



Palliative Care and Pain Management in Vermont

A Public Report

Prepared by:

Vermont Ethics Network and members of the Palliative Care
and Pain Management Task Force – August 2010

Introduction

Every year about 5,200 Vermonters conclude their lives. About 1,200 of them do it well: free from pain, surrounded by loved ones, emotionally supported, with their affairs in order and some measure of spiritual calm attained. The other 4,000 experience needless physical pain, preventable emotional suffering, futile medical intervention, isolation, and bankrupting expense.

Vermont's experience mirrors that of the nation. Of the 6,500 Americans who die every day, about 2,000 complete their lives in peace; the others suffer unduly and avoidably. Meanwhile health expenses have become the nation's leading cause of personal bankruptcy. End-of-life care in particular has become a primary contributor to runaway medical costs for insurers and for government benefits programs.

This situation is not the fault of medical professionals. Rather, it is the result of their success. In recent years the health system has made enormous strides in reducing sudden causes of mortality (stroke, heart attack, accidents), leading to longer lives of higher quality for millions of people. However, that accomplishment means that many more people now die of slow causes (cancer, dementia, organ failure).

The challenge therefore is to reorganize the health system to bring it in best alignment with the needs of Vermonters when they are experiencing the greatest medical vulnerability of their lives.

Hospice meets many of these needs, by providing patient-centered care in the home, with medical services supplemented by social, emotional and spiritual support for the patient and family. Advance directives are also important; these documents express a person's treatment preferences, or appoint someone to make care decisions on a person's behalf, if the patient is unable to express those choices himself.

Palliative care is a third essential ingredient for building a health care system that reflects how people's lives conclude today. This medical model concentrates foremost on relieving pain, breathing difficulty and other symptoms. In addition, palliative care attends to patients' non-medical needs much in the manner of hospice: education of the patient and family, ethical consultations, involvement of clergy, support from community volunteers, or all of the above.

In Vermont palliative care remains an area warranting improvement, for several reasons:

- Palliative care is available to people still receiving curative treatment. Medicare rules disqualify such people – patients receiving dialysis for example -- from receiving hospice care. Since stopping dialysis is rapidly fatal, these patients have nowhere to turn for treatment of their pain, breathing difficulties and non-clinical needs. Palliative care gives them an avenue.

- Palliative care is comfort care that can be provided in the home, hospital, nursing home or other settings. Hospice care is available primarily in the home. For some patients, that location may not be an option because their illness is too advanced or there are no caretakers in the home. Some communities have responded by building inpatient hospice facilities (Vermont Respite House in Williston is a widely praised example). But Vermont cannot afford to build such facilities in every community. It may be better for patients and more cost efficient for the health system to deliver this care within the existing infrastructure of hospitals and other health facilities.
- Patients who are not dying still need palliative care. Many people need better help with pain and emotional support during illness. Vermont's community hospitals, for example, have done excellent work in posting pain severity charts in emergency rooms, so patients learn that their pain matters and that pain relief is available.

The benefits of palliative care are proven by extensive published research. Foremost, people enjoy higher quality of life, regardless of whether or not the illness leads to their eventual demise. Pain is minimized, spiritual needs are met, isolation is reduced, and families are supported and aided.

Moreover, a growing body of evidence indicates that patients who receive palliative care live longer than those who do not. Although palliative care patients choose fewer interventions and less technology, they experience reduced stress, emotional concern and physical pain – all factors in longevity.

Meanwhile palliative care patients cost the health system less money. One hospital found the cost of care for the last two weeks of life of palliative patients was less than half that of ordinary patients (\$5,313 vs. \$12,319). Another hospital, whose service area includes portions of Vermont, measured reducing spending for palliative patients of \$700 per person per day.

Obviously the benefits of palliative care are far more than economic. With the objective of giving Vermonters a longer life of higher quality, palliative care reflects the proper goals of any health system: to educate patients and families so they can make informed decisions, to assure comfort as much as medically possible, to anticipate potential crises in order to prevent them, and to address non-medical needs as competently as medical ones.

Vermont has work to do, to increase access to palliative care, to achieve the cost reductions that palliative medicine makes possible, and to reduce preventable suffering.

Background and Vermont Legislative Efforts

Given what is known and largely accepted about the benefits of palliative care, efforts towards improvement have been the focus of national attention for the past several years, as well as the focus of the Vermont General Assembly.

In 2002, the Attorney General's issued a report highlighting how Vermont rated with respect to a range of end-of-life and pain criteria:

Attorney General's report (2002)

Criterion	Grade
Certification of medical professionals in palliative care	A
Hospitals reporting management/palliative care programs	C
Nursing home residents in persistent pain	C
State pain policies	D
Hospitals with hospice programs	D
State Advance Directive laws	F

The publication of this report mobilized Vermont policy makers to work with health care organizations, providers and interested individuals to make improvements in Vermont's statutes. This included the passage of:

- **Act 162 in 2004**, which combined the "Living Will" and "Durable Power of Attorney for Health Care" forms into a single "*Vermont Advance Directive for Health Care*" form. This statute also recommended a statewide form to be used for out-of-hospital Do-Not-Resuscitate (DNR) orders and orders regarding other life sustaining treatments (COLST form).
- **Act 25 in 2009**, which defined Palliative Care in Vermont as: "Interdisciplinary care given to improve the quality of life of patients and their families facing the problems associated with a serious medical condition. Palliative care through the continuum of illness involves addressing physical, cognitive, emotional, psychological, and spiritual needs and facilitating patient autonomy, access to information, and choice."

Act 25 also created a *Patients' Bill of Rights* for Palliative Care and Pain Management so that all patients would have the right to state-of-the-art pain management and explanation of all options at the end of life.

This legislation also required a detailed report on the possibility of concurrent palliative and curative treatment for children as well as more detailed reporting on deaths in Vermont. In May of 2010, the legislature included a provision in the SFY 11 appropriations bill requiring the Agency of Human Services to submit a waiver request to the federal Centers for Medicare and Medicaid Services (CMS), either as part of the Global Commitment for Health waiver renewal or as an amendment following renewal, to allow such a program to be implemented in Vermont. This work is currently underway.

In an effort to address the ongoing educational needs of providers, Act 25 required the Boards of Medical Practice and Nursing to issue a report regarding their recommendations for improving the knowledge and practice of health care professionals in Vermont with respect to palliative care and pain management.

Finally, Act 25 created the *Palliative Care and Pain Management Task Force*, to coordinate palliative care and pain management initiatives in Vermont; help people to gain access to services; and propose solutions for addressing gaps in services and educating consumers about their rights under the patients' bill of rights for palliative care and pain management.

Statewide Summit on Palliative Care and Pain Management

With the passage of Act 25 and the creation of the *Palliative Care and Pain Management Task Force*, the General Assembly requested that the Vermont Ethics Network (VEN) take the lead role in coordinating the initiatives of the task force. In an effort to more fully understand the structure of palliative care and pain management services throughout Vermont, VEN hosted *Paving the Way to Real Progress: A Statewide Summit on Palliative Care and Pain Management* on March 22, 2010.

The event drew over 100 professionals, community members and other stakeholders from across the state. It provided a unique opportunity for representatives and providers from Vermont's hospitals, nursing homes, home health and hospice programs to work with policy-makers, community members, and representatives from state and health related agencies on myriad issues related to palliative care and pain management.

Robert Macauley, MD, Director of Clinical Ethics and Pediatric Palliative Care at Fletcher Allen Health Care provided the keynote address. He presented a comprehensive overview of the current structure of palliative care and hospice services across Vermont. He provided a basic overview of what palliative care and hospice services provide, discussed trends over time and the evolution of services in Vermont. He reviewed data, addressed continuing medical education and pain management, and identified critical issues, including:

- Most physicians are unaware of the Patient Bill of Rights for Palliative Care and Pain Management
- Vermont is doing well with patients NOT dying in the hospital but relatively few dying patients use hospice services.
- Vermont has a wide distribution and availability of Home Health Agencies (HHAs), Skilled Nursing Facilities (SNFs) and hospice services for a rural state but the length of stay (LOS) in hospice is below the US average (57 days and 69 days respectively). Confirming the relatively low utilization of hospice in Vermont.
- Vermont physicians are generally confident in their skills (discussing palliative care, managing non-pain symptoms, using opioids to manage pain) according to the Vermont Board of Medical Practice (VBMP) Survey in 2009. Yet, a VEN Survey in 2009 identified insufficient provider education and training as a barrier and area for needed improvement.

- Supply and demand issues regarding treatment of pain were identified. Primary Care Providers (PCPs) send pain patients to pain specialists at the tertiary care center because of lack of time, infrastructure and training. Then pain specialists send patients back to PCPs because of lack of time, long-term relationship with the patient, and/or the need to use their limited time to focus on acute needs rather than chronic long-term needs. This leaves patients without adequate pain management and support.
- Lack of awareness and utilization of the Clinician Orders for Life Sustaining Treatment (COLST) form.
- Need for concurrent curative and palliative care for pediatric patients.

Following the keynote address by Dr. Macauley, a panel of speakers provided an overview of issues related to pain management. This panel consisted of:

- A pain specialist from the Center for Pain Management at Fletcher Allen Health Care, working in a tertiary care setting with patients who have acute pain needs.
- A primary care physician and pain specialist providing care in a rural primary care setting and addressing chronic pain needs.
- A representative from Vermont's Alcohol and Drug Abuse Program (ADAP), addressing issues of addiction, prevention and the prescription monitoring program.
- Two pain patients sharing their experience in obtaining pain management services in Vermont.

The morning concluded with a presentation by health care journalist Stephen Kiernan, who presented a four-point economic case for better end-of-life care.

- Recent Vermont data indicating that the majority of rising health care costs are due to excessive and inappropriate end-of-life care.
- State demographic trends revealing how these financial pressures are sure to increase, damaging Vermont's economy.
- National research and hospital models that show how benchmarks for palliative care and hospice can lower end-of-life care costs by up to 80 percent.
- Brand new findings for hospitals serving Vermont, upstate New York and New Hampshire that reveal how palliative care patients lower health care costs. One hospital found that palliative care inpatients cost \$700 less per patient per day.

Kiernan's presentation noted that these dramatic savings were not achieved by denying care or using gatekeepers to reduce clinical interventions, but rather by educating patients about the higher quality of care possible through palliation and hospice. He also provided evidence of a major insurer and other for-profit care providers, outside of Vermont, who are embracing these care models purely for the financial advantages.

The afternoon portion of the day was broken out into four different sessions and participants chose one session to attend. The sessions were:

1. Community Education and Awareness
2. Provider Training and Education
3. Issues of Access
4. Reimbursement, Coordination of Care and Other Systems Issues

Each session focused on what was currently available and working well and where the barriers existed. Preliminary recommendations were presented to the Vermont Legislature in April of 2010.

Overview of Palliative Care Services throughout Vermont

In preparation for the Summit, and to begin the process of understanding the availability of palliative care services across Vermont, the Palliative Care and Pain Management Task Force prepared and distributed a survey. The survey was sent to Vermont hospitals, home health and hospice agencies, nursing homes, and insurers, as well as private individuals with an active interest in end-of-life care, and the Dartmouth Hitchcock Medical Center. Ten hospitals, eight home health and hospice agencies, one private practitioner, one private nursing agency, and twenty nursing homes responded to the survey.

Results of the survey indicate that palliative care, hospice care, and pain management, are offered to Vermonters in a variety of settings. However, while not a comprehensive study, the information gathered also indicates inconsistency in the availability of options depending on where a person lives in the state. Focused efforts directed at improving standards of care in all regions of the state will be necessary in order to ensure that Vermonters are aware of and have access to the highest quality care possible, regardless of where they live. A centralized database where all Vermonters can seek information about available services and resources in their area will also be important. Organizations such as the Madison Deane Initiative, the Hospice and Palliative Care Council of Vermont, the Vermont Ethics Network, Area Agencies on Aging, Hospitals and Home Health and Hospice Agencies can serve as resources for Vermonters dealing with end-of-life issues.

In a rural state like Vermont, we are fortunate to have two tertiary care centers, in addition to our local community hospitals and other health systems that serve to meet the palliative, pain, end-of-life care health care needs of Vermonters. Both Fletcher Allen Health Care and Dartmouth Hitchcock Medical Center offer extensive palliative care services:

- Fletcher Allen Health Care's Palliative Care service has three palliative care certified physicians and two palliative care certified advance practice nurses. They offer a 24 hours a day, seven days a week palliative care hotline, a palliative care mentorship program for visiting nurses and physicians, site visits to community hospitals in the region and in upstate NY to provide palliative care education, and palliative care telemedicine consultation for outlying rural hospitals.
- Dartmouth Hitchcock Medical Center's Palliative Care Service is an interdisciplinary team made up of Palliative Medicine specialist physicians and nurse practitioners, along with a social worker, a pastoral care provider, complementary therapists and community volunteers. This service is available 24 hours a day, seven days a week for consultations with both hospitalized and home based patients. In addition, outpatient appointments are available throughout the week at DHMC.

The Madison Deane Initiative (MDI) has created a website to help Vermonters find information about services to assist with care at end-of-life. The *Vermont Palliative and End-Of-Life Care Resource Connections* can be found at www.vtpcrc.org. MDI's mission is to transform end-of-life care through education, collaboration and inspiration. The initiative serves as the educational arm of the VNA's End-of-Life Care services and was created in 1997 to educate the general public and medical professionals about quality care at the end-of-life. (www.vnacares.org/services/end-of-life-care/madison-deane-initiative)

The Hospice and Palliative Care Council of Vermont (HPCCV) is a non-profit, membership organization of hospice programs, volunteer hospices, and palliative care programs. The mission of this organization is to support hospice and palliative care with educational opportunities, peer meetings, and to be a community resource. The Annual Conference in June draws over 200 people from around the region with excellent speakers, workshops, and networking opportunities. (www.hpccv.org)

The Vermont Ethics Network (VEN) is a local non-profit organization that is dedicated to the advancement of ethical decision-making in health care. Their mission is to promote ethics as a core component of health care and health care decisions for individuals, clinicians, health care organizations, and the larger community. (www.vtethicsnetwork.org)

Survey Summary of Current Structure

Hospitals –

The ten Vermont hospitals who responded to the above survey reported a wide range of Palliative Care and Hospice services. Four hospitals state that they have physicians and/or nurses certified in palliative and hospice care, while the remaining hospitals are supported by local physicians or hospitalists with an interest in palliative and end-of-life care. While some of these hospitals reported that they have formal palliative care teams, others reported that their ethics committee served in this role, and still others used certified nurse's or standardized protocols to guide patient treatment plans. Palliative care teams consist of chaplains, social workers, physical therapist, home health and hospice representatives, and inpatient nurses and providers. At Fletcher Allen Health Care, the pediatric palliative care team also includes the child life specialist. Additionally, one hospital states that comfort care includes standardized orders; a nursing care plan; a private room; handmade quilts; comfort lighting and seating. Three of the hospitals reported being part of community-wide initiatives that include nursing homes, assisted living facilities, and local home health and hospice agencies working together.

Nursing Homes –

Forty nursing homes were surveyed by the Vermont Health Care Association, of the twenty that responded to the survey, 15 have hospice contracts, but all indicated having their own end-of-life programs in place as well. End-of-life care in these nursing facilities is tailored to the needs of the individual resident and their family. Many of the facilities have dedicated end-of-life rooms. Facilities who responded to the survey were consistent in offering pain management; massage therapy; emotional and spiritual supportive services; one-on-one companionship; music and aromatherapy; food, beverages and personal care amenities for family; private rooms for families when available, recliners for families; and remembrance

programs to assist staff and families with the grieving process, including facility memorial services, staff journals reflecting on the resident, and photos of the resident.

Additionally, seven of fifty eight residential care home members responded to the survey. These homes all have hospice contracts.

Home Health and Hospice Agencies –

Eight Home Health and Hospice Agencies responded to the survey on palliative care and pain management. Of those agencies responding, four reported having nurses and nursing assistants certified in palliative and hospice care. Half reported that they use an interdisciplinary team to support their patients. These teams consist of chaplains, social workers, physicians, nurses, physical therapy, and music therapy. The majority of the agencies report working closely with their local hospital to improve continuity of care for the patients they are serving.

Recommendations

Based on information gathered at the Summit, through surveys and during focus groups, it is clear that good work is happening across the state to address the increasing palliative care and pain needs of Vermonters. However, it is also clear that more work and attention to address gaps and barriers in services is still needed. Increasing the number of physicians and nurses trained and certified in hospice and palliative care would represent a positive step toward ensuring that access to expertise is available in every region of the state. Other recommendations that emerged include:

General Recommendations:

1. Expand the Palliative Care Case Consult Teleconferences offered by Fletcher Allen Health Care so that all Vermont hospitals, home health agencies, etc. can have access.
2. Support primary care providers in discussing advance care planning needs and completing advance directives with patients prior to life threatening disease/illness.
3. Develop improved systems for managing the chronic pain patient in the primary care setting (team approach).

Specific Recommendations:

1. Develop community education tools (i.e. Palliative Care Tool Kits, etc) and educational campaigns to improve public awareness about advance care planning, hospice and palliative care, etc.
2. Continue with quarterly broadcasts on *Across the Fence* through WCAX television (on topics of advance care planning, end-of-life, hospice and palliative care, etc).
3. Provide annual education programs to educate all health care providers about end-of-life care and pain management issues (i.e. Paving the Way to Real Progress: A Statewide Summit, March 2010).

4. Create opportunities for annual meetings/conferences for hospice, palliative care and pain management providers within Vermont for ongoing training, and to discuss current best practices, challenges, etc. This would include rural providers connecting with larger programs to share successes, challenges and exchange resources.
5. Provide opportunities for multi-institutional regional meetings via video or teleconference to allow providers in different settings (primary care, specialists, hospitalists, nursing home staff, home health staff, etc.) to meet to discuss needs and challenges and access expertise.
6. Expand case management services by providers trained in end-of-life care, for people with life threatening disease/illness.
7. Support and encourage policy improvements at the federal and state level which would expand access to hospice and palliative services. (i.e. participating in the national hospice demonstration project eliminating the six month prognosis and no curative care criteria for hospice eligibility, increasing the per diem rates for hospice care, elimination of “homebound” requirement for palliative care, pediatric waiver, etc.)
8. Improve systems for both consumers and providers to access information about available resources. (websites, list-serves, blogs, etc.)

Future Considerations:

1. Implement a volunteer program for in-patient palliative care patients.
2. Explore use of palliative care advisory councils.
3. Explore best methods for ongoing education in palliative care and pain management for physicians and nurses.

Conclusion

The Palliative Care Task Force is deeply committed to continued work in the area of palliative care, end-of-life care and pain management for all Vermonters. We have summarized the work completed during the first statewide summit in Vermont and plan to partner with other organizations to offer programming directed at improving quality of care for patients with life-limiting and chronic illness, and to address needs and gaps in services on an annual basis. The median age of Vermonters today is 37.7 years old, so many Vermonters will become part of the over 65 age group in the coming years.

What we know is this: In 2006, health care expenditures exceeded \$2 trillion dollars and are expected to rise drastically in the next decade. A disproportionate share is spent on end of life services. Thirty percent of Medicare expenditures are attributable to 5% of the beneficiaries who die each year. About one third of those expenditures occur in the last month of life (Zhang et al, 2009). The literature suggests that the majority of these costs are due to mechanical ventilator use and resuscitation. Acute care costs in the final 30 days of life account for 78% of costs incurred in the final year of life (Zhang et al, 2009). In truth, these figures are disturbing.

We do know that 70% of Americans state that they would like to die at home and yet only about 25% actually do. Hospice and palliative care services can be instrumental in promoting a more peaceful and dignified end-of-life experience through expert symptom control, and by providing services that address the emotional, social and spiritual aspects of care. The founding principles of hospice and palliative care center on comfort, and meeting the patient's and families needs.

Given the aging of America, with projected dramatic increases in the number of older Americans (by 2030 approximately 19% of all Americans will be over the age of 65), it is imperative that we examine both current practices in palliative care, chronic care and pain management and that we begin planning for the future. It is projected that the increase in the number of older adults will be coupled with an increase in need of services.

Currently, with the efforts dedicated to health care reform, it is an opportune time for Vermont to take a proactive approach at addressing the palliative and end-of-life care needs of its citizens. Expanding eligibility of the hospice benefit by removing the six-months or less eligibility requirement, and allowing for concurrent life-prolonging and palliative care would be a necessary and important step in increasing access to these essential services.

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