Integrated Palliative and End-of-Life Care

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Health and Social Care and Compassionate Communities to Provide Integrated Palliative Care

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42.1 Introduction

The work of Dr. Cicely Saunders, founder of the modern hospice movement in the 1960s, is considered the key milestone in the development of palliative care services (Saunders 2005). In contrast to the focus on curing in the contemporary medicalized paradigm, palliative care aims at alleviating the suffering of people with advanced diseases and who are at the end of their lives, supporting them, their families and caregivers with dignified, sensitive and patient-centered care (Hall et al. 2011).

Over 29 million (29,063,194) people worldwide died from diseases requiring palliative care in 2011. The estimated annual number of people in need of palliative care at the end-of-life is 20.4 million. The biggest proportion, 94%, corresponds to adults of which 69% are over 60 years old and 25% are 15–59 years old. Only 6% of all people in need of palliative care are children (WHO 2014a, b). Europe may count as many as 7000 patients per year per million inhabitants requiring palliative care at the end-of-life. Of these, 60% would require palliative care provided by a specialized palliative care team (Centeno et al. 2013).

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Data on palliative care need to be set within the context of the growing chronic care challenge to contemporary health systems, as the chronic patient of today will very possibly become candidate to palliative care as the disease progresses. Furthermore, due to the fact that 40% of the total health care expenditure of a chronic patient concentrates at the end-of-life, palliative care becomes an obvious key element in any chronic care strategy.

There are, however, better quality and more cost-efficient ways of treating people at the later stages of their chronic diseases and end-of-life than treating them in acute hospitals. As this chapter will show new innovative models of people-centered integrated palliative care, involving health and social care staff working together with sensitized community networks, which are flourishing around the world.

42.2 Defining Palliative Care and End-Of-Life Care

The World Health Organization (WHO) has defined palliative care 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, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO 2010).

Through the consideration of pain as well as other problems, the 2004 WHO definition of palliative care is itself a call for integrated person-centered care. Recent conceptual developments have added further explanation to the WHO definition to highlight the comprehensive nature of palliative care and in particular, care not limited to the moment of dying. The Worldwide Palliative Care Alliance (WPCA) policy statement on defining palliative care supports palliative care earlier in illness, so that it is provided "alongside disease-modifying treatment such as anticancer therapy or anti-retroviral therapy, for people with significant symptoms or who require other support" (WPCA 2009). The WPCA policy statement includes the following key points:

- palliative care is needed in chronic as well as life threatening/limiting-conditions.
- there is no time or prognostic limit on the delivery of palliative care: it should be delivered on the basis of need, not diagnosis or prognosis.
- palliative care is not limited to specialist palliative care services but includes primary and secondary level care.
- palliative care is not limited to one care setting: it is provided wherever a person's care takes place, whether this is the patient's own home, a care facility, hospice inpatient unit, hospital, or outpatient or day care service.

In the English context, the term “end-of-life care” has been used to refer to the care that takes place at a specific period of time preceding death. However, more contemporary uses avoid such meaning and instead refer to “the care and support needs of patients and carers regardless of diagnosis and regardless of the estimated period of time before death” (Addicott 2010).

The traditional service model conceptualized palliative care as replacing curative care once the latter were no longer effective. Instead, as Fig. 42.1 shows, the modern model (Ferris et al. 2009; Hui and Bruera 2015) sees palliative care as being provided at early stages of the disease to control symptoms to alleviate pain while the disease(s) progresses. This is concurrent with other curative healthcare treatments—hence the term “time based model” (Hui and Bruera 2015). Such approach requires the inclusion of supportive care, palliative care, hospice care and bereavement as part of a continuum of care.

42.3 Challenges for Providing Care to Palliative and End-Of-Life Patients

As the end-of-life approaches, symptoms prevalent become gradually intense, physical deterioration advances rapidly and the level of dependency grows to be complete. The risk of catastrophic impact on the household economy increases, and

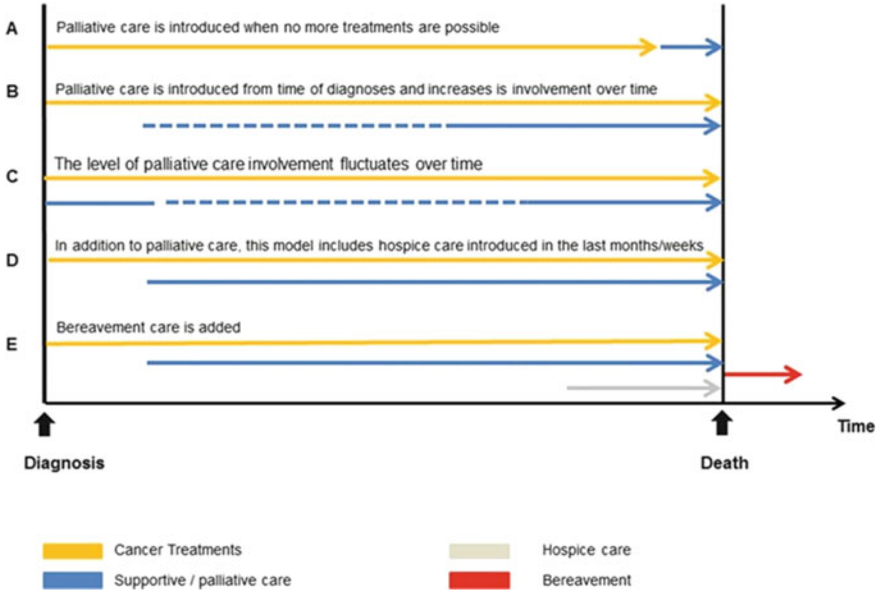

Fig. 42.1 Time-based model. *Source* Adapted from Hui and Bruera (2015)

thus the consequences of the illness are experienced, alongside emotional suffering and spiritual crises, not only by the patient but by his/her family and carers experience as well (Librada et al. 2015).

At a system level, the aging of the population and the chronic disease epidemic are changing how people suffer and what they die from. "Increasingly, more people die as a result of serious chronic disease, and older people in particular are more likely to suffer from multi-organ failure towards the end-of-life" (Davies and Higginson 2004). While traditionally, palliative care programs have been narrowly offered mostly to cancer patients, it is now being increasingly recognized as useful to people with advanced chronic conditions who are at risk of deteriorating and dying (Nuño 2014).

Healthcare systems, however, are not ready to cope with these changing dynamics. Where they exist, services for end-of-life multimorbid patients tend to remain fragmented and uncoordinated. True, many contemporary health systems have set up high-quality palliative care services, either at hospital, hospices or at home. As "most people prefer to remain in their home at the end of their life, various models of home-based end-of-life care exist, ranging from those that primarily offer nursing and personal care, to others that involve multidisciplinary teams" (Gomes and Higginson 2008; Nuño 2014). This, however, poses additional challenges to care systems, among other reasons, due to the progressive decrease in availability of family support networks at home. A retrospective study conducted in the region of Extremadura (Spain) in 2003 with 944 patients who had died showed that the risk of hospital admission (odds ratio) was 50% higher for patients who did not have a social support network at home. The reason for admission to a hospital was related to the lack of social support rather than to difficulties of symptom control. Patients with a Karnofsky index <50% (highly dependent) and lack of social support network, had a chance of 65% versus 45% of those who possessed social support network (Herrera et al. 2006a, b).

If it is not addressed as a cornerstone in the reorganization of the health and social care systems, it will result in their failure in the coming years. The lack of a supportive network increases the demand for more formal or informal social care, but the solution is not to compensate it by super specialized physicians and increased hospital-based services.

42.4 Goal of Integrated Care

42.4.1 What Needs Do End-of-Life Patients Have?

The complexity of each situation at end-of-life and the variety of psychosocial factors lead to a wide range of needs with different grade of severity, all of which need to be addressed. For example:

- Care needs regarding the patients' dependency: Assistance to perform daily activities, reduction of loss of sensory capabilities and compensating deterioration, training habits for improving personal autonomy, safety and protection measures as well as environmental adaptation.
- Caregivers' needs and social support network: Information about available support services, training of professionals and/or informal care givers, development of communication skills, psychosocial support of family members, balance of care activities/tasks and working life, prevention of family collapse, sharing experiences with other caregivers.
- Protection of the social role of the patient: Autonomy in decision making and communication of last wills, spiritual expression, leisure and entertainment, privacy versus intimacy, interpersonal and social relationships.

From the healthcare perspective, the palliative care range of support should not only be limited to provide specially trained medical and nursing services, but also seek to provide emotional support (psychotherapy, counseling, support services and caregiver relief). It should also support dependency care (support in home work/task/activities, support by personal care and occupational therapy) (Librada et al. 2015).

42.4.2 Health and Social Integrated Care Based on Empathy and Compassion

As the discipline of palliative care has been evolving, practitioners have gradually realized that palliative care cannot be considered solely from the health perspective (Juvero 2000; Georghiou et al. 2012). Health and social needs of the patient at the end-of-life and his/her family are closely related and have mutual influence. If any of these aspects is not well addressed, it can result in misuse of resources and overcharge. The lack of adequate social support causes increased consumption of healthcare resources. Although it is still necessary to improve specialized palliative care health teams, it is also relevant to meet the needs of social support for patients and their families (Herrera et al. 2013).

The call for coordination and integration of health and social care services patients at the end-of-life has featured strongly in recent declarations of international organizations. For example, the 2014 European Declaration on Palliative Care has called for

> a paradigm shift in health and social care towards basic palliative care skills for all health care professionals, to empower them to deliver patient-centred family-focused care for all people with a life-limiting illness, based on personalized or tailored care plans, with attention to all needs of the patient and his or her family (European Declaration on Palliative Care 2014; WHO 2014a, b).

Health and social care staff need to work in interdisciplinary teams, using empathy as the basis for analyzing the needs of patients and their families.

The 2014 European Declaration on Palliative Care understands empathy as the cognitive ability to perceive in a common context, what another individual may feel. Also it is described as a feeling of emotional involvement of a person in the reality that affects another with the aim to identify individual patients' and family caregivers' unique combination of needs (European Declaration on Palliative Care 2014). While empathy is a cognitive ability, compassion is the attitude toward others in trying to alleviate other's suffering, "an evolutionary construct that compels us to be concerned about the welfare and suffering of others" (Busek 2014). In sum, quality in palliative care requires people to have both empathy and compassion, forming interdisciplinary teams who are able to work together in a coordinated manner.

42.5 The Integrated Care Path

The specialist literature on integrated care has referred to a number of key elements that make possible integrated care at the service-delivery level, including the existence a single point of entry to holistic care assessments and joint care planning, delivered by multidisciplinary teams where one professional in particular act as care coordinator for patients (Goodwin et al. 2014). The home or the homely setting within the community are "the hub of care" (Ham et al. 2012), the preferred locations, alternative to hospitals, to provide palliative care services. Home is also the "preferred place of death" (Addicott 2010). Thus, the integrated palliative care path is built around these elements and has the home as the primary location of care.

These elements are embodied in the number of international innovative experiences that are providing high-quality integrated palliative care to end-of-life patients (Hall et al. 2011). For example, the Midhurst Macmillan Community Specialist Palliative Care Service in England is a community-based, consultant-led, specialist palliative care program (UK) "which covers approximately 150,000 people in a largely rural area" (Thiel et al. 2013: 7). A multidisciplinary team of nurses (who act as care coordinators), palliative care consultants, occupational therapists and physiotherapists work along side Macmillan Cancer Support volunteers to enable patients to be cared for at home. The team liaise with other healthcare providers, including general practitioners (GPs), district nurses and continuing care teams (Thiel et al. 2013).

The Marie Curie Nursing Service (MCNS) provides home-based care to around 28,000 people at the end-of-life annually in the UK. Although it initially focused on caring for people with cancer, it has increasingly provided care to people with other conditions. Staffed by registered nurses and senior healthcare assistants, the MCNS offers a number of different models of care, ranging from overnight nursing care booked in advance to urgent support in response to crises.

Similarly, in Andalusia, Spain, the Home and Ambulatory Care program of the Cudeca Foundation embodies these same key elements (OMIS 2015). Care to oncology patients is delivered at home by multidisciplinary teams of nurses, physicians, psychologists and social carers. Coordinated by the nurses, the team meets weekly to discuss, evaluate and monitor patients and adjust treatments if needed. Volunteers also have a role in the program by providing support and helping to transport patients from and to their home. Public patients are referred from the regional health service. While at the Cudeca program, there is intense liaising with the primary and hospital care levels, with whom they are aligned through agreed protocols.

The Milford Care Centre (Milford Care Centre 2015) is a voluntary not-for-profit organization which provides specialist palliative care and older person's services in the Mid-West of Ireland. Services include: 47-bed voluntary nursing home; a Day Care Centre for Older Persons; 30-bed Specialist Palliative Care Inpatient Unit; Palliative Care Day Care Centre (Specialist Palliative Care Day Unit); Community based, multi-disciplinary Specialist Palliative Care Team; and an Education, Research and Quality Unit.

Referral to specialist palliative care is made through the GP or hospital consultant. Patients living at home remain under the care of their GP, but they get the support from the Specialist Palliative Care team, which comprises a nurses (Clinical Nurse Specialists; Registered Nurses, Care Assistants), physiotherapists, occupational therapists, social workers. Then, the Palliative Day Care Centre bridges the interface between homecare services and Specialist Palliative Care Inpatient unit, so that patients can be referred smoothly from one to the other as required. In addition to the professionals above mentioned, the Day Unit multi-disciplinary team comprises dieticians, speech and language therapists, music and art therapists, etc. Referral to the inpatient unit can be also be made through the Specialist Palliative Care Day Unit or Hospice at Home services. Patients are accepted based on an overall assessment of their needs (e.g., medical needs, social circumstances, support required, etc.).

Weekly multidisciplinary care planning meetings are held in each area of care (Inpatient Unit, Hospice at Home service and SPC Day Unit). New patients are reviewed and care plans discussed and agreed; care plans for existing patients are also reviewed and updated as appropriate. Decisions about discharge of patients are discussed and agreed. Also, all deaths that had taken place since the previous meeting are reviewed and decisions made as to what level of immediate bereavement support may be required by particular family members.

In eastern Canada, the Nova Scotia Integrated Palliative Care strategy (Nova Scotia 2015) embodies the philosophy that care is delivered in a seamless manner by the various health care providers and services that function in the community. It is person- and family-centered rather than system-centered. There is integration between primary, secondary and tertiary care with a shared responsibility among all care providers along the continuum. Support to patients and families is available early in the disease process, and adapts as one's condition advances and changes. Support to families also continues on during the bereavement stage.

To meet the goal of keeping patients at home as much as possible, continuous and 24/7 support is very much needed, especially at night time and weekends. This can be delivered though telephone service or similar. In the UK, the Partnership for

Excellence in Palliative Support (PEPS) (Sue Ryder 2015) service provides 24-h support to patients in the last year of life and coordination of palliative care between 15 organizations across the county of Bedfordshire in England. A telephone number held at the PEPS center offers a single point of contact to provide a seamless service for patients, their carers and care professionals from qualified nurses when advice and support are needed. In Spain, the regional government of the Basque Country launched a specialized palliative home care program in 2014 termed SAIATU ("to try" in Basque language) (Herrera et al. 2013; Millas et al. 2015; Nuño 2014). The program provided in-home social support services rendered by specially trained caregivers, to complement the palliative clinical services offered by the public system as well as 24/7 telephone support. Initiated as a pilot in the Basque province of Guipuzcoa, lack of funding has prevented the experience to be sustained and scaled-up, however.

Integrated palliative care is not, however, exclusive of Western developed countries. The Hong Kong Special Administrative Region of China, for example, has introduced integrated palliative care pathways (Lo et al. 2009).

Colombia is taking promising steps toward the setting up of high-quality integrated palliative care programs and teams, applying the NEWPALEX® method developed by NewHealth Foundation (NewHealth Foundation 2015). This method sets up integrated care pathways and establishes specific programs and resources at the service-delivery level and offers basic and intermediate training for palliative care specialists. At present (Feb 2016), one-third of Colombia's population (around 16 million people) are registered with health insurance companies that, having applied the NEWPALEX® method, have included integrated palliative care in the basket of services to their insured members. For example, the model of palliative care included in basket of services of the health insurance company SURA is delivered by a multidisciplinary team who care for the physical, social, emotional, spiritual and psychological needs of patients (EPS SURA 2016).

At the core of the Colombian experience is the reorganization of the funding models by which health insurers pay health care providers for the existence and quality of palliative care services. These insurers are contracting with more than ten healthcare providers who have set up high-quality palliative care resources and programs.

42.6 Results of Integrated Palliative Care

There is growing research evidence that confirms that in-home palliative care achieves better quality of care, higher satisfaction rates and with lower costs than traditional models of hospital-based care (Brumley et al. 2007; Gomes et al. 2013). Results from the innovative experiences described above come to strengthen the case for integrated palliative care for patients and their families.

According to research, home-based palliative care provided under the Marie Curie Cancer Care MCNS model reduces the demand for costly and often undesirable hospital care, and allowing more people to die at home (Chitnis et al. 2012). 76.7% of those who received care under the MCNS model died at home, while only 7.7% died in hospital. In contrast, 35.0% of the controls died at home, while 41.6% died in hospital.

The SAIATU program has shown how resources developed from a social care perspective and with an emphasis on care integration can be cost-effective and efficient for a healthcare system and increase the satisfaction of families. Thus, comparison of SAIATU with traditional care (primary and specialized health care) and advanced care (primary and specialized health care and home care) resulted in a reduction in the intensity of external specialized care services utilization, emergency room visits, hospital admissions and length of hospital stays. Moreover, SAIATU favored the community intervention of primary healthcare professionals by increasing calls and interaction with caregivers trained by the family physician and community nurse. In consequence, it avoided diversions to unnecessary emergency services or inadequate early intervention of unnecessary specialized means (Herrera et al. 2013).

These results support other studies confirming that the activity of palliative care teams at home improves the performance of primary care professionals (Herrera 2006). This suggests that a more specialized palliative support, both medically and socially, does not antagonize with a strong primary care, rather on the contrary, it promotes synergies between levels of care and offers alternatives to unnecessary hospital admission. SAIATU's caregivers helped to detect problems in the patient early, liaising with primary care staff to visit patients when necessary. Finally, the results of the SAIATU also favored the possibility of dying at home when that was the preference of the patient. These data show that the integration of social status and health at the end-of-life enhances the overall efficiency of two subsystems: the health and social sectors.

In Colombia, first preliminary results of the country-wide transformative program explained above is showing reductions of approximately 10–15% in the costs of care at the end-of-life compared to standard treatments (mainly provided at hospital) (Montoya et al. 2014).

42.7 A New Paradigm: Compassionate Communities

In the context of the new paradigm of people-centered integrated care models, true integrated palliative care does not stop at the integration of health and social care services, regardless of how crucially important this is. Community-centered models for end-of-life care have been proposed, such as the "circles of care" model by Abel et al. (2013) "which appreciates the persons with illness in their everyday context of living within their communities, not separate individuals with needs that have to be met" (Abel et al. 2013: 3). The "circles of care" around the person cannot be fulfilled just by interdisciplinary healthcare teams, even if supplemented by trained social services. The care system will not be able to provide the care needed. It also requires the involvement of society through awareness and the raising of community networks. The real social change must come from the sensitized community, caring for their loved ones. Thus, the keystone of the new paradigm of people-centered integrated palliative care lies in the existence of networks of care (Herrera 2015).

At the international level, the “compassionate communities for end-of-life care” movement seeks to promote and integrate palliative care socially into everyday life (Kellehear 2005). People are trained to care for people at the end-of-life. But this does not stop at creating and managing volunteers’ teams. The concept goes much further: The aim is to enable society to accept and be involved in the accompaniment and care at the end-of-life as a natural act of compassion.

The movement is quickly spreading worldwide. In Kerala (India), the Institute of Palliative Medicine has been working for over 20 years in training community members and in promoting awareness of palliative care, and is now a World Health Organization (WHO) Collaborating Center for community participation in Palliative Care and Long Term Care. One of the key projects of the Institute, the “Neighborhood Network in Palliative Care” project has more than 60 units covering a population of more than 12 million people of Kerala and is probably the largest community-owned palliative care network in the world (Kumar and Numpeli 2005; Kumar 2013).

In Ireland, the Milford Care Centre is also urging forward the movement of Compassionate Communities through awareness and leadership experiences (Milford Care Centre 2015). In Spain, the non-for-profit organization, the NewHealth Foundation promotes the development of care networks between organizations and associations under the slogan “A Global Community United by the Vocation to Care” (NewHealth Foundation 2015). Through the leadership of the NewHealth Foundation, similar initiatives are beginning to evolve in Argentina and Colombia as well.

42.8 Conclusion

Over the past 40 years, palliative care programs around the world have aimed at alleviating the suffering of people with advanced diseases who are at the end-of-life, supporting them, their families and caregivers with dignified, sensitive and patient-centered care. As the discipline of palliative care has been evolving, practitioners have gradually realized that palliative care cannot be considered solely from the health perspective, but needs to incorporate social care and the involvement of the community as well.

The integrated palliative care model proposed in this chapter involves a set of professional health and social care services, which envelop the support and assistance of family and volunteers from an empowered community capable of caring for their families and neighbours.

In the context of the growing chronic care challenge to contemporary health systems, palliative care provides better quality, more cost-efficient ways of treating people at the later stages of their chronic diseases and end-of-life than treating them in acute hospitals. Thus, as a key element in any chronic care strategy, palliative care shows the way forward in the design of a service delivery model truly embedded in the emerging integrated care paradigm.

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