



Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach

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Purpose of review

We describe conceptual innovations in palliative care epidemiology and the methods to identify patients in need of palliative care, in all settings.

In middle–high-income countries, more than 75% of the population will die from chronic progressive diseases. Around 1.2–1.4% of such populations suffer from chronic advanced conditions, with limited life expectancy. Clinical status deteriorates progressively with frequent crises of needs, high social impact, and high use of costly healthcare resources.

Recent findings

The innovative concept of patients with advanced chronic diseases and limited life prognosis has been addressed recently, and several methods to identify them have been developed.

Summary

The challenges are to promote early and shared interventions, extended to all patients in need, in all settings of the social care and healthcare systems; to design and develop Palliative Care Programmes with a Public Health perspective. The first action is to identify, using the appropriate tools early in the clinical evolution of the disease, all patients in need of palliative care in all settings of care, especially in primary care services, nursing homes, and healthcare services responsible for care provision for these patients; to promote appropriate care in patients with advanced diseases with prognosis of poor survival.

Keywords

advanced chronic patients, chronic care, planning, policy, stratification

INTRODUCTION

The article summarizes the changes in needs and demands of patients receiving palliative care, the conceptual progress within the concept of Public Health Palliative Care, and the bases for a rational planning. The community-oriented and population-oriented approach should be employed to identify all types of patients in all settings using appropriate tools at the same time as implementing measures to improve the quality of care in all services from a District perspective. Palliative care needs to be inserted into Chronic Care Programmes.

The public health approach to palliative care

More than 75% of the population in middle-/high-income countries will die from one or more chronic conditions. Death is usually preceded by a protracted period of progressive disease which causes

physical and nutritional decline, emotional trauma, frequent crises of needs and demands, frequent ethical decision-making, frequent use of resources and considerable suffering to the patients and their families.

Palliative care was initially developed in the British hospice movement in the 1960s. Guided

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KEY POINTS

- Mortality and prevalence due to progressive chronic conditions with a limited life prognosis are over 75 and 1.2%, respectively, in high-income countries.
- Palliative care must be applied to patients suffering from all chronic diseases and conditions, early in the evolution, and in all settings of health and social systems.
- There are methods and tools to identify patients in need of palliative care.
- Palliative care must be an essential component of Chronic Care Programmes with a Community oriented and Public Health vision.

by the pioneering work of Cicely Saunders, the concept evolved to include multidimensional needs of patients with a comprehensive approach practised by a multidisciplinary team focussing, initially, on end-of-life cancer patients attended to in hospices.

The first reference to palliative care being identified as a public health topic was published by Eric Wilkes [1] in the 1980s, following the realization that most deaths were related to chronic conditions other than cancer, and which occurred in hospitals and at home without any palliative care specialist intervention. On the basis of this reality, he proposed developing palliative care in all settings, and has become the stated policy of the WHO [2].

The concepts and practices of the hospice movement have spread into all services and countries, with focus on different types of services and models of organization, while adopting the definition of palliative care. Although there has been a gradual incorporation of experiences of care for noncancer patients, the focus in most countries has, nevertheless, been to take care of cancer patients in late stages of disease. The concept and practice of palliative care as a national or regional policy began in Catalonia (Spain) [3^{*}] and Edmonton (Canada) [4], under the auspices of the WHO. The concept has been extended gradually as one of the elements of Cancer Programmes, or as specific National or Regional Palliative Care Programmes [5].

Conceptual transitions in palliative care

The most relevant conceptual transitions in palliative care, shown in Table 1, consist in extending care beyond cancer and into more general chronic conditions, promoting early palliative interventions in the clinical evolution of the disease, applying palliative care measures in all settings of the health-care system, and identifying complexity versus prognosis as criteria for specialist interventions.

Other care innovations involve the use of the comprehensive model of care and intervention in combination with advanced care planning and case management as core methodologies [6]. From the epidemiological perspective, the focus has shifted from cancer (around 25% of mortality) to all other

Table 1. Conceptual transitions in palliative care in the 21st century

Change from	Change to
Terminal disease	Advanced progressive chronic disease
Prognosis of weeks or months	Limited life prognosis
Cancer	All chronic progressive conditions
Disease	Condition (Frailty, pluripathology, dependency)
Progressive course	Progressive course with frequent crises of needs and demands
Mortality	Prevalence
Dichotomy curative - palliative	Synchronic, shared, combined care
Specific OR palliative treatment	Specific AND palliative treatment as needed
Prognosis as criteria for intervention of specialist services	Complexity as criteria
Rigid one-directional intervention	Flexible intervention
Passive role of patients	Advance care planning
Reactive to crisis	Preventive case management
Palliative care services	Palliative care approach everywhere
Specialist services	Actions in all settings of healthcare
Institutional approach	Community approach
No planning	Public Health Approach
Fragmented care	Integrated care

chronic conditions (around 50% of mortality), and from the concept of terminal disease to ‘advanced chronic conditions with a limited prognosis’ [7] involving several patterns (or trajectories) of progression [8]. Additionally, several surveys have shown that the prevalence of such patients in the general population could be as high as 1.33% [9]. Hence, the data highlight the need for palliative care to be a priority for policymakers, and also the concept that palliative care measures need to be applied in all settings of the country’s healthcare system (HCS). The population-based approach to mortality and prevalence can be put to use, preferably, in districts or sectors [10]. These transitions outline needs, demands and policies for improving palliative care in all settings. Together with instruments to identify chronically ill patients in need of palliative care, national policies are crucial in implementing actions [11].

IDENTIFYING INDIVIDUAL PATIENTS WITH PALLIATIVE CARE NEEDS

The criteria to identify a patient with an advanced disease combine levels of severity, progression, and advanced frailty.

Evolution of concepts of frailty, severity, progression and prognostic tools in patients with advanced chronic conditions

The concept of severity depends on the criteria for every specific disease, more than on the number of comorbidities [12]. Also contributing to severity, are general parameters such as functional [13] and/or nutritional status [14], intercurrent infections and the use of emergency healthcare resources [15]. Some of the geriatric syndromes such as delirium [16], dysphagia [17], sores/ulcers [18,19] and falls [20,21] have shown significant correlations with mortality. The criteria of progression are those aspects that are necessary in assessing the clinical evolution of disease, the degree of reversibility, and the response to previous therapeutic measures. Frailty syndrome has been defined as a state of vulnerability and risk of health deterioration. It has been associated with mortality, especially if at advanced and progressive stages [22,23]. Frailty is frequently associated with chronic conditions and consists of deficit accumulation [24], with the probability of death exponentially related to the number of deficits and their progression over time. Clinically, frailty can be identified by using the Multidimensional Geriatric Assessment, a specific tool with strong association with survival time [25].

Methods and tools to identify individual patients with palliative care needs

There are different experiences for the identification of patients with palliative care needs and the associated prognostic tools [26–29]. The Gold Standards Framework (GSF), and its tool the Prognostic Indicator Guidance (PIG) [30] were designed and developed in the United Kingdom, and have inspired similar tools elsewhere, such as the Supportive and Palliative Care Indicators Tool (SPICT) [31]. In Catalonia, a similar tool [Palliative Necessities (NECPAL) CCOMS-ICO tool] has been adapted, validated and currently introduced. [32–34] The GSF/PIG, SPICT and NECPAL general tools combine the perceptions of different healthcare professionals (‘the surprise question’) with the wishes and preferences of patients in relation to the limitations of curative therapies and the insertion of palliative measures (‘the choice question’). Clinical parameters (progressive, established and persistent functional and nutritional decline), the presence of comorbidities, the presence of geriatric conditions and syndromes (severe frailty, pressure sores, dysphagia, delirium, dementia and others) and the use of resources (especially emergencies) can be included as tools to identify advanced status of specific conditions (cardiac, respiratory or other). GSF implementation includes identifying patients and instigating new processes of care, education and training in the different settings together with actions to improve quality, including setting-up indicators to measure progress. Experiences of implementation of GSF, SPCIT and preliminary data from NECPAL in settings such as primary care, hospitals and nursing homes have demonstrated effectiveness in identifying patients in need and improvements in care quality in these settings [35–39]. The GSF-PIG, SPICT and NECPAL tools are especially useful because of their simplicity, feasibility, availability in all settings and their usefulness in the identification of patients in need of palliative care, especially for noncancer conditions.

The epidemiological perspective

From the epidemiological perspective, the focus has shifted from cancer mortality to all chronic conditions [8], and from the concept of terminal disease to ‘advanced chronic conditions with a limited life prognosis’ [7,40] with several patterns, or trajectories, of progression [8]. This approach supports the concept that palliative care measures need to be put to use in all settings of the HCS. The population-based approach to mortality and prevalence can be applied, preferably, in Districts or Sectors [10]. From the political and public health

perspective [41,42] access to palliative care needs to be considered a basic human right [43] and inserted into the civil laws and the HCS [44]. Transitions are procedures that define needs, demands and policies for improving palliative care in all settings. Policies are essential to implement actions altogether with instruments to identify chronically ill patients with palliative care needs.

Mortality and prevalence

The assessment of palliative care needs in populations can be determined using a combination of methods [45–47]. Mortality from chronic conditions can be estimated by ranking the chronic condition-related causes of mortality. The results of this methodology show that, in high-income countries, around 75% of the population will die from a chronic illness, with a cancer-to-noncancer ratio of 1 : 2.

The prevalence of chronically ill patients with palliative care needs has been determined in a recent study [9*] that showed prevalence in the total population of 1.33–7% in the elderly population (≥65 years), with a cancer-to-noncancer ratio of 1 : 8–10.

IMPROVING QUALITY OF PALLIATIVE CARE

General palliative care measures are the actions adopted in Health and Social Care Services (HSCS) to improve the quality of palliative care of the chronically ill, advanced, patients receiving attention.

Proposals to improve palliative care in conventional health and social care services

A list of proposed measures for the care of individual patients is shown in Table 2, and a list of general

measures is shown in Table 3. Among the measures to assess needs and to evaluate quality, the key recommended measures are the conduct of prevalence surveys that identify target patients with the described methodologies (NECPAL CCOMS-ICO tool), and a registry of these patients. Additionally, there are methods described to evaluate and improve the quality of palliative care in HSCS [48].

Proposals to assess needs and improve palliative care at the district level

The District is the natural scenario for planning palliative, chronic, and geriatric care. The elements for planning palliative care in a District are listed as follows:

- (1) Public health, population-based and community-oriented perspective
- (2) Needs assessment and context analysis (quantitative & qualitative)
- (3) Defining target population ([prevalence survey(s)])
- (4) Clear leadership and consensus with stakeholders
- (5) Defined model of care and intervention
- (6) Measures: identification and registry, implementation of specialist services, and improvement of conventional services
- (7) Education, training, and research
- (8) Quality evaluation and improvement
- (9) Systematic evaluation of results/indicators.

From a public health perspective, the key issues for planning or improving palliative care in a District begin with a comprehensive analysis, including quantitative assessment of patient needs (mortality,

Table 2. Six basic recommendations for providing care for identified patients in conventional health/social (nonpalliative care specialist) services

Dimension	Actions
Identify patients and their needs of palliative measures	Tool available Checklists: state of disease, co-morbidities, symptoms, functional status, nutritional status, aims, wishes, worries
Impeccable model of care Systematic approach for every dimension	Adopt and practise the multidimensional comprehensive model of care Square of care and intervention: disease, physical, psychological, spiritual, ethical, family, social, practical, financial, last days, bereavement
Initiate advance care planning Involve family and primary carer	Identify wishes, values, advance decisions and prevent risks Asses the practical, emotional, caring capacity, and the risk of burnout and complicated grief
Start case management	Follow up, accessibility, continuing care, emergency care, coordination with other services

Table 3. Six basic recommendations for improving the quality of palliative care in health and social care services

Dimension	Actions	Proposed indicators
Identification and registry of patients in need	Tool available	Tool
	CODE available	Protocol
	Protocol of implementation	Patients registered; N
	Register and codification	
Training	Mapping the levels of training	Training
	Train the referent health-care professionals	Protocols
	Protocols for prevalent clinical situations (pain, symptom control, last days, communication, etc)	
Team-work	Joint assessment, develop of objectives, and monitoring and follow up	Patient follow-up discussed
	Regular meetings	
Identify and provide care for the primary carers and family	Assess the capability for caring, identify risk of burnout	% assessment of family needs
	Access and support	% bereavement
	Bereavement programme	
Improve the intensity of care and accessibility	Increase home care	% increase home care
	Prevent crises	% patients having preventive measures
	Plan urgent, continuing care, and access	
Prevention, coordination, and patients' autonomy	Case management	% patients with Advance Care Planning
	Advance care planning	% reduction emergencies
	Emergencies	
	Role of services in follow-up	

CODE, Change acronym into 'Coding'

prevalence, ageing, complexity) in relation to resources (type and number of existing services), coverage, and health-care professional availability. The qualitative analysis could be used to assess the performance of the existing services and to explore areas of improvement. A systematic methodology has been developed [49,50]. An example of average needs in a District in Catalonia (Unpublished Observations, Gómez-Batiste, 2012.) with a catchments population of 200 000 inhabitants is presented as follows:

- (1) 1800 persons will die
- (2) 1300–1450 (75%) of them from chronic progressive diseases (25% from cancer, 50% from other chronic diseases)
- (3) There will be a prevalence of around 2500–2800 patients living with an advanced chronic disease, and with limited life prognosis
- (4) There will be 350 elderly with pluri-pathology and dependency
- (5) There will be 300 elderly with dementia
- (6) 1500 elderly will live in nursing homes or homes for the elderly

Once the needs have been assessed, combined actions and joint policies are implemented (Fig. 1) including (if needed) palliative care specialist services and general measures to improve palliative care in all services. Moreover, an education and training plan, a common clinical information system, a quality assessment and measures for improvement, and the evaluation of results with appropriate indicators need to be set up.

INTER-PHASE BETWEEN CHRONIC CARE & PALLIATIVE CARE MODELS AND POLICIES

Chronic care has been identified as one of the greatest challenges in health and social care in most countries [51] due to the increase of needs and demands and, as well, due to the increase of costs resulting from overuse of acute and emergency resources [52]. There have been important developments regarding models of innovation for the care of chronically ill patients recently. Of note among the most used, it is the Chronic Care Model and its adaptation by the WHO as the Innovative Care for

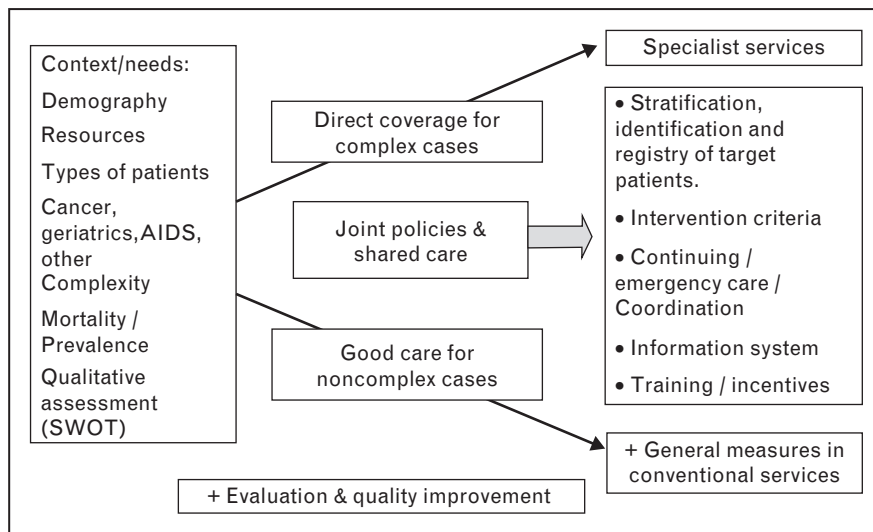


FIGURE 1. Sectorized palliative care planning. SWOT, Strengths/Weaknesses/Opportunities/Threats.

Chronic Conditions Model [53,54]. The Kaiser Permanent Model has been implemented in the USA and has achieved good outcomes in effectiveness and efficiency with respect to integrated care for chronic conditions [55]. In this model, between 1 and 3% of the chronically ill population would be in a state of advanced disease and/or clinical complexity, as defined by the presence of multimorbidity, geriatric syndromes and/or frailty, severe impairments, multiple emergency admissions and, polypharmacy, in addition to various degrees of dependency. In this group, the requirement is for a strategy of proactive case management to improve health outcomes, improve quality-of-life and reduce

the use of high cost services such as emergency admissions. This model has been successfully set-up in the United Kingdom [56]. In Catalonia, the Chronic Care Model is currently being implemented [57] (Fig. 2) and incorporates the NECPAL Programme as a standard policy for identifying and improving the care of patients with advanced conditions in need of palliative care measures. Many chronic conditions have similar clinical trajectories and end-of-life conclusions (comorbidity, incurability, progression, crises) and common patterns of resource use (needs and demands of acute and emergency care). In conventional care, the focus is usually based on a 'post crisis' model. The

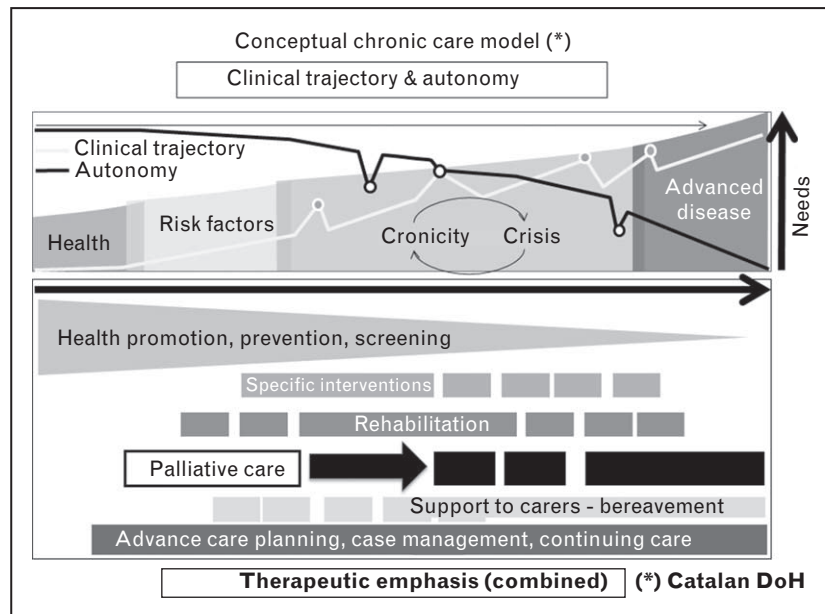


FIGURE 2. Conceptual chronic care model (Catalan Department of Health).

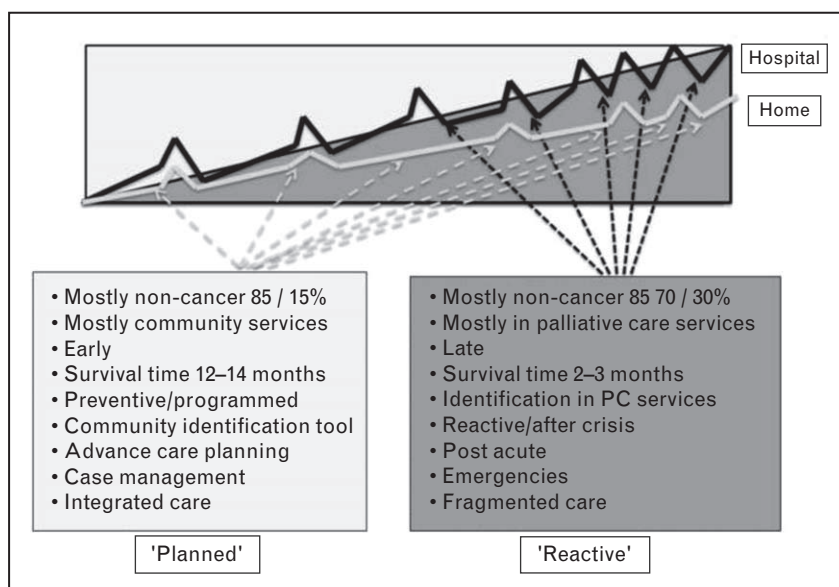


FIGURE 3. Models of palliative interventions in chronic care. PC, palliative care.

introduction of early identification followed by careful assessment, case management and advanced-care planning could progress into a 'preventive planned model' with resultant reduction in crises and avoidance of unnecessary (and expensive) acute/emergency interventions (Fig. 3) [58]. Because of these aspects in common, chronic care models should include strategies for health promotion, prevention and care of the specific disease conditions, as well as for the palliative care of patients with advanced disease in order to improve the quality of their care and to increase efficiency through optimum use of resources [59]. Also, the relationship between chronic demand and interphase has a place in National or Regional Cancer Programmes which have palliative care as a principal component.

CONCLUSION

Patients in need of general or specialized palliative care measures are present in almost all health and social care services. A high proportion of these chronically ill patients are cared-for in internal medicine, geriatrics, pneumology, neurology and cardiology services. There are simple feasible methods to identify such patients, to respond and to improve the quality of their individual needs. At a District level, there are systems to establish palliative care policies which combine measures in individual services with improvements in coordination and cooperation. Palliative care programmes and policies at either Regional or National levels need to be linked while having cancer, chronic care and geriatric care as basic components.

We have summarized the development of the concept of Public Health Palliative Care, and the models for identifying patients in need of palliative care and for improving the quality of care in health and social services provision for the population. It is neither a systematic review nor a research-based study.

Acknowledgements

None.

Conflicts of interest

There are no conflicts of interest.

REFERENCES AND RECOMMENDED READING

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 411–413).

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