

Palliative Care Program Development

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Introduction of Palliative Care

Only 20 countries (8.5%) have integrated palliative care into their health-care system [1]. Yet, some 40 million people worldwide lack access to palliative care services [1]. The reasons range from lack of pain medications, lack of personnel trained in palliative care, and lack of basic health care systems and transportation to name a few. In a historic process, the World Health Assembly finally declared palliative care a worldwide priority in 2014 and invited member states to invest a greater interest in palliative care [1].

Palliative care is defined by the World Health Organization as -

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual... Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. In regards to children, the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease [2].

Palliative care is appropriate for all persons of all ages with serious, life-threatening illness as well as those persons living with a persistent or recurring medical condition that adversely affect their daily functioning or will predictably reduce life expectancy such as cancer, heart disease, and dementia [3]. In many countries, the focus of palliative care has been on cancer care. However, it could easily be HIV/AIDS, congestive heart failure, cerebrovascular disease, neurodegenerative disorders, chronic respiratory diseases, drug-resistant tuberculosis, and diseases of older people [4].

Without the benefit of palliative-focused care, individuals with life-limiting illnesses do not clarify goals, wishes, and health preferences with respect to culture and ethnicity [5-8]. As a result, these patients may experience more aggressive and expensive medical interventions than necessary or preferred, and die at a higher rate at institutions such as hospitals or skilled settings [9]. In the last ten years, several studies have demonstrated that early integration of palliative care with life-sustaining treatments within cancer and non-cancer treatments promotes better quality-of-life, positively influence survival, and incurs less costs [5,6,8].

No matter what country, specific tenets exist for optimum palliative care: 1) care provision and care coordination is interdisciplinary; 2) the circle of care includes patients, families, palliative and non-palliative health providers who collaborate and communicate about care needs; 3) services are available concurrently either with or independent of curative or life-prolonging therapies; and 4) patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death [3].

Palliative Care Program Development

Palliative care programs can be developed in any country or region. For successful implementation, the development of a national strategy and policy review should include: national standards of care describing palliative care within a particular country; laws that acknowledge and define that palliative care is part of the healthcare system; clinical guidelines and protocols; establishment of palliative care as a healthcare specialty, and regulations that establish palliative healthcare providers with appropriate licensing provisions [4]. Those major steps must be tackled collaboratively. However, there are several steps to individual palliative care program development: completing a needs assessment, performing a community assessment, and developing a business plan. A needs assessment is essential (Table 1). This is a process to examine the health care culture and investment of a community in palliative care. No matter the country, the development of palliative care occurs at the national, regional, and local level. A community assessment determines the many unique features to each country in regards to laws, policies, and regulations, health care systems and personnel, culture and ethnicity, and access to medications and diagnostics. Finally, a business plan takes into consideration all the financial and strategic planning elements and establishes a road map and budget for palliative care development. It should answer: 1) Who - Who will receive services? Who will deliver services?; 2) What - What is the structure of the palliative care services? What are the services to be delivered?; 3) Where - Where will services be delivered? Where are the geographic boundaries?; 4) When - When will services be provided, around the clock, Monday through Friday, Business hours?; and 5) How - How will services be provided - for free, for a fee, and how will patients receive care?

Essentially, palliative care program development is determined by answering the questions of who, what, when, where, and how palliative care delivery will occur. To determine who and what, it is first necessary to perform a needs assessment. This includes an assessment of the region and their desire for palliative care services. Interviews should include patients and families and what they need to care for patients with serious illness, clinical providers and what they need to

better care for patients, and service providers. Most important in these interviews is to determine who are champions and supporters for developing palliative care services. These are agencies with whom a palliative care program can collaborate or partner with. These include

service agencies such as non-governmental organizations (NGOs), the Red Cross, health care clinics, clinical providers, community service workers, as well as religious agencies.

- Promotes information-gathering
- Allows patients and families to articulate their care experiences and needs
- Promotes identification of partners and stakeholders.
- Promotes integration of existing structures and systems.
- Allows education of perceptions of palliative care definitions and delivery
- Promotes assessment of palliative care education needs

Table 1: Needs assessment.

To further determine who, what, and how, it is important to next perform a community assessment (Table 2). This includes the demographics of the community that palliative care program is planned for. It includes: age range; ethnicity; culture; religion; common diseases and illnesses, and mortality from them; living conditions; and access to basic health care and medications. There will also need to be consideration of available palliative care staff. All models will need to be staffed by health care personnel familiar with palliative care. Again,

this will vary depending on the personnel available, their licensure, and scope of practice. Palliative care education may be directed towards any discipline specific providers, including community workers. Many countries have undergone training in the End of Life Nursing Consortium (ELNEC) International Curriculum or through other international initiatives, which have included community workers, nurses, physicians, chaplains, social workers, and health department staff

- Vital statistics, including cause of death, age at death and location of death
- Loss data
- Demographics of the community, for example- average age and the distribution of the target population by various categories including ethnicity
- Disease statistics, usually obtained from the health department or vital statistics division
- Identification of the unique characteristics that differentiate palliative care from other services in the community

Table 2: Community assessment.

With this information, palliative program development can be initiated. Critical factors for development include financial support, territory, organization structure, palliative care workforces, and community partnerships. Financial support includes a payment model or funding source. No factor has a larger impact as services cannot be delivered unless there is some funding and support to do so. In some countries, there may be ministries of health who offer support, while in others, it may be charitable organizations. Territory will impact development as well. Resources, this will change whether providers are traveling to see patients or patients are traveling to see providers. There will need to be consideration of terrain and seasonal access, cost of travel (vehicle, gas, drive time) and the geographic boundaries of care delivery.

Often palliative care specialists are in a tertiary setting such as a hospital or hospital based outpatient clinic.

Organizational structure influences palliative care development. Whether palliative care services are part of a current structure such as a hospital or home visiting service or a new entity, a need exists to create agreements, guidelines, and processes. The availability and expertise of palliative care staff will affect the initial development of a program. Finally, the community resources (both health care and social) will affect the scope of services to be provided.

Primary palliative care is delivered by generalist providers who have undergone some course work to have an understanding of common pain issues – a pain assessment and types of pain, some assessment in symptoms such as nausea and constipation, and can determine whether patients and family understand the disease or condition. They are able to access resources for patients and families. These providers are often in the community or primary care settings and include physicians, nurses, and community workers. Core services include primary palliative care such as basic communication, such as asking patients their understanding of their condition and what type of care they want; basic pain and symptom management such as the use of simple pain medications such as paracetamol and morphine; and understanding of community resources such as pharmacies, nurses who do home visits, and transportation [10,11]. Or there can be more specialty palliative care such as complex pain and symptom management, using the range of opioids and adjuvant medications and/or antiemetic; information and facts about serious illness to discuss goals of care appropriate to a culture; complex decision-making about serious illness management when there are a variety of treatment options; psychosocial support - to discuss concerns and fears about dying; spiritual care - to discuss spiritual issues about illness and dying; care coordination - to help families provide care for their loved one; medication management, and planning for end of life care [10,11].

A wide range of palliative care services can be provided. Specialty palliative care is delivered by health care providers (nurses, physicians, social workers, spiritual leaders, community workers) with specialty palliative care training, either graduate education, fellowships, or dedicated education programs. They understand complex pain and symptoms with the use of all opioids, the range of medications for all physical and psychological symptoms. They have expert communication skills to discuss the full range of palliative care topics.

A patient assessment includes management of physical, psychological, spiritual, and emotional symptoms, medication review, functional ability, cognitive assessment and safety. Environmental

issues include housing assessment with access to clean water, food, electricity, transportation, and access to emergency services. Caregiver assessment is the presence of another person to assist with care and

their ability to do so. A financial assessment includes ability to pay for medications and services. A community assessment includes neighbourhood safety and access to community services (Table 3).

<p>Patient Assessment</p> <ul style="list-style-type: none"> • Physical assessment of symptoms • Psychosocial assessment and coping assessment • Cognitive assessment and assessment of sensory impairment • Functional assessment for Activities of Daily Living (ADLs) and Independent Activities of Daily Living (IADLs) • Medication review and ability to follow medication regimen • Spiritual assessment and support • Goals of Care • Physical Safety with presence of domestic abuse (physical, sexual, financial, psychological, neglect)
<p>Environmental Assessment</p> <ul style="list-style-type: none"> • Access to clean water, food, and supplies • Electricity source • Transportation • Access to emergency services
<p>Caregiver Assessment</p> <ul style="list-style-type: none"> • Delineation of presence of a caregiver • Ability of caregiver to assist patient • Coping of caregiver • Safety of caregiver
<p>Community Assessment</p> <ul style="list-style-type: none"> • Neighborhood safety • Emergency services • Resources to assist - Aging services, legal services, mental health services, social services
<p>Financial</p> <ul style="list-style-type: none"> • Health insurance coverage • Access to privately paid services • Affordability of services, medications

Table 3: Range of palliative care services.

Palliative Care Program Models

Three major palliative care models exist based on settings. The first is hospital-based palliative care. Hospital-based palliative care is often the easiest to implement as it can be developed from a current hospital structure and system. There is a building in place and readily available services including a range of health care providers, medicines, supplies, and equipment. Hospital-based palliative care programs are by nature crisis-oriented and often necessitate 24/7 coverage. They also require collaboration of an interdisciplinary team which may or may not be under the auspices of a palliative care department [12].

The second model is clinic-based palliative care. This model is helpful for established clinics such as specialty clinics including oncology, pulmonary, or infection clinics. Clinic-based models necessitate different resources depending on the type of practice and ownership - outpatient clinic as part of a hospital, ambulatory clinic as part of a health system, independent clinic as part of a hospice or palliative care provider. The focus is on long-term continuity for

chronic issues and relationship building to avoid and take the place of both emergency visits and hospitalizations. Models include outpatient, ambulatory care clinics, independent clinics in the community, or a clinic run by a hospice [12]. Resources depend on the financial structure of the clinic, in particular whether it is hospital or system owned, independent, or supported philanthropically [12]. They may be associated with hospitals and have access to supplies, medications, personnel and include either interdisciplinary or multidisciplinary teams. Or the clinic may be freestanding and built on its own.

Home-based palliative care is growing, but it takes more intensive development. The focus is coordinating care from service agencies and delivering clinical care in the home. The benefit is keeping people in their homes and community. The challenges, depending on the country, include access to palliative care providers and medicines for pain and symptoms. Home-based models may be limited depending on the covered territory and financial implications of transportation for patients and providers.

Palliative care program development is a process. It should be done by a committee or group as this promotes collaboration. Although each community is unique, there are many common services. Therefore it is best to utilize resources rather than recreate the process. Free resources include the European Association of Palliative Care, the International Association of Hospice and Palliative Care, the Palliative Care Network, the Worldwide Palliative Care Alliance, and the California Health Care Foundation (Table 4).

European Association of Palliative Care
• http://www.eapcnet.eu/Home.aspx
International Association of Hospice and Palliative care
• http://hospicecare.com/home/
Palliative Care Network
• http://www.palliativecarenetwork.com/
Worldwide Palliative Care Alliance and World Health Organization
• http://www.thewhpc.org/ • Global Atlas of Palliative Care
California Health Care Foundation
• http://www.chcf.org/ • Snapshots of Palliative Care Practices • Up Close: A Field Guide to Community-Based Palliative Care in California • Innovative Models in Palliative Care Fact Sheet Available at • Weaving Palliative Care into Primary Care: A Guide for Community Health Centers

Table 4: Resources.

Conclusion

Throughout the world, palliative care is a priority. Program development planning is essential no matter where the palliative care service is located. Though many variables to palliative care are unique to a country and region, there are essential aspects of program development. A successful program is based on the unique features of a community. Performing a needs assessment and a community assessment will help highlight those characteristics and build upon them. It will also assist in determining community support and partnerships. Moreover, a needs assessment and a community assessment will offer essential elements in the development of a business plan that delineates core services and helps to formulate a budget to provide care. This will then help establish the model of palliative care delivery. Various resources and references exist to promote successful palliative care program development.

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