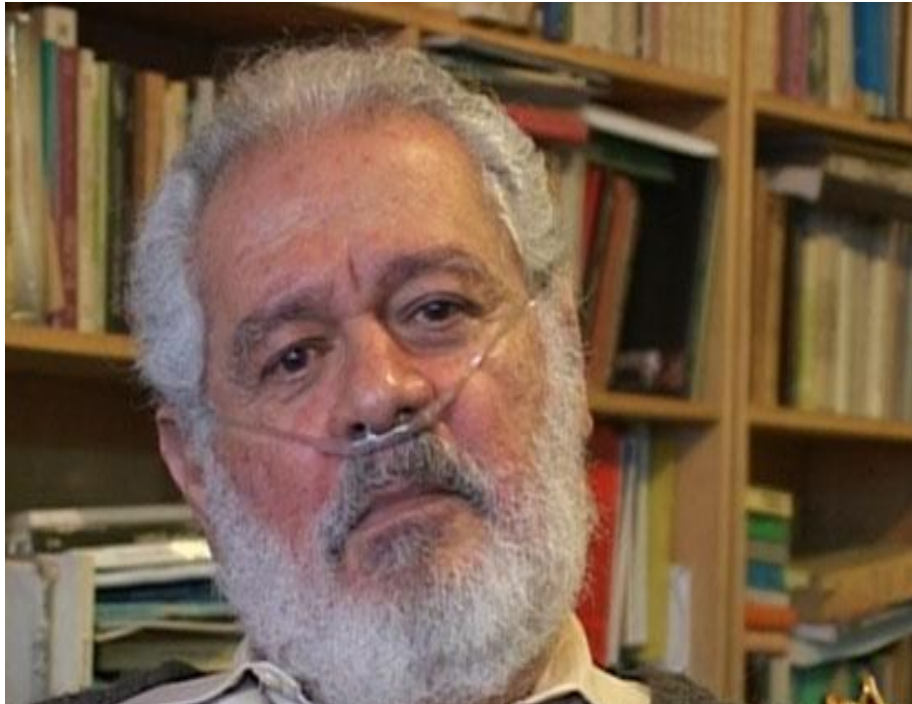
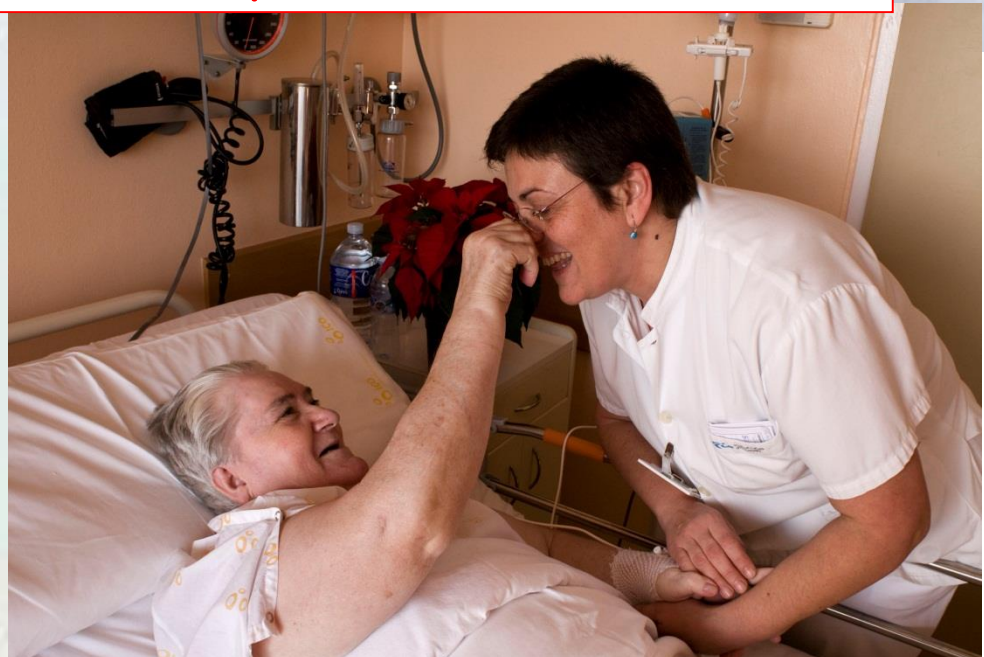


<https://www.airmeet.com/event/session?t=451b8b50-8f83-4b4a-9bbd-0ab5e265dce5>

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Lets talk about these persons



Prof Xavier Gómez- Batiste, MD, PhD

Director,

Qualy Observatory

**WHO Collaborating Center for Palliative Care Public Health ProgramsCatalan
Institute of Oncology ICO (2007-2020)**

Professor of Palliative Care. Faculty of Medicine. University of Vic

**Scientific Director. Programa for the comprehensive Care of people with
advanced chronic conditions. La Caixa Foundation.**

(Nov 2014-May 2015) Medical Officer for Palliative and Longterm Care, WHO

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Workshop: how to integrate palliative care into the health and social system

Aims of this workshop:

1. Sharing challenges
2. Explore answers

For the integration of palliative care

Outline list of dimensions workshop

- **Conceptual transitions and Challenges palliative care XXIc**
- **Epidemiology**
- **How to identify people with palliative care needs**
- **How to look after this people**
- **How to establish prognosis**
- **Ethical dilemmas of early identification**
- **How to change palliative care services' perspectives and practice**
- **Involving society**
- **Palliative care human right**

Proposed methodology

- For every dimension in the list
 1. Challenges
 2. Aims and actions proposed
 3. Barriers and difficulties

Conceptual transitions

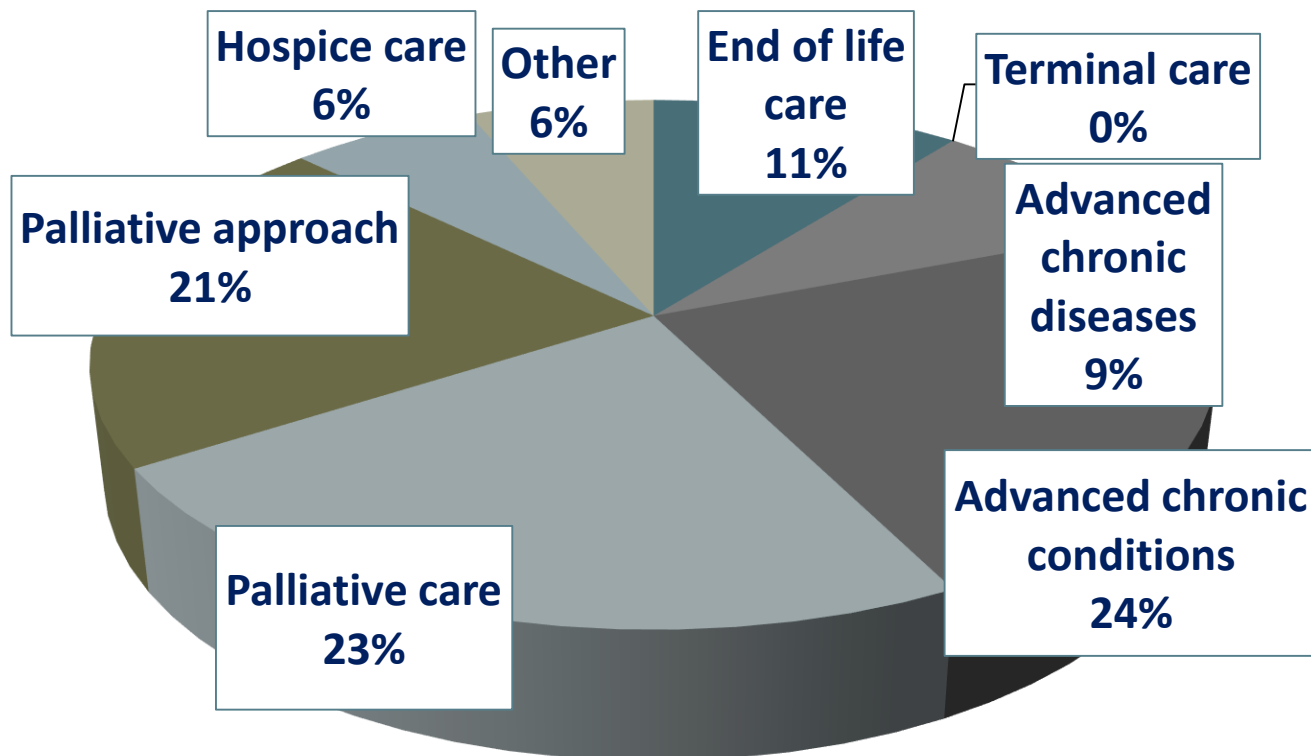
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Conceptual transitions in Palliative Care in the XXI century

FROM	Change TO
Terminal disease	Advanced progressive chronic disease
Death weeks or months	Limited life prognosis
Cancer	All chronic progressive diseases and conditions
Disease	Condition (multi-pathology, frailty, dependency, .)
Mortality	Prevalence
Dichotomy curative - palliative	Synchronic, shared, combined care
Specific <i>OR</i> palliative treatment	Specific <i>AND</i> 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 <i>approach</i> everywhere
Specialist services	+ Actions in all settings of health & social care
Institutional approach	Community approach
Services' approach	Population & district

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

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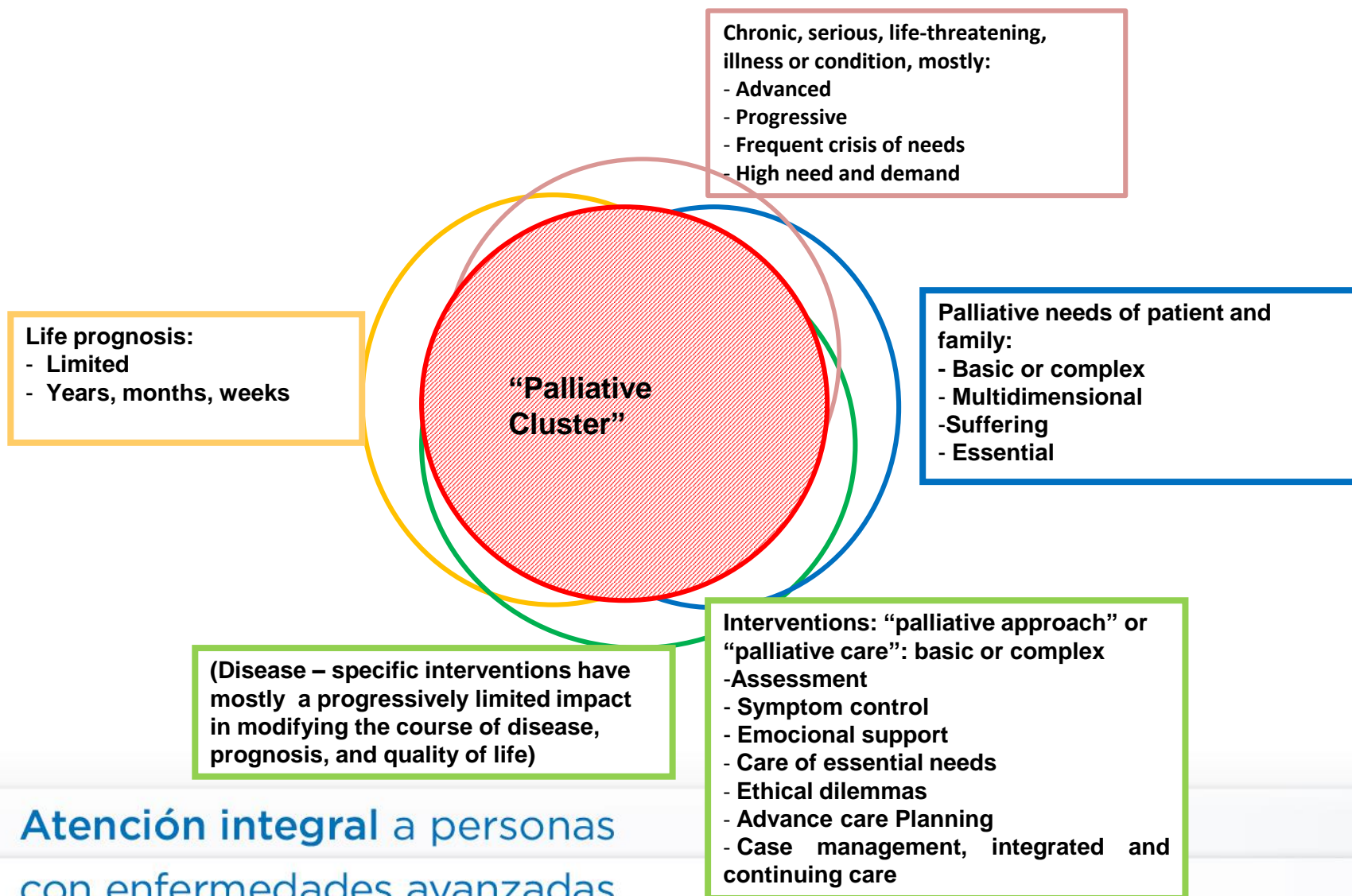
Proposed Terms

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Gomez-Batiste, Connor, Murray et al, 2017



Components target definition



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Conceptual transitions

1. Agree with the concepts?
2. Taxonomy?

Some quantitative data of prevalence and prognostic

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Palliative Care needs

The populational perspective:

- Mortality
- Prevalence (population, territory)
- Prevalence by settings

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

Palliative Medicine
201X, Vol. XX(X) 1–10
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0269216313518266
pmj.sagepub.com
SAGE

Xavier Gómez-Batiste^{1,2}, Marisa Martínez-Muñoz^{1,2}, Carles Blay^{2,3}, Jordi Amblàs⁴, Laura Vila⁵, Xavier Costa⁵, Joan Espauella⁴, Jose Espinosa^{1,2}, Carles Constante⁶ and Geoffrey K Mitchell⁷

Abstract

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

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

Design: Cross-sectional, population-based study. Main outcome measure: prevalence of advanced chronically ill patients in need of palliative care according to the NECPAL 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

Results: A total of 31.4% of the population in need of palliative care condition: 31.4% in nursing homes and 68.6% in the community.

Conclusions: The prevalence of people in need of palliative care is 31.4% in the community and 68.6% in nursing homes.

Prevalence of people in need of palliative care: 31.4% in the community and 68.6% in nursing homes.

Population:

4.5%: People with complex chronic conditions: PCC

1.5%: People with advanced chronic conditions: PCA

0.4%: PCAs with social needs (solitude, poverty, conflict)

In Hospitals
35-40%

Other Settings
GPs: 20/ year
Nursing homes: 60-70%



More than 85% of people with Advanced chronic conditions, palliative care needs, limited life prognosis live in the community (Home or Nursing home)

	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)	

- 60-65%: more female, with frailty and multimorbidity, at home or nursing homes, high prevalence of dementia
- 35-40%: more male, organ failure, cancer
- Cancer / non cancer 1/7
- >85% of people with advanced chronic conditions, palliative care needs and limited life prognosis are in the community, with a median survival of 2-3 years, cared for relatives and primary care services with a median survival of 2-3 years

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Who are they?

**Discussion: Agree with the epidemiology?
Same methods?
Is that so in your country??**

Special Article

Comprehensive and Integrated Palliative Care for People With Advanced Chronic Conditions: An Update From Several European Initiatives and Recommendations for Policy



Xavier Gómez-Batiste, MD, PhD, Scott A. Murray, MD, Keri Thomas, OBE, MBBS, MRCP, DRCOG, MSc, Carles Blay, MD, MSc, Kirsty Boyd, MD, PhD, Sebastien Moine, MD, MSc, Maxime Gignon, MD, PhD, Bart Van den Eynden, MD, PhD, Bert Leysen, MD, PhD, Johan Wens, MD, PhD, Yvonne Engels, PhD, Marianne Dees, MD, PhD, and Massimo Costantini, MD

Levels:

- Individual patients
- Services
- Territories

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ICO DiR. The 'Quality' End of Life Care
Observatory - WHO Collaborating Centre
for Public Health Palliative Care
Programmes

Discussion: Timely identification in your experience or settings

1. Tools?
2. Challenges
3. Aims and actions proposed
4. Barriers and difficulties

Vol. 53 No. 3 March 2017

Journal of Pain and Symptom Management 509

Special Article

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Table 1
Characteristics of Implementation Processes in Countries

	Dimension	Catalonia, Spain	Scotland, UK	England, UK	Nijmegen, The Netherlands	France	Belgium
<i>General aspects</i>	<i>Scope</i>	Formal Program at the Department of Health inserted in the Chronic Care Program. It includes clinical, epidemiologic, and services research and education and training on advanced chronic care and advance care planning	SPICT developed by literature review and experts consensus offered to GPs and more hospital doctors	GSF is now a comprehensive training program for a range of settings that includes training, tools, measures, and support leading to formal quality assurance	Tool to help GPs to identify patients with cancer, chronic obstructive pulmonary disease, or congestive heart failure in need of palliative care	Pilot project in a Multi professional Primary Healthcare Center, supported by the Regional Health Authority (SCoP3) ¹⁹	A CPPPC has been developed (<i>Pro-Spinoza</i>) ¹⁸
<i>Tool</i>		NECPAL CCOMS-ICO ^{7,29}	SPICT ^{17,30}	GSF PIG ⁸	RADPAC ¹⁶	SQ + SPICT_FR ³¹	SQ + SPICT

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	NECPAL CCOMS-ICO ^{7,29}	SPICT ^{17,30}	GSF PIG ⁸	RADPAC ¹⁶	SQ + SPICT_FR ³¹	SQ + SPICT
Main results	Up to 130,000 persons identified mostly in primary care services. Development of implications for public health and geriatrics Qualitative assessment currently ongoing	Various research studies providing evidence base. Most patients in Scotland now die with anticipatory care in place, supported by a Key Information Summary.	Up to 80% patients on primary care: 70% with ACP halving hospital deaths. In hospitals: 85% ACP, reduction length stay, more discharged home Less hospital use	Used in an RCT Despite a negative result in an RCT, the post hoc analysis indicates that this has the potential to improve the quality of palliative care	No results at the present moment. A mixed-methods research and an RCT are ongoing (funded by the French Ministry of Health)	Care plan defined: identification of palliative care needs. A quasi-experimental study of the implementation of the CPPPC is currently recruiting GPs and patients, motivating participants to apply
Difficulties and barriers	- Lack of training - Ethical debate on benefits/risks - Low implementation in hospitals	- Time, identifying the trigger - Lack of training and confidence	Cultural barriers, e.g., refraining from dying to active supportive care especially in hospitals, time to plan, some staff issues	Communicating the "marking moment" still difficult regarding organ failure Indicators that are quite	Lack of time and training to initiate ACP Fear of destroying hope/"loss of chance"	Taboo of palliative care GPs lack time Many single-handed practices. Poor linkages with other services

Atención integral a personas con enfermedades avanzadas

**RECOMMENDATIONS
FOR THE COMPREHENSIVE
AND INTEGRATED CARE OF PERSONS
WITH ADVANCED CHRONIC
CONDITIONS AND LIFE-LIMITED
PROGNOSIS IN HEALTH AND SOCIAL
SERVICES:
NECPAL CCOMS-ICO® 3.1 (2017)**

Research Team:

Author and main researcher: Xavier Gómez-Batiste
Collaborating team: Jordi Amblàs, Xavi Costa,
Joan Espauella, Cristina Lasmarías, Sara Elia, Elba Beas,
Bárbara Domínguez, Sarah Mir

ologia



NECPAL 3.1 2017

NECPAL CCOMS-ICO® TOOL VERSION 3.1 2017

Surprise question (to/ among professionals):

Would you be surprised if this patient dies within the next year?

YES, I would be surprised → **NOT NECPAL**

NO, I would not be surprised

**NECPAL
Parameters**

"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?	1
	- Need: Identified by healthcare professionals from the team	2
General Clinical Indicators: 6 months	- Nutritional Decline	• Weight loss > 10% 3
- Last 6 months	- Functional Decline	• Karnofsky or Barthel score > 30% • Loss > 2 ADLs 4
- Not related to recent/ reversible intercurrent process	- Cognitive Decline	• Loss > minimal or > 3 Pfeiffer 5
Severe Dependence	- Karnofsky < 50 o Barthel < 20	• Clinical data anamnesis 6
Geriatric Syndromes	- Falls - Pressure Ulcers - Dysphagia - Delirium - Recurrent Infections	• Clinical data anamnesis • ≥ 2 geriatric syndromes (recurrent or persistent) 7
Persistent symptoms	Pain, weakness, anorexia, digestive...	• Symptom Checklist (ESAS) • ≥ 2 persistent or refractory symptoms 8
Psychosocial aspects	Distress and/or Severe adaptive disorder	• Detection of Emotional Distress Scale (DME) > 9 9
	Severe Social Vulnerability	• Social and family assessment 10
Multi-morbidity	> 2 chronic diseases (from the list of specific indicators)	11
Use of resources	Evaluate Demand or Intensity of Interventions	• > 2 urgent or not planned admittances in last 6 months • Increase Demand/ Intensity of Interventions (homecare, nurse interventions, etc) 12
Specific indicators of illness severity/ progression	Cancer, COPD, CHD, Liver, Renal, CVA, Dementia, Neurodegenerative diseases, AIDS, other advanced illnesses	• To be developed as annexes 13

If there is at least 1 NECPAL Parameter: **NECPAL +**

NECPAL +

= **PS+**
"I would not be surprised"

+ At least 1
parameter associated

Codification and Registry:

They help to visualize the condition of "Advanced chronic patient" in the clinical available and accessible information

- Codification:

A specific code, as "Advanced chronic patient", should be used, as opposed to the common ICD9 V66.7 (terminal patient) or ICD10 Z51.5 (patient in palliative care service).

- Registry

Clinical Charts:

After the surprise question, the different parameters should be explored, and add + according to the positives found

Shared Clinical Chart:

Always match codification and registry of additional relevant clinical information that describes the situation and recommendations for care in specific previsible scenarios and other services (In Catalonia, PIIC)

Figure 1. NECPAL 3.1 «classic» with all components

Surprise question (to/among professionals):

Would you be surprised if this patient dies within the next year?

► YES, I would be surprised → NOT NECPAL ► NO, I would not be surprised

"Demand" or "Need"	<ul style="list-style-type: none"> - Demand: Have the patient, the family or the team requested in implicit or explicit manner, palliative care or limitation of therapeutic effort? - Need: identified by healthcare professionals from the team
General Clinical Indicators: 6 months <ul style="list-style-type: none"> - Last 6 months - Not related to recent/reversible intercurrent process 	<ul style="list-style-type: none"> - Nutritional Decline - Functional Decline - Cognitive Decline
Severe Dependence	- Karnofsky <50 o Barthel <20
Geriatric Syndromes	<ul style="list-style-type: none"> - Falls - Dysphagia - Recurrent infections - Pressure Ulcers - Delirium
Persistent symptoms	Pain, weakness, anorexia, digestive...
Psychosocial aspects	Distress and/or Severe adaptive disorder Severe Social Vulnerability
Multi-morbidity	>2 chronic diseases (from the list of specific indicators)
Use of resources	Evaluate Demand or intensity of interventions
Specific indicators of illness severity / progression	Cancer, COPD, CHD, Liver, Renal, CVA, Dementia, Neurodegenerative diseases, AIDS, other advanced illnesses



**Expert's
Selected Parameters
with prognostic value**

**PRACTICAL RECOMMENDATIONS
FOR IDENTIFYING
AND ESTABLISHING PROGNOSTIC
APPROACH OF PEOPLE WITH
ADVANCED CHRONIC CONDITIONS
AND PALLIATIVE CARE NEEDS
IN HEALTH AND SOCIAL SERVICES
NECPAL 4.0 PROGNOSTIC (2021)**


Authors and researchers: Xavier Gómez-Batiste, Jordi Amblàs,
Pamela Turrillas, Cristian Tebé, Judit Peñafiel, Agnès Calsina,
Xavier Costa, Josep Maria Vilaseca, Rosa Maria Montoliu

Collaboration team: Sarah Mir, Elba Beas, Marina Geli



Càtedra
de Cures Pal·liatives
UVIC-UCC
ICO - INSTITUT CATALÀ D'ONCOLOGIA

With the support of:

 Generalitat de Catalunya
Programa de prevenció i atenció
a la cronicitat

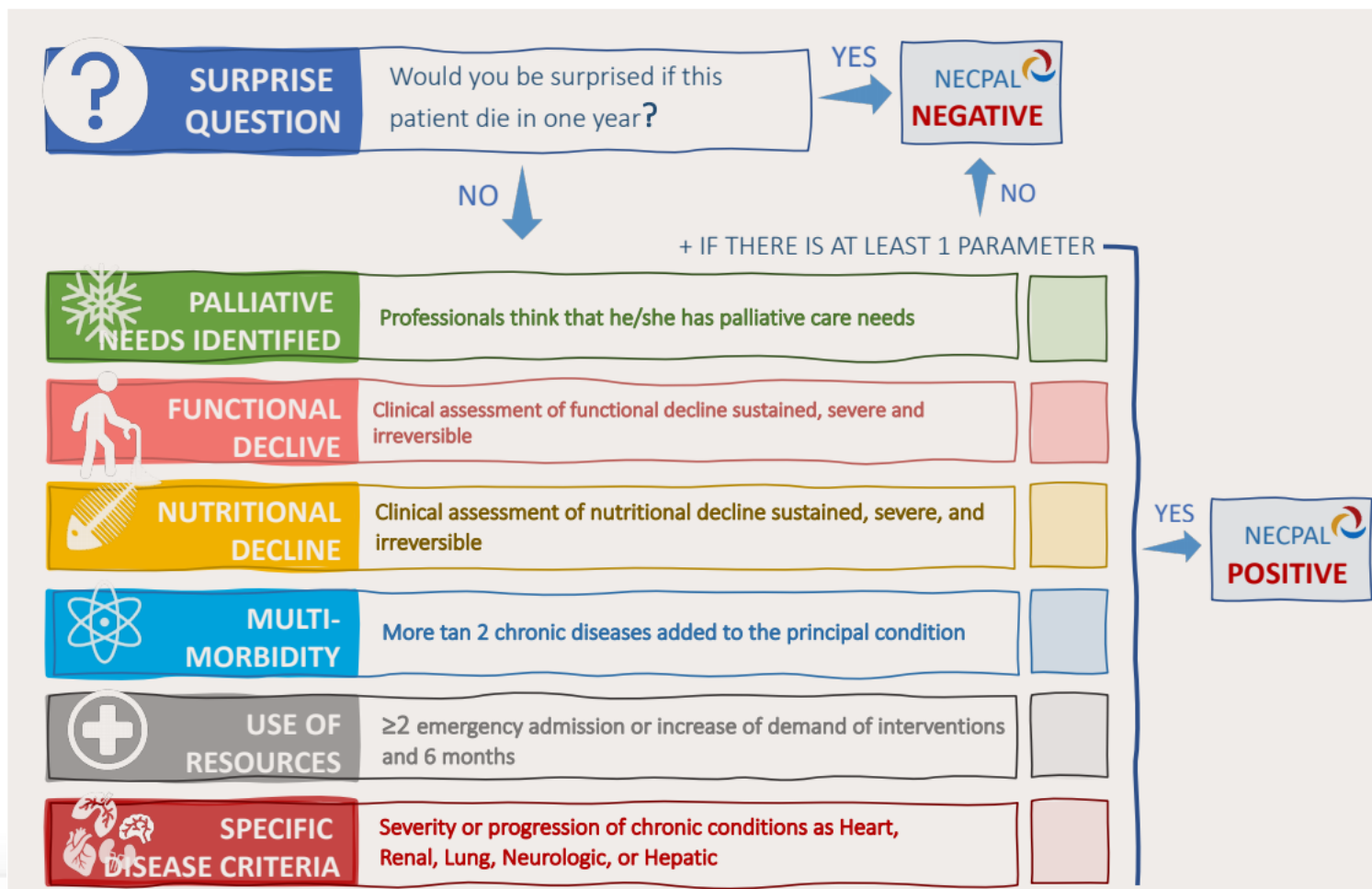
 Generalitat de Catalunya
Pla interdepartamental d'atenció
i interacció social i sanitària

NECPAL 4.0 PROGNOSTIC 2021

**Adding prognostic approach
to
palliative approach**

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con enfermedades avanzadas**

NECPAL TOOL VERSION 4.0 2021



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con enfermedades avanzadas

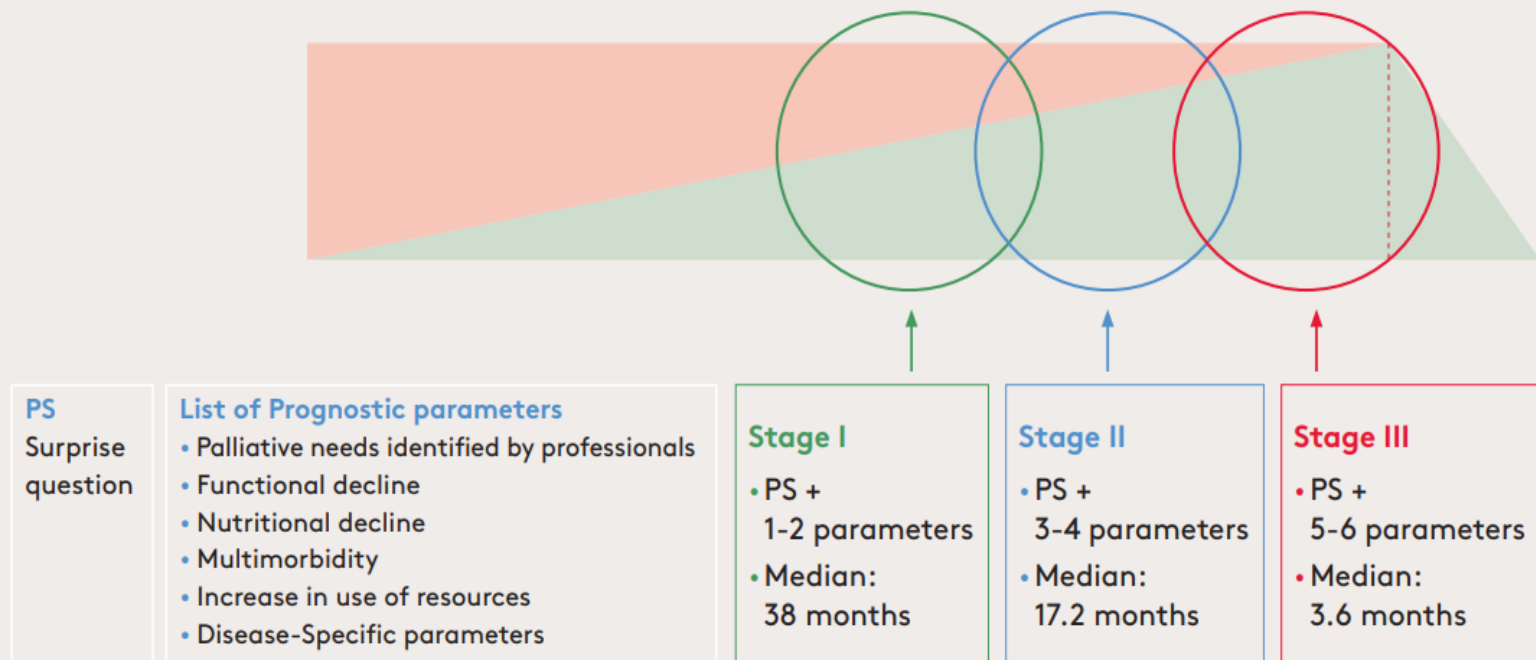
> "Situational" Checklist: identification of the prognostic risk to elaborate the prognostic approach:

- Situational prognostic checklist
- Risk estimation
- Criteria for prognostic approach

Listing the parameters with prognostic utility (palliative needs identified by professionals, functional decline, nutritional decline, multimorbidity, increased use of resources, and parameters of the specific disease).

The result of this procedure includes the patient MACA in one of these three prognostic stages:

The evolutive stage: can be determined according to the number of parameters affected. If 1-2 or 3-4 or 5-6



ASPECTS TO CONSIDER

How to manage the prognostic assessment in clinical practice

1. The prognosis is one of the elements to consider, added to the needs and demands .
2. The prognostic risk is applied to populations that accomplish criteria, but must be applied with caution to individual patients.
3. Once established, we will have a prognostic situational perspective, which can be valuable for a therapeutic approach.
4. It is recommended to update it regularly.

Discussion: How to improve palliative care approach in conventional services

1. Challenges
2. Aims and actions proposed
3. Barriers and difficulties

- Hospitals
- Community
- Nursing Homes
- Territories

Vol. 53 No. 3 March 2017

Journal of Pain and Symptom Management 509

Special Article

Comprehensive and Integrated Palliative Care for People With Advanced Chronic Conditions: An Update From Several European Initiatives and Recommendations for Policy



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**Atención integral a personas
con enfermedades avanzadas**

Action

1. Establish and document a formal policy for palliative approach
2. Determine the prevalence and identify patients in need
3. Establish protocols, registers, and tools to assess patients' needs and respond to most common situations
4. Train professionals and insert palliative care training and review in the conventional training process (sessions, etc.)
5. Identify the primary carers of patients and give support and care, including bereavement
6. Increase team approach
7. In services with high prevalence: devote specific times and professionals with advanced training to take care of palliative care patients (Basic Palliative Care)
8. Increase the offer and intensity of care for identified persons focused in quality of life
9. Integrated care: Establish links, joint information system, criteria intervention and access to palliative care specialized services and all services in the area
10. Address the ethical challenges of early identification and involve society

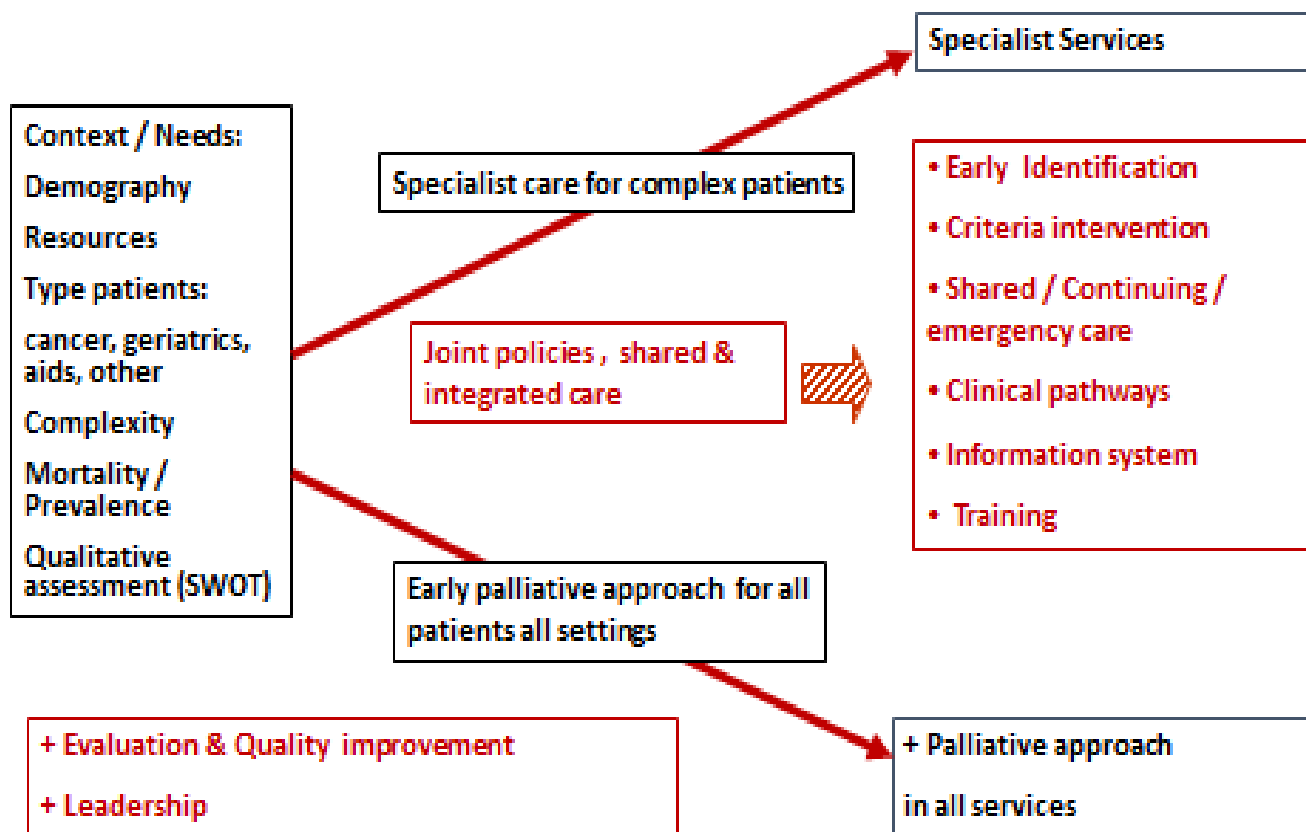


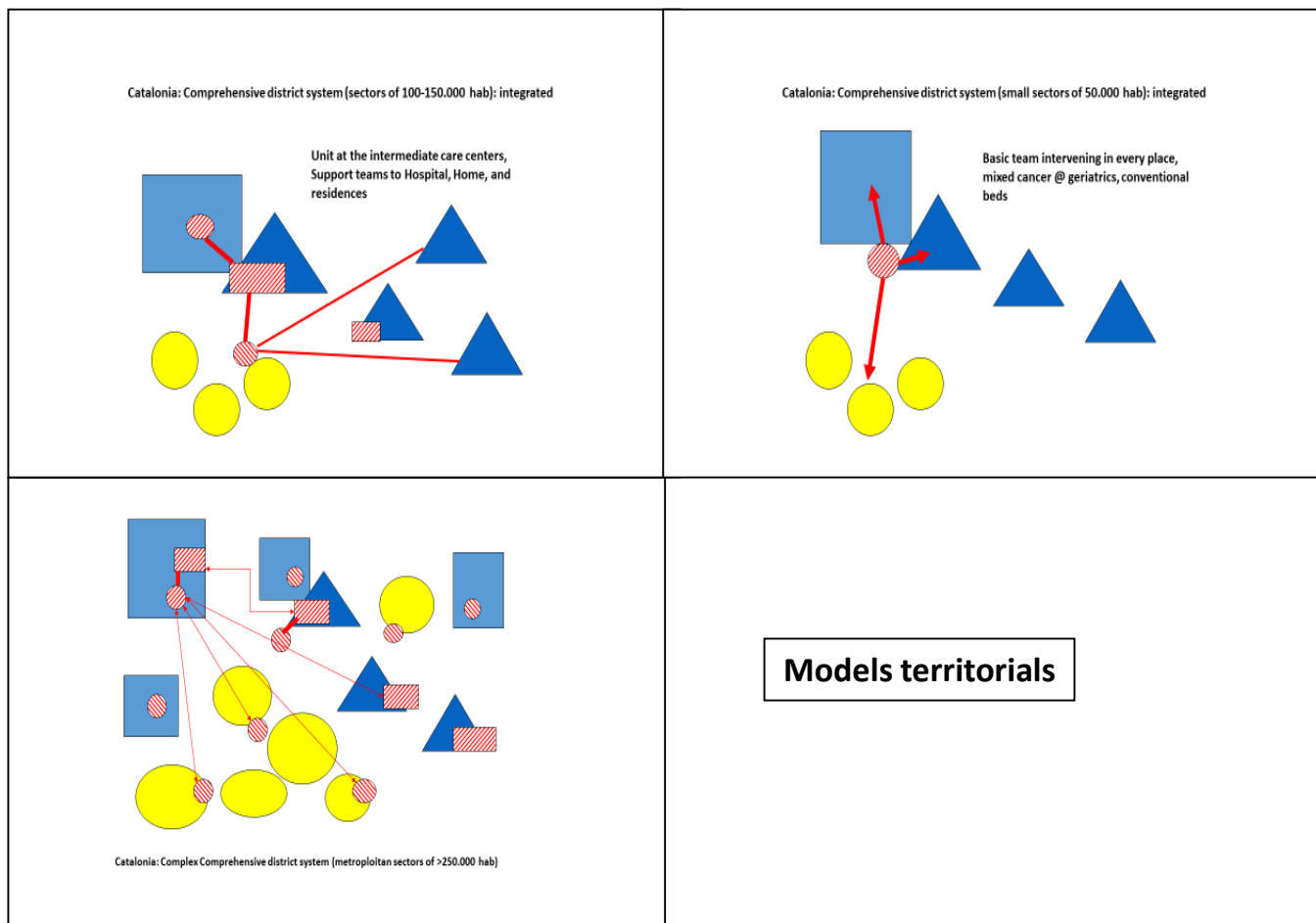
Obra Social "la Caixa"

Actions for Palliative approach in conventional services nursing homes

con enfermedades avanzadas

A model for District Palliative Care Comprehensive Planning





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con enfermedades avanzadas**

Qualitative Research

Barriers to GPs identifying patients at the end-of-life and discussions about their care: a qualitative study

Lucy V Pocock^a, Lesley Wye, Lydia R M French and Sarah Purdy

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Abstract

Background. Identification of patients at the end-of-life is the first step in care planning and many general practices have Palliative Care Registers. There is evidence that these largely comprise patients with cancer diagnoses, but little is known about the identification process.

Objective. To explore the barriers that hinder GPs from identifying and registering patients on Palliative Care Registers.

Methods. An exploratory qualitative approach was undertaken using semi-structured interviews with GPs in South West England. GPs were asked about their experiences of identifying, registering and discussing end-of-life care with patients. Interviews were audio recorded, transcribed and analysed thematically.

Results. Most practices had a Palliative Care Register, which were mainly composed of patients with cancer. They reported identifying non-malignant patients at the end-of-life as challenging and were reluctant to include frail or elderly patients due to resource implications. GPs described rarely using prognostication tools to identify patients and conveyed that poor communication between secondary and primary care made prognostication difficult. GPs also detailed challenges around talking to patients about end-of-life care.

Conclusions. Palliative Care Registers are widely used by GPs for patients with malignant diagnoses, but seldom for other patients. The findings from our study suggest that this arises because GPs find prognosticating for patients with non-malignant disease more challenging. GPs would value better communication from secondary care, tools for prognostication and training in speaking with patients at the end-of-life enabling them to better identify non-malignant patients at the end-of-life.

Key words: advanced care planning, family practice, general practice, palliative care, primary health care, terminal care.

Difficulties

- > no cáncer
- Talking prognosis
- Communication
- Coordination

Among us:

- How to manage after??
- Confusion temrinal/advanced
- Stigma
- ACP?
- Training
- Resources

Updating National / Regional / Territorial Plans

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Downloaded from spcare.bmj.com on January 7, 2013 - Published by group.bmj.com

Feature

How to design and implement palliative care public health programmes: foundation measures. An operational paper by the WHO Collaborating Centre for Public Health Palliative Care Programmes at the Catalan Institute of Oncology

Xavier Gómez-Batiste,^{1,2} Jan Stjernsward,^{1,2} Jose Espinosa,^{1,2}
Marisa Martínez-Muñoz,^{1,2} Jordi Trelis,³ Carles Constante⁴

Components Public health program

BOX 1 COMPONENTS AND FOUNDATION MEASURES OF PALLIATIVE CARE PUBLIC HEALTH PROGRAMMES

- ▶ Clear leadership and aims
- ▶ Needs and context assessment
- ▶ Clear model of care and intervention, and definition of target patients
- ▶ General measures in conventional services (especially primary care)
- ▶ Specialist services in different settings
- ▶ Sectorised networks with coordination, continuing and emergency care
- ▶ Education and training at all levels
- ▶ Research planning
- ▶ Availability and accessibility of opioids and essential drugs
- ▶ Legislation, standards, budget and models of funding and purchasing
- ▶ Social implication: volunteers, social involvement in the cultural, social and ethical debates surrounding end of life
- ▶ Evaluation and improvement of quality
- ▶ Action plans at short, medium and long term
- ▶ Evaluation of results, indicators

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

10 actions for establishing a national/regional policy for comprehensive and integrated palliative approach

X Gómez-Batiste, S Murray, S Connor, 2017

Discussion: Ethical dilemmas of timely identification

1. Challenges
2. Aims and actions proposed
3. Barriers and difficulties

Original Research and International Initiative

Ethical Challenges of Early Identification of Advanced Chronic Patients in Need of Palliative Care: The Catalan Experience

Xavier Gómez-Batiste, MD, PhD¹, Carles Blay, MD, PhD^{1,2},
 Marc Antoni Broggi, MD, PhD³, Cristina Lasmarias, BA, RN, MSc¹,
 Laura Vila, RN^{1,4}, Jordi Amblàs, MD, PhD^{1,5},
 Joan Espauella, MD, PhD^{1,5}, Xavier Costa, MD, PhD^{1,4},
 Marisa Martínez-Muñoz, RN, PhD¹, Bernabé Robles, MD⁶,
 Salvador Quintana, MD, PhD⁷, Joan Bertran, MD, PhD⁸,
 Francesc Torralba, PhD⁹, Carmen Benito, MD¹⁰, Nuria Terribas, BL¹¹,
 Josep Maria Busquets, MD³, and Carles Constante, MD¹²

Abstract

Palliative care must be early applied to all types of advanced chronic and life limited prognosis patients, present in all health and social services. Patients' early identification and registry allows introducing palliative care gradually concomitant with other measures. Patients undergo a systematic and integrated care process, meant to improve their life quality, which includes multidimensional assessment of their needs, recognition of their values and preferences for advance care planning purposes, treatments review, family care, and case management.

Led by the National Department of Health, a program for the early identification of these patients has been implemented in Catalonia (Spain). Although the overall benefits expected, the program has raised some ethical issues. In order to address these challenges, diverse institutions, including bioethics and ethics committees, have elaborated a proposal for the program's advantages. This paper describes the process of evaluation, elaboration of recommendations, and actions done in Catalonia.

Keywords

palliative care, ethics, advance care planning, chronic conditions, palliative care approach

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 2018, Vol. 33(4) 247-251

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Table 1. Potential Benefits of the Program for Early Palliative Care Provision, According to 5 Clinical Ethics Committees.

Benefits for patients	<ul style="list-style-type: none"> • Gradual introduction to the palliative approach: new perspectives and reflexive process on patients' needs and goals for care • A rational and reflexive decision-making process: patient autonomy through advanced care planning • Gradual adjustment to progressive impairment and loss: increase in the intensity and scope of care with a combined curative/palliative focus • Positive identification of individuals in vulnerable situations
Benefits for improving quality of care	<ul style="list-style-type: none"> • Identification of individuals with special needs who might otherwise remain unidentified • Promotion of active team discussion and revision of therapeutic goals • Promotion of integrated and continuing care and a rational approach to emergency care • Focused on improving quality of care

Table 2. Potential Risks of the Program for Early Palliative Care Provision, According to 5 Clinical Ethics Committees.

Risks for patients	<ul style="list-style-type: none"> ● Stigmatization: Loss of care and curative options ("negative discrimination") due to confusion between advanced and terminal disease ● Negative impact: Lack of involvement and permission of patients, with a possible impact due to prognosis awareness
Risks and barriers for improving care quality	<ul style="list-style-type: none"> ● Training deficits of health-care professionals: Lack of knowledge or resources to adequately meet patient needs ● Resistance of professionals due to the "dichotomy perspective" (antagonism: curative vs palliative) ● Changes in the role of palliative care services in the early palliative approach and the need to establish new criteria for intervention ● Potential misuse of the program to reduce costs of care at the end of life

Table 3. Questions and Answers on Implementation of the Program for Early Identification of Patients in Need of Palliative Care.

Frequent Asked Questions (By Professionals)	Answers and Recommendations
Program aims	<ul style="list-style-type: none"> To improve the quality of care of patients with advanced chronic conditions in all departments
Aims of identifying patients	<ul style="list-style-type: none"> Provides valuable clinical information to screen patients with advanced conditions and palliative care needs in primary care and other conventional treatment areas
Who identifies patients? Where?	<ul style="list-style-type: none"> Patients must be identified by a competent team (preferably a multidisciplinary team) who knows the patient. Careful assessment must be performed. Primary care services are the preferred place for identification Identifying patients in emergency services without previous contact is not advisable
Patient involvement	<ul style="list-style-type: none"> Patients must be actively involved in the process. They should be given sufficient information about the program, advanced care planning, and they should lead decision-making. Patient should be gradually informed about their situation and the purpose, meaning, benefits, and goals of being identified
Family involvement	<ul style="list-style-type: none"> Family caregivers must also be involved in the process
Prognostic value of identification	<ul style="list-style-type: none"> Recent data show higher mortality rates for patients with early identification (suggesting these are "at risk" patients) The prognostic value needs to be interpreted cautiously in individual patients
What does being NECPAL+ mean?	<ul style="list-style-type: none"> It means that the patient suffers from one or more advanced chronic conditions and that a palliative approach should be incorporated into the existing care plan
What to do after identification	<ul style="list-style-type: none"> Gradually implement a palliative care approach (reflexive process of assessment) accompanied by other perspectives (advanced care planning and case management) The patient should be registered through shared information systems and all available clinical data should be accessible for all departments, including information on patients' needs, established and agreed goals, and recommendations for future expected scenarios
How to improve the palliative approach in all settings?	<ul style="list-style-type: none"> Implementation of early palliative care needs to be accompanied by training strategies for health-care professionals and organizational changes in all departments
Do NECPAL+ patients need to be referred to a specialist palliative care service?	<ul style="list-style-type: none"> Not necessarily. Specialist intervention should depend on the complexity of needs and agreements between departments
What is the role of specialist palliative care services in the care of NECPAL+ patients?	<ul style="list-style-type: none"> As the primary reference for complex cases To provide advice and support to other departments to improve the quality of palliative care
Do NECPAL+ patients need curative measures?	<ul style="list-style-type: none"> Yes, the use of a palliative approach must be concomitant with all other measures that could benefit patient survival and quality of life
Is the aim to reduce the cost of care?	<ul style="list-style-type: none"> No. Palliative care programs could reduce resource usage and related costs, but only as a side benefit related to improved efficiency. However, this is not the primary aim of the program

Note. with the tool NECPAL CCOMS-ICO*

(*) Accessible at: http://ico.gencat.cat/en/professionals/serveis_i_programes/observatori_qualy/programes/programa_necpal/index.html

Discussion: how to adapt palliative care services to the new needs and demands???

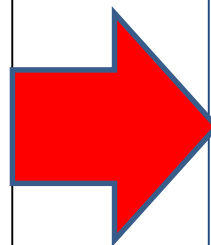
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Special Article

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 "Quality" 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

- 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 (2010)

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

Updating Palliative care service's perspectives and practice

- **Population based perspective**
- **Timely and all types of patients in need**
- **Proactive cooperative with other services**
- **Flexible shared models of intervention**
- **Focused in essential needs**
- **Oriented to outcomes**
- **Adjustment to client service's needs**
- **Society and community involved**

How to implement psychosocial and spiritual care



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



Professional Support

Specific support for healthcare workers in subjects such as communication in difficult situations and stress management



2. EL PROGRAMA

The Program in Spain

44 Teams

> 200.000 Patients

> 300.000 relatives

> 240 professionals

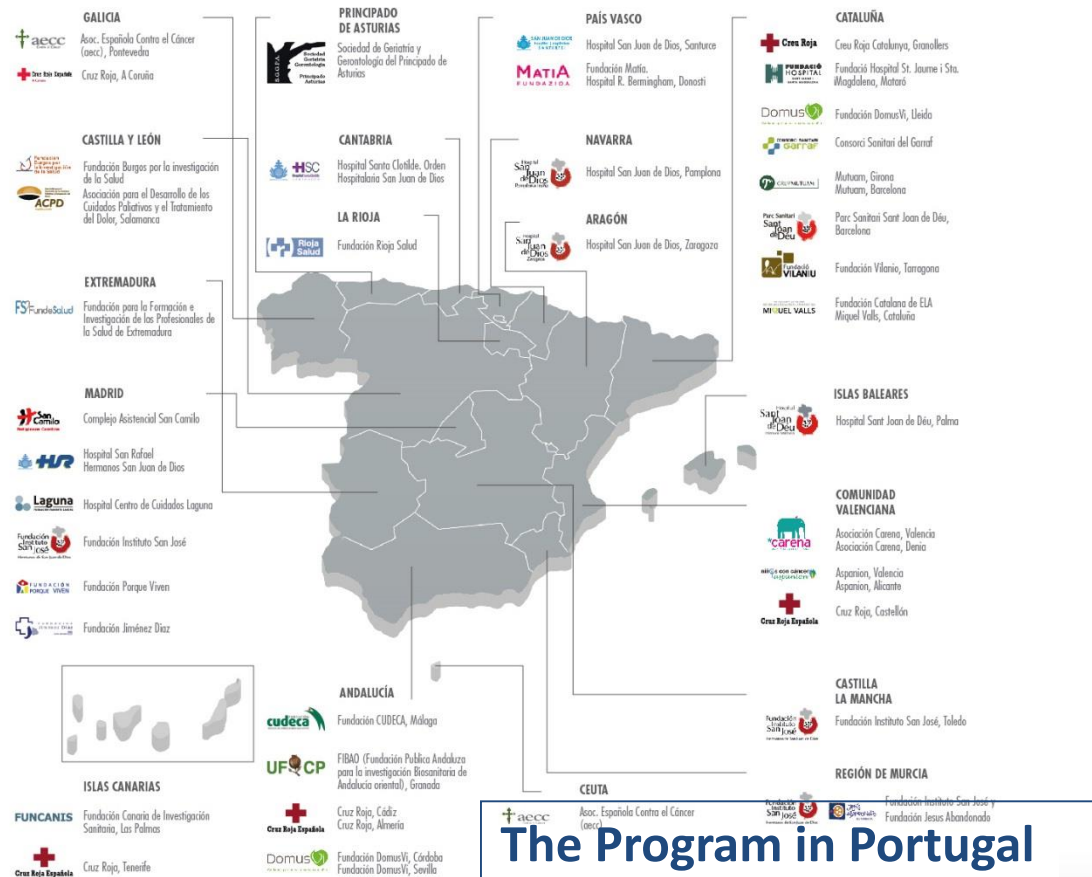
> 1.500 volunteers

44 | Equipos de Atención Psicosocial (EAPS)

128 | Centros sanitarios

133 | Equipos domiciliarios

*A fecha diciembre 2018



The Program in Portugal

10 Teams

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Main results 11 years

- **Quantitative:**
 - > 200.000 patients
 - 44 Teams > 240 Psychologists
- **Qualitative: effectiveness, satisfaction, stakeholders, social impact**
- **Systematic assessment**
- **Developing tools**
- **Developing training materials**

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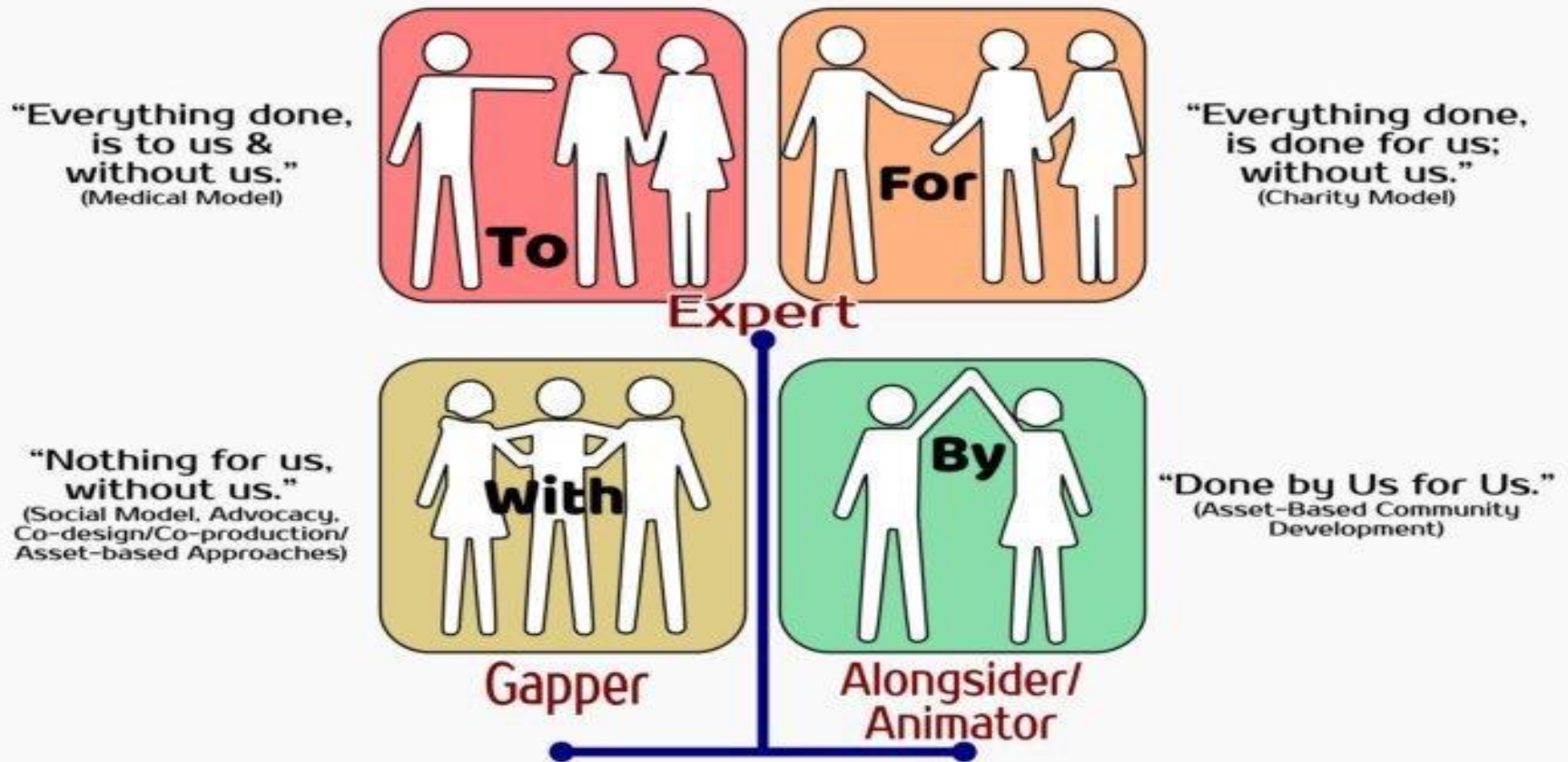


Discussion: how to involve society

- For every dimension in the list
 1. Challenges
 2. Aims and actions proposed
 3. Barriers and difficulties

New perspectives, new challenges:
Involving society

Evolute concepts: from Medical paternalism to Society leadership





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VIC, CIUDAD CUIDADORA



Ajuntament de Vic

CÁTEDRA DE
CUIDADOS
PALIATIVOS



 **mémora**
Fundación
comprometidas con la vida





Original Article

Compassionate communities: design and preliminary results of the experience of Vic (Barcelona, Spain) caring city

Xavier Gómez-Batiste^{1,2}, Silvia Mateu³, Susagna Serra-Jofre¹, Magda Molas³, Sarah Mir-Roca¹, Jordi Amblàs¹, Xavier Costa¹, Cristina Lasmariás^{1,2}, Marta Serrarols⁴, Alvar Solà-Serrabou³, Candela Calle⁵, Allan Kellehear⁶

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New perspectives, new challenges:
Inserting into academy

- **Chair of Palliative Care 2013:
1st in Spain**
- **Professorship Palliative Care:
unique in Spain**

**Atención integral a personas
con enfermedades avanzadas**

Chair ICO/UVIC-UCC of palliative care at the University of Vic – Central University of Catalonia: an innovative multidisciplinary model of education, research and knowledge transfer

Xavier Gómez-Batiste,^{1,2,3} Cristina Lasmarías,^{1,2,3} Jordi Amblàs,^{1,3}
Xavier Costa,^{1,3,4} Sara Ela,^{1,2} Sarah Mir,^{1,3} Agnès Calsina-Berna,^{1,5}
Joan Espauella,^{1,3} Sebastià Santaugènia,^{3,6} Ramon Pujol,¹
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► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/bmjspcare-2018-001656>).

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ABSTRACT

Objectives Generation and dissemination of knowledge is a relevant challenge of palliative care (PC). The Chair Catalan Institute of Oncology (ICO)/University of Vic (UVic) of Palliative Care (CPC) was founded in 2012, as a joint project of the ICO and the University of Vic/Central of Catalonia to promote the development of PC with public health and community-oriented vision and academic perspectives. The Initiative brought together professionals from a wide range of disciplines (PC, geriatrics, oncology, primary care and policy) and became the first chair of PC in Spain. We describe the experience of the CPC at its fifth year of implementation.

Methods Data collection from annual reports, publications, training and research activities.

Results Results for period 2012–2017 are classified into three main blocks: (1) Programme: (a) The advanced chronic care model (Palliative needs (NECPAL)); (b) the psychosocial and spiritual domains of care (Psychosocial needs (PSICPAL)); (c) advance care planning and shared decision making (Advance care planning (PDAPAL)); and (d) the compassionate communities projects (Society Involvement (SOCPAL)). (2) Education and training activities: (a) The master of PC, 13 editions and 550 professionals trained; (b) postgraduate course on psychosocial care, 4 editions and 140 professionals trained; and (c) workshops on specific topics, pregraduate training and online activities with a remarkable impact on the Spanish-speaking community. (3) Knowledge-transfer activities and research

projects: (a) Development of 20 PhD projects; and (b) 59 articles and 6 books published.

Conclusion Being the first initiative of chair in PC in Spain, the CPC has provided a framework of multidisciplinary areas that have generated innovative experiences and projects in PC.

INTRODUCTION

Training and education in palliative care (PC) is essential in the development of quality PC provision and major points of a Palliative Care Public Health Programme.¹ In 1992, the PC service at the Catalan Institute of Oncology (ICO) in Barcelona—a monographic cancer institute—developed its own training strategy, implementing basic and intermediate levels, and the first master's degree in PC started in 1997, jointly with the University of Barcelona.

Additionally, due to the experience acquired in the implementation of the Catalonia WHO Demonstration Project for Palliative Care and its international impact, there were increasing demands for support for the design, implementation and evaluation of PC services and programme in Spain, Europe and Latin America.² These policy activities, establishing contracts and agreements with public or private organisations, had the support, as main partner, of the Catalan Department of Health.



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

A

con enfermedades avanzadas

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 Espauella,⁴ Jose Espinosa,¹ Montserrat Figuerola,¹ Carles Constante⁶

ABSTRACT

Palliative care (PC) has focused on patients with cancer within specialist services. However, around 75% of the population in middle- and high-income countries die of one or more chronic advanced diseases. Early identification of such patients in need of PC becomes a priority. In this feature article we describe the initial development of the NECPAL (Necesidades Palliativas [Palliative Needs] Programme). The focus is on the development of the NECPAL tool to identify patients in need of PC; preliminary results of the NECPAL prevalence study, which assesses prevalence of advanced chronically ill patients within the population and all socio-health settings of Girona; and initial implementation of the NECPAL Programme in the region. As part of the Programme, we present the NECPAL tool. The main differences from British reference tools on which NECPAL is based are highlighted. The preliminary results of the prevalence study show that 1.45% of the population and 7.71% of the population over 65 are '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 plantar conditions or dementia. The pilot phase of the Programme consists of developing social policies to improve PC in three districts of Catalonia. The first steps to design and implement a Programme to improve PC for 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.

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 Espauella,⁴ Jose Espinosa,¹ Montserrat Figuerola,¹ Carles Constante⁶

vention, together with advance care planning and case management as core methodologies. From the epidemiological perspective, estimation has shifted from

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

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>).

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PALLIATIVE CARE PALLIATIVE CHRONIC CONDITIONS CHRONIC DISEASES ADVANCED CHRONIC CARE INTEGRATED CARE COMPREHENSIVE CARE COMPREHENSIVE COMPASSION EMPATHY SUFFERING FRAILTY PAIN FAMILY TEAMWORK SERVICES PROGRAMS PUBLIC HEALTH COMMUNITY EMOTIONAL SPIRITUAL SOCIAL ETHICS RESEARCH EDUCATION QUALITY PEOPLE CARE FAMILIES ILLNESS COMMUNICATION SUPPORT RESOURCE AVAILABILITY INTERDISCIPLINARY PATIENTS SYMPTOMS MANAGEMENT ACCESSIBILITY HEALTH CARE ADVANCE CARE PLANNING LIFE AUTONOMY PATIENT PER Integrated Care Support Interdisciplinary Patient Centered Decision-making Autono

Building Integrated Palliative Care Programs and Services

Edited by Xavier Gómez-Batiste & Stephen Connor

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Manual de atención integral de personas con enfermedades crónicas avanzadas

ASPECTOS GENERALES

Editores

Xavier Gómez-Batiste
Carles Blay
Jordi Roca



Manual de atención integral de personas con enfermedades crónicas avanzadas

ASPECTOS CLÍNICOS

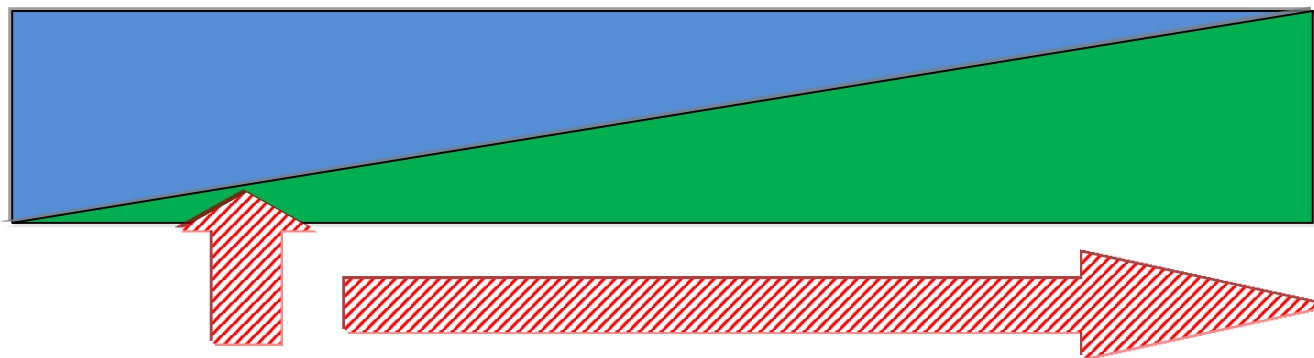
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Agnès Calsina-Berna

Coordinadora

Agnès Calsina-Berna





Palliative care XXI:

- 1. All chronic advanced patients**
- 2. Timely**
- 3. All dimensions**
- 4. All settings**
- 5. All professionals**
- 6. Multidimensional assessment and care, ACP, case management, integrated care**

Building Integrated Palliative Care Programs and Services

Edited by Xavier Gómez-Batiste & Stephen Connor



The most prevalent needed right consists in having access to quality palliative care, specially, for the most vulnerable “people without voice, like elder multimorbid frail women with dementia and isolated without family at home or in nursing homes”

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Conclusions

- 1. Palliative and chronic care must be integrated to provide a comprehensive and integrated approach, with Public Health vision, population based and systemic approach, and community perspective**
- 2. Palliative care services and programs must see this as an opportunity and be adapted to new needs**
- 3. Psychosocial and spiritual needs are essential components of care**
- 4. Society must be involved with an active role and leadership**
- 5. Palliative care is an essential component of pregraduate and postgraduate training of all professionals**
- 6. All this can be done!!!! With vision, leadership, and commitment**

Thank you very much!!!

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Observatorio 'Qualy' / Centro
Colaborador OMS Programas
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