

# How to design and implement palliative care public health programmes: foundation measures. An operational paper by the WHO Collaborating Centre for Public Health Palliative Care Programmes at the Catalan Institute of Oncology

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## ABSTRACT

This paper summarises the recommendations of the WHO Collaborating Centre for Palliative Care Public Health Programmes with respect to design and implementation of palliative care national or regional public health palliative care programmes in their initial phases. We describe the elements of a programme (leadership and aims; needs and context assessment; definition of the target patients; general measures in conventional services; specialist services in different settings; sectorised networks; education and training; availability and accessibility of opioids and essential drugs; legislation; standards; budget; valuation and improvement of quality; and evaluation of results and indicators) and the specific recommendations to implement the first steps of each component. Palliative care planning needs to be systematic, inserted in all levels of the healthcare system and adapted to the cultural and organisational status of the system. Coverage for all types of patients in need, together with equity and quality, are the main aims of programmes.

## INTRODUCTION AND BACKGROUND

In most countries there is a progressive increase in the number of individuals suffering from chronic illnesses (singly or, more usually, with comorbidities) with a limited prognosis and with enormous demands on care and resources of healthcare systems. More than 75% of the population will die from these chronic diseases, including cancer, progressive neurological disease, organ failure and others.<sup>1</sup>

Palliative care (PC) provision is effective, efficient and with high satisfaction on the part of these patients and their families.<sup>2</sup> The model of care and intervention are well defined, and several effective models of organisation are adaptable to every healthcare setting.

PC needs to be inserted within a national health system (NHS) (Servicio Nacional de Salud) and there are many experiences of planning and implementation of PC provision with this vision.<sup>3</sup>

## AIMS

This article summarises the key elements and recommendations for designing and building up PC programmes (PCP) with a public health (PH) perspective, focusing on the initial foundation

measures. It is based on the experience of the WHO Collaborating Centre for PHPCP at the Catalan Institute of Oncology (Barcelona, Spain) in designing, implementing and evaluating the Catalonia WHO Demonstration Project of PC, implemented 20 years ago, the experience obtained in supporting other countries in their programmes and the collected teaching materials, comments and evaluations of attendees, and from invited faculty experts at the training activities related to the support. Its main aim has been to act as an operational tool to help clinical and organisational leaders to implement specialist services in different settings of the healthcare system. It is based on the Catalan experience and also on the experience of cooperation with other countries. We tested our proposals in 18 workshops ('How to design and implement PCP and services with a PH perspective', and 'How to improve PC in a district') conducted by our team over the past 10 years in different settings and countries. A long and detailed version of this tool and the materials are summarised on our website,<sup>4</sup> with a complementary article 'How to design and implement PC services' (box 1).

## COMPONENTS AND FOUNDATION MEASURES OF PCPH PROGRAMMES

### PCPH programmes: definitions and concepts

We define PCPH programmes (PCPHP) as the systematic measures taken to improve quality of care for advanced and terminally ill patients and their families, within a population based context (national, regional or district level). The main aims are universal coverage, with quality care provided free to the user at the point of access. Most of these provisions are from the state funded NHS, with cooperation from other organisations (for profit and non-profit). The WHO Demonstration Projects were designed in the 1990s to develop a systematic implementation and evaluation of PC, the aims being to generate evidence<sup>5-7</sup> in support of the recommendations of international bodies.<sup>8,9</sup>

### Context analysis, needs assessment and target population

The context analysis includes demographic, social and geographic aspects as well as data on the

## Feature

**BOX 1 COMPONENTS AND FOUNDATION MEASURES OF PALLIATIVE CARE PUBLIC HEALTH PROGRAMMES**

- ▶ Clear leadership and aims
- ▶ Needs and context assessment
- ▶ Clear model of care and intervention, and definition of target patients
- ▶ General measures in conventional services (especially primary care)
- ▶ Specialist services in different settings
- ▶ Sectorised networks with coordination, continuing and emergency care
- ▶ Education and training at all levels
- ▶ Research planning
- ▶ Availability and accessibility of opioids and essential drugs
- ▶ Legislation, standards, budget and models of funding and purchasing
- ▶ Social implication: volunteers, social involvement in the cultural, social and ethical debates surrounding end of life
- ▶ Evaluation and improvement of quality
- ▶ Action plans at short, medium and long term
- ▶ Evaluation of results, indicators

models of organisation accessibility and funding of existing healthcare services (primary care, hospital services, nursing homes and home care services), their prevalence of advanced terminal patients and their capacity and quality in the provision of appropriate PC to look after these patients.

In developed countries with ageing populations (15–20% >65 years of age) and mortality levels around 9/1000/year, we estimate that 60–75% of the population will die as a result of a chronic advanced progressive illness that includes a period of terminal illness.<sup>10</sup> The most frequent causes are: cancer (20–25%), chronic organ failure (cardiac, pulmonary, hepatic and renal), neurological diseases, HIV/AIDS and other infectious conditions (35–45%). Of note are comorbidities, frailty related to ageing and the acute exacerbations of all of the chronic conditions mentioned above. The death rates from these conditions are known, or can be estimated, in most countries.

Once the death rates are known, an additional piece of information of considerable interest is an estimation of prevalence, or the total number of patients having advanced diseases at a defined period of time (box 2).

Our preliminary data from a population based prevalence study show that the total prevalence of patients with advanced chronic diseases with a limited lifespan prognosis is approximately 1.4% of the adult population in the district of Catalonia.<sup>11 12</sup>

**Defining target patients**

To define target patients and to assess PC needs in individual patients and in settings of conventional healthcare services, we recommend using an adapted version of the Prognostic Indicator Guidance of the Gold Standards Framework, which has been translated into several languages, or the Scottish Supportive and Palliative Care Indicators Tool.<sup>13 14</sup> Such tools are simple, easy to use, sensitive and available to any healthcare service. They have been demonstrated to have a positive impact on improving PC in various settings.<sup>15–17</sup> Also, these tools help

**BOX 2 SIMPLIFIED METHOD OF ESTIMATING POPULATION PALLIATIVE CARE NEEDS FOR 1 MILLION INHABITANTS IN A DEVELOPED COUNTRY WITH AN OVERALL MORTALITY RATE OF 9/1000/YEAR (WHO COLLABORATING CENTRE-ICO, 2009)***Mortality:*

1. Overall: 9000/million
2. 70% (6300/million=6.3/1000) from chronic progressive illness
  - ▶ 25% (2250) cancer
  - ▶ 45% (4050) non-cancer
3. Proportion non-cancer/cancer=1.5–2

*Prevalence:*

1. 1.4% of adult population (14000/million habitants) have one or multiple chronic conditions and a limited life expectancy in high income countries
2. The prevalence by setting is variable according to the composition and case mix of patients
3. The proportion cancer/non-cancer is 9 : 1.

*Optimal direct coverage by specialist palliative care services (per million and related to mortality)*

Cancer: >60% of mortality ≥1350

Non-cancer: 30–60% of mortality=1215–2430

in determining the prevalence of patients with advanced illness in population based surveys and also those individuals with need of PC measures. Our adapted version of the tool (NECPAL CCOMS-ICO) is shown in box 3.

**Leadership, key stakeholders and core nominal group**

At the national level, an effective combination consists of leadership at the level of the Ministry of Health, involving policy makers and funding bodies working with an integrated multidisciplinary team of clinicians and other healthcare professionals (PC and allied disciplines), and also involving non-governmental organisations, academics and managerial experts. At the local level of individual services, well trained clinical leaders with leadership and organisational competence is one of the most relevant factors for success.

**Principles, values and aims of PCPHPs**

Most frequently, the principles and values of PCPHPs and services are to provide care for persons in vulnerable situations. As such, they are based on compassion, respect, ethical commitment and interdisciplinary collaboration. More broadly, they are associated with the principles of PH, including equity of access, quality of care (effectiveness, efficiency, accessibility and safety), accountability and sustainability.<sup>3</sup>

**Clear definition of the model of care and intervention**

The model of care is the ‘soul’ of a PC organisation or programme, and the conceptual basis to guarantee the quality of care and to avoid misunderstandings. Prior to implementation, it is fundamental to clearly define the model of care and intervention and base it on the multidimensional needs of patients and their families.<sup>18</sup> We define the microorganisation of PC as ‘the systematic approach’ (careful assessment followed by definition of objectives, actions and appropriate follow-up) to the multidimensional needs of patients and their families, practised by a competent multidisciplinary team which makes use of

### BOX 3 SIMPLIFIED METHOD OF ESTIMATING POPULATION PALLIATIVE CARE NEEDS FOR 1 MILLION INHABITANTS IN A DEVELOPED COUNTRY WITH AN OVERALL MORTALITY RATE OF 9/1000/YEAR (WHO COLLABORATING CENTRE-ICO, 2009)

The NECPAL-CCOMS-ICO tool for identifying palliative care population in health care services (adapted version of the Gold Standards Framework/Supportive and Palliative Care Indicators Tool recommendations)

1. The surprise question: Would you be surprised if this patient dies in 1 year?
2. Implicit or explicit demand on Limit of Therapeutic Efforts or request for palliative measures by patient, family or team members (\*)
3. Clinical dimensions: persistent, gradual irreversible, not linked to intercurrent disease in the past 6 months (combining severity and progression) (\*)
  - ▶ Functional decline (Karnofsky Performance Status or Barthel)
  - ▶ Nutritional decline (weight loss >10% or serum albumin <25 g/l)
  - ▶ Geriatric syndromes and conditions (severe frailty, etc) (\*)
  - ▶ Refractory ulcers or repeated infections
  - ▶ Severe emotional distress (\*)
4. Use of resources: >3 hospital emergencies or urgent admissions in 6 months
5. Comorbidities: >3 advanced chronic diseases
6. Specific tools for specific organ failures (cancer, cardiac, respiratory, renal, etc)

\*Elements added to the Supportive and Palliative Care Indicators Tool and Prognostic Indicator Guidance/ Gold Standards Framework tools

clinical ethics for decision making, and with advanced care planning and case management as methodologies.

#### Models of organisation: levels, settings, scenarios, definitions and standards<sup>19 20</sup>

Specialist PC services can be defined as interdisciplinary teams with advanced training that are devoted to advanced and terminally ill patients and their families. Specialist PC services can be defined as interdisciplinary teams with advanced training, devoted to the care of complex advanced and terminally ill patients and their families. The most relevant elements of specialist service structure are advanced training, and good clinical and organisational leadership.

There are different levels and types of services that can be applied, in combination or individually. These include: support teams (in hospital, at home or both); units (beds); outpatient clinics; day care hospitals; and individual hospices. These services and activities can be undertaken in any setting within the healthcare system. There may be differences in the levels of complexity of patients (young, refractory symptoms and adjustment difficulties) and also interventions (access to radiotherapy or invasive technology) or length of stay ('chronic' vs 'acute' beds). A comprehensive PC network is a system of integrated PC services offering all services in a geographically defined district. 'Reference' PC services are defined by providing high complexity interventions, advanced training and research,

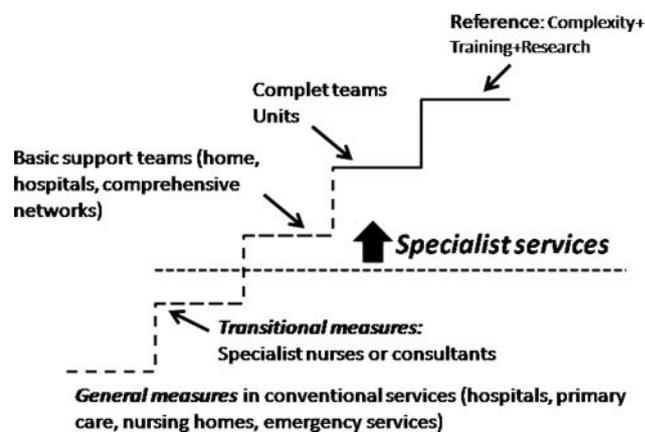


Figure 1 Levels of complexity of palliative care planning.

and are usually located in tertiary care hospitals associated with university teaching facilities. The hospice movement consists of an independent organisation focusing on PC, although in some countries other types of care provision are involved.

The levels of complexity of PC specialist services are shown in figure 1. The recommended standards of specialist services in western European countries are listed in box 4.

We use the term transitional measures when there is specific implementation of any resource devoted to PC in a conventional service, but not fulfilling the criteria of a specialist team.

#### Models in demographic or specific scenarios

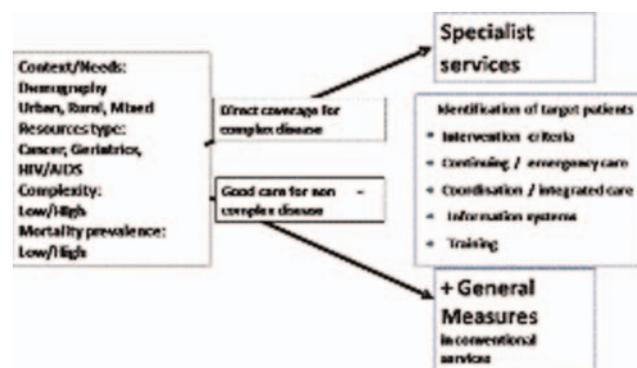
District or sector wide planning and organisation are the bases for the organisation of geriatric, chronic and PC services. The first step would be to identify similar settings (such as cancer institutes, nursing homes and acute bed hospitals) and demographic scenarios (such as metropolitan, rural and urban) and then to define the models of organisation adapted to their needs and resources. For instance, in rural areas with a small population, it may not be necessary to have specific PC beds and a basic mixed support team attending all types of patients could be sufficient; in metropolitan districts it will be necessary to have all levels of PC organisation and disease specific services. To establish district plans, we can use the same methodology as for regional or national plans (figure 2), including

### Box 4 Simplified method of estimating population palliative care needs for 1 million inhabitants in a developed country with an overall mortality rate of 9/1000/year (WHO Collaborating Centre-ICO, 2009)

Standards of specialist services in developed countries (WHO Collaborating Centre-ICO, 2009)

- ▶ 1 Support team (ST) accessible in all settings
- ▶ 1 Home care ST (HCST)/100–150000 inhabitants
- ▶ 1 Hospital ST (HST)+outpatient clinic (OutP) in hospitals
- ▶ 80–100 beds/million inhabitants (20–30% acute, 40–50% in medium stay and 30–40% in nursing homes)
- ▶ Reference services with HST, palliative care unit, OutP, research and education in university hospitals and cancer comprehensive centres
- ▶ Sector models (metropolitan, urban, rural)

## Feature



**Figure 2** Sectorised planning. needs assessment (demographic, mortality, prevalence and existing services, etc), the definition of the model of PC services adapted to needs, the general measures to be adopted by the conventional services and the criteria for intervention of specialist services, joint policies, emergency and out of hours care.

### Initial implementation of PC services

We can establish several steps in the implementation of specialist PC services. Initially, the main goal is to consolidate a solid core with a diversified nucleus of services provided by health-care professional leaders who can generate good short term outcomes, serve as organisational reference and spread clinical knowledge. Support teams in cancer centres, hospitals or in the community are good examples.

### General PC measures in conventional services

These measures are oriented towards improving the care of patients who, suffering from any advanced condition, represent a high prevalence and demand on such services (table 1). The most frequent services are: primary care, oncology, geriatrics, internal medicine, nursing homes, social health centres and intermediate care centres. This general approach is crucial to achieve good care for all patients.

### Indicators, standards and quality improvement

In the initial phase of development, consensus between policy makers, physicians, professional bodies and managers is required to define the indicators, standards and mechanisms of quality evaluation and improvement. Consensus can be reached using the published experience (European Association for Palliative Care (EAPC), Canada, USA, Australia, Spain) and adapting it to the required situation.<sup>21–24</sup>

### Initial training strategies

Initially, and in the absence of formal training methodologies, the main objective of the training strategy is to build up a core nucleus of leaders with pioneering experiences. Once this is established, they can become referents for the training of other specialist and conventional services that provide PC.

Methodologies such as mentoring, twinning and modelling are strongly recommended. Organisational training can be achieved quickly and effectively by visiting well experienced reference centres and adapting their models to local needs.

**Table 1** Proposed palliative care measures within conventional services: primary care, oncology, geriatrics and nursing homes (WHO Collaborating Centre-ICO, 2009)

Aim	Primary care	Hospital care
Improving the skills of professionals in healthcare provision	Basic and intermediate training in PC	
Identification of patients in need (Gold Standards Framework/SPICT*/NECPAL†)	Identification of patients in need	
Registries	Use of tools Clinical charts with registries (symptom checklist, etc), assessment tools, etc	
Internal and external reference professionals in healthcare provision	Specific reference professionals (doctors, nurses, others) with advanced training and dedication to PC	
Improving accessibility of patients and families	Promotion of home care Phone support programmes Access to rapid consultation Direct access to PC beds information Free access of families to hospital	
Improving continuing care and emergency care	Advance care planning, continuing care, 24 h phone access, preventive attitude, tailored emergency care, direct access to PC beds	
Specific times and places for patients and their families	Specific times for advanced patients and their families	Specific outpatient times for advanced patients and their families Advanced terminal patients grouped in units
Improving family care	Education and support for carers Prevention and treatment of complicated bereavement	
Promotion of team-work	Team meetings Team support and burn out prevention	
Promotion of privacy and dignity		Individual bedrooms
Assessing and improving the quality of care	Policies: pain, last days, etc End of life inserted within the quality assessment	
Coordination and integrated care with specialist palliative care services	Criteria of intervention and shared care with PCS Nurses able to demand and prescribe services	

\*SPICT, Supportive and Palliative Care Indicators Tool.

†NECPAL, a tool developed by the WHO Collaborating Centre for Palliative Care Programmes. PC, palliative care; PCS, palliative care services.

### Initial research strategies

Initial research strategies focus on describing the needs and contexts, and in recognising data and indicators which can be monitored to provide evidence of progress (see evaluation and follow-up below).

### Essential drugs and opioids: availability and accessibility

Specific policies for availability and accessibility of essential drugs are mandatory, based on established clinical guidelines. A list of essential drugs for PC must be made<sup>25</sup> and a specific plan for its implementation must be in place by the time the services commence. There are excellent references of successful policies.<sup>26</sup>

Changes in legislation must include essential drug availability in every setting (hospitals, community care and nursing homes) for all prescribing physicians with reasonable limits on dosage.

Additionally, comprehensive training must be undertaken to target services and to reduce negative myths related to misuse, diversion, toxicity and drug abuse. Oral and subcutaneous morphine combined with co-analgesics and general measures are still the most effective, efficient and cheap treatments for severe pain associated with cancer. Public funding of these drugs is essential so as to make these critical drugs available to patients in times of need, irrespective of the individual's economic status.

### Legislation

The legislation of PC includes:

- ▶ Insertion of PC into existing policies (global or specific health plans for cancer, geriatric medicine, AIDS and other chronic conditions).
- ▶ Formal approval and recognition of national plans.
- ▶ Basic legislation (laws, decrees and ministerial orders) that could be generic.
- ▶ Specific changes to assure opioid availability.
- ▶ Standards and definitions of services.
- ▶ Funding and purchasing of outsourced PC services.
- ▶ Other related legislations: advance directives and autonomy, rights of patients, ethical committees and support (funding or changes in labour legislation) for carers.

### Budget, funding and purchase of PC

Developing an overall budget for PC is strongly advised, the funding or purchase of which is often included within the general models of the specific country. There are several ways of funding/purchasing services based on structure, activity and outcomes, and encouraged by quality, education and research.<sup>27</sup>

Identification of resistances and barriers as well as opportunities and alliances in PC represents a radical innovation and change in the model of care and organisation of healthcare provision. Resistances and barriers may arise as a result of misunderstandings, power issues, personality clashes or corporate interests. In contrast, there are frequent alliances in favour of PC implementation. Support comes from public, social and political leaders, allied services (including ethics committees, quality concerns in primary care, geriatric care, nursing, social work and psychological assistance).

In some countries undergoing reorganisation of their healthcare systems, PC, geriatric care and care for the chronically ill are becoming relevant issues in policy making and, as such, PC can be a very important factor in the innovative response to the needs and demands on healthcare resources.

### Advocacy

Advocacy can be defined as the process of influencing targets that help in the development of services. It is recommended to select appropriate messages for the different targets, such as policy makers, managers, academics, social and political leaders, and communication media. The best advocacy, when targeting public support, derives from exemplary services with clear evidence.

### Evaluation and follow-up

It is crucial, in the initial phase, to define the aims and actions to be implemented in the short, medium and long term. Indicators and mechanisms of evaluation of improvement in programmes and services need to be selected.

There are several ways of conducting evaluations, whether quantitative or qualitative. Indicators must be chosen according to their relevance to quality and feasibility. Coverage, quality, accessibility and equality of access are the key issues requiring monitoring. Coverage may be related to the proportion of patients receiving attention from specialist services (direct coverage), patients receiving more appropriate attention in conventional services (indirect coverage) and the districts and care settings having services available (geographical or settings coverage). The structure, activities and outputs of specialist services can be collected in a directory or registry that may be accessible to patients as well as healthcare professionals. The quality of services can also be measured by focusing on effectiveness, efficiency, cost, cost/effectiveness and patient satisfaction. Opioid consumption is a cornerstone of results, but the data are sometimes difficult to retrieve due to the registry itself or confusion as to the items registered (eg, prescription for methadone to assist addiction withdrawal). Different approaches for evaluation of the Catalonia WHO Demonstration Project at 20 years have been published.<sup>28</sup> Another interesting source is the PC Outcomes Collaborative Programme in Australia, which benchmarks five outcomes for every occasion of service in PC.<sup>29</sup>

### FREQUENT DILEMMAS IN THE INITIAL PHASES

There are frequent questions and dilemmas that can be resolved with common sense.

1. Where to place the services?

In the initial phases, the criteria for implementing services are based on feasibility, available leadership and on the impact of the referral service. More generally, the initial aim would be to begin with different models of services in different settings (hospital, home, intermediate care in rural and urban settings).

2. Who are the target patients in the initial phases?

In most countries, the PC remit is to provide care for advanced cancer patients and, subsequently, extended to cover other terminally ill patients.

3. How many specialist services are needed?

This can be very variable. A good criterion for the long term aim is to have at least one service available in every district, and for patients from every setting to have access to some specialist services.

4. How many specialist beds are needed?

The need for PC beds is variable and depends on patient needs and on the capacity of existing services. In our country, the estimate is between 80 and 100 beds per million inhabitants.<sup>30</sup> These beds can be located in acute hospitals, intermediate care or nursing home settings, in various proportions.

5. Do we need extra beds for implementing specialist PC units?

No. In most countries the PC specialist units result from the reallocation of pre-existing beds, or even reassignment within the context of bed number reduction.

6. Which is the best model of service?

There are no major differences between the different models of services. In the initial phase, it is recommended to start with support teams as these are the most feasible. The hospice initiatives and Macmillan Nursing could be the first service of choice as they are supported by charitable institutions and non-governmental organisations which play a significant role in countries such as the UK.

## CONCLUSIONS AND RECOMMENDATIONS

In most countries, nearly 75% of the population will die from a chronic progressive disease. The process will cause suffering, have a considerable impact on patients and their families, and will be a drain on available resources. PC must be considered as one of the essential conventional elements of a publicly funded NHS. There are successful experiences in designing, implementing and evaluating PCPs with a PH WHO perspective. Clear and effective leadership is vital. Partnership between the health administrators, policy makers, non-governmental organisations, scientific societies, managers, healthcare professionals and society in general should be encouraged. Mechanisms that encourage participation are strongly recommended, especially in the early stages of implementing foundation measures. There are defined aims (coverage, equality of access and quality of care); elements (context analysis, assessment of needs, defining target patients and populations); clear models of care and intervention; measures in conventional services; measures for implementing specialist services; models in sectors and settings; opioid and essential drugs accessibility and availability; training and research strategies; evaluation and monitoring; legislation, budgeting and financing models; action plans for the short, medium and long term; and combined actions (catalytic, new services, reallocation of resources) that must be applied to achieve success. Rational planning is crucial for effective and efficient outcomes.

The WHO and its Collaborating Centres are strongly committed to promoting PHPCP.

## LIMITATIONS OF THIS ARTICLE

This operational paper describes the key issues in the design and implement of PCPHP based on the experience we have acquired at the WHO Collaborating Centres, particularly in using the material for training activities linked to these experiences. Although based exclusively on the Catalan experience of the WHO Demonstration Project, this article can be useful in other contexts since it is mainly methodological.

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## How to design and implement palliative care public health programmes: foundation measures. An operational paper by the WHO Collaborating Centre for Public Health Palliative Care Programmes at the Catalan Institute of Oncology

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