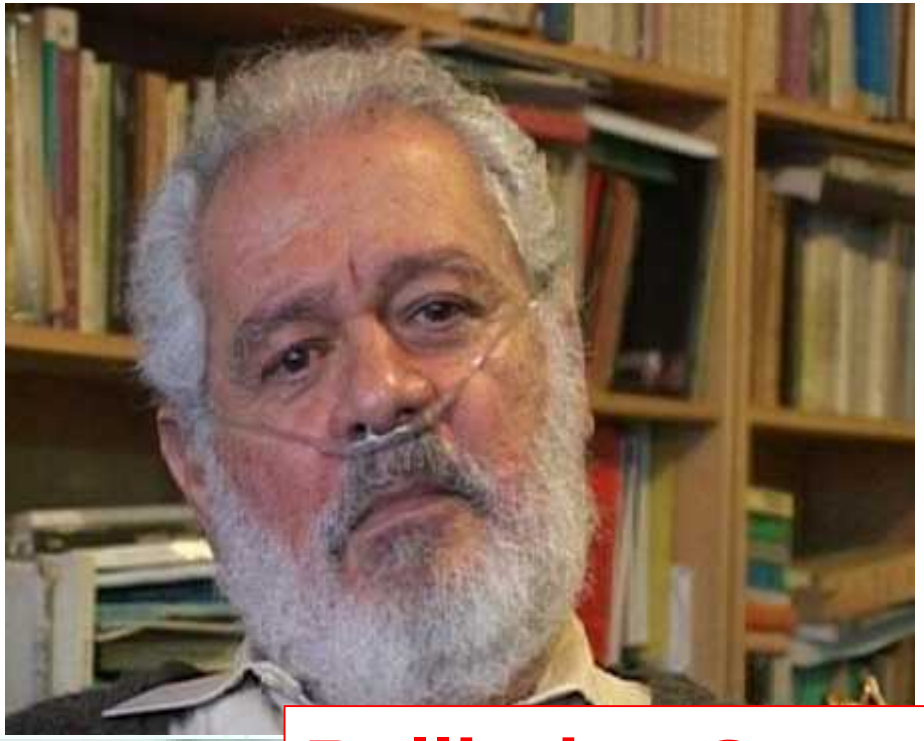
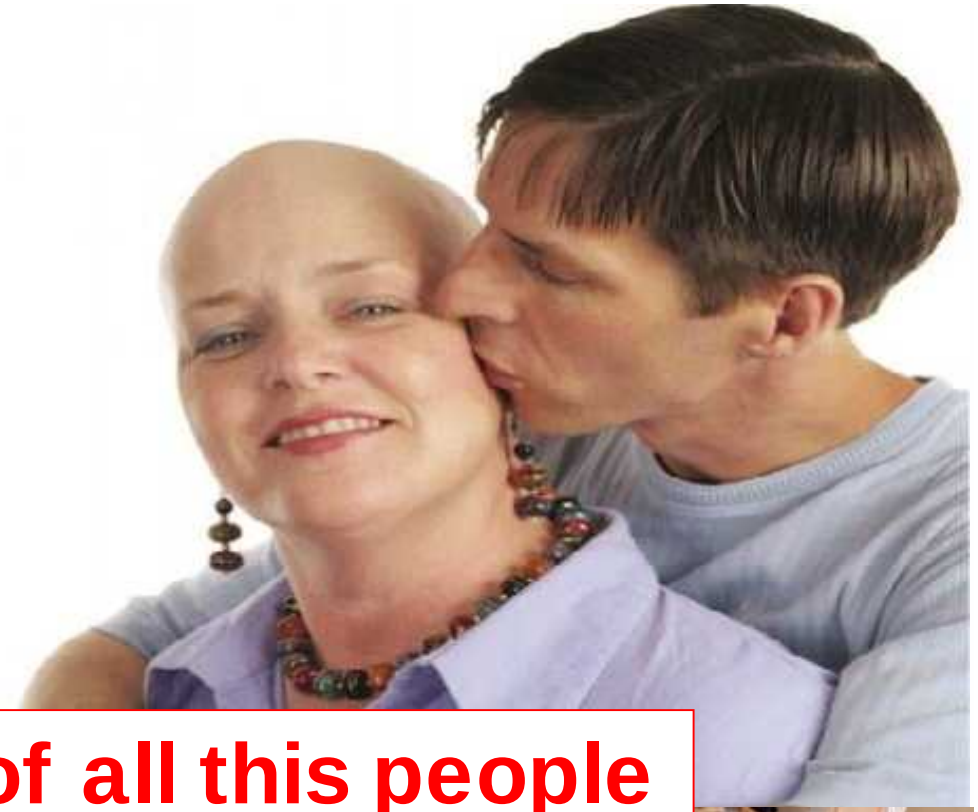




Palliative Care of all this people

Dirección científica

CÀTEDRA DE CURES PAL·LIATIVES

ICO Institut Català d'Oncologia

Obra Social

Prof Xavier Gómez- Batiste, MD, PhD

Director,

Qualy Observatory

WHO Collaborating Center for Palliative Care Public Health ProgramsCatalan Institute of Oncology ICO

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

Atención integral a personas con enfermedades avanzadas

Dirección científica

CÀTEDRA DE CURES PAL·LIATIVES

ICO Institut Català d'Oncologia

Obra Social "la Caixa"

Palliative care for people with Advanced Chronic Conditions

"If you do the things like you did…….
You will get the results you got!!!"

Albert Einstein

Atención integral a personas con enfermedades avanzadas

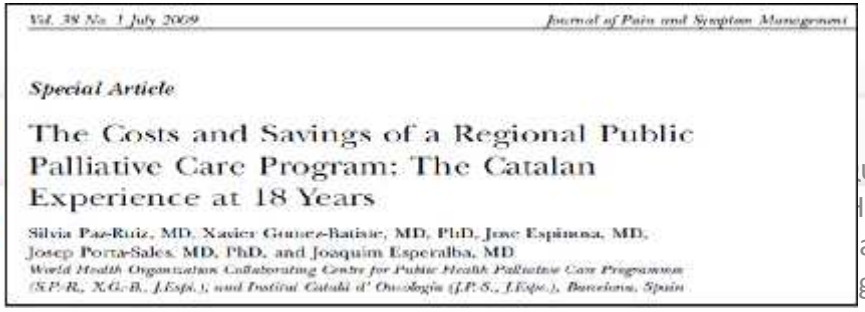
Dirección científica

Existing Palliative Care has shown effectiveness and efficiency

- Improves symptoms
- Reduces suffering
- Reduces complex bereavement
- Increases satisfaction
- Reduces suffering

- Reduce use of hospital beds
- Reduce admissions and length of stay in hospital
- Reduce emergencies
- Cost of Palliative care beds 50% of conventional
- Increases home care
- Cost of health care 70% in the last 6 months
- Cost of hospitals is 70% of the cost of End of life care

- Added values:
- Comprehensive
- Patients and families
- Essential needs
- Interdiscilpinary
- Dignity
- Ethics
- Humanism



Vol. 38 No. 1 July 2009 Journal of Pain and Symptom Management

Special Article

The Costs and Savings of a Regional Public Palliative Care Program: The Catalan Experience at 18 Years

Silvia Paz-Ruiz, MD, Xavier Gomez-Batiste, MD, PhD, Jose Espinosa, MD, Josep Porta-Sales, MD, PhD, and Joaquim Esperalba, MD

World Health Organization Collaborating Centre for Public Health Palliative Care Programmes (S.P.-R., X.G.-B., J.Esp.), and Institut Català d' Oncologia (J.P.-S., J.Esp.), Barcelona, Spain

522 Journal of Pain and Symptom Management Vol. 31 No. 6 June 2006

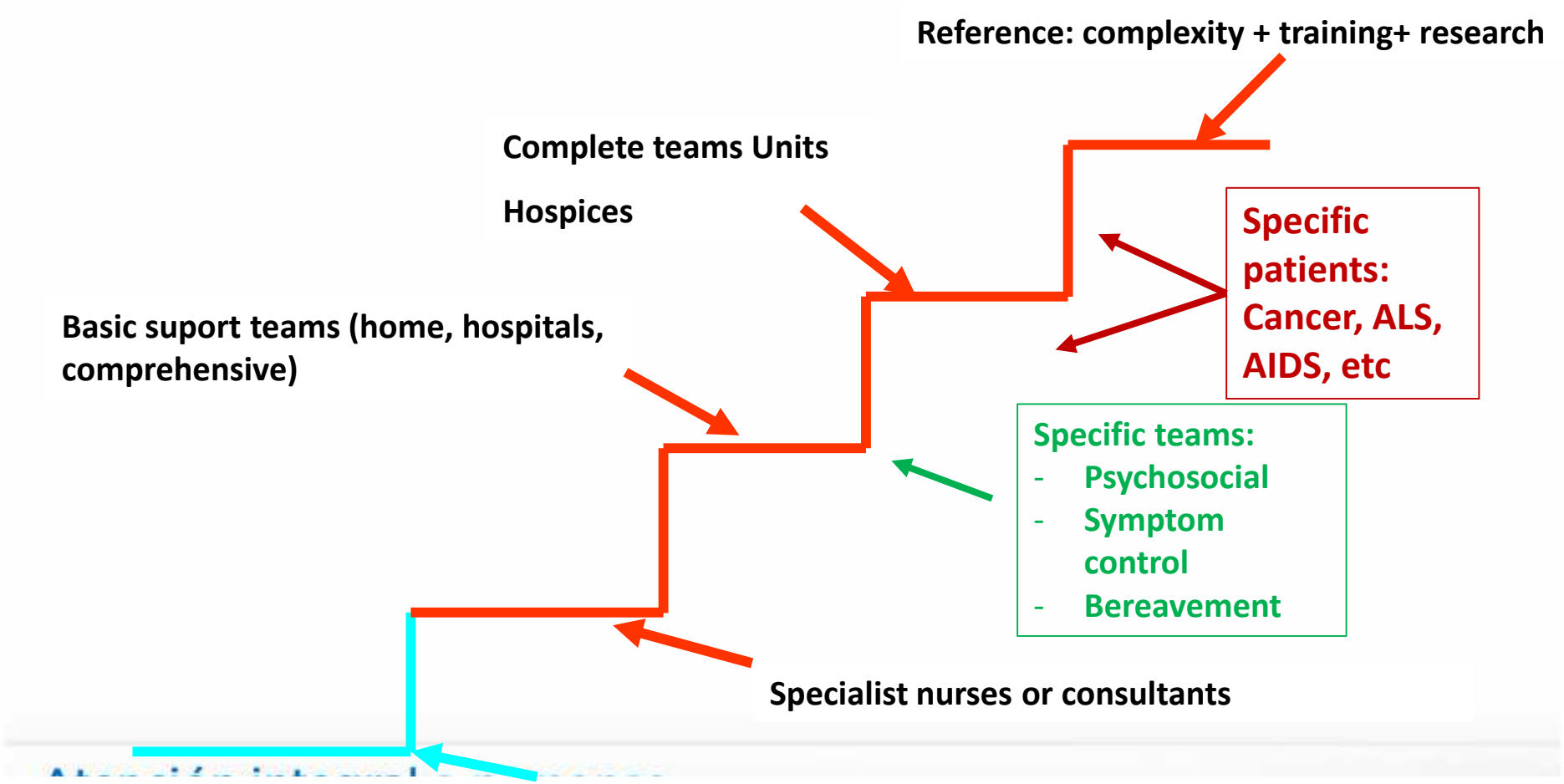
Original Article

Resource Consumption and Costs of Palliative Care Services in Spain: A Multicenter Prospective Study

Xavier Gómez-Batiste, MD, PhD, Albert Tuca, MD, Esther Corrales, RN, Josep Porta-Sales, MD, PhD, María Amor, MD, José Espinosa, MD,

Levels of complexity of Palliative Care provision

Obra Social "la Caixa"



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

Special Article

The Catalonia World Health Organization Demonstration Project for Palliative Care Implementation: Quantitative and Qualitative Results at 20 Years

Xavier Gómez-Batiste, MD, PhD, Carmen Caja, RN, Jose Espinosa, MD, Ingrid Bullich, RN, Marisa Martínez-Muñoz, RN, Josep Porta-Sales, MD, PhD, Jordi Trelis, MD, Joaquim Esperalba, MD, MBA, and Jan Stjernsward, MD, PhD

The "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

Obra Social "la Caixa"

- 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

Obra Social "la Caixa"

New perspectives, new challenges:

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

Obra Social "la Caixa"

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 *OR* palliative treatment	Specific *AND* palliative treatment needed
Prognosis as criteria intervention	Complexity as criteria
Rigid one-directional intervention	Flexible intervention
Passive role of patients	Advance care planning / Autonomy
Reactive to crisis	Preventive of crisis / Case management
Palliative care services	+ Palliative care *approach* everywhere
Specialist services	+ Actions in all settings of health & social care
Institutional approach	Community approach
Services' approach	Population & district
Fragmented care	Integrated care

Gómez-Batiste X et al, Current Opinion in Supportive Palliative Care, 2012; Gómez-Batiste X et al, BMJ SPCare, 2012
Gómez-Batiste X et al, Medicina Clínica, 2013

Palliative Care needs

The populational perspective:

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

Dirección científica

CÀTEDRA DE CURES PAL·LIATIVES

ICO Institut Català d'Oncologia

Obra Social "la Caixa"

Original Article

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

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

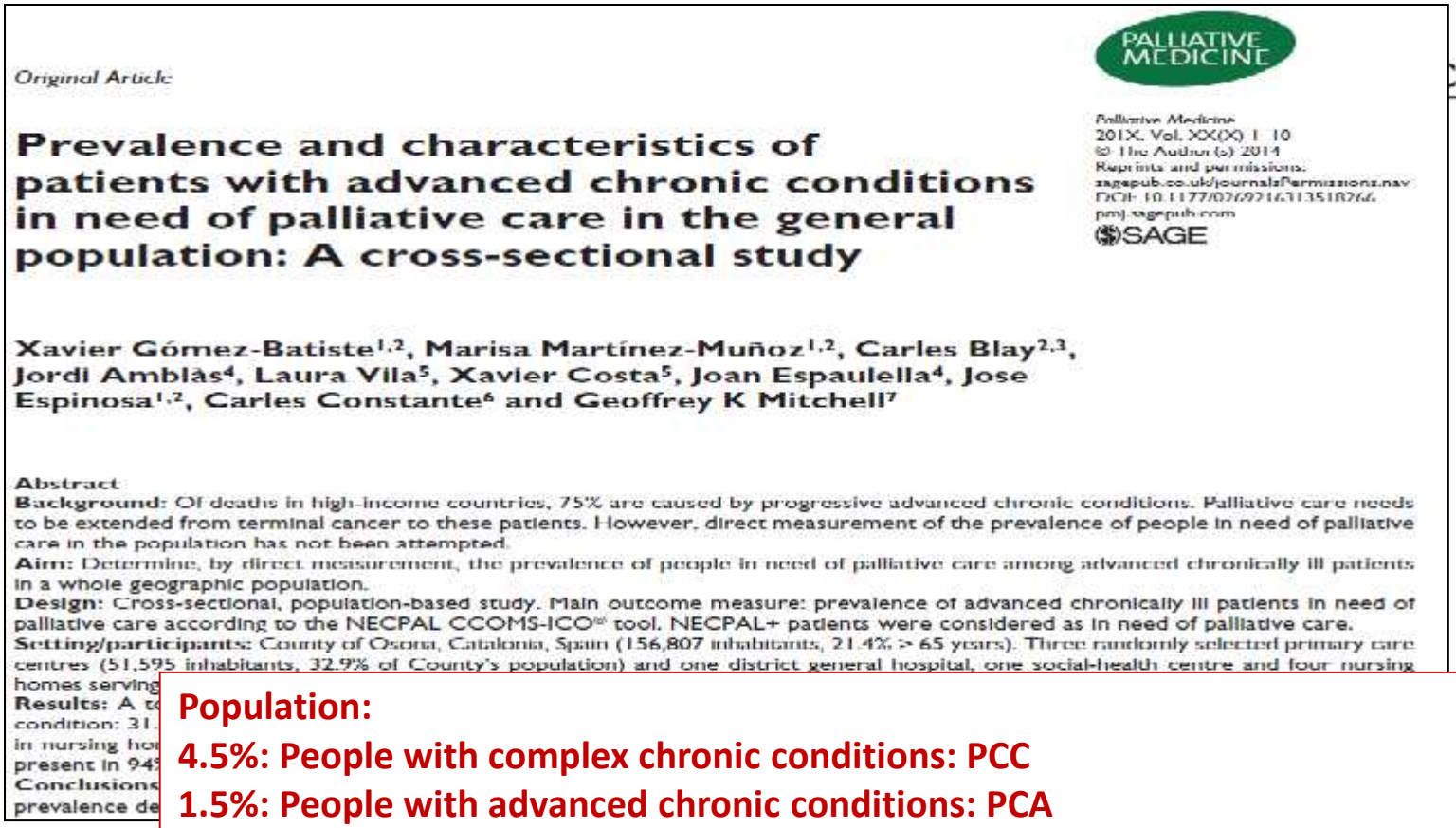
PALLIATIVE MEDICINE

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

DOI: 10.1177/0269216313489367
pmj.sagepub.com
SAGE

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

Atención integral a personas
con enfermedades avanzadas



Original Article

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

PALLIATIVE MEDICINE

Palliative Medicine
201X, Vol. XX(X) 1–10

DOI: 10.1177/0269216313510266
pmj.sagepub.com
SAGE

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

Abstract

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

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

Design: Cross-sectional, population-based study. Main outcome measure: prevalence of advanced chronically ill patients in need of palliative care according to the NECPAL CCOMS-ICO© tool. NECPAL+ patients were considered as in need of palliative care.

Setting/participants: County of Osona, Catalonia, Spain (156,807 inhabitants, 21.4% > 65 years). Three randomly selected primary care centres (51,595 inhabitants, 32.9% of County's population) and one district general hospital, one social-health centre and four nursing homes serving

Results: A t
condition: 31
in nursing ho
present in 94
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%

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

Dirección científica

CÀTEDRA DE CURES PAL·LIATIVES

ICO Institut Català d'Oncologia

Obra Social "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 (%)	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 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

Atención integral a p

con enfermedades av

Who are they?

Dirección científica

Chronic Disease / Failure / Condition	N (+/- 10%)
Geriatric syndroms & pluripathology	415
Dementia	300
Cancer	170
Cardiac	140
Respiratory	80
Neurological	80
Renal	40
Liver	26
Other	40
Total	1.300

Estimation of prevalence in a district of 100.000 hab in Spain (+/- 10%)

Aten

con enfermedades avanzadas

Dirección científica

Símptoms	TOTAL
Pain	40 (50,6%)
Weakness	61 (78,2%)
Depression	50 (63,3%)
Anxiety	54 (70,1%)
Somnolence	32 (41%)
Anorexia	40 (50,6%)
Insomnioa	33 (41,8%)

% patients NECPAL+ at HUB symptoms ≥ 4/10 (ENV)

Dirección científica

CÀT DE PAL *Original Article*

Utility of the NECPAL CCOMS-ICO© 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

Xavier Gómez-Batiste[1,2], Marisa Martínez-Muñoz[1,2], Carles Blay[2,3], Jordi Amblàs[2,4], Laura Vila[2,5], Xavier Costa[2,5], Joan Espaulella[2,4], Alicia Villanueva[6], Ramon Oller[7], Joan Carles Martori[7] and Carles Constante[8]

PALLIATIVE MEDICINE

Palliative Medicine
1–10

DOI: 10.1177/0269216316676647
pmj.sagepub.com
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Obra Social "la Caixa"

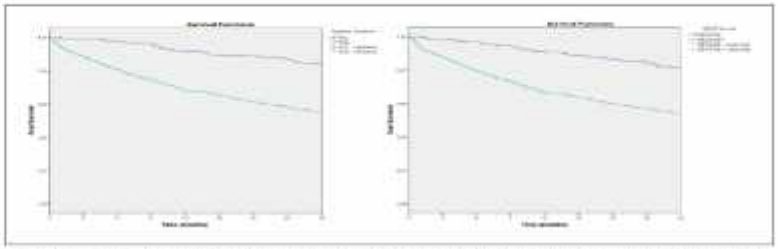


Figure 1. Survival at 24 months for both instruments: on the left, a comparison between SQ+ and SQ- patients (log-rank test: chi-square 58.007, p-value = 0.000); on the right, a comparison between NECPAL+ and NECPAL- patients (log-rank test: chi-square 44.717, p-value = 0.000).

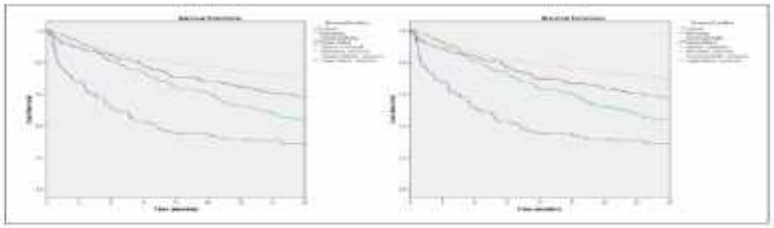


Figure 2. Comparison of survival by disease/condition: on the left, SQ+ patients (log-rank test: chi-square 90.974, p-value = 0.000); on the right, NECPAL+ patients (log-rank test: chi-square 82.350, p-value = 0.000).

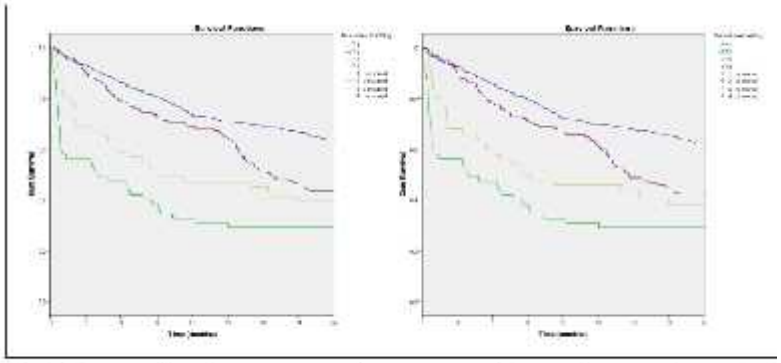


Figure 3. Comparison of survival by recruitment setting (1 = primary care services, 3 = intermediate care centre, 3 = acute hospital and 4 = nursing home): on the left, SQ+ patients (log-rank test: chi-square 76.648, p-value = 0.000); on the right, NECPAL+ patients (log-rank test: chi-square 70.070, p-value = 0.000).

What is already known about the to

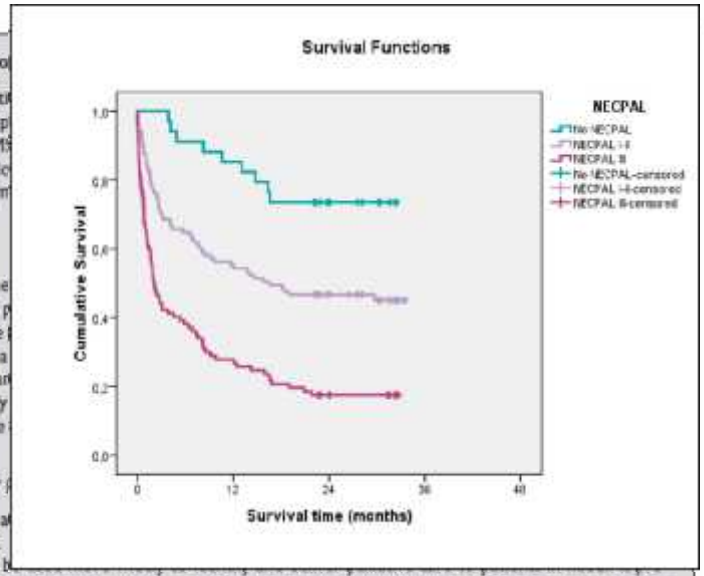
- Prediction of mortality can be esti
- The Surprise Question (SQ) is a p
- The SQ and the NECPAL CCOMS likely in need of palliative care. Ho with a need for evidence to inform

What this paper adds?

- The NECPAL tool, which combine care with a reasonable degree of p
- Despite a high proportion of false abilities which are important for a is needed to improve specificity ar
- The NECPAL tool allows to verify tion which has been proven to be

Implications for practice, theory or

- The NECPAL tool can be used in a for early palliative care at 2 years.
- This tool, or similar ones, should b sent, this population is under-identified and untended.
- Wider implementation of this tool would better establish the burden of disease and would be a first step in improving the quality of palliative care in the population and in all settings of care.

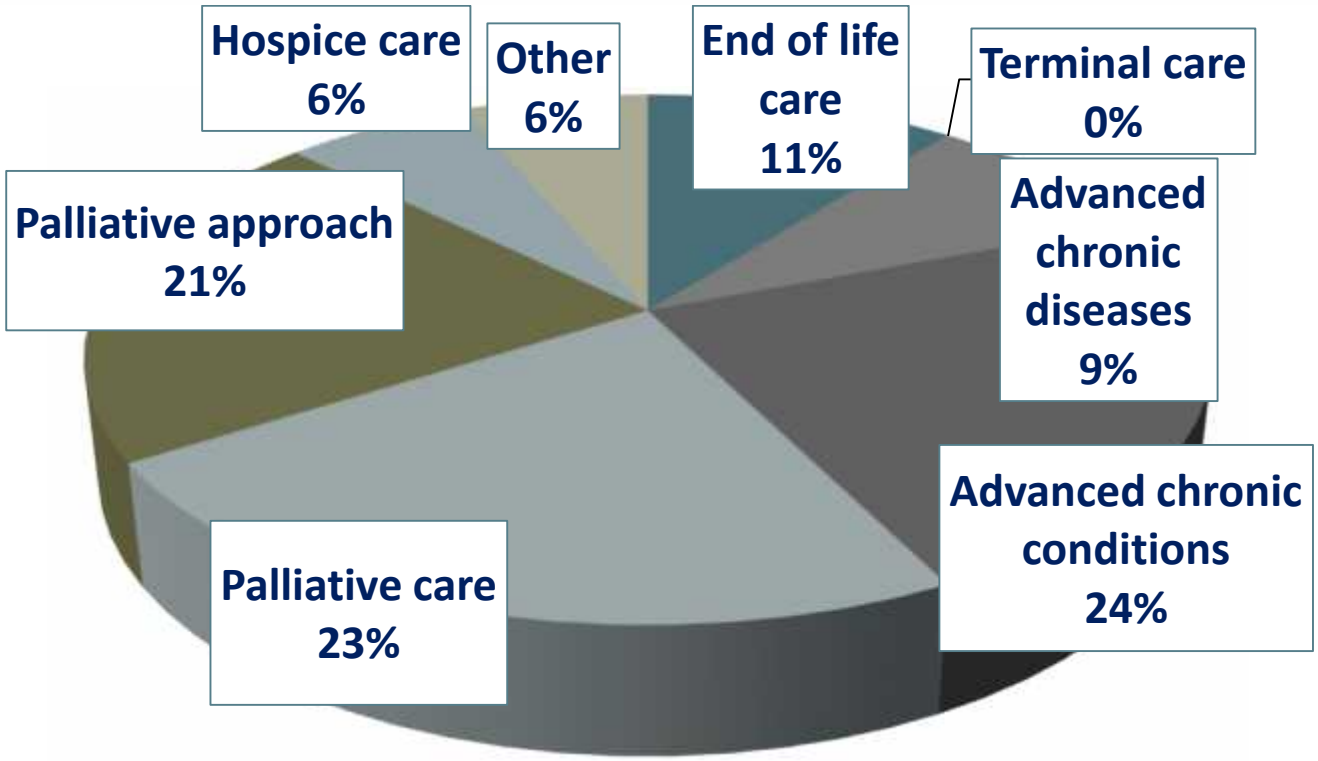


Atención i

Median survival: 2 years from identification

con enfermedades avanzadas

Dirección científica



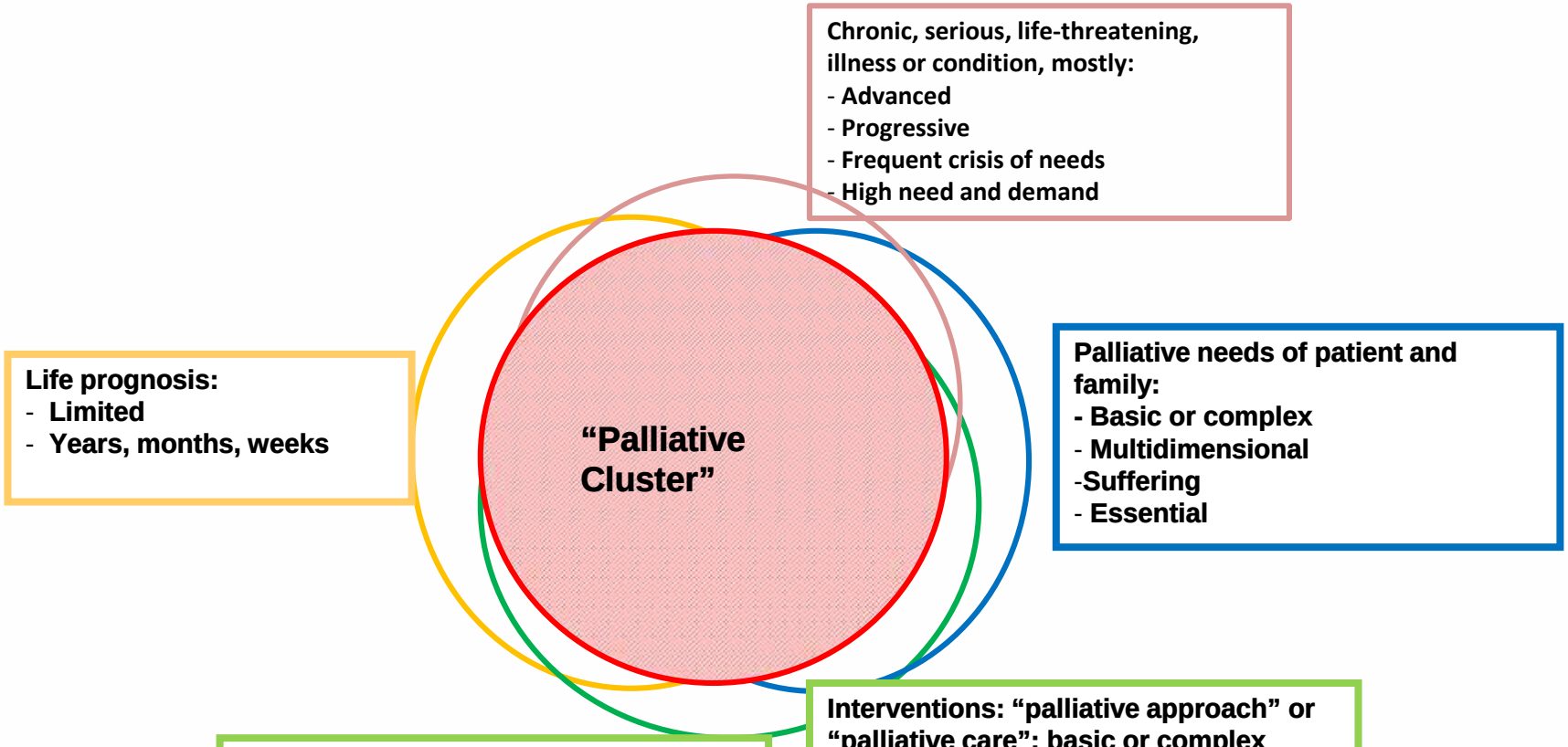
Proposed Terms

Atención integral a personas con enfermedades avanzadas

Gomez-Batiste, Connor, Murray et al, 2017

Obra Social "la Caixa"

Componentes definición del target

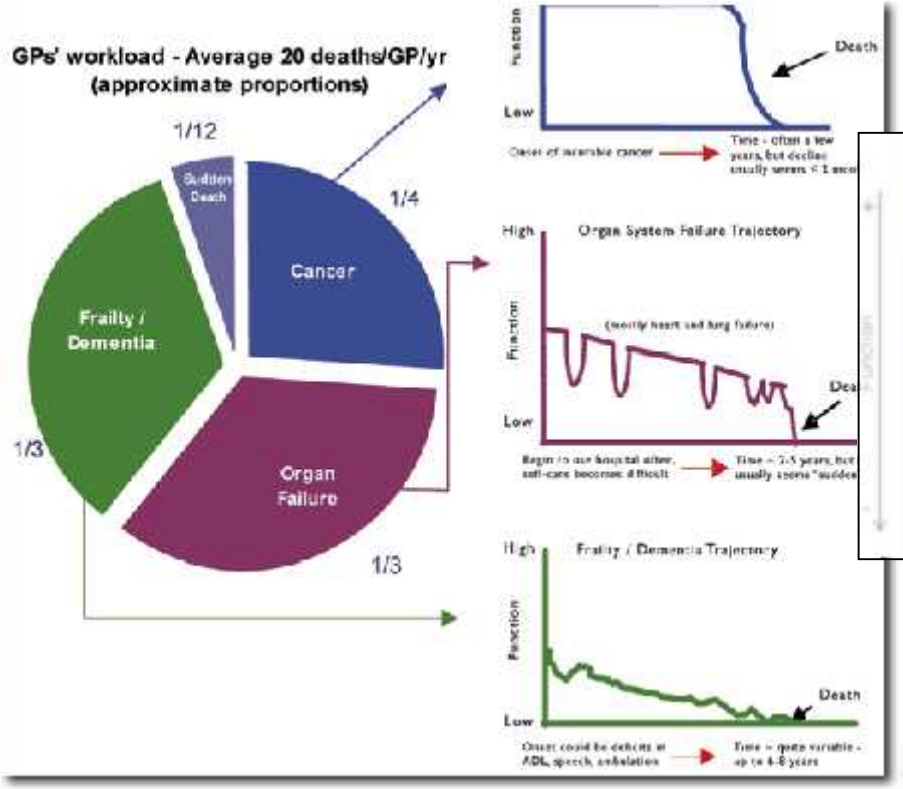


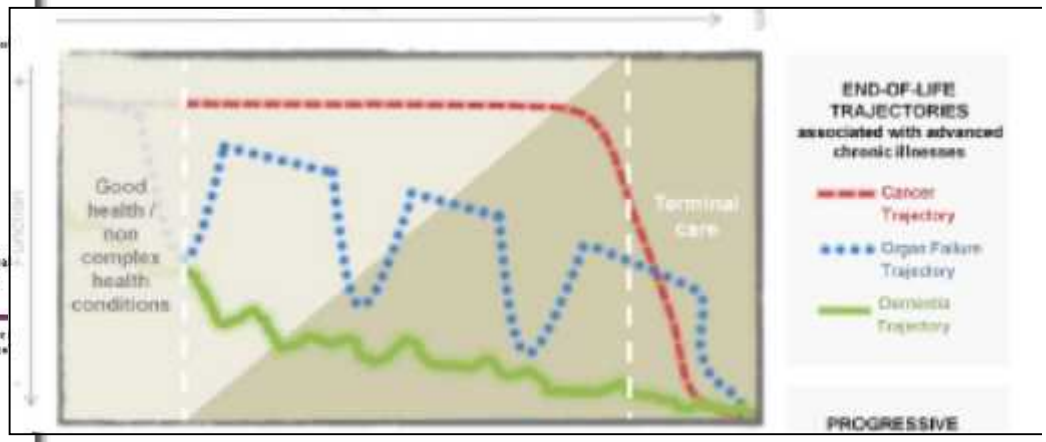
Open Access Research

BMJ Open Identifying patients with advanced chronic conditions for a progressive palliative care approach: a cross-sectional 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 Martínez-Muñoz,[5] N Molist,[1,2] C Blay,[2,6] X Gómez-Batiste[2,7]

Obra Social "la Caixa"





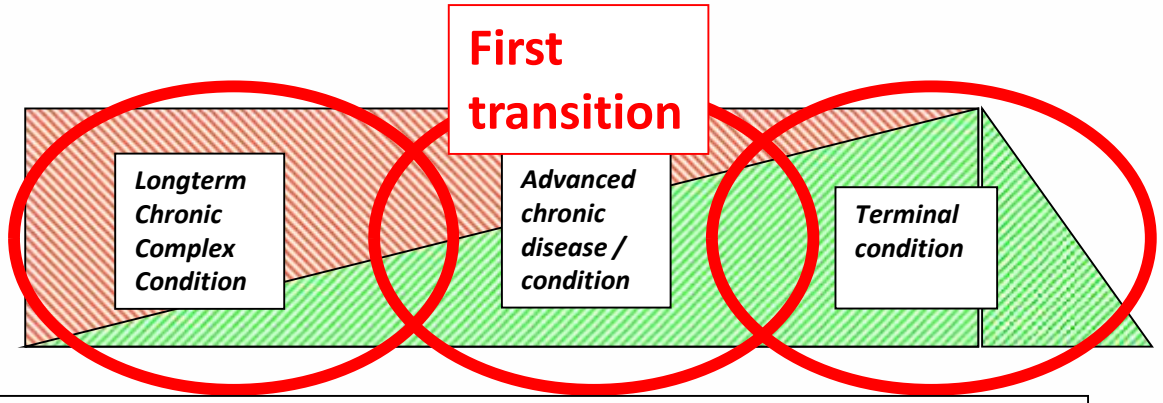
Atención integral a personas con enfermedades avanzadas

Dirección científica

CÀTEDRA DE CURES PAL·LIATIVES

ICO Institut Català d'Oncologia

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



"Complex Chronic condition"
- **Disease-centered**
- **Survival, sec/tert prevention**
- **Build confidence**
- **Shared Decission-making**
- **Common language**
- **Advance directives**
- **Disease / Care management**
- **RHB**
- **Primary & secondary specialist care**

1st transition: "Advanced chronic condition"
- **Condition & QoL**
- **Multidimensional assessment**
- **Advance Care Planning**
- **Values & Preferences &Scenarios**
- **Crisis prevention**
- **Gradual palliative care approach**
- **Gradual essential needs management & Integrated care Primary care & secondary & occasional palliative care**

"End of life or terminal"
- **QoL**
- **Review & Adjust frequently**
- **Essential needs**
- **Sedation**
- **Elarging / shortening life**
- **Nutrition/hydration**
- **Bereavement**
- **Primary & palliative care (if needed) shared care**

"Palliative paradigms"

Paradigm sXX

- Mae
- 62 years
- Careed by wife
- Lung Cáncer
- Admitted in a Pall Care unit
- Will die in 7 weeks
- "Terminal patient"

Paradigm sXXI

- Female
- 82 years
- Widow, looked after by daughter
- Multimorbidity, dementia, dependency
- Home or nursing home
- Primary care services
- Will live for 24 months
- Advanced chronic patient
- Need of a palliative approach"

People with palliative care needs
- Cause 75% mortality
- Are 1.5% of population
- Are present in all Settings of care
- Are easily identificable

Is a systemic challenge

Need a systemic approach based in a population perspective and a community approach

RECOMENDACIONES
PARA LA ATENCIÓN INTEGRAL E INTEGRADA DE PERSONAS CON ENFERMEDADES O CONDICIONES CRÓNICAS AVANZADAS Y PRONÓSTICO DE VIDA LIMITADO EN SERVICIOS DE SALUD Y SOCIALES:
NECPAL CCOMS-ICO© 3.1 (2017)

Equipo investigador:

Autor e investigador principal: Xavier Gómez-Batiste
Equipo de colaboración: Jordi Amblàs, Xavi Costa, Joan Espaulella, Cristina Lasmarías, Sara Ela, Elba Beas, Bárbara Domínguez, Sarah Mir

CÀTEDRA DE CURES PAL·LIATIVES

UVIC UNIVERSITAT DE VIC UNIVERSITAT CENTRAL DE CATALUNYA

ICO Institut Català d'Oncologia

Con el soporte de:

Generalitat de Catalunya
Programa de prevenció i atenció a la cronicitat

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

UVIC UNIVERSITAT DE VIC UNIVERSITAT CENTRAL DE CATALUNYA

ICO Institut Català d'Oncologia

NECPAL 3.1 2017

INSTRUMENTO NECPAL-CCOMS-ICO© VERSIÓN 3.1 2017

PACIENTE: _____ HC: _____

FECHA: ___/___/___ SERVICIO: _____

RESPONSABLE(S): _____

Pregunta sorpresa (a/entre profesionales)	¿Le sorprendería que este paciente muriese a lo largo del próximo año?		☐ Sí (-) ☑ No (+)
"Demanda" o "Necesidad"	- Demanda: ¿Ha habido alguna expresión implícita o explícita de limitación de esfuerzo terapéutico o demanda de atención paliativa de paciente, familia, o miembros del equipo?		☐ Sí ☑ No
	- Necesidad: identificada por profesionales miembros del equipo		☐ Sí ☑ No
Indicadores clínicos generales de progresión: - Los últimos 6 meses - No relacionado con proceso intercurrente reciente/reversible	- Declive nutricional	• Pérdida Peso > 10%	☐ Sí ☑ No
	- Declive funcional	• Deterioro Karnofsky o Barthel > 30% • Pérdida de > 2 ABVDs	☐ Sí ☑ No
	- Declive cognitivo	• Pérdida > 5 minimental o > 3 Pfeiffer	☐ Sí ☑ No
Dependencia severa	- Karnofsky <50 o Barthel <20	• Datos clínicos por anamnesis	☐ Sí ☑ No
Síndromes geriátricos	- Caídas - Úlceras por presión - Disfagia - Delirium - Infecciones a repetición	• Datos clínicos anamnesis ≥ 2 síndromes geriátricos (recurrentes o persistentes)	☐ Sí ☑ No
Síntomas persistentes	Dolor, debilidad, anorexia, disnea, digestivos...	• Checklist síntomas (ESAS) ≥ 2 síntomas persistentes o refractarios	☐ Sí ☑ No
Aspectos psicosociales	Distrés y/o Trastorno adaptativo severo	• Detección de Malestar Emocional (DME) > 9	☐ Sí ☑ No
	Vulnerabilidad social severa	• Valoración social y familiar	☐ Sí ☑ No
Multimorbilidad	> 2 enfermedades o condiciones crónicas avanzadas (de la lista de indicadores específicos)		☐ Sí ☑ No
Uso de recursos	Valoración de la demanda o intensidad de intervenciones	• > 2 ingresos urgentes o no planificados en los últimos 6 meses • Aumento demanda o intensidad de intervenciones (atdom, intervenciones enfermería, etc)	☐ Sí ☑ No
Indicadores específicos de severidad/ progresión de la enfermedad	Cáncer, MPOC, ICC, i Hepática, i Renal, AVC, Demencia, Neurodegenerativas, SIDA, d'altres malalties avançades	• Ver anexo 1	☐ Sí ☑ No

Clasificación:		
Pregunta Sorpresa (PS)	PS + (No me Sorprendería)	√
	PS - (Me Sorprendería)	
Parámetros NECPAL	NECPAL + (de 1+ a 13+)	
	NECPAL - (Ningún parámetro)	√

Codificación y registro

Proponer codificación como Paciente con Cronicidad Avanzada (PCA)

Obra Social "la Caixa"

NECPAL 3.1 2017

Journal of Palliative Care
2018, Vol. XX(X) 1-5

DOI: 10.1177/0825859718788933
journals.sagepub.com/home/pal
SAGE

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

Xavier Gómez-Batiste, MD, PhD[1], Carles Blay, MD, PhD[1,2], Marc Antoni Broggi, MD, PhD[3], Cristina Lasmarias, BA, RN, MSc[1], Laura Vila, RN[1,4], Jordi Amblàs, MD, PhD[1,5], Joan Espaulella, MD, PhD[1,5], Xavier Costa, MD, PhD[1,4], Marisa Martínez-Muñoz, RN, PhD[1], Bernabé Robles, MD[6], Salvador Quintana, MD, PhD[7], Joan Bertran, MD, PhD[8], Francesc Torralba, PhD[9], Carmen Benito, MD[10], Nuria Terribas, BL[11], Josep Maria Busquets, MD[3], and Carles Constante, MD[12]

Ethical approach: Benefits & risks

Obra Social "la Caixa"

- 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

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

Journal of Palliative Care
2018, Vol. XX(X) 1-5
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DOI: 10.1177/0825859718788933
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SAGE

Xavier Gómez-Batiste, MD, PhD[1], Carles Blay, MD, PhD[1,2],
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X Gómez-Batiste et al, J of Palliat Care 2018

Dirección científica

CÀTEDRA DE CURES PAL·LIATIVES

ICO Institut Català d'Oncologia

Obra Social "la Caixa"

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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Niveles:
- **Individual paciente**
- **Servicio**
- **Territorio**

Atención integral a personas con enfermedades avanzadas

Table 2

10 Actions for Comprehensive Care of the Identified Patients in Services

Action	Method	Comment/terms
1. Multidimensional assessment	Use validated tools	- Suffering/well-being/adjustment - Psychosocial and functional - Assessment of careers burden, needs, and demands
2. Explore worries, fears, values, and preferences of patients and families	Start: Advance care planning - Shared decision making - Start discussion about the future	- Explore the emotional experience of the patient (and its evolution in time)[33] - Consider the illness narratives and life stories told by the patient[34]
3. Review state of diseases and conditions	Review disease: - Stage and prognosis - Aims and recommendations to prevent or respond to crisis or possible complications	- Do not forget nonspecific items and general indicators of functional decline in frail elderly[35] - Given that end of life is a trajectory (dynamic) and not a situation (static), consider the temporal evolution of these general indicators - Identify the current palliative care phase[36]
4. Review treatment	- Update aims - Adequacy - De-prescribing, if needed	- Discussing goals of care (short/mid/long term) with the patients may be a 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: - Assessment - Plan	- Define role in conventional followup, shared care, emergencies, and continuing care - Define referent professional (s)
7. Define, agree, and start a Comprehensive Multidimensional Therapeutic Plan	- Respecting patients' preferences - Addressing all the needs identified - Use the square of care model - Involving all team(s)	Including: - Needs assessment - Aims - Decisions
8. Organize care with all services involved, including the specialized palliative care services	- Case management - Shared care and decision making - Therapeutic pathways across settings - Look at care and setting transitions - Therapeutic conciliation between services	- Contact palliative care services for care of complex needs - Encourage continuing collaboration between services and develop partnership agreements - Involve patients and family carers patients when designing programs
9. Register and share key information with all involved services	- In clinical charts - In shared information - In anticipatory care planning booklet - In reports of multidisciplinary team meetings	- State of diseases, symptoms, emotional adjustment, family support - Patients' priorities and preferences (goals of care) - Possible crisis (out of hours handover forms, anticipatory prescribing) - Decisions made (e.g., referral to specialist palliative care service, treatment withdrawal/withholding) - Recommendations for care in all settings - Record, communicate, and coordinate the care plan across all settings
10. Evaluate/monitor outcomes	- Frequent review and update - After death, clinical audit	- Consider NICE quality standard[37] - Design research and generate evidence

Care of patients identified

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

Action	Methods
1. Establish and document a formal policy for palliative approach	- Evidence based - Involve patients in the design and implementation of the policy
2. Determine the prevalence and identify patients in need	- Stratify the population at need/risk (complex and advanced chronic patients)
3. Establish protocols, registers, and tools to assess patients' needs and respond to most common situations	- Evidence based
4. Train professionals and insert palliative care training and review in the conventional training process (sessions, etc.)	- Basic and intermediate level - Carry out process evaluation during programme's implementation[3,6]
5. Identify the primary carers of patients and give support and care, including bereavement	- Validated tools - Assess needs and demands - Increase access - Give education and support - Plan bereavement
6. Increase team approach	- Joint interdisciplinary 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)	- Trained referent professionals - Specific times in outpatients - Specific devoted areas in inpatients
8. Increase the offer and intensity of care for identified persons focused in quality of life	- Improve access and equity in the provision of palliative care - Increase offer of home care (if, primary care services)
9. [illegible] criteria intervention and access to palliative care specialized services and all services in the area	- Establish and/or update the role of palliative care specialized services - Establish partnerships between services - Define clinical care pathways - Clinical information available for all settings
10. Address the ethical challenges of early identification and involve society	- 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)

Actions for Palliative approach in conventional services

Palliative Care Services need to adapt to the new epidemiology

- From the
- Passive
- a bit narcissist
- Centered in service perspective

- To a
- Proactive
- Open
- Flexible
- Population-based
- Systemic

- **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 tra**
- **Pr**
  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

Actions in Catalonia 2013+

- Creation of the PPAC Program and linked to PC Program
- Definition of “Advanced” (MACA) and “Complex” (PCC) Chronic patients
- Focus in Primary Care: incentivation and training
- 25-29.000 Patients MACA identified / year with the NECPAL tool in PCS
- Creation of “Reference” and “liaison” Nurses
- Psychosocial La Caixa teams
- Support teams to nursing homes
- General basic & ACP Training: 5.000 primary care professionals
- Review standards and indicators

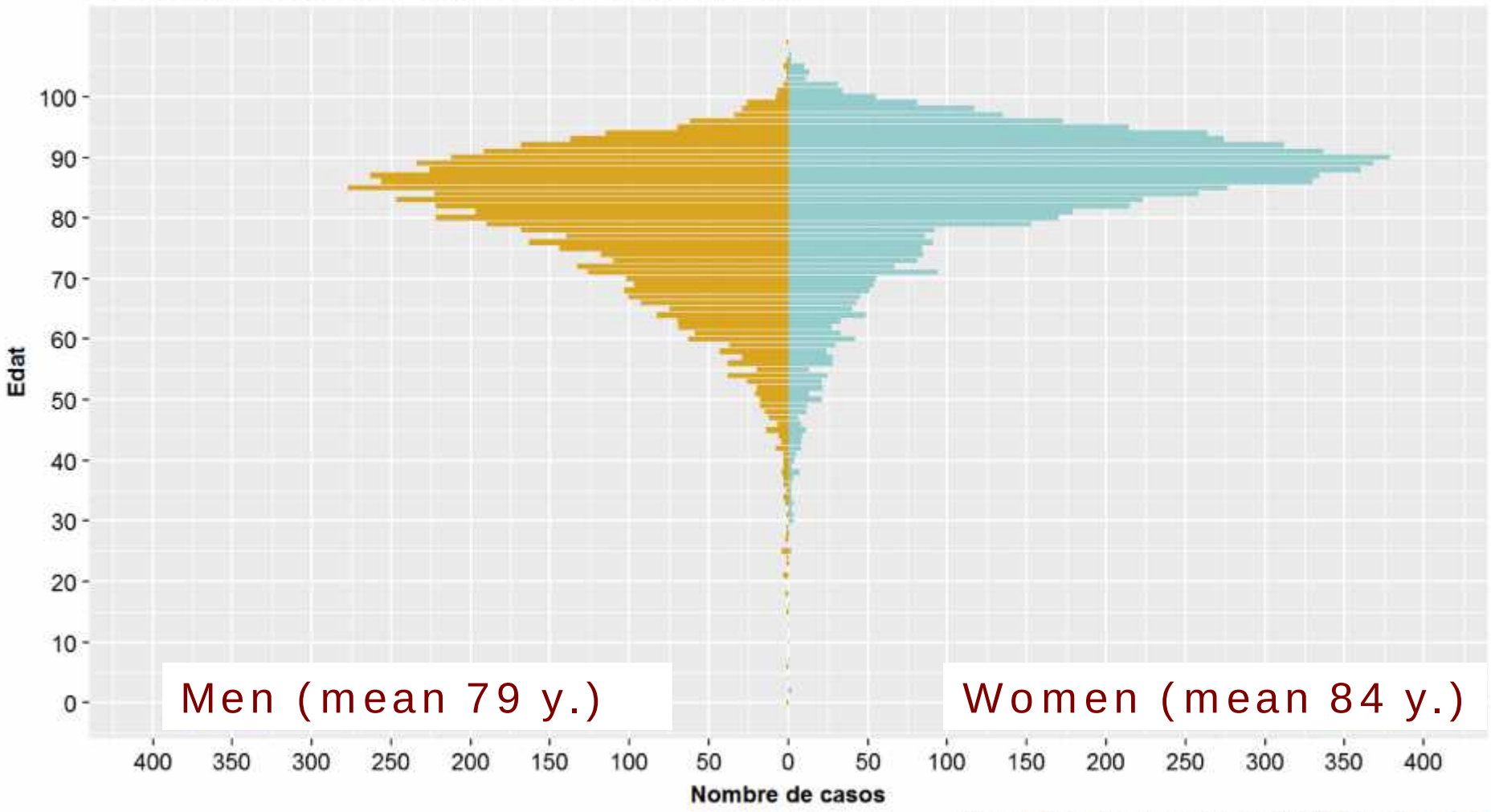
Results MACA / Terminal code identification Program DoH 2016/17 (*)

Type	Number	Coverage %
"Advanced" (MACA) (1)	26.716	47 / 112 = 42%
"Terminal" (V66 Z51.5) (2)	20.102 (**)	
"Complex" (PCC)	160.905	170 / 340 = 50%

(1) By Primary care services
(2) By Palliative Care services
(*) Merging process
(**) 2016
Source: https://msiq.catsalut.cat/index.html

“Advanced chronic disease” (MACA) profile

Who are MACA patients?



Font: Base de dades de morbiditat poblacional

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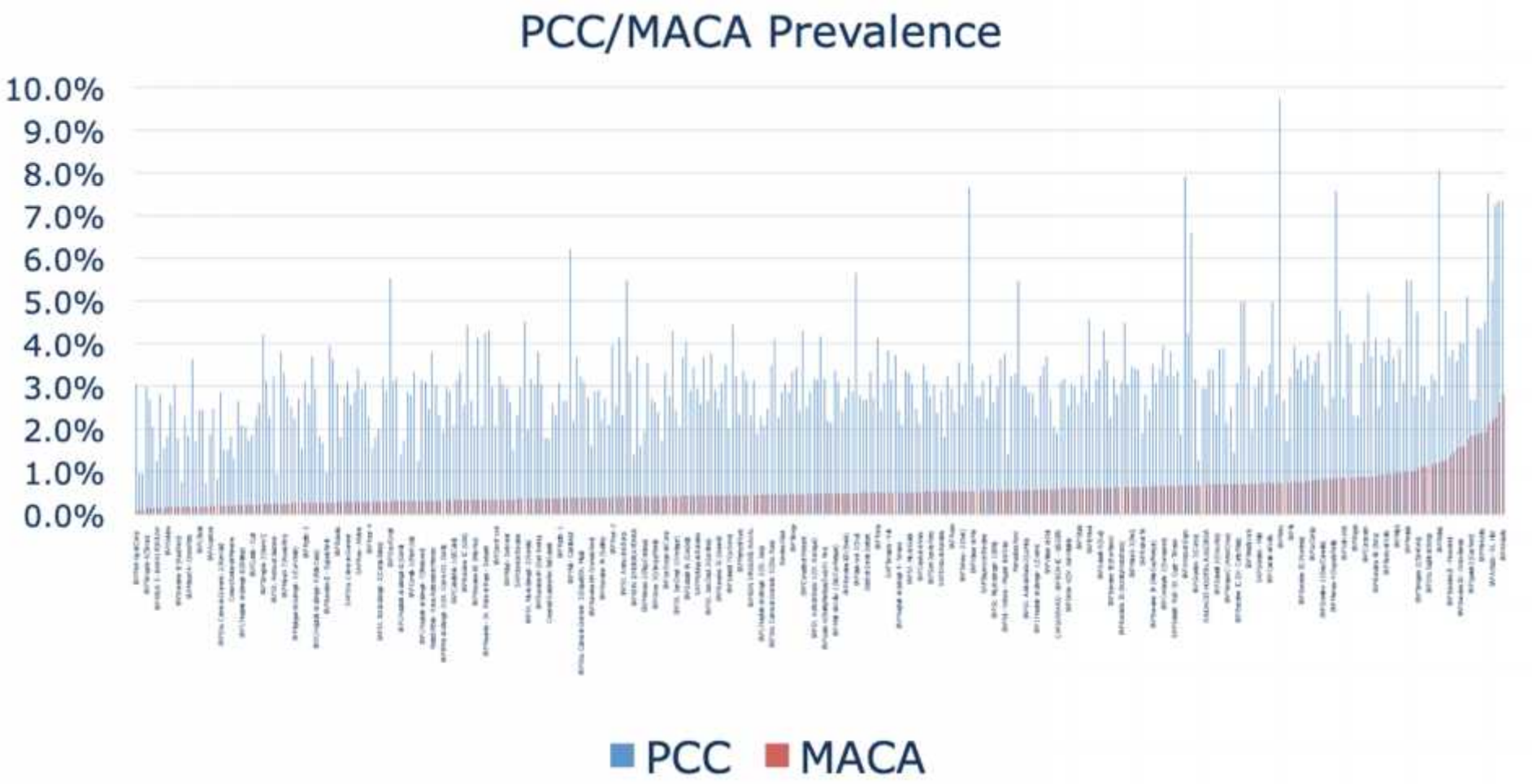
Source: Catsalut, 2017

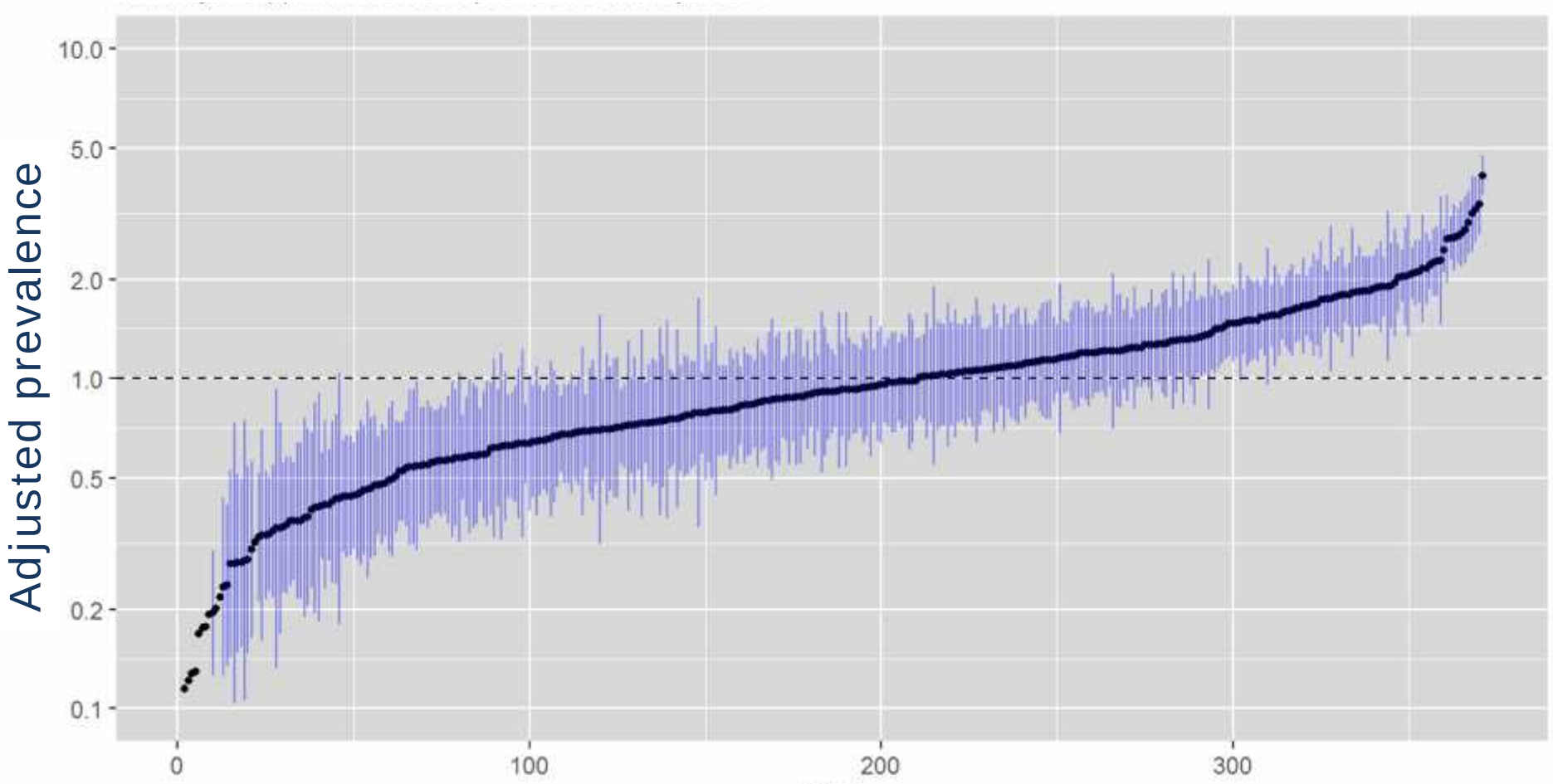
“PCC” and “MACA” prevalence

Initial Health Plan target “labelling” available since February 2013): 25.000 complex chronic patients should be identified by 2015
In December 2017 over 200.000 patients included
Almost 3,5% of general adult population (3% PCC / 0,5% MACA)



“Advanced chronic disease” (MACA) profile

MACA identification variability among 369 Primary Care centers



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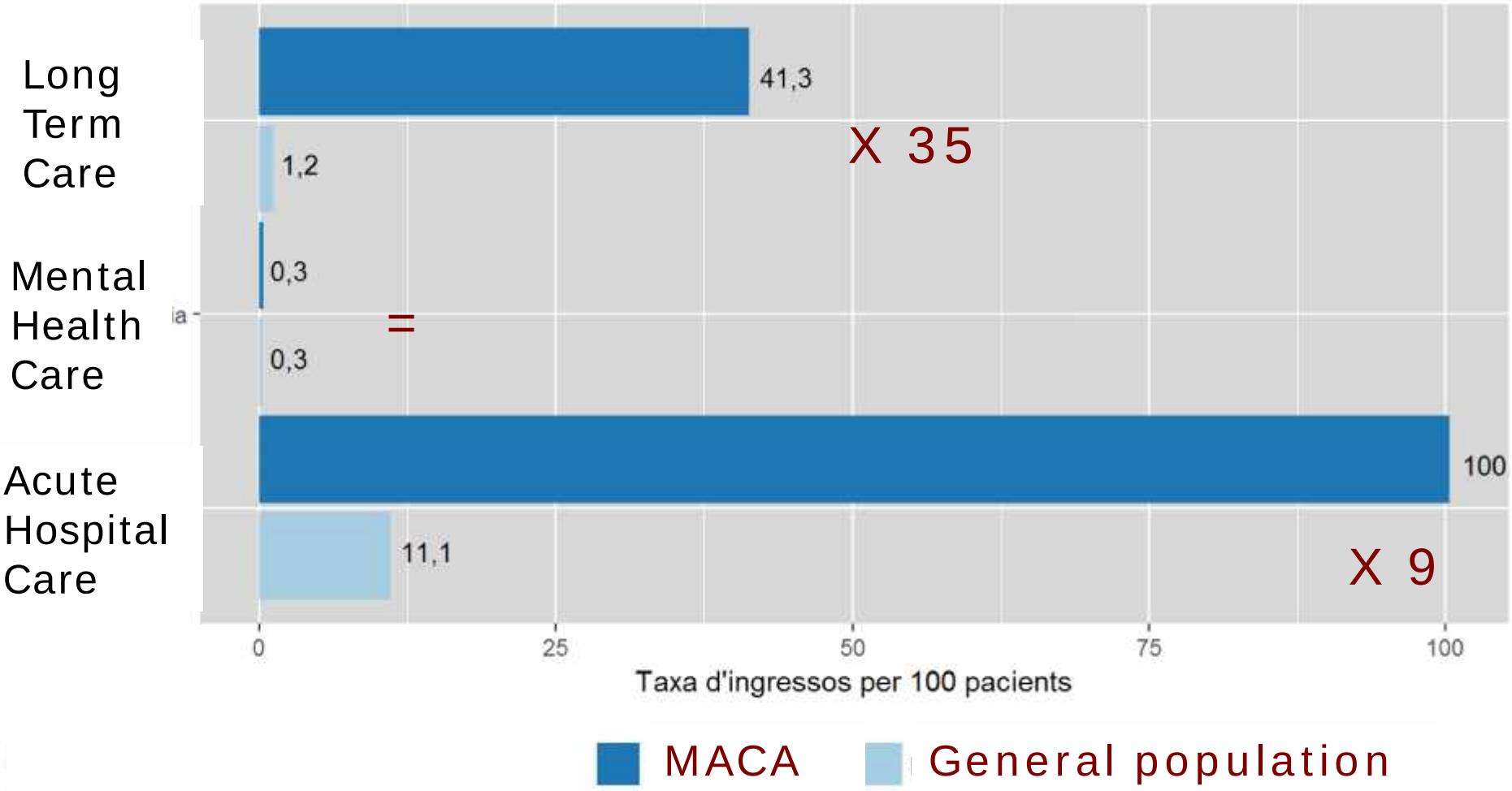
Font: Base de dades de morbiditat poblacional

Source: Catsalut, 2017

“Advanced chronic disease” (MACA) profile

MACA services utilization



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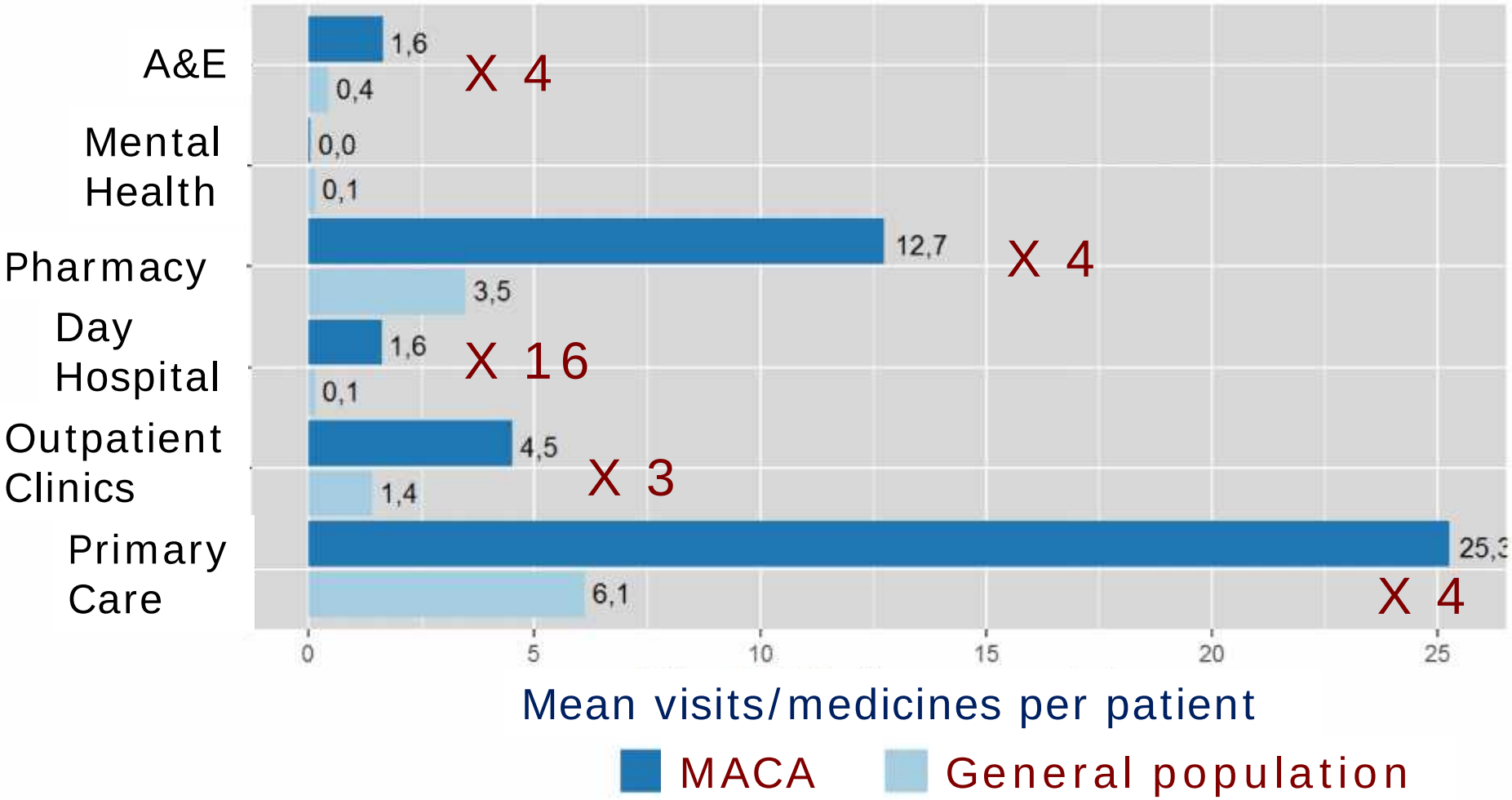
Source: Catsalut, 2017

“Advanced chronic disease” (MACA) profile

MACA services utilization



Font: Base de dades de morbiditat poblacional

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Source: Catsalut, 2017

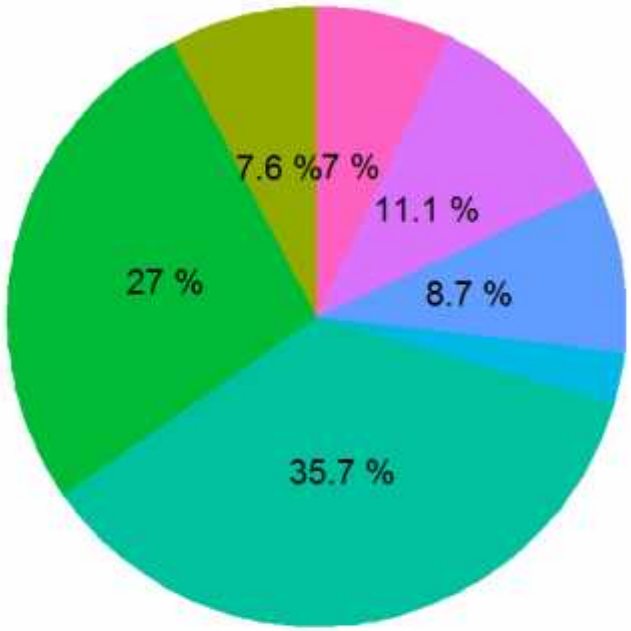
“Advanced chronic disease” (MACA) profile

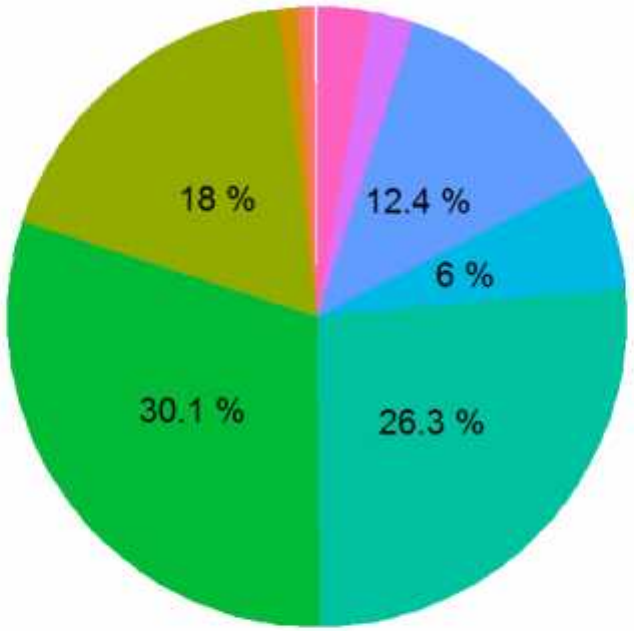
X 4

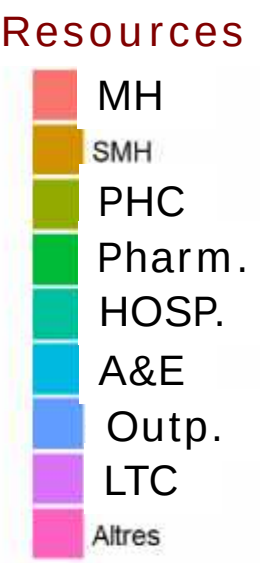
MACA cost compared to general population

MACA : 7095 € per person

General pop.: 969 € per person







Font: Base de dades de morbiditat poblacional

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Source: Catsalut, 2017

Dirección científica

CÀTEDRA DE CURES PAL·LIATIVES

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Obra Social "la Caixa"

CURRENT OPINION

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

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

Purpose of review
We describe conceptual innovations in palliative care epidemiology and the methods to identify patients in need of palliative care, in all settings.
In middle–high-income countries, more than 75% of the population will die from chronic progressive diseases. Around 1.2–1.4% of such populations suffer from chronic advanced conditions, with limited life expectancy. Clinical status deteriorates progressively with frequent crises of needs, high social impact, and high use of costly healthcare resources.

Recent findings
The innovative concept of patients with advanced chronic diseases and limited life prognosis has been addressed recently, and several methods to identify them have been developed.

Summary
The challenges are to promote early and shared interventions, extended to all patients in need, in all settings of the social care and healthcare systems; to design and develop Palliative Care Programmes with a Public Health perspective. The first action is to identify, using the appropriate tools early in the clinical evolution of the disease, all patients in need of palliative care in all settings of care, especially in primary care services, nursing homes, and healthcare services responsible for care provision for these patients; to promote appropriate care in patients with advanced diseases with prognosis of poor survival.

Keywords
advanced chronic patients, chronic care, planning, policy, stratification

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Obra Social "la Caixa"

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

Xavier Gómez-Batiste,[1,2] Marisa Martínez-Muñoz,[1,2] Carles Blay,[2,3] Jordi Amblàs,[4] Laura Vila,[3] Xavier Costa,[3] Alicia Villanueva,[5] Joan Espaulella,[4] Jose Espinosa,[1] Montserrat Figuerola,[1] Carles Constante[6]

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

con enfermedades avanzadas

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

OXFO

Qualitative Research

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.

Obra Social "la Caixa"

Dificultades:
-> en no cáncer
-Identificación pronóstica
-Comunicación con pacientes
-Coordinación con niveles

En Cataluña:
-Confusión Conceptos
-Estigma
-Qué hacer después?
-PDA?
-Recursos

Atención integral a personas con enfermedades avanzadas

The *La Caixa* Program Model of organisation:
42 "Psychosocial Teams" (2-3 Psy + 1 SW)
160.000 patients / 11 milion euros

Info

Compassive communities programs

Vic Ciutat Cuidadora

Dirección científica

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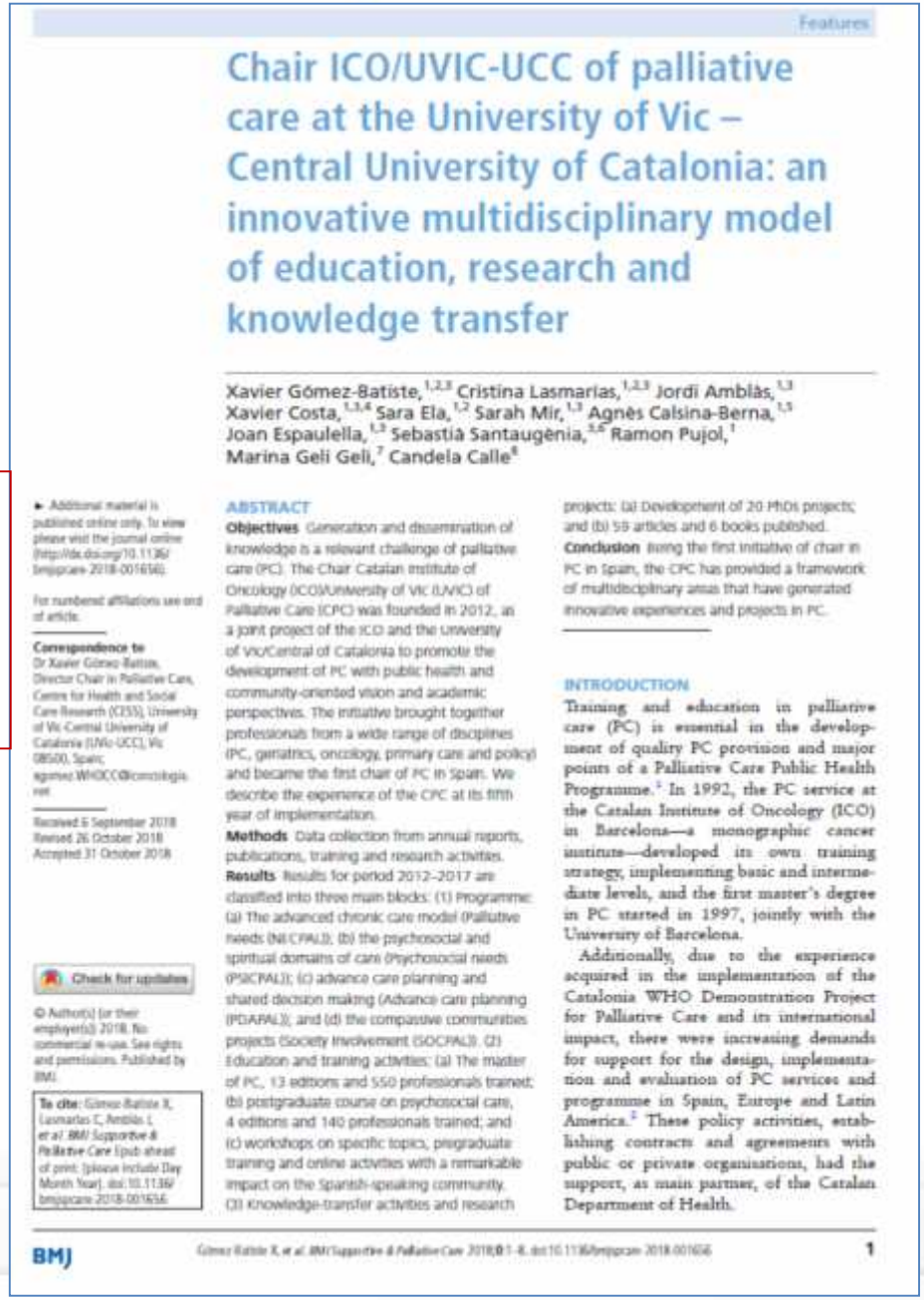
- **Chair of Palliative Care 2013: 1st in Spain**
- **Professorship Palliative Care: unique is Spain**



Features

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,[1,3] Joan Espaulella,[1,3] Sebastià Santaugènia,[3,5] Ramon Pujol,[1] Marina Geli Geli,[7] Candela Calle[8]

► Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/bmjspcare-2018-001656).

For numbered affiliations see end of article.

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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 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.[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.

Atención integral a personas con enfermedades avanzadas

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Obra Social "la Caixa"

Special Article

Community-Based Palliative Care: The Natural Evolution for Palliative Care Delivery in the U.S.

Arif H. Kamal, MD, David C. Currow, BMed, MPH, Christine S. Ritchie, MD, Janet Bull, MD, and Amy P. Abernethy, MD

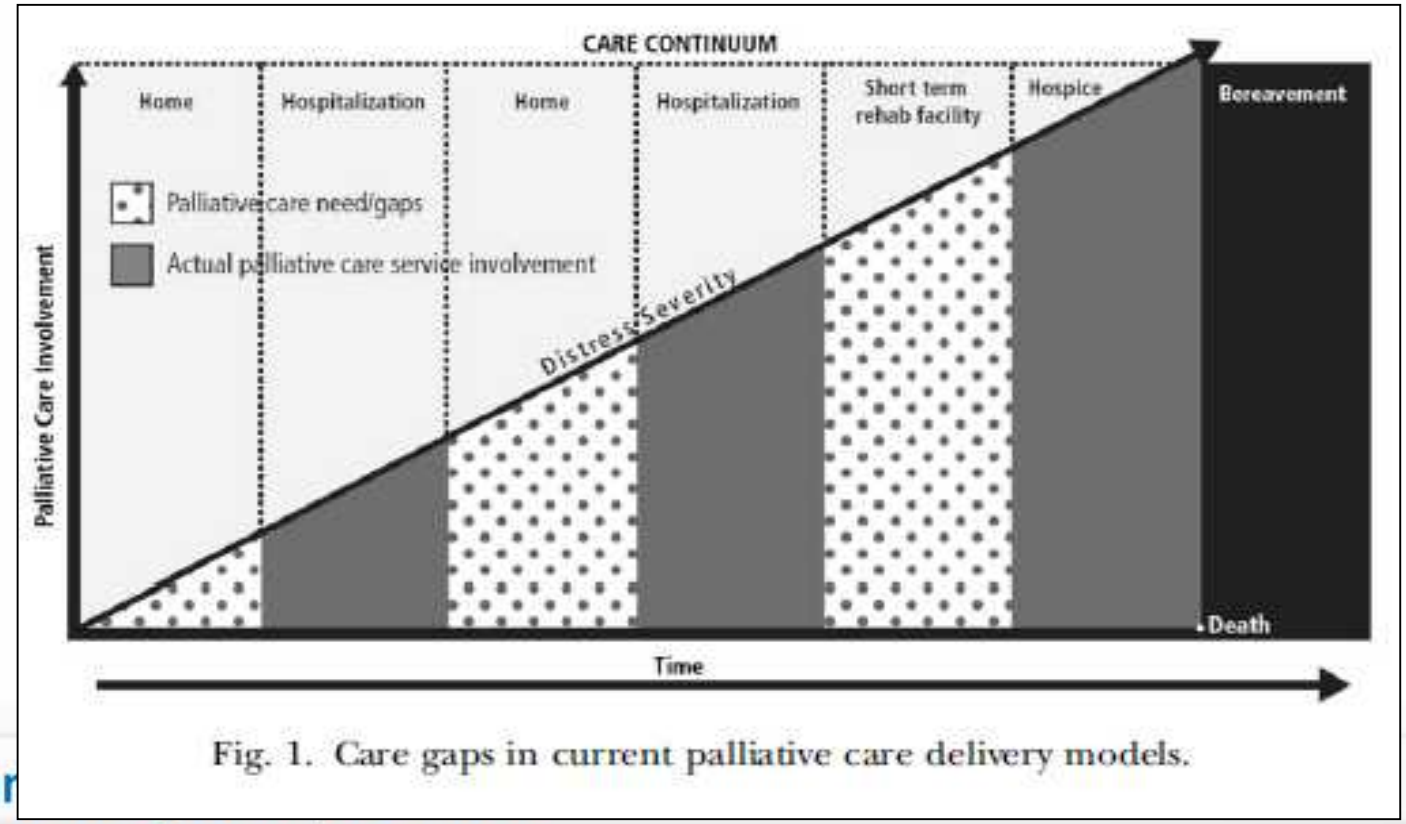

Fig. 1. Care gaps in current palliative care delivery models.

Atención

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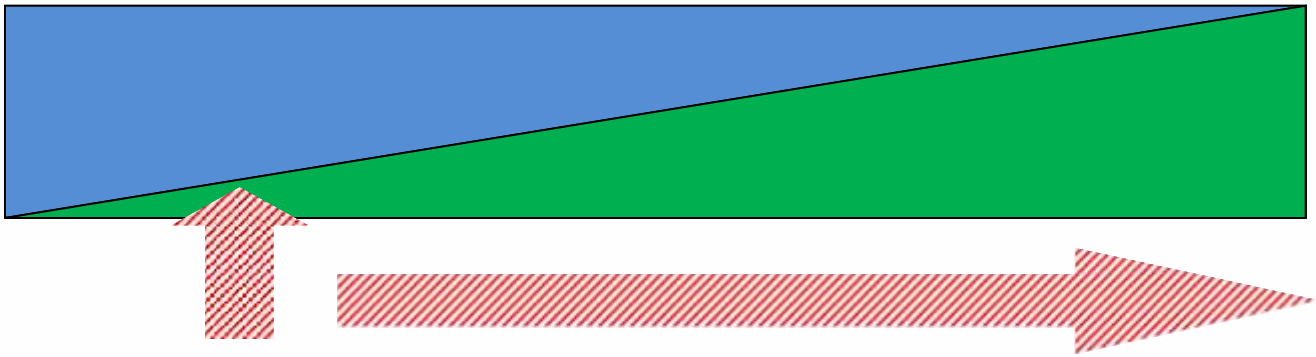

Palliative care XXI:

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**

Atención int
con enferme

Palliative Care as a human right
An excellent indicator of respect for human dignity

- **Systemic approach and challenge**
- **Population and community perspective**
- **Academic presence**
- **Social involvement**

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