

The WHO Collaborating Centre for Public Health Palliative Care Programs: An Innovative Approach of Palliative Care Development

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Abstract

Background: The designation of the Catalan Institute of Oncology (Barcelona, Spain) as World Health Organization (WHO) Collaborating Centre for Public Health Palliative Care Programmes (WHOCC-ICO) in February 2008 turns the institution into the first ever center of international reference in regards to palliative care implementation from a public health perspective. The center aims to provide support to countries willing to develop palliative care programs, to identify models of success, to support WHO's policies, and to generate and spread evidence on palliative care.

Objective: This article describes the WHOCC-ICO's contribution in the implementation of public health palliative care programs and services. The center's main features and future actions are emphasized.

Results: At the end of the initial four-year designation period, the organization evaluates the task done to reach its objectives. Such global assessment would take forward the quality of the institution, and generate a revision of its terms of reference for the next designation period.

Conclusions: Based on new evidence, the center has recently decided to expand its scope by adopting a community-wide chronic care approach which moves beyond cancer and focuses on the early identification of patients with any chronic disease in need of palliative care. Moreover, the center advocates the development of comprehensive models of care that address patients' psychosocial needs. This center's new work plan includes additional significant innovations, such as the startup of the first chair of palliative care in Spain. Such a whole new approach responds to the main challenges of current palliative care.

The WHOCC-ICO: Promoting Quality in Palliative Care

BASED ON THE EXPERIENCE OF THE WHO Demonstration Project of Palliative Care (PC) Implementation in Catalonia (Spain),¹ the aims of the WHO Collaborating Centre for Public Health Palliative Care Programmes (WHOCC-ICO) are to provide support to governments and/or health and social care organizations on the development (design, implementation, and evaluation) of PC programs; to cooperate with WHO's policies; and to generate evidence and knowledge. The terms of reference for the WHOCC-ICO were established in 2008 (see Fig. 1).

The organization's mission is to promote the improvement and development of PC as a public health element and a basic human right in Catalonia, Spain and other WHO

regions. The center is a consultant to health and/or social institutions.

The staff of the WHOCC-ICO is made up of professionals from a range of different disciplines: medicine, nursery, psychology, data management, social work, and administration. The center's main areas of expertise are, thus, diverse, and include public health policy in PC, models of PC planning and provision (PC approach and services), evaluation, quality improvement, development of psychosocial aspects in PC, and applied research and education.

Main Activities: Make Things Happen

The WHOCC-ICO focuses on designing, implementing, and assessing PC programs and services through evaluation

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FIG. 1. Terms of reference of the WHO Collaborating Centre for Public Health Palliative Care Programs (WHOCC-ICO).

and improvement of quality, research, and education.² Since 2008 it has conducted numerous projects and has rapidly expanded a portfolio of activities.

The nature of the center is goal oriented, flexible, and committed. The projects are adjusted to clients' and stakeholders' needs and demands, though in coherence with the center's terms of reference. Furthermore, the promotion of research and generation of evidence in public health PC is paramount. The center's main activities are described below.

Country Support and Strategy

The WHOCC-ICO offers support to national, regional, and local public PC initiatives in countries willing to establish PC programs. Such countries may have requested assistance to WHO offices or contacted the center directly. In any case, countries should demonstrate (1) commitment from their national or regional health authority to establish PC and/or a comprehensive cancer and/or geriatric and/or AIDS control program; and (2) committed leaders.

The WHOCC-ICO has developed an approach to demonstrate the first steps for establishing a national PC program.³⁻⁴

This methodology and a list of the countries to which the WHOCC-ICO has provided support in the implementation of PC programs are summarized in Figure 2.

Country support processes involve diverse actors (policy makers, health care professionals and leaders) and factors (political commitment, funding support, etc.). Our contribution as WHO Collaborating Centre is to provide guidance on the implementation phases, and the countries are expected to lead the development of their own PC program. As examples of country support, Tables 1 and 2 summarize the actions undertaken and the results observed in Portugal and Andorra. These countries received exclusive, specific, and continuous support from the WHOCC-ICO, whose intervention was formally linked to their ministries of health. Such political commitment allowed more consisted and comprehensive interventions to be conducted.

The WHOCC-ICO has mainly focused on capacity building activities. Several workshops and courses on the organizational aspects of PC have been carried out. The contents are always tailored to each specific country or institution. In this sense, the center has hosted international meetings meant to help countries generating a growing body of expertise and references.

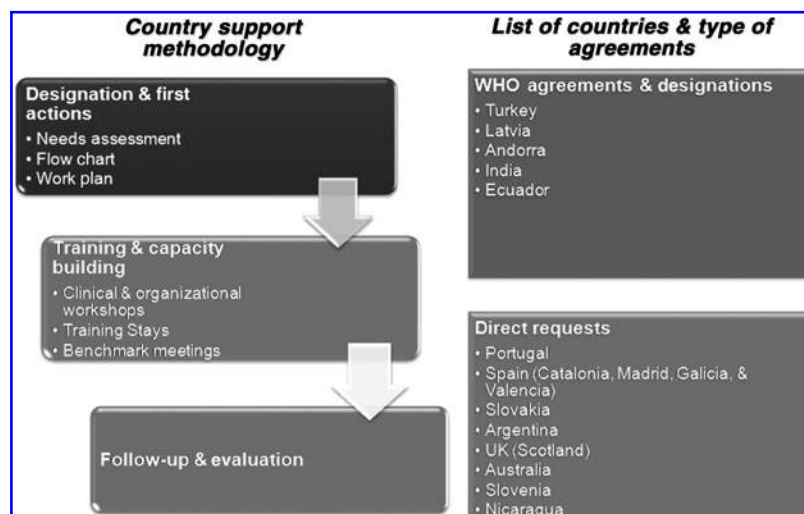


FIG. 2. Country support methodology and list of countries supported by the WHOCC-ICO (2008–2012 period).

TABLE 1. COUNTRY SUPPORT: ACTIVITIES UNDERTAKEN BY THE WHOCC-ICO AND OBSERVED POST-INTERVENTION RESULTS IN PORTUGAL (2008–2013)^{7–8}

<i>Activities</i>	
<ol style="list-style-type: none"> 1. Meetings of Ministry of Health 2. Creation of National Experts Committee 3. Design of National Plan 4. Training activities: <ul style="list-style-type: none"> • Workshop stakeholders (regional agencies, Ministry of Health) • Comprehensive training stays (visits to Catalonia; 25 professionals) • Participation in national & international congresses 5. Follow-up & evaluation activities: <ul style="list-style-type: none"> • Follow-up workshops (3) with National Experts committee, 2010–2012 • Follow-up workshop with six Portuguese health regions, 2013 	
<i>Results</i>	
<i>Policy & programs</i>	<i>PC services development</i>
<ol style="list-style-type: none"> 1. National Plan written 2. Legislation approved: decree, organizational model, financing model, standards, information system, pharmacy 3. Indicators stated 	<ol style="list-style-type: none"> 1. Services implemented (54): <ul style="list-style-type: none"> - Home care (10) - Hospital support teams (18) - Units (23) - Mixed (4) 2. Socio-health & palliative care network implemented

Such meetings also promote cooperation and benchmarking among participants. Furthermore, seminars become useful as they spread knowledge about evaluating projects or programs and services and about monitoring the results obtained. Some recent international meetings are discussed below.

- A workshop entitled Developing Capacity for PC in the European Region promoted by the WHO Regional Office for Europe underlined the importance of adopting systematic ways of developing PC services, learning from the experience of the participating countries and

TABLE 2. COUNTRY SUPPORT: ACTIVITIES UNDERTAKEN BY THE WHOCC-ICO AND OBSERVED POST-INTERVENTION RESULTS IN ANDORRA (2009–2011)^a

<i>Activities</i>	
<ol style="list-style-type: none"> 1. Meetings of Ministry of Health and Andorran Service of Health Care 2. Elaboration of a formal WHO Project. Terms of reference of the agreement of performance of work include: <ul style="list-style-type: none"> • The establishment of a group of experts in Andorra on both the clinical and the organizational level • The design of a public palliative care program • The initial implementation of a public palliative care program for Andorra • The elaboration of a plan for the evaluation and follow-up of the program 3. Design of National Plan 4. Training activities (clinical stays, workshops, courses, master of PC) focused on: <ul style="list-style-type: none"> • Organizational leadership • Clinical leadership • Palliative care concepts 5. Follow-up & evaluation activities: <ul style="list-style-type: none"> • Methodological support in the elaboration of follow-up indicators 	
<i>Results</i>	
<i>Policy & programs</i>	<i>PC services development</i>
<ol style="list-style-type: none"> 1. Buildup of the Strategic Plan of Palliative Care of Andorra 2. Definition of indicators & quality standards 	<ol style="list-style-type: none"> 1. PC network of Andorra implemented: <ul style="list-style-type: none"> • Consolidation of PC unit at the General Hospital 2. Core of competent professionals on PC for hospital & home care units: <ul style="list-style-type: none"> • 3–5 organizational leaders • 4–5 clinical leaders • 40 professionals (primary care & hospital) trained on PC (intermediate level)

^aData from technical report sent to WHO Regional Office for Europe in 2011.

agreeing on follow-up actions and capacity building work. Eight European countries (Albania, Andorra, Estonia, Latvia, Montenegro, Slovakia, Slovenia, and Turkey) participated in the meeting, held in Barcelona (Spain) in 2010. These countries had agreements with the WHO for the development and strengthening of PC services within their regions during 2008–2009. Additionally, representatives of Portugal, some Spanish regions (Catalonia, Madrid, Extremadura, Valencia, and Galicia) and scientific societies (European, Spanish, and Catalan societies for PC) participated in the meeting.

- A seminar devoted to policy and the necessary components for the development and implementation of PC within a public health system included standards, education and training, drug availability, service integration, and development, legislation, and financing. The participating countries to the First Central Asian Palliative Care Policy meeting included Tajikistan and Kyrgyzstan. The seminar was held in Barcelona (Spain) in March 2011 and was sponsored by the Open Society Foundation (OSF).
- At the end of 2011, the Pan American Health Organization (PAHO) office asked the WHOCC-ICO for its technical support to organize an international meeting in Honduras aimed to empower the participant countries—Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, Panama, and Dominican Republic—in the design and initial development of their national PC programs. Our center delivered lectures on the elements for the implementation and evaluation of PC programs; coordinated practical workshops; and provided documentation and direct assessment to the participants.

Demonstration to Expansion in Spain

The WHOCC-ICO also carries out projects devoted to promote palliative care at a national level. The main initiatives include:

- The program for comprehensive care of patients with advanced illnesses. This project, a funding initiative from “La Caixa” Foundation, aims to cover the emotional, spiritual, and social aspects of patients with advanced diseases (and their families). The program, built up in 2009, has implemented 32 psychosocial care teams (29 in Spain, 2 in Mexico, and 1 in Hong Kong). The teams provide complementary psychosocial intervention to that offered by the already existing PC services, which becomes a comprehensive care provision.⁷ The program has looked after 38,354 patients and 58,344 relatives, and has shown evidence of effectiveness and satisfaction.⁸
- The Catalan directory of PC services. The WHOCC-ICO has identified the existing PC services and provided a description of the model used for PC service provision in Catalonia (Spain).⁹
- The elaboration and evaluation of the Spanish National Strategy for PC.^{10–13}
- The elaboration of the Catalan Model for PC.^{14–15}

Academic Research and Development

Generating science-based evidence altogether with spreading knowledge are essential tasks for any WHO collaborating center. Since 2008, the WHOCC-ICO has elaborated a wide

range of tools and materials for dissemination purposes. They are meant to support training and implementation initiatives with a pragmatic action-focused perspective. The tools cover diverse aspects of PC such as organization and care models, programs and services, quality and improvement, psychosocial care, and identification and assessment tools. All documents are open and accessible at ico.gencat.cat.

Research projects have centered on health care services and symptom control epidemiology:

- Effectiveness of Spanish PC services in symptom control of advanced cancer patients.¹⁶
- Clinical and organizational results of hospital PC support teams in Spain, aimed at describing the clinical and organizational outcomes of hospital PC support teams' intervention in Spain.¹⁷
- Chronic pain in cancer patients in Catalonia: epidemiology, appropriateness of the analgesic treatment, and patients' satisfaction: project to establish the prevalence and etiology of chronic pain in cancer patients in Catalonia, to determine the appropriateness of treatments, and to explore patients' satisfaction with their use.^{18–19}
- Best practices in PC in Europe: project funded by the Public Health Executive Agency to define indicators of good practice on the organization and implementation of PC in seven European countries: Belgium, France, Germany, the Netherlands, Poland, Spain, and the United Kingdom.²⁰

New Opportunities and Challenges: Objectives for the Period 2012–2015

An updated and deeper analysis of patients' needs and demands together with conceptual progress and advances within the notion of public health PC have impelled the WHOCC-ICO towards an expansion to noncancer patients in the community. This new approach focuses on improving the quality of care in all services from a district perspective and responds to one of the main challenges of PC at the moment:^{21–24} the implementation of a much more anticipatory palliative care approach in caring for people with any progressive disease (not only cancer). Additionally, PC is currently being inserted into the chronic care program at the department of health in Catalonia (Spain).²⁵ Such new scope of work has led the center to generate innovative projects:

- Palliative care in the community: The **NECPAL program**

The NECPAL program (*NECesidades PALiativas*, in Spanish; Palliative Needs, in English) is based on previous experiences in the United Kingdom.^{26–27} the Gold Standards framework and the Supportive and Palliative Care Indicators Tool (SPICT). The early identification of patients with advanced chronic conditions in need of palliative care in any setting of the health system (especially primary care, nursing homes, and chronic care services) is the main objective of the program. It consists of three consecutive activities:

- Early identification of patients in need of PC in settings by using the NECPAL CCOMS-ICO[®] Tool (Centro Colaborador OMS-Instituto Catalán de Oncología, in Spanish; World Health Organization Collaborating

Centre – Catalan Institute of Oncology, in English) (previously validated).²⁸

- Implementation of a care pathway to improve their care.
- Implementation of training and quality improvement measures and actions to improve the quality of PC in services.

The NECPAL program seems to be improving the quality of PC, in primary care and other services in Catalonia.^{29–30} Additionally, the NECPAL CCOMS-ICO[®] tool is being used in other Spanish regions (Galicia and Basque country); and countries to which the WHOCC-ICO is offering support, such as Argentina³¹ or Ecuador, are adapting the program to their context.

- The **Chair of Palliative Care** at the University of Vic: "Ideas for better care"

Aimed at consolidating education and research programs, the chair of PC is oriented to community, chronic, noncancer, and geriatric PC from an academic perspective. Created in January 2012, it seeks to promote links with primary and geriatric care and to develop the community branch of the WHOCC-ICO.

Regarding education, the center leads a master of palliative care, currently in its ninth edition, which has already trained around 600 professionals (mainly physicians and nurses). It was the first official master of PC in Spain.

The research activities at the chair of PC are meant to cover epidemiology aspects (mortality, prevalence, population-based studies) and clinical issues in PC. A research group was created in April 2012 to promote projects centered on the advanced phases of chronic conditions. Furthermore, a doctorate program for the development of a PhD thesis has recently come into operation.

Evaluation

Evaluating the impact of public health programs becomes a difficult task.^{32–33} According to Lynch's proposal of levels of PC development,³⁴ we find evidence that our contribution may have improved the degree of PC development of those countries we have provided support to. However, we have not been able to implement specific evaluation procedures that allow us to measure the real impact of our interventions.

By contrast, we obtained outputs on our activities by sending a survey to a selection of key organizations and

TABLE 3. MAIN RESULTS OF THE EVALUATION SURVEY

Question	Items of response	Results n = 25
What type of activities have we been involved in? ^a	Training activities (workshops, courses, etc.) Consultancy Research projects & activities Elaboration of tools & writing of scientific publications	19 (76%) 14 (56%) 14 (56%) 12 (48%)
Please rate your overall level of satisfaction in regards to our cooperation with you.	High Fair Low	19 (76%) 5 (20%) 1 (4%)
How would you evaluate the feasibility/applicability of the activities we have been involved in?	Excellent Very Good Good Fair Poor	7 (28%) 11 (44%) 6 (24%) 1 (4%) 0
How would you evaluate our overall level of competence?	Excellent Very Good Good Fair Poor	13 (52%) 8 (32%) 2 (8%) 2 (8%) 0
How would you rate the relevance of WHOCC-ICO to palliative care development and implementation?	High Fair Low NA	20 (80%) 3 (12%) 1 (4%) 1 (4%)
What type of activities would you like to share with us in the following 4 years? ^a	Training activities (workshops, courses, etc.) Consultancy Research projects & activities Elaboration of tools & writing of scientific publications	9 (36%) 12 (48%) 13 (52%) 8 (32%)
According to your opinion, what should our functions & tasks be focused on for the next four years? ^a	Country support Consultancy Research projects & activities Training projects & activities Elaboration of tools, guides, & writing of scientific publications Community palliative care	13 (52%) 14 (56%) 23 (92%) 12 (48%) 12 (48%) 8 (32%)

^aPlease note that percentages of response do not total 100% because respondents could check all items of response that apply.

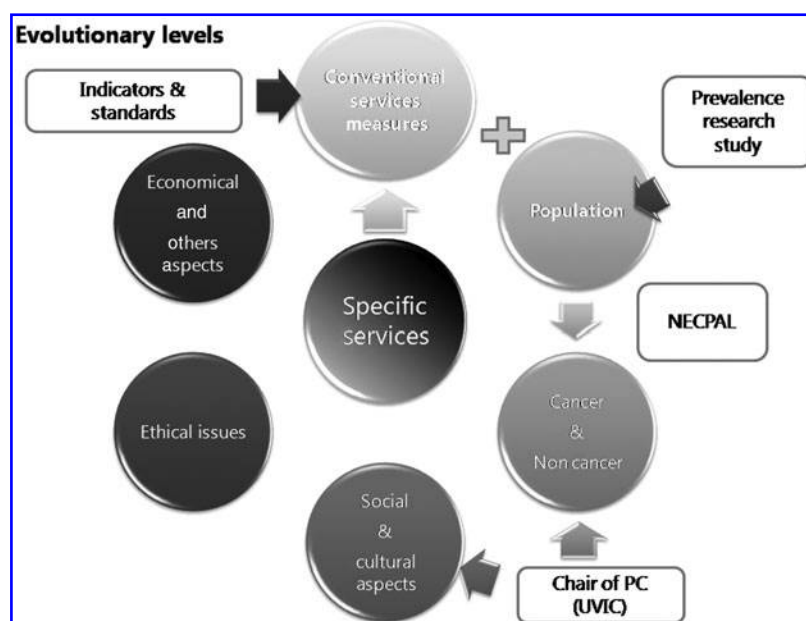


FIG. 3. Conceptual evolution of the activities developed by the WHOCC-ICO.

professionals (both at national and international levels) who had worked with us during the period 2008–2012. The questionnaire was conceived to assess and evaluate our level of competence. It was distributed to a total of 73 representatives of institutions and 34.25% completed it. The survey was mainly based on Likert-type scale methodology, though it included some open questions so that respondents could express their opinion and make proposals regarding our work methodology.

The survey revealed that the institutions that have worked with the WHOCC-ICO appreciate the center's capability and experience. Additionally, respondents provided valuable contributions regarding the center's scope of work and proposals of improvement. The comments were offered in a very constructive and positive tone. Accordingly, after internal discussion and acceptance by the WHO regional office for Europe, some of the suggestions given by the respondents were included as tasks to be developed in our official plan of work for the next years. The main results of the survey are shown in Table 3.

Discussion and Conclusions

The different actions performed by the WHOCC-ICO and the achievement of objectives resulted in its redesignation in February 2012. The evolution of the activities developed by the WHOCC-ICO and the current strategies and view of our center are shown in Figure 3.

The tasks of the WHOCC-ICO for the following four-year period are linked to the challenges of PC in the 21st century. Those include adopting a community approach (expanding towards chronic care), generating evidence, and spreading knowledge. Additionally, we intend to improve the evaluation of the impact of our interventions in those regions/countries that would require our support. This view needs to be implemented by exploring new ways of PC provision. New active and sustainable partnerships are being built with organizations and individuals sensitive to PC improvement.

The WHOCC-ICO has become a genuine, highly specialized center, focused on organizational and public health aspects of PC. It intends to respond to needs and aims in an effective and efficient manner and it is determined to extend its contribution to PC development in the future. Additionally, the center has created tools and generated new evidence in the early identification of advanced chronic patients, which represents an expansion of its area of influence to noncancer patients in the community. Such features are complementary to other initiatives and WHOCCs and appear to be appreciated by stakeholders, partners, and clients.

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Author Disclosure Statement

The authors declare that there is no conflict of interest and that no competing financial interests exist.

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