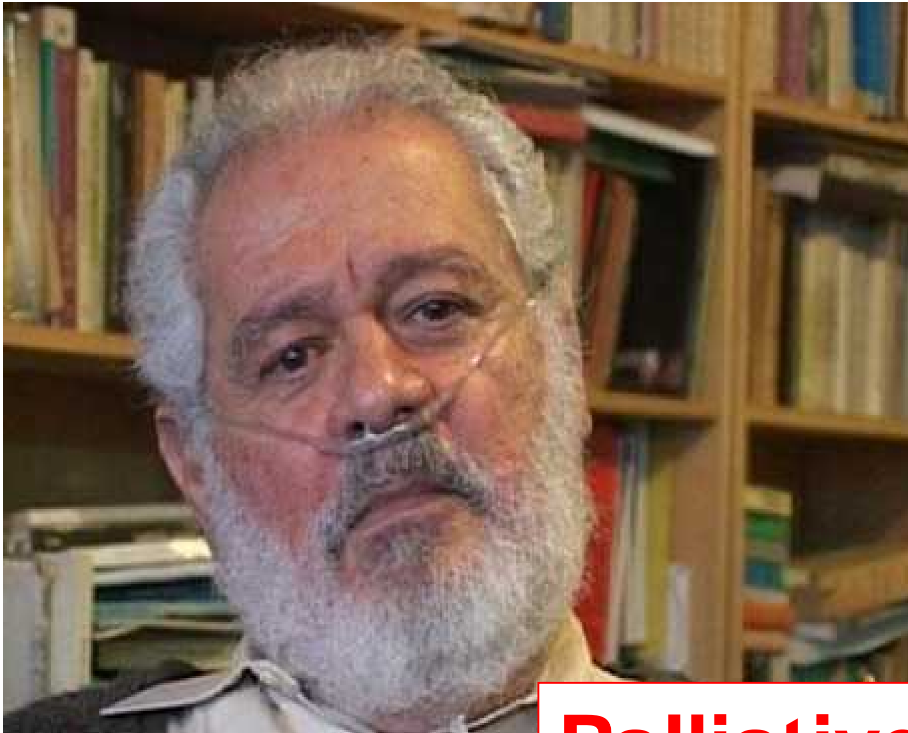


Palliative care for all

Dirección científica

CÀTEDRA DE CURES PAL·LIATIVES

ICO Institut Català d'Oncologia

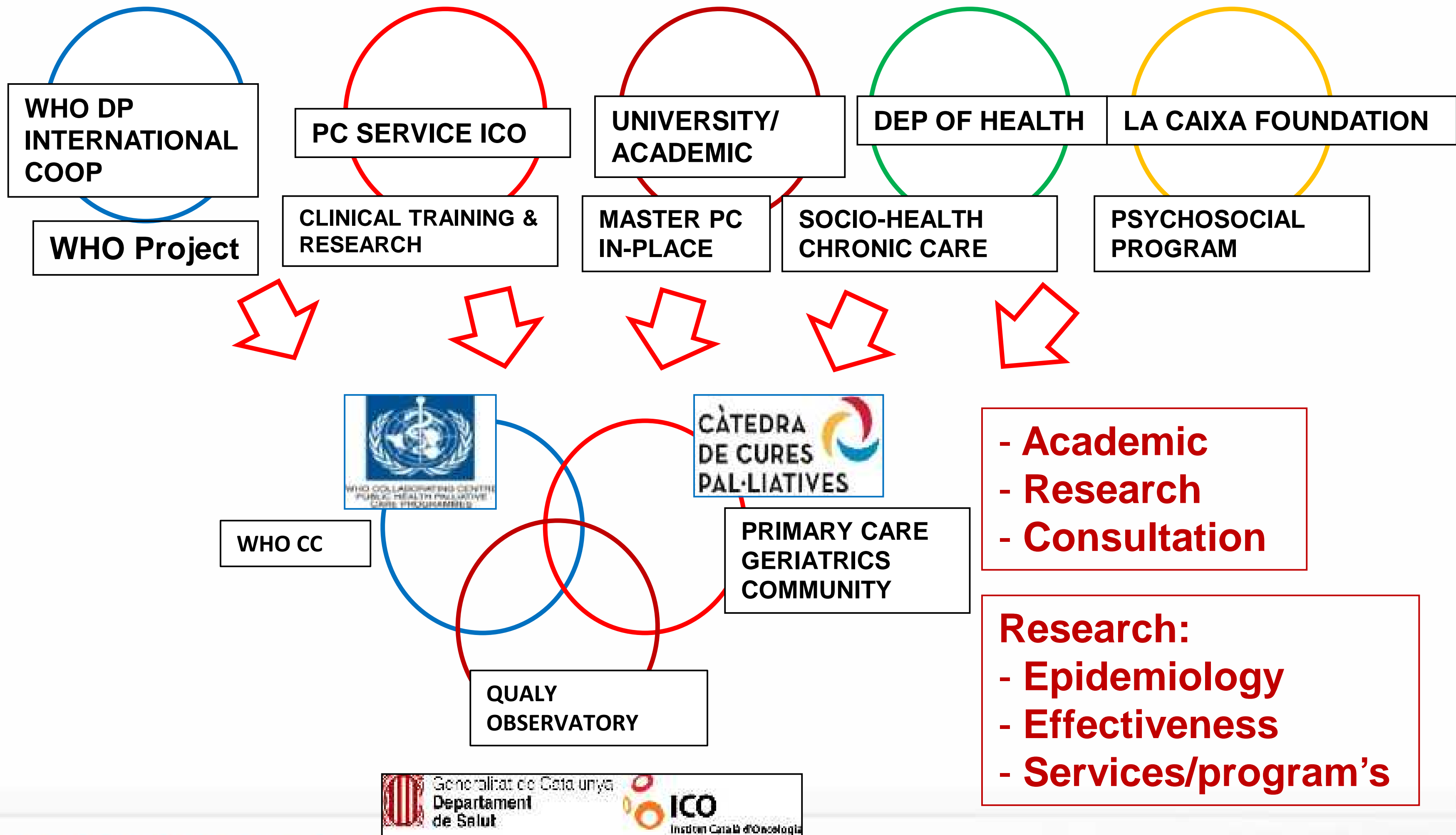
Obra Social

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

Obra Social "la Caixa"



- Academic
- Research
- Consultation

Research:
- Epidemiology
- Effectiveness
- Services/program's

Atención integral a personas con enfermedades avanzadas

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

Albert Einstein

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Models of Palliative Care provision

Dirección científica

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Key Points

Palliative care is the *comprehensive* and *integrated care* of *persons with advanced chronic conditions and limited life prognosis and their families.*

The target patients for a palliative care approach can be defined in terms of a cluster of symptoms or factors, including the presence of a chronic advanced disease or condition, a limited life prognosis, multidimensional needs, and the need for a comprehensive and integrated care.

Palliative care is the prevention and relief of suffering of any kind – physical, psychological, social, or spiritual – experienced by adults and children living with serious chronic, complex, or life-limiting health problems.

It is a person-centered accompanying of patients and their families throughout the illness course, including at the end of life that optimizes quality of life, promotes human development and well-being, and maximizes dignity.

Palliative care is a basic human right and an essential component of comprehensive and integrated care.

It should be practiced by health and social care providers of many kinds as well as by palliative care specialists and should be provided in any health care setting, including patients' homes.

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

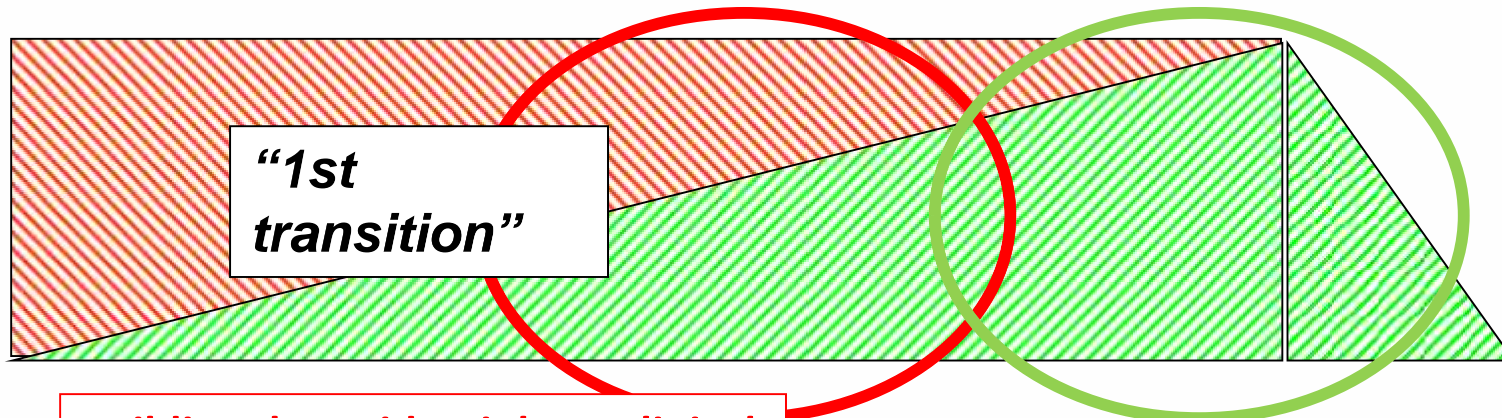
Gómez-Batiste X et al, Current Opinion in Supportive Palliative Care, 2012; Gómez-Batiste X et al, BMJ SPCare, 2012
Gómez-Batiste X et al, Medicina Clínica, 2013

Table 1 Conceptual transitions in palliative care in the twenty-first century. (From Gómez-Batiste et al. 2017c)

	From	Change to
Concepts	Terminal disease	Advanced progressive chronic disease
	Prognosis of weeks or months	Limited life prognosis
	Cancer	All chronic progressive illnesses and conditions
	Progressive course	Progressive course with frequent crises of needs and demands
	Mortality	Prevalence
Model of care and organization	Dichotomy curative or palliative	Synchronized, shared, combined care
	Specific or palliative treatment	Specific and palliative treatment as needed
	Prognosis as criteria for intervention of specialist services	Complexity/severity as criteria
	Late identification in specialist services	Early identification in community and all settings
	Rigid one-directional intervention	Flexible intervention
	Passive role of patients	Advance care planning
	Fragmented care	Integrated care
Perspective for planning	Palliative care services	Palliative care approach everywhere
	Specialist services	Actions in all settings of health care
	Institutional approach	Community approach
	Services' approach	Population approach
	Individual service	Systems approach

Palliative approach and care in the evolution of patients with advanced chronic conditions

Obra Social "la Caixa"



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

"Classical" Palliative care

- Living in the community or nursing homes
- Frailty, multimorbidity, organ failures, dementia, cancer
- Prognostic: limited life prognosis (median survival around 2 years)
- Progressive impairment and loss
- Complex clinical decission-making combining curative/palliative
- More focus on
  - Advance care planning
  - Essential needs (spirituality, dignity, relations, hope, autonomy)
  - Psychosocial aspects (emotional, loss, family)
  - Bereavement
- Organizational: all services involved

ial "la Caixa"

Original Article

Palliative Medicine
201X, Vol. XX(X) 1–10
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DOI: 10.1177/0269216313518266
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SAGE

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

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

Abstract
Background
Aim:
Design:
Setting/participants:
Results: condition: 31.3% advanced frailty, 23.4% dementia, 12.9% cancer (ratio of cancer/non-cancer = 1/7), 66.8% living at home and 19.7% in nursing home; only 15.5% previously identified as requiring palliative care; general clinical indicators of severity and progression present in 94% of cases.
Conclusion

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)

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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

Atención integral a p[...]

con enfermedades av[...]

Who are they?

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Definitions and models of palliative care provision

Atención integral a personas con enfermedades avanzadas

Dirección científica

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ICO Institut Català d'Oncologia

Obra Social "la Caixa"

Vol. 53 No. 3 March 2017 *Journal of Pain and Symptom Management* 509

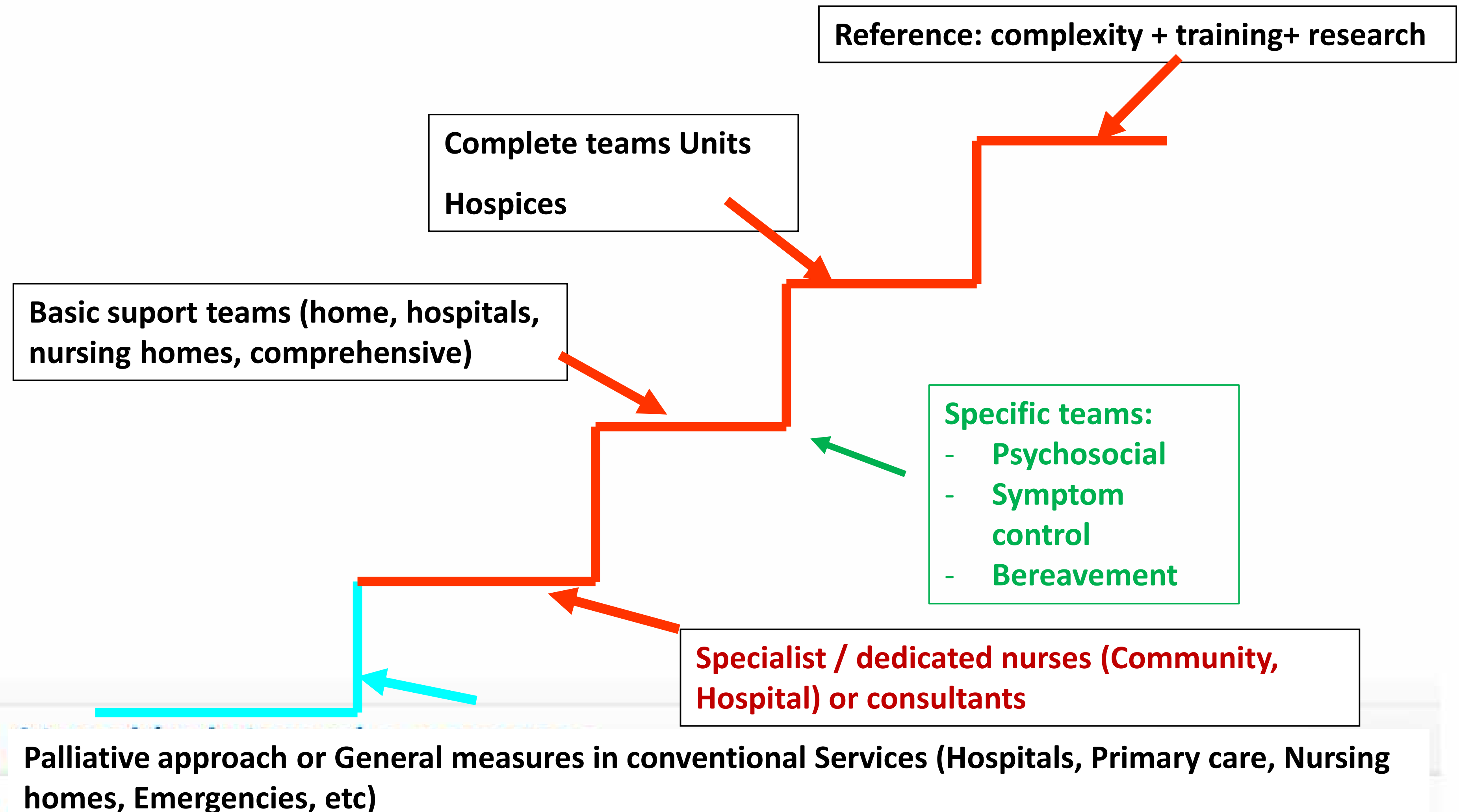
Special Article

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

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 of complexity of Palliative Care provision

Obra Social "la Caixa"



Key Points

- Definition: A specialized palliative care service is a healthcare resource devoted specifically to attending to the complex needs of patients with progressive, chronic life-limiting conditions and their families and to give support to other services. It is composed of a competent interdisciplinary team with advanced training, and clearly identified by patients and other services
- There are several types and models of PC services, including different activities: support teams, units, outpatient clinics, day hospitals, hospices, comprehensive networks.
- The key factors of to establish a new PC service include: leadership, training, institutional support, and the definition of the mission, values, aims, and internal and external consensus on the model of care and organization
- The most relevant aspect of the structure is a highly competent multidisciplinary team
- The most relevant criteria for success are the combination of good leadership, a competent team, and institutional support
- The process and activities of a specialized palliative care service are well described
- There are also transitional models of development
- Strategic planning and systematic quality evaluation and improvement are needed

Definition

A *specialized palliative care service*(SPCS) is a healthcare resource devoted specifically to attending to the complex needs of patients with progressive, chronic life-limiting conditions and their families and to give support to other [medical?] services. It is composed of *a* competent interdisciplinary team with advanced training, and clearly identified by patients and other services. There are several models of services ranging from basic support teams, which are interdisciplinary teams providing advice and support to other services at home, in hospital, or within comprehensive systems; inpatient units (beds in hospitals); outpatient clinics; and daycare hospitals. These services can be separate or combined, and can act as a comprehensive network if providing integrated care to all of the resources in a sector, or as a referral service if based in teaching institutions and offering complex interventions, training and research.

Wedefine *transitional measures* as the implementation of specific resources not fulfilling all the criteria of an interdisciplinary team, but devoted to attending to advanced and end-stage patients and their families in services other than the PC service (i.e., individual doctors or nurses providing consultation).

WHOCC Definitions: specialist palliative care services

"Palliative care specialist services are the specific resources devoted to care of advanced and terminal patients and their families. They include a well trained multidisciplonary team, who follows adequate care processes, and who are clearly identified by patients, families, and other services as referents. Moreover, such specialists hold an administrative identity, specific budget, and leadership. They include support teams, units, outpatient clinics, days care centers, hospices, and comprehensive networks"

WHOCC 2009

Structure

The most relevant element of the structure of a specialist palliative care service (SPC) is a competent inter-disciplinary team with advanced training and resources, which is able to respond to complex situations.

There are several levels of structure complexity depending on the structure and position in a sector (See below)

Types of specialized palliative care services

- **Individual specialized (or intermediate level):** individual professionals (usually doctors or nurses) with advanced training acting in other services or in the community. British Macmillan nurses are one example of specialized nurses acting in the community.
- **Outpatient clinics and day care:** can be based in any setting of the healthcare system, and are crucial for early palliative care intervention and shared flexible models of cooperation.
- **Mobile (or support) teams:** Interdisciplinary teams acting in support of other services. Can be based in hospitals, community/Home, or serve a district (acting in all or various settings).The basic mobile team will include a medical doctor and at least one nurse, complemented by others including psychosocial and spiritual professionals, therapy providers and community health workers. Volunteers enhance the mobile team.
- **Inpatient units** (called hospices in some locales with beds):can be based in any setting of the healthcare system (hospitals, intermediate care centres, long-term care, nursing homes):
  - Adapted to the organization of healthcare inpatient services;
  - Must respect privacy, and allow presence and access by families;
  - Units may specialize in caring for different types of patients (cancer, organ failure, geriatric, children, AIDS, dementia, etc., or mixed);
  - Can be based in acute, mid-term, or long-term settings or as individual stand-alone facilities;
  - Size and resources vary according to country and setting, regulations and standards;
  - Processes and model of care are common to all services;
  - Outputs and costs (mean age, length of stay, mortality) will be different according to types of patients.
- **Hospices**: organizations exclusively devoted to care of advanced/end-of-life care patients, and can include all types of activities including home and inpatient care. Generally owned by NGOs but can be part of any system. British hospices were the first organizations implementing modern palliative care in the 1960s, following the leadership and model of St Christopher's Hospice.
- **Comprehensive / integrated networks:** Organizations of specialized palliative care serving a population and acting in all settings of this scenario (hospitals, intermediate settings, nursing homes, community) and acting in an integrated way. In small districts, a specialized support team can be the only specialized resource needed to care in all settings. In districts with different providers, a common care pathway could be the formula for integrated care (figure 1). In metropolitan districts, a complex integrated model can include various levels of complexity.

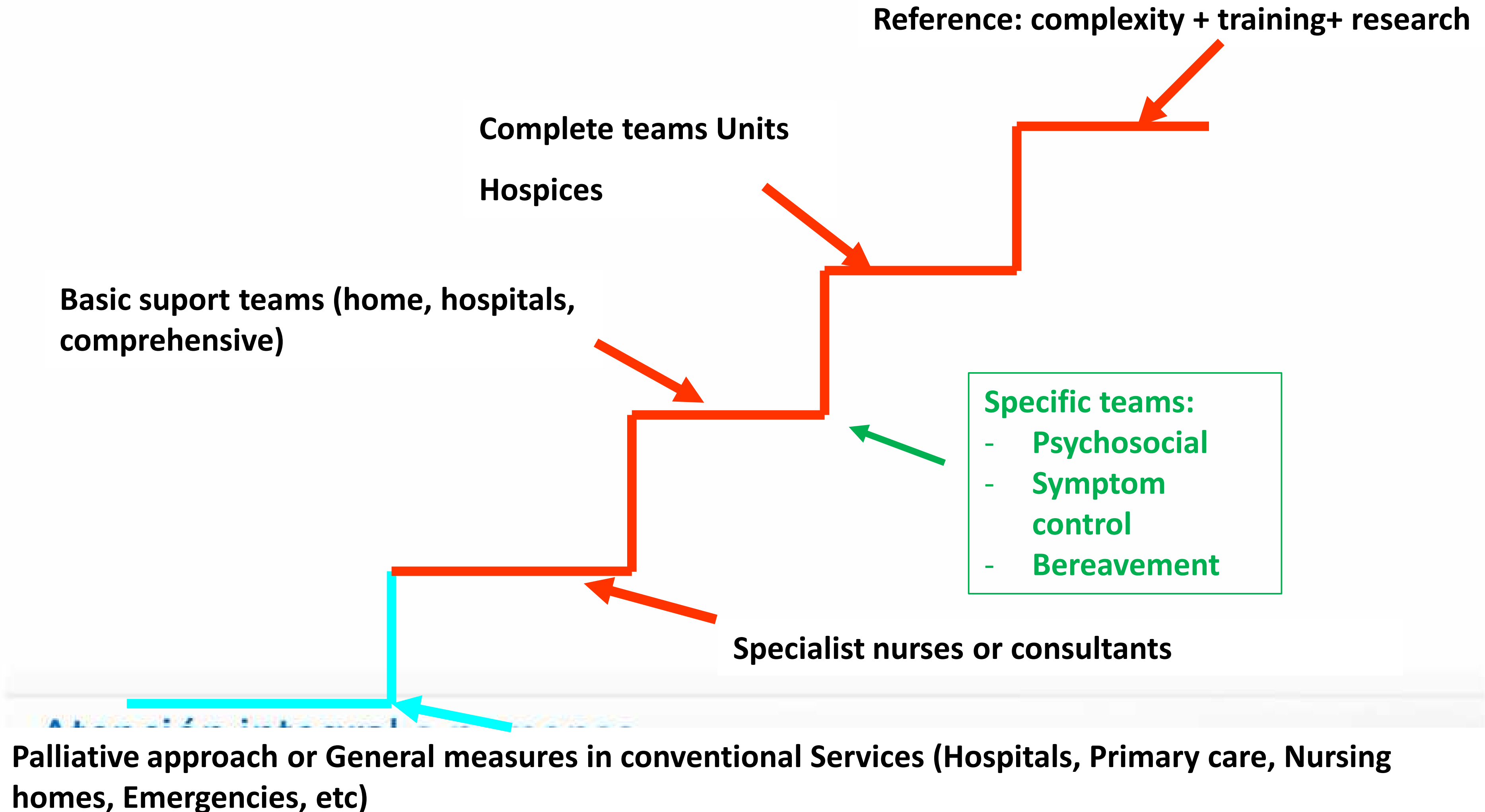
Transitional measures

Transitional measures are models of care delivering that use some specific resources (frequently individuals) such a specific nurse or consultant not fulfilling the criteria for a specialist service but devoted to advanced and terminal patients and families. TM can be the first step of further development of a specialist service.

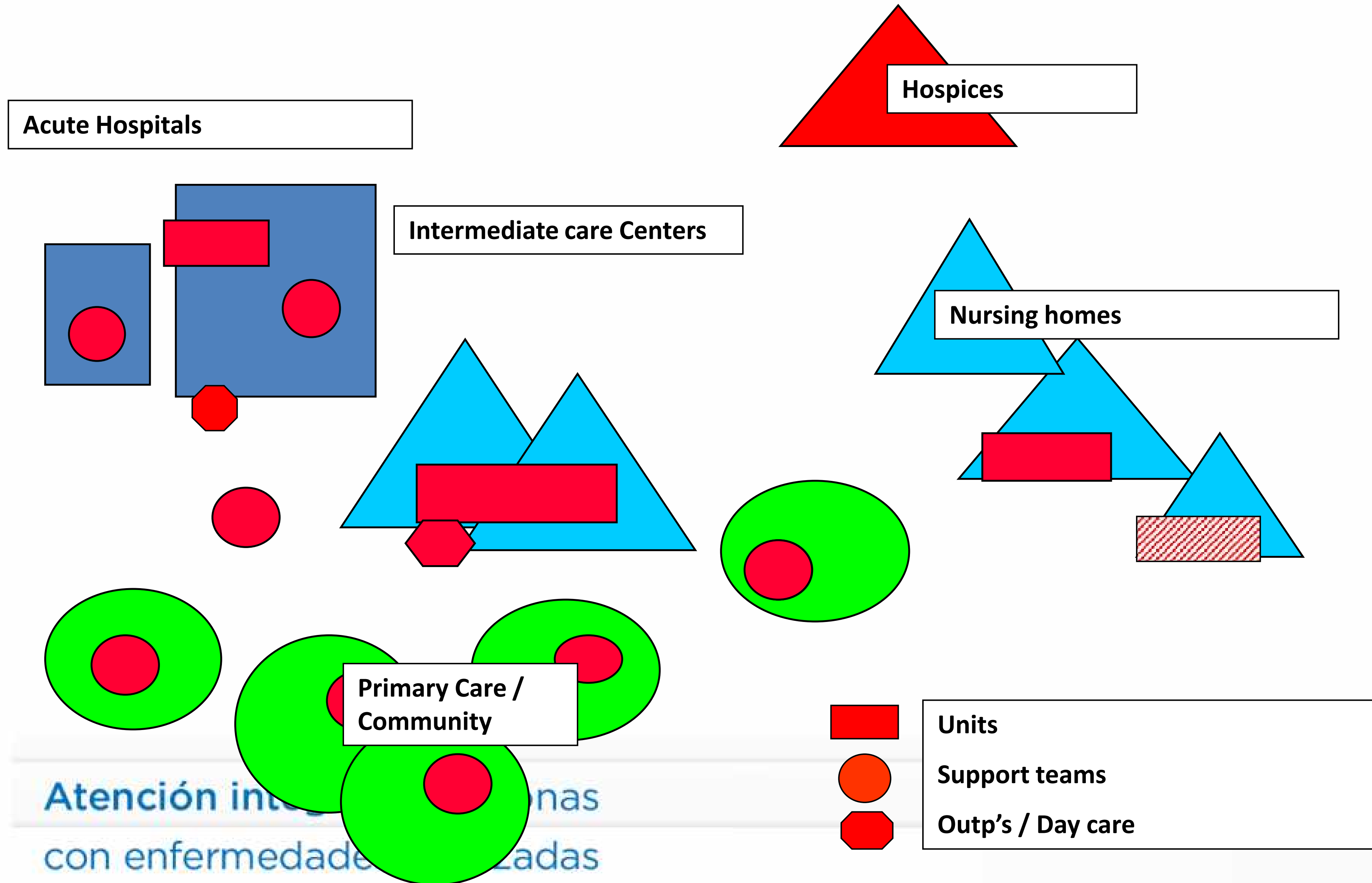
WHOCC 2009

Levels of complexity of Palliative Care provision

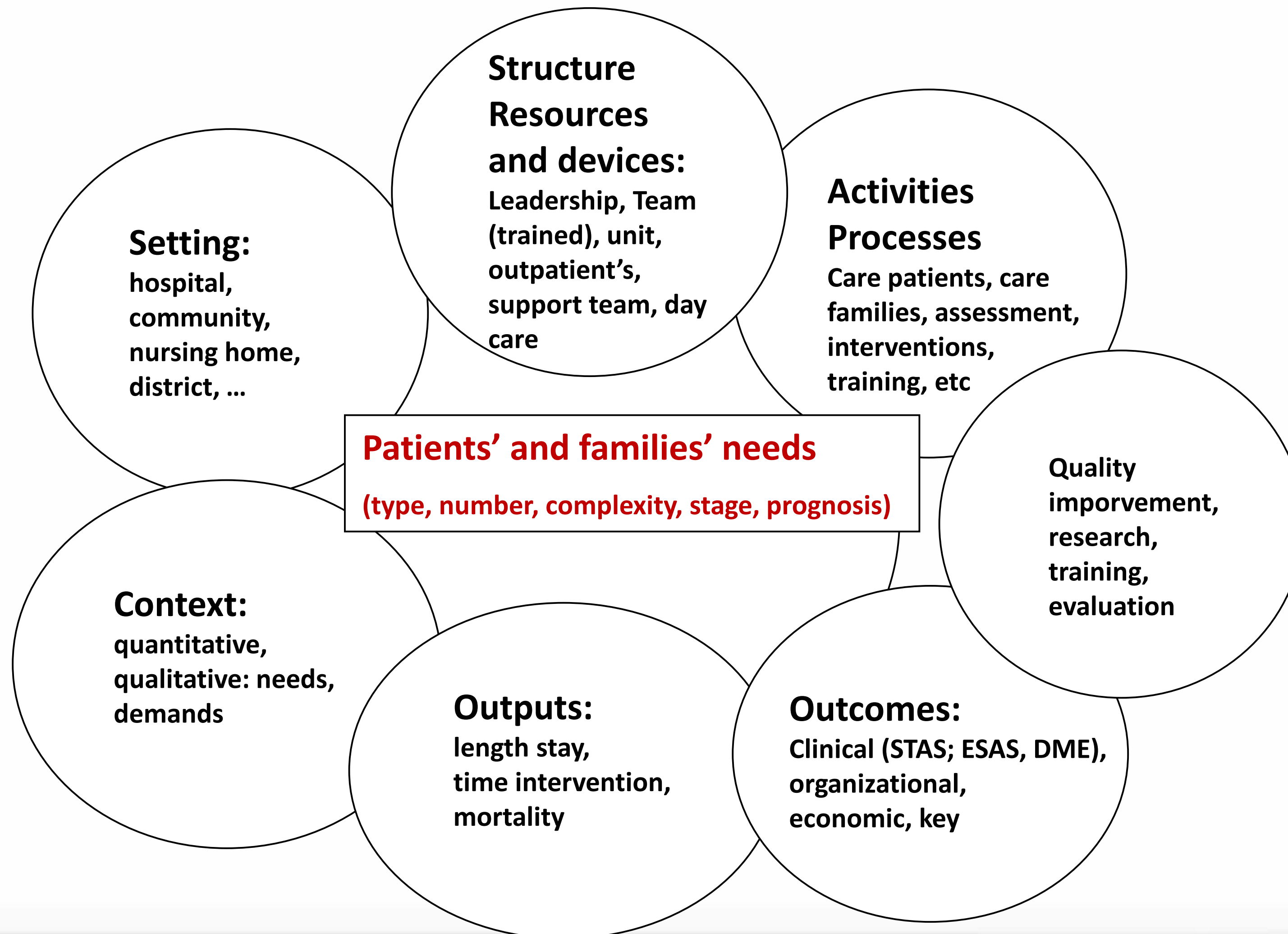
Obra Social "la Caixa"



Posible Specialist service's settings



Dirección científica



Service's description

Description services: elements

Context:
Demográphic, setting, etc.

Institution, Internal and external Clients

Activities: Processes, Types of activities

Patients / families:
Númber, type, complexity, dependency, prognosis

Team:
structure, training, activities, process

Quality, research, training

Results

Clínical: STAS, ESAS, emotional, experience, satisfaction, ..	Outputs: length stay, mortality, length intervention,	Other : impact, cost, social, society, culture

- Specific nurses and/or consultants
- "Monographic teams": symptom control , psychosocial, bereavement
- Support teams (basic, complete): in hospitals, community, nursing homes, comprehensive systems
- Units: type, dimension, placement
- Placement of beds: 10-20% acute, 40-60% sociohealth (mid-term), 10-20% residential, 10-20% hospices
- Reference services: training and research
- Comprehensive networks

Process: Common activities (process) of palliative care specialist services

Care of patients
Care of families and bereavement follow up
Ethical decision-making and advance care planning
Continuing care and case management
Liaison of resources
Support of other teams
Team work: meetings, roles, support, relations, climate
Registration and documentation
Evaluation of results
Internal training
External training to other services
Research and publications
Volunteers
Advocacy
Links to society

WHOCC Basic Indicators of SPCSs

Structure:
- Multidiscilinary team
- Advanced or specialist training
- Documentation
- Unit / office / setting / access criteria
- Policies

Process:
- Multidimensional evaluation of needs of patients and families
- Systematic elaborated multidisciplinar plan of care
- Systematic approach of process of care (square of care)
- Systematic monitoring and review of clinical outcomes and organisational outputs
- Team approach: meetings, plan, assessment, doccumentation
- Continuing care and accesibility
- Links with other services
- Documentation and tools complimented
- Bereavement process
- Education / Training / research
- Quality evaluation and improvement
- Links with society

Atención integral a personas

Adapted from SCBCP 1993 and SECPAL 2006

Generalist Palliative care or approach

Generalist Palliative care or approach **consist in the adoption of measures in any health or social service to look after persons with advanced chronic conditions. It includes generally the identification of patients their systematic needs assessment, the training of professionals, the referent professionals, the care of the family, and the case managemeng and link with other services. This approach is specially relevant in services with high prevalences of patients with advanced confitions, as primary care, some medical or surgical specialities, emergencies, and nursing homes**

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[38]
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) - Plan follow-up and continuity of care - Prevent and respond to crisis, plan emergency care
9. Integrated care: Establish links, joint information system, criteria intervention and access to palliative care specialized services and all services in the area	- Establish sectored policies - 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

Vol. ■ No. ■ ■ 2012 Journal of Pain and Symptom Management 1

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

Obra Social "la Caixa"

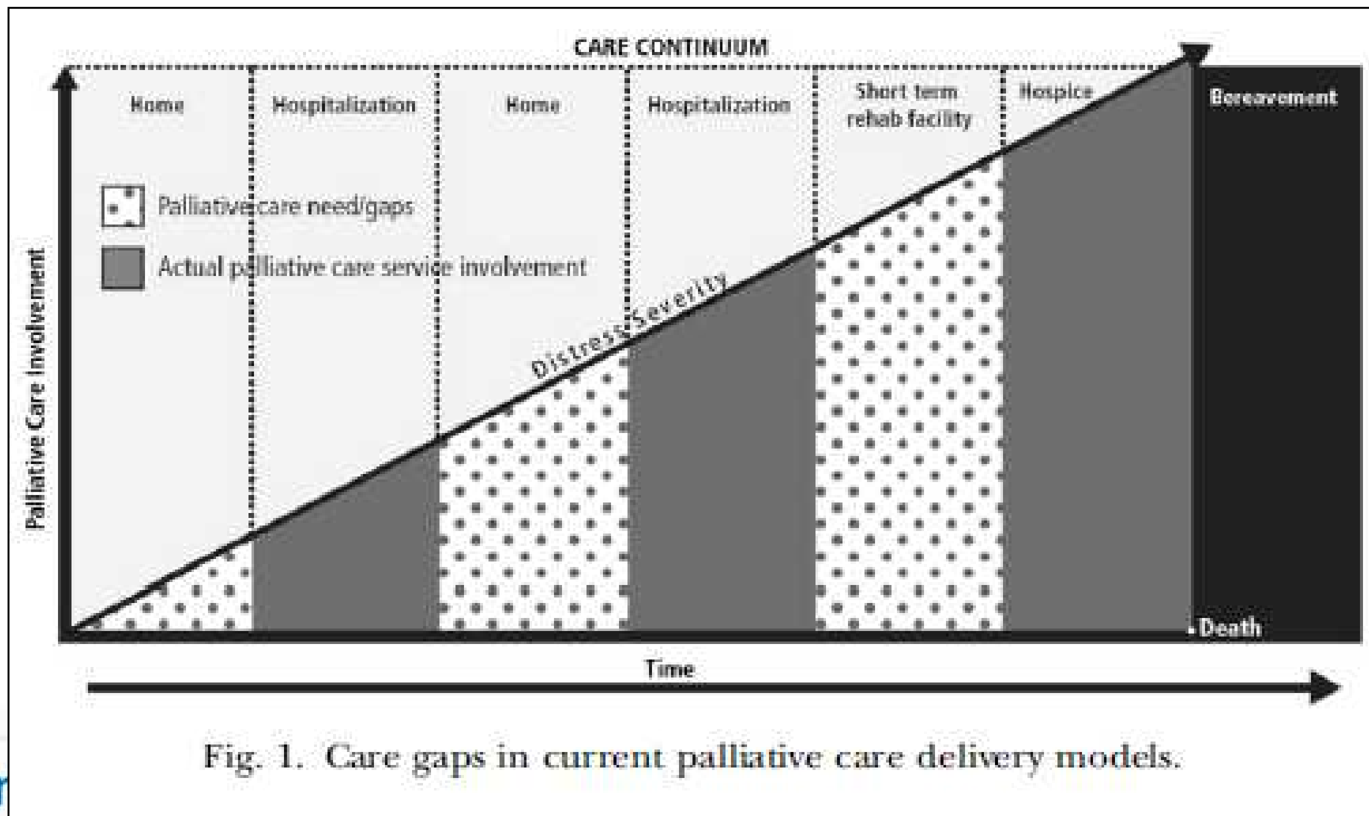
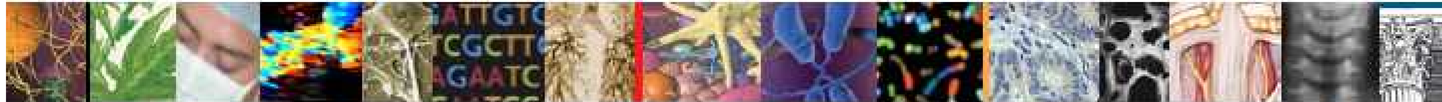


Fig. 1. Care gaps in current palliative care delivery models.

Atención

con enfermedades avanzadas



The NEW ENGLAND JOURNAL of MEDICINE

Social "la Caixa"

Generalist plus Specialist Palliative Care — Creating a More Sustainable Model

Timothy E. Quill, M.D., and Amy P. Abernethy, M.D.

Representative Skill Sets for Primary and Specialty Palliative Care.

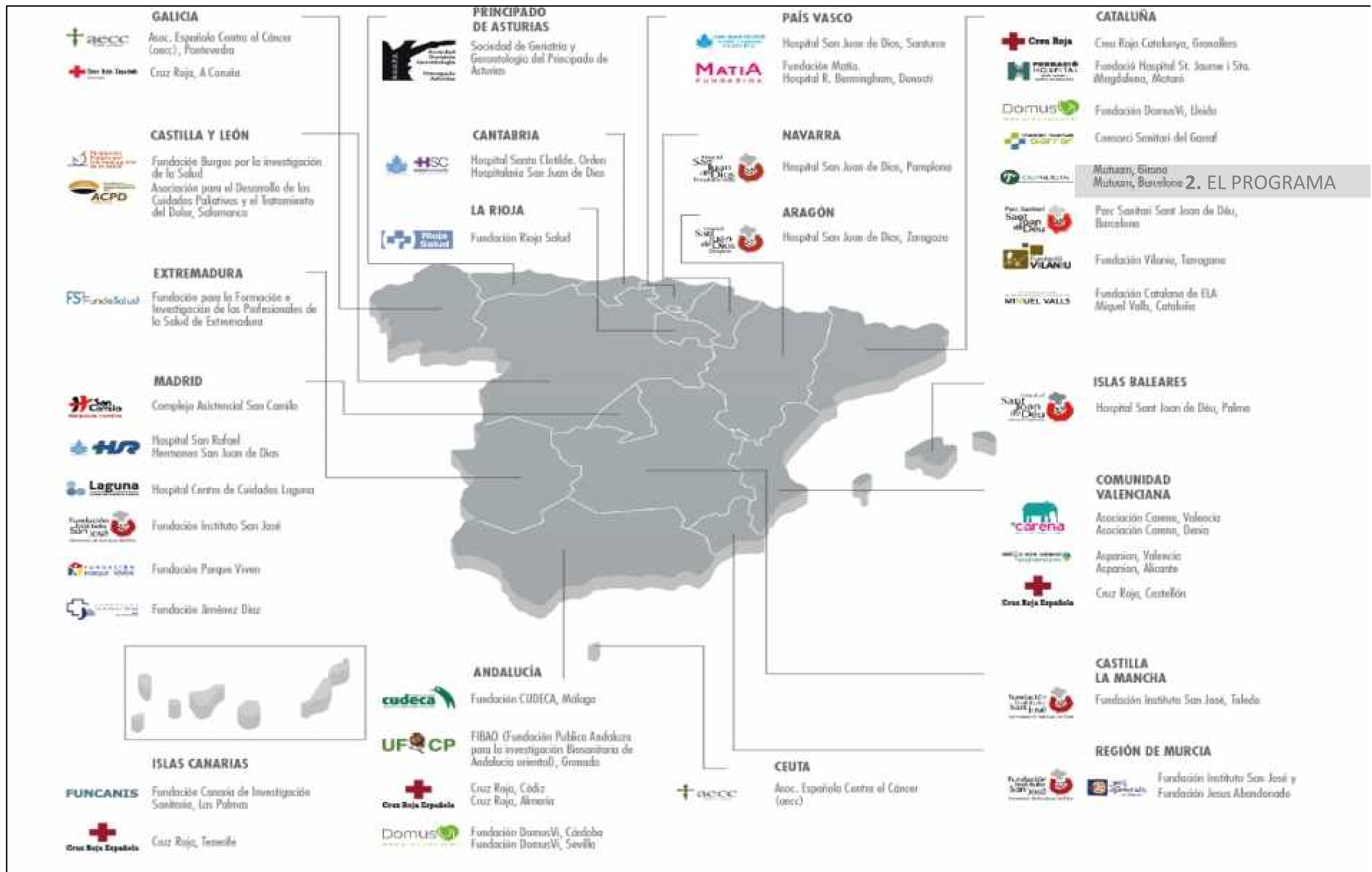
Primary Palliative Care

- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code status

Specialty Palliative Care

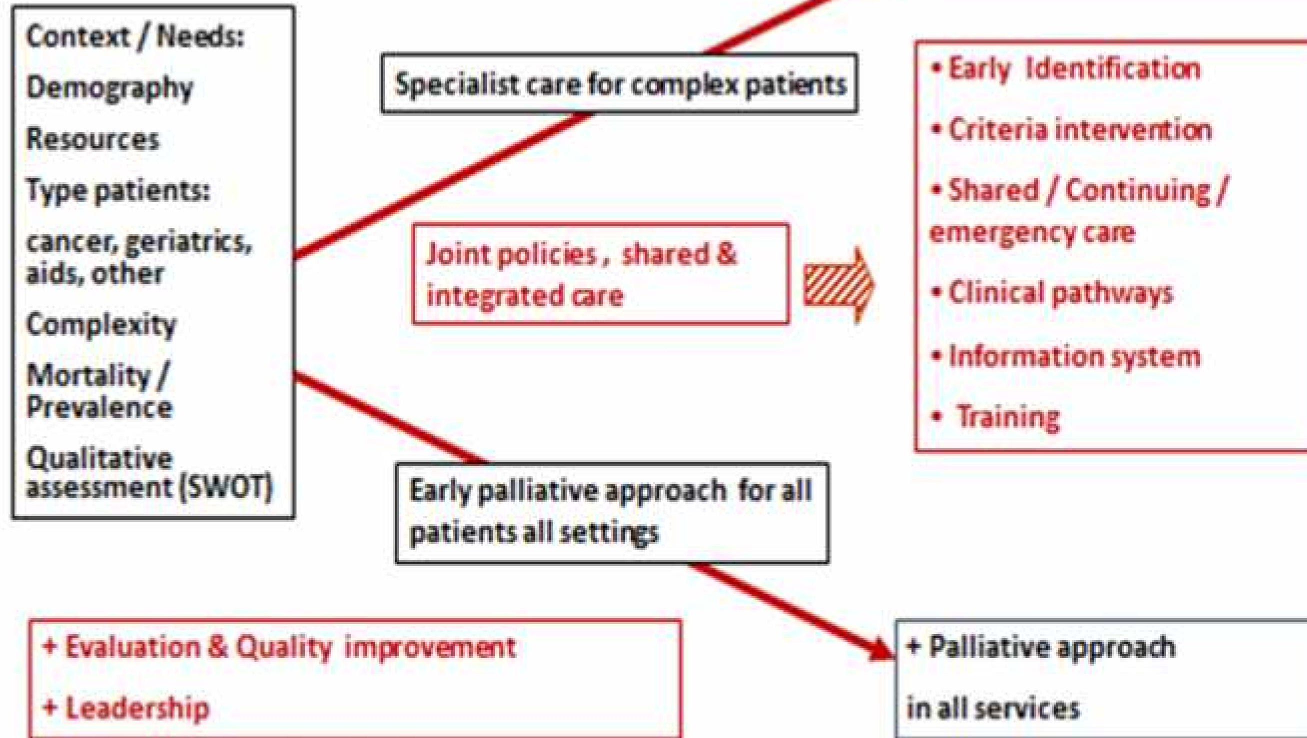
- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
  - Within families
  - Between staff and families
  - Among treatment teams
- Assistance in addressing cases of near futility

Atención integral a personas
con enfermedades avanzadas



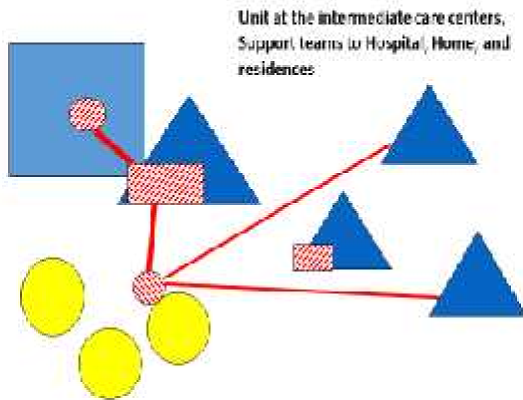
The *La Caixa* Program Model of organisation: 42 “Psychosocial Teams” (2-3 Psy + 1 SW)

District models

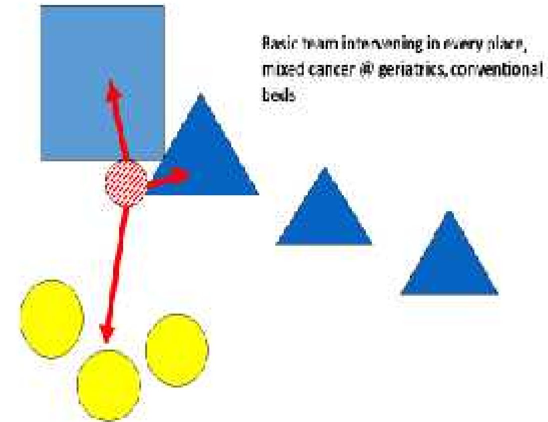

A model for District Palliative Care Comprehensive Planning
Specialist Services
Context / Needs:
Demography
Resources
Type patients:
cancer, geriatrics, aids, other
Complexity
Mortality / Prevalence
Qualitative assessment (SWOT)
Specialist care for complex patients
• Early Identification
• Criteria intervention
• Shared / Continuing / emergency care
• Clinical pathways
• Information system
• Training
Joint policies , shared & integrated care
Early palliative approach for all patients all settings
+ Evaluation & Quality improvement
+ Leadership
+ Palliative approach
in all services

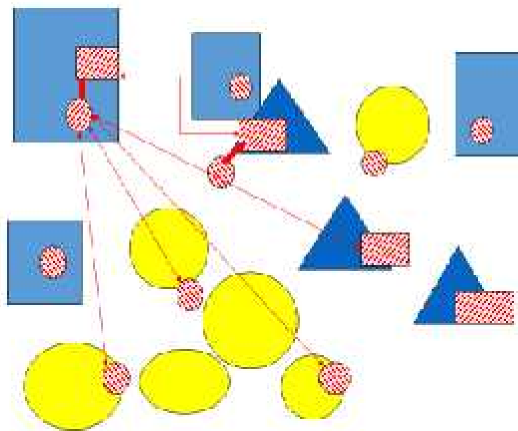
Dirección científica

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



Catalonia: Comprehensive district system (small sectors of 50.000 hab): integrated





Catalonia: Complex Comprehensive district system (metropolitan sectors of >250.000 hab)

Catalan models of district organisation of palliative care, according to demography

JOURNAL OF PALLIATIVE MEDICINE
Volume 13, Number 10, 2010
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2010.0069

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

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

con enfermedades avanzadas

TABLE 4. CONVENTIONAL AND SPECIALIST PALLIATIVE CARE SERVICES IN DIFFERENT TYPES OF SECTORS OF CATALONIA

Type	*Characteristics*	*Number*	*Conventional (nonpalliative care) resources*	*Palliative care resources*[a]
Rural	< 50,000 citizens	9	PCC	1 support team available in all settings (home, hospital, others)
Rural–urban	50–150,000 citizens Intermediate: rural areas with 1–3 small cities	18	CH PCC DGH PSHC	Unit in the SHC or DGH, HCST, HST, OPC
Urban (Girona, Lleida, Tarragona)	200–300,000 citizens 1 provincial capital	3	PCC CH 1 TH 1 DGH PSHC	Unit in Hospitals and SHC + 2 HST + 3 HCST
Metropolitan (Barcelona, Badalona, Hospitalet, Sabadell-Terrassa)	400–600,000 citizens Metropolitan Barcelona	7	PCC 1 TH DGH PSHC	5 levels of complexity of PCS: Reference unit + HST + OPC + HST in DGH + HCST / 100,000 citizens or district
Total	7,300,000 citizens	37	Hospitals PSHC PCT	HCST / 100,000 citizens HST in every Hospital Units 3 levels, OPC

[a]As agreed in the benchmark meeting.

PCC, primary care center; CH, community hospital; DGH, district general hospital; TH, teaching hospital; OPC, outpatient clinic; PSHC, polyvalent social health center; PCT, primary care teams; HST, hospital support teams; HCST, home care support teams; SHC, social health centers; PCS, palliative care services.

Concept of integrated system or network

"In which a service/team leads all the palliative care devices in a district or sector"

Dirección científica

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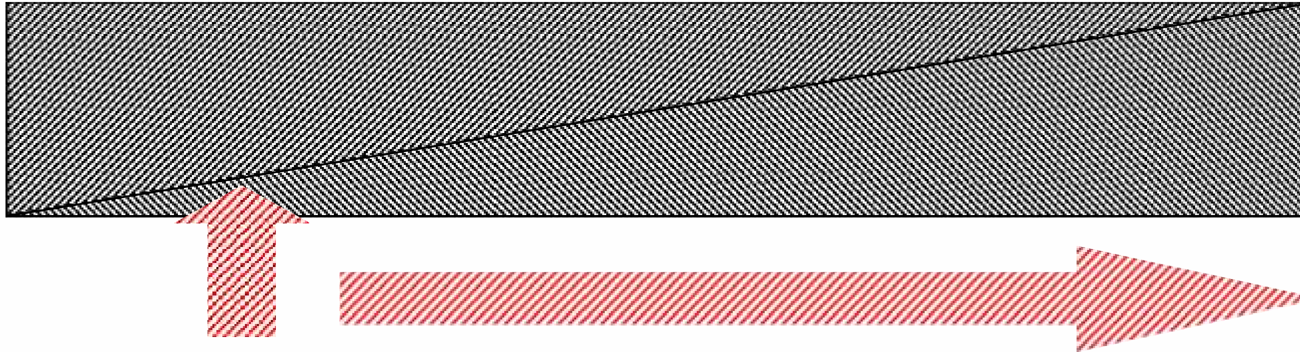

Atención int
con enferme

Atención paliativa s XXI:

1. **Todos los pacientes crónicos avanzados**
2. **Desde inicio necesidades**
3. **En todos los ámbitos**
4. **Todos los profesionales**
5. **Modelo de atención integral impecable**
6. **Planificación Decisiones Anticipadas**
7. **Gestión de caso y atención integrada**

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Obra Social "la Caixa"

Atención integral a personas con enfermedades avanzadas

Observatorio 'Qualy' / Centro Colaborador OMS Programas Públicos Cuidados Paliativos (CCOMS-ICO)