



## PALLIATIVE CARE WITH OLDER ADULTS

### SECTION I: INTRODUCTION & APPROACHES TO PALLIATIVE CARE

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#### Introduction

A recent multi-site study of hospital-based palliative care programs described their rationale and mission in the following way. “Advances in disease prevention, disease-modifying therapies, and medical technology in combination with the aging of the population have resulted in a dramatic growth in the number of adults living with serious illness. Despite enormous expenditures, patients with serious illness often receive poor quality medical care, characterized by untreated symptoms, unmet personal care needs, high caregiver burden, and low patient and family satisfaction. Palliative care is the interdisciplinary specialty that focuses on improving quality of life for patients with advanced illness and for their families through pain and symptom management, communication and support for medical decisions around goals of care, and assurance of safe transitions between care settings” (Morrison, Maroney-Galin, Kralovec, & Meier, 2005, p. 1784).

Social workers provide the majority of mental health, psychosocial, and bereavement services in hospice (Connor, 2007-2008) and in hospital-based palliative care. As the older population increases and requires more palliative services during advanced illness, it is essential for social workers to develop expertise in biopsychosocial assessment, evidence-based interventions, and service delivery systems that will enable them to address their special needs.

Though not often described as such, palliative care programs are in fact comprehensive systems of care or care coordination models that aim to organize patient care for patients with advanced illnesses to be more effective in meeting patients’ needs. Palliative care aims to be holistic in providing careful attention to pain and symptom management, attention to emotional and psychosocial issues, and fully integrating family caregivers in establishing goals of care. There are differences in the specific components of palliative care programs, where they are located, how they are conducted, and the personnel they use, though standards are being developed to create greater uniformity and consistency across programs (Ferrell et al., 2007).

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This module will address:

- ◆ Similarities and differences between hospice and palliative care approaches: their demographic and social contexts, and the epidemiology of diseases they treat.
- ◆ Special challenges for older adults with advanced disease.
- ◆ The changing course of advanced illnesses of older adults: three different trajectories.
- ◆ Emerging integration/collaboration of palliative and hospice care in the U.S.
- ◆ Social work expertise and unique contribution to palliative care.
- ◆ Biopsychosocial assessment.
- ◆ Assessment of U.S. population needs and preferences.
- ◆ Assessment of patients and families individual needs and preferences.
- ◆ Intervention models: tasks, psychosocial health needs and related services, and evidence based approaches.
- ◆ Social work's development of a subspecialty and leadership in palliative care.
- ◆ Critical health policy issues in the U.S. in palliative care.

### **Approaches to Care of Advanced Illness in Elders Palliative and Hospice Care**

#### **Synopsis**

There are two different approaches to the care of advanced or terminal illness in the United States: Palliative Care and Hospice. Both have emerged from a similar philosophy of care, but they differ on when and where care is provided. In the U.S. Hospice is most often provided in the home or in a long-term care facility. To obtain reimbursement, the patient must be off curative treatment, have a life expectancy of no more than 6 months, and have a care partner if services are to be provided in the home. In contrast palliative care is most often provided in the hospital or in an outpatient facility without the requirement of a specific prognosis, and it can be delivered in combination with curative treatment. As shown in Figures 1 and 2, each has a defined philosophy and model of care based largely on U.S. health care reimbursement structures. Figure 3 shows one effort to reconcile these two approaches and to extend care through the bereavement process of survivors. Currently hospice and palliative care proponents are testing models to integrate and reconcile their differences as they seek to permeate mainstream health care services with the palliative philosophy.

## Palliative care: Philosophy and Model

- ◆ Palliative Care is both a philosophy and a program model. It is a term used for an approach, initiated within Hospice that was developed to improve the quality of life of patients and their families facing the problems associated with life-threatening illness.

Improving the quality of life is accomplished through the prevention and relief of suffering by means of early identification and careful assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. This approach to care is now integrated into both hospice and palliative care programs though in somewhat different ways. Advocates of the palliative care approach believe that it should be integrated throughout medical practice with serious illness from diagnosis to terminal phases and across all sites of care. The WHO definition of palliative care, accessed on July 24, 2008, can be found in <http://www.who.int/cancer/palliative/definition/en/>.

The palliative care program model consists of the following nine components:

- 1) Provides relief from pain and other distressing symptoms.
- 2) Affirms life and regards dying as a normal process.
- 3) Intends to neither hasten nor postpone death.
- 4) Integrates the psychological and spiritual aspects of patient care.
- 5) Offers a support system to help patients live as actively as possible until death.
- 6) Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- 7) Uses a team approach to address the needs of patients and their families, including, if indicated, bereavement counseling.
- 8) Enhances the quality of life for the patient, and may also positively influence the course of illness.
- 9) 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.

As will be described in more detail below and in the policy section, the palliative care philosophy emerged from the hospice movement but differs from hospice in the U.S. in that it aims to help patients regardless of prognosis and at all stages of a serious illness, not just at the end of life. Palliative care also differs from Hospice in the U.S. in that it may be delivered simultaneous with curative or life-prolonging medical care and is not dependent on the patient's prognosis, i.e., expected time until death. Proponents believe that it should be an integral part of comprehensive care for patients of all ages with life-limiting illnesses. Practically, however, without the hospice benefit, palliative care often struggles to provide the skilled home care services and psychosocial support

available through hospice and needed during advanced stages of illnesses, for example 24-hour-phone consultation.

### Hospice: Philosophy and Model

- ◆ Hospice programs initiated the palliative care approach; however, in the U.S. treatment reimbursement restrictions prevent many patients from receiving this care.

Although Hospice programs developed and promoted a palliative approach, their functioning is shaped by the U.S. reimbursement structure. Hospices are only reimbursed for work with patients whose life expectancy, as determined by two physicians, is 6 months or less. Importantly, Hospice patients will not receive Medicare benefits if they are still receiving or pursuing curative treatments. These restrictions are limiting because it is increasingly difficult to accurately determine prognosis on an individual level. Technology and medical advances have blurred the line between advanced illness and end of life. Furthermore, curative treatments may also be palliative and with continued medical advances emerging it is difficult for some patients to agree not to participate in any curative efforts if they might extend their lives without increasing suffering of patient or family.

### Comparison of Models

Figure 1 shows the traditional model of intervening by Hospice after a terminal prognosis of no more than 6 months. Figure 2 shows the current palliative care model that aims to complement curative treatments throughout the illness experience, beginning at diagnosis. This reflects the contemporary focus on expanding palliative care beyond end-of-life care, in contrast to Hospice care, which begins 6 months before death. Figure 3 is an example of emerging newer models that exemplify a more holistic approach from the point of diagnosis that explicitly encompasses survivor bereavement following death.

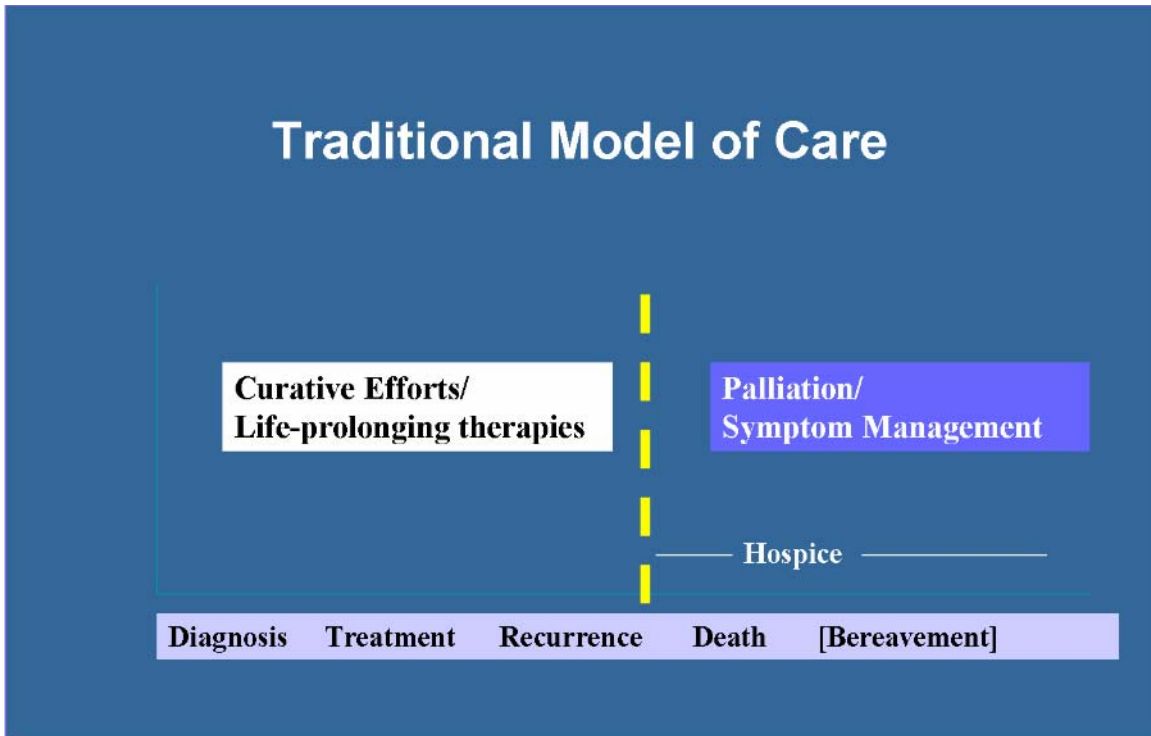


Figure 1: Traditional model of care.

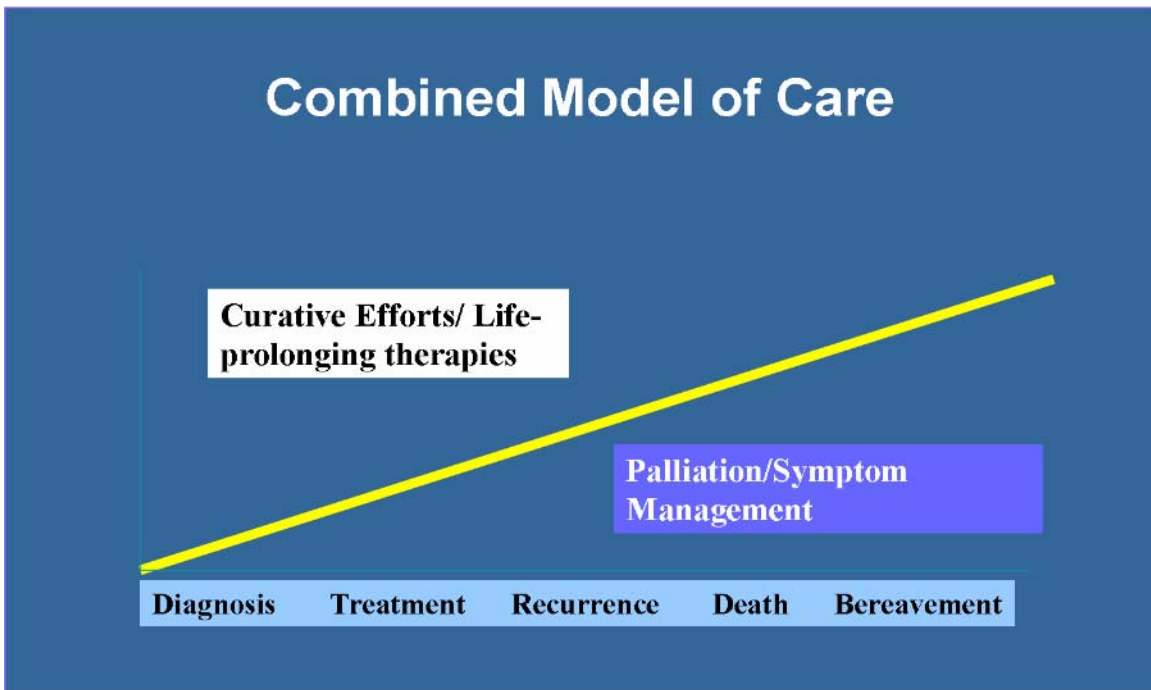


Figure 2: Combined model of care.

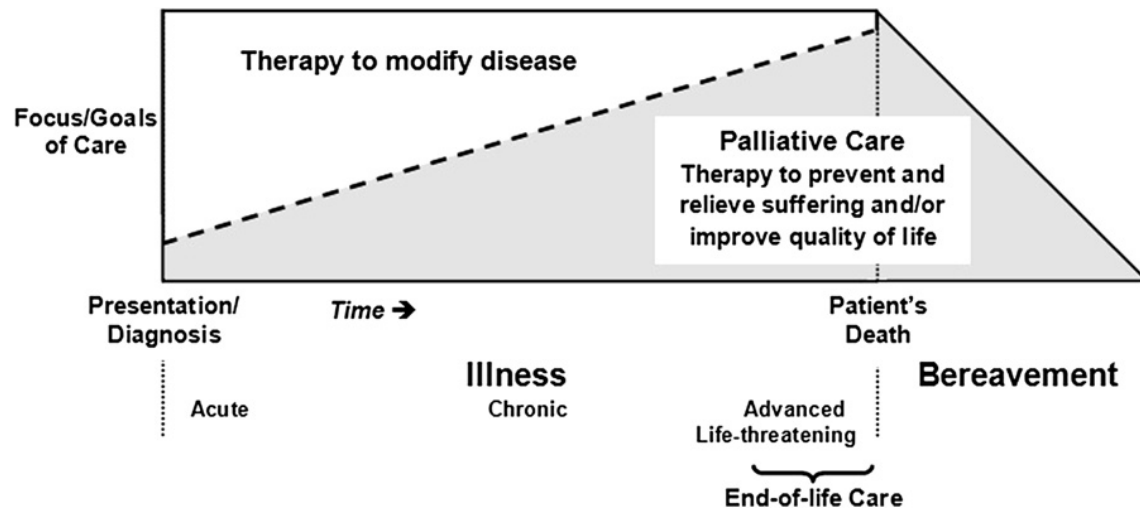


Figure 3: Note. From "A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice" by F.D. Ferris, H.M. Balfour, K. Bowen, J. Farley, M. Hardwick, C. Lamontagne, M. Lundy, A. & Syme, P. West, 2002, *Journal of Pain and Symptom Management*, 24(2), p.106-123. Copyright © 2002 by the Canadian Hospice Palliative Care Association. Adapted with permission.

## The Importance of Palliative Care Related to Demographic and Social Context and Epidemiology

### The Demographic Context of Advanced Illness

The populations in the U.S. and in many countries are aging. The number of Americans over the age of 65 has tripled in the 20<sup>th</sup> century. At the same time life expectancy has increased dramatically. More people are now living longer and the proportion of those living beyond 60 has increased, and will increase further over the next 20 years (Sepulveda, Marlin, Yoshida, & Ullrich, 2002). Table 1 documents the change in life expectancy in the U.S. from 1900 to 2000 as well as changes in where people die, how medical care is paid for, and the period of disability before death. By 2005, life expectancy had already increased to 77.9 years.

Table I: A Century of Change

	1900	2000
Life expectancy	47 years	75 years
Usual place of death	home	hospital
Most medical expenses	paid by family	paid by Medicare
Disability before death	usually not much	2 years, on average

*Note.* From *Approaching Death: Improving Care at the End of Life*, by M. J. Field & C. K. Cassel, Eds., 1997, Washington, DC: Institute of Medicine, Committee on Care at the End of Life. Copyright © 1997 by the National Academies Press. <http://www.iom.edu/CMS/3809/12687.aspx> Adapted with permission.

Improvements in public health, including the prevention and treatment of infectious diseases and other medical advances, have greatly reduced the proportion of deaths occurring in childhood and early adulthood. As a consequence, older adults account for an increasing number of deaths in the U.S. Preliminary data for 2005 show that of the 2,447,903 individuals who died in that year 1, 788,459 (73%) were over the age of 65 years (Centers for Disease Control [CDC], 2008) The number of oldest old, people over 85 years (who have the highest mortality rate), will double to 10 million by the year 2030. Comparatively little research has been carried out on their palliative care needs during advanced and terminal illness phases.

### The Social Context of Advanced Illness

Other social realities have forced and shaped the discussion of advanced and terminal illness in the U.S.

- 1) The aging of the Baby Boom generation. This highlights the expanding older population and their complex chronic illness related needs. Discussion of Medicare and Social Security are focused on the large number of people who will become eligible for those entitlements over the next 10 years and the smaller work force that will be called upon to support these entitlements.
- 2) High profile media debates. The debate about assisted suicide in high profile cases has increased attention to the realities of suffering at the end of life.
- 3) Increasing mass violence and both human caused and natural disasters. These events have made people more open to discussing difficult topics.
- 4) Caregiver burden. Because our institutions are accessible only to the most acutely severe conditions, family and community caregivers are shouldering an increasing burden for what has become a much longer trajectory of advanced illness (Field & Cassel, 1997).

- 5) Access problems at all levels. In the U.S. the numbers of uninsured continues to rise as employers pull back from the increasing costs of health care and benefits. Insurance companies avoid covering long-term severe conditions, especially in mental health. Newer legal, but especially illegal immigrants continue to be challenged by lack of health care. Notably, estimates are that over 10 million Hispanic undocumented immigrants live in the United States, and that their medical care is almost exclusively provided in emergency rooms (Weisman & Epstein, 2004). Medical and technological advances have created complex medical-ethical questions about when life ends and how patients can have some choice. The line between life and death has become blurred. Physicians are finding it increasingly difficult to give a prognosis, to know the dying trajectory – to answer the frequent question: “When does it end?” Older adults continue to outlive previous prognoses, even with multiple chronic conditions (Bern-Klug, 2004).
- 6) Quality of care problems. Criticisms continue to emerge about the quality of care in our current system, especially care of the aged, chronically ill, and dying population.

#### Changing Epidemiology of Disease

- ◆ As populations age, the pattern of diseases that people suffer and die from also changes. Increasingly more people die as a result of serious chronic illnesses such as heart disease, cerebrovascular disease (including stroke), respiratory disease, and cancer (Murray & Lopez, 1997).

Older people often suffer from multiple chronic conditions that might contribute to death, making it difficult to establish the main cause of death. Table 2 shows the changes in the ranking of the main causes of death as predicted for the year 2020 compared with the actual causes in 1990 (Murray & Lopez, 1997).



Table 2: Main predicted causes of death for 2020 and causes in 1990.

Disorder	Predicted Ranking 2020	Previous Ranking 1990
Ischemic heart disease	1	1
Cerebrovascular disease (including stroke)	2	2
Chronic obstructive pulmonary disease	3	6
Lower respiratory infections	4	3
Lung, trachea, bronchial, cancer	5	10

Adapted from Murray and Lopez (1997).

Longevity may not inevitably be accompanied by longer periods of disability towards the end of life (Andrews, 2001). Indeed, some recent studies show disability declining in successive cohorts of people as they age (Manton & Land, 2000). A recent study of older Americans from 1992 to 2003 found increases in active life expectancy past age 65 and decreases in life expectancy with severe disability (Cai & Lubitz, 2007). However, if more people live to older ages and if chronic diseases become more common with age, the number of people living with their effects will increase. More people will need some form of help towards the end of life. In particular, women are more likely than men to suffer from several chronic conditions such as osteoporosis and arthritis that may compromise this extended survival (Mathers, Sadana, Salomon, Murray, & Lopez, 2001). Women over 90 years of age also have a higher incidence than men of non-vascular dementia (e.g., Alzheimer's Disease), whereas men have a higher incidence of the rarer vascular dementia throughout the life cycle (Ruitenberg, Alewijn, van Swieten, Hofman, & Breteler, 2001).

## Major Challenges of Advanced Illness in Older Adults

### Greater Medical Complexity in Older Adults

- ◆ The problems of older adults with advanced chronic and terminal illnesses are different and more complex than those of younger people.
- 1) There is greater variation in the functional level of older adults depending on the presence and severity of multiple medical conditions. The

cumulative affect of multiple diseases may lead to greater impairment and care needs than expected with the advance of any one disease.

- 2) Older adults are more likely to experience adverse reactions to drugs due to not only the aging process, but also the presence of multiple medical problems.
- 3) The psychological reactions of older adults may be related to an accumulation of minor problems and their impact on functioning.
- 4) Problems of acute illness may be superimposed on physical or mental impairment, economic hardship, and social isolation (Raveis, 2007).

#### Changing Course of Advanced Chronic and Terminal Illnesses: Common Trajectories in Three Diseases

- ◆ The problems older people now experience in the last years of life are caused not only by the challenges of older age, but also by increased life expectancy and the nature and course of their final illness.
  - The prognosis of diseases in older adults, that is time till death, has become increasingly difficult to predict at the individual level (Hallenbeck, 2003; Hansen, Danis, & Garrett, 1997).
  - Advances in medicine and pharmacology have also made it more difficult to determine if someone in the advanced stages of a disease is dying or will die soon, and at what point further interventions will no longer extend life or reduce suffering.
  - When treatment becomes futile remains difficult to determine (Lynn et al., 1996). Currently this discussion often involves the question of the role of chemotherapy at the end of life for patients with cancer (Harrington & Smith, 2008). Recently, however, a broad range of other diseases have been treated by both Hospice and Palliative Care (Connor, 2007-2008).

Patients and families have predictable needs based on characteristics of the final illness. The examples of cancer, heart failure, and dementia illustrate some of these differences.

*Cancer* rates increase with age: 75% of deaths from cancer occur in people over 65 years. For women, the most common cancers are breast, lung, and colorectal. For men, the most common are lung, prostate, and colorectal. The prognosis for any individual depends on the extent of the growth at presentation and the response of the tumor to treatment. Treatment may include surgery, radiotherapy, and chemotherapy. As the first chart in Figure 4 shows, people with cancer may experience a long period of good functioning with limited impairment. They may not be severely restricted in their activities until the disease stops responding to treatment, at which point they

experience a relatively rapid decline. However, because of the historical association of cancer with disability, pain, and death in its terminal phase, patients may need considerable support, education, and continuous communication to cope adequately with their anxiety about this disease in its final stages. Patients with cancer and their caregivers say they want more information and involvement in decision-making. They experience better psychosocial adjustment if their pain and symptoms are controlled and when good communication is part of their care from the time of diagnosis. Because cancer has been somewhat more predictable in its advanced phases than other diseases (i.e., predicting time to death), it became the dominant model for both hospice and palliative care interventions. When diagnosed early, people living with cancer experience a long period of fairly good physical functioning, followed by a somewhat longer period of decline (Institute of Medicine [IOM], 2007).

**Heart failure.** Heart failure affects more than one in ten people over the age of 70. The 5-year mortality of 80% is worse than it is for many cancers (World Health Organization [WHO], 2004). The course of the disease as summarized in the second chart in Figure 4 is very different from that of cancer. There are intermittent exacerbations of the symptoms of breathlessness and pain followed by a gradual return to a level of functioning that is often fairly close to the previous level (McCarthy, Lay, & Addington-Hall, 1996; McCarthy, Addington-Hall, & Lay, 1997). Death may occur during one of the exacerbation crises, or the patient may experience a course of gradual decline over time. Considerable progress has been made in treating symptoms and managing medical crises. However, families often have difficulty understanding the complex drug regimes required. Patients with heart failure seem less informed about their diagnosis and prognosis and give little evidence of receiving the education from professionals that many cancer patients do (Selman, et al., 2007). Many professionals suggest they are reluctant to raise the issue of prognosis, in part because it has become increasingly difficult to predict when death is imminent with this disease. Yet even when the symptom burden of patients is similar to or in some instances greater than that of patients dying from cancer, patients with severe heart failure are rarely referred to specialist palliative care teams (Goodlin, et al., 2005; Horne & Payne, 2004). A survey of hospice medical directors about providing care to patients with severe heart failure revealed a lack of knowledge and expertise in treating this disease, insufficient identification of palliative interventions, and frequent underdevelopment of relevant standards, training, policies, procedures, and standardized care plans for management of heart failure patients (Goodlin et al., 2005). As a consequence, families report poor coordination and fragmentation of care, the lack of a single health professional to relate to, and less satisfaction with information and support available to them than families of cancer patients report. The case study included in this module exemplifies these gaps in care in advanced cardiac conditions and their effect on the patient's experience of

illness. This case also shows the occurrence of multiple crises with levels of functioning that gradually worsen over time.

**Dementia.** Dementia has been estimated to affect approximately 6% to 10% of individuals aged 65 and older. The prevalence increases with age, rising from 1% to 2% among those aged 65 to 74 to 30% or more of those aged 85 or older. The median length of survival from diagnosis to death is 8 years (Hofman et al., 1991).

As depicted in the third chart in Figure 4, there is often a slow progressive deterioration in the individual's ability and awareness (Hendrie, 1998). Common symptoms of dementia include mental confusion, urinary incontinence, low mood, constipation, and loss of appetite. The physical and emotional burden on family members is well documented, as is their grief as they slowly lose the person they knew (Diwan, Hougham, & Sachs, 2004). Patients' inability to communicate their wishes as the disease progresses raises many ethical issues and the need for a surrogate decision-maker. Making decisions for another individual about the use of antibiotics in the treatment of pneumonia at the end of life and the use of feeding tubes for hydration and nutrition is difficult for family members. Other questions arise with many life threatening conditions, but are particularly challenging when the individual is cognitively impaired. How and when should life-prolonging technology be used? When should its use end, and who should make that decision? How are these difficult decisions now being made, and how do families view the experience (Schulz & Martire, 2004)?

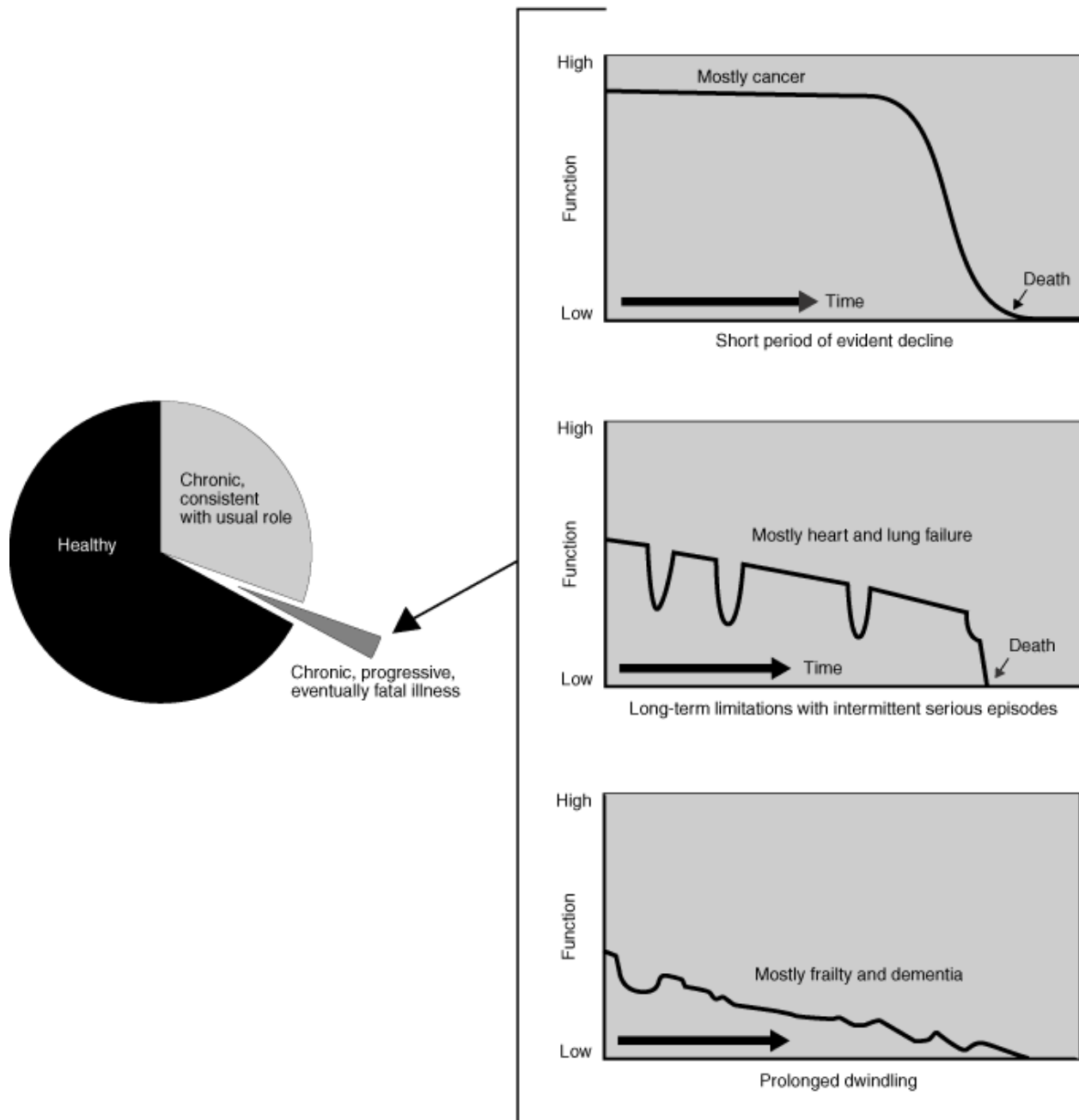


Figure 4: Note. Chronic, progressive, eventually fatal illness in the elderly: Three trajectories. From *Living well at the end of life: Adapting health care to serious chronic illness in old age*, by J. Lynn & D.M. Adamson, 2003, Washington, DC: RAND Health. Copyright © 2003 by the RAND Corporation. Adapted with permission.

## **The Emerging Integration/Collaboration of Palliative and Hospice Care in the U.S.**

Palliative and Hospice approaches to care for the dying have had different historical roots and reimbursement conditions in the U.S. that have shaped their models of service delivery. Learning about these roots and conditions will enable students to understand the modern practice differences and the role of social work in the model's development. Recently, practice reflects a movement toward greater integration in the following ways (Byock, 2000; Ferrell et al., 2007):

- ◆ Hospices, traditionally located in the community, now frequently provide service in long-term-care facilities, hospitals, and other health care programs. Some have recently developed palliative care services within their community-based hospice programs in order to serve people who wish to continue curative treatment during the dying process.
- ◆ Palliative care has emerged as a sub-specialty within medicine and a program within hospitals to provide cost savings and high quality alternatives to intensive care units for advanced illness. The aim is to better serve the growing population of patients who come to hospitals with advanced complex health problems. These patients report dissatisfaction with treatment by acute care focused hospitals and health care services that offer only curative treatment and limited opportunities for thoughtful patient and family discussion and decision-making. Palliative care programs continue to refer to Hospice when active treatment is no longer possible or desired by the patient so that the patient can receive a full range of in-home services supported by the hospice benefit.
- ◆ These different approaches also shape the social work role in ways that require different knowledge and skill sets for each. For example, hospice makes extensive use of home-based services in which the social worker has considerable autonomy with patient and family and also unique responsibility. In the hospital, the palliative care social worker collaborates extensively with multiple professionals and teams. Another difference is that patients electing palliative care that permits curative treatment as well as palliation are likely to be more ambivalent about confronting the terminal nature of their illness. This requires more flexible use of directness in interventions. Traditional hospice patients agree to forgo treatments that have a curative aim, thus indicating some level of acceptance of their terminal condition. Lawsen (2007) describes the experiences and challenges from the point of view of a practitioner who has worked in both models.
- ◆ Advocates of both approaches and their combinations are working to develop a model of a seamless continuum of services for terminally ill patients that

address their varied needs and preferences over the long course of their illnesses. A brief discussion of history, current challenges, goals, practices, and relationship to social work of both approaches follows.

### Origins of Hospice Care: London, England

The philosophical origins of palliative care as a service delivery approach came from the hospice movement, which began in the 1960s in the U.K. and spread to the U.S. in the 1970s. Dame Cicely Saunders who held degrees in medical social work, medicine, and nursing is recognized as the founder of this movement because she established the first research and teaching hospice, St. Christopher's Hospice, in London in 1967 (Monroe, Hansford, Payne, & Sykes, 2007-2008). She was inspired to provide more holistic and humane care of the dying by her social work experiences and observations of the suffering of injured soldiers and other terminally ill people during WWII and its aftermath. She challenged professionals to communicate to patients: "You matter because you are you, and you matter to the last moment of your life" (Monroe et al., 2007-2008, p. 64).

### Hospice and Social Work

- ◆ Some have described the entire hospice movement as an embodiment of social work values, principles, and practice.

Indeed social workers are the largest mental health discipline providing psychosocial services in both hospice and palliative care. Conner (2007-2008) reports, "Social workers have been providing the bulk of psychosocial services in hospice programs. This is due to the fact that social work is a required core hospice service and that social workers, if adequately trained in mental health, can also meet the hospice's required need for counseling services...there is growing concern that hospices and palliative care programs are not devoting adequate resources to psychosocial services, which are thought to be one of the defining characteristics of the field" (p. 97).

While hospice in England was provided primarily in an institution, care was initially provided in the home in the U.S., due to limited resources. Also home care reflected the U.S. hospice community's criticism of futile and often painful curative treatment given in hospitals at the end of life. Hospice providers aimed to promote acceptance of what is now called "A Natural Death," but one in which pain and uncomfortable symptoms are well controlled. Table 3 presents the varied environments in which hospices deliver services today and the practice issues for social work shaped by the environment of the setting.

Table 3: Hospice Social Work in Varied Environments.

<b>Environment</b>	<b>Environmental Issues</b>	<b>Practice Issues related to environment</b>
In-home care: individual residence	Homes range from trailers & apartments to large houses; rural to urban locations; clean/tidy to dirty/odorous. Pets: friendly or frightening. Photos & memorabilia help assessment come to life.	Assess social context & environmental needs. Understand caregiving systems, assess abilities & knowledge. Assist people who live alone.
In-home care: assisted living, retirement, senior housing	Facilities range from communal living/dining (all apartments open on core area) to individual apartments with kitchens & no structured contact with others. Staff can be very comfortable or uncomfortable with dying.	Rapport with facility. Educate staff about EOL.* Collaborate with the staff. Understand facility politics.
Free-standing inpatient units	Nonhospital setting. Children, pets allowed. Family can stay; open visiting hours. Comfortable surroundings 24-hour nursing care.	First contact may be in the final hours/days of life. High intensity, urgency of work; frequent death. Ongoing observation of pain, symptoms of dying, and death.
NH*-based hospice care	Resident becomes terminally ill and hospice called in (long-term placement), or Hospice patient is admitted to the nursing home (new placement).	Assess nursing home culture. (Is hospice welcome or a threat?) Help patient accommodate to NH living.
Residential hospice facilities	Home-like, non-acute care. Lives alone, no caregiver. Family/friends are unable to manage EOL care.	Longer term stay may allow for reminiscence, planning, family meetings Transitional plans needed; will the person stay here until death
Hospital-based hospice	Acute care facility. Designated hospice beds floor, or Beds scattered throughout hospital.	Team within a team (hospice plus hospital staff). Balancing the fiscal realities faced by hospice and hospital care (discharge planning may be a priority).
Bereavement counseling	Telephone contact. In-home counseling. In-agency counseling.	Hospice social worker assists the person in bereavement, or Separate bereavement counselors.

\*NH: nursing home; EOL: end of life.

Modified from Waldrop, D. (2006). Hospices, in *Handbook of Social Work in Health and Ageing*, B. Berkman (Ed.), p. 464 .

Hospice programs flourished after the development of the Medicare benefit in 1982. They have become well established in the health care system. Today more than 4200 are licensed, an increase of almost 1000 in just the past 2 years. In 2005, the National Hospice and Palliative Care Organization (NHPCO) reported that 1.2 million people received hospice care in the United States. They estimated that at least one of every three deaths, of all causes, in the United States took place under hospice care. In part



this reflects the growing need of services for an expanding older population as well as a growing acceptance of the palliative care philosophy in the U.S. health care system at the advanced stages of disease (Connor, 2007-2008).

### **Palliative Care Extends Reform to Hospitals, Institutions, and Professionals**

During the past decade there has been a strong national movement to permeate the larger health care system with the palliative philosophy throughout the course of treatment rather than only when death is imminent. Indeed some specialists believe they should de-couple palliative and end-of-life care in order to engage referrals. Many patients do not want to confront death until it is imminent. Physicians have established palliative medicine as a subspecialty within medicine. Since 2000, Palliative Care Programs have increased from 632 to over 1300 according to the Center to Advance Palliative Care (Morrison et al., 2005). More recently, these programs have been welcomed, indeed “embraced,” as an alternative within hospitals to intensive care of terminally ill patients (Kuehn, 2007). These programs were developed to address the vast unmet needs among aging and dying patients, but also to address concerns about the cost of care for a growing aging population (Morrison et al., 2008). (See discussion of costs of hospice and palliative approaches in the policy section.)

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## Curriculum Resources



### Suggested Readings:

#### Textbooks

In recent years social workers have produced some excellent textbooks in health and health and aging including several specifically addressing palliative care and grief and loss. Many chapters in these books have been used throughout the health resource reviews. These handbooks and texts are a great resource for social work students and practitioners who are seeking to familiarize themselves with state-of-the-art social work practice and research in a broad range of important substantive areas in health and aging.

- Berkman, B. (2006). *Handbook on social work in health and aging*. New York: Oxford University Press.

*The Handbook on Social Work in Health and Aging* is a very comprehensive, highly readable, and authoritative handbook on a broad range of topics in health and aging. It reviews the major practice, education, research, and policy issues with older adults. The editorial committee and the authors of individual chapters are the leaders in the field of health and aging. Most authors have been integral to the development of the highly successfully Hartford Geriatric Initiative; therefore, it is important for students to become aware of their work. The literature reviews are extensive, documenting the evidence base and major conceptual frameworks used in practice and research. Many relate to topics, such as advanced chronic illness and long-term care that are integral components of hospice and palliative care. This is a tremendous resource for students and faculty seeking an up-to-date synthesis of research literature in specialty areas related to health and aging.

- Csikai, E. L. & Jones, B. (2007). *Teaching resources for end-of-life and palliative care courses*. New York: Lyceum Books.

This book is an excellent compendium of curricula resources and course syllabi for social work classes in palliative care, grief, and loss across the lifespan. It is divided into courses for BSW and MSW in end-of-life care, palliative care, grief and loss, across the lifespan, and other specialty areas. The presentation of material varies quite a bit across sections, but there is something for everyone here: classroom exercises, assignments, videos, selected client book lists, self-reflection outlines, class evaluations, bibliographies, a timeline of major historical events people have experienced, and much more.

- Hooyman, N. R., & Kiyak, A. H. (Eds.). (2008). *Social gerontology: A multidisciplinary perspective*. Boston, MA: Allyn & Bacon.

*Social Gerontology: A multidisciplinary Perspective* is a classic text in the field of social gerontology that is comprehensive, highly readable, theory- and evidence-based, and full of pictures, charts, and graphs that make it very popular with students working with older adults. It takes a strengths-based and resiliency approach to the topic utilizing an active aging framework and incorporating international information as well as U.S. data in the demographics section. The second section focuses on the biological and physiological context of social aging, and presents detailed discussions of the major chronic illnesses now

experienced by older adults. The third section addresses the psychological context of social aging including cognitive changes, mental health issues, love, intimacy, and sexuality. The fourth section covers the social context of aging that includes social theories, social supports/networks, opportunities for caregiving, productive aging including paid and nonpaid roles and activities, death, dying and bereavement, and resilience in race and gender. The fifth section addresses policy initiatives to improve the social problems identified. This text is up to date, authoritative, detailed, and comprehensive with relevance to health, illness, and loss woven throughout many sections. A great resource for bibliography and data for student papers in a variety of specialty areas for older adults and health.

## Articles/Chapters

- Goldstein, N. E., Back, A. L., & Morrison, R.S. (2008). Titrating Guidance: A model to guide physicians in assisting patients and family members who are facing complex decisions, *Archives of Internal Medicine*, 168(16), 1733-1739.

This article presents a model for communication and decision making between physicians and their patients that takes account of where they are in the disease and treatment process and the patient and families' preferences and values. Their model incorporates degree of predictability of outcome and likelihood of the patient continuing acceptable quality of life. They review previous approaches to decision making: i.e. paternalism, and autonomy which have proven inadequate in the face of multiple medical possibilities for extending life, even with often unacceptable suffering. They suggest a shared decision making process that elicits and takes account of the physicians own reactions as well as patient and family preferences.. This model has application for social workers and other health professionals as well as providing insight into the physicians' challenges in managing communication over the course of an advancing illness.

- Sykes, N. (2008). End of life issues. *European Journal of Cancer*, 44, 1157-1162.

This article, written by a physician, describes the current understanding of key symptoms that permit a diagnosis of the dying process. This is an important knowledge base for social workers in health care so that they can fully incorporate the biological aspects in their discussions with patients and families and in their assessments. The author describes key symptoms of dying that include pain, breathlessness, secretions, and restlessness, and reviews how they are currently managed in palliative care. Importantly he discusses the ethical issues confronted in using opioids and sedation to relieve the patient of symptom distress and pain while maintaining life. The "principle of double effect" is reviewed. This principle suggests that an action (medication) which causes a serious adverse effect that has been foreseen, even death, is morally allowable if the intention behind the action was to do good (eg. relieve pain and suffering) and not to harm the patient. Reviewing different opinions about this principle, the relationships to euthanasia and assisted suicide are important to an optimal social work health practice knowledge base in palliative care.

- Owen, R., & Jeffrey, D. (2008). Communication: Common challenging scenarios in cancer care. *European Journal of Cancer*, 44, 1163-1168.

Communication has increasingly been found to be a core of emotional support during treatment of life-threatening illness, especially advanced illness. Communication skills are presented as discrete learned behaviors. While this article is aimed at physicians who have a specific area to discuss with patients, it highlights for social workers the critical transitions in the advanced illness process and communication challenges faced at each point. Often social workers are asked to participate in these discussions and to

follow up with the family afterward to provide clarification and support for next steps. For example the authors discuss changing the goals of care and talking about prognosis and talking about death and dying. Regarding treatment, they review withholding and withdrawing life-prolonging medical treatments, questions of whether the patient wants to be resuscitated (DNR orders), stopping palliative chemotherapy, dealing with inappropriate treatment requests. In all of these areas they discuss various misunderstandings patients have about these complex medical issues and suggest ways to explain or clarify them to patients and family members.

Finally they review what the patients experience during the process: information needs, a wish to deny or protect themselves from harsh realities, disappointment when treatment is unsuccessful, prolonged sense of hopelessness without being able to substitute realistic hope, dealing with despair and anger. Other communication problems involve groups: confusion or conflict within families, differences between members of a multidisciplinary team. The authors address physicians' reluctance to "share" the patient with other specialists or ask for help by referring to another discipline. They conclude by emphasizing the importance of core techniques of communication: being mindful of the emotional impact of the situation, adjusting to different communication needs of different individuals, maintaining a collaborative approach with patients, and trying to understand the situation as the patient and family perceive it.



### Web Resources:

- Social Work Hospice and Palliative Care Network  
[www.swhpn.org](http://www.swhpn.org)

This is the website for the newly formed 501c3 organization for social workers in hospice and palliative care. Its aim is to advance this specialty within social work practice, education, research, and policy. It provides up to date resources, conference announcements, a newsletter and other e-blasts of current events, advice from experts on particular topic areas, and a members only virtual practice community for discussion and networking. Members also have free access to the Journal of Social Work in end-of-life and palliative care. This network seeks to advance the role of the social worker in caring for the seriously ill, providing relief from pain, improving quality of life, supporting family and friends, assisting with difficult decision-making, and working with trauma, grief and loss.

- Center to Advance Palliative Care  
[www.capc.org](http://www.capc.org)

The Center to Advance Palliative Care (CAPC) provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings. CAPC is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness. It is primarily aimed at physicians and nurses, but increasingly content addresses psychosocial issues. Resources such as reliable and valid clinical outcome measures, reviews of articles, commissioned reviews, and post graduate training opportunities on developing palliative care programs are valuable.



- Center for the Advancement of Health

<http://www.cfah.org/>

This website has many resources geared directly for consumers or patients related to health education, becoming more informed and engaged in managing one's health and health care,

- National Hospice and Palliative Care Organization

[www.nhpco.org/templates/1/homepage.cfm](http://www.nhpco.org/templates/1/homepage.cfm)

This is the web site of the national hospice organization that supports and advocates for providers of Hospice in the US. It provides up to date information on reimbursement and government policies and actions that impact on the development and growth of hospice.

- American Academy of Hospice and Palliative Medicine

<http://www.aahpm.org/>

The Academy is the professional organization for physicians specializing in hospice and palliative medicine. Membership is also open to nurses and other healthcare providers who are committed to improving the quality of life of patients and families facing life-threatening or serious conditions. For 20 years, the Academy has dedicated itself to advancing hospice and palliative medicine and improving the care of patients with life-threatening or serious conditions. It was originally organized as the Academy of Hospice Physicians in 1988.

- Growth House

<http://www.growthhouse.org/>

Growth House, Inc. is an award-winning site that provides a broad range of resources for life-threatening illness and end of life care. Their primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Their [search engine](#) gives you access to over 4,000 pages of reviewed educational materials from over forty major health care organizations. They aspire to be a portal to the best materials from partner organizations, including the full text of several books.