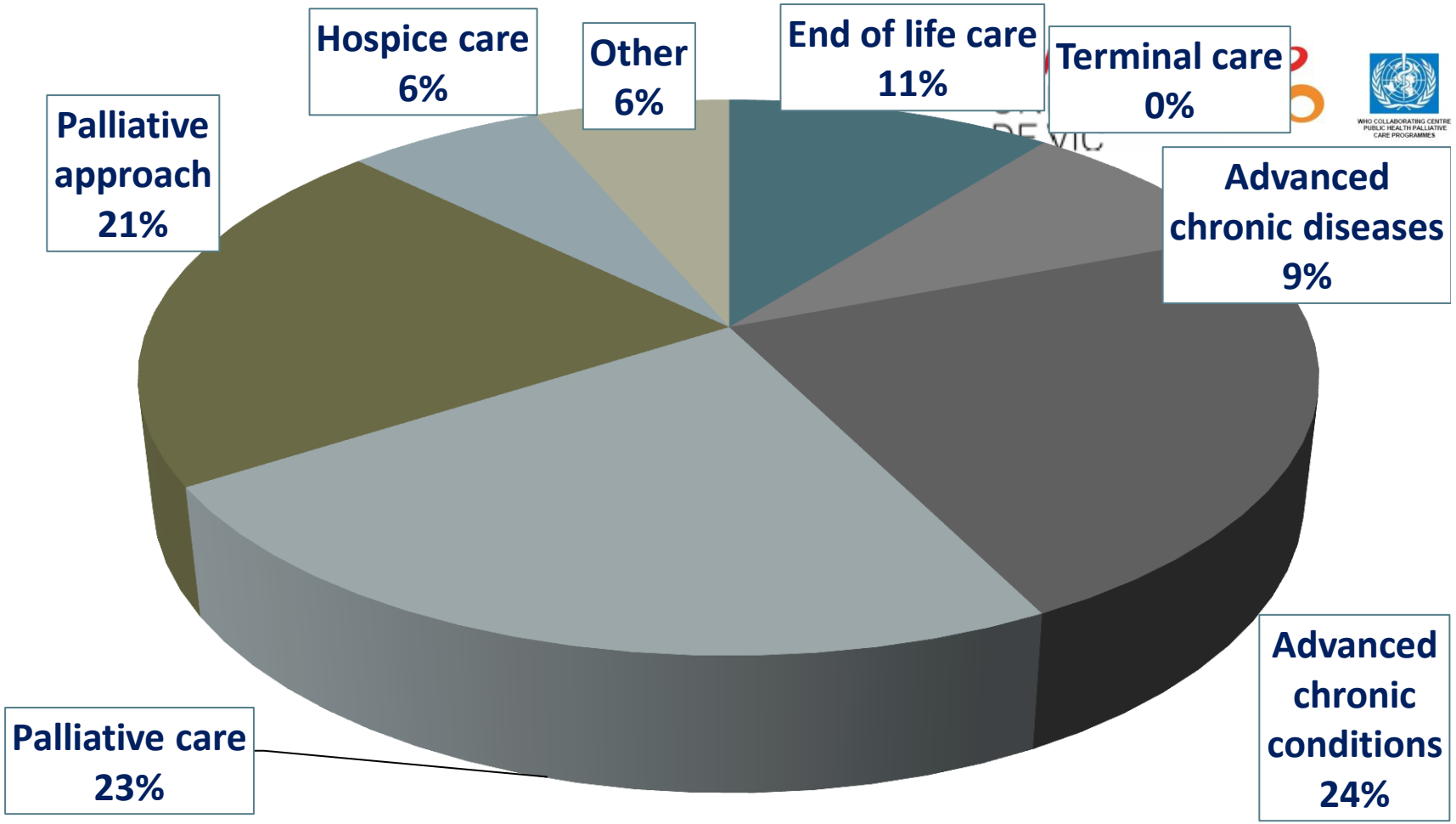
Life prognosis:
- Limited
- Years, months, weeks



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

(Disease – specific interventions have mostly a progressively limited impact in modifying the course of disease, prognosis, and quality of life)

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



Terms considered most appropriate to describe the initiative

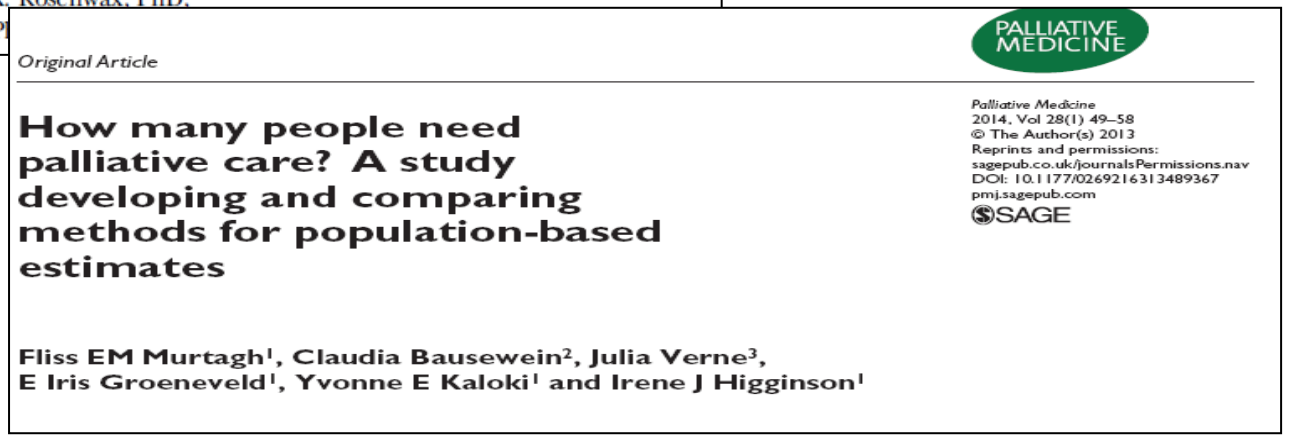
"Comprehensive, person-centred and integrated palliative approach and care for persons with complex advanced chronic conditions in all settings"

Vol. 32 No. 1 July 2006 Journal of Pain and Symptom Management 5

Original Article

A Method for Defining and Estimating the Palliative Care Population

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



Original Article

PALLIATIVE MEDICINE

How many people need palliative care? A study developing and comparing methods for population-based estimates

Palliative Medicine
2014, Vol 28(1) 49–58

DOI: 10.1177/0269216313489367
pmj.sagepub.com
SAGE

Fliss EM Murtagh[1], Claudia Bausewein[2], Julia Verne[3], E Iris Groeneveld[1], Yvonne E Kaloki[1] and Irene J Higginson[1]

Estimations: based in mortality

Generalitat de Catalunya
Departament de Salut

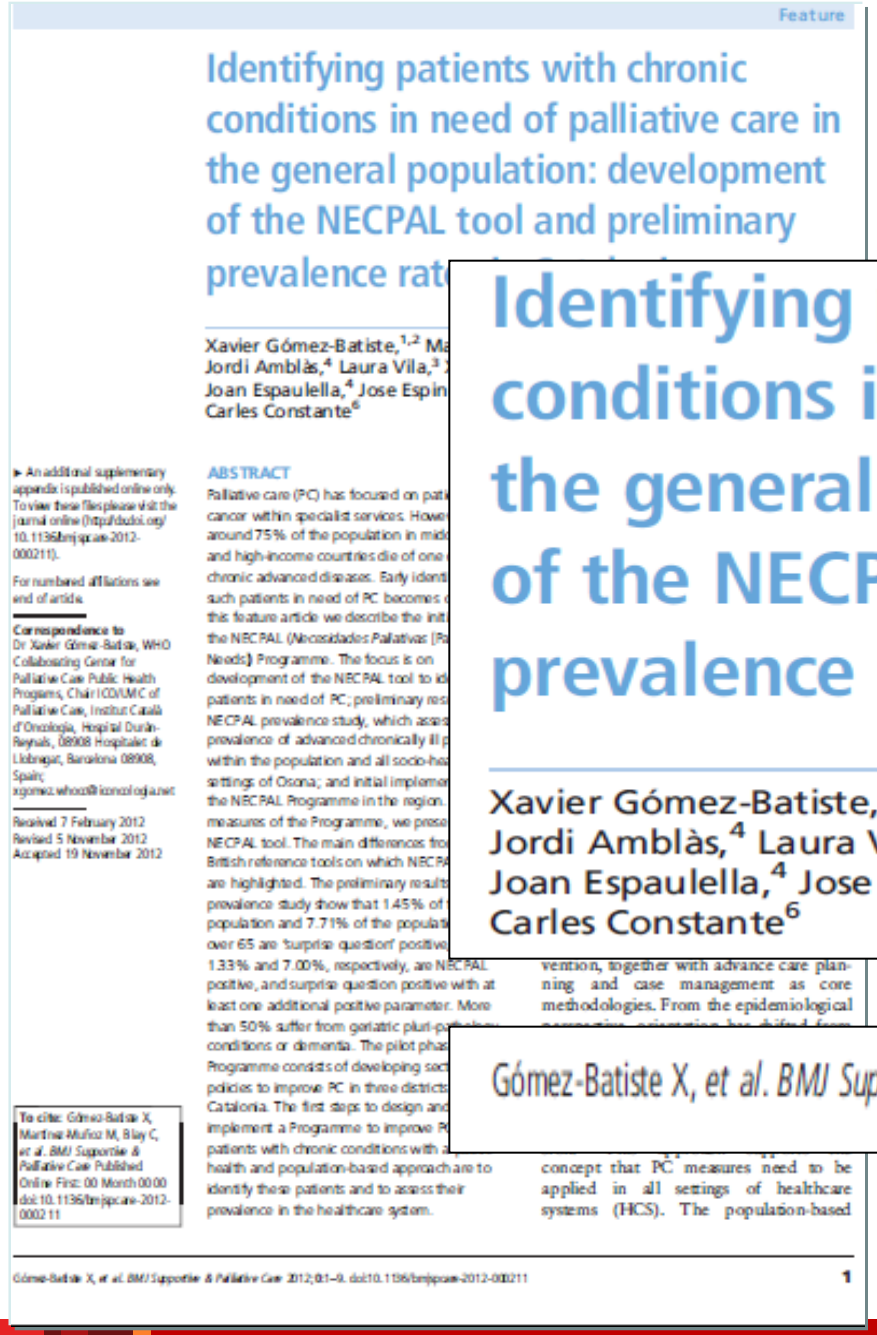
ICO
Catalan Institute of Oncology

UVIC
UNIVERSITAT DE VIC

WHO COLLABORATING CENTRE
PUBLIC HEALTH PALLIATIVE
CARE PROGRAMMES

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



Feature

Identifying patients with chronic conditions in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rat

Xavier Gómez-Batiste,[1,2] Ma
Jordi Amblàs,[4] Laura Vila,[3]
Joan Espaulella,[4] Jose Espin
Carles Constante[6]

ABSTRACT

Palliative care (PC) has focused on pati
cancer within specialist services. Howe
around 75% of the population in mid
and high-income countries die of one
chronic advanced diseases. Early identi
such patients in need of PC becomes
this feature article we describe the init
the NECPAL (Necesidades Paliativas (Pa
Needs) Programme. The focus is on
development of the NECPAL tool to id
patients in need of PC; preliminary res
NECPAL prevalence study, which asses
prevalence of advanced chronically ill p
within the population and all socio-he
settings of Osona; and initial implemen
the NECPAL Programme in the region.
measures of the Programme, we prese
NECPAL tool. The main differences fro
British reference tools on which NECPA
are highlighted. The preliminary result
prevalence study show that 1.45% of
population and 7.71% of the populati
over 65 are 'surprise question' positive
1.33% and 7.00%, respectively, are NECPAL
positive, and surprise question positive with at
least one additional positive parameter. More
than 50% suffer from geriatric pluri-pathology
conditions or dementia. The pilot phas
Programme consists of developing sect
policies to improve PC in three districts
Catalonia. The first steps to design and
implement a Programme to improve P
patients with chronic conditions with a
health and population-based approach are to
identify these patients and to assess their
prevalence in the healthcare system.

vention, together with advance care planning and case management as core methodologies. From the epidemiological
concept that PC measures need to be applied in all settings of healthcare systems (HCS). The population-based

► An additional supplementary appendix is published online only. To view these files please visit the journal online (http://dx.doi.org/10.1136/bmjspcare-2012-000211).

For numbered affiliations see end of article.

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

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

NECPAL CCOMS-ICO 3.0 2016©

PATIENT: ..... HC: .....

DATE: ..... / ..... / ..... SERVICE: .....

RESPONSIBLE(S): .....

Surprise Question (to/among professionals)	Would you be surprised if this patient dies within the next year?		☐ Yes ☑ No (-) (+)
"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?		☐ Yes ☑ No
	- Need: identified by healthcare professionals from the team		☐ Yes ☑ No
General Clinical Indicators: in the last 6 months - Severe, sustained, progressive, not related with recent concurrent process - Combine severity WITH progression	- Nutritional Decline	• Weight loss > 10%	☐ Yes ☑ No
	- Functional Decline	• Karnofsky or Barthel score > 30% • ADLs >2	☐ Yes ☑ No
	- Cognitive Decline	• Loss ≥ 5 minimental or ≥ 3 Pfeiffer	☐ Yes ☑ No
Severe Dependence	- Karnofsky <50 or Barthel <20		☐ Yes ☑ No
Geriatric Syndromes	- Falls - Pressure Ulcers - Dysphagia - Delirium - Recurrent infections	• Clinical data anamnesis ≥ 2 recurrent or persistent	☐ Yes ☑ No
Persistent symptoms	Pain, weakness, anorexia, dyspnoea, digestive...	• ≥ 2 symptoms (ESAS) persistents or refractory	☐ Yes ☑ No
Psychosocial aspects	Distress and/or Severe adaptive disorder	• Detection of severe emotional distress > 9	☐ Yes ☑ No
	Severe Social Vulnerability	• Social and family assessment	☐ Yes ☑ No
Multi morbidity	>2 advanced chronic diseases or conditions (from the list of specific indicators)		☐ Yes ☑ No
Use of resources	Evaluate Demand/intensity of interventions	• > 2 urgent or not planned admittances in last 6 months • Increase Demand/intensity of interventions (homecare, nurse interventions, etc)	☐ Yes ☑ No
Specific indicators	Cancer, COPD, CHD, Liver, Renal, CVA, Dementia, Neurodegenerative diseases, AIDS, other advanced	• To be developed as annexes • Criteria of severity and progression	☐ Yes ☑ No

Classification:		
Surprise Question (PS)	SQ + (I would not be surprised)	√
	SQ - (I would be surprised)	
NECPAL Parameters	NECPAL + (de 1+ a 13+)	
	NECPAL - (No parameters)	√

Codification and Registry

Propose codification as Patient with Advanced Chronic Conditions (PCC)

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The NECPAL-ICO-CCOMS © Tool

Original Article

PALLIATIVE MEDICINE

Palliative Medicine
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SAGE

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

Xavier Gómez-Batiste[1,2], Marisa Martínez-Muñoz[1,2], Carles Blay[2,3], Jordi Amblàs[4], Laura Vila[5], Xavier Costa[5], Joan Espaulella[4], Jose Espinosa[1,2], Carles Constante[6] and Geoffrey K Mitchell[7]

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 CCOMS-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

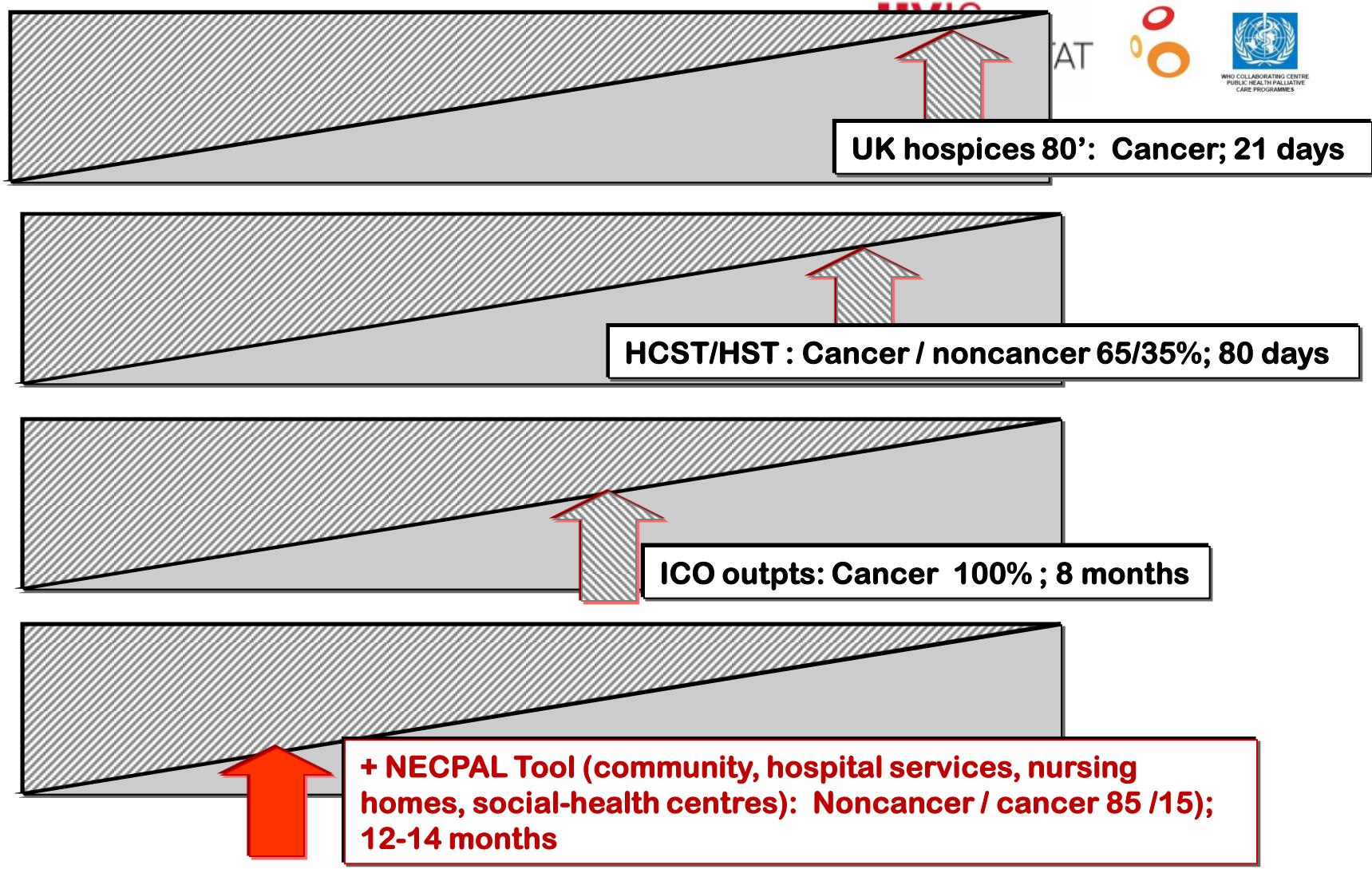
	Cancer	Organ failure	Dementia	Advanced frailty	P- value
Age Mean (SD)	73.3 (13.9)	76.0 (14.0)	85.5 (6.5)	87.0 (6.8)	<0.001
Male N (%)	58 (57.43)	138 (54.12)	37 (19.89)	84 (29.47)	< 0.001
Female N (%)	43 (42.57)	117 (45.88)	149 (80.11)	201 (70.53)	

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

Male 75y
cancer & organ failures

Females > 85y
Severe frailty, multimorbidity & dementia

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



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

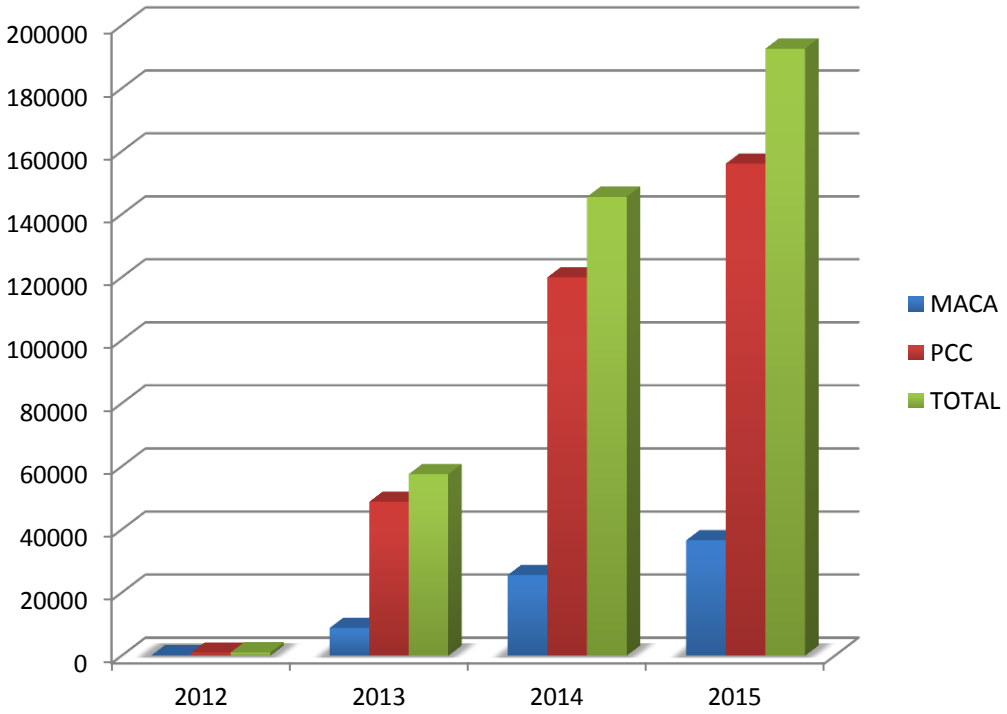
In Primary care services:

- **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



MACA: 36.553

PCC: 156.083

TOTAL: 192.636

SOURCE: HC3, 2015

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

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

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

Action	Method
1. Multidimensional assessment: symptoms, emotional, essential-spiritual, adjustment, resources, context	Use validated tools
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 accesibility, home care, intensity of care, etc
6. Case management, preventive approach, continuing care, coordination and integrated policies, district approach

• Establish and document a formal policy for palliative approach
• Determine the prevalence and identify patients in need
• Establish protocols, registers, andtools to assesspatients' needsandrespond to most common situations
• Train professionals and insert palliative care training and review in the conventional training process (sessions, etc)
• Identify the primary carers of patients and give support and care, including bereavement
• Increase team approach
• In services with high prevalences: devote specific times and professionals with Advanced training to attend palliative care patients (Basic Palliative Care)
• Increase the offer and intensity of care for identified persons focused in quality of life
• Integrated care: Establish links, joint information system, criteria intervention and access to Palliative Care Specialized services and all services in the area
• Address the ethical challenges of early identification

10 actions to improve palliative approach in services

X Gómez-Batiste, S Murray, S Connor, 2016

District Palliative Care Planning

Specialist Services

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

- 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

- 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, agreeand 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 identifed 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

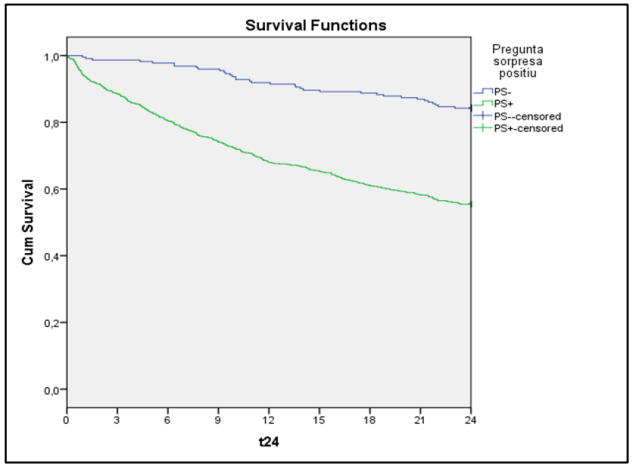
Ethical approach: Benefits & risks

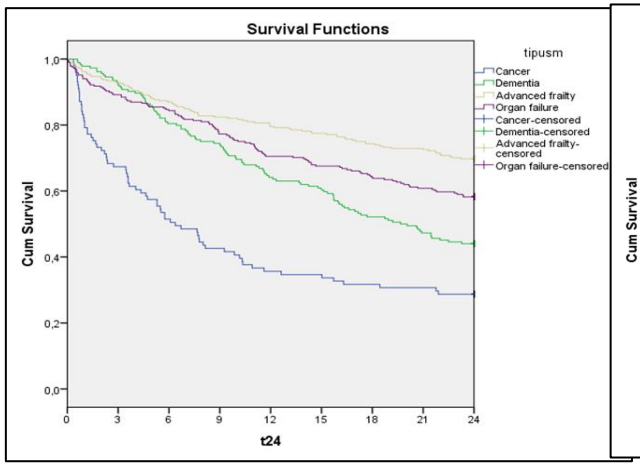
- Starting Systematic process: Needs assessment, Advance Care Planning, Review of Condition and treatment, Family involvement, Case management, Continuing care, etc
- Patient's involvement/ACP
- Starting palliative perspective
- Adequation vs limitation of resources
- Increasing home care

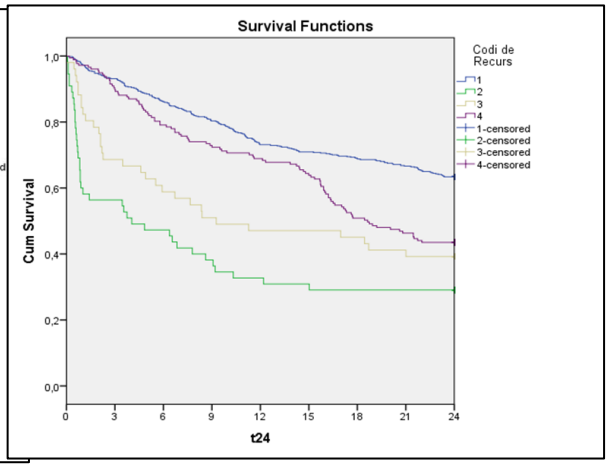
- Estigma
- Abandonment
- Dichotomic perspective
- Reducing curative opportunities
- Impact on patients and families
- Misuse to reduce cost

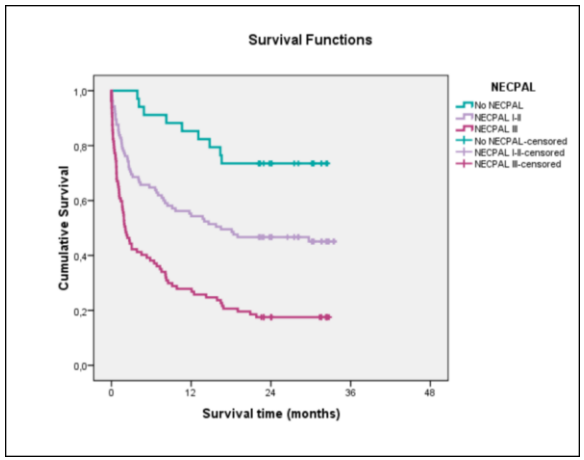
X Gómez-Batiste et al, J of Palliat Care 2016, in press

Prognostic approach









X Gómez-Batiste et al, Palliat Med, 2016, 2nd review
A Calsina et al, J of PM, sended

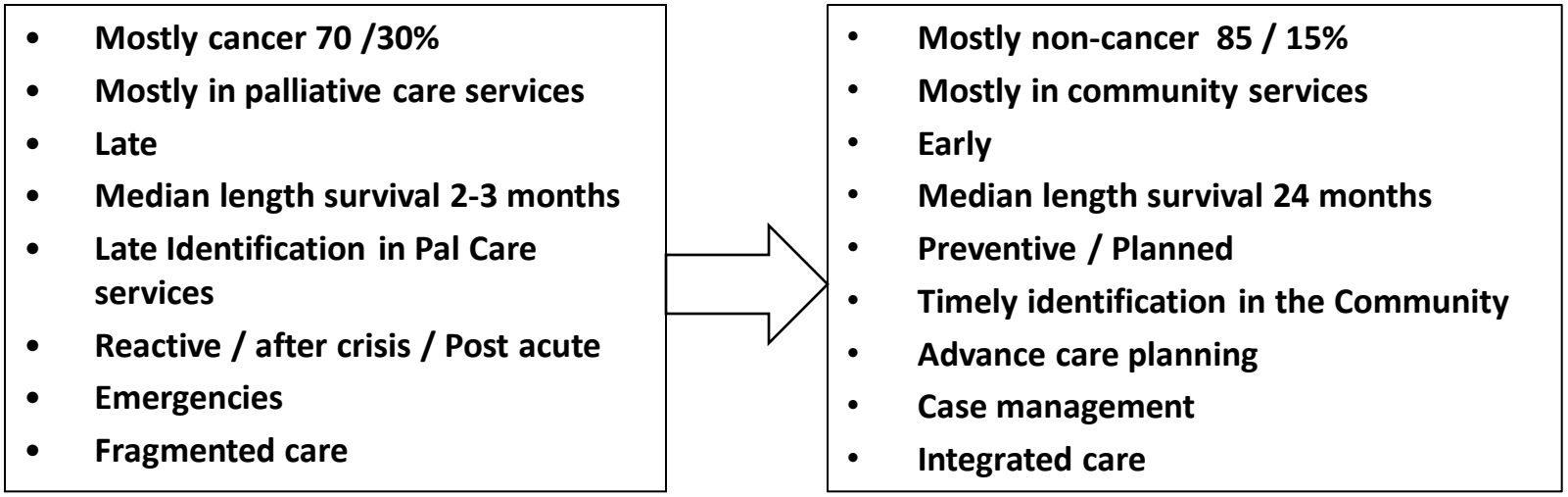


FIGURE 4: Models of palliative interventions in chronic advanced palliative care

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

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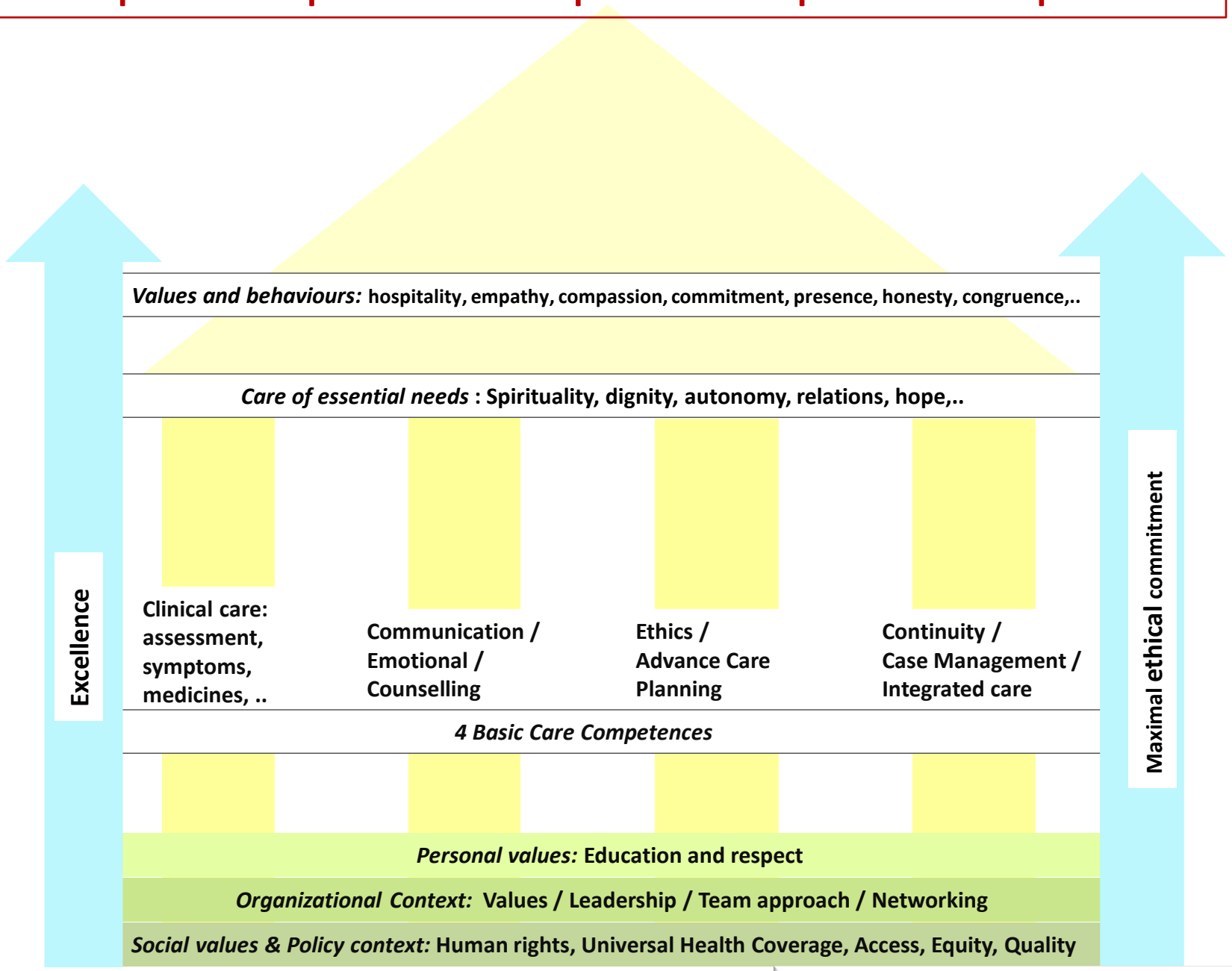
New perspectives, new challenges:

- **Care of essential needs**

Model of personal & profesional competencies for palliative care provision



Maté-Méndez J, et al. J Palliat Care 2013; 29(4): 237-243

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

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Steps for excellent care

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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

Obra Social
Fundación "la Caixa"

What we do

Emotional and social care

Providing psychological and social care measures to help patient and family to face the illness

Spirituality

Includes spiritual aspects that enable patient and family to serenely 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

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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

Map showing third sector partner organisations

Concept of Psychosocial support teams giving support to existing services

Palliative and Supportive Care (2011), **9**, 239–249.

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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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]
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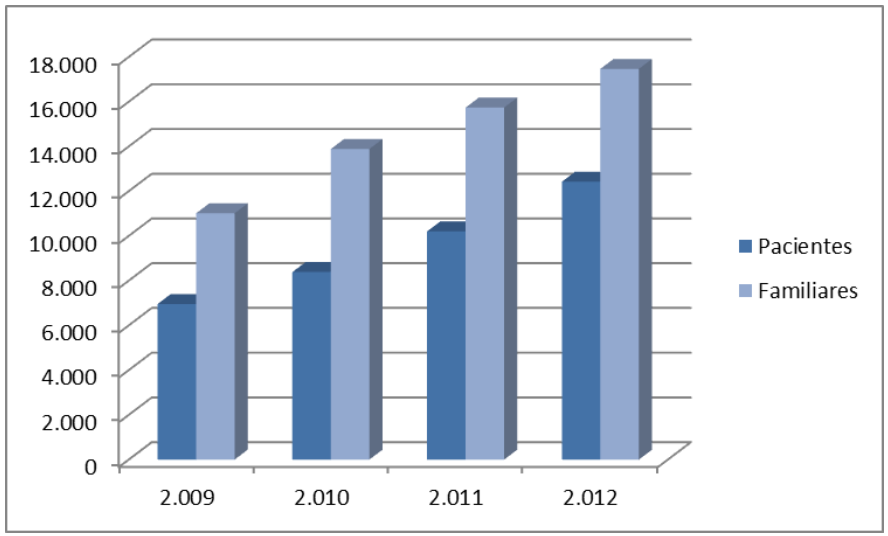
MARC SIMÓN, M.B.A.,[2] CANDELA CALLE, M.D.,[3] JAUME LANASPA, M.B.A.,[2] AND
WILLIAM BREITBART, M.D.

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

	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**



>200.000 persons careed

8.5 milion Euros / year

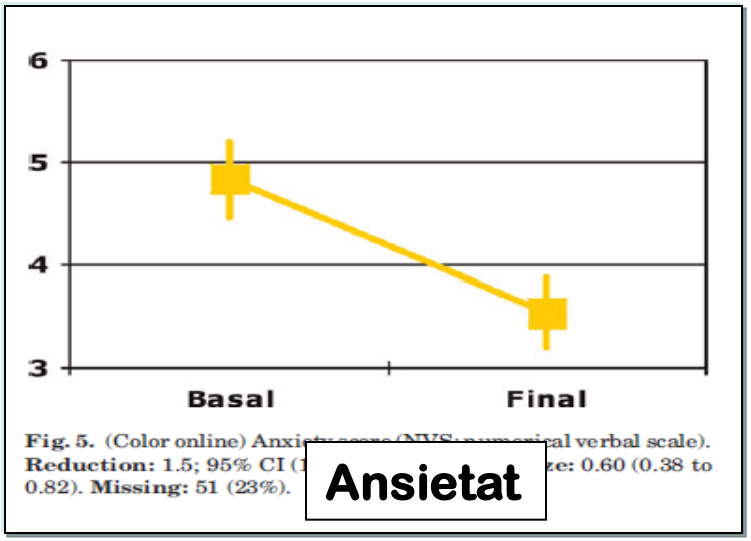


Fig. 5. (Color online) Anxi… (NVS: numerical verbal scale). **Reduction:** 1.5; 95% CI (1… …ze: 0.60 (0.38 to 0.82). **Missing:** 51 (23%).

Ansietat

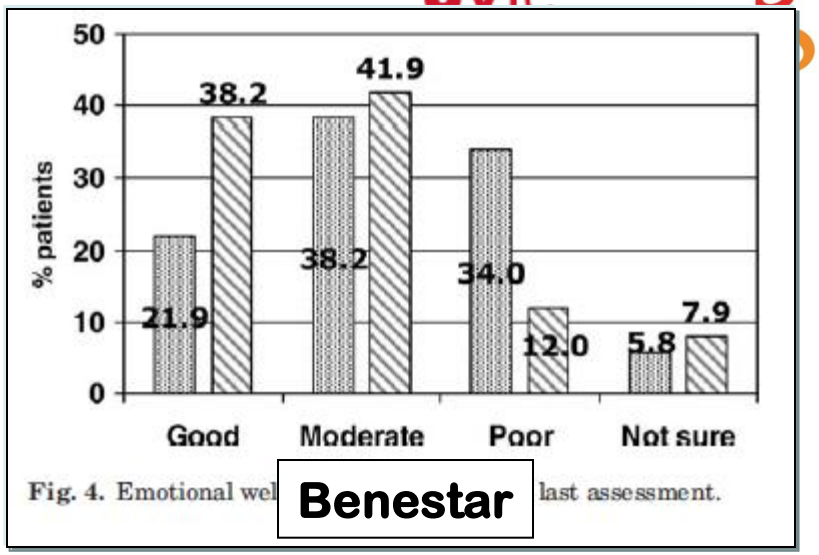


Fig. 4. Emotional wel… last assessment.

Benestar

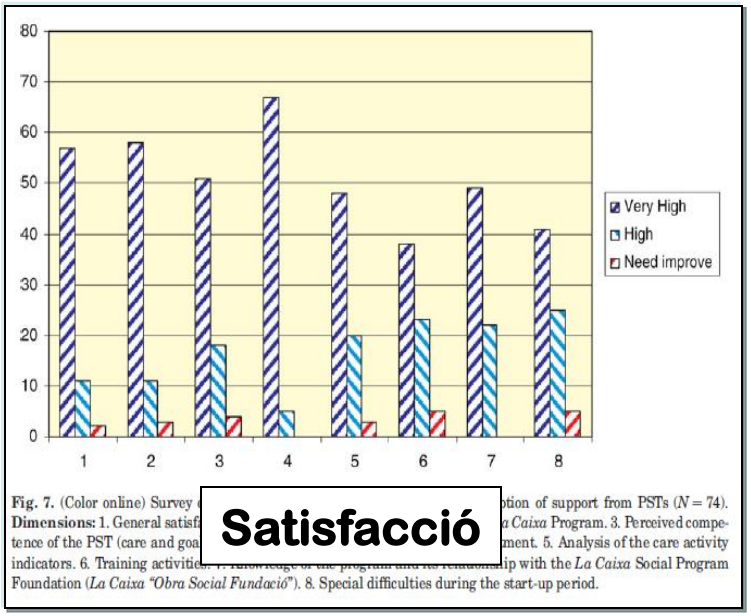


Fig. 7. (Color online) Survey … …otion of support from PSTs ($N = 74$). **Dimensions:** 1. General satisf… …a Caixa* Program. 3. Perceived competence of the PST (care and goa… …ment. 5. Analysis of the care activity indicators. 6. Training activities. … …ip with the *La Caixa* Social Program Foundation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

Satisfacció

Other Results:
Efectiveness
Satisfaction:
Families
Stakeholders
Quality / organizational audit

Interaction
Chronic
&
Palliative Care

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CURRENT OPINION

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]

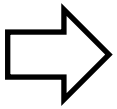
Purpose of review
We describe conceptual innovations in palliative care epidemiology and the methods to identify patients in need of palliative care, in all settings.
In middle–high-income countries, more than 75% of the population will die from chronic progressive diseases. Around 1.2–1.4% of such populations 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

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

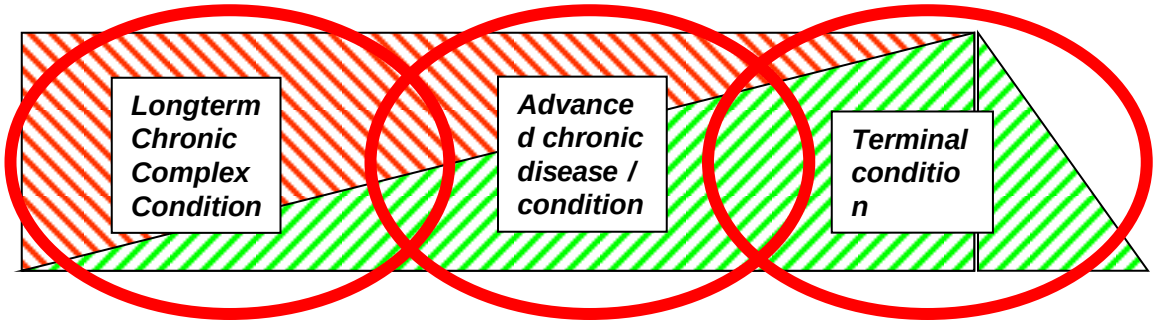


- Mostly non-cancer 85 / 15%
- Identification mostly community services
- Early
- Median length survival 24 months
- Preventive / Programmed
- Advance care planning
- Case management
- Integrated care

Models of palliative interventions in chronic care: from late, institutional, reactive and fragmented to early, community, preventive and integrated

XGB et al, 2012

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



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

"Complex Chronic condition"	*"Advanced chronic condition"*	*"End of life or terminal"*
- Disease-centered - Survival, sec/tert prevention - Build confidence - Shared Decission-making - Common language - Advance directives - Disease / Care management - RHB - Primary & secondary specialist care	- 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	- QoL - Review & Adjust frequently - Essential needs - Sedation - Elarging / shortening life - Nutrition/hydration - Bereavement - Primary & palliative care (if needed) shared care

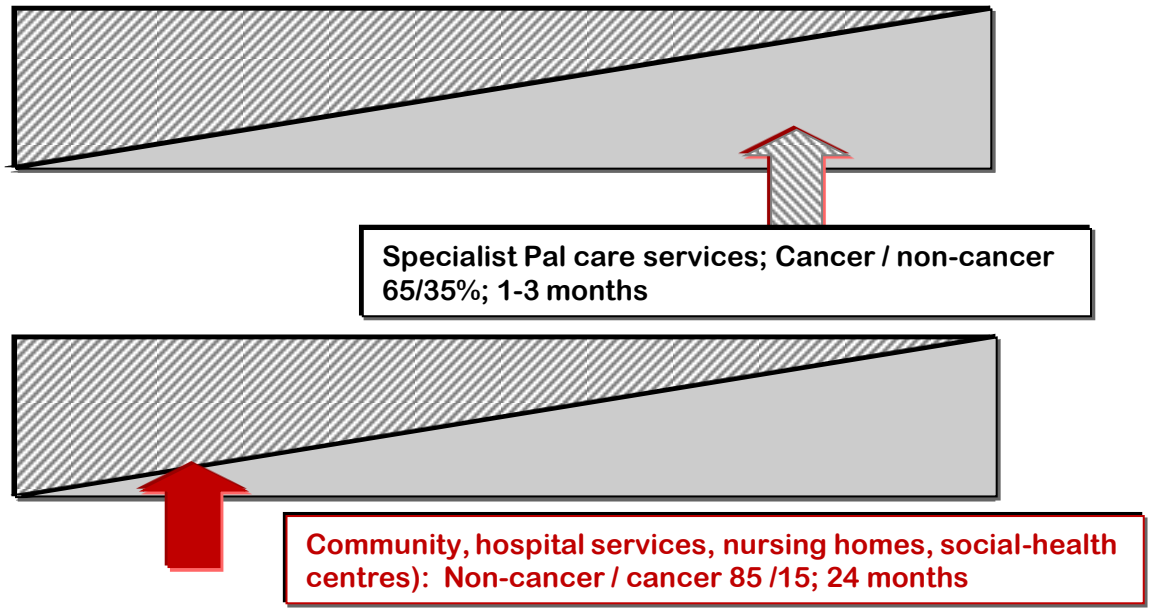


FIGURE 8: Place of identification, types of patients, and median survival of patients with c palliative care needs identified in the community

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

SERVICE DELIVERY
& SAFETY

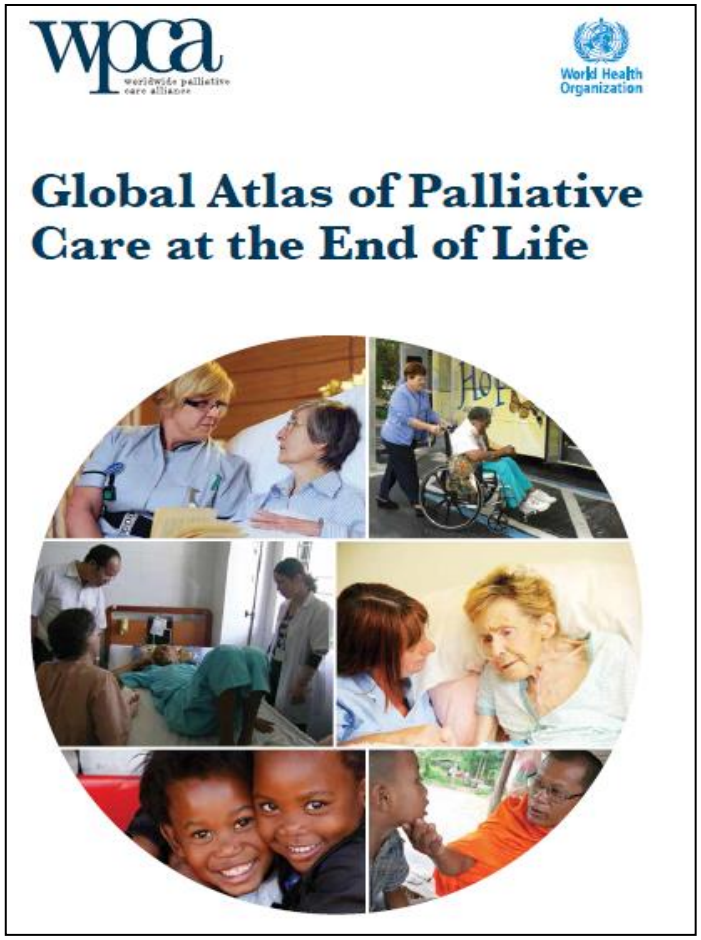
WHO INITIATIVE FOR PALLIATIVE CARE: STRATEGY AND ACTION PLAN

World Health Organization

WHA Resolution 67.19: SCOPE & MODEL ISSUES

(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*



Needs assessment and Context analysis: The Global Atlas

- 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)

Level		*Description*	*N (%)*	
Group 1		No known activity	75 (32.0)	No services: 42.0%
Group 2		Capacity building pioneers with no services	23 (10.0)	
Group 3	3a	Isolated provision	74 (31.6)	Isolated: 31.6%
	3b	Generalized provision	17 (7.3)	Generalized Provision: 26.6% (Inserted 19.3%) (Fully integrated 8.6%)
Group 4	4a	Preliminary insertion in the mainstream	25 (10.7)	
	4b	Full integration into the mainstream	20 (8.6)	

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

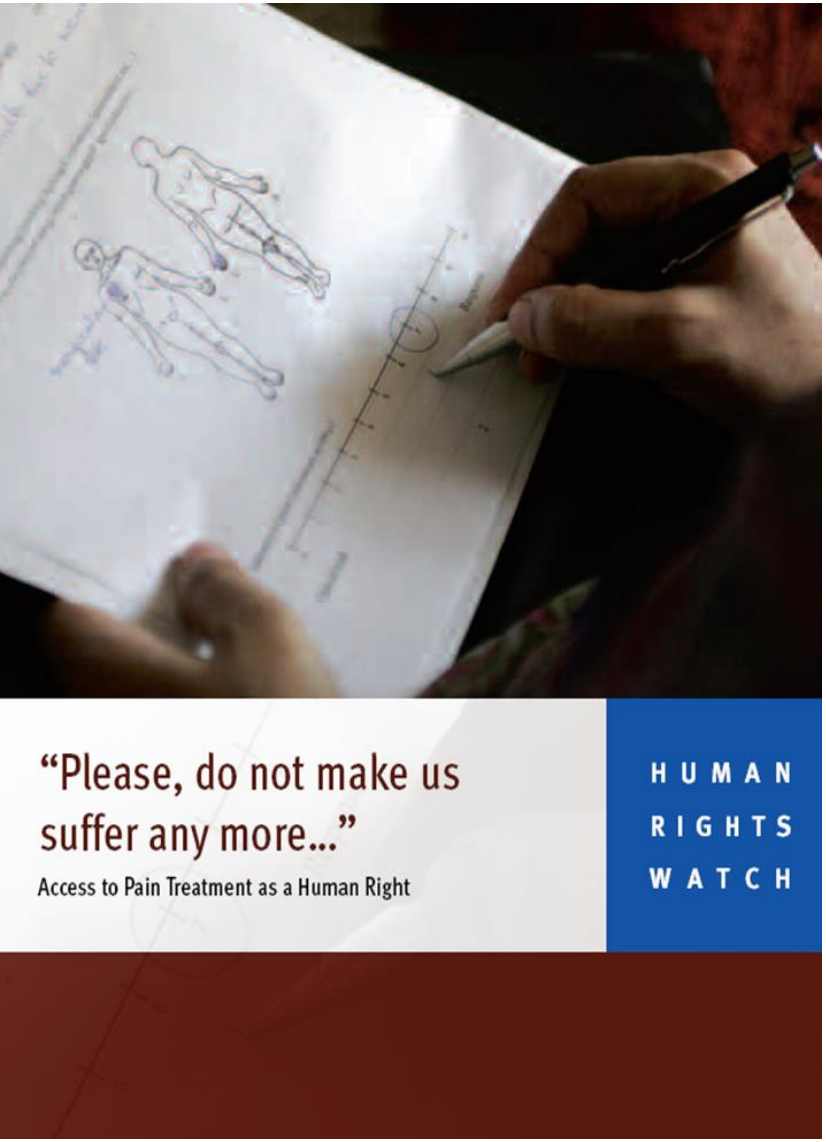
All patients
All conditions
All time
All needs
All professionals
All settings
All countries

Operational objectives to start 2015-2016

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

Expected outcomes 2015-2020

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



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WHO COLLABORATING CENTRE PUBLIC HEALTH PALLIATIVE CARE PROGRAMMES

Palliative care: basic human right indicator of degree of respect for human dignity All countries

Palliative care: the soul of the health care system

World Health Organization

You all matter for WHO