Special Article

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

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Abstract

In 2015, the World Health Organization (WHO) Demonstration Project on Palliative Care in Catalonia (Spain) celebrated its 25th anniversary. The present report describes the achievements and progress made through this project. Numerous innovations have been made with regard to the palliative care (PC) model, organization, and policy. As the concept of PC has expanded to include individuals with advanced chronic conditions, new needs in diverse domains have been identified. The WHO resolution on "Strengthening of palliative care as a component of comprehensive care throughout the life course," together with other related WHO initiatives, support the development of a person-centered integrated care PC model with universal coverage. The Catalan Department of Health, together with key institutions, developed a new program in the year 2011 to promote comprehensive and integrated PC approach strategies for individuals with advanced chronic conditions. The program included epidemiologic research to describe the population with progressive and life-limiting illnesses. One key outcome was the development of a specific tool (NECPAL CCOMS-ICO©) to identify individuals in the community in need of PC. Other innovations to emerge from this project to improve PC provision include the development of the essential needs approach and integrated models across care settings. Several educational and research programs have been undertaken to complement the process. These results illustrate how a PC program can respond and adapt to emerging needs and demands. The success of the PC approach described here supports more widespread adoption by other key care programs, particularly chronic care programs. J Pain Symptom Manage 2016;52:92–99. © *2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Palliative care, chronic care, planning, WHO Demonstration Projects, public health policies

Introduction

The Global Context

Palliative care (PC) has been successfully incorporated into the public health systems of many countries.[1–6] However, there is great variability among countries in terms of this development of PC and barriers to access to essential medicines still persist.[7] In May 2014, the World Health Organization (WHO) Health Assembly approved Resolution 67/19 on "Strengthening of palliative care as a component of comprehensive care throughout the life course," which became a milestone in the commitment of WHO. The resolution encourages all governments to design and implement PC programs in their countries and facilitate access to essential medicines.[8] Following this resolution, several WHO initiatives[9] were

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implemented. The most important ones are the WHO global strategy on people-centered and integrated care and the universal health coverage and patient safety and quality[10] initiatives.

The Evolution of the WHO Demonstration Project of PC in Catalonia

The WHO Demonstration Project, launched in Catalonia (Spain) in 1990, was the first formal PC program to be incorporated into a public health system[11] with all the essential elements of a public health program.[12,13] During the first 20 years of its implementation, a complete comprehensive palliative network was developed, focusing primarily on implementation of Palliative Care Specialized Services (PCSS), access to essential drugs, and training of health care professionals. As a result of this initiative, coverage for cancer patients in this region is high.[14]

Several quantitative and qualitative evaluations have been carried out to identify the program in terms of its strengths and weaknesses.[15] The main weaknesses identified to date include low or insufficient coverage for noncancer patients and in some conventional services. Other weaknesses are related to access, in the sense that PC is sometimes administered late and the continuity of care is not always adequate. Variability in the provision of PC depending on the service (e.g., primary care vs. nursing homes) is also an area in need of improvement. Moreover, undermet needs include the psychosocial, spiritual, and bereavement requirements of both patients and families. More research is needed and evaluation strategies could be improved. Finally, the financing model is another area in need of updating.

Based on these findings, several initiatives have been implemented[16] to improve the model of care. Several conceptual transitions in PC have been identified during the last 10 years, in particular a new community-oriented and population-based PC approach.[17] This approach focuses on the early provision of PC for all types of patients in all care settings.

The epidemiology of PC needs also has been updated, either based on mortality[18] or on prevalence,[19] and tools to help identify new targets for PC,[20] such as elderly people with multimorbidities, advanced frailty, or dementia living in the community. The concepts of "first transition" and the "palliative approach" also have been adapted to the care of these patients, timely identified in all care settings, especially in primary care and nursing homes.[21]

Aims

The present report describes the results of the WHO Demonstration Project at the 25th year of its implementation in Catalonia. It includes the evolution of the program in terms of areas of innovation, lessons learned, and implications for policy (Table 1).

PCSS in Catalonia

To obtain data on the Catalan PC services, we have retrieved information from diverse sources, including the Directory for Palliative Care Services of the Department of Health, the contracts of the Catalan Health Service's funding agency providers, and direct contact with stakeholders and organizations that provide PC. Data on structure and outputs of specialized PC services are listed in Table 2.

Previous evaluations performed to identify the characteristics and activities of PC services have pointed to several areas in need of improvement. In response to those evaluations, new models of PC provision and innovation have recently been implemented (Table 3).[22] The most significant developments are briefly described subsequently.

The Model of Care for Psychosocial and Spiritual Needs

The "La Caixa" Foundation[23] and the WHO Collaborating Center for Public Heath Palliative Care Programs in Barcelona jointly designed and implemented a *Program for the Comprehensive Care of Patients with Advanced Chronic Conditions and Their Families* in 2009. The aim of this program was to address the emotional, social, and spiritual aspects of patients (and their families) with advanced diseases. The program has created 42 psychosocial care support teams in Spain, mainly consisting of psychologists and social workers, which support existing PCSS in the psychological, social, and spiritual care of patients. In the years since this program first started, team members have developed a variety of tools, protocols, training, and evaluation material. Studies performed to assess the program have found good evidence of effectiveness and satisfaction.[24] Eight of these 42 psychosocial care teams operate in Catalonia, caring for 11,574 patients and 14,283 families from 2009 to 2014.

Implementation of PC Support Teams for Nursing Homes[25]

A total of 20 support teams were created to work in nursing homes (with 16,646 residents) in three urban regions. These teams provide support for patients with complex and advanced chronic illnesses. The structure includes 21 full-time doctors and 46 nurses working in 319 nursing homes. They have identified 6437 (38.6% of the total) patients with complex and advanced illnesses in need of PC.

Table 1
Key Points

What is already known about this topic
- Palliative care is an essential component of public health systems
- Palliative care specialized services are effective, efficient and patients (and families) in need are satisfied with these services
- The main focus of regional and national palliative care programs has been on providing specialized care to terminal cancer patients in institutions

What this article adds
- Update of a WHO Demonstration Project at 25 years in accordance with WHA Resolution 67/19
- Evidence about the population needs of palliative care
- Description of the implementation of a systematic program to timely identify individuals from within the community and in all care settings who are in need of palliative care

Implications for policy
- Existing or new public palliative care programs could learn much from the extensive experience gained over the last 25 years. Most programs will need to update and expand their need assessment processes to stay current with recent research, with a population approach. This includes, in particular, a need to apply the palliative approach to individuals with chronic conditions in all care settings, but especially individuals living in the community and also in nursing homes or other institutions.
- Existing palliative care services need to be modernized, improved and offered in all care settings, especially primary care and nursing homes
- The palliative care approach should be incorporated into chronic care programs as a key component.

Primary Care Support for Nursing Homes: "Geriatr-ICS" Program

This program has developed a systematic intervention of primary care services in nursing in two urban regions. The program includes identification of patients in need of PC, review of the therapeutic objectives, and inclusion of the clinical data in the joint information system and education and training activities for the nurses employed at 181 nursing homes (8743 beds).

As a result of this initiative, hospital admissions have been reduced by 26.9% (from 35.7% in 2012 to 26.1% of residents in 2014) and emergency department visits have been reduced by 16.1% (from 66.4% to 62.2%). In contrast, since 2012, the use of primary care emergency services has increased by 20.4%, whereas the cost per resident has decreased by 18.1%. The mean number of neuroleptics prescribed per patient has also decreased significantly.

Table 2
Palliative Care Specialized Services in Catalonia: Structure and Selected Output Measures (2010–2014)

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

HCST = Home Care Support Team; PCU = Palliative Care Units; WHO = World Health Organization; WHOCC = WHO Collaborating Center.
[a]The HCSTs took care of 15,325 patients, with a mean age of 75.5 years and a mean length of intervention of 80.2 days.
[b]HCSTs data include only patients codified as "terminal" and do not include yet the patients registered as "advanced" identified through the NECPAL tool.
[c]The PCUs cared for 9136 patients (mean age 77.6 years), with a mean length of stay of 15.6 days.
[d]Catalan Institute of Oncology.

Addition of Case Management Nurses in Primary Care Services

Primary care services have included specific case management nurses, with specialized training, to provide care of individuals with complex and advanced chronic conditions. These nurses also act as coordinators and reference professionals within different health care services.[26]

Epidemiology of Advanced Chronic Conditions in Catalonia

As part of a project to identify PC needs in the general population, the NECPAL CCOMS-ICO© tool[27] was designed by the Qualy Observatory/WHO Collaborating Centre for Palliative Care Public Health Programmes of the Catalan Institute of Oncology in Spain. This validated tool seeks to identify individuals in need of palliative and, in contrast to other instruments, it places a greater emphasis on frailty, multimorbidity, and geriatric syndromes as triggers of palliative needs.[28]

The wider aim of the NECPAL initiative is to identify PC needs in the population and to improve integrated PC for all patients in all settings of care with a community perspective. It has several components, including

Table 3
Summary of Relevant Innovations, 2010–2015

Dimension	Action
Policy/public health: • Interaction chronic/palliative care • Alignment with the World Health Organization Resolution of Palliative Care, people-centered, and integrated care initiatives	• Development and validation of the ***NECPAL-CCOMS tool*** to identify individuals in need of palliative care • Development and validation of the ***ENP tool*** for psychosocial and spiritual needs[22] • Determination of prevalence of individuals with palliative care needs and limited life prognosis in the population • MACA/NECPAL program for early identification, registry and palliative approach/care of individuals with palliative care needs in the community (primary care and nursing homes) from the Department of Health • Integrated care in districts • Codification and registry (complex/advanced chronic) of the joint information system
New specific services/organizational changes	• Psychosocial Support Teams • PC Support Teams in Nursing Homes • Primary Care Support for Nursing Homes (Geriatr-ICS Program) • Case management nurses in primary care services
Model of care	• Essential needs of patients • Spiritual care development • Comprehensive/integrated model of care and intervention in individuals with advanced chronic conditions
Training	• Chair of Palliative Care at the University of Vic • Chair of Palliative Care at the International University of Catalonia • Advance care planning (ACP) • Psychosocial/spiritual postgraduate course • Palliative care in the chronic care model
Research	• Eight palliative care-related PhD projects • Research group at the Catalan Institute of Oncology

epidemiologic assessment, implementation, and evaluation in the context of an updated conceptual framework to increase the interaction between chronic and PC. In addition, an important objective is to include PC as an essential component of the chronic care model.[29]

Once the tool had been fully developed, a population-based prevalence survey[19] was carried out to identify individuals in the community with previously unidentified need of PC services. The aforementioned survey found that 1.5% of the population (in a study population in which one of five individuals were elderly) was in need of PC because of limited life prognosis. The most frequent conditions were multimorbidity in frail elderly women (>65%) and organ failure.

Additional surveys in specific settings have shown prevalence rates of 20%–25% (general practitioners), near 40% (acute bed hospitals), and more than 60% (nursing homes). Moreover, a recent cohort study found that the NECPAL tool can be used as a screening method to identify patients with PC needs and to help determine prognosis.

The Chronic Care Program[30] at the Department of Health and the Social Welfare Department was launched in 2011 to develop a comprehensive policy to meet the increasing needs of chronic conditions. In cooperation with the Social Welfare Department,[31] a proposal was developed in 2014 for a comprehensive, integrated model of care with a population- and community-oriented perspective. This program has several components, including health promotion, prevention, and care of complex and advanced chronic conditions. In fact, many of the innovative initiatives in this program have been incorporated into the Catalan Healthcare System. The most relevant components of the program are as follows:

1. Early identification of patients with advanced chronic conditions in primary care services: Quantitative results show that more than 100,000 patients with complex and advanced chronic conditions have been identified through the Chronic Care Program, and several research projects are currently assessing the impact on both patients and professionals.
2. Advanced care planning and case management processes model: Implementation of the NECPAL program in Catalonia led to the realization that a model of advance care planning specifically adapted to our context was needed. To address this challenge, a collaborative, comprehensive review process was undertaken. This project, launched by the Chair of Palliative Care at the University of Vic and the Catalan Department of Health, reviewed numerous successful international initiatives.[32–37] Then, a group of 60 multidisciplinary experts was created to develop a conceptual framework and an implementation guide.[38,39] Additionally, an extensive training program targeting primary care professionals is currently underway.
3. Essential needs and patient-centered care model[40]: The aim of this proposed model was

to identify the essential needs of patients and then to use this information to develop a conceptual framework for improving the care and training model. This proposal was developed at the Catalan Institute of Oncology, based on an expert consensus methodology, and five main essential needs were identified: spirituality, dignity, autonomy, key relations, and hope. A conceptual framework was proposed to develop the necessary skills needed to provide patient care that meets these needs. A pilot program is underway at the Catalan Institute of Oncology.

Other PC Achievements in Catalonia

International Cooperation: The WHO Collaborating Center for Public Health Palliative Care Programs

The WHO Collaborating Center (WHOCC) for Public Health Palliative Care Programs was designated in 2008 to generate and disseminate experience and evidence. The WHOCC provides technical advice and support to countries and organizations, develops tools and training materials, and disseminates knowledge.[41] Since its creation, the WHOCC has developed multiple tools and manuals and provided technical support to numerous countries and regions, mainly through capacity-building activities (meetings, workshops, and courses) focused on implementation and evaluation of PC programs and services.[42]

Academic Development of PC: Chairs of Palliative Care

Advanced training and education in PC are essential for the development of high-quality PC delivery. In this sense, Catalonia holds the only two existing Chairs of Palliative Care in Spain, which demonstrates the strong support for PC in the region.

The Chair of Palliative Care at the University of Vic,[43] directed by Professor Xavier Gómez-Batiste and Dr. Carles Blay, was created in 2011. This chair focuses on promoting a public health, community-oriented approach, and on expanding access to PC to include individuals with advanced chronic conditions, not limited to cancer. It is a shared project involving primary care, geriatrics, and nursing homes. Through the Chair, education, training, and research projects focusing on new perspectives of PC (community and chronic care) have been developed. The most important activities are as follows:

Master of Palliative Care of the Universities of Vic and Barcelona: Advanced training in PC has a long history in Catalonia. This Master's program has trained most of the PC doctors and nurses in Catalonia over the course of its existence (10 graduate classes). Recently, the program content has been updated to widen the scope to include the care of persons with advanced chronic conditions. As a result of this new perspective, the student profile has evolved from health care professionals interested in specializing in PC toward health care professionals who work in primary care, nursing homes, and other conventional services responsible for caring for patients with chronic advanced illness.[44]

Postgraduate Course on Psychosocial and Spiritual Care of Persons With Advanced Chronic Conditions: This one-year course was started in the year 2015 and is focused on the management of psychosocial and spiritual needs of individuals with advanced chronic conditions. It is based on the experience of the La Caixa Program described earlier.

Online Course for Care of Individuals With Advanced Chronic Conditions in the Community: This is an intermediate, free of charge online course to introduce the main concepts of PC to primary care doctors and nurses.

Manual for the Comprehensive and Integrated Care of Individuals With Advanced Chronic Conditions[45]: This manual was published in the year 2015 and is a valuable reference tool, with a specific focus on the PC approach.

PhD Projects: A total of eight PhD projects focused on a global evaluation of the Chronic Care Program are currently in progress.

Chair of Palliative Care at the International University of Catalonia[46]: This chair, held by Professor Josep Porta-Sales, was created in 2013 to promote education and research activities focused on the clinical, ethical, and social aspects of end-of-life care. It provides pregraduate training, and it is currently developing research in hematologic PC.

Discussion

In Catalonia, the first PC program was initiated more than 25 years ago. During the ensuing years, many innovations and improvements have been made. Innovations include not only increased coverage to provide timely PC for patients with illness other than just cancer in all care settings but also in the tremendous improvements in the care model. Thanks to extensive research, we have been able to better identify the essential needs of patients and, consequently, to develop services focused not only on physical needs but also on the psychosocial and spiritual issues of patients. Taken together, these developments seek to provide a much more closely integrated and comprehensive framework to address the wide scope of patient needs.

The key components of innovation in health care include solid, evidence-based educational and training

strategies. The WHOCC of Palliative Care Public Health Programs and the Chair of Palliative Care at the University of Vic are recognized leaders in education and evaluation of PC initiatives and have become the key organizations to disseminate these concepts to other countries. These perspectives are fully consistent with WHO Resolution 67.17, the aim of which is to strengthen PC efforts around the globe.

Although many local initiatives and a few national initiatives (e.g., the Scottish Partnership for Palliative Care[47]) are designed to expand the PC approach and develop essential needs care, to our knowledge, none of the existing programs have such a wide scope as the WHOCC program, which has contributed a multiplicity of tools, evaluation instruments, and research studies to furthering the widespread implementation of PC into the health care system and wider community. The leadership shown by the Department of Health in Catalonia in terms of the development of policy innovations and a commitment to improving PC might be a model for existing Palliative Care Programs in other countries and regions of the world.

Limitations

This special article is based on the direct search of the organizations involved in the planning, funding, or providing of PC services in Catalonia, the Chronic Care Program, and the related activities of education and research using our own data. Some of the current existing activities might be not included. Clinical, economic, and other types of qualitative outcomes in patients and families are not yet provided in this analysis and are currently being explored in the PhD research projects.

Conclusions

PC programs need to be evaluated and updated regularly and systematically. Evaluation should include a review of the PC needs and identification of areas requiring improvement. As we have shown, it is valuable to combine both quantitative and qualitative methodologies.

Based on our experience, we believe that both new and existing PC programs (regional or national) should incorporate an integrated, community-oriented approach to identify individuals living in the wider community who are potentially in need of PC services. This implies updating need assessments based on recent research, timely identification of persons in need, and improvement of the PC approach in all care settings. Given the importance of primary care services, general practitioners should be empowered and trained to identify individuals in need of PC services. This can be achieved through the implementation of specific tools (e.g., the NECPAL tool) and by improving training and quality improvement processes. In all cases, any new initiatives should be integrated into existing PC services. In particular, improvements are needed in the psychosocial and spiritual dimensions of care. The ethical aspects of early identification need to be addressed to increase the benefits and reduce the risks of PC. Similarly, chronic care programs and services need to incorporate the PC approach as an essential component.

Although tremendous progress has been made in the last 25 years, further research and education are needed to better understand the needs and characteristics of persons in need of PC and to conclusively demonstrate the benefits of the PC approach in all settings.

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