TOOLKIT FOR DEVELOPING

Hospice and Palliative Care Programs

IN THE DEPARTMENT OF VETERANS AFFAIRS MEDICAL CENTERS

A Veterans Health Administration Project
Supported by the
Office of Academic Affiliations
in Conjunction with
Geriatrics and Extended Care
in the Office of Patient Service

A Product of the
VA Training and Program Assessment for Palliative Care (TAPC) Project
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A Toolkit for Developing Hospice and Palliative Care Programs in the Department of Veterans Affairs Medical Centers

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Introduction

Created for local champions seeking to improve care through the end of life for veterans and their families, this Toolkit aims to assist clinical and administrative staff expand existing or develop new palliative care and hospice programs in Department of Veterans Affairs (VA) healthcare facilities. One of four products of the Training and Program Assessment for Palliative Care (TAPC) Project, this toolkit contains important "how to" information about program development within the VA healthcare system, comprehensive descriptions of model palliative care programs, examples of successful palliative care proposals; and a list of resources. It is designed to be a dynamic document, published both as hard copy and on line at www.va.gov/oaa/flp, and will expand and evolve as new information and data become available.

The first section of the Toolkit, "Building or Expanding Palliative Care Programs in the Department of Veterans Affairs Healthcare System", is a monograph written by James Hallenbeck, MD, VA Palo Alto Health Care System, Palo Alto, CA. Originally distributed at the March 2001 VA National Leadership Conference for Pain Management and End-of-Life Care as a preconference seminar, this document provides a roadmap for making the case in proposing and developing palliative care programs. Beginning with the "demographics of dying" in VA; it focuses on common management concerns and offers suggestions for overcoming them, including a comprehensive look at data gathering and analysis. At the end of the document is a chart that outlines the management concerns and accompanying recommendations.

"Inpatient Hospice/Palliative Care Programs", also written by Dr. Hallenbeck, provides comprehensive information for creating and managing a hospice and palliative care inpatient unit. Using the Palo Alto Hospice inpatient unit as a model, this section describes the advantages and disadvantages of several models of inpatient units and the steps to evaluate for size and type; identifies staffing needs and discusses potential turf issues; discusses management issues; and addresses a myriad of other topics related to developing and operating successful inpatient units.

Geetika Kumar, M.D., Hospice and Palliative Care Medical Director, and Kathy Hayes, MS, RNC, CHPN, Hospice & Palliative Coordinator, Dayton VA Medical Center, provide a strategic plan for creating a hospice and palliative care inpatient unit. Drawn from their own experiences, this section outlines the steps they took to conceptualize, develop, and implement their unit. A unique aspect of their program is their Advanced Care Planning Computer Software Program. Currently available to VISN 10 facilities, this program identifies out-patients currently eligible to receive palliative care services based on ICD code and utilization of Emergency room and ICU visits.

Written by Linda Ganzini, M.D. and Joan Caley, RN, MS, CNAA, the third section is a proposal to create a palliative care consult team at the Portland VA Medical Center in Portland, OR. It provides useful background information about the need for palliative care services and presents a methodology and a detailed description of how to cerate and maintain the team. While Portland's palliative care team is just getting underway, this proposal is a practical and detailed guide that will assist other facilities in taking the necessary steps to begin any new program.

The James A. Haley Veterans Hospital in Tampa, Florida offers a comprehensive overview of an award-winning Home Based Primary Care (HBPC) Program into which the concepts of palliative care has been integrated. Submitted by June Leland, M.D., the program's medical director, this section describes the multiple areas of impact this full-service, model home care program has had on care through the end of life for chronically ill veterans.

Ken Rosenfeld's "Pathways of Caring", a three-year pilot program supported by the Robert Wood Johnson Foundation (RWJF) and a VA Health Science Research and Development (HSR&D) Career Development Award conceptualizes a case management approach to palliative care and addresses the issues of continuity and coordination of care. The Pathways of Caring program offers an innovative and compelling system for identifying seriously ill, high risk patients and tracking them through the illness trajectory. With a focus on continuity and coordination rather than diagnosis and prognosis, the Pathways program was able to accept patients with widely divergent goals of care and, importantly, forge a working, productive relationship with its community-based hospice partner.

A succinct overview of "Advance Illness Coordinated Care" (AICC) model , conceived by Daniel Tobin, MD, describes a specialized case management approach. Developed by The Life Institute and The Center for Advanced Illness Coordinated Care, AICC works with the primary provider and healthcare system to integrate a six-visit intervention by a nurse or social worker into routine care for patients with advancing illness. By building relationships with these patients, AICC-trained professionals seek to reduce the barriers to palliative care, increase referrals to hospice, and promote quality of healthcare across settings of care. There is also evidence of significant cost avoidance by starting the difficult conversations early and providing support through the various stages of a progressive illness.

The final section of this toolkit offers an abundance of web-based resources to assist the local champion in creating or enhancing palliative care programs in his or her facility. Listed in alphabetical order and annotated, these resources provide valuable portals into the cyberspace of hospice and palliative care. Of note, the Center to Advance Palliative Care's (CAPC) web site offers a myriad of information and tools for creating a palliative care business plan; Growth House, Inc.'s Inter-Institutional Collaborating Network (IICN) links major organizations internationally in a shared online community, including the private VA Pain

Management and End-of-Life Online Conference; the *Toolkit of Instruments to Measure End of Life Care* provides access to free patient-focused, family-centered survey instruments; and VHA's *Your Life, Your Choices* offers *a* workbook on advanced directives that helps patients and family members with developing clear instructions about how to proceed during a medical crisis or how to respond to a long-term disabling illness.

About the TAPC Project

VA historically has taken a leadership role in the promotion and development of fields of clinical practice that will enable better care of veterans. In the late 1990's the Office of Academic Affiliations (OAA) addressed the need for clinicians trained in end-of-life care by initiating the VA Faculty Leaders Project for Improved Care at the End of Life. OAA was awarded a $985,000 grant by the Robert Wood Johnson Foundation to support the project. The purpose of the two-year project was to develop benchmark curricula for end-of-life and palliative care--and strategies for their implementation--for training resident physicians in general internal medicine and the subspecialties of internal medicine at 30 competitively selected VA facilities.

At the conclusion of this successful program (www.va.gov/oaa/flp), OAA launched the VA Training and Program Assessment for Palliative Care (TAPC) Project in collaboration with Geriatrics and Extended Care in the Office of Patient Services. The purpose of the TAPC Project was to provide information and tools to help facilities enhance or expand palliative care services throughout the Veterans Health Administration (VHA). Grounded in the belief that excellent care and training go hand-in-hand, the project also sought to facilitate the development of an interprofessional palliative care fellowship program for physician and associated health trainees.

Initiated in September 2000, TAPC Project activities were conducted over the span of one year. TAPC Project Committee members (see list of names below) participated in one of four workgroups, primarily through conference call meetings. At the conclusion of the TAPC Project, workgroups had achieved the following major accomplishments:

- **Conducted a system-wide survey** to identify existing palliative care programs within the VA and to help understand both strengths and weaknesses of these programs. Such information should be useful in expanding both programmatic and educational initiatives throughout VA as well as providing the opportunity for local benchmarking. An Executive Summary of this survey is available on line at www.va.gov/oaa/flp and VA Intranet at vaww.va.gov/oaa/flp.
- **Created an online toolkit** that includes information to assist in the development and implementation of palliative care services. This toolkit contains vital information about creating or enhancing palliative care programs and includes descriptions of four models: inpatient, consult team, case management, and home based primary care. Intended to be a dynamic document that will continue to evolve, it can be accessed on line at www.va.gov/oaa/flp and VA Intranet at vaww.va.gov/oaa/flp.
- **Launched the Interprofessional Fellowship Program in Palliative Care,** the purpose of which is to develop leaders with vision, knowledge, and commitment to lead palliative care into the 21st century. Six training sites and one hub site were competitively selected. They include Palo Alto (also the Hub Site), Bronx, West Los Angeles, Portland, Milwaukee, and San Antonio.

A unique component of this fellowship program is that, in addition to providing fellowship training, each training site is required to develop and implement an *Education Dissemination Project* related to extending palliative care education and clinical expertise beyond the training site. The purpose of this component of the fellowship program is to enhance the education of health professionals and the quality of care provided to patients at additional sites.

- **Designed a palliative care and training newsletter** and determined strategies to publish and disseminate system-wide and identified key VA staff to assume ongoing responsibility for content. The newsletter will be housed in the Bronx GRECC and distributed electronically through e-mail distribution lists and posting on appropriate websites.

These remarkable achievements were accomplished over the span of just one year by the following group of dedicated professionals, most of whom are VA staff. Without their considerable contributions of skills, time, and energy, none of this would have been possible. It is to them, and the veterans they serve, that this toolkit is dedicated.

Executive Committee:
- Linda Johnson, Ph.D., R.N., TAPC Project Director, and Acting Director, Associated Health Education, Office of Academic Affiliations
- Evert Melander, M.B.A., TAPC Financial Manager, and Director, Administrative Operations, Office of Academic Affiliations
- Judy Salerno, M.D., Associate TAPC Project Director and former Chief Consultant for Geriatrics and Extended Care Strategic Healthcare Group in the Office of Patient

TAPC Project Committee
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- Hugh Maddry, M.Div., D.R.E., Deputy Director, National VA Chaplain Center, Hampton, VA
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- Paul Rousseau, M.D., GEC Administrator, Phoenix VA Medical Center, Phoenix, AZ
- Scott Shreve, D.O., Associate Chief of Staff-Extended Care, Lebanon VA Medical Center, Lebanon, PA

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Building or Expanding Palliative Care Programs in the Department of Veterans Affairs Healthcare System

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The Department of Veterans Affairs (VA) has much to be proud of in the care delivered to veterans. In comparison to the private sector the quality of care we provide is generally excellent. VA has a particularly distinguished record of providing needed services that have been neglected by the private sector such as care for patients with spinal cord injuries. VA also took a leadership role in the development of Geriatrics as a specialty. VA mandated hospice consult teams and a national pain strategy well before such concepts became popular elsewhere. Still, it is clear that we can and must do more. Because a growing percentage of our veteran population is aged and suffering from serious, chronic illness, greater attention must be paid to *palliative care* (addressing the miseries associated with chronic illness).

Nobody is opposed to the alleviation of suffering and good end-of-life care. Clearly, we all have a personal stake in developing a care system that can meet the needs of our families, friends and ourselves. Good intentions, unfortunately, are not enough. If we are to provide better care, we must change our health care system in certain ways. In a large health care system like VA such change is not easy. This essay is written to help local champions in VA work as change agents for better palliative care within their facilities.

Recently, a number of excellent articles and manuscripts have been written, providing guidance as to how to develop or expand palliative care services. However, we have unique challenges and opportunities within VA. While significant differences exist between Veterans Integrated Service Networks (VISN) and individual VA facilities, certain common issues arise when proposing new or expanded palliative care services. This document will address some of these issues in order to provide local champions with the necessary tools to 'make the case' that change is needed. A persuasive case will be made that good palliative care is not an *option* for VA but a *necessity* if we are to be true to our mission. Local champions must work hard and take advantage of local opportunities (and even luck) if they are to succeed.

A common assumption is that clinicians and administrators in VA want to provide the best possible care for veterans. However, in a large health care system with a fixed budget and multiple conflicting demands relative to budget allocation, if palliative care is to expand something else must shrink. This zero-sum reality is a major barrier (but perhaps not THE major barrier) to change in VA. While we can help the local champion address certain common concerns of management, this is only the beginning. Deeper concerns must also be addressed.

VA Demographics and a look to the future

Before addressing common concerns of management, let us set the stage by briefly reviewing some demographics. While much of the focus here and throughout this text will be on examining patient deaths, it is important to remember that palliative care is not just end-of-life care. We base our analysis on deaths because they are discrete events and easy to track via VA databases.

It is predicted that the peak burial year for the National Cemetery Administration, overseeing veteran burials, will be 2008. Because of the large number of WWII generation veterans, now in their 80's, the next 8 years will witness a rising death rate for veterans, continuing a trend that is already in effect. In FY 2000 27,200 veterans died as inpatients in VA acute or extended care wards (4.5% of enrolled veterans). Inpatient deaths per 1000 discharges have increased 8% from FY96-2000. While the exact number of enrolled veterans dying outside VA facilities is not known, it is estimated to be of the same order of magnitude as inpatient deaths. Thus, approximately 50,000 enrolled veterans are dying each year and that number will continue to rise over the next 8 years.

Fifty thousand enrolled veteran deaths is less than 10% of the estimated 574,000 annual veteran deaths nationwide. These 574,000 veteran deaths represent approximately 25% of the annual United States death rate of 2.3 million. That a minority of veterans die while enrolled in VA care should not be surprising, as this reflects the fact that a minority of veterans receive their care from VA. Of importance to this discussion is the fact that relatively minor shifts in seriously ill and dying patients from the private sector to VA could radically increase the number of patients dying under VA care.

There is a strong possibility that such a shift will occur. While improvements in the quality of care for sick in dying patients in VA may attract newly enrolled veterans, of greater import will be broader demographic changes in the population as a whole. Just when veteran deaths will be tapering off in 2008, the 'baby-boom' generation will begin to reach the age of 65 and become eligible for Medicare (see Graph 1).

The rapid growth of 'baby-boom elders', coupled with fewer children of baby boomers able to provide home-care for these elders is likely to put severe pressure on our national health care system. Already, many established VA inpatient hospice units are noticing that as many as 40-50% of their patients are newly enrolled veterans. The reason these veterans come to the VA to die is frequently because they lack caregivers at home and the private sector lacks comparable services. Thus, it seems likely that VA increasingly will be called upon to care for a larger number of very sick and dying patients

Figure 8–2. Population Age 65 and Older, 1980–2030

Millions
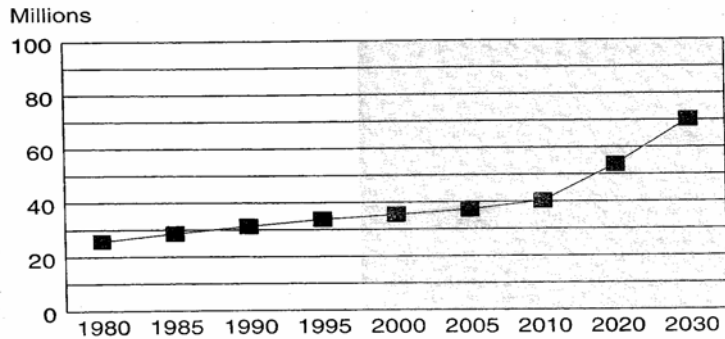
Source: U.S. Bureau of the Census Statistical Abstract, 1996.

Graph 1. Baby boomers become eligible for Medicare just as veteran deaths peak.

The following discussion will be organized around concerns managers may voice when new or expanded palliative care programs are proposed. Certain suggestions are made for possible data collection to help the champion 'make the case' for expansion. The goal of such data collection is not research per se or a 'needs assessment' and often requires looking at a small sample of relevant cases. For some interventions little or no data may need to be collected. However, if managers and institutional leaders believe that their institution is somehow significantly different from those reviewed in published studies, the champion may need to offer enough data to demonstrate a local need and reason for change.

Management Concern #1: We cannot afford to create or expand palliative care services.
We need to understand this statement better before providing a counter-argument. It is not a simple reflection, accurate or otherwise, of a fiscal assessment. It arises from complex assumptions that must be teased apart and systematically addressed.

Is palliative and end-of-life care optional?
One reason managers may believe we cannot afford palliative care is that they think such care is optional. Such a belief system should be approached with respect. Like the rest of the American health care system, we have developed a form of medicine that is *cure* based and mechanistic in its approach to illness. Illness is conceived as residing in specific parts of the human body. (Kleinman A. *Writing at the Margin.* U. Calif Press. Berkeley. 1995:21-40.). The hope and the myth of modern biomedicine is that if we just can fix enough broken parts of the body, then people will be cured. From this perspective suffering is *derivative* to cure; if we can just cure everything, then suffering will disappear. This prevalent belief is naïve on two counts. First, we have not managed to cure everything. (In fact we have created new forms of aging and dying.) Second, not all suffering results directly from the body. When Kübler-Ross first asked to speak to dying patients in a hospital in Chicago, she was turned down NOT

because of direct resistance to her request, but because managers sincerely believed that there *were* no dying patients in that hospital. In this model of medicine people do not die, they code. Death is a regrettable failure of current scientific understanding, which requires not a change in how we deal with dying but more intense efforts to 'get it right' the next time.

Our society has developed the concept of a right to health care and a belief that the bare minimum is a right to acute care. Society is seriously conflicted as to whether or not there is a basic right to palliative and end-of-life care. While the Supreme Court in its decisions addressing physician assisted suicide *implied* that there is a right to palliative care, such right has not been codified in health care funding mechanisms or insurance plans. While VA has established hospice as a basic eligibility entitlement, mandating that VA facilities pay for *home hospice* care, if an enrolled veteran is not otherwise eligible under Medicare, special eligibility status has not been established for dying patients unable to use home hospice. It is therefore understandable that VA managers reflect this same ambivalence as to whether palliative care is optional or not.

This belief system starts with the premise that absolutely essential health care – the rock-bottom minimum requirement, is acute care in the hospital. Everything else is secondary and in the presence of a tight budget, optional. Society generally supports this premise. Acute care hospitals are indeed important. However, they were designed primarily for cure and, if not cure, then life-prolongation. Any proposal for increased palliative care in a VA perceived as threatening this primacy will fail. On the surface, given the zero-sum game of VA budgeting, it is easy for VA managers to see palliative care as such a threat. While better palliative care may require some shifting of resources from acute care elsewhere (to home care for example) we believe that the only way acute care VA hospitals will remain open and functional in the future is if good palliative care is instituted. It is therefore essential to reframe the statement regarding palliative care as an option; the issue is not palliative vs. acute care. Palliative care is essential IF we are to continue to have a health care system within VA in which acute care is provided.

Recently, the Millennium Bill established for the first time formal eligibility for extended care within VA for service-connected (>70%) veterans. Extended care services encompass nursing home care both within VA and, by contract, home based primary care and adult day health care. Much of this care is palliative in nature. Despite this congressional mandate and a growing population of veterans in need of such services, the percentage of the VA budget dedicated to long term care has remained relatively static at 14%. Significant regional variation exists by VISN as to the provision of such services. While enactment of the Millennium Bill is a step forward in formally recognizing the palliative needs of our veterans, the local champion must bear in mind that historically care beyond the acute care hospital (and tightly linked ambulatory clinics) has been viewed as being optional, an extra to be provided 'as resources allow'. The idea that home care, adult day health care and nursing home care, if done skillfully may actually conserve resources, is foreign to VA culture. While it may be

counterintuitive, the percentage of the VA budget dedicated to Extended Care must increase (and proportionately the percentage dedicated to acute care must shrink) *if* acute care is to survive within VA.

Acute care, so highly valued within VA and American health care culture, is recognized by VA managers as the greatest money looser. This is because under the Veteran Equitable Resource Allocation (VERA) VISN reimbursement is limited to two classes of patients, basic and special. The basic category comprises the majority of admissions and results in lower allocation rates. A more thorough discussion of VERA is provided below in the section entitled, "VERA Reimbursement and Other Income."

While some reduction in the numbers of acute care beds has occurred in reaction to VERA reimbursement, the dominant response seems to be to shorten acute care stays as a means of minimizing loss. Managers also see the importance of getting people out of acute care as soon as possible. Extended Care (nursing home beds, sub-acute units, home based primary care) is generally recognized as a 'decompression valve' for acute care. The local champion can use this tension to argue for expanded palliative care, both in acute and extended care.

While managers are aware of the imperative to get patients out of acute care as soon as possible, most are not aware of the potential value of palliative and extended care services in *keeping* patients out of the hospital or averting admissions altogether. As institutional tension generally does not exist on this point, the local champion needs to make the case that averting an admission all together is better than shortening a length of stay.

Two reasons why managers have been so slow to recognize this are likely. First, totally averting admissions seems to threaten the very reason-for-being of acute care. It suggests the very scary notion that a number of existing acute care admissions are totally unnecessary. More obviously, it is much easier to follow actual numbers like decreasing lengths of stay as a measure of cost control than to estimate the number of admissions averted. While indirect cost savings resulting from averted admissions are just as 'real' as those resulting from shorter lengths of stay, they must be estimated, which makes them seem less real. People tend to pay more attention to money and numbers they can see than money and numbers they estimate.

Perceiving palliative care as *optional* also implies that VA facilities have a *choice* as to whether or not to care for seriously ill and dying veterans; it is clear that they are caring for these patients now. And while facilities have no control over their patient population of veterans, they can *choose* a relative emphasis given to cure, life-prolongation and palliation. In addition, VA facilities have some options regarding *where* to provide the care – whether palliative and end-of-life care should be provided in intensive care units, acute care, nursing homes or home care – and the *quality* of that care.

In some VAs occupancy rates for acute care beds are low. There may be internal pressure to "keep the census up" to justify having an acute service. Even at VA facilities with full acute wards the message VA managers are likely to hear from admitting ward services is, "we need more staff and resources to take care of all these very sick patients." Acute care services (except for physician residents) are not likely to admit that some patients in acute care would be better served elsewhere. When it comes to acute care, VA managers are used to hearing, "more, more", not "less, less".
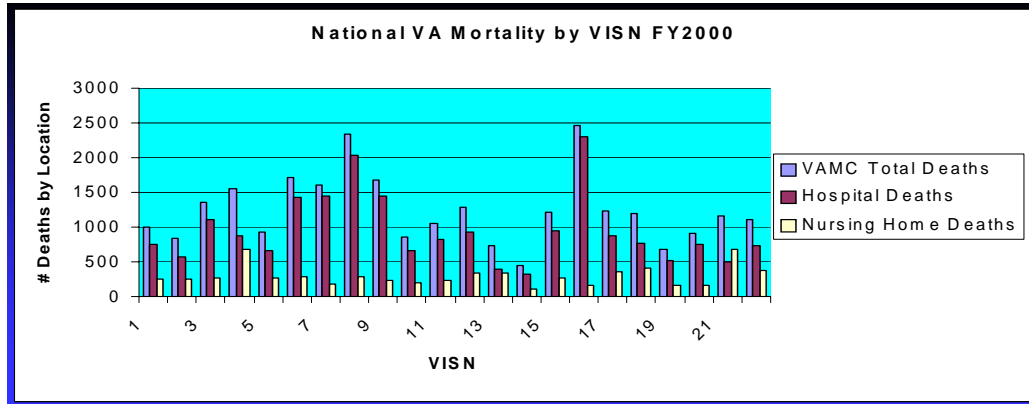
Beyond this, VA managers and clinicians may have trouble recognizing that, contrary to the cure paradigm described above, much acute care is really palliative and/or end-of-life in nature. As obvious as this may seem to a palliative care advocate, the prevalence of palliative and end-of-life care in the acute care hospital needs to be proven.

<u>Suggestion # 1: Demonstrate the extent of palliative and end-of-life care currently delivered in your acute care hospital.</u>

> Quantify the number of deaths in acute wards and the ICU.
> > o Total number
> > o As a percentage of admissions to that unit

Numbers of deaths and location of death are relatively easy to obtain, as death and location of death exist as fields in common VA databases. If unable to obtain these, the Office of Decedent Affairs probably has copies of death certificates. Nationally, in FY 2000 7,382 deaths occurred in medical and surgical ICUs in VA facilities, 23% of all admissions. Nationally, in FY2000 8,469 deaths occurred in acute medicine, 3.6% of admissions. This data is interesting in two regards. ICU deaths nationally almost equal acute medicine deaths. (In some VA facilities ICU deaths exceed general medicine deaths.) While ICUs are ostensibly about saving lives, VA managers may not realize that of all inpatient venues of care (except for dedicated palliative care units) ICUs have the highest death rate. ICUs are major sites for end-of-life care.

There is remarkable variance in terms of the numbers and percentages of ICU deaths across VISNs as well as among individual VA facilities and, as we shall see, in the percentage of deaths occurring in specific venues of care. (See graph 2 below) The variance is so great that it is impossible to believe that it reflects rational allocation of resources according to varying need. Other factors must be at work. Pointing out such variance can at least get managers to consider the possibility that at least some terminal admissions are avoidable.

National VA Mortality by VISN FY2000

 # Deaths by Location (y-axis)
VISN (x-axis)

Legend:
- VAMC Total Deaths
- Hospital Deaths
- Nursing Home Deaths

Graph 2: Demonstrates variance across VISNs in numbers of death by location. Note for example VISNs 3, 6, 7, 8 and 16, where the vast majority of deaths occur in the hospital. Contrast this with VISN 21, where more deaths occur in nursing homes than in acute care.

If we compare deaths by location in three VA facilities with dedicated hospice wards in their Extended Care sections to national data, we see striking similarities among the three facilities (Palo Alto, Dayton and Lebanon) and equally striking differences from national data. These three facilities are very different from each other in a variety of ways –geographic location, urban, suburban and rural, but share similar size (circa 25 beds) palliative care wards in Extended Care. While this does not prove that having a hospice ward will reduce deaths in ICUs and acute care, it does suggest that deaths in ICUs and acute care may be reduced by developing dedicated palliative care services.

FY 2000 Inpatient Deaths by Location

National vs three stations with palliative care units

Legend:
- ICU (all)
- General Medicine
- Intermediate Medicine
- Nursing Home
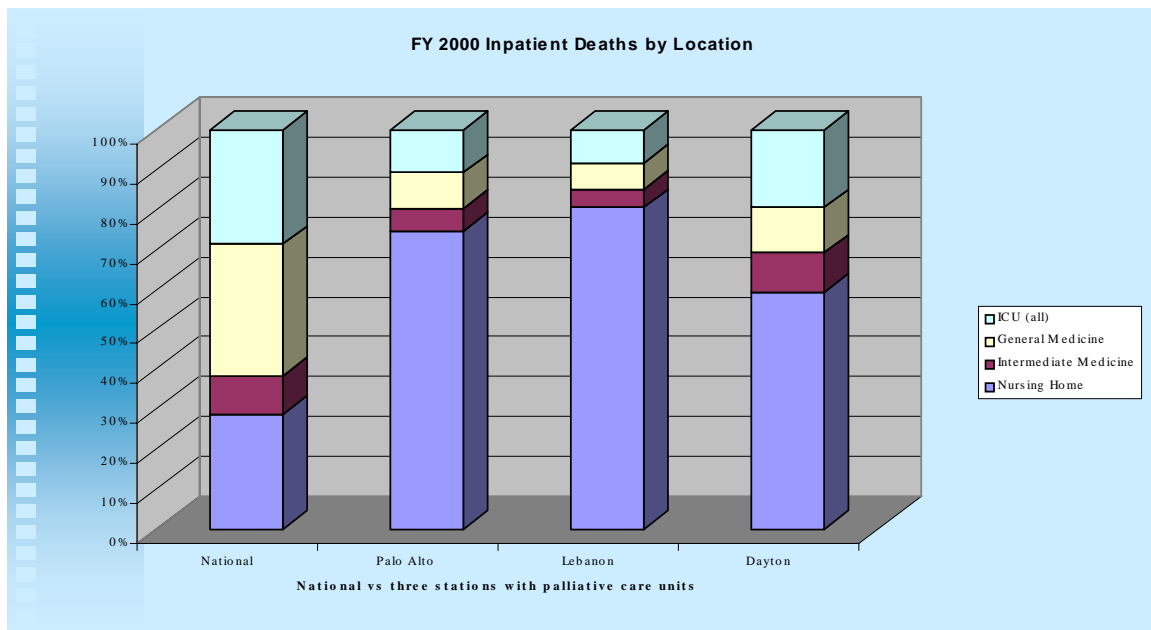
Graph 3: Percent Inpatient Deaths by Location- comparing National data to Palo Alto, Lebanon and Dayton VAs.

<u>Suggestion #2: Do a chart review of a percentage of charts in acute medicine</u>.

Categorize the charts according to the major goal of admission:
   A. Identifying new problem (diagnosis)
   B. Curing known problem
   C. Prolonging life
   D. Providing palliation

For A-C also note the incidence of common palliative problems arise – pain, dyspnea, nausea/vomiting, weakness, agitation, confusion, etc. It is also recommended that any underlying serious, life-limiting illnesses be identified.

What you will likely find is that most admissions are for known problems and that cure is often not a realistic goal. Performing such a review, if done thoughtfully, will highlight common problems in how clinicians think about care. For example, a patient with advanced Alzheimer's disease may be admitted with his third bout of aspiration pneumonia. The pneumonia may be considered a "new problem" and treatment, antibiotics, aimed at "curing" the pneumonia, which may or may not prolong life. The patient may also require palliation for agitation and dyspnea. In such a case it is critical to understand that the pneumonia is probably not just an 'accident' but part of having Alzheimer's, which is not curable. *The key point to get across to managers*: Most admissions to VA hospitals are for chronic, well-understood and incurable illnesses, where major goals of care are life-prolongation and palliation.

Hopefully, managers will come to realize that palliative and end-of-life care are ALREADY major functions of the acute care hospital. This realization does not automatically imply that we need to do anything different.

Management Concern #2: Deaths in acute care are unavoidable. There is no need to change or add services.
Such a statement suggests that deaths in acute care, while sad, are unpredictable or, if predicted, *unavoidable*; there is no place else to go. The second statement, about no need to change, also assumes that *quality of care* is not an issue. Let us address these two concerns separately.

Unavoidable death
Certainly, some acute care deaths are truly unavoidable and unpredictable. An otherwise healthy patient gets pneumonia and sepsis. It is not clear whether he will be cured or will die. A full-court press, including ICU care, is appropriate. Following valiant efforts, it is discovered that recovery is impossible. Treatment is withdrawn and the patient dies. While very appropriate, such deaths are rarities in VA facilities. Most acute care deaths occur in patients with well-known, serious life-limiting or frankly terminal illness.

<u>Suggestion #3: Identify a sample of acute (ICU and ward) deaths and review for cause of death and underlying illness.</u>

If help is available with VA databases, deceased patients can be sorted by ward (ICU, acute medicine) and subsequently by Diagnosis Related Groups (DRG). It is also advised that either chart reviews or reviews using health summary programs in DHCP can further identify this information. What you likely will find is that most deaths occur in patients with serious chronic or terminal illnesses. For example, a sample chart review of patients at VA Palo Alto HCS found that the vast majority of deaths were due to chronic illness: forty-one percent had metastatic cancer.

Palo Alto VA: Acute/ICU Deaths: 30 pts Discharge Diagnoses

Legend:
- Met cancer
- Cirrhosis
- End-stage renal
- Hip fx
- Stroke
- Heart dx
- COPD
- Aneurism
- Pericarditis
- Sepsis
- Head injury
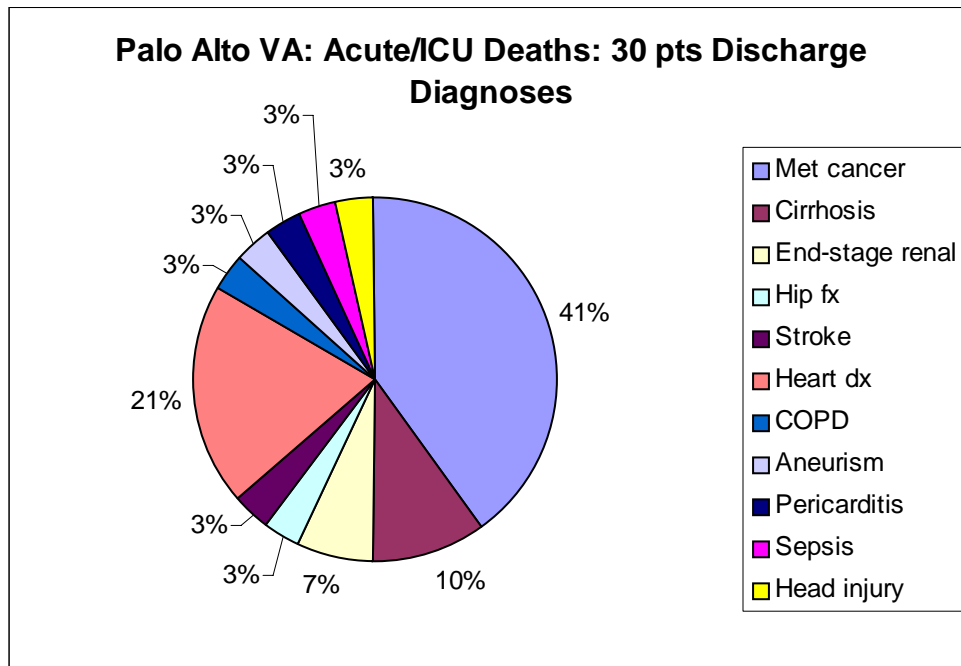
Graph 4. A sample of 30 acute and ICU deaths at Palo Alto VA. Note top three causes of death – metastatic cancer, cirrhosis and end-stage renal disease, all chronic, terminal illnesses.

The point here is that most deaths occur in patients who, while not necessarily identifiable as imminently dying on admission, would meet criteria such that the average clinician would not be surprised if the patient died at some time in the next year or so – a way of identifying patients with serious, life-limiting illness.

Let us pretend that your manager now agrees that most dying patients in acute care had such illnesses. Acute care deaths could still be unavoidable if:
- A) Patients wished aggressive life-prolonging or curative efforts, despite being offered other options for palliation; or
- B) There simply was no other place to go or better place to receive treatment.

Suggestion #4: Review charts to see if patient preferences were discussed and if so, what the quality of that discussion was.

This level of review may require pulling hard-copy charts. Likely, what you will find is that in many cases no discussion was held or it was overly simplistic (Full Code or DNR). You may wish to use a rating scale such as, 0 = no discussion in progress notes, 1 = progress notes state "DNR" or "Full Code" without further elaboration, 2 = DNR or Full Code per patient (or surrogate decision maker) 3 = documentation of treatment options beyond resuscitation in any form 4 = a note documenting an intelligent discussion of relevant options. It is likely in the conducting of such a review only a few patients will be identified where hospice or comfort care options were clearly offered and declined. Particularly for patient with non-cancer diagnoses, it will be rare that options for care such as home hospice will be raised and documented in the chart.

Suggestion #5: For these same charts upon review would it seem reasonable that an alternative venue of care might have been chosen?

This is a difficult assessment. It depends upon both patient and VA specific variables. For example, a homeless patient has no home in which to receive home care or a patient with a home does not meet home hospice criteria. VA variables can be quite obvious: does the VA *have* a Home Based Primary Care (HBPC) program and could it provide needed care to enable a patient to die at home – or subtle: a VA nursing home transfer might be appropriate, but there is a two week delay in admissions, which might exceed the patient's life-expectancy. Likely what will be found in such a review is that some patients could receive desired care in a different venue; dying in acute care is not necessarily an unavoidable fate. Specific system changes, such as fast-tracking certain nursing home admissions or bolstering HBPC programs to enable them to provide good end-of-life care (such as developing the ability to deliver medications when needed to the home and off-hour coverage) might increase the ability to have patients die elsewhere.

Quality of care
The lack of tension for change regarding palliative and end-of-life care in acute care results both from a sense of inevitability and a belief (or hope) that dying in acute care is not so bad. Some may acknowledge that dying in acute care might be undesirable, even unpleasant but any unpleasantness is unavoidable as, "our staff provide the best possible care." These assumptions should be challenged in order to create some tension for change.

Suggestion #6: Review charts for quality of end-of-life care and study the ability of the system to meet patient and family needs in acute care.

It is recommended that some very common problematic practices in end-of-life care be surveyed, such as appropriate treatment for pain, dyspnea and other common symptoms. Likely deficiencies will be identified.

Simple things to monitor:
1. Are patient and family preferences clearly documented?
2. Is there documentation of pain scores?
3. Did patients with metastatic cancer and chronic pain receive long-acting opioids or only PRN doses?
4. Did patients on chronic opioids have proper laxative regimens (something beyond DSS) – senna or an osmotic agent?
5. Were short-acting breakthrough doses of opioids dosed at proper intervals? (Current recommendations suggest q2 hour dosing when opioids are used without acetaminophen.)
6. Was reasonable palliation offered for patients dying with dyspnea? (Using opioids and/or benzodiazepines.)
7. Was depression assessed and treated in dying patients?
8. Did patients die with agitated delirium?
9. What evidence exists of support being offered to family?
10. Were spiritual needs addressed?
11. Was a bereavement follow-up call made?

The above reflect relatively non-controversial best practices for dying patients and good hospice programs would be expected to meet such standards. In most acute care settings a review would likely reveal serious deficiencies.

We have addressed issues of demographics, where people die, and quality of care. It should be possible to make a compelling case that most of the care provided by VA is for chronic illness and palliation is a key component of good care. Current care practices often falls short of best practices. This will not likely be enough to enable significant programmatic change. We need to address directly the problem of funding – an unpleasant topic for most palliative care champions, who are rightly more motivated by what should be done than by how to pay for it.

Management Concern #3: If we expand palliative care, something else will have to contract. We just don't have enough money to spend more on palliative care now.
The first part of this statement invokes the zero-sum game problem. While expanding programs can be challenging, even fun, cutting programs for managers is extremely painful. The more any such cuts relate to loss of personnel and/or cutting programs that have strong advocates the more painful any such cuts will be. To the extent "trimming" can result from non-personnel costs (such as pharmacy, lab expenses, etc.) the more appealing such cost-savings will be. This will be discussed further.

The second sentence finally gets to the money issue. This statement labels palliative care as an additional cost and tends to cut-off any notion of cost-savings. Were this to be completely true, efforts to expand palliative care would be doomed. Let us systematically look at the money issues.

Cost-savings
In a zero sum game cost savings can accrue if the cost of programmatic expansion is less than the amount of money saved by cutting costs elsewhere. This simple math ignores quality. Let us begin with the obvious. The cheapest way to provide medical care (at least in the short run) is not to provide it at all. While some might suggest that we leave end-of-life care to Medicare and nursing home care to Medicaid or private resources, this is neither entirely feasible nor is it in keeping with our mission. Providing poorer care may also save money. Clearly, this is not our intent. For the sake of argument we can imagine that any programmatic expansion is good if it results in costs savings and clinical outcomes at least as good as occurred prior to the expansion. Of course, we hope that clinical outcomes resulting from palliative care expansions are superior. The following discussion assumes that clinical outcomes resulting from palliative care efforts are at least equal to those prior to any such efforts.

Essential steps in making the case for cost savings are the following:
1. The cost of providing care per unit of care with programmatic expansion is less than the cost per unit, as it exists, without palliative care.
2. Units of care being compared are similar.
3. The cost of expansion can be reasonably covered by cost savings elsewhere in a manner that is politically acceptable.
4. There is no evidence of degradation in the quality of care. Hopefully patient and family satisfaction increases.

The cost of providing care per unit of care with programmatic expansion is less than the cost per unit as it exists without palliative care.
Comparing costs among programs is difficult. Units of care must be defined and comparable. Can one really compare the costs of home care to those in a nursing home or ICU? Difficult as such comparisons can be, they are not impossible. Sometimes we can directly compare costs such as the cost per day in one unit as compared to another. Sometimes we must use proxies. For example, in establishing an HBPC program with an emphasis on keeping patients out of the hospital who do not want to go to the hospital, estimated cost-savings can be inferred by comparing the cost of the home care intervention relative to estimated cost savings resulting from patients not being admitted, who otherwise would have been.

Suggestion #7: Do a cost analysis for patients dying in acute care. Compare this, if available, to the cost per day in a hospice unit.

The easiest and most direct cost comparison is the cost per day of care. A facility can compare similar episodes of care – for example, the cost per day for a terminal admission (resulting in death) in the ICU, acute wards, nursing home or hospice unit. In VA this is best done by comparing Decision Support Services (DSS) costs for groups of patients. DSS is a method of tracking costs common to all VA facilities and therefore potentially a powerful tool for comparing systems of care. DSS is far from perfect. However, it has three major advantages over what is available in the private sector:

1. It more directly measures costs (as compared to charges, which variably correlate with real costs);
2. Costs are automatically attached to episodes of care, minimizing the need for time-intensive data collection; and
3. Because DSS is a common standard, it is possible to compare costs across programs, facilities or VISNs. However, to use DSS, the champion must be aware of what DSS does and does not do.   Buy-in from those administering DSS is essential if a meaningful analysis is to be done.

DSS Methodology
DSS can reasonably estimate non-personnel costs attached to a patient or group of patients. DSS is most accurate in calculating how much money was spent on expenses like pharmacy or lab work.

Personnel costs for an individual or group are more problematic. They are calculated by summing the total personnel costs mapped (assigned) to the unit per unit time and then attaching a percentage of this total cost to that individual (or group). Thus, if looking at personnel costs attached to an individual on a particular ward for a given day with a census of 15 patients, a 15th of the personnel costs (fixed and variable) mapped to that ward would be attached to that individual. Thus personnel costs, if accurately mapped, can be reasonably calculated for a group of patients such as on a ward for a day or longer period of time. DSS is less accurate in calculating individual costs, as the current model cannot correct for varying acuity and associated workload on a ward; everybody gets the same percentage personnel cost regardless of actual utilization.

Mapping is the process by which personnel costs are assigned to a specific unit and, as just described, then attached to individuals or groups of individuals. Each VA employee's work is mapped by percentage to certain cost areas. If an employee spent 70% of his/her time on ward A and 30% on ward B, for example, these percentages would be used to attach proportionately any work done to those areas. Poorly mapped areas can be a significant source of error- over or underestimating costs, as personnel costs, particularly in palliative care, make up the bulk of the real cost of care. For example if the above employee was mapped 70% and 30% for wards A and B, but really spent 15% on ward C, no cost will be attached to ward C and wards A and B will incorrectly absorb a higher percentage of the employee's cost than actually was incurred.

Thus, DSS is not error free. However, the larger the areas of comparison, the more likely it will be that errors will cancel out. Comparing two individuals on two wards is much more problematic than comparing two wards.

While one must be mindful of these concerns, remember, you are not doing publishable research, you are trying to build a case for expansion using reasonable, but not necessarily perfect data.

<u>Doing a cost comparison</u>
In doing a cost analysis involving acute care the following parameters are particularly relevant:
1. Cost per day
2. Length of stay
3. Cost per admission (cost per day times length of stay)
4. Case-mix adjustment
5. Analysis of cost differences

By way of example, a study at VA Palo Alto HCS compared patients dying in acute care to those dying in their inpatient hospice ward and examined the above parameters. As the ward with hospice patients exclusively treats such patients, it was relatively easy to compare the cost of their care to that of dying patients in acute care. (Hospice programs sharing a ward with another, usually long-term care population will need to sort out those patients treated in hospice by Social Security numbers, as there is currently no other way to identify hospice patients within the VA database.) Patients dying in acute care over nine months were sorted out and DSS costs calculated for these patients. These costs were compared to costs associated with stays on the hospice ward.

This study revealed that the average cost per day for deaths in acute care (ICU and acute wards) was $887/day. (Indirect costs as calculated by DSS were not used in this analysis). The initial estimated cost on the hospice unit was $449/day. As a check for Palo Alto's acute care cost per day, comparisons were made with two other VA facilities in VISN 22 for cost/day per terminal admission. Those facilities costs were $900 and $840 per day, suggesting that this methodology is reliable. The mapping of costs to the Hospice ward was then reviewed. Numerous mapping errors were discovered. A number of staff not actually working on the hospice ward were mapped to the ward. Following remapping, the estimated cost per day dropped to approximately $350 per day.

Clearly, it is less expensive to care for dying patients in Palo Alto's inpatient hospice ward as compared to acute care. Patients dying in acute care often had very long lengths of stay. For example, of those patients eventually transferred to Palo Alto's hospice, the average length of stay was 25 days prior to transfer and 19 days following transfer. The total cost of acute care prior to transfer was $21,000, dropping to $8,000 for their stay on hospice.

As the total cost of an admission is the cost per day times the length of stay most terminal admissions in acute care are very expensive. There is no evidence that the length of stay of dying patients treated on an inpatient hospice ward would be longer or shorter than in acute care. However, that most lengths of stay for dying patients are so long in acute care makes potential cost-savings realized by treatment in a venue with a significantly lower cost per day significant.

<u>Case-mix</u>
Cost comparison does not prove anything. Of course patients dying in hospice are cheaper to treat. They have different needs and are fundamentally different from those dying in acute care.

The above comment raises the question of case mix; are we comparing comparable units of care? More expensive care could be justified if patients dying in acute care were significantly different from those dying in hospice. While certainly this is so to some degree, managers and clinicians probably overestimate the extent to which differences in cost per day are accounted for by case-mix.

Two pieces of evidence were examined in the Palo Alto study. First the cost per day fell dramatically when patients were transferred to the hospice ward, as presented above. To a degree such patients act as their own case-controls. However, it could be argued that lower costs represented an appropriate shift in care for patients and therefore was justifiable; care was appropriately aggressive until it was discovered that further aggressive care was 'futile' and then transfer effected, with cheaper care instituted. As previously suggested, reviewing a sample of acute care deaths should quickly reveal that the majority of deaths are due to chronic or frankly terminal illnesses identified at the time of admission. In the Palo Alto study most patients admitted to acute care had terminal diagnoses at the time of admission. Thus, patients dying in acute care strongly resembled those dying in hospice in terms of disease processes and prognoses, making it difficult to argue that they differed substantially in case-mix.

It could also be argued that even if patients were similar in disease process, they differed substantially in terms of their goals of care. That is, the patients dying in acute care wanted to be there. As previously suggested, a review of documentation of patient preferences in the chart will likely reveal a lack of evidence that this is so. At Palo Alto a retrospective chart review frequently revealed poor documentation of patient's preferences in acute care. Only one chart of 55 acute care charts reviewed clearly stated that hospice was offered and declined. A number of charts documented patients' desires to " go home." Based on this chart review we cannot prove that patients actively sought more aggressive care. We can say that there is no evidence this was a significant factor resulting in acute care being a location for dying.

Analysis of Cost Differences
Even if this is so, we are not going to save any money by investing in new palliative care programs, as most of our costs are fixed. That is, staffing of the acute wards will not substantively change.

This statement begs two questions. *Why* are costs decreased when patients are treated in a different venue, such as an inpatient hospice unit and *can* cost-savings really be shifted to enable a palliative care program to be created?

A study of the costs associated with hospice and non-hospice terminal admissions was also conducted as a part of the Palo Alto study.   Less money was spent on personnel costs, primarily nursing, for patients cared for in hospice. While absolute staffing ratios (number of nurses per patient) were not radically different between acute care (non-ICU) and hospice, the majority of nurses on the hospice ward were Licensed Vocational Nurses or Nursing Assistants, resulting in significant savings. The biggest difference occurred in costs related to medical procedures, which decreased from 21% of total costs for non-hospice terminal admissions to 2% in hospice. In absolute dollars medical procedures in hospice were approximately 1/25th the cost in acute care. Pharmacy costs only decreased in percentage terms from 8% of costs to 7%. However, given that *total* hospice costs were almost a third acute care costs, this represented a 55% reduction in pharmacy costs. The costs of medical procedures and pharmacy are minimally dependent on personnel costs and are therefore less fixed. Politically, non-personnel costs savings such as these are much more acceptable to managers than cost savings through personnel reductions.

The potential effect on personnel related cost savings are more complicated. It is true that if only minor, transient shifts of patient care occur from acute care to other venues, staffing in acute care will not likely change. Ward personnel costs are both fixed and variable. A substantial and sustained reduction in acute care workload, resulting from a shift to another (more appropriate) venue, should be accompanied by a proportional drop in acute care staffing. Variable personnel costs are largely nursing costs, which were the major cost of caring (55%) for dying patients in acute care. This effectively demonstrates that much of the costs saved by Palo Alto's hospice were variable and not fixed.

Quality of the data
Ok, your data is suggestive of cost savings. However, the quality of your data is poor. There still could be a selection bias. Are there any randomized-controlled studies demonstrating the cost-effectiveness of interventions such as hospice?

Academic clinicians often forward this argument. The definitive randomized study has not and probably will never be done. Two major problems exist. First, our society has framed care at the end of life as one in which patient preferences are to be respected. We cannot "randomize" people to dying in the ICU versus hospice, as we recognize that patient and family choice are integral to where people end up. Patient choice likely affects outcomes as well.   "Blinding" such a study would also be impossible. The truth is most organizational changes are exceedingly complex and cannot readily be reduced to comparative clinical trials. Most change in the real world happens without randomized control studies. It is still possible to collect data that supports certain changes and data can be followed to measure change once initiated. Most champions are not so much interested in research for publication as making a reasonable argument that something new should be tried. Easily obtained, 'messy', but compelling data is far better than difficult, expensive and lengthy clinical trials if the goal is organizational change. Another way to look at the above statement is to flip it on its head. While admitting that data supportive of certain palliative care

interventions is limited, it seems fair to ask, 'what is the quality of *your* data supporting the status quo? What is the cost-effectiveness of dying in the ICU or acute care?'

While no one definitive study will likely be done proving the value of palliative care, a number of smaller studies are beginning to appear supporting various palliative care interventions. Such data can support your locally collected data. Data is beginning to emerge suggesting significant cost-savings associated with interventions such as palliative care consultation teams and effective home management. For example reductions in hospital and ICU stays and better utilization of resources with no increase in risk-adjusted mortality have been demonstrated. (Lilly et al Am J Med 2000; 109:469, Dowdy et al Crit. Care Med 1998; 26:252, Jurchak et al J Clin Ethics 2000; 11:49-55, Carlson et al JAMA 1988; 259:378, Campbell et al Heart & Lung 1991; 20:345, Campbell et al. Crit Care Med 1997; 25:197.)

To highlight one recent study, Campbell demonstrated that palliative care consultation in the ICU resulted in significant cost savings. She demonstrated that the cost per day of inpatient care decreased on average from $6,545/day to $1,645/day when a transition was made from aggressive life-prolonging care to comfort care, based on changes in TISS (Therapeutic Intervention Scoring System) scores, that have been demonstrated to correlate with costs. (Dickey et al. Int Care med 1998; 24:1009-1017) In comparing patients with multi-organ system failure with a 100% predicted mortality, it took a standard ICU team 7.3 days (+ or – 11.4 days) to transition to comfort care, whereas with a palliative care consultation it took 2.2 days (+ or – 3.2 days) to effect such a transition. (Campbell, Guzmen, not yet published, presented at the first annual CAPC (Center for the Advancement of Palliative Care) conference 12/2000.) In the aggregate these studies are powerful arguments in favor of expanding palliative care services.

However, when encountering information that runs counter to what one believes or would like to believe, it is human nature to rationalize that somehow the information does not apply to oneself or one's organization. By way of example, palliative care leaders often present data from the SUPPORT study, demonstrating the prevalence of poor end-of-life care, to hospital leaders as an argument for why better palliative care must be provided. (SUPPORT principle investigators. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA*. 1995; 274:1591-1598.) The most common first reaction of hospital managers in hearing appalling statistics about intensity of pain at the end-of-life, for example, is to rationalize that somehow the SUPPORT study hospitals were fundamentally different from their own hospital. The same likely will be true when presenting arguments suggesting an economic advantage to a palliative care program or expansion. Some argument will likely arise to the effect that 'while that might be true elsewhere, it will not work here because…' Thus, local data must be combined with the presentation of data from published studies.

VERA Reimbursement and Other Income
The current reimbursement system for VA patients consists of capitated reimbursement for care under VERA, as well as certain co-pays and third party payments. Under VERA patients may be low or high VERA, depending on certain workload criteria being met. In FY 2000 the reimbursement rate for low VERA patients was $3,249 per year and for high VERA patients, $42,153. Patients staying over 30 days in a VA nursing home or with six visits or more in HBPC become high VERA patients. Actual money for such care is distributed to individual VISNs, who are guided by VERA calculations in distributing lump sums of money received among specific programs and facilities. Bear in mind that dollars distributed to VISNs for their budgets are based on prior calculations and the Congressional allocation of total dollars for VA for that year (the pie to be divided up). Thus, at a national level except for reimbursement outside of this pie (relatively small co-pay and third party payments) the total dollar pool for a given year is fixed.

To the extent a bigger piece of the pie is 'justified' based on VERA calculations for a facility or VISN, the remaining pie must be smaller for everybody else – the zero sum game. If, for example, every veteran miraculously fell into the high VERA reimbursement category, this would grossly exceed budgeted dollars and it would be impossible for all facilities to be so reimbursed. VERA therefore is a way of *justifying* reimbursement; it does not *earn* any new income. Nevertheless VISNs and facilities compete for their slice of the pie based on VERA calculations. Historically, reimbursement systems within VA are changed or adjusted every few years. Therefore, caution is advised for those hoping to 'game' the VERA system by maximizing 'points' under VERA by having 31 day nursing home stays and 6 visit HBPC enrollments, for example.

What is striking about the current VERA system is that it is a very pro-palliative care reimbursement system. Acute care is an absolute looser under VERA. Most single acute care admissions exceed in cost the annual low VERA capitation rate of $3,249. In contrast people admitted to an inpatient hospice in VA have a life expectancy of days to a few months, enabling numerous patients to exceed the 30-day minimum required for high VERA. This is the ideal VERA scenario. Studies at both Palo Alto VA and Lebanon VA demonstrated that enough patients were admitted to their inpatient hospice units meet high VERA criteria to make these programs profitable. For example at Palo Alto VA, of 237 veterans admitted, 40 patients were high VERA. Category C patients receive no reimbursement under low VERA, but are eligible for high VERA if meeting LOS criteria – an argument for admitting category C patients to inpatient hospice programs.) Forty high VERA patients on a 25-bed unit at $42,153/patient results in $1.7 million in VERA reimbursement, roughly equal to the cost of the entire program ($1.8 million/year). Low VERA reimbursement, co-pays and third party payments resulted in an additional $400,000 in reimbursement for a total direct income of $2.1 million and a profit of $300,000 per year. Thus, beyond any cost-savings to the facility resulting from any cost-efficiencies, (which we suggested were considerable) the Palo Alto program was profitable.

So, not only is palliative care 'the right thing to do', not only does it appear to be more cost-effective, in the current reimbursement system it is profitable, where acute care, especially ICU care, is not. If the VA system were entirely rational, which no health care system really is, VERA should have been a strong incentive to reduce spending in acute care and increase it in areas such as HBPC and nursing home short-stay programs such as hospice, where money is to be made under VERA. Oddly, this has not happened. The percentage of expenditures going to long-term care nationally (14%) has not significantly changed, despite obvious fiscal incentives, compelling demographic changes of an aging population and even a Congressional mandate as manifest in the Millennium Bill. Why?

The Real Problem

The discussion above has focused on data collection as a means of building tension for change. A compelling case can be made that palliative care makes sense morally as well as fiscally- especially in VA. Yet VA, like all other health care systems in America, has been slow to embrace substantive change. The problem may be that institutions, like organisms, are self-preserving. In myriad and complex ways institutions struggle to maintain a certain status quo. Change is threatening. The dilemma, of course, is that the environment within which institutions exist is not static and thus change is inevitable. There is a constant tension between the tendency to resist change and the necessity of change if the institution is to adapt.

This philosophical diversion is offered to the reader in preparation for the possibility that rational, thorough arguments as to why palliative care services should be instituted or expanded will still be met with strong resistance and minimal change. Rationality is not enough. However, as the easiest defense of a resistive institution is the 'money argument', the rational case must be made so as to mitigate this concern. Likely, only then will a serious dialogue begin as to difficulties inherit in launching a new venture.

By way of general advice the more managers and clinicians come to understand that the change proposed improves the chances of survivability of the institution, rather than threaten that institution, the more likely it will be embraced. Thus, if the perception is that a proposed palliative care service threatens acute care it is doomed to failure. If instead, the perception is that a more developed system will enable acute care to focus on what is most appropriate for acute care and serves acute care services by helping staff deal with difficult patients, palliative care can been seen as helping acute care and therefore may be entitled to some new funding to support this service.

Tell the Stories

Most people relate better to stories and pictures than to data; we remember the screaming girl in the picture from Vietnam, the brave man staring down a tank in Tien An Mien Square. Because the world is so complicated, we all search for stories that distill down a complex problem into something easy to recall and to comprehend. Thomas L. Garthwaite, M.D., VA Under Secretary for Health, at a

VA Faculty Leaders conference, held in Atlanta June 2000, related the fact that 2010 was projected to be the busiest year for VA cemeteries. This is how he was best able to understand that 2008 was going to be a very busy year for end-of-life care in VA. Imagine the mind-numbing blur of statistics Dr. Garthwaite must face on a daily basis. This simple story of VA cemeteries allowed him to understand the need for better end-of-life care.

Suggestion #8: Find some local stories that explain why palliative care services must be expanded.
Simple as this suggestion may sound, it is difficult to find just the right story. Imagine how many photos were taken during the war in Vietnam to find a handful that told the story. The ideal story is dramatic, memorable, but cannot be dismissed as exceptional, a fluke. The ideal story appeals not just to the head or the pocketbook, but also to the heart. One example is offered.

In June 2000 VA Palo Alto HCS started a palliative care consult team. The team was possible because of wise leadership at the facility that saw the local funding of a palliative care fellowship program as a 'good investment'. Other support for the team such as funding for the attending physician and members of the interdisciplinary team had not yet materialized. One of our objectives was to prove that the team desired regular funding.

Shortly after starting the service we received a consult in the intermediate ICU for a 60 year-old man who had undergone heart valve replacement nine months previously. While surgery was entirely appropriate, his post-operative course was disastrous. He ended up with severe neurological impairment, on dialysis, and living in the ICU for nine months. He had a full code status.

Immediately before his surgery as a part of pre-op the patient had been asked if he 'wanted everything done'. He replied yes. He was full code. Neither the wife nor clinicians had engaged in a more detailed discussion of what to do if things went poorly. The wife throughout the patient's post-op course had adamantly argued that 'everything be done', consistent with the patient's expressed wishes pre-op. However, deeper inquiry revealed that the wife was seriously conflicted. She felt a strong obligation to abide by the patient's pre-op request. Her own opinion was that further care was useless, perhaps even harmful to the patient, but loyalty was an important value to her; she felt a responsibility to abide by his stated wishes. She was being a dutiful surrogate decision maker – so she thought.

We explored the context in which the patient had requested that 'everything be done'. "Do you think, when he said that, he imagined his current state as a possibility?" "No," she replied. "He probably just meant everything that could be done in terms of the surgery." "Do you think he would have wanted to live like this?" "Absolutely not." During the consult we help the wife understand the context within which the patient had asked for everything. We affirmed that she had done an admirable job in her loyalty to him. We helped her base a decision to discontinue dialysis more on her understanding of her husband's values than

on a single pre-operative statement. We discussed how we could treat dyspnea that might arise secondary to dialysis discontinuation. And we offered her support. The patient was transitioned to hospice care. We did not bother to calculate the astronomical cost of 9 months in the ICU on dialysis. We may use this case to point out that shortening or averting only one such case could fund the palliative care consult team for a year or more. We are also using the case to make the argument for mandatory palliative care consultations in the ICU for patients meeting certain criteria.

Summary

Fostering change is hard work. Difficult as the task ahead is, we have much working in our favor. The VA is an ideal system within which to promote palliative care. Economically, it makes sense. Palliative care is consistent with our mission and it is the right thing to do. Time is also on our side. We all have a stake in developing a better system of health care, as most all of us will one day need such care. Finally, those working in health care in general and VA in particular really want to be helpful. We went into this business in order to help. While it may take some longer to understand the advantages of improved palliative care than others, if we appeal to the good, we will eventually prevail.

Management Concerns and Suggested Actions

Management Concern #1: We cannot afford to create or expand palliative care services.

Suggestion #1	Demonstrate the extent of palliative and end-of-life care currently delivered in your acute care hospital.	**Quantify the number of deaths in acute wards and the ICU**. • Total number • As a percentage of admissions to that unit
Suggestion #2	Do a chart review of a percentage of charts in acute medicine.	**Categorize the charts according to the major goal of admission**: • Identify new problem (diagnosis) • Cure known problem • Prolong life • Provide palliation

Management Concern #2: Deaths in acute care are unavoidable. There is no need to change or add services.

Suggestion #3	Identify a sample of acute (ICU and ward) deaths and review for cause of death and underlying illness.	**Review charts and/or perform a data sort of deceased patients by ward, DRG, or discharge diagnosis**.
Suggestion #4	Review charts to see if patient preferences were discussed and if so, what the quality of that discussion was.	**Perform chart review and assess documentation of patient preferences**: 0 = no discussion in progress notes 1 = progress notes state "DNR" or "Full Code" without further elaboration 2 = DNR or Full Code per patient (or surrogate decision maker) 3 = documentation of treatment options beyond resuscitation in any form 4 = a note documenting an intelligent discussion of relevant options

Suggestion #5	For these same charts upon review would it seem reasonable that an alternative venue of care might have been chosen?	**Identify patient variables** • Medical status and prognosis • Patient-centered treatment goals • Psychosocial needs and availability of community support system • Spiritual needs **Identify facility variables** • Nursing home • Hospice/palliative care consult service • Hospice/palliative care inpatient unit • HBPC program
Suggestion #6	Review charts for quality of end-of-life care and study the ability of the system to meet patient and family needs in acute care.	**Survey end-of-life practices in facility by reviewing documentation in charts**: • Are patient and family preferences clearly documented? • Is there documentation of pain scores? • Did patients with metastatic cancer and chronic pain receive long-acting opioids or only PRN doses? • Did patients on chronic opioids have proper laxative regimens (something beyond DSS) – senna or an osmotic agent? • Were short-acting breakthrough doses of opioids dosed at proper intervals? • Was reasonable palliation offered for patients dying with dyspnea? (Using opioids and/or benzodiazepines.) • Was depression assessed and treated in dying patients? • Did patients die with agitated delirium? • What evidence exists of support being offered to family? • Were spiritual needs addressed? • Was a bereavement follow-up call made?

Management Concern #3: If we expand palliative care, something else will have to contract. We just don't have enough money to spend more on palliative care now.

Suggestion #7

Do a cost analysis for patients dying in acute care. Compare this, if available, to the cost per day in a hospice unit. Essential steps in making the case for cost savings include:
- The cost of providing care per unit of care with programmatic expansion is less than the cost per unit, as it exists, without palliative care.
- Units of care being compared are similar.
- The cost of expansion can be reasonably covered by cost savings elsewhere in a manner that is politically acceptable.
- There is no evidence of degradation in the quality of care.

Compare Decision Support Services (DSS) costs for groups of patients
- Cost per day
- Length of stay
- Cost per admission (cost per day times length of stay)
- Case-mix adjustment
- Analysis of cost differences

Analyze case mix
- Identify disease process, prognosis, and goals of care for patients admitted to acute (compare with hospice patients if possible)
- Identify patient preferences for treatment goals

Analyze cost differences
- Personnel
- Medical procedures
- Pharmacy
- Other

Calculate high and low VERA reimbursement for patients in different clinical settings

Suggestion #8

Find some local stories that explain why palliative care services must be expanded

- Search for stories that distill down a complex problem into something easy to recall and to comprehend.
- The ideal story is dramatic, memorable, but cannot be dismissed as exceptional, a fluke.
- The ideal story appeals not just to the head or the pocketbook, but also to the heart.

Inpatient Hospice/Palliative Care Programs:
The Palo Alto Example

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History

The earliest inpatient hospice programs in VA began in 1975, approximately 3-4 years after the first hospices[*] were established in America. Prior to 1983, the year the Medicare hospice benefit was established, the first hospices in the United States were inpatient units. While the Medicare hospice benefit encouraged community–based home hospice care, because VA is outside of Medicare, VA hospices evolved from these original nursing home based inpatient units. In contrast, home hospice care has not developed in VA. Veterans needing home hospice are dependent upon community hospice agencies developed under Medicare guidelines.

Inpatient hospice care in VA has evolved almost exclusively within VA nursing homes. Only recently have some VA facilities begun to explore the provision of hospice care in dedicated beds within acute care. Three models of inpatient care have been utilized: dedicated wards, dedicated beds within a ward and scatter beds. These models have certain advantages and disadvantages.

Models of Inpatient Care: Advantages and Disadvantages

Dedicated Ward: Relatively few dedicated hospice wards exist within VA. The major advantage of a dedicated ward is that the care team has a clear, unified mission – the provision of hospice care. As will be discussed further, this unified mission focuses the team both structurally and philosophically. Some disadvantages include: 1) enough eligible patients must be available to fill this number of beds and 2) inflexibility in bed utilization. Another disadvantage cited by some is isolation of hospice beds to a designated ward, unfortunately suggesting that perhaps care of the dying or alleviation of suffering are the exclusive provinces of the dedicated ward and not relevant elsewhere in the facility.

Dedicated beds: The greatest number of hospice beds in the VA is dedicated beds within nursing home wards having broader missions. The advantage of such an approach is that a small number of beds (5-25) can define a hospice 'unit' within a larger ward. Given current referral patterns, this model may best accommodate the needs of many facilities. Many such dedicated bed groups tend to have dedicated day nursing staff, who identify with the hospice team. On evening and night shifts, given lower staff:patient ratios, nursing staff is usually not dedicated to the hospice unit. The model is more flexible than the dedicated ward model in that 'swing beds' between traditional nursing home beds and hospice beds may accommodate shifting needs as

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[*] In the following discussion the word hospice will be used to apply to units functioning in a broader capacity by providing palliative care – that is, not exclusively care for dying patients.

demands for hospice or nursing home beds rise or fall. This model enables unit identity to develop. Such unit identity is important in developing a sense of a focused mission for team members and may result in improved care being delivered. Relative to a dedicated ward, a disadvantage of this model is that the culture of the hospice unit may come into conflict with the larger, usually more dominant culture of the nursing home ward (and the nursing home facility).

As physical boundaries between the hospice sub-unit and the ward often do not exist and they function under a combined nursing administration, conflicts may arise in terms of staffing needs, work organization and philosophies of care. While guidelines have not been established for 'appropriate' nursing staffing of hospice units relative to nursing home units, the general consensus is that the staff to patient ratio in a hospice unit is higher than in a standard nursing home. Increased staffing is justified by the more rapid turnover of beds, the rapidly changing status of patients and the legitimate, but time-consuming need to attend to psychosocial needs of patients and families. One issue that may come up in staffing a hospice ward appropriately is potential resentment from nursing home staff on the same (or adjacent) ward(s), especially during inevitable staff shortages, when a relative excess of staff is obvious in the hospice section. On the other hand, staffing a hospice unit identically to a nursing home may result in either staff burnout or poor care

Cultural and organizational conflicts may arise in such mundane ways as having a shared nursing report on day shifts, if day staff are segregated to either hospice or nursing home patients. For such dedicated staff, hearing about patients for whom they are unlikely to provide care and where issues raised may be very foreign to their perceived mission may result in alienation. If shared, interdisciplinary team meetings tend to be dominated by attention to those factors most relevant to the dominant ward culture (and most emphasized by JCAHO surveyors). Standard nursing home interdisciplinary meetings may ignore issues of great relevance to hospice staff and patients.   Interdisciplinary team meetings poorly structured to meet hospice patient needs likely will result in staff alienation and sub-optimal care plans.

Some units with dedicated beds do not have a dedicated staff. The beds may serve geographically to identify patients with somewhat different care goals, but staff are not so differentiated. The advantage to this structure is that in-group – out-group disputes between the hospice sub-unit and the ward are less likely to occur. It can also be argued that by exposing all staff on the ward to hospice patients, the general attitudes, knowledge and skills relative to the provision of hospice care broadly improve, enabling staff to apply this knowledge elsewhere, as appropriate. The down-side to this approach is that it presumes that staff are able to 'shift-gears' in terms of their care when leaving one ward sub-unit and moving into another sub-unit. It also presumes that with a homogenized ward structure adequate attention can be delivered to more labor-intensive hospice patients without making more formal organizational distinctions beyond geography. For example, wards with a medication nurse may utilize such a nurse across hospice and non-hospice sub-units. While such an approach may work for medication distribution, if no distinction is made between nursing home and hospice

patients in staffing workload, hospice patients may receive inadequate attention or nurses working in hospice will burn out.

Scatter beds: Much of the above discussion in terms of dedicated beds on a given ward applies to scatter beds. The obvious advantage to a scatter bed approach is that you can put any patient into any available bed without worrying about whether there is a good match between patient goals and ward mission. Scatter beds offer maximum flexibility. Scatter beds also offer the opportunity to disseminate good hospice care anywhere in the facility, as potentially all beds can be deemed hospice beds. Because beds are scattered, territorial disputes, a significant problem with dedicated beds, are minimized. At their best scatter bed hospice patients are attended by a dedicated, but mobile hospice/palliative care team. 'Bed and body' care is delivered by the general ward staff, but specialized hospice services, including the plan of care are developed and managed by a dedicated team. At their worst, scatter beds are an excuse for having no hospice program at all – what one could euphemistically call 'virtual hospices'. Such scatter bed programs have no dedicated team or services, but may argue, usually with little evidence, that their care for all is so good they do not need a separate, dedicated team to care for hospice patients. Again, while data is lacking and a formal study comparing these models would be most welcome, common sense suggests that if no specific identification or differentiation of patients needing hospice or palliative care services has been made by an institution, likely efforts to improve the quality of care for such patients have been minimal and resultant care outcomes are suboptimal.

Acute Care Wards and Beds as Compared to Nursing Home Beds
The recent VA palliative care survey suggests that very few VA facilities are currently experimenting with dedicated acute hospice/palliative care beds. While palliative care consult teams in acute care appear to be expanding, enabling a scatter-bed approach to care for some patients in acute care, given the common availability of nursing home beds within facilities, the most energy seems, reasonably, to be directed toward developing consult teams and expeditiously transferring patients either home or to VA nursing home hospices. (Note: unlike the private sector most VA facilities have some nursing home beds available in close proximity to acute care beds.)

For palliative and hospice patients the distinction between acute care and nursing home care exists more in terms of organizational culture than in terms of care patient needs of the relevant population. As discussed above, the staffing ratio for hospice/palliative care wards should be greater than for nursing homes, and for nurses this ratio may approach that which is appropriate in acute care. A major distinction in nurse staffing between acute care and a hospice/palliative care unit is that while the absolute staffing ratios may be similar especially on day shift, fewer RNs are necessary on a hospice ward, as the need for skilled RN interventions (complex procedures and IVs) is less than in acute care. Thus, staff costs should be significantly less in a hospice unit, given relatively fewer RNs, despite similar staffing ratios on day shift. (See more detailed discussion of staffing for nurses later.)

A far bigger issue is that the organizational *culture* of the nursing home is very different from acute care. Nursing home admissions traditionally occur Monday through Friday during regular hours. While this structure may be well suited for planned transfers into nursing homes for patients with long-term, chronic needs, it serves those with hospice/palliative care needs poorly. Such patients may present to the emergency room or have treatment withdrawn and shifts made to palliative goals at any hour. Medically, these patients could be accommodated by a hospice program in a nursing home. The problem is that appropriate staff, physicians, ward clerks, nursing staff and other relevant members of the hospice team likely are not immediately available on off-hours. In theory, for nursing home hospices adjacent to acute care wards, necessary staff could be floated from acute care to the nursing home hospice unit to accommodate such admissions, thereby averting an otherwise unnecessary and undesired acute care admits. After all, it is rarely a question as to whether the patient *will* be admitted or transferred if already in the ER or ICU, but rather only *where* the patient will end up; an admit to the nursing home hospice unit by a ward team simply averts the same admission to acute care.

In Palo Alto we have enabled ward teams (and the ICU) to admit to our hospice ward (technically a nursing home ward in the same building as acute care) around the clock, as beds and nursing staff are available. Such admissions are an *option* for ward teams. They are free to admit to acute care if they wish. In addition to receiving superior palliative care, an additional advantage is that when patients are transferred during normal working hours from the ER to the hospice physician team, because there has been no change in bed classification (from acute to nursing home), a discharge summary by the ward team is not required. Thus, a direct admission saves work for the ward team (and money for the hospital). While this system has become popular, we initially had to overcome resistance to two beliefs: 1) the belief that it was 'impossible' to admit to a nursing home after hours (it is not) and 2) something terrible would happen if acute care providers admitted to a nursing home (nothing terrible happened). The firewall between our acute care and dedicated, nursing home hospice ward clearly existed more in people's minds than in reality. We have even had ICU teams following a dying patient from whom treatment has been withdrawn in our 'nursing home' ward. Informally, ICU staff have told me how grateful they are to have this option. In discussing possible treatment withdrawal, they find it useful to state that there is a *specialized ward*, which will be able to provide better and more appropriate care for a dying veteran. Having actually cared for patients on our ward, ICU staff can now speak from experience in stating this.

One of the simplest ways to increase the number of dying veterans appropriately admitted to hospice/palliative care wards is to challenge similar mind-sets. Many more patients could be admitted to and die in a more appropriate setting IF people challenge assumptions as to what constitutes nursing home care and who should provide it. This particular tactic, opening up a hospice ward around the clock, if admitting physicians are available, strikes me as one of the most cost-effective (virtually no additional cost, significantly less expense and improved outcomes) ways of improving the quality of palliative care in VA.

The more dedicated hospice and palliative care services are, the better they are likely to be. However, It is also true that the development of dedicated wards is not feasible at this time for many. Thus, facilities considering expanding hospice and palliative care inpatient services should focus on what they can do to improve upon what they already have. If a facility is currently functioning with a scatter bed approach without a dedicated team, perhaps the next step is getting a dedicated team before moving to dedicated beds. To this end the following suggestions are made:

Steps for Evaluating Size and Type of Inpatient Unit

The first step for any type of expansion is to know your population and its needs.

1. **Survey terminal admissions for the past year. Where did patients die, from what and how long did it take? Where did they come from?**
   Attention should be paid to the number of patients dying in the ICU, acute care and your nursing home (assuming your facility has all such venues). It is not a difficult sort at all for Information Resource Management Service (IRMS) programmers to look at who died where and from what for inpatients. (It is much harder to identify outpatient deaths.) Having identified such patients, you may want to understand in more detail some things about these terminal admissions. The Health Summary Option is a very useful tool for such a survey. Using health summary you will be able to identify cause of death, length of stay, ward transfers, where people came from and even get some notion of quality of care delivered, by looking at medications given to determine if reasonable medications were given for important symptoms such as pain, dyspnea or constipation. Many clinicians and administrators will underestimate both the number of deaths in acute care (including ICU) and the lengths of stay for such admissions (and thus associated expenses). For the VA nationwide 64% of inpatient deaths occur in acute care, the remainder in nursing home or intermediate medicine beds.[*] Many will also assume that such deaths in acute care are unavoidable. You will likely find that most patients dying in acute care in VA facilities have the same serious, life-limiting and terminal illnesses as those dying in your nursing home. In a survey in Palo Alto, for example, of a sample of acute care deaths, 41% of 30 deaths reviewed were from metastatic cancer. It is reasonable to extrapolate that with the development of an improved hospice program (and active case finding) a percentage of these deaths might have occurred in your program.

   You may also be surprised at how many people are already dying in your nursing home.   For this population attention to length of stay and diagnosis is useful in judging the size of a program expansion you wish to undertake. Long-term residents and those with slow neurodegenerative disorders such as Alzheimer's disease may be better served and more appropriately die in a nursing home rather than in hospice. On the other hand, patients admitted to the nursing home with relatively short, terminal phases to their illnesses, are likely better served in dedicated beds. After such an

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[*] Based on FY 2000 national inpatient mortality rates.

analysis you may find that you have enough patients per year to support a dedicated bed section within a nursing home ward without any active recruitment of patients. (See below for calculations).

2. **Identify potentially new sources of patients.** Dedicated programs with good reputations have often found that as many as 50% of admitted veterans will be new to the VA. Outreach to community hospices and hospitals will likely be very successful in attracting new veterans – if you have a quality program. The demographics supporting this statement are striking. Currently, approximately 26,000 veterans die as inpatients each year in VA facilities. (Of these it is currently estimated that less than 9000 receive any hospice or palliative care, including consultation.)[**]   However, the total number of veterans dying each year is approximately 674,000 or 29% of the 2.3 million Americans dying each year. Most veterans do not utilize the VA for their healthcare. In most locales while there are adequate numbers of home hospices, inpatient hospice services are still quite rare; most home hospices admit to skilled nursing facilities if dying at home is not possible. Thus, there is a desperate need in the community at large for the type of inpatient hospice care VA facilities can offer. Many veterans so recruited will be new Category A patients. Internally, advertising your program and 'recruiting' patients from both inpatient wards as well as outpatient programs such as Home Based Primary Care (HBPC) may significantly increase the number of patients referred to you. By way of example, with the implementation of aggressive recruitment efforts, Palo Alto increased its annual admission rate for its hospice ward for veterans from 120 per year to over 350 per year.

3. **Estimate how many beds will be occupied on average at any given time in your nursing home if you serve the appropriate population.** This is your "average daily census" for your hospice program. This calculation is relevant whether you have a scatter-bed or dedicated bed program. It gives you an estimate of what your workload is or will be. The relevant equation is: (Number of admits per year) *divided* by 365 *multiplied by* (average length of stay). For example, if a program had 100 hospice admissions per year with an average length of stay of 25 days (100/365 X 25) would average 6.85 beds being occupied.

While this number will give a rough estimate of bed capacity, caution is in order. This number tells you nothing about the natural flux in census populations. Hospice admissions tend to be sporadic. In contrast to standard nursing home beds for long-term care, which tend to work with an almost infinite demand for services that can be scheduled for orderly admissions, workload for a hospice unit tends to resemble more acute care in its variability. Some days nobody needs admission. The next day 3-4 people may need admission. Similarly, people die and leave the unit with great unpredictability. Some days no patients die, some days 3-4 patients die (in our unit).

In Palo Alto, we have noticed that while our average length of stay is approximately 15 days, the distribution of patient lengths of stay around this mean value is

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[**] Based on TAPC 2001 study asking respondents to estimate the number of patients served. 9000 is a high-end estimate of patients served.

anything but a bell-shaped curve. Indeed, our length of stay distribution is bi-modal. Some patients come only for a day or so, while others may be around for months. The standard deviations around both mean lengths of stay and the average daily census for a hospice unit are likely to be much wider than for a standard nursing home ward. Administrators, who come to expect nursing home beds to run at 85% or greater occupancy, will be frustrated by the 'inability of the hospice ward to keep up its census.'

While the average length of stay for a hospice program almost certainly will be less than for standard nursing home beds (if the nursing home has long-term patients), more patients will 'circulate' through a particular bed each year. My impression is that most dedicated bed hospice programs in VA run an average occupancy rate of closer to 65-70% than 85%. Based on this estimate, if one calculated that the average bed occupancy was to be 7, as in the above example, unless one wanted to frequently deny care to veterans in need, one would best plan for a higher number of beds. Again using the above example, to calculate a reasonable number of beds, you would divide 7 by the estimated bed occupancy rate (7 *divided by* .7 = 10). So, 10 beds would likely be more appropriate. Misunderstandings about this have sadly resulted in unnecessary tensions between hospice programs and administrators.

4. **Decide upon a ward structure – dedicated ward, dedicated beds (with or without dedicated nursing staff) or scatter beds.** This decision should be made based upon both the estimated number of patients you anticipate serving and real politics associated with ward structure and location, what constitutes your hospice/palliative care team and what your facility will support. While it is my bias that the more dedicated the beds and service the better the care, a key question is – will you likely serve enough patients to justify dedicated nursing staff? My impression is that if one estimates operating 6-7 beds (with an average census of 4-5 patients), then dedication of one day RN, constituting the core of the dedicated staff, becomes feasible and you have the start a dedicated nursing team. (See staffing estimates below.)   For smaller populations, dedicated beds without dedicated staff or scatter beds may be more practical. For larger bed groups than 6-7, determinations of unit size are often guided by ward structure and competing missions for bed space. Larger units can 'extend' RNs by adding on LVN or NAs. However, with greater size also mandates a more evolved support structure such as dedicated intake workers.

5. **Figure out who will constitute your care team, their roles and percentage time dedicated to their work.** It would make sense to adjust the hospice/palliative care team to estimated workload. While not ideal, determination of unit size and structure (items 3 and 4 above) may flow more from available staff than from rational workload calculations. Regardless, except for large, dedicated wards it is likely that most staff will split their work between at least two work areas. Careful attention to roles and percentage time dedication will help avoid staff stress. You may also identify a 'weak link' or rate-limiting step in your ability to care for patients, relative to other

FTE. The addition of a dedicated intake worker or more physician staffing might enable you to serve significantly more patients.

Unit Staffing: Roles, Responsibilities and Workload
Physicians: A physician with strong palliative care skills on the team will significantly improve the quality of care as well as the over all program. Physician FTE is expensive relative to other team members and some may be concerned about physicians 'taking-over.' Programs that develop with the mindset that physicians are only necessary for "signing-off orders" that Nurse Practitioners and Physician Assistants cannot write (such as for opioids) will do their programs and their patients a severe injustice. In addition to their essential medical skills, physicians also add weight to the team's authority, given that some physicians and many patients and families will only hear certain things from a physician, no matter how reasonable or correct other team members may be. In reviewing current palliative care programs in VA, I found that all developed programs had strong (and skilled) physicians on their teams. [***]

It is very difficult to calculate a correct physician:patient FTE ratio. Staff physician workload depends on a number of variables: patient turnover (more than census, as both admits and discharges are physician labor intensive), the availability of nurse practitioners and physician assistants and the availability of trainees. Physicians commonly have other responsibilities prohibiting discrete percentage FTE assignments. Physicians may also rotate assignments to the unit. While there is no specific staffing ratio, the following should serve as warnings that physician involvement is inadequate:

- Inability to identify a physician with oversight responsibility for physician aspects of the program. Physicians without special interest or training may rotate responsibilities, but with little interest or commitment to the program, jeopardizing the integrity of the program and care to patients.
- Team meetings and other core team events where the physician is either not present or functions at the margin of the group.

Nurse Practitioners/Physician Assistants: The 2001 TAPC Palliative Care Survey demonstrated that more Nurse Practitioner (NP) and Physician Assistant (PA) staffing (FTE) are dedicated to palliative care in VA than physician FTE and that PAs are key members of the hospice/palliative care team in many facilities. NPs and PAs have not been traditional members of community hospices and thus guidelines for their roles and education relative to palliative care have lagged behind other disciplines. Many NP/PAs share responsibility with physicians in the care of patients and frequently have additional duties beyond hospice. As with physicians, it is difficult to calculate NP/PA:patient ratios. Regardless of staffing ratios, however, there are relationship issues that affect the functioning of the hospice when NP/PAs and physicians are both part of the team.

Careful attention must be paid to the roles, tensions, and policies surrounding the relationship between NP/PA and the supervising physician. A significant problem facing NP/PAs is that much of the 'work' needed in hospice has organizationally and culturally been identified as being within the province of the physician. For example, one of the

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[***] As demonstrated by the 2001 TAPC Palliative Care Survey

most challenging tasks in palliative care is addressing 'difficult decisions' for patients, which frequently relate to shifting goals of care and often treatment withdrawal or withholding. Because of the high stakes involved in such decisions, our society has also traditionally viewed the task of addressing such decisions as a physician task. For this reason, your facility's policies on advance directives and resuscitation status may state that it is a *physician* responsibility to discuss, document and write orders related to treatment withdrawal or resuscitation status.

On many wards a division in labor is made between NP/PAs and physicians such that NP/PAs do histories and physicals, write orders (except for controlled substances) and physicians supervise this work, write for controlled substances and discuss 'difficult decisions' as the needs arise. In those programs with such a system, some care must be taken. The "H&P" on admission to hospice is less a *task*, a history to be *taken* from the patient for example, than a *process* of establishing an important relationship between patient, family and clinicians. Many being admitted to hospice are terrified that they are coming to "the dying place." Families are often exhausted and feel guilty that somehow they were not able to handle the patient of home. The "H&P" first encounter is critical in demonstrating that we care about the patient and family and that hospice is about living well until death. Care must be taken to provide NP/PAs with proper training in establishing this positive relationship and ensuring continuity of care and communication between members of the team, including the physician.

Unlike many standard nursing home admissions, where "transfer orders" can be copied with minimal amendments, admits to hospice usually require significant changes in medications. This reflects both the rapidly changing medical status of such ill patients and, sadly, at times unskilled care prior to admission or transfer. Thus, whoever is writing orders must have the necessary knowledge and skill to make such adjustments.

Another source of tension can occur if NP/PAs are administratively under a different service line than physicians. While the debate over the relative roles of these clinicians in healthcare will undoubtedly continue, those of us working in hospice do not have the luxury of waiting for others to figure it out. As most hospice/palliative care programs are marginally staffed at best, our patients cannot afford unresolved tensions, inefficiencies or gaps in care resulting from some unspoken turf battle between physicians and NP/PAs. Thus, frank discussion on these points is advised.

Nurse Managers and Clinical Nurse Specialists: These positions are separated out from the nursing staff positions below, as roles are significantly different.

Nurse Managers: Likely, for dedicated beds or even dedicated wards the nurse manager has supervisory responsibilities beyond the hospice. For example, our busy, 25-bed ward with more than 400 admissions per year only requires 0.5 nurse manager FTE. While this seems appropriate in terms of workload, a challenge for nurse mangers is supervising different units with very different philosophies of care and workload needs. Most nurse managers of hospice units in VA probably have more experience with supervising traditional nursing home wards than hospices and their primary

responsibility is generally for more traditional beds. In such cases it is too easy to see the nurse manager as the "keeper of the time card" or as an "outsider" relative to the hospice unit culture. Efforts should be employed to make sure nurse managers are not only knowledgeable about hospice care but, ideally, have done it. As there may be some nurse managers managing hospice units who have never actually worked as staff RNs in hospice, their credibility may be at risk.

Clinical Nurse Specialists: Clinical nurse specialists often play a special role on hospice units. They are valuable repositories of knowledge, experience and leadership for the hospice team. They may function as liaisons between the unit and other venues of care. In addition to intake work, they may perform consults or work as core members of a palliative care consult team. Staffing ratios are impossible to define, as staffing is highly dependent on the specific duties undertaken by the CNS relative to administration, clinical care and education both on and off the hospice unit. It is not an accident, I think, that our hospice was founded in 1979 by Vicki Ellis, CNS, who is still at the very core of our unit.

Nursing Staff: Historically, nurses have been at the heart of hospice. Philosophically, hospice care seems more to arise more from nursing as a profession than the world of physicians. Cicely Saunders, founder of the modern hospice movement was first a nurse (and a social worker) and *then* became a physician. In her recounting of the history of hospice, Dr. Saunders is quite clear that the important innovation of giving morphine on a regular basis, rather than having patients 'earn their morphine' through pain came from nurses, not physicians. In community hospices nurses are central both to clinical care and often administration. This appears true in VA as well.

Hospice in VA evolved largely out of nursing home culture. While undoubtedly much good has come of this, enabling perhaps greater acceptance of end-of-life care as a legitimate nursing home mission than in community nursing homes, some 'bad habits' may also have been formed. For example, in our hospice when we had dedicated beds instead of a dedicated unit, for many years nursing report was combined for the hospice and the rest of the ward and did not include other team members. While nurses sometimes complained that they had to listen to report on patients for whom they did not care, when our hospice was small, this was not a major problem. It was easy to stop by the hospice and 'check-in' with the nurse about what was going on. Physicians and others would then separately round to see patients as needed. When our unit expanded and became a dedicated ward, we initially continued this model. However, when there was more than one RN, we noticed communication breaking down. Nurses reported to nurses and physicians (and other clinicians) rounded on patients in parallel. We finally recognized that we needed a daily combined morning report – at least with the charge nurse, physicians, social workers, our clinical nurse specialist, psychologist and other available disciplines. Nurses assume a dominant role in this report. Physicians are asked to evaluate specific problems on patients as identified by the nurses. This new model more closely replicates the relationship between physicians and nurses in home hospice.

While nursing is usually very active in directing the plan of care in nursing homes, they may take a relatively passive role when it comes to ordering specific therapies and medications. This is quite different from home hospice, where nurses often actively suggest specific therapies, medications and even dosage adjustments to physicians. While we are fortunate, I think, to have more active physician and NP/PA involvement than most home hospices have, I think we could benefit from more active involvement from RNs working in hospice. When I first started in hospice, I would get notes from nurses saying, for example, "Mr. Smith is constipated, please evaluate," which I did. My problem as a physician was that I did not have the same 'intimate' relationship with the patient that the nurses did. Details of bowel consistency, eating habits, responses to prior laxatives were often difficult to decipher. I found it much more effective and efficient to 'empower' nurses by ensuring that they understood principles of constipation management and then encouraging them to make explicit suggestions for medications. While all such medications are sold to the public over-the-counter, on inpatient wards a physician (or NP/PA) order is required. Still, it does not seem medically unreasonable that an RN take charge of this in initially, suggesting specific changes. In addition to better patient outcomes (especially for problems such as constipation) and more efficient use of physician time, this approach also seems to enhance job satisfaction for nurses. Of course, this approach requires well-trained nurses, ideally hospice certified, who are comfortable taking such an active role.

Nursing staff expenses are by far the greatest cost for hospice patients (as they are in acute care). It is no surprise, then, that great concern arises regarding staffing ratios in nursing. With a dedicated ward it is easy to attach nurse staffing to patients and easy to track using Decision Support Service (DSS) methodology. For dedicated beds or scatter bed models because hospice/palliative care patients are not (yet) recognized as a distinct category of patient, following staffing and costs is more difficult.

The big question for nurses and administrators is, "What is the appropriate staffing ratio for nurses on a hospice unit? This is a surprisingly difficult number to calculate and there is no apparent consensus as to appropriate staffing. Published staffing ratios exist for non-VA, acute care palliative care wards, but a systematic survey of VA staffing for hospice units has not been performed. (The 2001 TAPC palliative care survey looked only at total nursing FTE, but did not directly examine staffing ratios)

The Palo Alto hospice unit, while technically in "Extended Care" has a patient turnover rate rivaling that in acute care. The effect of turnover affects different staff differently. The work of physicians, RNs, intake staff (such as social workers and clinical nurse specialists in our facility) and ward clerks is highly dependent on turnover. This is because admissions and discharges are very labor intensive for these disciplines. Specifically regarding nurses – RNs are busiest on admission, establishing care plans and coordinating care, and on discharge, as they are often involved in notification of family and the provision of acute bereavement support. In contrast LVN and NA workload is more dependent on the daily census. Simplistic equations relating staff:patient ratios risk missing this important factor.

Staffing needs also vary by shift and on weekends. If your facility does not admit on weekends, then RN staffing can be adjusted down somewhat based on this. As elsewhere, the greatest number of staff are required on day shifts, somewhat less on evenings and even less on nights. Although official standards have not been written for VA, ideally at least one hospice trained RN should be available (even if only in a supervisory fashion) for all shifts.

By way of example, here are the nurse staffing ratios for Palo Alto for an average daily census of 20:

	RNs	NAs	LVNs
Days	2	2	2
Evenings	1	1.5	1
Nights	1	1	1

Hospice nurses may be particularly challenged in coping with late afternoon and early evening staffing. If the hospice unit follows the traditional nursing home model, then all core staff (physician, NP/PA, CNS, SW) and the unit ward clerk may promptly depart at the end of "regular working hours" (4-4:30 PM). The problem is, just when these core staff are leaving, family members of patients are getting off work, calling in to check on loved-ones and visiting. (While this is true elsewhere in the nursing home, the volume of visits and calls is significantly greater in hospice) The evening RN must then assume ward clerk and social work duties among others. Answering telephones is a very inefficient use of an RN's time. Hospice philosophy prides itself on being "patient and family centered" and yet when families are most able to visit (evenings and weekends) is when core VA staff are least likely to be available. Our unit is still very much struggling with this issue. We are attempting to compensate by having a part-time social worker available in early evenings and having volunteers answer telephones.

Social Workers: Like clinical nurse specialists, social workers may perform special liaison duties with wards and organizations outside the hospice unit. Like the CNS the social worker may work assisting in patient intake. They are core members of the team, especially in terms of working with families. Staffing ratios, again, are difficult to calculate. Significant job overlap may exist with members of other disciplines, relative to tasks like intake or with other mental health workers such as psychologists in addressing patient and family psychosocial concerns.

Psychologists: Traditionally, psychologists have not been included as core hospice members under Medicare home hospice model. Psychological and social needs of both patients and families in home hospice including bereavement support have traditionally been provided by social workers often with help from chaplains and volunteers. Psychologists can be particularly helpful in managing patients and families with particularly severe grief reactions and where pre-existing mental health problems complicate hospice admissions, as they frequently do in VA.

Chaplaincy: VA has a distinguished record of providing spiritual support for its veterans. Units may struggle over issues of dedicated FTE for hospice support. Issues include the need for some patients to be attended to by a chaplain of a specific denomination or faith and the adequacy of their training in hospice and palliative care. While access to the widest possible array of spiritual support for patients and families is advisable, the hospice program will benefit from having dedicated and skilled chaplaincy support to the extent this is possible.

Other Staff: A variety of other clinicians and staff may compliment the team, including occupational (0.5 FTE in our unit) and physical therapists, massage therapists (0.5 FTE in our unit). The benefit these associated health professionals offer is increased mobility, independence and enhanced quality of life, which is critical to good care. Because hospice patients' functional statuses change rapidly, a rapid response is necessary by clinicians.

Some special activities can be developed and overseen by such staff. For example, our occupational therapist has a "video legacy" program in which tapes (video or audio) of hospice patients are made and given or mailed to family members. Families have described such tapes a family treasures. We also employ massage therapists, who both perform massage on patients, families (and occasionally staff) but also teach families to give their loved ones a massage. We have found massage to be a valuable means of treating pain, providing relaxation for agitated patients and enhancing connection between families and patients.

The Decedent Affairs clerk can also be incorporated into the team. This person usually meets families at their most vulnerable moment. Recently, our experienced and highly respected clerk retired. Her replacement (administratively under the "Business Office") had been told that part of her job was to encourage autopsies. While a wonderful person, we found she had received no training for this task from clinicians and initially she was awkward with families. A special effort to give her communication skill training and education about acute bereavement significantly improved her important work with families.

Volunteers: Historically, VA has championed the use of volunteers in serving veterans. Hospice as a movement also has a strong history of volunteerism. However, the recent palliative care survey suggested that volunteers were under-utilized in serving veterans in hospice and palliative care. Only 33 out of 106 facilities with inpatient services reported using volunteers at all in hospice or palliative care. This may come from excessive reliance on the part of VA hospices in recruiting volunteers through traditional volunteer services. Traditional VA volunteers are more likely to be veterans or veteran spouses, who may have difficulty dealing with other veterans who are dying. Traditional volunteer activities (escorting patients, barbeques etc.) may not meet hospice patients' needs. Hospice units considering developing a serious volunteer program are encouraged to learn from their community hospices neighbors.

Adequate training, careful screening, consistent supervision, and regular support are essential to a well-run volunteer program. Volunteers need education and a context within which to share their experience. Many also are looking for a healthy opportunity to socialize. Young hospice volunteers may be exploring job opportunities or trying to improve their résumé for school. Volunteers may also use this opportunity to work with their grief over a loss of a loved one. Bereaved family members of patients who have died in your hospice may want to volunteer to 'payback' your unit. Properly organized, a volunteer program not only significantly enhances patient care and builds a sense of community, but also can offset costs. Many 'duties' currently undertaken by staff, especially nursing staff are well within the scope of volunteerism. Sitting and talking with patients, feeding, escorting patients, answering telephones, helping with mailings, can be done by trained volunteers.

Hospice Unit Relationships with Others: Hospices as organizations do not and cannot exist in isolation. Hospice units are organized within a particular ward in a particular building of a VA facility with a unique social organization. In turn, this facility exists within a complex greater VA organization. Hospices also exist within a broader community, which includes home hospices, hospitals, civic, educational and news organizations. The hospice that ignores this greater social context does so at its peril, for skillful integration into the greater VA and non-VA community is essential if the hospice is to thrive and survive.

Many forces conspire to thwart such integration. Most VA hospice/palliative units are in nursing homes and often nursing homes make people uncomfortable. Less status is given within the social hierarchy to healthcare nursing homes and those who work in them. Despite the fact that nursing homes are growing in size and importance as sites of healthcare, they also tend to be avoided by educational institutions. Medical schools and schools of nursing lag behind in recognizing the need for nurses to learn explicitly about palliative and end-of-life care. On top of this base-line prejudice against nursing homes, hospice units must contend with common fears and prejudices about what hospice care entails.

It is easy for VA hospice units to be estranged from the greater hospice and palliative care community as well. Community home hospices are strongly shaped by Medicare regulations and Joint Commission on Accreditation of Healthcare Organization (JCAHO) standards, which have little impact on VA hospice units. Outside VA the greatest advocacy for inpatient palliative care has arisen relative to acute care, not nursing home palliative care programs. Many of the concerns of acute care hospitals (such as Medicare coding for physician care) are irrelevant to VA hospice units. Even those groups such as the American Medical Directors Association advocating strongly for improved palliative care in nursing homes are fighting battles that are only tangentially relevant to VA hospice units (e.g., Medicare and Medicaid reimbursement). The extensive experience of VA hospice units in the delivery of nursing home-based care, which has evolved on a separate track from the private sector, has been invisible to the greater hospice and palliative care community.

Managing your managers

The question is not whether we should speak up and participate (we must) but what message we wish to convey. If our only message to top management, for example, is that we are under-funded and under-staffed (while perhaps true) we are teaching them to ignore us. A wise saying about management is: "First, manage yourself. Then, manage your managers. Only then can you manage subordinates."

Most managers feel misunderstood and beset upon. In their minds they are practicing lifeboat triage. They see themselves not as captains of luxurious ocean liners, but rather of lifeboats with not enough seats for all the people in the water.

"Building or Expanding Palliative Care Programs in the Department of Veterans Affairs Healthcare System", found elsewhere in this toolkit, reports the economic rationale for establishing and supporting hospice and palliative care in the VA. One of your jobs is to make your CEOs aware of such data. However, data is rarely enough. Even with good data CEOs may still believe that to bring you into the lifeboat is to toss some else (who already has a seat) out, which is painful for them. If supporting your unit is viewed on balance as causing more pain for your CEO, you will likely not be supported. So the question is, how do you actually *help* lessen the boss's pain?

To this end, you need to figure out what is currently causing your boss pain. In terms of an inpatient unit (as well as consult teams) likely one pain results from the need to move people out of acute care (and especially ICU) as expeditiously as possible. This pain may relate both to a need to decrease the average length of stay for patients and for many VAs nursing shortages in acute care. Rather than come to your boss with your problem, approach him or her with a proposed solution to *his/her* problem (which may in fact require bolstering your unit). Other headaches for managers may be JCAHO accreditation. How can your unit help your facility meet more stringent standards for pain and symptom management?

The offices of bosses and CEOs (chiefs of service, chiefs of staff and directors) are magnets and concentrators for problems. Most bosses just put out fires from morning to night. One insolvable problem after another falls in their lap. Good news, if present, is a rare respite from a deluge of serial disasters. *Bottom line – the bosses are desperate for good news.* You will do much for your unit by sharing good news with the boss, when it arises.

Fortunately, the opportunities for good news in hospice are great. Families are often grateful and write letters and make donations (which can be used to support staff morale and for educational activities such as travel to hospice and palliative care conferences, thus sparing the travel budget – good news!) If other staff in units such as the ICU or ER are pleased with your assistance in getting a patient to your unit, that's good news! You might encourage them to send a quick email to the boss, letting him/her know how helpful you've been. If someone in your unit or your unit is recognized by a non-VA organization for their contribution to palliative care or hospice, that's great news! Any public affirmation from outside VA that your organization is

providing superior care will be most welcome. Such contributions may be articles, awards, grants or research. They may also be as simple as a home hospice agency with which you work writing your CEO in appreciation for your valuable contribution. Your facility probably has a communication officer. One job of that person is usually to publish a periodic newsletter. When something good happens on your unit, notify this person! Keep your unit in your facility press. Do you have a computer bulletin? Having a special conference? Get it both into the bulletin and get flyers posted. Our unit sponsors a monthly "Topics in Palliative Care" for the entire facility. This conference, while still poorly attended by outside facility staff, is worth its weight on gold in that it we stay on the radar screen of the facility by posting very prominent posters and always announcing this in DHCP. This past month we invited the head of the autopsy section to discuss autopsies. He was grateful for the opportunity, and this brought in new attendees to the conference and solidified our alliance with Pathology Service. We learned much from the presentation and perhaps the presenter learned something from our questions. This example raises a broader issue:

Finding your Allies in the Institution

Returning to the lifeboat analogy, if it is just you in the water versus them (especially if they already have a seat in the boat), you will probably lose. You have a much better chance of 'getting a seat' if someone else in the boat is encouraging the boss to take you in and support you. So, who are your allies?

The "Easy Allies": Easy allies are those friends in the institution who have always been with you. They may be social workers, members of the ethics committee or a related field, like pain management. They may even be personal friends in the institution, who have come to know your unit and its mission. These allies can be rallied formally and informally. Formally, committees or advisory groups may be formed. Such committees may be standing or ad hoc. For example, in our institution our unit was instrumental in working with allies to form a standing "Pain Committee", which is helping us meet JCAHO pain standards. Good news! We have also created "ad hoc" committees (formally at the request of the Chief of Staff) to survey the quality of end-of-life care in the facility. Such groups not only do good things for your institution (hopefully), to the extent that they are seen as being supported by your hospice unit, they will in turn support your unit.

The "Invisible Allies": Invisible allies may not even know they are allies and you may not readily be able to see them; they are invisible. Many invisible allies exist simply because everybody will eventually have to struggle in their personal lives with palliative and end-of-life care issues. I have heard countless stories of how a facility was changed 'overnight' because a boss realized that the system must change, because of a personal story. Stay alert to the possibility of serendipity.

The existence of some invisible allies can be predicted and these allies should be sought out. The ICU likely contains many such allies. Most ICU staff (physicians, nurses and others) like to save the lives of those patients who can truly be saved. They

hate providing care that is perceived to be futile at best. Such staff can be potent allies. Have you invited them to visit your unit? Perhaps, you can give a talk on how your unit might help them with dying patients. Perhaps one of them could give a talk for your group on their perceptions of end-of-life care in the ICU. Invisible allies may also be found among clinicians of various disciplines exposed to dying patients in a wide variety of venues, but who feel overwhelmed, inadequately trained and poorly supported.

The Quality Management Team (QMT) probably has invisible allies. Recent changes in JCAHO regulations mandate excellent pain and symptom management, but also education in these areas. How can you help them meet their objectives (and in turn, how can they help you meet yours)?

Your residency program may have invisible allies that do not yet know they are allies. Recent changes over the past 1-2 years have increased dramatically requirements for training in issues related to palliative care. Some training in end-of-life care is now required, for example, for all medical students, Internal Medicine residents. Likely, training requirements for other disciplines are also emerging. Trainees are very potent (but usually invisible) allies. To the extent you can build educational programs that not only meet training requirements by program directors, but result in trainees asking for greater training opportunities, your unit will be supported and will thrive.

The "Reluctant Allies": I do not believe anyone thinks we should deliver poor palliative or end-of-life care to patients. However, these allies may be 'reluctant' for a variety of reasons. They may have mistaken notions about what really happens in hospice. Issues of territoriality and competition may arise. Some specialties have a hard time accepting that anyone else could possibly have anything to offer in the care of the patients they serve. Some 'allies' are so reluctant that they become frank barriers; like tall mountains, it is usually easier to go around them then over or through them. However, by staying true to our mission (to serve veterans), being sensitive to issues of territoriality and encouraging dialogue, some reluctant allies may eventually become good friends of your program.

Allies help allies. As a strategy (and as friendly intent) we should try to help others in our facilities. However, it is also fair to ask for support back. Staff in many hospice programs are already stretched very thin. Being excessively altruistic will result in burnout or ineffectiveness. It is therefore fair to state clearly (without whining) what will be needed to support a particular effort. If for example you are lucky enough to have a residency program begging you to take trainees, but what they want is a quick show-and-tell exposure taking up one half-day a week (10% FTE) of your physician's time, it is fair to raise the issue of how this time might be compensated. Compensation could occur by increasing FTE (rarely popular with bosses) or decreasing other duties of the physician. You might be able to negotiate with the residency program to encourage residents to do month long electives on the unit, where they could assist you in the work of the ward, thereby 'repaying' your educational efforts.

Collaborating with Outside Agencies

Effective collaboration with outside agencies, especially home hospices, is essential for unit success. Home hospices are often sources of referral for veterans. Some programs report that as many as 50% of admitted veterans are new to the VA system. Beyond collaborating in the care of individual veterans, working with partners is essential in building a positive reputation for your unit and the VA (and thus generating good news!). If you have a hospice unit, are you a member of the National Hospice and Palliative Care Organization (NHPCO) or your state hospice/palliative care organization? If not, why not? While VA hospices fall outside JCAHO hospice accreditation, this does not prohibit hospices from joining national and local organizations. Our hospice unit is particularly active in the local chapter of our state hospice and palliative care organization (CHAPCA). This participation has been a great way to get to know and be known by the community hospices in our neighborhood. We have been able to help the organization (and the cause of palliative care) by providing meeting space gratis for community meetings such as one we sponsored after the Moyer's series in our facility auditorium. This participation 'gets us on the radar screen' of the entire community, when they come to visit our facility. In turn, the hospices helped our unit win awards such as a "One from the Heart" award from the largest community hospice, an associated county award for service to the community and, recently, a Circle of Life Citation of Honor award from the American Hospital Association. None of these awards would have been possible without strong community support. Good news! Good news!

At a national level joining major organizations such as NHPCO or professional organizations such as the American Academy of Hospice and Palliative Medicine (AAHPM) or Hospice and Palliative Nurses Association (HPNA), participating and presenting in their meetings increases the visibility of VA and veterans, earning us a deserved seat at the table. Such participation also generates good news nationally and locally as our involvement and leadership becomes apparent. Remember, 674,000 veterans (29% of all Americans) will die this year. This fact alone (known by few in or outside VA) entitles us to be major players in policy making and end-of-life care leadership.

Managing News Organizations

If and when good news happens in your unit that is worthy of comment in your local paper, you are encouraged to work with your communication officer to get the word to your local press. Hospice and palliative care issues are hot topics right now in the media and a lot of wonderful things are happening in VA.

Education and the Hospice Unit

Education in the hospice unit is important for many reasons. Recent studies have documented broad deficiencies for healthcare workers from a variety of disciplines in basic palliative care skills. Inpatient hospice units are one of the best places to teach

and foster such skill development. Beyond this, properly managed, education can help support your unit.

We have noticed a growing tendency on our unit for our staff to be asked to give presentations in our facility about palliative care. We welcome this, both because of intrinsic educational importance, but also because such presentations are an opportunity to find allies. 'Getting trainees to work on the ward' is important educationally as well. Recent articles and commentaries in palliative care suggest that while we have improved exposure to palliative care, experiential learning (learning by doing) is essential if we are to address attitudinal and skill objectives in learners.

Thus, hospice units are encouraged to push aggressively for experiential learning for trainees. Doctors, nurses, social workers, pharmacists, psychologists and chaplain trainees should ALL be rotating through your unit, if your facility has training programs in these disciplines. Such rotations should be experiential and contribute to the care actually delivered on the unit.

Hospice and Palliative Care Strategic Plan for an Inpatient Unit: The Dayton Example

Hospice and Palliative Care Sub-Council
Geriatric Extended Care Line (GECL)
Geetika Kumar M.D., Hospice and Palliative Care Medical Director
Kathy Hayes, MS, RNC, CHPN, Hospice & Palliative Coordinator
Dayton VA Medical Center

Introduction

With the advancement in medicine and medical care, patients with chronic diseases, now live longer. For example, the development of antibiotics and other advances in medical technology has prolonged the lives of patients, who in the past would have died of infectious diseases. Today, society has prolonged the process of dying and has recognized the need for pain and symptom management, supportive care needs, and advanced care planning, which has not received worthy attention. Due to the aging of the Veteran population, there is and will continue to be an increase in the need for Hospice and palliative care services.

Rationale

The Under Secretary of Health for Veterans Affairs has mandated hospice and palliative care as a benefit for Veterans. In doing so, the VA palliative care standard was developed and implemented in VA Medical Centers throughout the United States. With the addition of dedicated palliative care beds and services, supportive care will be provided to Veterans in palliative care versus higher cost rescue care in the acute care setting.

Geriatric Extended Care Line (GECL) Hospice and Palliative Care Sub-Council Goal

Every Veteran enrolled in the VA Healthcare System in Ohio, who has a serious, life-limiting illness shall have access to hospice/palliative care services and shall have an understanding about the availability of these services. This goal addresses the VA's commitment incorporating Hospice as a basic health benefit and addresses the intent of the VA National Hospice Study, which recommends that Community Hospices provide home hospice services while the VA provides the inpatient Hospice/palliative care.

Palliative Care Mission Statement

Palliative care provides active total care of patients whose disease is not responsive to curative treatment. This comprehensive, interdisciplinary care focuses primarily on promoting quality of life for patients living with advanced, progressive, incurable illness and for their families. Key elements for supporting the patient and family to live as well as possible in the face of life-threatening illness include; assuring physical comfort, psychosocial and spiritual support, and provision of coordinated services across various sites of care, including bereavement, while remaining sensitive to cultural, and religious values, beliefs and practices.

Definitions:
*Hospice***:** The comprehensive, symptomatic treatment of patients with terminal diagnosis who are expected to live less than six months.
*Palliative Care***:** Takes the concept of hospice care and extends it to patients with greater than six months to live. Palliative care consists of a combined management model and blends comfort care with aggressive care appropriate to the identified goals of care. Encourages advance care planning, including advance directives, through ongoing dialogue among providers, patient and family. Palliative care guides patients and families as they make the transition through the changing goals of care.
Advanced Care Planning Computer Software Program: As part of the comprehensive care planning process the Dayton VA has available for VISN 10 facilities the *Advanced Care Planning Computer Software Program*. This program provides an initial computer screen of out-patients currently eligible to receive palliative care services based on ICD code and utilization of Emergency room and ICU visits. This system provides the initial screen to identify and support the need of increased palliative care programs within VISN 10 and its many benefits and outcomes. This software also increases the awareness of the palliative care team to the number and location of available patients that may require palliative services.

Short-Term Objectives
- Develop and approve budget for dedicated unit to include:
  1. Cost for dedicated staff positions (needed staff positions are listed later in this document)
  2. Dedicate space and building management resources
  3. Cost to redecorate area into homelike setting
- Install and utilize Advanced Care Planning Software, which gives the approximate number of patients within your medical center population that may qualify for palliative care services
- Recruit volunteer services to solicit donations for home-like furnishings for unit
- Decorate dedicated unit in home-like furnishings to include visiting area, kitchenette and sleeping area for families
- Interview and appoint Interdisciplinary Team
- If you are called a hospice you must make sure you are meeting the Medicare conditions of participation when you set up and operate your program.
- Ongoing training for interdisciplinary team in symptom management and end of life care
- Contact Voluntary service to recruit volunteers interested in assisting in palliative care
- Train interested Volunteers in hospice/ palliative Care Volunteer Program
- Implement effective admission process and procedures
- Educate VAMC physicians, nurses, social workers, and chaplains on hospice/palliative care services and admission criteria
- Initiate VAMC hospice and palliative care consultations throughout medical center
- Initiate pilot plan of program
- Network with community hospice programs, hospital discharge planners, VAVS and community organizations to increase their awareness of available VA palliative Care services
- Coordinate and provide bereavement services for hospice and palliative Care deaths

- Reanalyze above process and realign process to meet changing need of patients
- Implement full-action plan for palliative care beds
- Send out Family Satisfaction Survey to families 3 months following patient's death.
- Conduct periodic follow-up of plan

Long-Term Objectives
- Coordinate advanced care planning for all of the palliative care patients within the medical center
- Initiate palliative care out-patient clinic for symptom management of home patients
- Provide 13 months bereavement for all VAMC deaths
- Implement clinical demonstration site for end-of-life research
- Conduct evaluation of plan

Palliative Care Eligibility Criteria
Eligibility to participate in the palliative care program is based on disease severity and utilization measures specific to major disease categories, which would apply for patients with advanced, progressive, incurable illness. For example, patients would qualify when an illness becomes severe enough to shape much of the person's life and is expected to be fatal. This is commensurate with the VA palliative care standard which identifies the following:

Patients with diagnosis of cancer of liver, pancreas, esophageal, trachea, bronchus, lung, colon, leukemia, lymphosarcoma, lymphoma, multiple myeloma not being treated for cure, patients with metastatic cancer of the breast or prostate or patients with melanoma, AIDS, chronic renal failure on dialysis, or patients with CHF or COPD who have two or more hospitalizations or one or more ICU admissions for CHF or COPD in the last six months, and other diseases as indicated.

Examples of Appropriate Patients
Patients with terminal disease, refractory to curative medical interventions, with complex pain/symptom management needs
- Cancer Patients
- Post 72 hour CVA
- End-stage cardiac refractory to curative medical interventions, NYHA class III or IV function on a usual day for CHF and ejection fraction of <30%
- End-stage pulmonary disease refractory to curative medical interventions
- COPD with continuous oxygen (pO2<55 at rest)
- End-stage Dementia
- Liver Disease
- Renal Disease
- Amyotrophic Lateral Sclerosis
- Palliative Chemotherapy
- Palliative Radiation Therapy
- Nutritional Supportive Therapies
- Blood Product Therapies

Levels of Palliative Care
Dedicated inpatient palliative care to consist of the following levels:
- Symptom Management
- Respite
- Short-Term Residential
- Bereavement for family

Outpatient palliative care to consist of
- Palliative care clinic
- VA case manager managing care for cancer, CHF, and COPD patients
- Community Home Care or hospice active in homecare of patient and family
- Bereavement for family

Outpatient Hospice Care Consists of coordination of home services with a Community Home hospice agencies.

Utilizing the Strengths of Interdisciplinary Resources
The Hospice and Palliative Care Interdisciplinary Team will provide coordination of care to assure that changing needs and goals are met and to facilitate communication and continuity of care in the following settings:
- Dedicated inpatient hospice and palliative care unit,
- Consult service within the Dayton VAMC,
- Palliative care in the outpatient clinic,
- Advanced care planning throughout the Dayton VAMC, and
- Coordination of services with home care and home hospice agencies.

Requires an interdisciplinary approach drawing on the expertise of a dedicated team consisting of:
- Hospice/Palliative Care Coordinator, 1 FTEE
- Physician, .5 – 1 FTEE (depends of number of beds)
- Palliative Care Nurse Practitioner, 1 FTEE
- Hospice/Palliative Care Case Manager, 1 FTEE
- Social Worker, .5 – 1 FTEE (depends on number of patients); hospice standard is 30-40 patients per social worker
- Chaplain, .5 FTEE (depends on number of beds)
- Psychologist, .25 – .5 FTEE
- Bereavement Coordinator, 1 FTEE, ideal
- Discharge Planner, .30 FTEE
- Rehabilitation Therapist, .20 FTEE as needed
- Dietician, .5 FTEE(depends on number of beds)
- Music/Recreational Therapist, .25 FTEE
- Pharmacist, (currently staffed)

Minimum Nursing ratio required due to increased acuity of hospice and palliative care patients (The numbers noted below are for a 36 bed unit.)

Nurse Manager	1 FTEE
RN	14.6 FTEE
LPN	2 FTEE
NA	8 FTEE

Shift Breakdown

12:00 AM – 8:00 AM	7:30 AM – 4:00 PM	3:30 PM- 12:00 AM
RN - 3	RN - 8.6	RN - 3
NA - 3	LPN - 1	LPN - 1
	NA - 5	NA - 3

Palliative Care Outcomes
- Documentation of individualized "Advanced Care Plan" for comprehensive, coordinated, palliative care services that minimizes physical and psychological suffering and optimizes the patient's quality of life.
- Patient/Family satisfaction measured with patient/family satisfaction survey.
- Pain management plan is effective as measured by pain rating scale and patient satisfaction survey.
- Utilization costs of providing care in palliative care setting versus rescue care in traditional settings of ICU, ACU and acute care.
- Decreased rate of palliative appropriate diagnosis receiving rescue care in traditional acute care setting.
- Primary care provider compliance throughout all settings with advanced care plan and DNR.

This recommended hospice and Palliative Care Model supports innovation, research, education and dissemination of best practices and models of care (s*ee Figure 1 at the end of this document).*) This program will also meet the standards as set by VHA, JCAHO long-term care, subacute care and hospice care, Medicare, and National Hospice Organization.

Community Impact: The greatest impact occurs with our veteran stakeholder, who will have increased access to hospice and palliative care services either in the home or in a VA inpatient hospice and Palliative Care unit. Veterans will also receive the most appropriate care at the end of life. The community hospice partners will benefit with the collaboration of services for veterans living in their community and VA will benefit with positive public relations in regard to the care provided to the veteran.

Accountability: The VA Palliative Care Performance Standard, the National Hospice Guidelines for hospice programs Medicare Standards for hospice Programs and JCAHO standards will be utilized to measure outcomes. Accountability will be by the Local Care Line Manager and the hospice Coordinator.

Conclusion:

Palliative Care guides the patients and their families as they make the transition through the changing goals of care and supports patients as they address issues of life completion and life closure. Support of the family following the death of the Veteran is an important aspect of hospice and palliative care.

It is the goal to integrate the advances in palliative care effectively into standard clinical practice. Dr. Ira Byock Director of The Palliative Care Service in Missoula, Montana and the Promoting Excellence in End-of-Life Care, says it best: "Working together we can ensure that wherever people are treated, whether in hospice or palliative care programs, they will be able to feel wanted, worthy, and dignified, despite their terminal frailty and physical dependence."

Figure 1

Dayton VA Hospice and Palliative Care Model
Extended Care Service Line
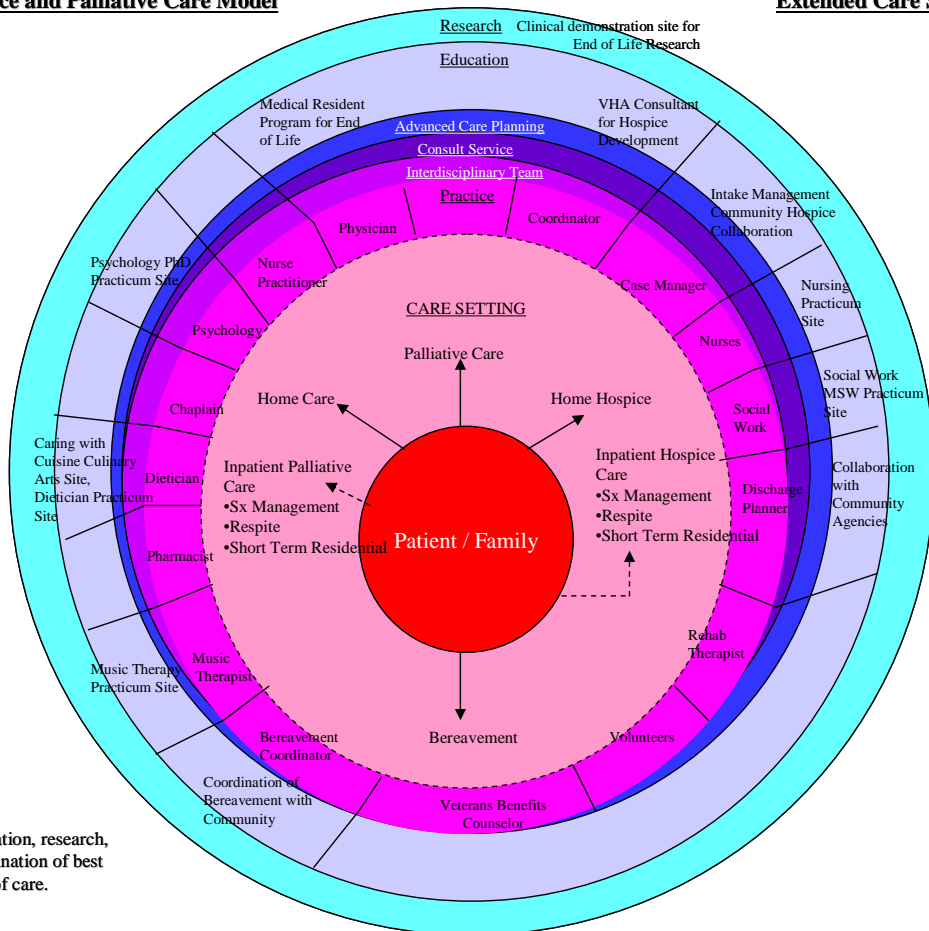
Palliative Care Consult Team Proposal:
Portland VA Medical Center[*]

Linda Ganzini, M.D., Staff Geropsychiatrist
Joan Caley, RN, MS, CNAA, Director Skilled Care Unit
Portland VA Medical Center, Portland, OR

Executive Summary

This proposal for Palliative Care Team was developed by an interdisciplinary workgroup as an action plan for palliative care that was presented to the Executive Management Team in October 1999. That action plan was for the Palliative Care Workgroup to develop a plan and make recommendations for how PVAMC could improve the delivery of palliative care across the continuum of care. This plan builds on an earlier proposal submitted by Dr. Linda Ganzini, reflects current community practice, and is consistent with VA Headquarters, state and national initiatives on improving end-of-life care.

The proposal presents an extensive discussion on the background of the problem and problem identification, discusses project methodology including clarification of terms, analysis of several PVAMC data sets, benchmarking and market survey data, and maps the project to VHA Strategic goals and objectives. Based on this discussion, the establishment of a Palliative Care Team is proposed, including organization and staffing, staffing and resources costs, implementation plans and measures of success. The following recommendations are proposed for EMT discussion and approval:

1. The workgroup strongly recommends that any continued efforts to address palliative care reside in the Medical Practice Group SBU. Palliative care is a Medical Center issue affecting many patients and has potential to improve the care of patients in all care settings.

2. There are three options for how extensively to implement a Palliative Care Team:
   A. Provide full funding for comprehensive team as outlined in this proposal, including FTEE and all the education resources.
   B. Provide start-up funding to include the Clinical Nurse Specialist (1.0 FTEE), Program Analyst (1.0 FTEE), and Internist/Palliative Care Specialist (0.5 FTEE) positions to further refine and implement a "scaled down" version this proposal.
   C. No funding -- Maintain status quo

3. Assign responsibility to the PCT (only if funded or other determination by EMT):

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[*] The appendices referenced throughout the "Palliative Care Team Proposal" are not included in the TAPC Toolkit.

A. To develop a data system to better identify and target patient populations needing palliative care.
B. To develop a proposal in response to the January, 2001 call for a clinical initiative RFP (in process)

4. Request that the Medical Staff Council (MSC) develop and initiate a plan for medical consensus building.

5. Consider the establishment of an advisory committee to support the implementation of the PCT (which would sustain the interest and buy-in of staff who committed to this workgroup).

6. Integrate the PCT proposal into the development of the care management model currently being developed by the Medical Center.

7. Implement the POLST form as part of revisions to Medical Center policy on advance directives (in process). Although approval of these recommendations will require FTEE and dollar resources, adequate funding will be essential to assure successful implementation and outcomes evaluation.

PALLIATIVE CARE TEAM: Problem Statement
A. Background of the Problem
End of life care for Veterans at PVAMC is broken. Over the last decade, there have been numerous efforts by individuals, groups, services and/or programs trying to fix the problem. Although there have been some improvements, not all have been sustained nor has a consistent, coordinated approach been developed. End of life care continues to be fragmented, care outcomes are not measurable, data is poor, cost data is irretrievable, and levels of patient/family satisfaction are unknown. Most important, care delivery is not based on a comparable standard of care throughout the organization nor is care delivery consistent with community standards.

A brief look at the history of some of these efforts may help to understand the issues and the need to develop a better approach to palliative care. In 1992, a VHA directive mandated that all VA's have hospice services. In 1992-1993, PVAMC participated in extensive training and met the intent of the mandate by establishing a Hospice Advisory Committee to implement the directive. At that time, two major problem areas were identified, including pain management and continuity of care. The Hospice Pain Consultation Team (HPCT) was formed to address the foremost concern of inadequate pain management for terminally ill veterans. ***This team was formed without any dedicated resources.*** The team was interdisciplinary and originally included nurses, a pharmacist, an oncologist and an anesthesiology physician. The focus of the team was on pain management, and its services were only available for inpatients. Outpatients could only be seen in the SSCU. This team never offered continuity of care, bereavement support, services for outpatients, or psychological and spiritual

counseling. The advisory committee became inactive after initiating the HPCT, having addressed only one of the two major problem areas that had been identified.

In the first three years of existence, the HPCT received 50-60 consults per year. In 1996, they received 96 consults. With the advent of the inpatient hematology/oncology team in 1997, the numbers began to decline. In July 1999, the inpatient hematology/oncology team changed its operations and now only cares for patients actively receiving active chemotherapy; also, their case manager who was on the HPCT retired early this year. This year, to date, the HPCT has received only four patient referrals. There has been increasing difficulty with the referral process and a decreasing number of consults related to staff turnover at the unit level and the lack of a clear policy about referrals to the HCPT. A Medical Center Memorandum was initially developed but never approved by all reviewers because of issues related to resources. In addition, ability to respond in a timely manner to consults has resulted because of the lack of dedicated staff. The only remaining RN on the HPCT is limited to seeing patients on her own unit; two other RNs have left the team for other VA duties. The team pharmacist has moved to program management, limiting her time. The physician member, an oncologist, left the VA two years ago and has not been replaced. In essence the HPCT is slowly disappearing with a declining number of referrals, a diminishing response rate to referrals and decreased levels of staff to support full functioning of the team.

In regards to hospice referrals, the Community Health Coordinator has been able to obtain hospice in the community for VA patients having Medicare or Medicaid. In the situation where the patient is not eligible for Medicaid and Medicare, community hospice organizations may assume the veteran's care on a charity basis. In rural areas where resources for charity work are not available, veterans have died without hospice support because of lack of financial resources. Although hospice services are available and can be arranged for most veterans needing hospice care, many terminally ill veterans die receiving minimal palliative care and often without the support of hospice. The Director of the Home Care Program has just recently completed work on the establishment of a contract for fee-basis hospice services and is now working with the Director of the NSCU on a contract for hospice services for veterans who need care in the NSCU. Currently, an informal arrangement exists for the continuation of these services in the NSCU (with two community hospices) on an individual, case-by-case basis. Although these efforts are in the best interests of some veterans, they are happening in isolation and are not well coordinated with the planning or needs of others in the medical center.

In early 1999, Dr. Linda Ganzini led the efforts of an interdisciplinary workgroup that developed a proposal for a palliative care consultation team. Her group proposed the development of a team that would coordinate system wide care and services for dying veterans and their families. The proposal was reviewed

and discussed in several high level committees, including EOG, Operations Council, and EMT with feedback about the need to further develop the proposal in the context of a business plan. This earlier work of Dr. Ganzini and her team has been integrated into the work plan of the expanded palliative care workgroup and ultimately in this proposal.

In August of 1999, the EMT addressed issues related to NSCU staffing and workload. One of the issues identified for further action was the need to "prepare a plan for the optimal use of all sixty-two NSCU beds that also provides hospice and respite services." (Appendix A)   Issues identified in that memorandum have been addressed in the development of this proposal.

There are still lingering misperceptions about what hospice is. Hospice is a term that describes a <u>philosophy</u> of care, and most often refers to a <u>program</u> that provides palliative and supportive services mostly in the home setting for persons with six months or less to live in the normal course of an illness. The family/caregivers are the unit of care and have access to hospice staff around the clock. Although care may occasionally be provided for a short period of time in a hospital or nursing home for acute pain or symptom management, hospice is not to be confused with a location of care. Because of the confusion regarding the term hospice, we will refer to "hospice" as a community program. We will use "palliative care" as the more inclusive term describing a philosophy of care. Therefore, this proposal will focus on the development of a palliative care team based on a philosophy of care which includes referrals to community hospice programs.

There is other evidence of inadequate attention to the care of the dying in the measurement of end-of-life planning in the national performance contract and EPRP measures. In the most recent quarter for which the workgroup has data on the complete measure for the Medical Center (last quarter, 1997), the end of life planning performance standard (the palliative care index) was satisfactorily met in only 38% of cases. After this data was released, the methodology for measurement was changed to reflect only the presence or absence of an advance directive, an area in which we had high scores. This change in measurement methodology falsely conveyed an impression that there was improvement in the palliative care measure, although using all the criteria in the performance measure did not reflect a high level of performance when a review was conducted by the workgroup. In the FY00 Performance Contract, the palliative care measure will apply only to long term care, rather than to care across the continuum.

Educational initiatives have been spearheaded nationally and locally with many PVAMC staff members participating. PVAMC physicians attended the National VA Leadership Conference on Pain Management and End of Life Care. A team from PVAMC attended the Conference on Improving the Care of the Dying in Oregon sponsored by the OHSU Center for Ethics. (Appendix B) PVAMC had a

pre-doctoral nursing fellowship in end-of-life care. Several staff members have attended conferences with state-of-the-art presentations on palliative or end-of-life care. Most recently, a member of this workgroup attended a national conference on hospice and end-of-life care. Much of the information from these conferences has not been systematically integrated into care at PVAMC because staff have had no common point of contact for information sharing. Thus, innovations and/or good ideas from interested staff are seldom initiated or are developed in isolation and not available to all patients who might benefit, further contributing to fragmentation in the delivery of palliative care.

There are many ongoing individual efforts throughout the medical center to address the needs of veterans who need palliative care. Three more examples are identified below. In late 1998, the medical center, working closely with Social Work, developed an overprinted palliative care progress note to heighten awareness of medical center staff about palliative care need for patients and improve documentation in inpatient settings. The Cancer Committee has continued to identify issues with continuity of care for terminally ill veterans, but admit they have not made an impact. They support the concept of a palliative care consultation team. Jan Nauertz-Orr in Mental Health has spearheaded the recruitment of volunteers for the Compassion in Action (CIA) program. (Appendix C). The list goes on of similar efforts or activities occurring over the last several years to improve the care of dying or chronically ill veterans who could benefit from a more systematic, consistent and coordinated approach to their needs for end-of life or palliative care.

Most recently, there has also been considerable interest in the larger health care community of which the VA is a part. The Robert Wood Johnson Foundation is especially interested in end-of -life care and has funded numerous efforts to improve palliative care, including the Center to Advance Palliative Care (CAPC) at the Mt. Sinai School of Medicine, and the study *Barriers to Improving the Care of the Dying* conducted by OHSU Center for Ethics. Robert D'Antuono, Deputy Director, CAPC, visited PVAMC and met with members of the palliative care workgroup. This visit was prompted by the information provided by the OHSU Center for Ethics about sites developing palliative care teams from the conference attended by members of the workgroup in the fall of 1999. Mr. D'Antuono consulted with the group for two hours providing valuable insights and offering recommendations for the success of this proposal. He corroborated our finding that while practicing good palliative care produces positive clinical outcomes, it is difficult to measure cost savings. The OHSU Center for Ethics continues to be very involved in the development of this proposal. Both the CAPC and the OHSU Center for Ethics have provided letters in support of the development of a palliative care team at PVAMC. (Appendix D)

B. Problem Identification

The breadth and scope of activity described in the *Background of the Problem* section is illustrative of the problem and is best characterized as an ongoing process of "fits and starts". There have been many attempts at many different levels of the organization to address the need for a palliative care program. Although there have been some improvements, not all have been sustained nor has a systematic, consistent, coordinated approach been developed. Palliative care continues to be fragmented, care outcomes are not measurable, data is poor, cost data is irretrievable, and levels of patient/family satisfaction are unknown. Care delivery is not based on any comparable standard of care throughout the organization nor is care delivery consistent with community standards.

Although the current state of palliative care at PVAMC needs to be addressed, our problems mirror the findings of the study performed by the OSHU Center for Ethics on *Barriers to Improving the Care of the Dying.* (Appendix E) This was a statewide study and would have included Veterans from the Portland VA. The findings in the study identified barriers in three major areas: (1) Advance planning, (2) Pain and symptom management, and (3) Communication and logistics.

As a foundation for the study, two commonly referenced conceptual models were used. The models contrast how palliative care is most often delivered (the Cure-Care Model) and how research suggests a shift to a model of care with an emphasis on earlier intervention (the Continuum of Care Model). The current practice at PVAMC is more like the Cure-Care Model and should be changed to be more consistent with the Continuum of Care Model. In striving for this model, palliative care would be initiated much earlier in the progression of the disease rather than so near the time of death.

PALLIATIVE CARE TEAM: Project Methodology
A. Workgroup Membership

An interdisciplinary group comprised of the following individuals assessed the current state of palliative care and worked collaboratively to develop a plan for improving the delivery of palliative care across the continuum. In addition to large workgroup meetings, break-out groups addressed specific issues such as: (1) Development of the team, process and guidelines, (2) MD involvement and medical consensus building, (3) Measurement and evaluation, (4) Advanced Directives and POLST adoption, (5) Flagging, screening and electronic referral, and (6) System-wide staff education strategies, culture change, and marketing.

B. Definitions/Terms Used

There has been a lot of confusion about terms. This section will provide a common set of definitions and terms used.

What is palliative care?
Palliative care refers to the comprehensive management of the physical, psychological, social, spiritual and existential needs of patients with incurable, progressive illnesses. The goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms, and restoration of functional capacity, while remaining sensitive to personal, cultural and religious values, beliefs and practices. Palliative care is the most appropriate approach to patients who are dying, but is also appropriate for patients with serious, albeit incurable, disease who are still pursuing aggressive life-sustaining treatment.

What are the features of palliative care?
Assessment and management of physical symptoms. Palliative Care Teams (PCTs) are frequently consulted to evaluate many symptoms including pain, nausea, fatigue, dyspnea, dry mouth, edema and pruritus. Common psychiatric disorders seen in palliative care include anxiety, depression, delirium and sleep disorders. The palliative care team can be helpful to the primary care provider in deciding when not to pursue aggressive diagnostic treatment. The palliative care team may recommend symptomatic treatment of a symptom and assist in determining the point at which a diagnostic procedure is no longer indicated based on the patient's goals and expected survival.

Assisting the patient identify goals for end-of-life care. In palliative care all interventions are made in the context of the patient's personal goals. Examples of goals include avoiding hospital admission, returning home, better pain control, or seeing a child graduate. Decisions about treatment range from cardiopulmonary resuscitation and mechanical ventilation to antibiotics, non-oral feedings, artificial hydration, vital sign monitoring, and preventative medical approaches. The PCT works with the primary medical team, family and patients to help them understand the prognosis and make appropriate decisions.

Assessment and management of psychological and spiritual needs. The PCT addresses existential and spiritual concerns including the search for meaning, fears, and prioritization of goals and values.

Assessment of patient's support system: PCTs not only assess what social support is available, but also, in some cases, the patient's fears of burdensomeness to others.

Communication of estimated survival. PCTs develop a great deal of experience in estimating patient survival and communicating this sensitively to family and patients. There is now an extensive data base in cancer patients which allows estimation of survival. The ability to estimate survival in patients with heart disease, lung disease and AIDS is more difficult (Weissman, 1997).

How is palliative care different than hospice?
The goals of hospice and palliative care are similar and the terms have been used interchangeably. Palliative care is an approach to care for dying persons based on clinical, social and spiritual principles. The term "hospice" most often refers to a program that provides support services for terminally-ill persons and their families in the community. Referral to community hospice requires that all attempts at life prolongation or curative therapy are forgone.

As such, the patient's psychological attitude must be one of acceptance of death. Palliative care is more inclusive, involving patients who are severely ill and needing attention to suffering but are not terminally ill, patients who are terminally ill but not ready to accept hospice, dying patients who are still pursuing life-sustaining therapies, patients transitioning to hospice, patients who are refusing hospice for other reasons, and patients who are unable to afford hospice. As an academic field, the American Board of Medical Specialties now offers Added-Qualification in Palliative Medicine.

About one-third of the patients seen by the OHSU palliative care team do not have a terminal diagnosis. They have severe complex medical problems, with multiple hospitalizations. Examples of these non-terminal disorders include inflammatory bowel disease, enterocutaneous fistulae, long-term ventilator dependence, and ischemic peripheral vascular disease. In about 60% of cases the patients are referred because they needed hospice-type services, but are not candidates for hospice care because they wanted some type of life-sustaining treatment. In many cases the team assists in transfer to hospice (Bascom, 1997).

In 1994, the Oregon Death with Dignity Act, legalizing physician-assisted suicide, passed by referendum. The success of this measure was perceived as an indication of voter's fears of pain and lack of control in the dying process. In response to the Oregon Death with Dignity Act, most major health care systems in Portland, including OHSU, Legacy Emanuel, and Providence and hospitals in Salem, Medford and Bend initiated comfort, supportive and palliative care teams at that time (Task Force for Care of Terminally Ill Oregonians).

C. PVAMC Data Analysis
The workgroup reviewed and analyzed several data sets. The group found it difficult to do a comprehensive analysis because the data sources are not complete (e.g. "if the patient didn't die in the hospital, we can't get death data"), issues of primary and secondary diagnosis confound data extraction, and there is an overall lack of a systematic approach to collecting data over the continuum of care. In an attempt to identify and further address the problem, the following data sets were reviewed and are summarized below:
♦ Hospice Referral Data (FY98)
♦ EPRP Data Palliative Care Index (FY98 and FY99)
♦ HPCT Referral Data

- Cancer Death Data
- DSS Data Review
- Palliative Care Chart Review
- Summary of Case Studies
- Barriers to Improving Care of the Dying Study

Hospice Referral Data (FY98)

Out of the 105 referrals made to Hospice in 1998, <u>48% received LESS than 30 days of care</u>. Research has shown that Doctors' prognostic estimates are a central element of both patient and physician decision making especially at the end of life, and Doctors' prognostic estimates in their terminally ill patients are often wrong and usually optimistic. This data strongly correlates with the findings in a major study, published in the British Medical Journal, that claims doctors overestimate survival by a factor of five (Christakis, 2000). (Appendix F) This suggests that undue optimism about survival prospects may contribute to late referral for hospice care, resulting in LOS rates far short of the three months hospice doctors and nurses generally consider the ideal.   The creation of a PC team could address this by allowing the primary care physician to take the lead and providing the consultation needed to address end-of-life care. (Appendix G)

EPRP Data Palliative Care Index (FY98 and FY99)

The Denominator for the Palliative Care Index is composed of patients with diagnoses of Cancer, COPD and CHF. The Numerator is composed of patients noted above, with documentation of at least one element of a palliative care plan. This plan can be either a program (Community Hospice or HBPC) or an individualized plan. *Fully successful* for the Palliative Care Index is 94% in a snapshot taken that combines performance in the 3rd and 4th quarters. *Exceptional* is 98% **AND** effective palliative symptom management (assessment 100%, interventions 95%, evaluation 90%)

The individualized plan must contain one of the following:
- Care Alternatives - a Patient/Family discussion
- Advance Directives – a discussion
- Palliative symptom management (pain, dyspnea, mental distress etc.)
- Patient support – psychological, social & spiritual
- Family support – counseling, respite care, referral to community resources
- Continuity of care

A palliative care measure that contains only one of the above elements (the presence of an advanced directive) is NOT considered to be a successful care plan by the workgroup membership or by experts in the field of end of life care. This palliative care index would look very different if ALL of the above elements were reviewed. Given the chart reviews and in-depth case studies already performed, PVAMC would fail miserably at meeting the varied needs of Veterans at the end of life. All of the above elements of a palliative care plan should be included in the index. Most important, PVAMC should go beyond what is

"required" by the current index and address the needs of Veterans by adopting this comprehensive approach regardless whether it is measured by the index.

In addition, EPRP looks only at the primary diagnosis. If the patient presents for an acute problem while also carrying a chronic disease diagnosis that may be terminal or incurable, the patient would enter the system with an acute primary diagnosis, hence the difficulty in defining the patient population eligible for palliative care. (Appendix H)

HPCT Referral Data

	6/1/98 – 12/31/98	1/1/99 – 12/31/99	1/1/2000- - present
Referrals for pain management	15	17	4
Seen within 24 hours	7	12	2
Seen within 72 hours	1	1	NA
Not seen (consult sent to wrong mail group or no one available to do consult)	7	4	2

The HPCT continues to receive some requests for consults despite team membership being tenuous and lack of a clear referral process. Patients who were not fortunate enough to receive consultations were located on all patient care units throughout the hospital (e.g. MICU, 5D, 6D, 6C, 8D, and 9C).

Cancer Death Data

The Cancer Data Center staff reviewed the number of cancer patients first seen in 1994, 1995, and 1998 regardless of stage of disease, who are deceased. This includes patients who were initially diagnosed and treated here, and those who came here after their initial treatment elsewhere, either for progression of disease or recurrence. This group is one of many ideally suited from which to gather the data to determine patient load for the Palliative Care Team. This data shows that there are 200 patients who died within the first year of being seen at PVAMC for their cancer who could be candidates for palliative care.

In addition, we looked at those cancer patients diagnosed in 1998 at distant stage, who have expired (82), and where they lived. Those patients who lived in our locality OR who died here and did NOT live close-by totals 43 persons. This very preliminary data would indicate that at least half of the patients seen here for cancer may avail themselves of palliative care on a long-term or at least short-term basis. The remaining 39 patients would have more than likely needed short-term palliative care while here. The majority of these were referred to Hospice or other care agencies outside of PVAMC's service area.

DSS Data Review
In an effort to determine the need for palliative care, DSS staff were asked to identify those patients in Fiscal Years 1998 and 1999 who had 4 or more visits to the Emergency Care Unit. For those patients, the top three diagnoses were to be identified as well. In both FY98 and FY99, 14% of those visiting the ECU did so more than 4 times in a year, accounting for just over 1,600 visits. Of the patients with 4 or more Emergency Care Unit visits during FY 1999, the frequency of <u>primary</u> diagnoses were tabulated. Tabular data is provided for a) diagnoses with 50 or greater encounters and b) diagnoses identified as being of particular interest to the Palliative Care Committee. (Appendix I)

DSS staff was then asked to identify various counts of patients and of utilization in Fiscal Year 1999 from a list provided by the Palliative Care Team of populations that they felt might generate a referral for palliative care. DSS staff identified the appropriate codes (ICD9 and CPT) for each population and used Clinical Cost Manager to generate reports of patients receiving care in each population, in both the inpatient and outpatient setting. For a patient to be included in one or more of the population sets, the ICD9 or CPT code had to be included in their outpatient or inpatient DSS record (derived from Vista). We have included the codes in the results table. (Appendix J)

Although, DSS provides a wealth of data, identifying a target population that could be managed by a PCT is difficult because of issues related to primary/secondary and admission/discharge diagnoses. Clearly, the potential use of DSS data is important but only if data can be extracted in a useful and meaningful way. The unsuccessful attempt to gather supportive data illustrates the need for further development of methodologies for data collection and data extraction to measure outcomes and cost for a population of patients who would benefit from palliative care.

Summary of Case Studies
In September 1999, the Palliative Care Workgroup was able to benefit from the expertise of a Nursing Pre-doctoral Fellow in conducting comprehensive case study reviews on five charts of veterans who died at PVAMC. These charts were from the same sample of charts reviewed by EPRP which showed performance at the 100% level (measuring only the presence or absence of an advance directive).   The following is a summary of the issues identified in this review.

1. There were issues with pain and symptom management:
♦ Pain assessment techniques and strategies and patient's responses
♦ Plans for administration of pain medications and use of PRN orders for pain
   "In one case a patient was admitted for pain management and comfort care only; the patient died on day 5; although the patient was seen by several specialists and was involved in ongoing diagnostic work-ups, he received only

6mg of morphine and 4mg of Versed during his entire length of stay which was not adequate to control his pain."

2. There were issues with the level of aggressive treatment and how to balance treatment with palliative care and patient preferences.
"In one case, a patient who specifically requested *comfort care only* still received very aggressive measures."

3. There were issues with the involvement of the family and the need for increased attention to spouses and other family members. Family communication needs more attention.
"In many of the charts, the family may have been very helpful at delineating the code status or helping to advise the team of the patients' wishes regarding the degree of care."

Palliative Care Chart Review
A palliative care chart review was performed on 9/28/99 of 12 closed records. (Appendix K) While the standard for Advanced Directives/Advance Directive Screen was met at 100%, other palliative care documentation was lacking. Documentation in either the progress notes or by discussion with the Veteran or their family is required for meeting the standard. Given this, PVAMC did not fare well with the following measures:
♦ 42% were not informed of their prognosis
♦ 25% of those with a Cancer diagnosis, no stage was indicated
♦ 27% did not have a discussion of Hospice or Care Alternatives
♦ 63% had no documentation of psychosocial and/or spiritual counseling
♦ 29% of the charts did not indicate any discharge planning
♦ 44% did not have complete data on pain assessment

Barriers to Improving Care of the Dying Study
Oregon Health Sciences University's Center for Ethics conducted a study that for the first time quantified the experiences of dying Oregonians and their families in homes, nursing homes and hospitals. This study is of particular importance to the measurement of end-of-life care as it uses family recounts of the experience of death rather than a patient survey. The findings relating to deaths in hospitals correspond with the research performed by the workgroup and serve to further illustrate the need for a comprehensive approach to palliative care.

Pain in Hospitalized Patients: Analysis of study data regarding family reports of decedent pain revealed a troubling trend: In late 1997, more family members reported moderate to severe pain in their hospitalized dying loved ones than had been reported throughout early to mid-1997. This trend could not be explained by cause of death, seasonal effects, or other artifacts. Late 1997 was an unusual time in the state: Oregonians were exposed to an intensive media campaign debating physician-assisted suicide that educated them about end-of-life care; physician-assisted suicide became legal; and shortly after, the DEA issued a

letter of concern regarding the use of controlled substances with the intent to shorten a patient's life. Research is under way to further assess this pain trend.

Hospital Systems Issues
♦ **Multiple Providers**
   Families and hospital providers reported difficulties when multiple physicians care for the same patient.
♦ **Space Issues**
   Providers noted that hospitalized patients are often moved from room to room for administrative reasons. This is stressful for patients and families who see it as an unnecessary burden in the last days of life. Many reported that there is no special place in many hospitals to die when discharge is not feasible or desirable.
♦ **Emotional Support Needs**
   Many providers reported that they do not have adequate therapy, social work, and pastoral care staff to attend to the emotional and spiritual needs of patients as well as family members at the time of death.

To Improve Advance Care Planning
♦ **Families want to:**
   - Have their loved ones' wishes honored regarding life-sustaining treatment;
   - Be respected in their role as surrogate decision maker and be included in discussions about their loved ones' care at the end-of-life; and
   - Receive assistance in honoring their loved ones' wishes for location of death.
♦ **Providers want to:**
   - Have easy access to documents such as living wills that outline patients' wishes;
   - Have advance directive forms such as the polst that transfer with patients across settings; and
   - Know that patients with the guidance of trained health care professionals complete advance directive documents.

To Improve Pain and Symptom Management
♦ **Families want to:**
   - Have their loved ones' comfort be a priority;
   - Work with providers who aggressively manage pain and other distressing symptoms; and
   - Receive timely responses to requests for additional pain medication.

♦ **Providers want to:**
   - Have opportunities for continuing education and mentorship in palliative care, pain control, and symptom management;
   - Have skilled consultation available for patients whose symptoms are difficult to control;

- Be able to educate families about pain and symptom management, as well as the dying process; and
- Work in an environment that supports aggressive pain management.

To Improve Communication and Logistics
♦ **Families want to:**
- Receive practical help with transportation and transfers between settings;
- Have providers who communicate with each other and function as a team;
- Receive honest information from health care providers who are available, responsive, and caring.
- Have an opportunity to speak with providers after their loved ones' death;
- Be provided with emotional and spiritual support; and
- Have a comfortable, private room where they can say goodbye to their dying loved ones.

♦ **Providers want to:**
- Have medical records and medications transferred with patients;
- Have easy access to patient medical records;
- Have the resources to care for dying patients in the setting they desire;
- Be free of excessive financial or regulatory restraints in providing comfort care at the end of life and have universal hospice access;
- Have a special place, tailored to fit the needs of the dying and their families, in hospitals and long-term care facilities; and
- Work in systems that make compassionate care a priority and provide the resources to make it possible.

D. Benchmarking/Market Survey

One of the opportunities the palliative care workgroup had was to participate in an invitational conference for health institutions from across the state of Oregon on state-of-the-art approaches to the delivery of palliative care. The conference was specifically designed for health care professionals who are leaders in improving the care of dying in their organizations. The goal was for each team to develop an action plan and to identify the next steps to further improve care of the dying in their organization. The PVAMC team actively participated in the conference and developed an action plan for the next steps. The team had the opportunity to interact, exchange ideas and do some preliminary benchmarking with other leaders and teams from across the state and came away from the conference with renewed enthusiasm for how we should proceed.

To improve end-of-life care, health care systems across the state are proactively addressing the need for palliative care. Most are developing specialized programs, including palliative care teams some of which travel to the patients' bedside regardless of where they are receiving their care. We are aware of several, including the Oregon Health Sciences University Comfort Care Team, the Providence Portland Supportive Care Team, the Rogue Valley Medical Center Supportive Care Team, the St. Charles Comfort Care Team, and the Salem Hospital Comfort Care Team. Oregon is a leader in developing innovative

approaches in end-of-life care, and the provision of palliative care is the community standard.

In addition to developing a palliative care teams, creating a special place to die is becoming a community standard in Oregon, for example in addition to a comfort care team, the St. Charles Medical Center in Bend has developed a special place for patients and families at the end of life: The Comfort Care Unit. A multidisciplinary team of providers staffs the unit. Patients are given large, sunny rooms with extra chairs, privacy, and the services of the team to help them through the dying process. Traditionally, acute-care settings do not have these kinds of units. However, the St. Charles Medical Center Board of Directors created an initiative to support this much needed service and healing space, demonstrating the kind of progressive thinking needed to effect system change to improve end-of-life care. This unit serves as one innovative model of quality care for people who die in acute-care hospitals. St. Charles has addressed palliative care from the time of admission to the hospital (including the ECU) through stays in the intensive care, med-surg units and ultimately, for some, a return to die in the patients' home.

In addition to private sector attempts to better address end-of-life care, many VA's have developed palliative care teams and programs. Their efforts have ranged from creating a palliative care board (Loma Linda, CA) to a palliative care consultation team with 24 hour 7 days a week coverage (Connecticut) to a 20 bed palliative care unit (Dayton VAMC). Providing comprehensive, interdisciplinary care seamlessly across all levels of care to Veterans with advanced, progressive, incurable illnesses and for their families has been the driving force behind their efforts. The focus of these efforts has not only been on improving care, but also for examining utilization. The Columbia, MO VAMC developed a tracking system to monitor acute hospital and emergency room utilization. A monthly summary of hospitalizations, BDOC and ER visits per veteran per enrolled are generated. This data is compared with the hospital and ER utilization for each Veteran over the 2 years prior to enrollment, and with a concurrent control of those with CHF and COPD who met the screening criteria before the program was initiated. By implementing this system, a 40% reduction in hospitalizations, acute BDOC, and Emergency Room Visits is expected.

E. Project Mapping to VHA Strategic Goals & Objectives
What is the VA Doing Nationally?
The VA recently outlined several major goals at the National Strategy Conference to Improve Care at the End of Life including: "Every veteran with a serious, life-limiting illness receiving care from the VA healthcare system shall have a comprehensive, individualized care plan that supports self-determined life closure, safe and comfortable dying, and effective grieving" and "Every veteran enrolled in the VA healthcare system who has a serious, life-limiting illness shall have access to hospice care and comprehensive palliative care services and shall have an understanding about availability of those services." Kenneth Kizer, MD MPH reinforced that quality of end-of-life care was a top priority for the VA and stated "We are in a unique position to do this. We deal with a

disproportionately older population that is burdened with excessive chronic illness. In addition, unlike other health care organizations, we are judged primarily on whether we do the right thing for our patients. And this is the right thing to do." (Beckwith, 1998). This is also consistent with the current initiative of "Pain as the 5th Vital Sign" to improve pain control.

The VA also recently received a grant from the Robert Wood Johnson Foundation for $985,000 to establish a two-year VA faculty leaders program for end-of-life and palliative care. Thirty faculty fellows were selected from VA-affiliated internal medicine programs throughout the country. The fellows worked to integrate palliative care into education and training in patient care. Molly Osborne, M.D., a VA pulmonologist and Assistant Dean of Education at OHSU, was selected. This 0.1 FTE position lasted one year and was dedicated to curriculum development on end-of-life care for internal medicine residents. A second year was continued at .05 FTE (2-3 hours/week).

Care at the end of life also raises special issues that JCAHO has addressed in new standards specifically related to pain management and decision making at the end of life. These standards focus on 1) the initial pain assessment and regular reassessment of each resident's pain level, 2) management of the pain identified and 3) appropriate education for the resident and family to understand pain and the importance of effective pain management.   The Medical Center is required to collect data to monitor its performance regarding the appropriateness and effectiveness of pain management**.**

How does This Proposal Relate to PVAMC Tactical Plan?
Several of the objectives of the PVAMC Tactical Plan (FY2000-2001) drive the development of the Palliative Care Team. These objectives include:

- **Quality**
  Care will be managed to optimize healthcare outcome including preventive health care.
  > Identify those cohorts of patients at risk for poor outcomes or inappropriate utilization.
- **Customer Satisfaction**
  Coordination of Care
  > Develop process to clearly convey to patients what the next step in their care will be.
- **Education/Information**
  Known Customer Satisfiers/Dissatisfiers
  > Shared decision making, including advanced directive, patient responsibiliti*es for care, etc.*
- **Access**
  > Referral processes will be managed to ensure timely, appropriate, and coordinated services to patients and referring clinicians**.**

PALLIATIVE CARE TEAM: Future Development Plans/Goals & Strategies
A. Future Organization and Staffing
We propose the development of a palliative care consultation team (PCT) at the Portland VAMC. This team would coordinate system-wide care and services for dying veterans and their families. The PCT would be interdisciplinary and offer consultation to both inpatients and outpatients. The team would assist the medical center in instituting VA mandates regarding palliative care. The team would use total quality improvement methods to improve care delivery to dying persons. The PCT would offer case management for a targeted population identified as needing palliative care (e.g. including those with extreme suffering, noncompliance, frequent ECU visits, behavioral problems, lack of social support, or family dysfunction). The team would also focus on system-wide education on care of the dying.

Mission Statement
The mission of the Palliative Care Team is to preserve dignity and improve quality-of-life for seriously ill or dying veterans.

Vision Statement
To provide the following services for seriously ill or dying veterans and their families, we will:
♦ Coordinate system-wide care and services.
♦ Provide comfort and minimize suffering using an interdisciplinary approach to include emotional, physical, spiritual, and social support provided in an ethical fashion throughout the continuum of care.
♦ Coordinate system-wide education of providers and trainees regarding care.
♦ Facilitate research opportunities in areas concerning care and needs.
♦ Implement interventions that promote maximum healing for bereaved families.
♦ Measure outcomes, family/patient satisfaction

Function and Structure of the Team
The PCT will provide service on three levels: (1) consultation, (2) co-management, and (3) case management. Determining the level of service will be based on the patient's needs, location of services available, primary care involvement, and other VA or community resources available to the Veteran and their family. The team will include a nurse clinical specialist who will serve as a team leader and coordinator, program analyst/administrative support, an internist, psychiatrist, pharmacist, social worker, chaplain, community health coordinator, and dietitian. Referrals to the PCT may come from any member of the care team in addition to self or family referrals. A primary function of the PCT will be to support primary care providers.

The team will incorporate telemedicine into delivering excellent end-of-life care to those who are unable to travel to Portland. Providers will be able monitor those palliative care patients from remote sites, including their bedside. This

technology greatly affords the patient with the opportunity to remain at home and still receive optimal care.

The PCT will coordinate system-wide education regarding palliative care needs. The PCT will interact with the Portland VAMC education service, residency training directors, and other training programs in planning and coordinating education needs. For example, the PCT would work closely with Molly Osborne, M.D., Ph.D., who was the Robert Wood Johnson awardee for the VA Faculty Leadership project for improved care at the end-of-life. The PCT will support and cooperate with research on end-of-life issues.

Patient Identification and Eligibility
For the most part, patients eligible for the services of a palliative care team, will include severely and chronically ill <u>or</u> dying patients who are <u>not</u> receiving care in a hospice program. In addition to patients with terminal cancer diagnoses, one of the largest groups that could be served are Veterans in the end stages of life with chronic disease processes (i.e. COPD and CHF). The goal of the team would be consistent with the "Continuum of Care Model" planning for the patients end of life needs much earlier in the progression of the disease. Referrals for hospice care would be but ONE of the options available for patients managed by the team. The PCT will proactively identify patients with the aid of the flagging/screening/new patient groups who would benefit from the services of the team—this process will be seamless to the Veteran patient.

Many consultations will be completed by the team during an inpatient stay at any location in the Medical Center. Initially, a half-day palliative care clinic will be developed for outpatient evaluations and follow-up of some patients. The palliative care clinic will be staffed by all team members and will work collaboratively within the primary care model.

Staffing Resources
The Palliative Care Team will be staffed by an interdisciplinary team, including the following (Specific duties of each member are described in Appendix L):

♦ **Clinical Nurse Specialist/Case Manager/Team Coordinator (1.0 FTEE)**
This position is seen as the most important role of the team; the coordinator will be the "glue" that binds the team together. The person selected for this role should be able to build relationships, communicate effectively, effect change, perform critical analysis, plan and organize effectively, work autonomously, and have knowledge of VA services, palliative care, hospice, pain management, and community resources and services.

As coordinator, the nurse assists patients with incurable, progressive diseases to achieve the best possible quality-of-life through relief of suffering, control of symptoms, and restoration of functional capacity by facilitating timely and appropriate interdisciplinary health services while maintaining cost effectiveness

in the provision of health services. The nurse coordinator will be responsible for establishing communication links between community agencies (i.e., hospice, home care) and Portland VAMC providers.

♦ **Program Analyst/Administrative Support (1.0 FTEE)**

This position is of equal importance to success of the team. Like other models in the Medical Center, this position will manage in partnership with the Clinical Coordinator all the program operations focusing primarily on administrative and evaluative functions. The person selected for this role should be able to build relationships, communicate effectively, effect change, perform critical analysis, plan and organize effectively, work autonomously, and have knowledge of program management and evaluation methodologies.

♦ **Other Members of the Interdisciplinary Palliative Care Team would include:**
  ♦ Social Worker
  ♦ Internist/Palliative Care Specialist
  ♦ Pharmacist
  ♦ Psychiatrist
  ♦ Chaplain
  ♦ Community Health Nurse
  ♦ Dietitian

B. Staffing/Resource Costs

Estimates of staffing/resource costs are based on the staffing resources of other palliative care services from teams developed in the private sector and within the VHA.

	FTEE	Estimated Costs
CNS/Case Manager/Team Coordinator	1.0	$72,800
Program Analyst/Administrative Support	1.0	$43,000
Social Worker	1.0	$59,800
Internist/Palliative Care Specialist	0.5	$70,000
Pharmacist	0.2	$14,700
Psychiatrist	0.2	$36,000
Chaplain	0.2	$8,554
Community Health Nurse	0.2	$14,560
Dietitian	0.2	$8,600
Sub Total	4.0	**$328,014.00**
Education/Marketing Strategy Personnel and Resource Costs (Appendix M)		**$40,076.00**
Grand Total		**$368,090.00**

Telemedicine Consultative Services are provided in-kind. The costs associated with equipment cannot be determined until a patient population has been defined.

All workgroup members agreed strongly that these resources must be dedicated, and that they could not just be added onto the current workload of existing staff within the medical center without realigning current duties. Opportunities may also exist for redeployment of existing resources.

C. Education and Marketing Strategy

The Education Committee developed both marketing and education strategies for Palliative Care. The strategies outline the key components of an educational program to support a model and ongoing program of Palliative Care within our institution. The intent is to reach all health care workers and employees who would be directly and/or indirectly involved in the program in the medical center as well as in regional facilities. Personnel and resource costs are also included.

Marketing Component

Marketing strategies for the development of a PCT will include the following:
♦ Create a logo for Palliative Care Advice Team (PAT).
♦ Display logo with marketing items (flyers, posters) prior to the launch of Palliative Care (PC), through its implementation and continue throughout the practice of PC in the medical center. Who is PAT? PAT is coming.
♦ Posters – Use to advertise in the medical center, Portland and Vancouver. Example: Use to display the definition of PC, the five principles of PC, etc.
♦ Ribbons – Select a color theme for PAT. Palliative Care Team wears ribbons on their identification badge in the corresponding color.
♦ Flyers – Place in strategic locations such as the lobby, elevators, bathrooms, Xerox machines, break rooms, and classrooms.
♦ Sites – Link marketing with Salem, Eugene, Roseburg, and White City.
♦ Programs – Include the Patient and Family Education Resource Centers and Hospital Based Home Care in the marketing process.
♦ System wide e-mails

Education Component

Education/training will target many audiences; direct and indirect health care workers as well as patient and family members. Process (how to access) and level of content (what is PC and how it is provided) will vary with the different target audiences. This is based on the principle of 'not everyone needs to know everything about PC'.   Initial and ongoing education will be provided.
♦ PAT extension. Dial 5QPAT (57728) to call in referrals and consults.
♦ Video – One video for staff and one for veterans. Send to veteran organizations.
♦ Poster – From a larger document, break down salient points.
♦ Closed Circuit TV – Place content about PC on CCTV.
♦ Orientation – Begin education in the orientation process.
♦ Brochure/Pamphlet – Place in accessible area for physicians and staff. Place in Patient and Family Education Resource Center (PERCS). Make available to staff in Salem, Eugene, Roseburg and White City.

♦ Health Promotion – Link into health promotion, clinical reminder for end of life care.
♦ Technology – Integrate PC into technology as appropriate; CPRS, add to and update, Power Point Program, Web site.
♦ Resource Consultants – Expert resource available for consultation 24 hours per day. If a staff member has questions the PC expert can be contacted by phone.

Patient & Family Education
The basic principle underlying education for patient and family members is to provide resources to help make patients better advocates for themselves.
♦ Process – Patients and families need to know how to access PAT.
♦ Pamphlet/brochure – Develop a PC brochure designed to the understanding and reading level of veteran patients. Place brochures in patient's rooms; place in pamphlet racks on wards and in clinics (Portland and Vancouver). Share with other hospitals and outpatient clinics in the state. Explore the option of adopting the End-of-Life material developed by Seattle VA.
♦ Newsletter – Place article in the Patient and Family Newsletter
♦ Phone – Utilize the 'hold line' on the telephone. Take this opportunity to put a descriptive piece about PC on the hold line.

Potential Problems that could be encountered in the Development of an Education Program throughout the Medical Center
♦ The length of time medical media takes to produce a finished video.
♦ VHAPOR access. Limited numbers of nurses have VHAPOR access.
♦ Lack of a collaborative approach to continuity of care in the management of pain.
♦ Staff have limited time to devote to PC training and education to learn about PC.
♦ Expense of any newspaper advertising.

D. Implementation Plan, Measures & Milestones
The implementation plan, measures and milestones will be developed contingent upon recommendations approved by the Executive Management Team.

E. Plans, Goals & Strategies for Addressing Stakeholders
The plans, goals and strategies for addressing stakeholders will be developed contingent upon recommendations approved by the Executive Management Team.

Palliative Care Team: Measures Of Success
Deming has been quoted as saying, "if you don't measure it, you can't improve it!" Conducting an audit (i.e., a systematic critical analyses of the quality of care) that builds upon the initial work of the workgroup will be the first step of the PCT in identifying opportunities to improve and enhance the care of dying Veterans and their loved ones.   Measurement of the processes and outcomes of care take

on a significant role in this initiative. In order to look at the process and determine a baseline, the data acquired from the sources mentioned in the data analysis section will be combined along with an initial survey of family members after the patient's death. In utilizing the "Barriers to Improving Care of the Dying Telephone Survey" developed by OHSU, the PCT team will know the types of barriers Veterans as well as their families face at PVAMC. Specifically, this tool will serve to further examine the three main areas that create barriers to Veterans in receiving appropriate palliative care:

♦ Advance planning (e.g. living wills, honoring wishes for life-sustaining treatment, physician's orders for life-sustaining treatment (POLST), and location of death),
♦ Pain and Symptom Management (e.g. reports of pain, pain management, distressing emotional and physical symptoms), and
♦ Communication and logistics (transfers, support from clinicians, hospice, ethnic and cultural issues, and communication).

The team will use "The Sourcebook on Dying for Health Care Managers" for developing outcome measures for the PCT and strategies for quality improvement. In 1996, the Institute for Health Care Improvement developed a "Breakthrough Series" on end-of-life which serves as the basis of this manual. The book details strategies that have been successful in other hospitals in the areas of pain management, dyspnea, advance care planning and family involvement. The manual also outlines use of TQI and the Plan-Do-Study-Act model for innovative care for dying patients.

Developing specific outcome measures to examine the effectiveness of palliative care at PVAMC are key to the success of the PCT and ultimately the satisfaction of the Veterans we serve. Several research efforts have shown that merely getting patients to write advance directives does not lead to improved patient outcomes. By allowing the EPRP data (which currently measures success based on the presence or absence of an advance directive) to be the defining measure of adequate palliative care, PVAMC fails to properly address the needs of dying Veterans and their families.

PALLIATIVE CARE TEAM: Recommendations
1. The workgroup strongly recommends that any continued efforts to address palliative care reside in the Medical Practice Group SBU. Palliative care is a Medical Center issue affecting many patients and has potential to improve the care of patients in all care settings.
2. There are three options for how extensively to implement a Palliative Care Team:

    A. Provide full funding for comprehensive team as outlined in this proposal, including FTEE and all the education resources.
    B. Provide start-up funding to include the Clinical Nurse Specialist (1.0 FTEE), Program Analyst (1.0 FTEE), and Internist/Palliative Care

Specialist (0.5 FTEE) positions to further refine and implement a "scaled down" version this proposal.

    C. No funding -- Maintain status quo

3. Assign responsibility to the PCT (only if funded or other determination by EMT):

    A. To develop a data system to better identify and target patient populations needing palliative care.

    B. To develop a proposal in response to the January 2001 call for a clinical initiative RFP (in process).

4. Request that the Medical Staff Council (MSC) develop and initiate a plan for medical consensus building.

5. Consider the establishment of an advisory committee to support the implementation of the PCT (which would sustain the interest and buy-in of staff who committed to this workgroup).

6. Integrate the PCT proposal into the development of the care management model currently being developed by the Medical Center.

7. Implement the POLST form as part of revisions to Medical Center policy on advance directives (in process).

APPENDICES *(Note: This is a list of the appendices that were attachments to Portland's Palliative Care Team Proposal. The actual documents have not been included in this Toolkit.)*
A. Hospice and Respite Care Memorandum
B. Action Plan for Palliative Care Memorandum
C. Compassion in Action Program Information
D. Letters of Support from OHSU Center for Ethics and Center for the Advancement of Palliative Care
E. OHSU's "Barriers to Improving Care of the Dying" Study
F. Extent and Determinants of error in doctor's prognoses in terminally ill patients: prospective cohort study, British Medical Journal, February, 2000 & Corresponding Oregonian Article on Hospice Referral, February 17, 2000
G. PVAMC Hospice Referral Data
H. EPRP Data
I. DSS Data Study 1
J. DSS Data Study 2
K. Palliative Care Chart Review
L. Specific Roles of Palliative Care Team Members
M. Education/Marketing Cost Breakdown

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Integrating Palliative Care into a Home Based Primary Care Program

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The James A. Haley Veterans Hospital's Home Based Primary Care (HBPC) program, a designated Program of Excellence, was activated in October 1983 with a staff of 7.5 FTEE and two productivity standards: an average daily census of 50 patients and an average of 350 visits per month. In 1998, the HBPC Program and Medical Directors created a new Program Initiative, "Care of Veterans with Life Limiting Illness" for the purpose of expanding the HBPC program and targeting patients who met VA-defined criteria for providing end-of-life care. This paper will describe the Tampa HBPC program and its history, the reasons why it was designated as a Program of Excellence, and the benefits of integrating a comprehensive array of home-based services, including palliative and hospice care, into a home care program.

During Fiscal Year (FY) 2000, the Tampa HBPC program, with 11.0 FTEE, served 451 unique patients, had an average daily census of 182.4 and made 7,882 home visits. The Tampa HBPC program has demonstrated substantial reductions in acute hospital days (53%), primary care visits (74%) and ER visits (53%) among the veterans served, while maintaining very high patient satisfaction. The Tampa HBPC service is available to patients 24 hours, 7 days per week through an on-call program staffed by HBPC nurses. The Geriatric Medicine Section provides medical support for the on-call nursing staff. The Tampa HBPC program was the first to offer a 24/7telephone accessibility program.

The Tampa HBPC is committed to creative program development to meet the home care needs of the veterans served by the Tampa VA Health Care System. New program components include:

- TeleHome Care
- Home ventilator
- HBPC Lakeland
- Home infusion therapy
- HBPC consult service
- HBPC-Hospice collaboration

In recognition of the success of the HBPC Psychiatry Program, we received the Rainbow award for excellence in integrating geriatric psychiatry and primary care. In April 2000, VISN 8 home and community care service line funded a demonstration project that expanded our HBPC-Psychiatry into the autonomous PPHC (psychiatric primary home care) Program.

We were selected as one of the HBPC sites in the AHEAD (Advances in Home Based Primary Care for End of Life in Advanced Dementia). In FY2000, we completed a two year randomized controlled research study entitled "Care of Veterans with Life Limiting Illnesses".

A commitment to education has characterized the Tampa HBPC. For the last 14 years, HBPC has provided a home care educational experience to fourth year medical students of the College of Medicine, University of South Florida as well as medical residents and geriatric fellows. Nursing students, dietetic and social work interns also have regular rotations through the HBPC program. Training occurs in the interdisciplinary setting, with emphasis on delivery of primary care in the home. The educational and clinical aspects of the program have been the subjects of several national presentations and training videos.

Three of the original 7.5 employees, including the HBPC Program Director, hired in 1983 remain employed at the Tampa HBPC. The HBPC Medical Director trained in HBPC as a medical student (1988), medical resident (1991 and 1992) and geriatric fellow (1993). The rest of the current team members have worked an average of 9.3 years in HBPC. Morale is high and teamwork is exemplary.

RATING FACTORS

A. EXCELLENCE IN CLINICAL CARE OUTCOMES.
During the last 17 years, the Tampa HBPC has cared for many hundreds of chronically ill and terminally ill patients. Patients with a variety of diagnoses and nursing needs have been successfully cared for at home. The primary focus of the HBPC program is the frail, chronically ill, homebound veteran patient. In 1998, we reported that our most common diagnosis was late effects of CVA, with lower percentages for CHF and COPD. The trend toward higher medical acuity in hospitalized patients filters down to HBPC. In FY2000, the most common primary medical diagnoses were CHF (20%), COPD (10.9%) and CVA (10%). Diabetes represents a significant secondary diagnosis for 30% of our patients. Dementia is a concomitant diagnosis for 26% of the HBPC patients. HBPC also provides care at home for ventilator dependent and oxygen dependent patients, patients requiring infusion therapy, total parenteral nutrition and enteral nutrition. Two HBPC nurses are certified in chemotherapy and two nurses are IV certified. Two of our team members, the dietician and a nurse were recently certified as diabetic educators as part of our evolving diabetes telehomecare initiative.

Outcome Measures for Patients Admitted in FY 2000
In FY2000, 160 veterans were admitted to the HBPC program. Those who did not complete six months on HBPC were excluded from analysis. The medical records of the 76 patients who remained on HBPC for at least six months constitute the sample for the four outcome measures.

(1) Percentage of HBPC patients who are able to identify that they wish to die at home
In our sample, 78% of the patients indicated that they preferred to die at home. For a variety of reasons, primarily the lack of an able and willing caregiver, a much smaller percentage actually died at home.   Thirteen patients died after at least 6 months on the program. Almost 50% (7 patients) died at home.

(2) Percentage of decrease in the number of patient visits to primary care clinics for the six-month period after admission to HBPC compared to six months prior to admission to HBPC.
During the period 6 months prior to admission to HBPC these 76 patients reported for 198 Primary Care visits. This percentage decreased by 74% for a total number of 53 Primary Care visits for the ensuing 6 months.

(3) Percentage of decrease in the number of acute hospital days for the six-month period after admission to HBPC compared to six months prior to admission to HBPC.
There was a 53% decrease in acute hospital days (from 458 to 214) six month after admission to HBPC for these 76 patients.

(4) Percentage of decrease in the number of emergency room visits for the six-month period after admission to HBPC compared to six months prior to admission to HBPC.
There was a 53% decrease in emergency room visits (93 to 44) six month after admission to HBPC.

B. EXCELLENCE IN STRUCTURE AND PROCESSES

The HBPC Tampa program strives for excellence in designing a care delivery system that is both effective and productive in meeting not only the patients' needs but also the hospital's, our internal customer, needs. The program is accredited by JCAHO and the JCAHO grid scores exemplify the team's commitment to performance improvement. In l989 the program scored 62, in 1992 the score went up to 90 and in the most recent survey (1998) it scored 98.

The Tampa HBPC program fulfills the DVA Under Secretary for Health's five domains of value of health care:

1) Access -- the Tampa HBPC program personnel are accessible to patients and/or their caregivers 24 hours a day, 365 days a year. During regular working hours patients contact the HBPC office and the HBPC Program Director manages any problems or requests. During regular working hours, hospital staff and the staff of community agencies contact the HBPC office for assistance. At night, on weekends and holidays, HBPC nurses, carry patient summaries and have computer access to VISTA, are available by telephone to allay concerns, triage medical problems and resolve situations either by phone or by making a home visit.   The nurses have direct, continuous access to the faculty and fellows of the Geriatrics Section. These doctors are able to consult with the nurses,

prescribe medications and communicate with the MOD (Medical Officer on Duty) if admission to the hospital is deemed necessary. During a 4-month trial of the on-call program, it was found that 76% of all calls for help were resolved by telephone calls alone. Off-hours emergency room visits were decreased by 63% and hospital admissions decreased by 91%. Following the 4-month trial, it was concluded that the on-call program was well worth the cost (approximately $21,000 per year) because of the reduction in unnecessary utilization of health resources. It is also a great source of reassurance to the patients and their caregivers.

Another example of improvement in access to clinical services is the expansion of therapy services to patients living in the city of Lakeland (60 miles from Tampa) The Tampa HBPC was given an additional Kinesiotherapy FTEE as a result of reorganization of the Physical Medicine and Rehabilitation (PM&R) Service. Since the new KT lives in Lakeland, we developed the HBPC-Lakeland program and began recruiting patients needing therapy. Orthopaedics, PM&R and Community Nurse coordinators refer patients for therapy that would have otherwise been referred to a local home care agency paid by VA Fee Basis at a cost of $85 per therapist visit. The comparable cost for a visit by the HBPC KT is $49.98.

When the workload became too large for the therapist to treat two days per week, we established a rehabilitation program in the Lakeland VFW Hall. An agreement was reached for the VFW to provide the space and utilities and for the hospital the necessary rehabilitation equipment. Patients and families agree to provide transportation to the VFW. Patients are initially treated in their homes and then in a group setting at the VFW as they become more mobile. The therapist not only treats these patients but also provides case management services. We obtained authorization to use a GSA van to deliver adaptive equipment to the homes of the HBPC patients, saving our facility hundreds of dollars in delivery charges.

In 2000, we expanded our geographic reach to provide home-based primary care services to these and other frail and medically ill veterans. This expanded the services of the HBPC interdisciplinary team to Lakeland and surrounding communities, improving access to veterans for whom travel to the CBOC was unrealistic. This opened the door to not only treatment, but also education and preventative services to these veterans. TeleHomeCare as described below augments this service.

The HBPC TeleHomeCare program, developed with the support of the Cardiology and Pulmonary Medicine sections, educates and monitors patients with CHF and/or COPD who live further than 30 miles from the hospital. These patients, who had no prior access to HBPC services, are contacted on a regular basis by HBPC staff and receive an intensive health education program with a strong self-management component. Home Telemedicine units are utilized. The

goal of this program is to improve patients' ability to self manage their disease and to reduce hospitalizations and Emergency Room visits. Patients selected for this program have all been hospitalized more than 2 times in the year prior to HBPC Telemedicine admission. The results of this Quality Improvement Initiative are discussed in the section labeled Excellence in Teaching and Research.

2) Cost – Issues of cost effectiveness will be addressed under Excellence in Cost Effectiveness. Additionally, the Tampa HBPC team has decreased some of the fee basis skilled nursing payments by admitting patients needing fee basis home care for either short-term skilled nursing services or therapy services in the Tampa area. A home infusion therapy program was developed by HBPC to meet the needs of patients without health insurance. Two nurses were certified in infusion services and the other two are in the process of certification. The HBPC Program and Medical Director were instrumental in designing a program of closer medical supervision of patients receiving home care services reimbursed by Medicare or fee basis. This was done in an effort to reduce overall home care costs and improve continuity of care.

3) Quality – Quality management activities over the last nine years have resulted in standardization of the care provided by the team. As an example, in 1990 we established standards for monitoring of specific medical treatments (warfarin, theophylline, diuretic therapy, thyroid replacement, and oxygen) and the documentation of patient education. In 1993 the team addressed diabetes management through a QA activity, resulting in a policy specific to the roles and responsibilities for individual providers (nursing, dietetics, medicine). In FY2000, one of our performance improvement measures documents HgbA1C <9.0% in approximately 90% of our diabetic patients. In 1995, we began assessing pain on each visit, 4 years before the VA's initiative to establish pain as the fifth vital sign.

The Tampa HBPC program provides primary health care in the patients' homes. Therefore, our primary consideration of quality is the degree to which we offer high quality primary care at home. Primary health care is defined as accessible, comprehensive, coordinated, continual, accountable and acceptable as described below:

a) **Accessible** – The HBPC patient and or his/her caregiver has access to his/her providers of care on a 24 hour basis, 365 days a year.
b) **Comprehensive** – The HBPC team is able to treat and manage the majority of health problems arising in the HBPC population at home. Since 1989 preventive health care has been monitored and compliance documented. Forms were revised in 1996 in accordance with VA Preventive Health Guidelines. The Tampa HBPC also follows and monitors compliance of the Chronic Index health care guidelines.
c) **Coordinated** – The HBPC team coordinates the patient's care by referring patients to appropriate specialists, providing pertinent information to and

seeking opinions from these specialists, and explaining and teaching diagnoses and treatment to patients and caregivers.

d) **Continuity** – Regular home visits are made by the HBPC team to patients and complete medical records are regularly reviewed and used in planning and coordinating the health care.

e) **Accountable** – In the delivery of quality care in the home, where care is provided by an interdisciplinary team and by the home caregiver, in an environment where care is not easily observed by a supervisor or the physician, it is important to have written and specific policies and procedures, scope of services, and defined clinical privileges and protocols.   The HBPC team has established and adheres to policies and procedures including an admission and discharge policy with specific criteria, patient rights and responsibilities, team's rights and responsibilities, treatment plans and reviews of the plans on a regular basis, patient care documentation, advance directives education and patient health education. A Quality Management and Risk Management plan are developed on an annual basis and integrated into the hospital's plans. Reports of performance improvement are prepared on a quarterly basis and presented to the VAMC Quality Management Committee on an annual basis.

f) **Acceptable** – The patient and his/her caregiver must agree to receive care from the HBPC team and always participate in the development of the treatment plan. The high patient satisfaction scores document the acceptability of HBPC services.

4) Functional Status – HBPC program uses a functional assessment form designed for HBPC use several years ago. Utilizing Katz functional ADL (Activities of Daily Living) scale, the patient's functional status is assessed at least every 90 days and it is documented on the formal treatment plan review. Additionally, an environmental assessment is made on admission of the patient to the program and if he moves to a different place of residence during an HBPC episode of care. Appropriate adaptive equipment is provided to the patients when needed to enhance the patient's functional ability and safety.   Home improvements to facilitate patient access to the home are also facilitated by the therapists. HBPC therapists have provided in-service education to medical residents and social workers regarding the importance of ordering the appropriate adaptive equipment. HBPC therapists are often consulted by other primary care providers to perform ADL and home safety evaluation in the home.

An unexpected outcome measure of our research study was the significant (at .009p level) improvement in the functional activities of daily living three months after admission to the HBPC program.

5) Satisfaction – As stated previously, patients and their caregivers must accept HBPC care before they can be admitted. Data on patient satisfaction will be provided under Excellence in Customer Service and/or Patient Satisfaction.

C. EXCELLENCE IN CUSTOMER SERVICE AND/OR PATIENT SATISFACTION

HBPC measures patient satisfaction with the care provided by utilizing a questionnaire distributed by the Customer Feedback Center once a year. HBPC Tampa supplements this by utilizing the Ware Satisfaction with Care questionnaire. It is distributed to all TeleHomeCare patients on admission, at 3 months and at 12 months. It was also distributed to research patients, both control and intervention groups. Below are the results:

Care of Veterans With Life-Limiting Illnesses Research Project
Satisfaction with Care (Modified Ware)
Higher scores on all scales indicate more favorable attitudes.

@ Baseline Variable	HBPC	Control	Prob>|T|
Access to Care and availability of resources	55.43	56.13	.902
Technical Quality	62.00	64.38	.707
Communication	58.33	56.11	.777
Interpersonal Care60.80	60.80	64.83	.559
Outcomes	69.00	65.00	.522
General Satisfaction	57.17	57.08	.988

@ 3 months Variable	HBPC	Control	Prob>|T|
Access to Care and availability of resources	76.97	51.69	.0002
Technical Quality	78.41	58.59	.005
Communication	75.78	53.13	.006
Interpersonal Care	83.41	68.08	.010
Outcomes	82.39	58.85	.002
General Satisfaction	68.37	52.60	.003
@12 months Variable	HBPC	Control	Prob>|T|
Access to care and availability of resources	87.22	63.28	.0006
Technical Quality	82.95	70.83	.141
Communication	83.33	64.58	.042
Interpersonal Care	86.82	65.00	.0183
Outcomes	87.50	65.63	.025
General Satisfaction	73.86	62.15	.089

HBPC TeleHomeCare
Higher scores on all scales indicate more favorable attitudes

Variable	@ Baseline	@ 3 Months	@ 12 Months
Access to Care and availability of resources	57.25	70.04	.67.89
Technical Quality	68.00	70.31	73.5
Communication	64.67	69.01	71.01
Interpersonal Care	69.6	76.95	78.6
Outcomes	67.5	70.88	73.5
General Satisfaction	43.00	42.75	44.01

Our internal customers, primarily the physicians and social workers in the inpatient setting, have also expressed their satisfaction with the care provided by the HBPC team. Speaking about our newest component, the HBPC Consult service, the hospitalists write: "the HBPC referrals for home IV antibiotics, physical therapy and wound care is a wonderful addition to the improvement in our standard of care. The response time is rapid and things are progressing efficiently". "The new procedure has streamlined my workload. No muss. No fuss." The medical/surgical social workers write: "great improvement in patient care and expediting pt's d/c". "Good communication… doctors appear to like the new system. They seem to like the quick responses and it appears to help facilitate the discharges much quicker".

D.   EXCELLENCE IN COST EFFECTIVENESS (efficiency and productivity)

The national productivity measures for the HBPC program are several years old. When the Tampa HBPC program was activated in 1983 the productivity measures were: average census of 50 and average monthly visits of 350. We have exceeded these measures since FY 1985. In FY2000, the average daily census was 182.4 with an average number of visits of 657. During the second quarter of FY 00, VISN 8 Extended Care Council selected HBPCs' average daily census as one of the performance measures for extended care in VISN 8. Tampa HBPC leads other VISN 8 HBPC programs on this measure.

VISN 8 HBPC Average Daily Census

HBPC Programs	QTR 2 FY 00	QTR 3 FY 00	QTR 4 FY 00
No. 1	118	117	110
No. 2	149	152	159
No. 3	116	124	130
No. 4	94	83	88
Tampa	183	175	179

Another VISN 8 extended care performance measures tracks patient infections and whether these infections are treated in the home or require hospitalization. Below are the results:

VISN 8 HBPC Number of Infections Resulting in Hospitalization

HBPC Programs	Qtr2 FY 00	QTR 3 FY00	QTR 4 FY 00	QTR 1 FY 01
No.1	1 out of 24	5 out of 23	8 out of 23	4 out of 19
No.2	11 out of 31	9 out of 20	3 out of 17	8 out of 37
No.3	2 out of 11	3 out of 12	3 out of 8	1 out of 8
No.4	10 out of 12	4 out of 14	5 out of 12	8 out of 9
Tampa	1 out of 12	3 out of 10	1 out of 6	1 out of 6

VISN 8 HBPC Program Directors evaluated our patient populations and found them to have comparable acuity, functional ADL status, incontinence pattern and diagnoses

The efficiency of the HBPC team is recognized by administration and hospital staff. In an effort to integrate a fragmented process of planning for home infusion therapy of hospitalized patients we were asked to assume responsibility for this process. An HBPC consult service was developed with the creation of a template that includes all the orders needed by home health agencies and the contracted home infusion company. We are successfully discharging patients within one working day of consultation.

The cost effectiveness of the Tampa HBPC program is also demonstrated by the above reported reductions in acute hospital days and Emergency Room visits. In addition to cost avoidance and according to the Tampa's VERA FY 00 report, 206.13 PRPs (pro-rated patients) in fiscal year 2000 were distributed to the HBPC complex patient class. In FY 00, the cost per patient day at the Tampa HBPC program is reported in the Cost Distribution report (CDR) as $15.75 lower than the national HBPC average cost per day of $19.82.

The only other home care program in this community that is comparable to HBPC in its design is Lifepath Hospice. Like HBPC, Hospice provides comprehensive, coordinated, interdisciplinary care in the home to terminally ill patients. Hospice is reimbursed by Medicare at the rate of approximately $100 per patient day of care. This rate includes not only the provision of skilled nursing and social work services but also medications and nursing supplies for the terminal illness, adaptive medical equipment, oxygen, home health aides, volunteers, etc.   The HBPC cost per patient day of $15.75 also includes the services of the HBPC team (physician, nurses, social worker, dietitian, pharmacist and kinesiotherapist) as well as medications and nursing supplies for all medical problems, laboratory tests, prosthetics and equipment including oxygen and radiology services. HBPC cares for a generally less ill population, but at a very large cost advantage to hospice care in the home.

E. EXCELLENCE IN TEACHING AND RESEARCH

A commitment to education has characterized the Tampa HBPC. For the last 14 years, HBPC has provided a home care experience to fourth year medical students, medical residents and geriatric fellows of the College of Medicine, University of South Florida.   An example of this commitment is our present HBPC Medical Director. June Leland, M.D., trained in the Tampa HBPC as a medical student, twice as a medical resident and then again during of her geriatric fellowship. She became the Tampa HBPC second Medical Director in 1998 after the retirement of the founding Medical Director.

The medical students attitudinal change from the experience in HBPC was studied and its results were presented at the 4th Annual Symposium for Teaching Internal Medicine in Philadelphia, PA. Nursing students, dietetic and social work interns also have regular rotations through the HBPC program. In 1989, a paper was presented to the Association for Gerontology in Higher Education discussing HBPC as an excellent site for gerontological and geriatric education as well as for the practice of primary care in the home.

Participation in research has resulted in nationally refereed publications coming directly from the program and its staff. The first refereed publication by our first medical director came directly out of the program's cooperative evaluation of a functional assessment instrument. Multiple national presentations have highlighted the educational and clinical aspects of the program. More recent academic activities have included work with the GAO resulting in the publication "VA's Approaches to Meeting Veterans' Home Health Care Needs" and a publication on Post-Acute Care in the state medical journal.

In 1998, the HBPC Program and Medical Directors were successful in their application for a New Program Initiative, "Care of Veterans with Life Limiting Illness". The intent was to expand the HBPC program and to target patients who met VA-defined criteria for providing end-of-life care. At the request of Headquarters, a formal single site randomized pretest-posttest control group

research design was developed by the Hines HSR&D staff to evaluate the new program. The research design included only patients with a diagnosis of CHF and/or COPD with 2 or more hospital admissions or 2 or more ER visits or 1 ICU stay in the year prior to admission to the study.   Through the interest expressed by to care for this patient population we were invited to participate in the IHI (Institute for Healthcare Improvement) in their collaborative study "Approaching the End of Life with CHF and COPD". We have also been invited to participate in Dr. Joanne Lynn's planned national research study on M*ediCaring.* We have the support of the hospital to participate in this endeavor.

Modeled after hospice, it offers comprehensive, integrated, interdisciplinary services, and the coordination of care throughout the continuum. Hospice care has historically not been available to those with advanced congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD) for a variety of reasons. Often the patients are not willing to forgo aggressive attempts at relief from an exacerbation of disease, with the idea of prolonging life. The medical system itself has difficulty relinquishing the curative rather than supportive model of care, leaving the patients and providers few alternatives, and little control.

We recognized that our HBPC program, without particular respect to prognosis, was able to provide hospice like care to a number of chronically ill veterans in our community. It provides a hospice like model of integrated interdisciplinary services that are comprehensive and span the continuum of care. Like hospice, we recognize the medical, psychosocial, and existential components of caring for the frail elderly. We developed this program to expand our services to meet the needs of a veteran population of seriously ill veterans, with ultimately fatal disease. We provided comprehensive, integrated supportive community based program of services home based medical care, nursing, dietary, pharmacy, social work, psychological and spiritual counseling. We provided 24-hour access to appropriate emergency services, durable medical equipment, environmental adaptations, personal care, rehabilitation, respite care, and coordinated hospitalizations.

In addition to the population we cared for locally, we developed and implemented a program of TeleHomeCare for those veterans living further than 30 miles from our facility. As with those we visited locally, we used the criteria of two hospitalizations or emergency room visits per year for a principal diagnosis (ICD-9 coding) of CHF or COPD or one intensive care unit admission in the 12 months prior to the study. The population that we served locally was randomized with a control group. The telemedicine patients did not undergo randomization, as this was part of a quality improvement effort on the part of our program.

Project goals
- Reduce hospitalizations and emergency room visits through improved care, thus offsetting the costs of the program
- Establish advance directives for each patient

- Reduce inappropriately aggressive or unwanted interventions, according to the directive
- Educate patient and caregiver with respect to disease process and likely outcomes
- Improve patient satisfaction with care
- Utilize disease specific assessment tools and protocols to evaluate disease severity
- Design and implement a program of telemedicine

Outcomes for the Controlled Study

	HBPC	Control	P value
Patients enrolled at baseline (N)	25	30	
Barthel score at 3 months relative to baseline	3.90	-7.92	.009 ∗
Barthel score at 12 months relative to baseline	-1.00	-10.75	.3958
Ware Scale at 3 months Access to Care and availability of resources Technical Quality Communication Interpersonal Care Outcomes General Satisfaction	N=22 76.97 78.41 75.78 83.41 82.39 68.37	N=24 51.69 58.59 53.13 62.08 58.85 52.60	 .0002∗ .005∗ .006∗ .010∗ .002∗ .003∗
Ware Scale at 12 months Access to Care and availability of resources Technical Quality Communication Interpersonal Care Outcomes General Satisfaction	N=11 87.22 82.95 83.33 86.82 87.50 73.86	N=12 63.28 70.83 64.58 65.00 65.63 62.15	 .0006∗ .141 .042∗ .0183∗ .025∗ .089
SF36V at 3 months and 12 months			N/S
Mortality (subjects)	3	3	
Post Enrollment Data Average Hospital Admissions post enrollment Average Total Hospital Days/LOS Average ICU admissions post enrollment Average ICU length of stay post enrollment Number of Clinic Visits post enrollment Number of ER Visits post enrollment	 .90(n=20) 4.70 .60 1.20 9.20 1.10	 .73(n=22) 7.45 .18 2.59 13.77 1.05	 .70 .54 .20 .58 .07 .92

There were no statistically significant differences between the control and treatment groups at baseline.
Barthel Score is a measure of functional independence; higher numbers indicate more independence
Ware scale measures satisfaction with care
∗ Statistically Significant

Of 55 total patients, 44 (80%) of them used some sort of durable medical equipment at some time during the 12-month period of follow up. For 42 patients, there are at least 6 months worth of data. 60% of all orders for DME

were for patients receiving HBPC. 32% of the control group did not utilize any DME, while only one HBPC patient did not utilize any DME. All CHF patients in the study were provided with scales to monitor weight.

Outcomes for the TeleHomeCare QI Initiative

Total Hospital Days
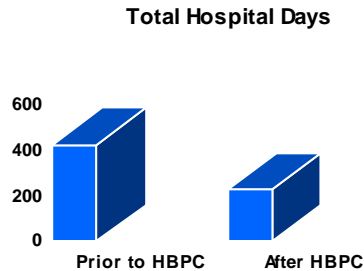
In addition to a 48% decrease in hospital days, there was a 41% reduction in emergency room visits and improved satisfaction with respect to availability and quality of the services that increased with duration on the program.

We learned that we could provide high quality care to patients living at a distance from the medical center using a telemedicine unit. In retrospect, we should have used all the tools used by the study patients in order to get an equivalent data set. We tracked the number of patients completing advance directives, and used the Ware Satisfaction with Care Questionnaire. The written protocols for this program are attached in Appendix B.

We are aware that the limited numbers of patients does not allow us to make strong positive statements about our interventions, and the numbers became smaller as the diseases and program progressed.   The faith that our patients have demonstrated in us and the stories they have shared ensure that the program will continue. Many have been willing to speak publicly (including the recent AMSUS meeting) and passionately about the care they have received. Many have discussed the prospect and plans for death with us, and left a legacy for us to share with other patients.

F. EXCELLENCE IN USE OF HUMAN RESOURCES
The Tampa HBPC program was activated in 1983. Three of the original staff of 7.5 FTEE are still working in the program. The Program Director, Mrs. Ofelia Granadillo, LCSW, was the director of the then HBHC program in New Orleans VAMC for several years. She transferred to start the program in Tampa in 1983. She instructed the other team members on the delivery of health care in the home and was able to facilitate the growth of a group of health care providers into an interdisciplinary team. Julie Rose, RN and Leslie McHale, RN had several years of inpatient medical surgical nursing experience prior to starting in HBPC in 1983. Mr. John Lamonda, KT, Mrs. Paulette Elliott, LCSW and the program support assistant, Mrs. Kathryn A. Day, have been with HBPC for 10 years. The other kinesiotherapists, Mr. Rudolph McNeil and the dietitian, Mr. Robert Blalock began working in HBPC about 6 years ago. The medical director, Dr. June Leland, the part-time Pharm D, Dr. Russell Gape and one of the other nurses, Ms. Candace Norris joined HBPC around 1998. Our newest addition to

the team, Mrs. Edna Sanchez, came to us from the private sector 2 months ago. She replaced a nurse who transferred to another hospital in the VA system.

The competency of all team members is evaluated on, at least, an annual basis by their peers and supervisor. Evaluation often includes direct observation of care delivery in the home or in an outpatient setting. All team members' performance is rated according to written, measurable guidelines specific to their home care duties. Team members are frequently recognized with special performance awards by their individual services. The most recent of these is an award received by Mr. Blalock, RD and Candace Norris, RN for completing their certification as a diabetic instructor.

The HBPC Program and Medical directors are both recognized as national leaders in home care. The program director has participated in standard setting, in writing the HBPC Program Guide and several VA position papers on home care. She is a resource to all other HBPC program directors and orients the new program directors. The HBPC Medical Director is certified as a home care medical director and as a Hospice and Palliative Medicine physician. She is the author of several refereed articles on pain management and other end of life issues. Both are frequently called upon to make presentations at national conferences on the HBPC TeleHomeCare program.

In an interdisciplinary team there is constant blending of the roles and cross training. HBPC offers the individual professionals the opportunity to work together as part of a close-knit team. All team members have been trained by the physician and nurses to improve their power of observation of key symptoms and their urgency to assist them with determining when patients need evaluation by the physician, either in the patient's home, in clinic or in the Emergency Room. All team members assist each other to benefit the patients and their caregivers.

The Tampa HBPC team has been recognized as a Program of Excellence in 1997 and 1999. It has also been recognized with a Commendation, 5 Certificates of Appreciation, several "Outstanding" performance appraisal ratings and innumerable verbal and e-mail messages from administration, physicians, social workers, and other colleagues. Most importantly, the HBPC team is recognized by our patients and families with cards, letters, phone calls, etc.

Home care in a large metropolitan area is not easy. High crime areas, traffic problems the weather, loading and unloading cars, etc are all barriers the staff faces every day. What better evidence that we are an "employer of choice" than an average of 9.3 years of employment?

Pathways of Caring:
A Pilot Program for Palliative Care Case Management Services*

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Program Design

The Pathways of Caring program was conceived as a demonstration project targeting four poor-prognosis conditions (inoperable non-small cell lung cancer (NSCLC), advanced congestive heart failure (CHF), and end-stage chronic obstructive lung disease (COPD), but whose principles could be applied to every GLA veteran diagnosed with a chronic, life-limiting condition. In designing the program we targeted two difficulties experienced by the most frequent palliative care program design, i.e., inpatient consultation teams and/or palliative care or hospice units. First, most of these programs rely solely on referrals from providers, which limit the number of patients served to a small minority of patients in need of palliative services. Second, most programs deliver care only acutely (e.g. the palliative consultation team) or after the goals of care have switched to comfort rather than survival duration (e.g. home or inpatient hospice). We felt that a program that could identify and enroll a larger number of the population-in-need and could provide palliative services over a longer period of time might offer significant advantages over traditional models.

The demonstration project utilized a conceptual model for quality end-of-life care with eight general dimensions: 1) self-determination; 2) symptom management; 3) multidimensional quality of life (including physical, emotional, social, and spiritual well-being); 4) family well-being in care giving and bereavement; 5) patient and family satisfaction with care; 6) survival duration; 7) care near the time of death (including care setting and end-of-life interventions); and 8) resource use and costs. These outcome areas were organized into five specific quality goals by which the program sought to improve upon the VA's existing care structure:
1. Identification of poor-prognosis patients early after diagnosis;
2. Development of care goals that are based on the patient's values and preferences, and delivery of care that remains true to those goals;
3. Comprehensive care throughout the patient's illness, addressing the full range of patients' physical, emotional, social, and spiritual needs;
4. Continuity of care and coordination of services across providers and venues of care;
5. Support for families' care taking and emotional needs during their loved one's illness and following bereavement.

The Pathways program operationalized these areas through specific processes of care: 1) systematic case-finding mechanisms; 2) comprehensive needs assessments; 3) intensive nurse case management services; 4) mechanisms to

achieve coordination and continuity of care across venues of care; and 5) family support services.

1. Case-finding mechanisms are used to identify patients soon after determination of a poor prognosis.

- **Lung cancer** patients are identified through contacts in locations where information on newly diagnosed patients is processed – pathology lab (tissue diagnosis), tumor board, and radiation oncology clinic. Reviews of tumor staging and screening for program eligibility criteria (e.g. residing outside of a nursing home, having a telephone) were used to select program-appropriate patients.
- **CHF** patients are identified through physician referrals and computerized searches for high-risk features (e.g. two or more emergency room (ER) visits or hospitalizations in one year plus a low ejection fraction on echo).
- **COPD** patients are identified from the institution's home oxygen program registry and through computerized searches for hospitalizations and/or ER visits. Following case identification, the patient's continuity provider (if there is one) is contacted for concurrence regarding the patient's program-appropriateness. The patient is then invited to enroll in the program; at the same time the patient and his or her caregiver (usually a family member) are invited to participate in the program's survey (evaluation research) arm.

Upon enrollment, each patient is given an in-depth condition-specific educational brochure. The brochure includes discussions of the disease process including general prognostic information*;* common symptoms and their management; emotional and spiritual issues and support strategies; and the importance of advance care planning. Each patient is also given a general program guide describing in detail the program's goals, system of care, and survey strategies, as well as providing contact information including a 24-hour emergency pager number.

2. Enrollment. Each newly enrolled Pathways patient (and family member, if possible) takes part in a two-hour outpatient *needs assessment* occurring as part of the program's biweekly team meeting.

- The needs assessment includes functional and symptom assessment, identification of social and financial issues, nutritional evaluation, assessment of emotional and spiritual resources, and advance care planning.
- It is conducted in consecutive 20-minute appointments with each Pathways team member including case manager, social worker, dietitian, chaplain, psychologist, and physician director (who performs advance care planning). Chart documentation is made of each assessment, including prominent documentation of patients' surrogate decision maker and end-of-life treatment wishes, if expressed. If specific needs are

identified during the initial evaluation, appropriate follow-up is arranged with the relevant provider.

3. Case Management Services. The lynchpin of the Pathways program is its *case management* service, which supports patient education about condition and prognosis, prompt symptom identification and management, continuity and coordination of care, and consistency to treatment goals across care settings.

- A single nurse case manager with advanced training in palliative care manages up to 50 Pathways patients.
- Case managers act primarily through regularly scheduled telephone monitoring, during which time they review patients' symptoms and other concerns using standardized, condition-specific protocols. For example, for CHF patients case managers' weekly contacts include reviews of patients' daily weights, medication adherence, dyspnea and fatigue symptom scores using 0-10 point scales, and assessments of emotional well-being.
- Unscheduled phone contacts to case managers are also encouraged when patients' symptom control is inadequate or for other "urgencies." Phone visits are also an important opportunity for patient and family education, in symptom self-management as well as about transitions in care including hospice.
- Case managers are in contact with patients' continuity physicians and specialists on an as-needed basis, and referrals are made to other members of the Pathways team (e.g. social worker, dietitian, psychologist, or chaplain) as patients require their services. Active issues for each patient are reviewed with the entire interdisciplinary team at the biweekly team meetings.
- Hospitalizations are a particularly vulnerable time for patients, threatening both continuity relationships and the overall goals of care. The pilot program has developed several mechanisms to promote continuity and consistency to goals of care in these situations.
  1. First, patients and families are educated to phone the case manager early for uncontrolled symptoms, which may obviate the need for emergent care.
  2. Second, each patient's computerized medical record includes a "flag" that alerts ER staff and medical inpatient teams to the patient's participation in case management, and instructs them to contact the case manager immediately.
  3. Third, the case manager receives a computer notification each time a Pathways patient is admitted to the hospital. The case manager acts as a consultant to the inpatient medical team to insure adequate symptom management and consistency to overall care goals.
  4. In addition, case managers confirm the medical teams' knowledge of any advance directives or limitations to aggressive care (this information is also flagged in patients' electronic medical record).

- Case managers also serve an important role in the period following each program patient's death, by coordinating families' interactions with the VA's decedent affairs office and by conducting periodic bereavement follow-up calls until 13 months following the patient's death. Family members identified as in need of bereavement services are referred to community support agencies, or occasionally to the program psychologist or social worker for brief psychotherapy.

4. Coordination of Services across Venues. Most Pathways patients have (or will have) significant functional impairment and often have poor social support, both of which place them at risk of poor access to needed services and poor coordination of those services. Moreover, given the severity of patients' illnesses most patients continue to need specialty medical services and occasional hospitalizations until late in their disease course (often because patients are often unwilling to forego curative therapies for intercurrent illness, making them ineligible for hospice care). The program has used several mechanisms to *maintain comprehensiveness and coordination of services across venues.*
- First, case manager telemonitoring identifies a broad range of physical and psycho/socio/spiritual needs for which needed resources can be recruited.
- Second, as patients decline and become functionally homebound, case managers transition them into the VA's HBPC program while continuing to coordinate patients' home-based and hospital care.
- Third, the program has developed a strong alliance with Trinity Care, a local home care and hospice agency. Trinity provides home nursing as well as physical and occupational therapy services to Pathways patients. Our collaboration maintains continuity and communication through a designated Trinity liaison nurse, who facilitates home care and hospice referrals and who communicates regularly with our case manager about our patients.
- Fourth, the program collaborates closely with a volunteer organization called Compassion In Action (CIA), whose goal is to support veterans during their dying process regardless of setting. CIA volunteers visit program inpatients in the acute hospital or nursing home to address symptom control and emotional and spiritual support needs, and participate in the biweekly team meetings.

5. Family Support. The program recognized families are important stakeholders in patients' illnesses, and may require substantial emotional and caretaking support. While the Pathways program is unable to offer families a full range of support services, the program case manager and social worker regularly monitor family members' needs and offer support services as needed. Available program services include family therapy with the program psychologist as well as spiritual counseling by the chaplain. After a patient's death, the program sends a sympathy card to the family signed by all program staff. Follow-up phone calls to the family are made by the case manager at 1, 6, and 12 months in order to

assess the need for ongoing bereavement support. If further support needs are identified, the loved one is referred to a community-based bereavement support group.

Challenges and Opportunities

Partly as a result of its somewhat-innovative design, the program has experienced significant tension as it interfaces with the existing care structure. Rather than provide direct patient care the Pathways program was intended to support GLA providers in caring for their patients. The program's design essentially challenged providers to increase their commitment to continuity of care. However, in doing so the program uncovered significant system-of-care barriers.

- **Providers' chronically-overbooked clinics** (with appointment wait times of 1-2 months) made it virtually impossible to maintain good continuity-of-care when patients developed new problems requiring providers' prompt attention. This led to unnecessary visits to the urgent care clinic or even emergency room, outcomes the program specifically sought to avoid.
- **Lack of primary care provider.** At the time of enrollment in our program many patients had never been assigned a primary care provider. Given the long wait before any new patient can be scheduled into a provider's clinic, the Pathways physician director often had to assume principal responsibility for patients' care for several months after program entry.
- **Resistance from physicians.** The program's model to support patient-provider continuity has occasionally been met with resistance from physicians. These physicians may feel that they lack sufficient palliative care expertise to assume primary care responsibility for their patients yet may also be reluctant to receive technical guidance from a nurse case manager. In addition, some physicians feel overly taxed for time by program patients, whose complex needs often demand greater attention than other primary care outpatients. As a result, not infrequently providers have felt unable (or unwilling) to assume a primary care role for program patients, further adding to the Pathways physician director's principal care responsibilities.
- **Cure vs. comfort paradigm.** The program has occasionally faced barriers to its goal of introducing palliative principles into patients' care earlier in their illness course. Some providers continue to see the program as equivalent to hospice, i.e. as an "either-or" to active medical treatment. As a result, they may be reluctant to make early referrals, leading to patients enrolling in Pathways only when specialists have "nothing more to offer." These same providers may also be less-than-enthusiastic about the program's encouragement of open discussions about prognosis and goals of care. In addition, providers' difficulty in recognizing the program's supportive goals has led them to label patients who are enrolled in the program as "terminal," even when they might live for years with their chronic conditions. Paradoxically, this labeling has occasionally led to

confusion about goals of care or the appropriateness of aggressive treatment.

- **Hospice enrollment.** The program's willingness to accept patients with widely divergent goals for their care has created challenges, and ultimately important evolution, in our relationship with our hospice partner. One of the program's goals was to encourage earlier enrollment in hospice, i.e. prior to the final days or weeks of life. At the same time, more often than not program patients were unwilling to forego all life-prolonging treatments (e.g. evaluation for infection or hospitalization for IV antibiotics) until their final weeks of life. We recognized that in order to achieve early hospice referral TrinityCare would have to be willing to enroll patients who would benefit from hospice services but whose goals included a desire to live longer, if possible. This created a significant challenge to TrinityCare, which is bound by Medicare hospice regulations regarding life expectancy and goals of care and by its own commitment to comfort-oriented care. Nevertheless, TrinityCare recognized our two organizations' common vision and committed itself to fully integrate hospice into the Pathways care structure. Every hospice referral was made through the liaison with explicit communication about the patient's goals and treatment preferences. This information was then communicated to the hospice team to insure that there was no confusion about the patient's individualized goals, including those aimed at prolonging life. Over the course of the project, the Pathways-TrinityCare relationship achieved a high degree of mutual satisfaction with the collaborative care model.

Summary

Pathways of Caring has demonstrated a promising model to provide high-quality care for patients with three poor-prognosis conditions. Our program's explicit case-finding mechanisms permitted us to identify patients soon after determination of a poor prognosis, overcoming the late referrals that plague palliative care consultation services and hospices. Comprehensive needs assessments including frank prognostic information permitted patient-centered goal-setting, and such discussions were generally welcomed by patients and families as well as providers. Intensive case management services facilitated aggressive symptom management and played a critical role in providing continuity of care and in coordinating transitions in goals of care across care settings. The program's interdisciplinary team supported patients' and families' physical, emotional, social, and spiritual needs throughout patients' illness course. Finally, ongoing evaluation activities will permit us to improve the quality of the program's services on a continuous basis. The program has learned important lessons with regard to handling constraints on resources, collaborating with primary care providers and specialists, as well as building an evaluation framework that best suits the program's design and goals. These lessons will serve us well during the program's expansion and institutional integration.

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Advanced Illness Coordinated Care Program[*]

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Introduction

The Advanced Illness Coordinated Care Program (AICC) is a comprehensive, multi-pronged approach to facilitating good advanced illness/end-of-life care within mainstream medicine. The program uses a specialized case management approach, working with the primary provider and healthcare system to integrate a six-visit intervention by a nurse or social worker into routine care for patients with advancing illness. The intervention is integrated within community health services delivery model and reduces the barriers to palliative care by a) introducing advanced illness and end-of-life discussion among providers and patients, b) ensuring support for quality advanced illness care at all levels of the healthcare organization, and c) providing patient-centered care that encourages mutual-participation relationships, informed choice, and patient autonomy. Initial outcome data for the program show increased hospice and palliative care utilization, improved patient quality of life in advanced illness, and significant cost avoidance. Best practices in chronic illness-coordinated care demonstrate the potential of such a model for the integration of care fragmented by setting or provider and its potential for raising the overall quality of healthcare.

The initial three sessions of the intervention focus on relationship building, assessment, and planning, while the subsequent three sessions focus on helping patients and families transition into the dying process. The AICC program uses a content-based, patient-centered communication model and supervision program developed by Daniel Tobin, M.D. and Dale Larson, Ph.D. This model is currently being implemented in 18 VA Hospitals throughout the country, a 22-site Robert Wood Johnson Promoting Excellence at the End of Life grant, and throughout Catholic Healthcare's Supportive Care of the Dying programs nationwide. Several Blue Cross/Blue Shield plans, as well as other payers throughout the country, are currently reimbursing for the AICC program. Assessment and intervention components of the AICC Program have also been integrated into palliative-care initiatives and end-of-life care programs in a variety of other settings throughout the nation.

A curriculum and corresponding Training Manual (Tobin & Larson, 2000) have been developed that presents operational guidelines and a content–based communication model for AICC programs. The operational guidelines enable providers, health systems, and insurers to plan, implement, and manage AICC programs. In addition, the AICC Training Manual presents the structured, content-based conversation model for advanced illness/end-of-life coordinated

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[*]It is important to remember throughout the process that AICC does not replace current services but is designed to reduce barriers to accessing palliative care

care. This conversation model unfolds in the context of the six AICC meetings between the Care Coordinator and the patient. The concepts on which the model is based were initially presented in the trade text, *Peaceful Dying* (1999, Perseus Books) by Daniel Tobin, M.D., and are briefly summarized below.

Basic AICC Model Concepts
Module 1: Individuality of Disease and Choice
Individuality of disease and choice refers to the individual's unique experience of illness and to the individual's responsibility (in partnership with primary physician and loved ones) for decision-making in medical care. The individual's unique experience of illness remains a central focus throughout the six care coordination sessions.

The issue of individual responsibility for decision making cannot be overemphasized. The diagnosis of advancing illness and the demands of treatment often lead to an overwhelming sense of powerlessness for patients and their loved ones. The Care Coordinator assists patients and their families to take personal control and responsibility through specific education and counseling interventions. In the first session with the patient (patient and family/caregivers), there are four key assessment goals:
1. A sense of the patient's personal history,
2. Decision-making style,
3. Personal understanding of his/her illness, and
4. A sense of spirituality

Module 2: Confronting Fear and Taking Control
Confronting fear and taking control are critical action steps in working with our personal and cultural fears of dying. Confronting fear in this context means approaching rather than avoiding the difficult emotions associated with advancing illness. Fear and anxiety are often the dominant emotions patients present, but there is a wide range of possible emotional reactions.

A diagnosis of advanced illness evokes both fear and anxiety; the emotional reality is a painful blurring of the distinction between them. In addition, the diagnosis and illness are usually perceived as undesirable, uncontrollable, and unexpected-the same three features that researchers agree affect people most negatively.

In order to confront fear, patients and their families must be able to address and express their fears around patient's advanced illness. During the second and third meeting of the intervention, the Care Coordinator can help the patient achieve a sense of control and mastery in this difficult situation by assisting the patient to slow down time and one's mind, and to create positive days. For many patients, fear-related issues will need to be addressed throughout the duration of the program.

Module 3: Practical Issues
Practical issues are concrete steps to help patients coordinate their care and gain control in advancing illness. The Care Coordinator and the patient, in consultation with the patient's health care team and family, address these practical issues during the fourth meeting of the intervention. Dealing with practical issues include:
1. Talking to the doctor,
2. Talking to the family,
3. Coming to terms with illness-related losses,
4. Referrals to counseling and support,
5. Advance care planning,
6. Addressing legal, financial, and business concerns, and
7. Examining spiritual views.

Module 4: The Turning Point
This is a pivotal phase in the AICC model. The timing of interventions is determined by the experiential movement of the patient in the direction of increasing confrontation with the reality of impending death. At a certain point in the coping process, a window of opportunity for peaceful dying usually presents itself. The goal of care coordination at this point, generally around the fifth meeting, is to enhance the patient's ability to take advantage of this opportunity. The Care Coordinator assesses if the patient is ready for a palliative care-based (versus curative care-based) medical plan.

Module 5: Finding Peace
Once the patient has decided to shift from curative to palliative care, the Care Coordinator can help the patient prepare for peaceful dying during the final meeting. It is important that family and loved ones are on the same page as the patient concerning the shift to care-oriented treatment. In addition, it is essential at this juncture to ensure the physician's support is reflected in orders that match the patient's wishes. There can be no ambiguity concerning this issue. Other important steps that the Care Coordinator and the patient must address in order to promote peaceful dying include:
1. Dealing with the suicide question,
2. Deciding the location of death,
3. Getting pain relief,
4. Dealing with physical changes
5. Nurturing body, mind, and spirit
6. Providing a venue for the patient to engage in life review,
7. Discovering the central nature of love in closure and completion,
8. Achieving peace of mind,
9. Planning the funeral or memorial service,
10. Preparing loved ones for bereavement, and
11. Obtaining the ultimate outcome of dying with tranquility.

AICC Program Planning & Implementation Checklist
Program Planning

- ☐ Obtain administrative decision/approval to proceed
- ☐ Identify group members who are willing to see patients as collateral duty, or to become full-time or part-time equivalents if applicable
- ☐ Identify a group leader (group consists of single practitioners, FTE's or members doing AICC as collateral duty)
- ☐ Identify physician champions (within pt. population from which referrals will begin, i.e., oncology, long-term care, palliative care-friendly medical staff, etc.)
- ☐ Inform all local champions of end-of-life care about plan to introduce AICC (i.e., hospice, homecare, transitional centers, bereavement, etc.)
- ☐ Obtain AICC presentation materials
- ☐ Present AICC model to previously identified champions
- ☐ Arrange training session for potential Care Coordinators
- ☐ Identify referral practice
  - ☐ Electronic referral process
  - ☐ Identify "point" person to process referrals
  - ☐ Finalize staffing plan
- ☐ Enter standardized progress note into record keeping system

Community Education Process

- ☐ Present & network to all members of the continuum of care, i.e., hospice, homecare, ethics committee, inpatient, outpatient, pain management & palliative care programs
  - ☐ Physicians – Schedule Grand Rounds, distribute brochures
  - ☐ Chief of Staff & Hospital Director
  - ☐ Non-physicians (RN, SW, clergy, hospital staff)
  - ☐ Lay community & volunteers
- ☐ Identify data collection potential (EPRP criteria)
- ☐ IRB submission where necessary

Program Implementation

- ☐ Patient identification
- ☐ Assign consults
- ☐ Arrange for oversight of dedicated staff

Program Supervision & Evaluation

- ☐ Review AICC training concepts (self-evaluation)
- ☐ Establish bi-monthly meeting time for care coordinators & team leader
- ☐ Establish protocol for chart review
- ☐ Establish guidelines for group supervision-case review

Steps for Establishing an Electronic Consult System for AICC

☐ A request needs to be generated through your Automated Data Process Application Coordinator (ADPAC) to have your local IRM set up menu options; i.e., order entry, electronic signature code, order screen

☐ "Advanced Illness Care Coordination" needs to be added as a consult option to the order screen for consults

☐ The names of care coordinators need to be added into the system as individuals that can generate consults

☐ Each site needs to identify a person who will "receive" the consults & can also receive the "view alert" which lets them know there is a new consult. This person announces, via the VISTA system, the new consult to the AICC group to establish who will take on the case.

Guidelines for Generating Electronic AICC Consults

☐ A physician, nurse, social worker or chaplain can request advanced illness coordinated care services. In addition, patients can request services by calling the number on the back of the brochure.

☐ When entered, an electronic consult is automatically printed to a printer designated by the Site Coordinator. The Site Coordinator will also receive a view alert to notify them of a new consult.

☐ The Site Coordinator receives consult electronically and assigns patient to a team member within a reasonable time frame (48 hours excluding weekends and holidays). This is done via e-mail or telephone. When consult has been assigned to team member, comment is added electronically identifying team member. A view alert is sent to the individual who requested consult.

☐ Team member is given a patient satisfaction survey with self-addressed envelope for return to Site Coordinator (this is to be completed by patient or significant other, if patient is unable to do so). In addition each team member is expected to identify at least 2 outcomes that changed because of the intervention.

☐ Team member will notify primary care provider and/or attending via e-mail or telephone that consult has been received and assigned to them.

☐ After initial visit, electronic consult is completed. Subsequent visits are documented using the formatted electronic progress note.

☐ Site Coordinator will hold weekly or bi-monthly meetings. The agenda for these meetings will include continuing education, ongoing training, case review and problems or concerns team members may have regarding program.

☐ On a monthly basis the Site Coordinator will provide statistical data to the Network Office. This will include the following: name, social security number, diagnosis, ICD 9 code, date of referral, who referred consult, team member assigned and disposition of case.

For More Information
For further information about the AICC model and training manual, please
contact: Crystal Moore, Ph.D.
The Life Institute
VA Healthcare Network Upstate New York at Albany
113 Holland Ave. (111T)
Albany, NY 12208
518-626-6093

Web-Based Resources

Aging with Dignity
http://www.agingwithdignity.org/
Aging with Dignity was established to provide consumers with the practical information, advice and legal tools needed to ensure end-of-life wishes will be respected. This website offers a multitude of materials, including the award-winning "Five Wishes" advance directive and its companion guide, "Next Steps".

American Academy of Hospice and Palliative Medicine
www.aahpm.org

American Bar Association's (ABA) Commission on Legal Problems of the Elderly
http://www.abanet.org/elderly/update.html
ABA recently published "End of Life Care Issues Legislative Update,", which includes summaries of end-of-life care legislation enacted in states from January to June of this year. The review looks at laws affecting surrogate decision-making, do-not-resuscitate orders, palliative care, and assisted suicide.

American Board of Hospice and Palliative Medicine
http://www.abhpm.org
The American Board of Hospice and Palliative Medicine promotes excellence in the delivery of medical care to all patients with advanced, progressive illness through the development of standards for training and practice in palliative medicine. ABHPM sponsors a certification program for Palliative Medicine and is developing standards for graduate training in palliative medicine.

Americans for Better Care of the Dying (ABCD)
www.abcd-caring.org
Americans for Better Care of the Dying (ABCD) is a Washington, DC based, not-for-profit organization dedicated the ensuring that all Americans can count on good end of life care. Through community education and public advocacy, ABCD strives to help organizations and individuals fix their own community care systems and assist health care organizations in implementing rapid-cycle quality improvement methods.

American College of Physicians-American Society of Internal Medicine
Physician's Guide to End-of-Life Care **edited by Lois Snyder, JD, and Timothy Quill, MD**
http://www.acponline.org/catalog/books/endoflife.htm?hp
Developed by members of the ACP-ASIM (American College of Physicians-American Society of Internal Medicine) End-of-Life Care Consensus Panel, the Physician's Guide to End-of-Life Care is a comprehensive manual designed to help professionals learn about and provide good palliative care. The book is divided into three sections containing clearly focused, practical information with

illustrative cases. Topics include communications, relationship building, the goals of palliative care; evidence-based approaches to pain, depression, and delirium; intractable suffering; and legal, financial, and quality issues.

American Osteopathic Association (AOA)

http://www.aoa-net.org
Go to http://www.aoa-net.org/Publications/DO/endcare801.pdf for a downloadable article, *Learning to ease the dying process",* by Staff Editor, Nancy Vitucci.

American Pain Society

http://www.ampainsoc.org/
The American Pain Society is a multidisciplinary organization of basic and clinical scientists, practicing clinicians, policy analysts, and others. The mission of the American Pain Society is to advance pain-related research, education, treatment and professional practice.

BioMed Central

http://www.biomedcentral.com/),
BMC Medical Education covers undergraduate, postgraduate, and continuing medical education. The journal is one of the 60 or so journals published by BioMed Central (a recently established online publishing house that is committed to making original research articles in biological and medical science freely available to all.

Care and Health.com

http://www.careandhealth.com
Care and Health.com is a major on-line resource for people in the care sector. The site has a database of all UK approved social work courses, extensive policy and law references, a sector specific care jobs service, daily news, features on professional practice, over 1400 links to other sites, discussion areas and guides to finding the right training courses.

The Center to Advance Palliative Care

www.capcmssm.org
The Center to Advance Palliative Care (CAPC) is a resource to hospitals and health systems interested in developing palliative care programs. The Center serves a broad constituency of providers and interested groups - including physicians, nurses, educators, policymakers, health researchers, payers, students and, ultimately, patients and their families - in an effort to improve the availability and quality of palliative care. CAPC is a national initiative supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by Mount Sinai School of Medicine.

Center to Improve Care of the Dying
http://www.medicaring.org/
CICD has worked with over one hundred health care organizations to implement quality improvement projects in end-of-life care. CICD is part of RAND Health, a non-profit research organization.

Completing a Life: A Resource for Taking Charge, Finding Comfort, and Reaching Closure
http://commtechlab.msu.edu/sites/completingalife/
Created at Michigan State University by the Communication Technology Laboratory and the Palliative Care Education & Research Program, this website offers an interactive CD-ROM inviting patients and families to learn about the practical, emotional, spiritual and medical issues faced by those dealing with advanced illness.

Curriculum Guidelines for Family Practice Residents - End of Life Care
http://www.aafp.org/edu/guide/rep269.html
Provided by the American Academy of Physicians, these guidelines have been endorsed by the American Academy of Family Physicians and were developed in cooperation with the Association of Departments of Family Medicine, the Association of Family Practice Residency Directors and the Society of Teachers of Family Medicine.

Dying Well
http://www.dyingwell.org
Dr. Ira Byock, long time palliative care physician and advocate for improved end-of-life care, and a past president of the American Academy of Hospice and Palliative Medicine, provides written resources and referrals to organizations, web sites and books to empower persons with life threatening illness and their families to live fully.

Edmonton Regional Palliative Care Program
http://www.palliative.org/
The objective of this web site is to provide information about and the resources available in the Regional Palliative Care Program for the general public and health care professionals. Clinical tools include:
- Assessment tools and Guidelines developed by the Regional Palliative Care Program and references for assessment tools used by not developed by the program;
- Palliative Care Tips, "how-to" practical suggestions for common problems in the terminally ill;
- Journal Watch A selection of journal article reviews pertinent to palliative care;
- Nursing Notes: Articles written by palliative care nurses for nurses;
- Editorial Reflections, Multidisciplinary reflections on issues in palliative care;

- Publications, A list of publications in referred journals by the members of the Capital Health Authority Regional Palliative Care;
- Care Givers Guide, A Caregiver's Guide presents family caregivers the medical and nursing information they will need in clear, easily understood language.

End-of-Life Nursing Education Consortium (ELNEC) Project
http://www.aacn.nche.edu/ELNEC/
The End-of-Life Nursing Education Consortium (ELNEC) project is a comprehensive, national education program to improve end-of-life care by nurses, and is funded by a major grant from The Robert Wood Johnson Foundation. Primary project goals are to develop a core of expert nursing educators and to coordinate national nursing education efforts in end-of-life care.

Education for Physicians on End-of-life Care (EPEC)
http://www.epec.net/
EPEC is supported by a grant from The Robert Wood Johnson Foundation. It is designed to educate all physicians on the essential clinical competencies required to provide quality end-of-life care. The EPEC Curriculum is comprised of a set of two loose-leaf binders The Trainer's Guide with accompanying computer disks of 540 slides in Power Point and videotapes contains all the materials needed for a presenter to teach the subject. The Participant's Handbook has the written material for use as handouts at educational sessions. A CD-ROM version was also produced. All of these products are available to be purchased at cost through the AMA catalog. For ordering information click here.

The End of Life Physician Education Resource Center (EPERC)
http://www.eperc.mcw.edu/start.cfm
Home of "Fast Fact and Concepts", the End of Life Physician Education Resource Center (EPERC) is a central repository for educational materials and information about end of life (EOL) issues. The purpose of EPERC is to assist physician educators and others in locating high-quality, peer-reviewed training materials. This Web site supports the identification and dissemination of information on EOL training materials, publications, conferences, and other opportunities. Educators are invited to submit palliative care educational tools they have developed to EPERC. Go to http://www.eperc.mcw.edu, open "Submit Materials" and click on "Submit Item".

Fast Facts and Concepts
TO FIND PRINTER FRIENDLY Fast Facts: Login at http://www.eperc.mcw.edu, click on "Educational Materials" in the EPERC navigation bar, and then on the "Fast Facts" tab in the left hand column. This will bring up the index of all of them. Once you've opened a Fast Fact from the index you are given the option to click on "Print Preview". This option provides a printer friendly version and there is no special software needed. ANOTHER way of finding the Fast Fact index is after logging in, click on the

white search button in the left hand column. You will find a search screen that lists all resource categories available on EPERC. Clicking on "Fast Facts" will take you to the index.

FEPI/ Family Experiences Productions, Inc.
http://fepi.home.texas.net
fepi@texas.net
Healthcare quality of care video programs, including Facing Death via Videotape, Video streaming, Web clips and DVD.

Finding Our Way: Living with Dying in America
http://www.findingourway.net/
Finding Our Way is a fifteen-week newspaper series funded by the Robert Wood Johnson Foundation. Publication dates are September 10, 2001 – December 17, 2001 and all articles are downloadable from the website. The series is being distributed throughout the country by Knight Ridder/Tribune Information Services. The Finding Our Way national public education initiative is focused on bringing practical information to the American public regarding end of life and its surrounding issues.

Growth House, Inc.
www.growthhouse.org
The Growth House web site is an international gateway to resources for life-threatening illness and end of life care. Our primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. The hypertext topic pages explain major issues and link users to "best of the net" resources around the world that meet our review standards. For an overview of this site, see the topic index. The search engine offers access to the net's most comprehensive collection of reviewed resources for end of life care. Over one hundred health care web sites offer remote access to a database to complement their own content.

Inter-Institutional Collaborating Network on End of Life Care (IICN)
http://growthhouse.net/~growthhouse
This subscription-only site links major organizations internationally in a shared online community and is the home for the VA Pain Management-EOL Online Conference. The VA forum exists as a central location for VA staff to ask questions, share information, and discuss topics that can range from managing patient care to sharing thoughts and opinions regarding VA and national policy issues. Go to the IICN link above to join the IICN. After subscribing, send an email message to vha@growthhouse.net to request membership in the VA online conference.

Institute for Healthcare Improvement
http://www.ihi.org/
The Institute for Healthcare Improvement (IHI) is a Boston-based, independent, non-profit organization working since 1991 to accelerate improvement in health care systems in the United States, Canada, and Europe by fostering collaboration, rather than competition, among health care organizations. IHI provides bridges connecting people and organizations that are committed to real health care reform and who believe they can accomplish more by working together than they can separately.

Institute of Medicine: Report on the Committee on Care at the End-of-Life
http://www.iom.edu/
Click on "Recent Reports" for links to *Improving Palliative Care for Cancer: Summary and Recommendations* (June 19, 2001) and other IOM reports related to hospice and palliative care.

International Association for the Study of Pain
http://www.iasp-pain.org/
IASP is an international, multidisciplinary, non-profit professional association dedicated to furthering research on pain and improving the care of patients with pain. Membership in IASP is open to scientists, physicians, dentists, psychologists, nurses, physical therapists, and other health professionals actively engaged in pain research and to those who have special interest in the diagnosis and treatment of pain. Currently IASP has 6754 individual members from 113 countries.

Journal of Pain and Symptom Management
http://www.elsevier.com/inca/publications/store/5/0/5/7/7/5/index.htt
Journal of Pain and Symptom Management provides the professional with the results of important new research on pain and its clinical management.

Journal of Palliative Care
http://www.ircm.qc.ca/bioethique/english/publications/journal_of_palliative_care.html
The Journal of Palliative Care, published by the Center for Bioethics, is a Canadian-based, peer-reviewed, international and interdisciplinary forum for practical, critical thought on palliative care and palliative medicine.

Journal of Palliative Medicine
http://www.liebertpub.com/JPM/defaultstatic.asp
The Journal of Palliative Medicine focuses on care near the end-of-life and is particularly interested in novel education methods and resources, new approaches to end-of-life service delivery, scientifically rigorous clinical research reports and health policy documents.

Last Acts
www.lastacts.org
Last Acts is a Robert Wood Johnson Foundation-funded national campaign
aimed at improving care at the end of life. Offering a multitude of resources, its
website and online forum offers materials and resources for the public,
healthcare professionals, policy makers, journalists, and partner organizations.

Compendium of Health Care Organization Guidelines and Position Statements on Issues Related to the Care of the Dying
Produced by the Last Acts Campaign's Standards and Guidelines Committee,
the Compendium is a collection of guidelines, standards and policy statements
assembled as a reference to current deliberation regarding appropriate end-of-
life care. To order this publication, go to:
http://164.109.40.20/scripts/la_tsk01.exe?FNC=DisplayAPublication__Ala_newtsk_publication_home_html___56
3

To view the document in PDF version, go to:
http://www.lastacts.org/files/publications/2001guidelinescompendium.pdf

Medscape
http://www.medscape.com/mp/rc/cancerpain
Cancer Pain Management Resource Center is a collection of the latest medical
news and information on cancer-related pain. This resource includes news,
conference summaries, articles, and other up-to-the-minute resources available
on Medscape. From this site you can also visit the Pain Management Resource
Center.

The Meducator
http://www.meducational.com/journal
Authors from around the world are invited to submit papers for publication.
Submission of papers from authors in developing countries is especially
encouraged. The guidelines for submission are available on the website.

National Hospice and Palliative Care Organization (NHPCO)
www.nhpco.org
The National Hospice and Palliative Care Organization is the largest nonprofit
membership organization representing hospice and palliative care programs and
professionals in the United States. The organization is committed to improving
end of life care and expanding access to hospice care with the goal of profoundly
enhancing quality of life for people dying in America and their loved ones.

National Hospice and Palliative Nurses Association
www.hpna.org/
The purpose of the HNPA is to exchange information, experiences, and ideas; to
promote understanding of the specialties of hospice and palliative nursing; and to
study and promote hospice and palliative nursing research.

On Our Own Terms: Moyers on Dying End-of-Life Tools
http://www.pbs.org/wnet/onourownterms/tools/
Located on the official website for the landmark PBS series, *On Our Own Terms*, these tools provide valuable information for patients and their families as well as community organizations seeking to improve end-of-life care locally, regionally, and nationally.

Partnership for Caring
http://www.partnershipforcaring.org
Partnership for Caring: America's Voices for the Dying is A national nonprofit organization that partners individuals and organizations in a powerful collaboration to improve how people die in our society. Among other services, Partnership for Caring operates the only national crisis and informational hotline dealing with end-of-life issues and provides state-specific living wills and medical powers of attorney.

Project on Death in America
http://www.soros.org/death/
The mission of the Project on Death in America is to understand and transform the culture and experience of dying and bereavement through initiatives in research, scholarship, the humanities, and the arts, and to foster innovations in the provision of care, public education, professional education, and public policy.

Promoting Excellence in End-of-Life Care
www.promotingexcellence.org
Dedicated to long-term changes in the health care system to improve care for dying persons and their families, this website provides direction and technical assistance to innovative demonstration projects in end-of-life care settings. The Promoting Excellence grantees are on the leading edge in measuring quality of palliative and end-of-life care. This site makes available the evaluation tools grantees have chosen or developed for their projects.

PubMed
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=PubMed
PubMed, a service of the National Library of Medicine, provides access to over 11 million citations from MEDLINE and additional life science journals. PubMed includes links to many sites providing full text articles and other related resources.

Robert Wood Johnson Foundation
http://www.rwjf.org/index.jsp
- A major funder for national end-of-life projects, The Robert Wood Johnson Foundation was established as a national philanthropy in 1972 and today it is the largest US foundation devoted to improving the health and health care of all Americans.

University of Wisconsin Pain and Policy Studies Group
http://www.medsch.wisc.edu/painpolicy
The mission of PPSG is to "balance" international, national and state policies to ensure adequate availability of pain medications for patient care while minimizing diversion and abuse, and to support a global communications program to improve access to information about pain relief, palliative care, and policy.

Toolkit of Instruments to Measure End of Life Care
http://www.chcr.brown.edu/pcoc/charthtm.htm
These measurement tools should identify opportunities for improving medical care, examining the impact of interventions or demonstration programs, and holding institutions accountable for their quality of care. The Toolkit takes steps toward crossing this measurement barrier by creating patient-focused, family-centered survey instruments that address the needs and concerns of patients and their families, as defined by them. With funding from the Nathan Cummings Foundation and the Robert Wood Johnson Foundation, we have assembled an authoritative bibliography of instruments to measure the quality of care and quality of life for dying patients and their families. Based on these reviews, we have created the Toolkit instruments, which are available on this site at no charge.

Veterans Health Administration (VHA) Office of Academic Affiliations (OAA)
www.va.gov/oaa/flp
The Office of Academic Affiliations created a website for the VA Faculty Leaders Project during the course of the Project. Having now been transitioned to OAA's End-of-life and Palliative Care website, it provides access to this Toolkit as well as other educational and training materials and resources focused on hospice and palliative care.

Veterans Health Administration (VHA) National Ethics Center
http://www.va.gov/vhaethics
The National Center for Ethics is VHA's primary office for addressing the complex ethical issues that arise in patient care, health care management, and research. Founded in 1991, the Center is a field-based national program that is administratively located in the Office of the Under Secretary for Health. The main office of the Center is located in White River Junction, VT. Center staff members are also based at VA headquarters in Washington, DC, the New York Harbor Health Care System in New York City, and the Puget Sound Health Care System in Seattle, WA.

Veterans Health Administration (VHA) Your *Life, Your Choices, a* Workbook on Advanced Directives
Internet: http://www.va.gov/resdev/programs/hsrd/ylyc.htm
VA Intranet: http://vaww.va.gov/resdev/programs/hsrd/ylyc.htm
A new workbook, *Your Life, Your Choices,* helps patients and family members with developing clear instructions about how to proceed during a medical crisis or

how to respond to a long-term disabling illness. The workbook provides guidance about a living will, describes certain health conditions and treatments, explains how to create an advanced directive, and gives advice on how to discuss these issues with family members and health care providers.

Who's Right? (Whose Right?): Seeking Answers and Dignity in the Debate over the Right to Die
http://www.focusonethics.com/whosright.html
The editors (one of whom is a 14-year survivor of Lou Gehrig's Disease) provide interviews with 10 individuals who have faced terminal situations and have made decisions on how they will handle their own end of life. In and around the interviews are the commentaries of 31 experts from various fields (medical, psychology, religion, law, hospice, psychiatry, legislation).