Ensure quality public health programmes: a Spanish model

In the second of a two-part series, **Xavier Gómez-Batiste**, **Frank Ferris**, **Silvia Paz**, **Jose Espinosa**, **Josep Porta-Sales**, **Jan Stjernswärd** and **Joaquim Esperalba** look at a pragmatic approach to improving the quality of palliative care public health programmes

alliative care public health programmes (PCPHPs) were proposed by the WHO in the 1990s, and have since been developed, to ensure that palliative care is a key element of any public healthcare system.¹ Several programmes have shown good results in terms of coverage, effectiveness, efficiency and satisfaction with the service.²⁻⁴

When considering how to evaluate and improve the quality of a PCPHP, several approaches can be used, either quantitative or qualitative or both. This article reviews the aims of PCPHPs, the indicators needed to evaluate them and suggested areas for improvement.

The authors propose a mixed model combining quantitative and qualitative aspects of care. This model involves selecting key elements of a palliative care service and using a pragmatic but systematic approach. That approach is based on common quantitative indicators as well as on an adaptation of the EFQM model of evaluation and improvement of quality. (The EFQM model is a framework for

Key points

- Palliative care public health programmes (PCPHPs) were proposed by the WHO in the 1990s, and have since been developed, to ensure that palliative care is a key element of any public health system.
- There is a growing need for systematic assessment tools to evaluate PCPHPs, assess the quality of the service they provide, devise ways of improving their outcomes and establish markers to enable comparison between services.
- The authors propose a mixed quantitative and qualitative model that has been used to evaluate a 15-year project in Catalonia (Spain), the WHO Demonstration Project. It could serve as a pragmatic tool to evaluate PCPHPs and compare programmes in similar geographical areas.

organisational management systems promoted by the European Foundation for Quality Management – see the first article on this subject in the previous issue of this journal.⁵) The model proposed here has been tested to evaluate a 15-year project in Catalonia (Spain), the WHO Demonstration Project.^{6,7} It could be of interest to planners, finance departments, decision-makers and service managers.

The need for a systematic approach

Access to palliative care is now seen as a basic human right and, therefore, the provision of such care should be one of the key elements of any healthcare system. Palliative care has been shown to be both effective and efficient.⁸⁻¹⁰

Since 1990, several regional and national governments have developed models of palliative care, one of them being the WHO Demonstration Project.²⁻⁴ More recently, the WHO principles for public health programmes have been disseminated and recognised worldwide. Today, many regions and countries follow these principles to implement their programmes using a systematic approach.^{8,11-16}

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Definitions and aspects of care

A PCPHP can be defined as one that covers a specific population, adopts the principles and methodology of public healthcare and is led by a public health administration – in collaboration with healthcare professionals, service providers and academics.

It may be local, district-wide, regional or national. It is publicly financed and its main aim is to implement systematic, quality palliative care that is accessible and equitable.⁸

The key requirements of a PCPHP are summarised in Box 1. A PCPHP requires clear administrative leadership, professional, organisational and academic consensus, and clearly defined short-, medium- and long-term objectives.

It should be based on an assessment of the needs of the population for cancer and non-cancer care, as well as on a description of the healthcare system and of pre-existing services.

It requires the implementation of specialist services; the improvement of care in conventional services; the improvement of access to, and availability of, opioid drugs; appropriate legislation to secure the provision of services and the access to, and availability of, opioids; quality standards; systems of finance and payment; education and training (initially focused on clinical and organisational leaders); and research strategies (which, in many countries, will at first be merely descriptive).

The formal action plan needed at the start should combine supportive measures (a support team in a hospital or in the community), parallel implementation of new services, and reallocation of resources. The results and quality of services need to be systematically evaluated and improved using indicators.

A PCPHP can be described in terms of:

- Its structure what it has at its disposal (human resources, units, beds, and so on)
- Its activities what it does (number of patients, number of visits, and so on)
- Its outcomes what it achieves (clinical care, outputs, finance, and so on).

The core qualitative aspects of a PCPHP (see Box 2) are different from those of a single palliative care service because they relate to a whole population and several services, rather than to individual patients and their families.

Evaluation of PCPHPs

A PCPHP can be evaluated using a similar method to that used for palliative care services;⁵ that is, by looking at its structure, activities and outcomes using a quantitative and/or qualitative approach and setting up indicators. An approach combining quantitative and qualitative aspects is of particular interest, as it provides richer data than a quantitative or qualitative approach alone.^{6,7}

Certain principles must be assumed, such as the need to base any evaluation on the needs of patients and their families; the need to adopt a population-based perspective; the need to select

Box 1. What does a palliative care public health programme (PCPHP) require?

- Clear leadership, general consensus and clearly defined short-, medium- and long-term objectives
- Needs assessment and description of existing services
- Implementation of specialist services; improvement of conventional services and of access to opioid drugs;
- adequate legislation; standards; financing systems; education and training; research strategies
- An action plan combining supportive measures, parallel implementation of new services and reallocation of resources
- Systematic evaluation and improvement using indicators

Box 2. Core qualitative aspects of a PCPHP

- Coverage (cancer and noncancer patients)
- Availability of, access to, and equity of services
- Quality of the different specialist services
- Co-ordination between departments
- Access to, and availability of, opioid drugs
- Number and experience of healthcare professionals
- Education and training
- Evaluation
- Research
- Funding

indicators that can be measured and therefore used to compare services.

Initial and long-term aims

A good way to start is to collect key quantitative data to show the baseline situation. A simple way to do this could be to look at a needs assessment and then check how resources are currently used to respond to those needs. For example, one could review emergency services, hospitals, place of death and opioid consumption. This would provide data that could be monitored over time.

In Catalonia, for example, it was crucial to find out, before palliative care services were implemented, what resources were used by cancer patients in their last month of life; not only to assess needs at the time (data showed an overuse of emergency services and hospital beds), but also to provide data to assess the impact of the new public health programme.

Activities and outcomes need to be measured in the short, medium and long term, according to the aims set for designated periods. For example, the initial aim in implementing services could be to identify and develop core experiences in key places – such as the main hospital or the most active community health service – while the long-term aim could be to disseminate information. In education, the initial aim could be to establish a nucleus of

clinical and organisational leaders, while the long-term aim could be to introduce education and training at undergraduate level.

The measures required when setting up a PCPHP (see Box 3) could stipulate that each initial action should be started once a decision has been taken.

A formal plan with clear aims, covering all the elements of the PCPHP, should be designed. Initially, emphasis can be put on building service capacity and ensuring that the necessary framework is in place – including adequate legislation and the required budget. The palliative care plan must be incorporated into the conventional, pre-existing health plans, including cancer control programmes, geriatric services, AIDS services and other services dealing with chronic conditions. Special attention should be paid to those palliative care services that are highly complex but deal with a relatively small number of patients, for example paediatics or AIDS services in prisons.

The palliative care plan must be incorporated into the conventional, pre-existing health plans

Structure, activities and outcomes

With regard to the structure of PCPHPs, the main factors to consider are:

- The presence of a formal plan
- The involvement of the department of health
- The number and type of specialist services to be implemented
- The number of beds
- The legislation regarding services and access to, and availability of, opioids
- Indicators
- Definitions.

Activities that should be planned as part of a PCPHP include:

- The number of patients expected to be treated and the number of visits expected to be made by specialist services
- Training (type of courses, attendance)
- Prescription of opioids.

Some of the key outcomes to aim for when setting up a PCPHP are:

- To cover the needs
- To ensure accessibility of services
- To ensure opioid availability
- To keep costs acceptable and within budget. For the services, the main outcomes are effectiveness, efficiency and/or satisfaction.

Using the information thus gathered, it is possible to assemble a list of indicators, which can be adjusted to take account of the population or other parameters. Examples of indicators are the number of specialist doctors

Box 3. Measures required when setting up a PCPHP

- A consensus between healthcare leaders, healthcare professionals and decision-makers on the need to implement the PCPHP, as well as palliative care advocacy
- Needs assessment studies
- An approved formal plan
- Adequate legislation
- Indicators
- Backing from the department of health
- The development of matured teams to act as expert consultants for the junior initiatives
- Training and continuous education to guarantee capacity-building and the availability of 'trainers for trainees'

or nurses, the opioid consumption and the number of beds per million of population.

Indicators are useful when comparing services but they must be used with caution. For instance, the place of death should no longer be used in isolation as an indication of the quality palliative care, as it is influenced by other parameters such as the availability and accessibility of beds.

Finally, it is important to distinguish between different levels of indicators, used either for basic monitoring of a programme, to focus analysis on one specific area (for example, accessibility), to evaluate specific parameters of the specialist services, or for research (for which in-depth analysis is needed).

Quantitative and qualitative indicators

Most of the indicators described so far, expressed in numbers or proportions, are quantitative. For instance, in a developed country such as Spain, providing 70% of all terminal cancer patients with adequate palliative care would be a good result. The following figures would also be satisfying: a coverage of 80% or more of a geographical area or population; one home care support team per 100,000–150,000 inhabitants; one available support team in every hospital; and 80–100 beds per million of population.

It is essential to make a quantitative evaluation of services, but it is also crucial to evaluate them qualitatively. Indeed, many elements of the services are better described in qualitative terms; for example, the length of palliative care involvement from the moment the patient is admitted into the service or the availability of the service at weekends.

Table 1. Square of qualitative evaluation and improvement for a PCPHP									
Aspects of a palliative care public health programme	Principles	Quantitative evaluation	Strong points	Weak points	Areas for improvement	Objectives/ priorities	Actions (short-, medium- and long-term)	Indicators	Team member in charge of process
Coverage									
Equity /access / services / opioids / continuing care / departmental co-ordination									
Quality of services									
Professionals									
Evaluation and monitoring									
Training									
Research									
Finance									

What is an indicator?

An indicator is a quantitative way to measure a dimension or aspect of care. Indicators are normally the result of a fraction (xxx/yyy), and can be of *structure* (having a protocol in which the evaluation is 'yes' or 'no'), *activities* (normally expressed as a number or percentage), *outcomes* (expressed as a percentage) and *other* types (for example, an 'indicator of alarm' allowing detection of a harmful situation, such as the overuse of emergency services).

Indicators should be simple, sensible, specific, effective, efficient and easy to measure. The source of the information used and the frequency with which it is recorded must be clear. It is also crucial to establish who will be responsible for monitoring the collection of information. In addition, each indicator should be defined by its name, type, definition of terms, justification, target population and fraction elements.

Good examples of indicators are the type and number of specialist services (*structure*), the number of visits carrried out (*activities*) and the coverage or percentage of patients seen by specialist services (*outcomes*). In some cases, where it is difficult to record information with total accuracy, figures will need to be estimated.

For each indicator, an acceptable standard should be set against which outcomes can be measured. For example, in Spain, provision of adequate palliative care to 70% of all terminal cancer patients would be seen as the standard to aim for.

Box 4. Basic quantitative indicators for monitoring a palliative care public health programme(PCPHP)

Structure

- Formal palliative care plan approved by the department of health
- Elements such as services, units, teams, beds
- Comparison between the various elements and the standards
- Number of healthcare professionals
- Finance models and budgets
- Legislation regarding opioids
- Indicators and standards

Activities

- Type and number of specialist services
- Number of patients (cancer/non-cancer) seen by specialist services
- Training activities; research; quality improvement
- Measures taken to improve care in conventional services

Outcomes

- Direct coverage of cancer and non-cancer patients
- Beds per million population, services per million population, geographical coverage, and so on
- Opioid consumption (for morphine, daily defined doses)
- Length of stay, length of intervention, place of death, and so on
- Clinical outcomes: effectiveness, efficacy, satisfaction
- Organisational outcomes: efficiency, use, individual/ global cost
- Economical outcomes: individual/global cost, estimated savings
- Educational outcomes: number of professionals trained; availability of basic and advanced palliative care training courses; professorships; research (clinical, organisational, evaluation of services); number and impact of publications

Quantitative evaluation

When monitoring the *structure* of a PCPHP, basic quantitative indicators are: the formal palliative care plan approved by the department of health (including elements such as services,

units, teams and beds); a comparison between the various elements and the ideal standards against which they can be measured; the number of healthcare professionals; finance models and budgets; the presence of legislation regarding opioids; indicators and standards.

The indicators used to monitor *activities* must reflect the activities carried out by the palliative care network. They can include the type and number of specialist services, the number of patients (cancer and non-cancer) seen by specialist services, training activities, research and quality improvement.

The main outcomes that need to be monitored are the direct coverage of cancer and noncancer patients (proportion of cancer and noncancer patients cared for by the specialist palliative care teams); the beds per million population, services per million population and geographical coverage; the opioid consumption. It is also essential to consider outputs such as the length of stay and duration of intervention. Palliative care services should also be measured by their clinical outcomes (effectiveness, efficacy, satisfaction), organisational outcomes (efficiency, use, cost) and economical outcomes (cost, estimated savings). 17-19 Educational outcomes can include the number of professionals trained, the number of professorships, the research conducted and the number and impact of publications.

The quantitative indicators needed to evaluate structure, activities and outcomes of a PCPHP are summarised in Box 4 (page 197).

Qualitative evaluation

Qualitative evaluation can be carried out using the qualitative aspects listed in Box 2 (page 195). From this pragmatic approach at the basic level, it is possible to move on to a greater degree of complexity and focus. Different aims relating to different aspects of the PCPHP can be identified, either by qualitative analysis or by other means, and more complex research can be carried out.

Gómez-Batiste *et al* have reported elsewhere on the methodology for the qualitative evaluation.⁶ A multidisciplinary group of experts from different areas of the healthcare system chose aspects to be evaluated,⁶ most of which were among the aspects of a PCPHP listed in Box 2 (page 195).

Some aspects that we recommend should be evaluated are: the coverage of the service (focusing, for example, on continuity of care and weekend coverage); accessibility, equity and

quality of services; co-ordination between departments; the patterns of opioid prescription; the proportion of healthcare professionals trained in palliative care and the level to which they have been trained; education and training; evaluation; research; and funding.

Once it has been decided which aspects are to be evaluated, it is necessary to define the principles of care and to check the quantitative aspects; the next stage is to identify strong and weak points, areas that need improvement, objectives, actions that need to be taken in the short, medium and long term, and indicators. Finally, it is essential to identify an individual team member who will be responsible for carrying out the evaluation process. Table 1 (page 197) shows the square of evaluation and improvement for a PCPHP. Box 5 (page 199) sums up the different stages of the process. This process is similar to the ones used for evaluating services and patient care that were described in the first article of this series.⁵

Evaluation of the Catalonia WHO Demonstration Project

For the qualitative evaluation of the Catalonia WHO Demonstration Project after 15 years, we added qualitative evaluation to a conventional quantitative evaluation. We defined the aspects that needed to be evaluated. For each aspect, a list was drawn up of priorities and guiding principles; the quantitative data available; strong and weak points; areas for improvement; objectives; short-, medium- and long-term actions; and indicators for measuring progress. The results are shown in Box 6 (page 199).

The qualitative analysis added value to the quantitative analysis, allowing us to identify many aspects that needed to be re-evaluated to further improve quality. It generated a list of proposals that are now being implemented, including, for example:

- Improving continuity of care through call centres and training of the emergency teams
- Allowing oncology nurses to identify needs and request early intervention of palliative care services
- Developing a core set of indicators for emotional assessment and interventions.

Conclusions and recommendations

As is the case for palliative care or conventional healthcare services,⁵ there are several ways of evaluating PCPHPs – according to the elements,

It is essential to identify an individual team member who will be responsible for carrying out the evaluation process levels, timeframe, aims (monitoring, focusing on specific aspects, conducting research), feasibility and type (structure, activities, outcomes) of the different aspects of the programmes. The evaluation can focus on some specific aspects – such as access to opioids, equity of services, access to services, quality of services, results or any other element – as has been described elsewhere recently. 5,20

What we propose is a mixed – quantitative and qualitative – model, which can be used at a basic level and combines the most relevant parameters. We used it to evaluate the Catalonia WHO Demonstration Project after 15 years and, as a result, several measures have been implemented to improve on weak points that had been identified. It could serve as a pragmatic tool to evaluate PCPHPs and compare programmes in similar geographical areas. Further research will be necessary to demonstrate its accuracy and reliability.

References

- 1. Stjernswärd J, Colleau SM, Ventafridda V. The World Health Organization Cancer Pain and Palliative Care Program. Past, present, and future. *J Pain Symptom Manage* 1996; **12**: 65–72.

 2. Gómez-Batiste X, Porta-Sales J, Pascual A *et al*. Catalonia WHO
- 2. Gómez-Batiste X, Porta-Sales J, Pascual A *et al.* Catalonia WHO palliative care demonstration project at 15 Years (2005). *J Pain Symptom Manage* 2007; **33**: 584–590.
- 3. Fainsinger RL, Brenneis C, Fassbender K. Edmonton, Canada: a regional model of palliative care development. *J Pain Symptom Manage* 2007; **33**: 634–639.
- 4. Herrera E, Rocafort J, de Lima L *et al*. Regional palliative care program in Extremadura: an effective public health care model in a sparsely populated region. *J Pain Symptom Manage* 2007; **33:** 591–598. 5. Gómez-Batiste X, Ferris F, Picaza JM *et al*. How to ensure good quality palliative care: a Spanish model. *European Journal of Palliative Care* 2008; **15:** 142–147.
- 6. Gómez-Batiste X, Minguell C, Nabal M et al. Evaluación cualitativa de la situación a los 15 años y propuestas de mejora del Proyecto Demostrativo OMS de Cuidados Paliativos de Cataluña. Medicina Paliativa, Madrid, 2008 (In press).
- 7. Ingleton C, Davies S. Mixed methods for evaluation research. In: Addington-Hall J et al (eds). Research methods in palliative care. Oxford: Oxford University Press, 2007: 191–209.
- 8. Stjernswärd J, Foley KM, Ferris FD. Integrating palliative care into national policies. *J Pain Symptom Manage* 2007; **33:** 514–520. 9. Brennan F. Palliative care as an international human right. *J Pain Symptom Manage* 2007; **33:** 494–499.
- 10. Gysels M, Higginson IJ. *Improving Supportive and Palliative Care for Adults with Cancer. Research Evidence Manual.* London: NICE Guidance on Cancer Services. 2004.
- 11. Council of Europe. Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care. Stockholm: November 2003.
- 12. Kaasa S, Jordhøy MS, Haugen DF. Palliative care in Norway: a national public health model. *J Pain Symptom Manage* 2007; **33**: 599–604.
- 13. Cancer Care Ontario. Palliative care strategy: improving the quality of palliative care services for cancer patients in Ontario. October 2006. http://www.cancercare.on.ca/index_planning.htm# PalliativeCare (last accessed 21/05/2008)
- 14. Stjernswärd J. National palliative care program: Georgia. http://www.parliament.ge/files/619_8111_336972_Paliativi-Eng.pdf (last accessed 21/05/2008)
- 15. Davaasuren O, Stjernswärd J, Callaway M *et al*. Mongolia: establishing a national palliative care program. *J Pain Symptom Manage* 2007; **33:** 568–572.
- 16. Stjernswärd J. Uganda: initiating a government public health approach to pain relief and palliative care. *J Pain Symptom Manage* 2002; **24:** 257–264.
- 17. Roca Casademunt R. Efectividad en el control de síntomas: estudio multicéntrico. [Symptom control effectiveness: multicenter study.] *Jornada Nacional de la Sociedad Española de Cuidados Paliativos* (SECPAL) 2005; octubre: 27–29.
- 18. Serra-Prat M, Gallo P, Picaza JM. Home palliative care as a cost-saving alternative: evidence from Catalonia. *Palliat Med* 2001; **15**: 271–278.
- 19. Gómez-Batiste X, Tuca A, Corrales E et al. Grupo de Evaluación-

Box 5. The stages of the qualitative evaluation process

- For each area, set up a list of priorities and guiding principles
- Check quantitative aspects
- Identify strong points
- Identify weak points
- Identify areas for improvement
- Identify objectives and priorities
- Identify actions to be taken in the short, medium and long term
- Identify indicators for measuring progress
- Identify a team member in charge of the evaluation process

Box 6. Results of the qualitative evaluation of the Catalonia WHO Demonstration Project

Strong points

- Region of 7.3 million inhabitants
- High coverage of cancer patients
- Adequate geographical distribution of palliative care services
- High coverage of cancer and non-cancer patients at home
- Healthcare professionals' commitment
- Public health planning
- Palliative care programmes well inserted into the regional public health system
- Diverse models of palliative care provision
- Effectiveness, efficiency, satisfaction

Weak points

- Low coverage of non-cancer patients, meaning inequitable access to palliative care
- Important variations between geographical sectors and specialist and non-specialist services
- Difficulties in access and in continuing care (off hours, weekends)
- Late intervention of palliative care services
- Poor evaluation, emotional support and bereavement support
- Low income, low level of support and lack of academic recognition for healthcare professionals
- Complexity of the financial model
- Lack of research initiatives and poor production of scientific evidence

SECPAL. Resource consumption and costs of palliative care services in Spain: a multicenter prospective study. *J Pain Symptom Manage* 2006; **31:** 522–532.

20. Gómez-Batiste X, Paz S. Public palliative care: review of key developments and implementation issues. *Current Opinion in Supportive Pall Care* 2007; **1:** 213–217.

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