

Development of Palliative Care: Past, Present, and Future

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Abstract

Palliative care is an essential element of any health care system and a component of comprehensive and integrated care. Access to good palliative care is a basic human right. Palliative care has evolved since its modern foundation: the *British Hospice model* proposed building comprehensive models of care (responding to all dimensions of needs of patients). Palliative care has since spread into all the different settings of the health care systems.

Key evolution of palliative care provision includes:

- The design and implementation of public health models as national or regional palliative care programs, and the policy proposed by the WHO in the World Health Assembly Resolution WHA67.19 in 2014: "Strengthening of palliative care as a component of comprehensive care throughout the life course."
- The shift from the institutional and late care of terminal cancer patients toward the timely community- and population-based perspective and links to chronic care models.
- Initiatives of *compassionate communities* which aim at involving society to change attitudes toward end of life and propose integrated care at the community level.

1 Aims of This Chapter

To describe the development of palliative care from the initial experience of the British Hospices in the 1960s toward the public health approach from the 1990s onwards.

Definitions and Concepts in a Historical Perspective

2.1 Short History of Early Modern Palliative Care

Modern palliative care was initiated at St Christopher's hospice in 1967 (The term "palliative care" was first used by Dr. Balfour Mount at the Royal Victoria Hospital in Montreal Canada in 1974. The English word "hospice" translated in French speaking Canada as poor house, and In Spanish it means "house for abandoned children") by Cicely Saunders, who created a conceptual frame to identify the multidimensional needs of patients and their families and the concept of treating "total pain," defined as the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles. A new model of care was proposed to respond to those multidimensional needs with symptom control, emotional support, and communication as the main elements; the patient and family as the unit of care; and promoting quality of life as the main purpose of care. To provide this approach, the practice of a competent interdisciplinary team was developed with contributions from all disciplines. This concept was initially provided in British inpatient hospices, with strong commitment and community and social support, with great success focused mainly on the care of patients with terminal cancer and very limited prognosis in hospice units across the UK.

2.2 Diversification and Spread into Other Systems

Gradually by the 1970s, this model of care developed different types of organizations, such as home care services (St Christopher's), outpatient clinics and day care (St Luke's), and support teams (Thelma Bates). Palliative care was also extended into other settings such as acute bed hospitals (Royal Victoria Montreal), cancer institutes (Royal Marsden), support teams (St Thomas'), and comprehensive networks, and to look after other types of patients (AIDS (Krakauer et al. 2007), motor neuron disease, organ failure, etc.). From the mid-1970s to the late 1980s, palliative care services were disseminated into many other countries (Europe (Luczak 1993; Kaasa et al. 2007; Mosoiu et al. 2007), and some low- and middle-income countries (Stjernswärd 2002; Davaasuren et al. 2007)), adapting gradually to their health care systems and cultures.

2.3 The Public Health Programs

In the 1990s, the concept of palliative care as a public health topic was developed at the WHO, and several regions and countries (Catalonia and Extremadura in Spain (Gómez-Batiste et al. 1992; Herrera et al. 2007); Alberta, Canada (Fainsinger et al. 2007); Kerala, India (Kumar 2007); and others) developed palliative care programs with systematic planning and aims of coverage and equity.

During the 1990s, theory, education, and research were extended in many countries, academic positions were established, pre-graduate and postgraduate medical and nursing training developed, training for other members of teams created, and the specialty of palliative medicine established. It is now a recognized specialization in at least 30 countries. Experience, evidence, organizational indicators and standards, and many clinical procedures were developed during this period and added to textbooks and specialized journals (Connor and Sepulveda 2014).

2.4 Palliative Care in the Twenty-First Century

More recently and related to the increased prevalence and mortality of people with all chronic conditions, the concept of a palliative care approach has been developed, alongside the need for timely identification of people with all types of advanced chronic conditions in all settings of care, using community and population perspectives (Gómez-Batiste et al. 2012). In May 2014, the World Health Assembly approved the resolution on palliative care, "Strengthening of palliative care as a component of comprehensive care throughout the life course," to promote the concepts of palliative care for all people in need, from the time of diagnosis, in all settings of care (World Health Assembly 2014). Tools to identify patients at these so-called first transitions have been developed, and the concept of a palliative care approach in all settings is currently being extended, with public health policies implemented to develop these approaches.

Palliative care has been adapted to growing needs, extending from the focus on the care of patients with terminal cancer in institutions and interventions based in prognosis toward a wider perspective that includes the concept of "life-limiting" illness and early intervention; the care of persons with all types of serious chronic diseases and conditions, not just cancer (Murray et al. 2005); and planning based on prevalence, rather than mortality (Table 1).

This change in perspective has radically altered the scope of palliative care and its provision, toward a public health, global, population, and community perspective, introducing the concepts of the palliative care approach in all settings (Stjernsward et al. 2007; Stjernsward and Gomez-Batiste 2008), in combination with the initial concept based on specialist services, in the context of universal health care coverage and access (World Health Organization 2015a, b).

2.5 Summary of Key Current Concepts in Palliative Care

As a result of all these transitions, palliative care can be operationalized by several definitions and concepts (Table 2).

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	From	Change to
Concepts	Terminal disease	Advanced progressive chronic disease
	Prognosis of weeks or months	Limited life prognosis
	Cancer	All chronic progressive illnesses and conditions
	Progressive course	Progressive course with frequent crises of needs and demands
	Mortality	Prevalence
Model of care and	Dichotomy curative or palliative	Synchronized, shared, combined care
organization	Specific or palliative treatment	Specific and palliative treatment as needed
	Prognosis as criteria for intervention of specialist services	Complexity/severity as criteria
	Late identification in specialist services	Early identification in community and all settings
	Rigid one-directional intervention	Flexible intervention
	Passive role of patients	Advance care planning
	Fragmented care	Integrated care
Perspective for	Palliative care services	Palliative care approach everywhere
planning	Specialist services	Actions in all settings of health care
	Institutional approach	Community approach
	Services' approach	Population approach
	Individual service	Systems approach

Table 1 Conceptual transitions in palliative care in the twenty-first century. (From Gómez-Batiste et al. 2017c)

2.5.1 Updated Definition of Palliative Care According to the WHO Ad Hoc Technical Advisory Group on Palliative and Long-Term Care (TAG) (Gómez-Batiste et al. 2017a)

- *Definition of Palliative Care.* Palliative care is the comprehensive and integrated care of persons with advanced chronic conditions and limited life prognosis and their families.
- *Definition of Palliative Care.* Palliative care is the prevention and relief of suffering of any kind – physical, psychological, social, or spiritual – experienced by adults and children living with serious, chronic, complex, and life-limiting health problems and the promotion of dignity, best quality of life, and adjustment to progressive illnesses, using best available evidence. It is a person-centered accompanying of patients and their families throughout the illness course, including at the end of life that optimizes quality of life, promotes human development and well-being, and maximizes dignity.

Palliative care is a basic human right and an essential component of comprehensive and integrated care for persons with serious chronic, complex, and life-limiting health problems that should be practiced by health and social care providers of many disciplines, as well as palliative care specialists, and should be provided in any health care setting, including patients' homes.

Key principles of palliative care provision include the concepts of **comprehensive care** (responding to all multidimensional needs of patients and families), **integrated care** (into all services and settings, with coordination of care), **quality** (responding with effectiveness and efficiency), and **universal access** (equity, coverage, integration into all levels of the health system). The **values** of compassion and commitment are needed to care for persons who are in a frail and vulnerable situation (Gómez-Batiste et al. 2017a).

By operating as an *approach*, palliative care can be provided:

Table 2 Levels of the palliative care model. (Adapted from Gómez-Batiste et al. 2017a)

Targets and time

Palliative care is needed by persons suffering from all types of serious complex/chronic or progressive conditions in all settings

It is applicable early and timely in the course of serious chronic, complex, or life-limiting health conditions/illness in conjunction with disease-modifying or potentially curative therapies, for people living with long-term sequela of diseases or treatments, and to neonates and children with serious congenital or acquired health problems

Model of care

Palliative care starts with a multidimensional assessment of physical, emotional, social, and spiritual needs, values, and preferences of patients and their families followed by a systematic approach to care

It focuses on the essential needs of patients and their families such as spirituality, dignity, autonomy, hope, growth and well-being, and key relationships

It uses ethical principles and advance care planning to identify patients' priorities and goals in the case of children, the developmental stage, for care at the end of life, and shared decision-making along the process

It never hastens nor postpones death intentionally

It provides family care and personalized bereavement support for adults and children as needed

It should be integrated into standard responses to humanitarian disasters

Model of organization

Palliative care should be integrated into every setting of the health care system and should be accessible by anyone in need

It should be a standard part of training for medical and nursing students, primary care providers, and health care workers. It should be practiced by medical doctors, nurses, social workers, spiritual supporters, community health workers, therapists, volunteers, and other allied health professionals and caregivers, with adequate training

It should use a three-level structure: palliative care approach in all settings, general basic palliative care, and specialist palliative care with adequate skills at each level

It is best practiced by a competent interdisciplinary team

It uses care management principles to prevent crises and assure integration and continuity of care along the different settings

It encourages active involvement in care giving by family members, communities, and community members

It has proven its effectiveness in addressing patients and families' needs, and efficiency in the provision of care

Much avoidable pain and suffering continues to exist at the end of life. In both resource-rich and resource-poor countries, fewer than 14% of people currently access any end-of-life palliative care. The only way that palliative or end-of-life care can reach the vast majority of people who need it in any country is by integrating its availability in all settings for care: hospitals, care homes, and the community

- 1. To all patients with progressive life-threatening illnesses
- 2. At all times. Be introduced at diagnosis of a life-threatening illness, not just in the last weeks or days
- 3. In all dimensions. Help integrate physical, social, psychological, and spiritual, not just the physical
- 4. In all settings. Extending its reach to people in hospitals, care homes, and most strategically in the community
- In all regions of the world not just in economically developed countries
- 6. To all family members. Support family caregivers, at all stages (before, at the time of death, and after)

- 7. To all ages: applied to children with lifethreatening illnesses as much as adults
- To all society: Promote a public discourse about living in the face of dying and maximizing individual and community assets to promote individual and community growth

2.6 Models of Palliative Care Organization and Provision

2.6.1 Models of Organization

Persons with palliative care needs are cared for and attended to in all settings of the health care system (European Association for Palliative Care 2009). Palliative care can be provided in all of these settings with different levels of complexity

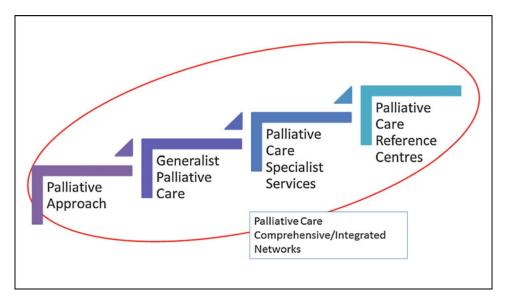


Fig. 1 Levels of palliative care complexity. (Adapted from Luyirika et al. 2017)

and organization, according to the needs of patients and their families. In the context of universal coverage, all health care services need to address palliative care (Gomez-Batiste et al. 2008a).

2.6.2 Levels of Organization

Several levels of palliative care organization can be identified (Fig. 1). In the evolution of palliative care organization, there are also transitional models which can be the first actions prior to developing a specialist service.

2.6.3 Palliative Care Approach in All Settings of Care

Most health services attend to persons with advanced chronic conditions in different proportions and at different times in their disease process evolution. To assure quality of care and universal coverage for palliative care patients, the palliative care approach must be implemented in all services in the health system, especially primary care (for early identification and with a population perspective) and other services with highest proportions of palliative care needs.

The conventional medical services attending higher proportions of patients with palliative care needs are primary care, oncology, geriatrics, HIV/AIDS, and nursing or care homes. But all services have patients in need of different proportions of palliative care involvement.

There are measures that can be taken in any service to guarantee good quality of palliative care:

- 1. Establish and document a policy for palliative approach.
- 2. Identify patients in need using validated tools; these would identify needs, stratify the population at risk, and determine the prevalence.
- 3. Establish protocols, registers, and tools to assess patients' needs and respond to most common situations.
- 4. Train professionals and integrate palliative care training and review in the conventional training process (sessions, etc.).
- 5. Increase accessibility to continuing and emergency care, home care (if primary care services), and access for families in hospitals.
- 6. Identify the carers of patients and give them support and care, including bereavement support.
- 7. Increase team approach to jointly assess, plan, and implement care.

- 8. Establish links and criteria for intervention and access to palliative care specialized services in the area.
- 9. Evaluate results of the palliative approaches.

2.6.4 Primary Versus Specialist Palliative Care

With upwards of 61 million people needing palliative care annually and a very limited number of specialists, it is essential to the future of palliative care that primary care providers have the skills and knowledge to provide palliative care in their practices. An estimated two-thirds of those needing palliative care could be cared for without having to see a palliative care specialist (Connor and Sepulveda 2014). Additionally, specific times could be devoted to attend to those patients with higher needs. Some examples could be specific outpatient clinics in an oncology service for advanced patients, or specific times for bereavement or family support, specific home care visits, or programs of telephone support. In hospitals, patients with palliative care needs can be placed in designated areas (with individual bedrooms, etc.). Or in outpatient clinics, specific times and days can be devoted to these patients. This can also be the first stage before implementing a palliative care specialized service. To help differentiate primary and specialist palliative care, Quill and Abernathy (2013) distinguished the essential skill sets of each:

Primary Palliative Care

- Basic management of pain and symptoms
- · Basic management of depression and anxiety
- Basic discussions about:
 - Prognosis
 - Goals of treatment
 - Suffering
 - Code status

Specialty Palliative Care

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals of methods of treatment

- Within families
- Between staff and families
- Among treatment teams
- · Assistance in addressing cases of near futility

2.6.5 Specialized Palliative Care Service

A specialized palliative care service is a health care resource devoted specifically to attending to the complex needs of patients with progressive chronic life-limiting conditions and their families and to give support to other services. It is composed of a competent interdisciplinary team with advanced training and clearly identified by patients and other services.

There are different models and types of specialist services worldwide: Support teams (at home, hospitals, or comprehensive systems in territories), units, outpatient clinics, day hospitals, hospices, and comprehensive networks.

The key factors in the foundation of specialized services are leadership, training, institutional support, and the definition of the mission, values, aims, and internal and external consensus on the model of care and organization (Gómez-Batiste et al. 2008b). The most relevant aspect of the structure is a highly competent interdisciplinary team and the process/activities of PCS are well described (Table 3). The most relevant outcomes are the improvement of the quality of life of persons attended and their relatives. The most relevant criteria for success are the combination of good leadership, a competent team, institutional support, strategic planning, systematic quality assessment, and performance improvement. In most countries that recognize palliative care as a specialty, it is as a subspecialization.

Palliative care services can have diverse models of organization – according to needs of patients and the settings – including inpatient care (in specialist units or support to other services), outpatient clinics, home care, day care, phone/ online support, continuing care, or emergency palliative care.

Palliative care services have demonstrated effectiveness, efficiency, and generate improvement of the quality of life of patients and their

 Table 3
 Common activities (process) of palliative care specialist services. (Adapted from Gómez-Batiste and Connor 2017)

Care of patients: Interdisciplinary whole person assessment; care plan development; skilled medical, nursing, psychosocial, and spiritual intervention; follow-up and continuity of care Care of families and bereavement follow-up Ethical decision-making and advance care planning Continuing care and case management Liaison of resources Support of other teams Team work: meetings, roles, support, relations, climate Registration and documentation Evaluation of results Internal training External training to other services Research and publications
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1
Quality assessment and performance improvement
Volunteers
Advocacy
Links to society

families (Gomez-Batiste et al. 2008c; World Health Organization 2016).

In many countries, a "service" is an administrative concept, and can include different activities or resources (outpatients, inpatients units, support teams, etc.). In others, every activity will be named "service." A "palliative care team" is the specialized professional group providing these services or activities.

2.6.6 Elements of Specialized Palliative Care Services

- **Outpatient Clinics and Day Care**: Can be based in any setting of the health care system, and are crucial for early palliative care intervention and shared flexible models of cooperation (Gómez-Batiste and Connor 2017).
- **Mobile (or Support) Teams**: Interdisciplinary teams acting in support of other services. Can be based in Hospitals, Community/Home, or serve a district (acting in all or various settings).
 - The basic mobile team will include a medical doctor and at least one nurse, complemented by others, including psychosocial and spiritual professionals, therapy providers, and community health workers. Volunteers enhance the mobile team.

- **Inpatient Units** (called hospices in some locales with beds): Can be based in any setting of the health care system (hospitals, intermediate care centers, long-term nursing homes)
- Adapted to the organization of health care inpatient services
- Must respect privacy, and allow presence and access of families
- Units may specialize in caring for different types of patients (cancer, organ failure, geriatric, children, AIDS, dementia, etc. or be mixed)
- Can be based in acute, mid-term, or longterm settings or as individual stand-alone facilities
- Size and resources vary according to country and setting, regulations, and standards
- Processes and model of care are common to all services
- Outputs and costs (mean age, length of stay, mortality) will be different according to types of patients.
- **Hospices:** Organizations exclusively devoted to care of advanced/end-of-life care patients, and can include all types of activities including home and inpatient care. Generally owned by NGOs but can be part of any system. The British Hospices were the first organizations

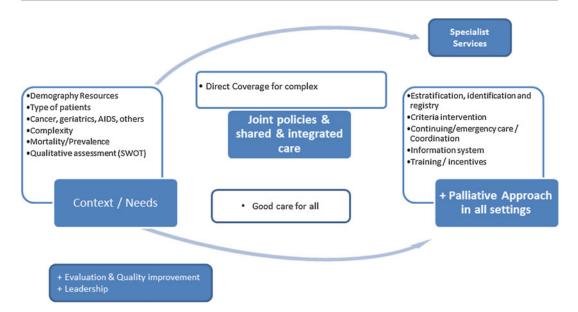


Fig. 2 Population and territorial approach for integrated palliative care. (Adapted from Luyirika et al. 2017)

implementing modern palliative care in the 1960s following the leadership/model of St Christopher's Hospice.

Comprehensive/Integrated Networks: Organizations of specialized palliative care, serving a population and acting in all settings of this scenario (hospitals, intermediate settings, nursing homes, community) in an integrated way. In small districts, a specialized support team can be the only specialized resource needed to care in all settings. In districts with different providers, a common care pathway could be the formula for integrated care. In metropolitan districts, a complex integrated model can include various levels of complexity.

3 Population/Territorial Palliative Care: Integrated Models

The population and territorial perspectives are the key elements of a public health approach. The aim is to build an integrated model, bringing together all services involved.

A policy for a territory must start with an assessment of needs and context, mixing quantitative and qualitative methods. The aging

proportion is a key factor. Once done, the next step might be to stratify the population, identifying the different groups that could be in need (McNamara et al. 2006; Murtagh et al. 2014). There are several tools to identify the people in need (Maas et al. 2013; Gómez-Batiste et al. 2017b). The most frequent figures in our context (21% of population over 65 years old) are that 4% of the population have complex chronic conditions, and may need intermittent and gradual palliative care interventions, the 1.5% are people with advanced/progressive chronic conditions and a limited life prognosis (Gómez-Batiste et al. 2014), and 0.4% have added social vulnerability (isolation, poverty, limitation of access, etc.). The next step is to define the roles of services, the pathways for patients (specially focused in transitions), and combined with an information system, incentives, training for professionals, and quality improvement. The most relevant factors for success are leadership and a funding model which incentives integrated over fragmented care (Fig. 2).

Policies for these different populations at risk must include the aims of care, the clinical issues, the ethical issues, and organizational issues (Fig. 3).

Adapting the clinical, ethical & organizational perspectives of palliative approach & palliative care to the evolution of persons with advanced chronic conditions

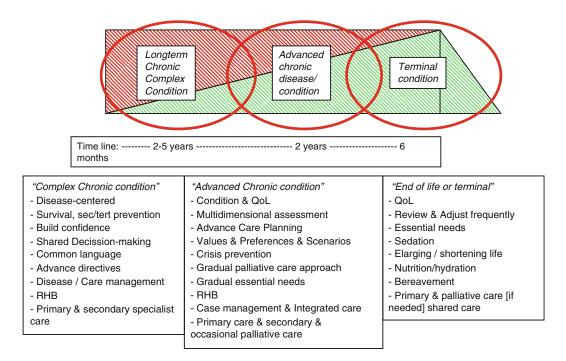


Fig. 3 Clinical, ethical, and organizational aims in different phases of evolution of chronic conditions. (Adapted from Gómez-Batiste et al. 2017a)

4 The Public Health National Policies and Practices

- 1. Establish a formal national or regional policy with participation of patients and all stakeholders (professionals, managers, policymakers, funders)
- 2. Determine (or estimate) the population- and setting-specific mortality and prevalence and needs assessment
- 3. Elaborate, agree, and validate an adapted tool for the identification of those in need of PC
- 4. Establish protocols to identify these patients in existing services
- 5. Establish clinical protocols and guidelines to assure good comprehensive, person-centered care for the identified patients
- 6. Identify the specific training needs, train professionals, and insert palliative care training in all settings

- Promote organizational changes in primary care, specialized palliative care service, conventional services, and integrated care across all settings in districts
- 8. Identify and address the specific ethical challenges
- 9. Insert palliative approach in all policies for chronic conditions (cancer, geriatrics, dementia, HIV, other, etc.)
- 10. Establish and monitorize indicators and standards of care and implementation plans and generate research evidence

Most of palliative care plans must be adapted to the extension of palliative care to all patients, at all phases, in all services. We can propose a recommendation to build up **National or Regional Programs**.

5 The Social Involvement: Compassionate Communities

In recent years, a new approach has been developed, as a necessary complement of the public health perspective. The programs of compassionate communities propose a new perspective of social involvement, empowering society and its organizations to participate in the change of culture and vision about end of life and in the design and evaluation of services (Kellehear 2013). It is a very interesting approach, which opens the scope of palliative care toward end of life and improves the so far paternalistic relationship of palliative care networks and services with society, frequently focused only in volunteers and funding (Abel et al. 2013; Abel and Kellehear 2016). The most relevant aims of these programs are to change the cultural and social approaches to end of life and dying, and also to provide integrated systems of care, especially for people combining a limited life prognosis and social vulnerability.

6 Conclusions and Summary

Palliative care has evolved since its modern foundation in the 1960s from the British Hospice *model*, from where the comprehensive model of care (responding to all dimensions of needs of patients) and microorganization (as the team approach) were built. From this context, palliative care has been extended into the settings of the health care systems, with different organizational models of teams and services. A more developed model is the comprehensive and integrated network in territories. The other key evolutions moved from the institutional and end-stage care of terminal cancer patients to the timely, community- and population-based perspective and links to the chronic care models. The other key element has been the design and implementation of public health models as national or regional palliative care programs, and the policy proposed by WHO in the World Health Assembly Resolution WHA67.19: "Strengthening of palliative care as a component of comprehensive care throughout

the life course." More recently, there are new initiatives of *compassionate communities* with the aim of further involving society in the cultural changes toward end of life and propose integrated care at the community level (Kellehear 2015).

Palliative care is a key element of any health care system, and access to good palliative care is a basic human right (Human Rights Watch 2009).

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