

## Lets talk about these persons









## Thank you for this opportunity to share our experiences Ready to learn

Atención integral a personas





## 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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## **Outline lecture**

- Conceptual transitions and Challenges palliative care XXIc
- Epidemiology
- How to identify people with palliative care needs
- How to look after thie people
- How to establish prognosis
- Ethical dilemas of early identification
- Implementing psychosocial and spiritual care
- Inserting into academy
- Involving society
- Palliative care human right

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### **Conditions to die in Peace (Expert's group WHOCC / Chair)**

- Spirituality, transcendence, beliefs, values, meaning of life, connection with God, to Self, to Nature
- Love, support, company of beloved (family and friends), social suport and relations
- Legacy: family, heritage, professional, society
- Autonomy and control on decisions: placement, treatment choices, service choice
- Personal and behavioral resources: hope, positive thinking, optimism, humor, generosity
- General resources: context, security, economic, ....
- Symptom control
- Guarantee and access to good care

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## **Existing Palliative Care has shown effectiveness and efficiency**

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Institut Català d'Oncologia

- 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

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- 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

Vol. 38 No. 1 July 2009	Journal of Pain and Symptom Management		522 Journal of Pain and Symptom Management	Vol. 31 No. 6 June 2006
Special Article			Original Article	
The Costs and Savings of a Regio	onal Public			
Palliative Care Program: The Cat	alan u		Resource Consumption and Costs of Palliativ	e
Experience at 18 Years		) Collabe	Care Services in Spain: A Multicenter	
Silvia Paz-Ruiz, MD, Xavier Gomez-Batiste, MD, PhD, Jose I Josep Porta-Sales, MD, PhD, and Joaquim Esperalba, MD	Espinosa, MD,	lth Pallia	Prospective Study	
World Health Organization Collaborating Centre for Public Health Palli (S.PR., X.GB., J.Espi.); and Institut Català d' Oncología (J.P.S., J.Es	ative Care Programmes	rammes	Xavier Gómez-Batiste, MD, PhD, Albert Tuca, MD, Esther Corrales, RN, Josep Porta-Sales, MD, PhD, Maria Amor, MD, José Espinosa, MD,	



## Levels of complexity of Palliative Care provision









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92 Journal of Pain and Symptom Management	Vol. 52 No. 1 July 201	6
Special Article		
The Catalonia WHO Demonstration Project of Palliative	CrossMan	rk
Care: Results at 25 Years (1990-2015)		
Xavier Gómez-Batiste, MD, PhD, Carles Blay, MD, MSc, Marisa Martínez-Muñoz, RN, PhD, Cristina Lasmarías, RN, BA, MSc, Laura Vila, RN, MSc, José Espinosa, MD, MSc, Xavier Co Pau Sánchez-Ferrin, MD, Ingrid Bullich, RN, MSc, Carles Constante, MD, and Ed Kelley, F	osta, MD,	

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

JOURNAL OF PALLIATIVE MEDICINE Volume 13, Number 10, 2010 Mary Ann Liebert, Inc. DOI: 10.1089/jpm.2010.0059

> Quality Improvement in Palliative Care Services and Networks: Preliminary Results of a Benchmarking Process in Catalonia, Spain

Xavier Gómez-Batiste, M.D., Ph.D.<sup>1</sup> Carmen Caja, R.N.<sup>2</sup> Jose Espinosa, M.D.<sup>1</sup> Ingrid Bullich, R.N.<sup>2</sup> Josep Porta-Sales, M.D., Ph.D.<sup>3</sup> Carme Sala, M.D.<sup>4</sup> Esther Limón, M.D., Ph.D.<sup>5</sup> Jordi Trelis, M.D.,<sup>6</sup> Antonio Pascual, M.D., Ph.D.<sup>7</sup> M. Luisa Puente, M.D.<sup>8</sup> on behalf of the Working Group of the Standing Advisory Committee for Palliative Care

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## The WHO Demostration Project of Palliative Care in Catalonia Obra Social "la Caixa"

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### Catalonia WHO Demonstration Project on Palliative Care Implementation 1990-1995: Results in 1995

Institut Català d'Oncologia

Xavier Gómez-Batiste, MD, M. Dulce Fontanals, Jordi Roca, MD, J. M. Borràs, MD, Pau Viladiu, MD, Jan Stjernswård, MD, and Eduard Rius. MD Palliative Care Service (X.G.B.), Catalan Institute of Oncology, and Advisor for Palliative Care, Catalan Health Service; "Life to the Years" Frogram (M.D.F.), Catalan Health Service; Hospital Sta Creu (J.R.), Vic, and Catalan Society for Palliative Care (J.R.); Cancer Program (J.M.B.), Catalan Department of Health; Catalan Institute of Oncology (P.V.); Department of Health (E.R.), Government of Catalanis; Barcelona, Spain; and Cancer Unit (J.S.), World Health Organization, Ceneva, Switzerland

### Catalonia WHO Palliative Care Demonstration Project at 15 Years (2005)

Xavier Gómez-Batiste, MD, PhD, Josep Porta-Sales, MD, PhD, Antonio Pascual, MD, PhD, Maria Nabal, MD, PhD, Jose Espinosa, MD, Silvia Paz, MD, Cristina Minguell, MD, Dulce Rodríguez, MD, Joaquim Esperalba, MD, Jan Stjernswärd, MD, PhD, FRCP (Edin), and Marina Geli, MD on behalf of the Palliative Care Advisory Committee of the Standing Advisory Committee for Socio-Health Affairs, Department of Health, Government of Catalonia Palliative Care Advisory Committee (X.G.-B., A.P., M.N.), Standing Advisory Committee for Socio-Health Affairs (X.G.-B.), Department of Health (C.M., M.G.), Government of Catalonia; Palliative Care Service (J.P.S., Jos.E., S.P., J.E.), Institut Català d'Oncologia; Catalan-Balear Society for Palliative Care (D.R.), Barcelona, Spain; Cancer Control and Palliative Care (J.S.), World Health Organization; and International Palliative Care Initiative (J.S.), Open Society Institute, New York, New York, USA

### Spain: The WHO Demonstration Project of Palliative Care Implementation in Catalonia: Results at 10 Years (1991–2001)

Xavier Gómez-Batiste, MD, Josep Porta, PhD, MD, Albert Tuca, MD, Esther Corrales, RN, Federico Madrid, MD, Jordi Trelis, MD, Dulce Fontanals, SW, Josep M. Borràs, PhD, MD, Jan Stjernswärd, PhD, MD, Antoni Salvà, MD, and Eduard Rius, MD

Palliative Care Service (X.G.-B., J.P., A.T., E.C., F.M., J.T.), Institut Català d'Oncologia, Barcelona, Spain; Fundació SAR (D.F.), Barcelona, Spain; Institut Català d'Oncologia (J.M.B), Barcelona, Spain; Global Cancer Concern (J.S.), Stockholm, Sweden; Divisió Sociosanitària (A.S.), Servei Català de la Salut, Barcelona, Spain; and Ministry of Health (E.R.), Government of Catalonia, Barcelona, Spain

#### 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

#### Special Article

## The Catalonia WHO Demonstration Project of Palliative Care: Results at 25 Years (1990–2015)

Xavier Gómez-Batiste, MD, PhD, Carles Blay, MD, MSc, Marisa Martínez-Muñoz, RN, PhD,
Cristina Lasmarías, RN, BA, MSc, Laura Vila, RN, MSc, José Espinosa, MD, MSc, Xavier Costa, MD,
Pau Sánchez-Ferrin, MD, Ingrid Bullich, RN, MSc, Carles Constante, MD, and Ed Kelley, PhD
The Qualy Observatory/WHO Collaborating Centre for Palliative Care Public Health Programmes (X.G.B., M.M.-M., C.L., J.E.), Institut
Catala d'Oncologia; Chair of Palliative Care (X.G.B., C.B., M.M.-M., C.L., I.V., J.E., X.C.), University of Vic, Barcelona, Spain; Chronic
Care Program (C.B.), Department of Health, Government of Catalonia; Socio-Health Plan (P.S.-F, I.B.), Department of Health, Government of Catalonia, Barcelona, Spain; Planning Department (C.C.), Department of Health, Government of Catalonia; Primary Care Services (L.V., X.C.), District of Osona (Barcelona), ICS Catalunya Central, Barcelona, Spain; and Department of Service Delivery and Safety (E.K.), WHO Headquarters, Geneva, Switzerland



Generalitat de Catalunya Departament de Salut

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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 "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

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







### **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,	
<b></b>		.)	
From Cancer to all conditions	Mortality	Prevalence	
Terminal to advanced	Dichotomy curative - palliative	Synchronic, shared, combined care	
Specialist to all Services	Specific OR palliative treatment	Specific AND palliative treatment needed	
Services to population	Prognosis as criteria intervention	intervention Complexity as criteria	
	Rigid one-directional intervention Flexible intervention		
	Passive role of patients	Advance care planning / Autonomy	
	Reactive to crisis	Preventive of crisis / Case management	
	Palliative care services	+ Palliative care approach everywhere	
	Specialist services	+ Actions in all settings of health & social care	
	Institutional approach	Community approach	
	Services' approach	Population & district	
	X et al, Current Opinion in Supportive Palliative Care, X et al, Medicina Clínica, 2013	2012; Gómez-Batiste X et al, BMJ SPCare, 2012	
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con enfermedad	les avanzadas		







**Proposed Terms** 

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Gomez-Batiste, Connor, Murray et al, 2017

## **Components target definition**









New perspectives, new challenges:

- Palliative approach / chronicity: NECPAL Program
- Essential needs Psychosocial spiritual care: La Caixa Program
- Social involvement: Compassive communities
- Academic: Palliative Care Chairs







### **Palliative Care needs**

The populational perspective:

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

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Original Article
Polliative Medicine
2014, Vol 28(1) 49–58
Polliative Me

Fliss EM Murtagh<sup>1</sup>, Claudia Bausewein<sup>2</sup>, Julia Verne<sup>3</sup>, E Iris Groeneveld<sup>1</sup>, Yvonne E Kaloki<sup>1</sup> and Irene J Higginson<sup>1</sup>

75% population die by Chronic Conditions Cancer / Noncancer 1/2

## Atención integral a personas





## Some quantitative data of prevalence and prognostic

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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)





### NECPAL 3.1 2017

NECPAL

Research Team:

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

#### 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 Po	rameters
"Demand" or "Need"	<ul> <li>Demand: Have the patient, the family o palliative care or limitation of therapeut</li> </ul>	r the team requested in implicit or explicit manner, ic effort?	1
	- Need: identified by healthcare profession	hals from the team	2
General Clinical Indicators: 6	- Nutritional Decline	• Weight loss > 10%	3
months - Last 6 months - Not related to recent/	- Functional Decline	<ul> <li>Karnofsky or Barthel score &gt; 30%</li> <li>Loss &gt;2 ADLs</li> </ul>	4
reversible intercurrent process	- Cognitive Decline	Loss > minimental or > 3 Pfeiffer	5
Severe Dependence	- Karnofsky <50 o Barthel <20	Clinical data anamnesis	6
Geriatric Syndromes	- Falls - Pressure Ulcers - Dysphagia - Delirium - Recurrent Infections	<ul> <li>Clinical data anamnesis</li> <li>≥ 2 geriatric syndromes (recurrent or persistent)</li> </ul>	7
Persistent symptoms	Pain, weakness, anorexia, digestive	<ul> <li>Symptom Checklist (ESAS)</li> <li>≥ 2 persistent or refractary symptoms</li> </ul>	8
Psychosocial aspects	Distress and/or Severe adaptive disorder	Detection of Ernotional Distress Scale (DME) > 9	9
	Severe Social Vulnerability	Social and family assessment	10
Multi-morbidity	>2 chronic diseases (from the list of specif	ic indicators)	11
Use of resources	Evaluate Demand or Intensity of Interventions	<ul> <li>&gt; 2 urgent or not planned admittances in last 6 months</li> <li>Increase Demand/ Intensity of Interventions (homecare, nurse Interventions, etc)</li> </ul>	
Specific indicators of illness severity/progression	Cancer, COPD, CHD, Lwer, Renal, CVA, Dementia, Neurodegenerative diseases, AIDS, other advanced illnesses	To be developed as annexes	13
			DAL .

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) Original Article



ial "la Caixa"

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 © The Author(s) 2014 Reprints and permissions: sagepub.co.uk/journalsPermissions.nav DOI: 10.1177/0269216313518266 pmj.sagepub.com (\$)SAGE

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

#### 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<sup>®</sup> 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 to condition: 31. in nursing hor present in 949 Conclusions prevalence de

**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%

con

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

CÀTEI DE CL		CO itut Català d'Or	ncologia		i	Obra Socia	l "la Caixa
			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 (%	5)	58 (57.43)	138 (54.12)	37 (19.89)	84 (29.47)	10.004
	Female N	(%)	43 (42.57)	117 (45.88)	149 (80.11)	201 (70.53)	0.001

• 60-65%: more female, with frailty and multimorbidity, at home or nursing homes, high prevalence of dementia

- 35-40%: more male, organ failutre, cáncer
- Cancer / non cáncer 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, careed for relatives and primary care services with a median survival of 2-3 years

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Vol. 53 No. 3 March 2017

### 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, MRCGP, 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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con enfermedades avanzados Public Health Palliative Care

Programmes

Action	Method	Comment/terms
1. Multidimensional assessment	Use validated tools	<ul> <li>Suffering/well-being/adjustment</li> <li>Psychosocial and functional</li> <li>Assessment of careers burden, needs, and demands</li> </ul>
2. Explore worries, fears, values, and preferences of patients and families	Start: Advance care planning	<ul> <li>Explore the emotional experience of the patient (and its evolution in time)<sup>3</sup></li> </ul>
1 5 51	- Shared decision making	- Consider the illness narratives and life
	- Start discussion about the future	stories told by the patient <sup>34</sup>
3. Review state of diseases and conditions	Review disease:	<ul> <li>Do not forget nonspecific items and general indicators of functional declin is facil eldert.<sup>35</sup></li> </ul>
	<ul> <li>Stage and prognosis</li> <li>Aims and recommendations to prevent or respond to crisis or possible</li> </ul>	<ul> <li>in frail elderly<sup>35</sup></li> <li>Given that end of life is a trajectory (dynamic) and not a situation (static),</li> </ul>
	complications	consider the temporal evolution of these general indicators - Identify the current palliative care
		phase <sup>36</sup>
4. Review treatment	- Update aims	<ul> <li>Discussing goals of care (short/mid/</li> </ul>
	- Adequacy	long term) with the patients may be a
	- De-prescribing, if needed	good opportunity to initiate anticipatory care planning
5. Identify and support family carer	- Assessment - Education and support	Promote: capacity of care, adjustment, and prevention of complex bereavement
6. Involve the team	Joint:	<ul> <li>Define role in conventional follow-up, shared care, emergencies, and</li> </ul>
	- Assessment	continuing care
	- Plan	<ul> <li>Define referent professional (s)</li> </ul>
7. Define, agree, and start a Comprehensive Multidimensional Therapeutic Plan	<ul> <li>Respecting patients' preferences</li> <li>Addressing all the needs identified</li> </ul>	Including:
	<ul> <li>Use the square of care model</li> </ul>	- Needs assessment
	- Involving all team(s)	- Aims
8. Organize care with all services involved,	- Case management	<ul> <li>Decisions</li> <li>Contact palliative care services for care</li> </ul>
including the specialized palliative care	- Shared care and decision making	of complex needs
services	- Therapeutic pathways across settings	- Encourage continuing collaboration
	- Look at care and setting transitions	between services and develop
	<ul> <li>Therapeutic conciliation between</li> </ul>	partnership agreements
	services	<ul> <li>Involve patients and family carers patients when designing programs</li> </ul>
<ol><li>Register and share key information with all involved services</li></ol>	- In clinical charts - In shared information	<ul> <li>State of diseases, symptoms, emotional adjustment, family support</li> </ul>
	<ul> <li>In anticipatory care planning booklet</li> </ul>	- Patients' priorities and preferences
	<ul> <li>In reports of multidisciplinary team meetings</li> </ul>	(goals of care) - Possible crisis (out of hours handover
		forms, anticipatory prescribing) - Decisions made (e.g., referral to
Care of patient	ts identified	specialist palliative care service, treatment withdrawal/withholding)
		<ul> <li>Recommendations for care in all settings</li> </ul>
		<ul> <li>Record, communicate, and coordinate the care plan across all settings</li> </ul>
10. Evaluate/monitor outcomes	- Frequent review and update	- Consider NICE quality standard <sup>37</sup>
	- After death clinical audit	- Design research and generate evidence

## Table 2

- Frequent review and update - After death, clinical audit

- Design research and generate evidence

Action	Methods
1. Establish and document a formal policy for palliative	- Evidence based
approach	<ul> <li>Involve patients in the design and implementation of the policy</li> </ul>
2. Determine the prevalence and identify patients in need	<ul> <li>Stratify the population at need/risk (complex and advanced chronic patients)</li> </ul>
<ol><li>Establish protocols, registers, and tools to assess patients' needs and respond to most common situations</li></ol>	- Evidence based
<ol><li>Train professionals and insert palliative care training and</li></ol>	- Basic and intermediate level
review in the conventional training process (sessions, etc.)	<ul> <li>Carry out process evaluation during programme's implementation<sup>38</sup></li> </ul>
5. Identify the primary carers of patients and give support and	- Validated to ols
care, including bereavement	- Assess needs and demands
-	- Increase access
	- Give education and support
	- Plan bereavement
6. Increase team approach	- Joint interdisciplinary approach
<ol><li>In services with high prevalence: devote specific times and</li></ol>	- Trained referent professionals
professionals with advanced training to take care of	- Specific times in outpatients
palliative care patients (Basic Palliative Care)	<ul> <li>Specific devoted areas in inpatients</li> </ul>
8. Increase the offer and intensity of care for identified	- Improve access and equity in the provision of palliative care
persons focused in quality of life	<ul> <li>Increase offer of home care (if, primary care services)</li> </ul>

#### 10 Actions for Integrated Palliative Care Approach in Health and Social Care Services

9.

criteria intervention and access to palliative care specialized services and all services in the area	<ul> <li>Establish and/or update the role of palliative care specialized services</li> </ul>
<ol> <li>Address the ethical challenges of early identification and involve society</li> </ol>	<ul> <li>Establish partnerships between services</li> <li>Define clinical care pathways</li> <li>Clinical information available for all settings</li> <li>Promote benefits (shared decision making, ACP, improved intensity and quality of care, palliative approach) and reduce risks (stigma, loss of curative opportunities, reduction in care)</li> </ul>
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Actions for Palliative approach in conventional services nursing homes





## **Updating National / Regional / Territorial Plans**

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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, 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 comprehensiveand integrated palliative approachX Gómez-Batiste, S Murray, S Connor, 2017

Fublic mealth Famative Care

Programmes





### 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

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Original Research and International Initiative

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

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#### 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.

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

Benefits for patients	<ul> <li>Gradual introduction to the palliative approach: new perspectives and reflexive process on patients' needs and goals for care</li> <li>A rational and reflexive decision-making process: patient autonomy through advanced care planning</li> <li>Gradual adjustment to progressive impairment and loss: increase in the intensity and scope of care with a combined curative/palliative focus</li> </ul>
Benefits for improving quality of care	<ul> <li>Positive identification of individuals in vulnerable situations</li> <li>Identification of individuals with special needs who might otherwise remain unidentified</li> <li>Promotion of active team discussion and revision of therapeutic goals</li> <li>Promotion of integrated and continuing care and a rational approach to emergency care</li> <li>Focused on improving quality of care</li> </ul>

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

Risks for patients	• Stigmatization: Loss of care and curative options ("negative discrimination") due to confusion between advanced and terminal disease
	<ul> <li>Negative impact: Lack of involvement and permission of patients, with a possible impact due to prognosis awareness</li> </ul>
Risks and barriers for improving care quality	<ul> <li>Training deficits of health-care professionals: Lack of knowledge or resources to adequately meet patient needs</li> </ul>
	• Resistance of professionals due to the "dichotomy perspective" (antagonism: curative vs palliative)
	<ul> <li>Changes in the role of palliative care services in the early palliative approach and the need to establish new criteria for intervention</li> </ul>
	<ul> <li>Potential misuse of the program to reduce costs of care at the end of life</li> </ul>

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

## ocial "la Caixa"

Frequent Asked Questions (By Professionals)	Answers and Recommendations
Program aims	<ul> <li>To improve the quality of care of patients with advanced chronic conditions in all departments</li> </ul>
Aims of identifying patients	<ul> <li>Provides valuable clinical information to screen patients with advanced conditions and palliative care needs in primary care and other conventional treatment areas</li> </ul>
Who identifies patients? Where?	<ul> <li>Patients must be identified by a competent team (preferably a multidisciplinary team) who knows the patient. Careful assessment must be performed.</li> <li>Primary care services are the preferred place for identification</li> </ul>
Patient involvement	<ul> <li>Identifying patients in emergency services without previous contact is not advisable</li> <li>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</li> </ul>
Family involvement	<ul> <li>Family caregivers must also be involved in the process</li> </ul>
Prognostic value of identification	<ul> <li>Recent data show higher mortality rates for patients with early identification (suggesting these are "at risk" patients)</li> <li>The prognostic value needs to be interpreted cautiously in individual patients</li> </ul>
What does being NECPAL+ mean?	<ul> <li>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</li> </ul>
What to do after identification	<ul> <li>Gradually implement a palliative care approach (reflexive process of assessment) accompanied by other perspectives (advanced care planning and case management)</li> <li>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</li> </ul>
How to improve the palliative approach in all settings?	<ul> <li>Implementation of early palliative care needs to be accompanied by training strategies for health-care professionals and organizational changes in all departments</li> </ul>
Do NECPAL+ patients need to be referred to a specialist palliative care service?	<ul> <li>Not necessarily. Specialist intervention should depend on the complexity of needs and agreements between departments</li> </ul>
What is the role of specialist palliative care services in	<ul> <li>As the primary reference for complex cases</li> </ul>
the care of NECPAL+ patients?	<ul> <li>To provide advice and support to other departments to improve the quality of palliative care</li> </ul>
Do NECPAL+ patients need curative measures?	<ul> <li>Yes, the use of a palliative approach must be concomitant with all other measures that could benefit patient survival and quality of life</li> </ul>
Is the aim to reduce the cost of care?	<ul> <li>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</li> </ul>

(\*)Accssible at: http://ico.gencat.cat/en/professionals/serveis\_i\_programes/observatori\_qualy/programes/programa\_necpal/index.html

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## **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

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X Gómez-Batiste et al, J of Palliat Care 2018



Family Practice, 2019, 1–5 doi:10.1093/fampra/cmy135

OXFO



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

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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.



## Difficcuties

- > no cáncer
- Talking prognosis
- Communication
- Coordination

## Among us:

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





## **Developing the NECPAL 4.0 prognostic**

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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)





### NECPAL 3.1 2017

NECPAL

Research Team:

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

#### 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 Po	rameters	
"Demand" or "Need"	<ul> <li>Demand: Have the patient, the family or the team requested in implicit or explicit manner, palliative care or limitation of therapeutic effort?</li> </ul>			
	- Need: Identified by healthcare professionals from the team			
General Clinical Indicators: ó months - Last ó months - Not related to recent/ reversible intercurrent process	- Nutritional Decline	• Weight loss > 10%	3	
	- Functional Decline	Karnofsky or Barthel score > 30%     Loss >2 ADLs	4	
	- Cognitive Decline	<ul> <li>Loss &gt; minimental or &gt; 3 Pfeiffer</li> </ul>	5	
Severe Dependence	- Karnofsky <50 o Barthel <20	Clinical data anamnesis	6	
Geriatric Syndromes	- Falls - Pressure Ulcers - Dysphagia - Delirium - Recurrent Infections	<ul> <li>Clinical data anamnesis</li> <li>≥ 2 geriatric syndromes (recurrent or persistent)</li> </ul>	7	
Persistent symptoms	Pain, weakness, anorexia, digestive	<ul> <li>Symptom Checklist (ESAS)</li> <li>≥ 2 persistent or refractary symptoms</li> </ul>	8	
Psychosocial aspects	Distress and/or Severe adaptive disorder	Detection of Ernotional Distress Scale (DME) > 9	9	
	Severe Social Vulnerability	Social and family assessment	10	
Multi-morbidity	>2 chronic diseases (from the list of specific indicators)			
Use of resources	Evaluate Demand or Intensity of Interventions	<ul> <li>&gt; 2 urgent or not planned admittances in last 6 months</li> <li>Increase Demand/ Intensity of Interventions (homecare, nurse Interventions, etc)</li> </ul>		
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

**YES**, I would be surprised  $\rightarrow$  **NOT NECPAL** 



#### Surprise question (to/among professionals): Would you be surprised if this patient dies within the next year?

NO, I would not be surprised

#### "Demand" or "Need" - Demand: Have the patient, the family or the team requested in implicit or explicit manner, palliative care or limitation of therapeutic effort? - Need: identified by healthcare protessionals from the team General Clinical Indicators: 6 - Nutritional Decline months Functional Decline - Last 6 months Not related to recent/reversible - Cognitive Decline intercurrent process Severe Dependence - Karnofsky <50 o Barthel <20 **Geriatric Syndromes** - Pressure Ulcers - Falls - Dysphagia - Delirium Recurrent infections 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 Cancer, COPD, CHD, Liver, Renal, CVA, severity/progression Dementia, Neurodegenerative diseases, AIDS, other advanced illnesses

## Expert's Selected Parameters with prognostic value


Dimension	Criteria	Additional		
Palliative needs identified	Professionals think that he/she has palliative care needs	Clinical assessment		
Functional decline	Clinical assessment of functional decline sustained, severe and irreversible	Loosing => 30% Barthel in 6 months		
Nutritional decline	Clinical assessment of nutritional decline sustained, severe, and irreversible	Loosing => 10% Weight in 6 months		
Multimorbidity	More tan 2 chronic diseases added to the principal condition	Added to principal disease		
Use of resources	> 2 emergency admissions or increase of demand of interventions i 6 months	Of any type of interventions		
Specific disease criteria	Severity or progression of chronic conditions as Heart, Renal, Lung, Neurologic, or Hepatic	Specific criteria		





**Survival by** number of parameters affected 1-2, 3-4, or 5-6

## Atención integral a personas

Original Article

Utility of the NECPAL CCOMS-ICO<sup>©</sup> tool and the Surprise Question as screening tools for early palliative care and to predict mortality in patients with advanced chronic conditions: A cohort study

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### Abstract

Background: The Surprise Question (SQ) identifies patients with palliative care needs. The NECPAL C tool combines the Surprise Question with additional clinical parameters for a more comprehensive assessme screening tools to predict mortality is still unknown.

Aim: To explore the predictive validity of the NECPAL and SQ to determine 12- to 24-month mortality. Design: Longitudinal, prospective and observational cohort study.

Setting/participants: Three primary care centres, one general hospital, one intermediate care centre, Population cohort with advanced chronic conditions and limited life prognosis. Patients were classified accor criteria and followed for 24 months.

Results: Data available to assess 1059 of 1064 recruited patients (99.6%) at 12 and 24 months: 837 780 were NECPAL+. Mortality rates at 24 months were as follows: 44.6% (SQ+) versus 15.8% (SQ-) versus 18.3% (NECPAL-) (p=0.000). SQ+ and NECPAL+ identification was significantly correlated v risk (hazard ratios: 2.719 and 2.398, respectively). Both tools were highly sensitive (91.4, Cl: 88.7-94.1 with high negative predictive values (84.2, Cl: 79.4-89.0 and 81.7, Cl: 77.2-86.2), with low specificity and p The prognostic accuracy of SQ and NECPAL was 52.9% and 55.2%, respectively. The predictive validit NECPAL

Conclusion: SQ and NECPAL are valuable screening instruments to identify patients with limited life pro palliative care. More research is needed to increase its prognostic utility in combination with other paramet

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# 武 Obra Social "la Caixa"

### Palliative Medicine 1 - 10

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Research

**BMJ Open** Identifying patients with advanced chronic conditions for a progressive palliative care approach: a crosssectional study of prognostic indicators related to end-of-life trajectories

> J Amblàs-Novellas, 1.2 S A Murray, 3 J Espaulella, 1.2 J C Martori, 4 R Oller, 4 M Martinez-Muñoz,<sup>5</sup> N Molist,<sup>1,2</sup> C Blay,<sup>2,6</sup> X Gómez-Batiste<sup>2,7</sup>

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end of article.

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advanced frailty patients with no advanced disease criteria Conclusions: Dynamic indicators are present in the 3 For numbered affiliations see trajectories and are especially useful to identify PACC for a progressive PC approach purpose. Most of the other indicators are typically associated with a specific trajectory. These findings can help clinicians improve

Objectives: 2 innovative concepts have lately been developed to radically improve the care of patients with advanced chronic conditions (PACC): early identification of palliative care (PC) needs and the 3 end-of-life trajectories in chronic illnesses (acute, intermittent and gradual dwindling). It is not clear (1) what indicators work best for this early identification and (2) if specific clinical indicators exist for each of these trajectories. The objectives of this study are to explore these 2 issues.

Setting: 3 primary care services, an acute care hospital, an intermediate care centre and 4 nursing homes in a mixed urban-rural district in Barcelona,

Participants: 782 patients (61.5% women) with a positive NECPAL CCOMS-ICO test, indicating they might benefit from a PC approach.

Outcome measures: The characteristics and distribution of the indicators of the NECPAL CCOMS-ICO tool are analysed with respect to the 3 trajectories and have been arranged by domain (functional, nutritional and cognitive status, emotional problems, geriatric syndromes, social vulnerability and others) and according to their static (severity) and dynamic (progression) properties

Results: The common indicators associated with early end-of-life identification are functional (44.3%) and nutritional (30.7%) progression, emotional distress (21.9%) and geriatric syndromes (15.7% delirium, 11.2% falls). The rest of the indicators showed differences in the associations per illness trajectories (p<0.05). 48.2% of the total cohort was identified as

the identification of patients for a palliative approach.

### Strengths and limitations of this study

- . This study innovatively explores the relation between end-of-life indicators used to identify patients with advanced chronic conditions (PACC) and the three archetypal end-of-life trajectories: acute (typically cancer), intermittent (typically organ failure) and gradual dwindlin (typically dementia or frailty).
- Analysing the characteristics of end-of-life indicators allows us to know which indicators most consistently identify patients for palliative care (PC). It also provides data on the characteristics that most commonly occur in each end-of-life trajectory
- . The large number of identified PACC but with no advanced disease criteria reveals that there is a real and not previously well-described cohort of people with advanced frailty and PC needs.
- . These concepts are useful for clinical decision making, for policymakers in designing appropri ate health services, as well as giving researchers a theoretical framework for future research.
- Study limitations include the heterogeneity in the collection of variables due to the multiple assessments from all healthcare system resources and the number of missing data in some variables.

### INTRODUCTION

Two concepts can be combined to illuminate care provision for patients with advanced chronic conditions (PACC): early identification of patients with palliative care (PC) needs and, second, end-of-life trajectories associated with advanced chronic illnesses. This gives a conceptual framework to understand the different characteristics of patients from their early identification for PC onwards.

## **NECPAL tool prognostication in** advanced chronic illness: a rapid review and expert consensus

Original research

palliative care needs (PCNs) in all settings

of care is a relevant challenge of palliative

sionals with decision-making, and empha-

sise some of the elements of care, such as

advanced care planning, spiritual needs

assessment, bereavement and end-of-life

Clinical prediction of survival (CPS) is

the most used trigger for the identifica-

tion of patients at the EoL, even though

several systematic reviews (SRs) have

highlighted clinicians' limitations for

distinguishing patients who have a limited

life prognosis.<sup>3-5</sup> Furthermore, prognostic

tools have been published for advanced

chronic diseases, although most have been

validated for a specific clinical condition

or care setting, or include variables that

are not necessarily easy to obtain in daily

practice.<sup>67</sup> All of the above emphasises the

need to provide clinicians with feasible

and reliable tools to use in daily practice

that take into account a necessary and

cautious approach of applying prognostic

risks of selected populations to individual

(EoL) decisions.

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### ABSTRACT

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BMJ

Objective To develop a proposal for a 2-year mortality prognostic approach for patients with advanced chronic conditions based on the palliative care need (PCN) items of the NECesidades PALiativas (NECPAL) CCOMS-ICO V.3.1 2017 tool.

Methods A phase 1 study using three components based on the NECPAL items: (1) a rapid review of systematic reviews (SRs) on prognostic factors of mortality in patients with advanced chronic diseases and PCNs; (2) a clinician and statistician experts' consensus based on the Delphi technique on the selection of mortality prognostic factors; and (3) a panel meeting to discuss the findings of components (1) and (2)

Results Twenty SRs were included in a rapid review and 50% were considered of moderate and functional decline, severe and refractory dyspnoea, multimorbidity, use of resources and specific disease indicators were found to be potentially prognostic variables for mortality across four clinical groups and end-of-life (EoL) trajectories: cancer, dementia and neurologic diseases, chronic organ failure and frailty. Experts' consensus added 'needs' identified by health professionals. However, clinicians were less able to discriminate which NECPAL items were more reliable for a 'general' model. A retrospective cohort study was designed to

Conclusions We identified several parameters with prognostic value and linked them to the tool's utility to timely identify PCNs of patients with advanced chronic conditions in all settings of care. Initial results show this is a dinical and feasible tool, that will help with clinical pragmatic decision-

### INTRODUCTION

The timely identification of patients

care (PC).1 To respond to this challenge, several tools have been designed and validated based on the initial experience with the Gold Standards Framework.<sup>2</sup> These originally focused on the early identification of patients with PCNs irrespective of their prognosis, preferably in the community, to gradually introduce a PC approach including a systematic needs assessment,

followed by a multidimensional model of care, advance care planning, review of diseases and treatment and integrated care across the system.<sup>1</sup> Additionally, this might be useful to identify patients with a limited life prognosis as a relevant aspect to help patients, relatives and profes-

guality. Despite methodological issues, nutritional evaluate this proposal in phase 2.

making and to define services.

Regarding this, the NECesidades PALiativas (NECPAL) CCOMS-ICO V.3.1 with advanced chronic conditions and 2017 tool which is a validated instrument

patients.

Gómez-Batiste X. et al. BMI Supportive & Palliative Care 2020:0:1-11. doi:10.1136/bmispcare-2019-002126

Atención integral a persona



### Original research

## **NECPAL** prognostic tool: a palliative medicine retrospective cohort study

Pamela Turrillas, 1.2 Judith Peñafiel, 3.4 Cristian Tebé, 3.4 Jordi Amblas-Novellas, 1,2,5 Xavier Gómez-Batiste 🥌 1,2,5

### ABSTRACT

Objective To develop and validate a prognostic model to assess mortality risk at 24 months in patients with advanced chronic conditions. Methods Retrospective design based on a previous population cohort study with 789 adults who were identified with the surprise question and NECPAL tool from primary and intermediate care centres, nursing homes and one acute hospital of Spain. A Cox regression model was used to derive a mortality predictive model based on patients' age and six previously selected NECFAL prognostic factors (palliative care need identified by healthcare professionals, functional decline, nutritional decline, multimorbidity, use of resources, disease-specific criteria of severity/ progression). Patients were split into derivation/ validation cohorts, and four steps were followed: descriptive analysis, predictors' assessment, model estimation and model assessment. Results All predictive variables were

independently associated with increased risk of mortality at 24 months. Performance model including age was good; discrimination power by area under the curve (AUC) was 0.72/0.67 in the derivation/validation cohorts, and correlation between expected and observed (E/O) mortality ratio was 0.74/0.70. The model showed similar performance across settings (AUC 0.65-0.74, E/O 1.00-1.01), the best performance in oncological patients (AUC 0.78, E/O 0.76) and the worst in dementia patients (AUC 0.58, E/O 0.85). Based on the number of factors affected, three prognostic stages with significant differences and a median survival of 38, 17.2 and 3.6 months (p<0.001) were defined. Conclusion The NECPAL prognostic tool is accurate and eventually useful at the clinical practice. Stratification in risk groups may enable early intervention and enhance policy-making and service planning.

### INTRODUCTION

The timely identification of patients with palliative care (PC) needs in all settings of care is of paramount importance to

### Key messages

- What was already known? NECPAL CCOMS-ICO, V.3.1 2017, is a validated instrument with widespread use to identify patients likely in need of palliative care (PC).
- The combination of the surprise question and some individual parameters of the NECPAL tool may have potential prognostic utility for estimating mortality in patients with advanced chronic diseases and PC needs
- Several generic and specific tools have been validated as prognostic instruments for specific clinical conditions and settings. However, comprehensive tools that timely identify mortality risk and include a PC need assessment together with a prognostic assessment are scarce and mostly valuable in late stages of advanced chronic conditions.

### What are the new findings?

- PC needs identified by healthcare professionals, functional decline, nutritional decline, multimorbidity, use of resources and disease-specific criteria of severity and progression are individually accurate in predicting 24month mortality risk in patients with advanced chronic diseases
- The NECPAL prognostic model, including these six variables plus age, generally performs well to predict 24-month mortality risk across different clinical conditions and care settings.
- The applications of this tool would allow to establish three major groups of risk. mortality identifying stages in patient's transition towards end-of-life care, with median survivals of 38, 17.2 and 3.6 months, respectively.

improve the quality of their care. This can be achieved through the gradual implementation of a palliative approach that includes a multidimensional needs assessment, a review of disease stages and therapeutics, and advanced care planning

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PRACTICAL RECOMMENDATIONSFOR IDENTIFYINGAND ESTABLISHING PROGNOSTICAPPROACH OF PEOPLE WITHADVANCED CHRONIC CONDITIONSAND PALLIATIVE CARE NEEDSIN HEALTH AND SOCIAL SERVICESNECPAL 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

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

## Atencion integral a personas

con enfermedades avanzadas

## **NECPAL 4.0 PROGNOSTIC 2021**

Adding prognostic approach to palliative approach





# HOW TO USE IT IN PRACTICE IN HEALTH AND SOCIAL SERVICES?

Steps: the first steps are similar to the previous versions:

- 1. Review the list of people attended by the service.
- 2. Elaborate a list of those persons with chronic conditions specially affected.
- 3. Apply the surprise question to doctors and nurses about well-known patients: "Would you be surprised inf this patient die in one year?" with clinical criteria.
- 4.In those patients in which the response was "I'm or we will not be surprised", explore the different NECPAL generic parameters and the specifics for conditions.

The result of this procedure will be **list of patients having palliative care needs and a limited life prognosis** (*Figure 1: NECPAL «classic»* 3.1)

## Atención integral a personas





## **NECPAL TOOL VERSION 4.0 2021**



## > Need's Checklist: Identification of palliative care needs to insert a palliative approach



- 1. Realize a rapid checklist of the need's dimensions.
- Complement with additional indicators and parameters if needed.
- Elaborate aims and actions to respond to the identified needs.
- Elaborate a comprehensive therapeutic plan.

The result of this procedure permits to identify palliative care needs and elaborate a comprehensive therapeutic plan:

### Actions for the comprehensive care of people identified

- 1. Multidimensional assessment
- Assessment of the stage of diseases and conditions and possible evolution
- Identify values, preferences, and start advance care planning
- 4. Identify and care principal career
- 5. Identify and activate referent profesional
- 6. Multidimensional Therapeutic Plan
- 7. Case management and integrated care with other services

## > "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



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CÀTI DE C PAL· 1





## **ASPECTS TO CONSIDER**

How to manage the prognostic assessment in clinical practice

- The prognosis is one of the elements to consider, added to the needs and demands.
- 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.

# Atención integral a personas





## Risks and benefits of the prognostic approach

- The most relevant benefit of the prognostic assessment is to contribute to the situational assessment and permits redefinition of the therapeutic aims, introducing gradually a palliative approach.
- This assessment must be shared with patients, relatives and team, with the rithm, intensity, and concretion adapted individually to the adjustment and preferences of patients.
- The most relevant risk consists in the automatic individual application of a population-based risk.

Atención integral a personas con enfermedades avanzadas





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# Atención in con enfermed activity area to a consistentifying prognosis with 6 simple parameters





New perspectives, new challenges: Psychosocial & Spiritual care





## What we do

<mark> Obra Social "la Caixa"</mark>

PAL·LIATIVES

WHO COLLASCINTING CENTRE PUBLIC HEALTH PALLATIVE CARE PROGRAMMES

nstitut Català d'Oncolor



5

2





### 2. EL PROGRAMA







# 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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# **Innovations in progress**

- The Volonteeers Program
- The "unwanted loneliness/isolation" Program
- Education for careers: the careers school
- Psychosocial on line care Program
- COVID support programs
- Professionals' online coaching and support
- Surveys professionals' mental health
- The Barcelona Center for people with advanced chronic conditions and additional social needs (unwanted isolation, poverty, severe distress, Access problems, complex bereavement, ....)
- + Nursing homes' program

Atención inte le people with advanced chronic conditions



con enfermedad



# Other programs of Nursing homes supports 1: Recommendations for ethical decission making in NHs



## Learning from Hong Kong experience!!!!!





New perspectives, new challenges: Involving society Evolutive concepts: from Medical paternalism to Society leadership











# **VIC, CIUDAD CUIDADORA**





de Vic CÁT CUIE











### **Original Article**

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

Xavier Gómez-Batiste<sup>1,2</sup>, Silvia Mateu<sup>3</sup>, Susagna Serra-Jofre<sup>1</sup>, Magda Molas<sup>3</sup>, Sarah Mir-Roca<sup>1</sup>, Jordi Amblàs<sup>1</sup>, Xavier Costa<sup>1</sup>, Cristina Lasmarías<sup>1,2</sup>, Marta Serrarols<sup>4</sup>, Alvar Solà-Serrabou<sup>3</sup>, Candela Calle<sup>5</sup>, Allan Kellehear<sup>6</sup>

Submitted Feb 27, 2018. Accepted for publication Mar 09, 2018. doi: 10.21037/apm.2018.03.10 View this article at: http://dx.doi.org/10.21037/apm.2018.03.10

Atención integral a personas con enfermedades avanzadas

# Viure amb sentit, dignitat i suport al final de la vida

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# Other programs of Nursing homes supports 2: Online Course of palliative care approch for 1.200 NHs in times of COVID

- 14 Modules on clínical, ethical and organizational issues
- Training material (powerpoints / lectures)
- To be shared within the teams
- Mandatory to 1.200 Nursing homes at the region (60.000 beds)
- Promoted by Department of Health and Welfare

Atención integral a personas

con enfermedad Learning from Hong Kong experience!!!!!





# Other programs of Nursing homes supports 3: Research: the RESICOVID Project

- Highly competitive
- Aims:
- Describe the impact of COVID in the NHs system
- Elaborate proposals of improvement
- Special focus on gender, mental health, and ethics
- Methods combined: representative sample of 1.200 NHs in the Region
- Big data / systematic review
- Mortality / morbidity during epidemic
- Qualitative of the impact & quantitative mental health
- Quality improvement
- 18 Months follow-up Atención integral a personas

con enfermedades avanzadas

Learning from Hong Kong experience!!!!!





New perspectives, new challenges: Inserting into academy





## Chair of Palliative Care 2013: • **1st in Spain**

**Professorship Palliative Care:** unique is 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, <sup>1,2,3</sup> Cristina Lasmarías, <sup>1,2,3</sup> Jordi Amblàs, <sup>1,3</sup> Xavier Costa, <sup>1,3,4</sup> Sara Ela, <sup>1,2</sup> Sarah Mir, <sup>1,3</sup> Agnès Calsina-Berna, <sup>1,5</sup> Joan Espaulella, <sup>1,3</sup> Sebastià Santaugènia, <sup>3,6</sup> Ramon Pujol, <sup>1</sup> Marina Geli Geli,7 Candela Calle8

### ABSTRACT

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**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 compassive 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 PhDs 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.<sup>1</sup> 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.<sup>2</sup> These policy activities, establishing contracts and agreements with public or private organisations, had the support, as main partner, of the Catalan Department of Health.

Gómez-Batiste X, et al. BMJ Supportive & Pallative Care 2018;0:1-8. doi:10.1136/bmjspcare-2018-001656

1

	Title	Authors	Year	Journal	IF *2016 Journal Citation Reports®	Citations * February 2018	Quartile/Percentile	
1	Effectiveness of psychosocial interventions in complex palliative care patients: a quasi-experimental, prospective, multicenter study.	Mateo-Ortega D, Gómez-Batiste X, Maté J, Beas E, Ela S, Lasmarías C, Limonero JT.	2018	Journal of Palliative Medicine	2.230		-	1
2	Intrahospital mortality and survival of patients with advanced chronic litnesses in a tertiary hospital identified with the NECPAL CCOMS- ICO® tool.	Calsina-Berna A, Martinez-Muñoz M, Bardés I, Beas E, Madariaga R, Gômez-Batiste X.	2018	Journal of Palliative Medicine	2.230		- :	1
		Amblás-Novellas J, Martori JC, Espaulella J, Oller R, Molist- Brunet N, Inzitari M, Romero-Ortuno R. Limón E, Blay C, Lasmarías C.		BMC geriatrics Formación Médica Continuada en Atención Primaría.	2.611		2	1 4
5	La planificación de decisiones anticipadas: hacia una cultura asistencial del siglo xol.	Lasmarias, C	2017	Health, Aging & End of Life Care	-		2	
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7	Comprehensive and integrated palliative care for people with advanced chronic conditions: an update from several European initiatives and recommendations for policy.	Gómez-Batiste X, Murray SA, Keri T, Blay C, Boyd K, Moine S, Gignon M, Van den Eynden B, Leysen B, Wens J, Engels Y, Dees M, Costantini M.	2017	Journal of Pain and Symptom Management	2.905		te	1
	screnning tools for early palliative care and to predict mortality in	Gómez-Batiste X, Martinez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X, Espaulella J, Villanueva A, Oller R, Martori JC, Constante C.	2017	Palliative Medicine	4 220	1	3	1
9	The Development of Palliative Care in Argentina: A Mapping Study Using Latin American Association for Palliative Care Indicators.	Mertnoff R, Vindrola-Padrós C, Jacobs M, Gómez-Batiste X.	2017	Journal of Palliative Medicine	2.230		t.	1
10	Palliative Care Education in Latin America: A systematic review of training programs for healthcare professionals.	Vindrola-Padrós C, Mertnoff R, Lasmarías C, Gómez-Batiste X	2017	Palliative & Supportive Care	1.199		r.	2
11	En busca de respuestas al reto de la complejidad clínica en el siglo XXI: a propósito de los índices de fragilidad.	Amblàs-Novellas J, Espaulella-Panicot J, Inzitari M, Rexach L, Fontecha B, Romero-Ortuno R.	2017	Revista Española de Geriatria y Gerontologia	0.427	6	3	3
12	Adverse Drug Events in patients with advanced chronic conditions who have a prognosis of limited life expectancy at hospital admission	Sevilla-Sánchez D, Molist-Brunet N, Amblás-Novellas J, Roura-Poch P, Espaulella-Panicot J and Codina-Jane C.	2017	European Journal of Clinical Pharmacology	2.902		6	1
13		Mas MA, Amblas-Novellas J	2017	Revista Española de Geriatria y Gerontología	0.427		-	3
	Panalive care from diagnosis to death	Murray SA, Kendall M, Mitchell G, Moine S, Amblås-Novellas J, Boyd K		British Medical Journal	20.7	1	1	1
15	multimorbilidad.	Espaulella-Panicot J, Molist-Brunet N, Sevilla-Sánchez D, González-Bueno J, Amblás-Novellas J, Solá-Bonada N, Codina-Jané C.	2017	Revista Española de Geriatria y Gerontología	0.427	8	2	3
16	Busca tu 1%: prevalencia y mortalidad de una cohorte comunitaria de personas con enfermedad crónica avanzada y necesidades paliativas.	Blay C, Martori JC, Limón E, Oller R, Vila L, Gómez-Batiste X.		Atención Primaria	1.042		1	2
	A propòsit del CAAPS sobre fragilitat i cronicitat complexa: algunes lliçons apreses	Limon E, Blay C, Burdoy E.		Butlletí de l'Atenció Primária de Catalunya				-
18	Cronicitat i complexitat clínica	Limón E, Blay C, Santaeugenia S , Contel JC, Hernansanz F, Alavedra C.	2017	Butlleti de l'Atenció Primària de Catalunya	-		-	-
19	Tercer Congreso de la Profesión Médica de Catalunya: consenso sobre los retos del profesionalismo y su impacto en las organizaciones docentes	Blay C, Limón E, Garcia F, Ledesma A, Sellarés J, Padrós J.	2017	Revista de la Fundación Educación Médica	2			-
20	¿Podemos integrar la atención nutricional en los distintos niveles	Blay C.	2017	Nutrición Hospitalaria	-		-	2
21	Perfil y evolución de pacientes crónicos complejos en una unidad de	Gual N, Yuste A, Enfedaque B, Błay C, Martin Alvarez R, Inzitari M	2017	Atención Primaria	1.042		2	2
22	at 25 years (1990-2015)	Gómez-Batiste X, Blay C, Martinez-Muñoz M, Lasmarias C, Vila L, Espinosa J, Costa X, Sánchez-Ferrin P, Bullich I, Constante C, Kellev E.	2016	Journal of Pain and Symptom Management	2.905		5	1
23	Vivir con la enfermedad pulmonar obstructiva crónica avanzada: el	Costa X, Gómez-Batiste X, Pla M, Martínez-Muñoz M, Blay C, Vila L.		Atención Primaria	1.042		5	2
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26	Desarrollo de la escala DME-C: una escala para la detección del malestar emocional de los cuidadores principales de personas con enfermedad avanzada o al final de la vida.	Limonero, J. T., Maté J, Mateo D, González-Barboteo J, Bayés R, Bernaus M, Casas C, López M, Sirgo A, Viel S, Sánchez C, Gómez-Romero MJ, Álvarez-Moleiro, Tomás- Sálado J.	2016	Ansiedad y Estrés	0.25		2	4
27	Innovando en la toma de decisiones compartida con pacientes hospitalizados: descripción y evaluación de una herramienta de registro de nivel de intensidad terapétutica.	Ambiás-Novellas J, Casas S, Catalán RM, Oriol-Ruscalled M, Lucchetti GE, Quer-Vall FX		Revista Española de Geriatria y Gerontología	0.427		3	3
28	Índice Frágil-VIG: diseño y evaluación de un Índice de Fragilidad basado en la Valoración Integral Gerlátrica	Amblás-Novellas J, Martori JC, Molist N, Oller R, Gómez- Batiste X, Espaulella J	2016	Revista Española de Geriatria y Gerontología	0.427		3	3
29	Frailty, severity, progression and shared decision-making: A pragmatic framework for the challenge of clinical complexity at the end of life	Amblås-Novellas J, Espaulella J, Rexach L, Fontecha B, Inzitari M, Blay C, Görnez-Batiste X.	2015	European Geriatric Medicine	0.272	1	3	3
	Promoting palliative care in the community: Production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care.	Murray SA, Firth A, Schneider N, Van den Eynden B, Gómez- Batiste X, Brogaard T, Villanueva T, Abela J, Eychmulter S, Mitchell G, Downing J, Satinova L, Van Rijswijk E, Barnard A, Lynch M, Fogen F, Moine S.	2015	Palliative Medicine	4.220	21	8	1
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32	Have we Improved Pain Control in Cancer Patients? A Multicenter Study of Ambulatory and Hospitalized Cancer Patients.	Porta-Sales J, Nabal-Vicuna M, Vallano A, Espinosa J, Planas-Domingo J, Verger-Fransoy E, Judià-Torras J, Serna J, Pascual-López A, Rodríguez D, Grimau L Mortans G, Sala- Rovira C, Catsina-Berna A, Borras-Andrés JM, Gómez- Batiste, X.	2010	Journal of Palliative Medicine	2.230	9	8	1
	circle and megaled care in outlional	Contel JC, Ledesma A, Blay C, González-Mestre A, Cabezas C, Puigdollers M, Zara C, Amil P, Sarquella E, Constante C	2015	International Journal of Integrated Care	-	1	t.	1
34	la atencion primana	Limón E, Blay C, Ledesma A.	2015	Atención Primaria	1.042			2
25	Atenció integrada. Oportunitat, repte, necessitat? Transformant l'atenció a les persones	Sarquella E, Ledesma A, Blay C, Contel JC, González-Mestre A, Viguera L	2015	Revista de Treball Social	3	9	8	-
36	Taskforce in primary palliative care	Murray SA, Firth A, Schneider N, Van den Eynden B, Gómez- Baliste X, Brogaard T, Villanueva T, Abela J, Eychmuller S, Mitchell G, Downing J, Saltinov L, Van Rijswijk E, Barnard A, Lynch M, Fogen F, Moine S.	2015	Palliative Medicine	4.220	2	3	1

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55 National Journals: 25 International Journals: 30			52.214		

Peer-reviewed/Indexed Journals: 40

- 55 Papers:
> 30 International
> 40 peer reviewed
- 5 books:
1 internacional







Estudiantes de 2º Curso Medicina UVIC/UCC construyendo competencias del medico ideal con pacientes, ciutadan@s y profesionales salud





GURRENT

# Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach

Xavier Gómez-Batiste<sup>a,b</sup>, Marisa Martínez-Muñoz<sup>a,b</sup>, Carles Blay<sup>b,c</sup>, Jose Espinosa<sup>a,b</sup>, Joan C. Contel<sup>c</sup>, and Albert Ledesma<sup>c</sup>

### 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

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

## prevalence rate

Xavier Gómez-Batiste.<sup>1,2</sup> Ma Jordi Amblàs,<sup>4</sup> Laura Vila,<sup>3</sup> Joan Espaulella,<sup>4</sup> Jose Espin Carles Constante<sup>6</sup>

cancer within specialist services. Howe

around 75% of the population in mide

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 initia

the NECPAL (Necesidades Pallativas (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-heat

settings of Osona; and initial implement

the NBC PAL 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 results prevalence study show that 1.45% of

population and 7.71% of the population

### ABSTRACT Palliative care (PC) has focused on pati

appendix is published online only. To view these files please visit the jarnal online (http://dxdoi.org/ 10.1136bmj spcare-2012-0002110.

An additional supplementary

For numbered all liations see end of article.

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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-pa 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

**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,<sup>1,2</sup> Marisa Martínez-Muñoz,<sup>1,2</sup> Carles Blay,<sup>2,3</sup> Jordi Amblàs,<sup>4</sup> Laura Vila,<sup>3</sup> Xavier Costa,<sup>3</sup> Alicia Villanueva,<sup>5</sup> Joan Espaulella,<sup>4</sup> Jose Espinosa,<sup>1</sup> Montserrat Figuerola,<sup>1</sup> Carles Constante<sup>6</sup>

vention, together with advance care planning and case management as core methodologies. From the epidemiological

Feature

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

Góme-Batiste X, et al. BM/ Supportie & Pallative Care 2012;0:1-9. doi:10.1136/bmjpcare-2012-000211



prevalence in the healthcare system.











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"* 

Atención integrar a personas





## Conclusions

 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
 Palliative care services and programs must see this as an opportunity and be adapted to new needs
 Psychosocial and spiritual needs are essential components of care
 Society must be involved with an active rol and leadership
 Palliative care is an essential component of pregraduate and postgraduate training of all professionals
 All this can be done!!!!! With vision, leadership, and commitment

## Atención integral a personas





con enfermedades avanzadas

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