Vermont Hospice Study Report

November 10, 2015

Prepared for:

Visiting Nurse Association of
Chittenden and Grand Isle Counties
Madison-Deane Initiative

FMI contact:
Elise J. Bolda, PhD
elise.bolda@maine.edu
Eliza Eager
eliza.eager@maine.edu

UNIVERSITY OF
SOUTHERN MAINE
Muskie School of Public Service

Table of Contents

This report was made possible by the contributions of the many providers and community members who participated in this study, the Vermont Hospice Study project management team and advisory committee, and our colleagues at the Muskie School.

Table of Figures

Recommended citation:

Bolda EJ, Eager EP, Werneke C, Wright C, Bean A, Richards M, Keller J, Ciolfi ML, Veller K, Thorpe N. Vermont Hospice Study Report. Prepared for Madison Deane Initiative of the VNA of Chittenden and Grand Isle Counties and the VNAs of Vermont by the Muskie School of Public Service, University of Southern Maine. Portland, ME. November 10, 2015.

Introduction

In Vermont, hospice use is particularly low. National Medicare hospice utilization trend data through 2012 indicated that Vermonters were less likely to use hospice services than residents of other states, and they used fewer days of care.

To explore more deeply why the hospice use rate in Vermont is among the lowest in the nation, the Visiting Nurse Association (VNA) of Chittenden and Grand Isle Counties' Madison-Deane Initiative commissioned the Vermont Hospice Study, with support from the VNAs of Vermont and Coverys Community Healthcare Foundation. The Madison-Deane Initiative is a program to transform end-of-life care through education, collaboration and inspiration.

This study was guided and overseen by a Study Advisory Committee (for a list of committee members, see Appendix A: Vermont Hospice Study Advisory Committee) that included physicians, hospice agency staff, policy makers, consumers, and faith communities. Committee members from diverse backgrounds and regions of Vermont were recruited to include perspectives on local cultural norms and healthcare.

This report presents findings from the six-month Vermont Hospice Study conducted between April 1 and September 30, 2015.

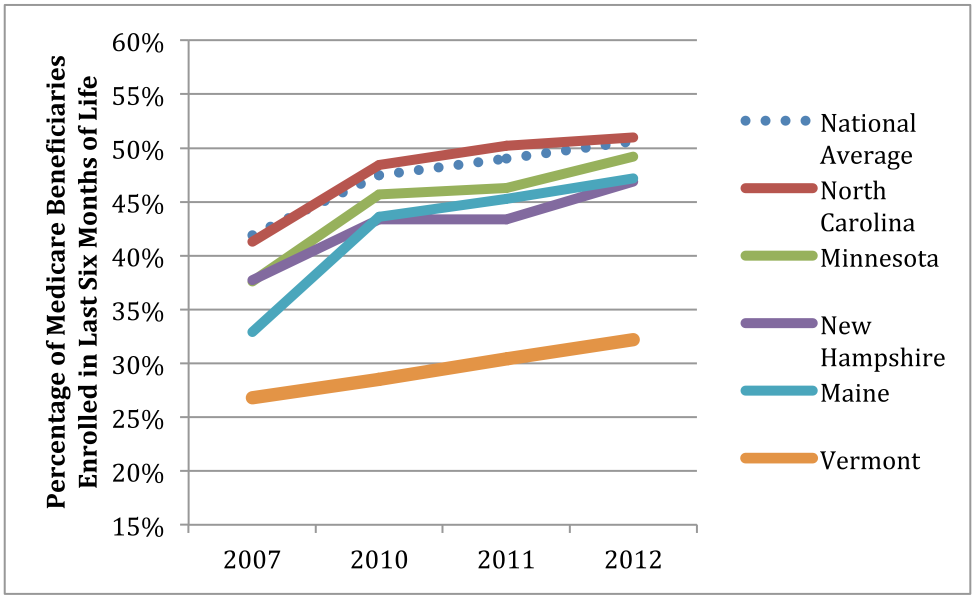
The Study began with a review of the literature to inform the development of the research questions, and methods. The Study questions formulated following review of the literature and secondary data, and discussion with the Vermont Hospice Study Advisory Committee were:

1. Is hospice use lower in Vermont due to reluctance of health care professionals to refer patients to hospice?
2. Is utilization of hospice in Vermont lower than in other states due to lower rates of hospice use by residents of nursing homes and assisted living facilities?
3. Is Vermont's relatively low utilization of hospice attributable to rate of deaths due to malignant neoplasms, chronic lower respiratory disease, and Alzheimer's disease that are higher than the national average?
4. Is Vermonters' utilization of hospice low because informal caregivers (family, friends, neighbors, etc.) lack confidence and are not prepared to give end-of-life care?
5. Are lower hospice use rates a function of the practices of Vermont hospice providers?

Background Data

While Vermont was an early adopter of hospice, use rates have been substantially lower than in other states for well over a decade. Vermont has seen little growth, in contrast to other low use states as shown in Figure 1: Hospice Enrollment Trends 2007-2012.[1] Vermont hospice use rates have remained low, unlike other northern New England states, Maine and New Hampshire, and other largely rural low hospice use states like North Carolina and Minnesota, where hospice use has increased.

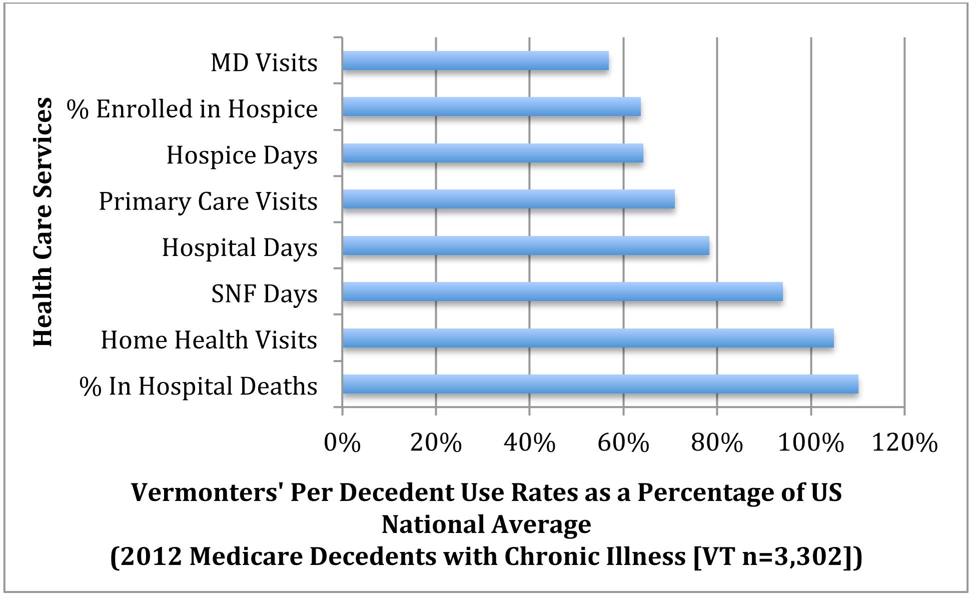
Figure 1: Hospice Enrollment Trends 2007-2012



Source: Dartmouth Atlas of Healthcare

Vermont Medicare beneficiaries' use rates of several other services in the last year of life were also below the national average. Notably, however, there were two areas in which use rates were higher than the national average: home health visits and hospital deaths, as can be seen in Figure 2: Vermonters' Use of Medicare Funded Services in the Last Year of Life, Compared with US Average (2012).[2]

Figure 2: Vermonters' Use of Medicare Funded Services in the Last Year of Life, Compared with US Average (2012)



Source: Dartmouth Atlas of Healthcare

Background Literature

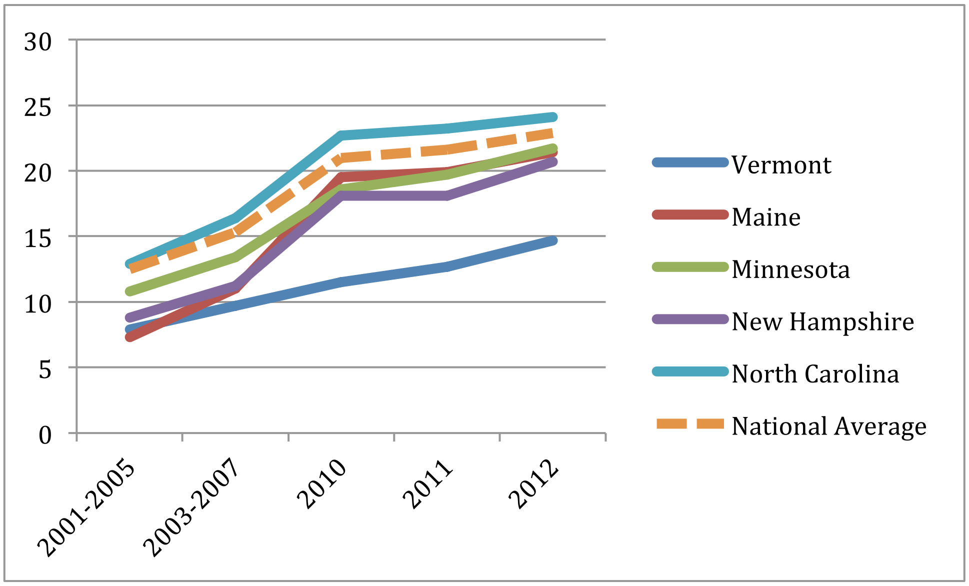
The national literature was reviewed to inform the development of research questions for this study, and to identify national trends for assessment of their effect on hospice use in Vermont.

In 2002, Last Acts reported that not quite fifteen percent of Vermonters used hospice, ranking Vermont fifth lowest in rate of hospice use by those aged 65 or older.[3] Twenty years later, hospice use by Vermont Medicare beneficiaries remains low. The 2012 Dartmouth Atlas of Health Care data placed Vermont sixth lowest among states in Medicare beneficiaries who died while enrolled in hospice in 2012 (32.3 percent of Vermont decedents compared with the national 2012 average of 50.6 percent).[2]

Vermont was an early Medicare Hospice demonstration state in the 1980s. Notably, Vermont had 100 percent coverage by Medicare certified hospice providers across the entire state before other rural states as early as 2006.[4] While other states with historically low hospice use rates increased hospice use in recent years, Vermont has persistently shown low rates of hospice use as depicted in Figure 1: Hospice Enrollment Trends 2007-2012. Maine, which had lower use rates than Vermont in 2003, saw a relatively steep increase in hospice use during the same period.

A similar pattern is evident in Figure 3: Hospice Days Per Decedent During the Last Six Months of Life. Maine and other states saw increasingly rapid growth in hospice use rates starting in 2001, while growth in Vermont has remained relatively flat, as depicted at the bottom of this chart.

Figure 3: Hospice Days Per Decedent During the Last Six Months of Life[5]



Source: Dartmouth Atlas of Healthcare

Maine's shift from ranking very low in hospice use to its current substantial hospice use rate was the result of research and intervention efforts framed in Fralich, Lenardson & Skillings' "A Review of the Literature on End-of-Life Care: Setting a Research Agenda for Maine" which, though now dated, identified many factors Maine and Vermont share.[6]

In general, rural residents nearing death use hospice less frequently than their more urban counterparts, even when controlling for access.[7] Many studies have examined rural access issues without examining other factors affecting utilization in non-urban areas. One study found geographic variation in end-of-life care to be influenced by factors including availability of medical resources and practice styles of local practitioners.[8] Greater distance from a hospice may impede the diffusion of knowledge about hospice in isolated communities and thereby reduce utilization.[9]

Estimation of the impact of hospice use on public spending has become more complex with increasing use and longer enrollments. Among Medicare decedents, evidence of Medicare savings for short stay hospice decedents persisted. Medicare savings varied by diagnosis and length of stay; however, there was some evidence that overall Medicaid expenditures may have been higher for hospice users compared with non-hospice users.[10] Research focusing on patients with poor prognosis cancers found significant savings among those who used hospice compared with similar hospice non-users.[11] Expenditures for heart failure patients were higher among hospice users than among non-users, though heart failure hospice users' rates of hospitalization and ICU use were lower.[12]

How and Where are Vermonters Dying?

Most Americans prefer to die at home. Enrollment in hospice service improved the likelihood of fidelity to patients' wishes regarding where they will die.[3,8,13,14]

According to the Vermont Department of Health, 5,500-5,600 deaths occur each year in Vermont. In 2009-2010 29 percent of Vermonters received hospice care in the last 30 days of life, increasing in 2011-2012 to 35 percent and up again slightly in 2013-2014 to 38 percent. The Vermont Department of Health reported a *decreasing* trend, 2009-2012, with the number of Vermonters who received hospice care and died at home shrinking from 59.3 percent in 2009-2010 to approaching 51.9 percent in 2011-2012. This rate was almost unchanged in 2013-2014, at 51.8 percent. At the same time, the percentage of Vermont deaths in nursing homes of people enrolled in hospice in the last thirty days life grew from 17.0 percent in 2009-2010 to 25.2 percent in 2011-2012, and 25.6 percent in 2013-2014.[15,16] Unfortunately, there may be significant limitations both to these data and to the reporting as the reporting systems changed during the report years.

Referral and Practice Patterns

Studies show an association between provider discussions regarding end-of-life care plans and hospice enrollment.[17,18] Hospice enrollment policies[19] and nursing home staff attitudes toward hospice[20] and facility practice patterns[21] affect enrollment as well.

Tupper (2007) found that referrals to hospice were "fragile systems of communication, fraught with miscues, missed understandings and missed opportunities."[22]

Bischoff, Sudore, Miao, Boscardin & Smith (2013) found that advanced care planning 1) increased the likelihood of hospice use, 2) decreased the likelihood of an in-hospital death, and 3) increased the likelihood of hospice stays longer than 3 days.[23] And, Mack, Cronin, Keating et al. (2012) reported that physician/patient discussions about end-of-life care were associated with increased likelihood of hospice use by cancer patients.[18] At the same time, Freund et al. (2012) reported that hospice discussions were documented for fewer than 15 percent of hospice eligible patients in 2009 at a tertiary care, academic medical center.[24] Most patients had met criteria for hospice enrollment as documented at a previous hospital admission during the year prior to the terminal admission. The authors concluded with discussion of the need for education of physicians to improve their recognition of terminal decline. Bernacki & Block (2014) provide an in depth review of best practices in physician communications regarding serious illness.[25]

Scheffey, Kestenbaum, Wachterman et al. (2014) found that among hospice users, those with clinic-based palliative care involvement prior to hospice enrollment had longer hospice stays (24 days) as compared to hospice users without a preadmission palliative care encounter (14 days).[26]

Zheng, Mukamel, Caprio & Temkin-Greener(2013) found that both nursing facility end-of-life care practices and patient characteristics influenced rates of hospice use. Facilities that were more likely to hospitalize patients were less likely to utilize hospice and were also likely to enroll patients in hospice closer to the time of death.[21]

Collaboration

Munn (2012) reported on focus groups for three different end-of-life process participants: patients, decedents' family members, and nursing facility staff (licensed, paraprofessional and social work). Munn (2012) found that hospice care contributed to improved end-of-life care. These focus group participants acknowledged that barriers to collaboration exist, however, all concurred that nursing facility and hospice collaborative models should be supported.[27]

Nursing home staff surveyed about their experience working with hospice patients reported that hospice made their jobs easier, was needed, and was appreciated by patients and families.[28]

Collaborative models for nursing home hospice care were widely reported, including discussions on models,[29] and methods for improving collaboration.[30]

Awareness

Cagle, Van Dussen, Culler et al. (2014) found that about 15 percent of randomly selected adults surveyed had not heard of hospice, and that of those, more than 20 percent had misperceptions about eligibility, coverage, hospice in nursing homes, and for people who live alone. Greater knowledge about hospice was associated with more favorable attitudes toward hospice. In an earlier pilot study of respondents recruited through area churches, all respondents (aged 43-85+) had favorable opinions about hospice, however, older respondents were more likely to see hospice enrollment as "giving up", while younger respondents were more likely to see hospice as a valuable service.[31]

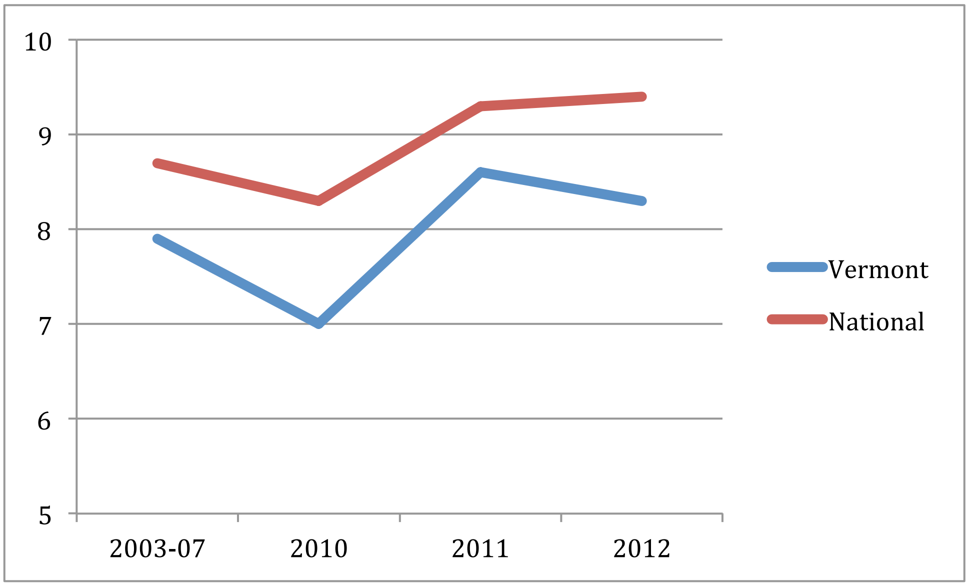
Hospice was perceived to be for the actively dying, significantly delaying, if not precluding, patients availing themselves of hospice benefits.[32]

Patients were not lone decision makers: one study found that 49 percent of family caregivers reported that their (dying) relative was not involved in the decision to enroll in hospice.[33]

Vermont Hospice Use Compared to National Rates

As noted above, Vermonters' use of hospice was among the lowest of all states, in both the number of Medicare decedents enrolled in hospice (2012 Vermont rate: 32.2 percent; 2012 US rate: 50.6 percent) and in days of hospice care (2012 Vermont: 14.7 days; 2012 US: 22.9 days).[2] In 2012, the hospice use rate during the last month of life among Vermont cancer patients, 47.1 percent, was somewhat higher than the rates for other diagnoses, but it was still substantially below the national average, 63.1 percent hospice enrollment rate for decedents with cancer. While the national average hospice use rates grew between 2007 and 2010, Vermont's rate declined slightly, although this trend in Vermont reversed by 2012.[34] As seen in Figure 4: Hospice Days Per Cancer Patient During the Last Month of Life, hospice use by cancer patients during the last month of life generally followed national trends.

Figure 4: Hospice Days Per Cancer Patient During the Last Month of Life[35,36]



Source: Dartmouth Atlas of Healthcare

Hospice Growth

There is considerable research on the growth of hospice, and particularly the increase in proprietary hospice providers entering the market.[37] Miller, Lima, Gozalo & Mor (2010) observed a doubling in average lengths of stay, and a marked increase in hospice enrollment by patients with non-cancer diagnoses, in their analyses of data from 1999 to 2006. In addition to longer stays, Sengupta, Park-Lee, Valverde, Caffrey & Jones (2014) observed other differential use patterns among proprietary providers as compared to non-profit hospices.[38] Proprietary providers were also found to serve more patients in nursing homes and assisted living facilities, and to have more live discharges than did non-profit hospice providers.[39]

Questions about the impact of type of ownership on quality of hospice care are emerging in the literature. For example, one study found that hospice providers that cared for more patients in nursing homes had lower staff to patient ratios than their non-profit counterparts.[40]

While the supply of hospice providers in Vermont has virtually doubled with the arrival of Bayada Home Health Care, the provider landscape has changed far less in Vermont than nationally. There are now two home health service providers in Vermont, with one non-profit and one for-profit provider serving each community. This growth, and the introduction of a proprietary provider, is a considerably less pronounced market shift than the dramatic changes in the national market. Nationally, the number of hospice providers has tripled, and the supply of for-profit providers has exceeded non-profit providers for nearly ten years.[41]

There is still no clarity in the literature on the effects of the addition of competitive hospice interests nationally.[42] Hunt (2014) provided an excellent review on topics including: growth and change in the hospice industry, aligning reimbursement with resource use, and payment system vulnerabilities. The authors concluded that while there was evidence of higher profitability among proprietary hospices relative to non-profit hospices, proprietary hospices also served more non-cancer patients who have been shown to have longer stays in hospice, and commented that in the absence of further research, it was premature to draw conclusions about quality of care.[42]

It is also too early to assess any impact attributable to the addition of competitive hospice interests in Vermont. Regardless of ownership trends, indicators associated with quality of end-of-life care bear watching. In contrast to national trends, in 2012 Vermont had an uptick in Medicare decedent hospital deaths, admissions during the last six months of life, days of hospital care and numbers of decedents admitted to intensive care units.[2] See Figure 1, Hospice Enrollment Trends 2007-2012. For the period 2003 to 2010, enrollment and days of hospice care per Medicare decedent in Vermont remained relatively flat, at or below national averages and appeared to shift in directions that follow national trend lines.[43]

A brief case study of hospice care in rural Maine suggests that the introduction of competition from for-profit providers can have a dramatic impact on small rural non-profit provider services. In Waldo County, the non-profit hospice provider’s average census is one-quarter of pre-competition, and referrals from area nursing homes have “dried up”.[44]

Researchers have made it clear that while investigation and policy debate is underway, it is important to remember that Medicare beneficiaries in nursing homes and those with dementia face complicated end-of-life experiences, unknown end-of-life trajectories, and pain that can be ameliorated with hospice supports.[42,45,46] For Vermont, the limited growth of hospice providers suggests that opportunities for increasing end-of-life care options for nursing home residents and persons with dementia may remain.

Hospice Care among Decedents with Specific Diagnoses

Hospice use varies by diagnosis. Some diagnoses make patients more, or less, likely to enroll in hospice, and to enroll earlier or later in the trajectory of their disease. Of interest for this assessment are diagnoses that predispose patients to under-use of hospice services due to either limited or late enrollment in hospice. Examples include patients with hematologic malignancies,[47] those with prostate cancer[48] and ovarian cancer[17] who have been found to be at increased risk for late referral to hospice, and those patients with heart failure who are eligible yet less likely to enroll than others.[49]

Aldridge, Canavan, Cherlin & Bradley (2015) found patients with non-cancer diagnoses to be the fastest growing sub-population of hospice users, with more than half having either short stays (7 days or less) or very long stays (180 days or more).[50] Among nursing home residents who used hospice, those who experienced longer stays were found to be equally likely to have cancer or non-cancer diagnoses, which lead the authors to recommend caution in policy change on nursing home hospice due to prognostic difficulties for nursing home residents.[51]

1 - Dementia

There has been a notable increase in hospice use by residents of nursing facilities with advanced dementia, though considerable variability was noted among states.[52] While dated, data from this research placed Vermont fourth lowest among states in hospice enrollment of this population, and second highest in the percentage of such residents with hospice stays of seven or fewer days.[52]

Among mortality follow-back survey respondents who were next of kin to decedents with dementia as cause of death, fewer unmet needs and higher quality of care was reported by families of hospice-enrolled decedents as compared to families of non-hospice decedents. Among these dementia decedents, those with nursing facilities stays were more likely to die in hospital, and were less likely to use hospice.[46] Skilled nursing facility residents with dementia who were hospice enrollees were less likely to die in hospital than non-hospice nursing facility residents with dementia.[53]

2 - Other Diagnoses

Nationally, hospice use by patients with non-cancer diagnoses grew significantly faster than hospice use by cancer patients 2000-2010. Use of hospice with primary diagnoses of mental disorders grew 327 percent, circulatory system 192 percent respiratory system 125 percent, and ill-defined conditions 501 percent.[50] During the same interval, hospice use with a primary diagnosis of cancer increased only 31 percent.[50]

Patients with some diagnoses were found to be generally under-referred to hospice, including prostate cancer,[54] hematologic cancers,[47,55] and heart disease.[12,49,56,57] In general, patients whose diagnoses had longer expected trajectories to death, and whose survival time was more difficult to predict, tended to be under-referred to hospice. Welch, Miller, Martin & Nanda (2008) found that the perception of uncertain prognosis delayed referral to hospice.[20]

According to the Center for Disease Control and Prevention (CDC) in 2013, among decedents with chronic illness, the most frequent cause of death in Vermont was cancer (n=1,325), followed by heart disease (n=1,206), chronic lower respiratory disease (n=364), stroke (n=281), Alzheimer's disease (n=284), and diabetes (n=168).[58] The prevalence of these illnesses in Vermont, combined with low hospice use rates, and the challenges of the disease trajectories associated with these diagnoses suggest opportunities for improvement.

Prognostication

End-of-life trajectories vary by diagnosis. Most patients with diagnoses of cancer or stroke have relatively short hospice stays, while patients with diagnoses of heart or lung disease have longer stays, and those with debility and dementia diagnoses have the longest stays.[59] While the Centers for Medicare and Medicaid Services (CMS) no longer permits use of debility and some dementia diagnoses for hospice enrollment, there is considerable literature in support of hospice care for those with advanced dementias, highlighting in particular the pain management benefits of hospice.[45,46] Tools to help predict end-of-life prognosis for patients with advanced dementia have proven inadequate[60] and are recognized as an area for improvement.[61] A more in-depth review of prognostication tools for dementia and the palliative care needs of those with dementia can be found in Fulton, Rhodes-Kropf, Corcoran, Chau & Castillo (2011).[62]

Patient Reported Outcome Mortality Prediction Tool (PROMPT), a prognostic tool for older adults in declining health living in the community, is in development and reported promising results relative to existing tools.[63]

Nursing Homes

There was evidence of increased use of hospice among nursing home resident decedents in the literature; and there was evidence that nursing home practice patterns have impact on hospice use, with higher hospice use rates among nursing homes with more residents with dementia.[64] Nursing home residents receiving hospice care are significantly less likely to be hospitalized[65] or to experience in-hospital death than are non-hospice nursing home residents.[66]

Efforts to increase nursing home residents' awareness of hospice care among nursing home residents and their families began more than a decade ago. Assessment of one intervention that provided a hospice information visit to nursing home residents or their proxies found that those visited had lower hospitalization rates among decedents.[67]

Increased nursing facility staff awareness and knowledge of end-of-life care practices was shown to improve hospice referral rates.[20] Nursing home administrators' positive perceptions of hospice improved referral rates as well.[68]

Tyler, Leland, Lepore & Miller (2011) found that nursing homes did not substitute hospice visits for regular staff time, but rather that CNA staffing rates increased with facility use of hospice.[69]

Hospice enrollment was found to improve pain assessment and management for nursing home residents at the end-of-life.[45] Research on nursing facility residents with advanced dementia found that those who elected hospice were more likely to receive pain management supports and were less likely to have unmet needs during their last week of life.[70] Tools to assist with observation and interpretation of patients' pain management needs are in development to help improve the end-of-life experience for nursing home residents with advanced dementia.[71]

In considering hospice use and nursing home residence, it is important to bear in mind that hospice patients are served in multiple settings. Patterns of use by people served only in home or only in nursing homes are distinctly different from patterns of use by those who transition from home to nursing facility. Hospice stays among patients transitioning from nursing home to home are shorter and likely reflect residents returning home with hospice very near death.[72] These varying needs illuminate the complexity and bi-directional nature of potential collaborations between hospice and nursing homes.

In 2012, the average number of days of care Vermont Medicare recipients in the last year of life received in skilled nursing facilities (SNF), 9.4 days, was below the national average of 10 days.[2]

Vermont's lower than national average SNF bed to decedent ratio (Vermont 54.9 beds/1000, US 59.2 beds/1000) may constrain access to care for persons at the end-of-life.[2] Conversely, declining nursing facility occupancy rates may increase the potential for collaboration between hospice and nursing facilities.[45] While the days of SNF per decedent in Vermont suggests opportunities for improvement in end-of-life care for nursing home residents, additional information is needed to ascertain whether the bed supply per decedent constrains options for greater use of nursing homes as a location of care for persons enrolled in hospice who need respite or inpatient care. Interpreting the net effect of these dynamics and potential for collaboration in Vermont will best be informed through dialog with hospice, residential care, and hospital providers.

A more exhaustive review of the literature on challenges associated with bridging the junction between hospice and residential long term care settings (nursing homes and assisted living) is found in Huskamp, Kaufmann & Stevenson (2012) "The Intersection of Long-Term Care and End-of-Life Care."[73]

Federal Policy Changes Shift Nursing Facilities' Incentives

The Affordable Care Act passed in 2010 included considering charging both hospitals and nursing facilities penalties for patient readmission to acute care within 30 days of discharge. Implementation of these hospital readmissions penalties is underway.

As a result of federal penalties, hospitals and accountable care organizations are establishing closer relationships with post-acute and long-term care partners. Similarly, nursing facilities also now face pressure to enter into such relationships: Medicare Payment Advisory Commission's (MedPAC) 2017 target date for implementation of nursing home readmissions penalties draws near.

Hospital readmission penalties target select heart and lung diseases for particular scrutiny. This is not surprising as patients with lung disease were found to be more likely to have an acute hospital admission,[74] and hospice enrollees with heart failure diagnoses were more likely to be re-hospitalized than were hospice enrollees with cancer.[56] Compared with cancer patients, heart failure patients using hospice were also more likely to enroll within three days of death.[56]

Hospital Use

Hospice providers that do not have inpatient/residential hospice beds under contract are faced with challenges when meeting patients' needs for general inpatient (GIP) level care. Absent nurse staffing to cover the care need at home, or the possibility of transfer to an inpatient hospice, agencies can be faced with discharging patients who turn to hospitals for emergency care.[75] Vermonters living in areas with smaller hospice providers may be at increased risk for this unintended consequence of hospice enrollment.

From 2010 to 2012, Vermonters in the last six months of life experienced increasing rates of hospital admissions and increasing days of inpatient acute care while the national average in-patient days decreased from 9.9 days in 2010 to 9.2 days in 2012. Specifically, in 2010 Vermonters used 6.6 days of hospital care in the last six months of life, and they used 7.2 days of hospital care in the last six months of life in 2012. [2] In contrast to decreasing national trends reported by Teno, Gozalo, Bynum et al. (2013),[76] in-hospital deaths among Vermonters increased from 2011-2012 and are now higher than the national average of 22.8 percent of Medicare deaths in hospitals.[34] Data for 2012 indicate that more than one-quarter of Medicare covered Vermonters died in hospitals (25.1 percent).[2] During this same period, dying Vermonters' use of intensive care/cardiac care (ICU/CCU) during their terminal admission also increased, though Vermonters' ICU/CCU use rate remained below the national average.[34]

Research suggests that access to general inpatient care (GIC or GIP) through hospice can be an important component of hospice care. One study found that 31 percent of late referrals to hospice require GIP level of care.[76] GIP care is also viewed as important to the quality of end-of-life care, and the absence of use of these services by enrollees of some larger hospice providers raises questions: "If a hospice of any decent size provides zero days of general inpatient care, I consider that suspect," Joan Teno, a researcher and clinician at Brown University who has spent most of her career studying the quality of care at hospices. "Sometimes patients need more help."[77]

According to a report from the National Hospice and Palliative Care Organization the level of GIP care provided by hospices increased from 2.7 percent in 2012 to 4.8 percent in 2013.[78] Chung & Burke (2012) wrote that the Office of the Inspector General (OIG) had planned a review of GIP care claims for hospice patients in 2013. The authors also reported finding that patients served by hospices in rural areas were more likely to use hospital services as hospice contract GIP beds and inpatient hospice options may not be available.[13]

In one study, more than three-quarters of hospice providers surveyed reported at least one hospice agency admission or retention policy that limited access to hospice care for patients with high-cost care needs.[19]

Post-Acute Care Trends

The trend toward higher hospital admission rates at the end of life in Vermont is not good news, but other statistics hold steady and are cause for Vermonters' pride: 30-day readmissions rates at 14.5 percent were seventh lowest among states and below the national average of 15.9 percent. Vermonters' readmission rates and emergency department visits have remained below the national average steadily since 2004. And, in keeping with best practice, Vermonters' rate of 30-day post-discharge visits with primary care providers is higher than the national average.[79]

Palliative Care and Hospice

Along with enviable post-acute care trends, Vermont achieved 100 percent access to hospital-based palliative care among hospitals with 50 or more beds by 2009.[80] Early research on the interaction between palliative care and hospice provided evidence of a positive association, by which hospice use and referrals increase with increased awareness, knowledge of, [67] and access to palliative care.[81] The growing interest in palliative care supported by patient-centered care planning, and other policy and practice changes have created a dynamic interface between hospice and palliative care. The magnitude and impact of this effect is difficult to assess due to the lag time between care delivery, access to data and in-depth research and analyses of related metrics.

Home Health at the End of Life

Vermonters' have a history of above average use of Medicare home health services during the last year of life. Data for the period 2001 through 2007 rank home health use by Medicare Vermonters in the last year of life as third highest among states, with average visits per decedent nearly double the national average during the period 2001 to 2005 (Vermont 12.0 visits; US 6.4 visits). By 2010, home health use in the last six months of life in Vermont had dropped to 8.8 visits per decedent, as the national average grew to 8.6 visits per decedent.[82]

Additional information from home health providers in Vermont is needed to shed light on the decline in home health use by decedents, and the nature of opportunities for improvement this convergence and counter-intuitive trend may afford.

Networks

The literature has yet to examine the interface between home- and community-based care providers, and their role in end-of-life discussions and in increasing awareness of hospice and palliative care. However, there are hints in the literature regarding the value of working with other home-based providers.[83] These community networks work with many of the most vulnerable older Vermonters and their families, including Choices for Care waiver participants. Findings from the 2010 focus groups convened to address barriers and approaches to improve access to hospice care in Vermont recommended changes in state policy to enable continued Choices for Care participation for hospice enrollees.[84] This policy change has been implemented; however, little is known about home- and community-based care agency staff awareness of this policy change or their familiarity with hospice and palliative care more broadly.

Findings from the Literature

Vermont's consistently low ranking by rate of hospice use among states poses a complex challenge for hospice supporters and providers in Vermont. Rural states which had low rates similar to Vermont's in the Last Acts Report in 2002 and in other early hospice use data have seen more growth in hospice use than Vermont. Several of these states are served in part by hospice providers that are among outliers subject to scrutiny by Centers for Medicare and Medicaid Services (CMS) and the Office of the Inspector General (OIG). These dynamics suggest that volume alone may not be the metric of central interest to hospice care providers, especially if quality end-of-life experience and appropriate use of services in keeping with patient preferences remain paramount, as they have long been in Vermont.

Accurate understanding of where and how Vermonters die may be complicated by the complex and unique infrastructure serving Vermonters at the end-of-life. Vermont has the unique Choices for Care 1115 waiver that now permits participants to remain in the program after enrolling in hospice. Medicare decedents in Vermont have a relatively high rate of use of home health services near the end-of-life.[2] Vermont is well along the path toward establishing a hospital based palliative care delivery network and has a fixed supply of hospice providers. Vermont is served by two leading academic medical centers that have both been reported to rank well and make progress toward quality end-of-life care, including relatively low acute care and ICU care use by decedents.[2] Vermont hospitals, more broadly, have a low readmissions rate relative to other states.[85] And, the state has a robust network of critical access hospitals and rural health centers, which may have an impact on hospice use and referral timeliness that was outside the scope of the research literature.

Research Questions

The literature and background data were presented to the Vermont Hospice Study Advisory Committee (see Appendix A: Vermont Hospice Study Advisory Committee Members). Following discussion with the Advisory Committee, five research questions were developed to guide this study:

1. Is hospice use lower in Vermont due to reluctance of health care professionals to refer patients to hospice?
2. Is utilization of hospice in Vermont lower than in other states due to lower rates of hospice use by residents of nursing homes and assisted living facilities?
3. Is Vermont's relatively low utilization of hospice attributable to rate of deaths due to malignant neoplasms, chronic lower respiratory disease, and Alzheimer's disease that are higher than the national average?
4. Is Vermonters' utilization of hospice low because informal caregivers (family, friends, neighbors, etc.) lack confidence and are not prepared to give end-of-life care?
5. Are lower hospice use rates a function of the practices of Vermont hospice providers?

To address the first four of these research questions on hospice utilization, research design focused on the perceptions of hospice among people engaged with end-of-life care and, potentially, referral to hospice. For the fifth question, to better understand the logistics of hospice referrals and utilization, information was gathered from Vermont hospice agencies as well as the sources listed above.

Methods

A mixed methods approach was used to address the five research questions, relying on both qualitative and quantitative data. Primary data collection included in person and conference call focus groups, web-based surveys, in-person and telephone interviews, and website analyses.

Community focus group participants were screened to include lay individuals having personal experience with a death in Vermont in the last five years. Professional focus group participants were screened to include hospice referral sources at patient transitions in and out of acute care. The web-based community survey was distributed to a convenience sample of self-selecting participants. The web-based professional surveys targeted four groups that make referrals to hospice: home health care and hospice staff; nursing home, residential care and assisted living staff (here referred to as residential long term care staff); hospital discharge planners; and Area Agency on Aging, Support and Services at Home (SASH), and Community Health Team staff (here referred to as Aging/SASH). Due to the nature of these sampling approaches, it is important to note that these findings are subject to selection bias and are therefore not representative.

The University of Southern Maine Institutional Review Board reviewed the proposed research and exempted the project from human subjects review because the study findings are not generalizable.

Information Sources

Data were collected from multiple sources with diverse perspectives, including: patient families, community members, direct care providers, hospitals, residential long term care, and health and human service agencies. Participant recruitment was the responsibility of the VNA of Chittenden and Grand Isle Counties (VNA research team), in partnership with the member agencies of VNAs of Vermont. The development of focus group protocols and survey instruments was the responsibility of the Muskie School research team with support from the VNA research team.

Focus Groups

Focus group participants were recruited by the VNAs and contacted by telephone and email to confirm availability and qualification according to study screening guidelines. Focus group protocols were substantively informed by findings from the literature, and included a scripted introduction including discussion of confidentiality and informed consent, definitions, questions and probes, and participant questionnaires. Two Muskie research staff participated in each focus group, one as facilitator and one as scribe. The sessions were recorded with the permission of all participants. Focus groups conversations were designed to last ninety minutes. Immediately following each session, Muskie research staff prepared a text record of the focus group conversation.

Community focus group screening criteria required participants to have experienced the death of someone close to them, with or without hospice in the past five years. Selection criteria excluded staff and volunteers with hospice organizations, and sought representation by gender, age and home ownership mirroring the population of Vermont. Recruitment for Community Focus Groups proved very challenging. Recruitment was successful in three of five regions of the state. Community focus groups engaged a total of 20 community members as noted in Table 1: Community Focus Group Participation.

Table 1: Community Focus Group Participation

Location	Participants
Montpelier	7
Burlington	9
Rutland	4
Total	20

Professional focus group recruitment criteria included hospice medical directors, primary care providers, hospitalists, palliative care champions, nursing facility medical directors, and hospital discharge planners. Seven of eight professional focus groups included hospice medical directors and hospitalists, six had palliative care champions, and all had nurses or social workers engaged in discharge planning. Several included nursing home medical directors and most had one or more other professionals. One additional focus group was more narrowly targeted to cancer care specialists.

Of the professional focus groups, five were conducted in person and four were conducted via conference call. Three in person professional focus groups had more participants than expected. The Brattleboro discussion was held at a regularly scheduled provider meeting; this group included both participants as recruited for in other groups, plus additional providers. One in person and two virtual professional focus groups had significant no-show rates. Table 2: Professional Focus Group Participation shows the distribution of the 82 professional focus group participants.

Table 2: Professional Focus Group Participation

Location – In Person	Participants
Montpelier	8
St. Johnsbury	11
Burlington	10
Rutland	5
Brattleboro	10 +(20)

Location - Virtual	Participants
Lamoille, Orleans, Essex	7
Franklin	2
Addison	4
Cancer Care	5

Surveys

Research staff at the Muskie School developed survey questions, integrating tools adapted from the literature.[31,86] All tools were pilot tested prior to administration. A 10-question series derived from the literature[31,41,86] was included in all surveys to assess awareness and knowledge of hospice. Survey data were collected from more than 1,400 Vermonters.

Due to the small number of responses for some questions, and to avoid possible misinterpretation, the smallest unit for reporting survey findings is multi-county region. The five aggregate regions are: Northeast Kingdom: Essex, Orleans, and Caledonia; Central Vermont: Orange, Washington and Lamoille; Champlain Valley: Grand Isle, Franklin, Chittenden and Addison; Southwest: Rutland and Bennington; and Southeast: Windsor and Windham. Sub-totals for both types of survey are provided in Table 3: Survey Respondents, by Region; county-level detail is provided in Appendix B: Survey Respondents by County.

Table 3: Survey Respondents, by Region

Region	Community Members	Providers
Northeast Kingdom	112	56
Central Vermont	232	63
Champlain Valley	483	188
Southwest	114	67
Southeast	119	70

Community survey respondents were recruited through hospice agency e-mail lists, community partner outreach (e.g. United Ways, American Association of Retired Persons, Chambers of Commerce, Alzheimer's Association, etc.), and Front Porch Forum postings. In addition, popular media aired news stories about hospice care and urged Vermonters to complete the online survey. As anticipated, community response rates were highest in the most populous counties and were very low in the most rural counties. Nearly 1,100 community members completed online surveys.

Provider survey respondents were recruited through state and local agencies and industry associations, with notes of encouragement from study advisory committee members. Four distinct, targeted e-surveys were disseminated to four professional groups, including: home health care and hospice staff; nursing home, residential care and assisted living staff (here referred to as residential long term care staff); hospital discharge planners; and Area Agency on Aging, Support and Services at Home (SASH), and Community Health Team staff (here referred to as Aging/SASH). See Table 4: Provider Survey Respondents.

Table 4: Provider Survey Respondents

Provider Survey Groups	Respondents	Total by Survey
Hospital Discharge Planners	(n=52)	52
Residential Long Term Care		57
Nursing Home Staff	(n=25)	(missing=1)
ResCare/Assisted Living Staff	(n=31)	
Aging/SASH	(n=103)	103
Home Health and Hospice		204
Health Staff	(n=79)	
Hospice Staff	(n=125)	

Interviews and Website Assessments

Muskie staff developed and pilot tested a semi-structured protocol for telephone interviews of 10 Vermont hospice agency directors including both non-profit agencies and Bayada. Question construction was informed by review of the literature, focus group discussions, and analysis. Most interviews lasted an hour. Interviewees were given the opportunity to provide opinions or share information beyond responses to the interview questions.

Semi-structured telephone interviews were conducted with nine state organization representatives from Vermont and comparison states. Interviews were conducted with: Hospice and Palliative Care Council Directors in Vermont, New Hampshire, and Maine; Vermont and Maine State Units on Aging; and Alzheimer's Association staff in Vermont, New Hampshire, Maine, North Carolina, and Minnesota.

In addition to interviews, the websites of hospice councils in Vermont, New Hampshire, Maine, North Carolina, and Minnesota were assessed. State hospice and palliative care website review identified the organizations' mission, number and array of educational and informational resources by audience, scheduled training events and conferences, number of staff, partner and development initiatives. For a complete list, see Appendix I: State Organizations, Websites.

Measures & Definitions

All web based surveys included a ten question series to assess respondents' knowledge of hospice modified from the Cagle, Van Dussen, Culler et al. (2014) 23-item knowledge of hospice test. This research was based on a telephone survey of community-dwelling adults living in the United States.[31] These questions included:

1. Anyone can request an evaluation for hospice enrollment. (True)
2. Hospice services are typically paid for by health insurance (True)
3. Hospice provides grief support to families. (True)
4. Hospice focuses on managing an individual's pain or other symptoms. (True)
5. Hospice must stop services if an individual lives longer than six months. (False)
6. Hospice provides medications, treatments, medical equipment, and supplies that are related to a patient's primary illness. (True)
7. Hospice staff is available by phone any time, day or night. (True)
8. People who live in nursing homes are eligible for hospice. (True)
9. Hospice is only for people who have a few days to live. (False)
10. A primary goal of hospice is to treat the emotional needs of the dying individual and their family. (True)

To establish common understanding and language about hospice and palliative care, definitions of both services were read to all professional focus group participants. These definitions were given as follows:

Hospice is a patient-centered philosophy of care that utilizes an interdisciplinary team of healthcare professionals to provide compassionate care including expert medical care, pain management, and emotional and spiritual support tailored to the patient's needs and wishes. Patients may receive care at their place of residence (including their private residence, nursing home, or residential facility), a hospice inpatient facility or an acute care hospital. A patient is eligible for hospice care when a physician determines that the patient has six months or less to live if the terminal illness runs its normal course. (Modified from: *National Hospice and Palliative Care Organization.)*

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment. (Modified from: *Center to Advance Palliative Care.)*

Analysis

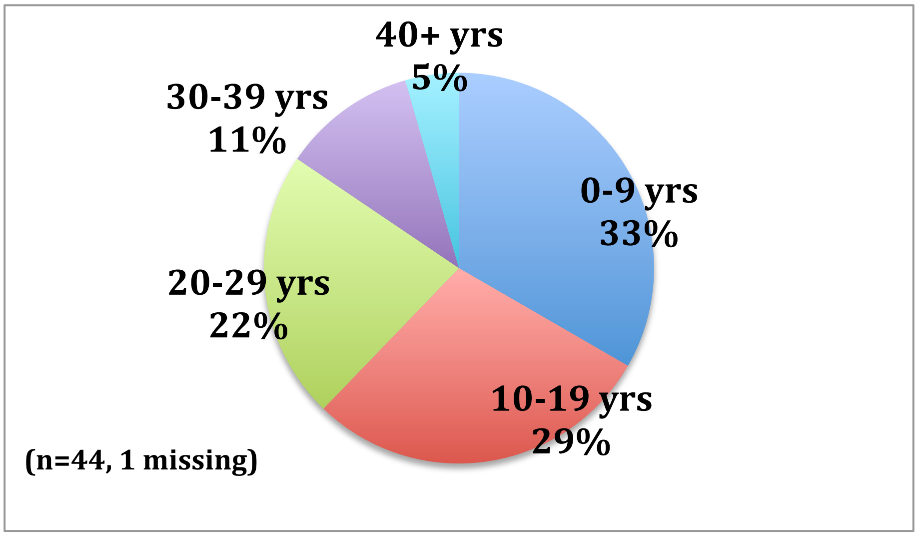
Analyses of data pertinent to the five research questions were conducted using qualitative and quantitative methods. Qualitative data from the twelve focus groups, open-ended questions on the community and provider surveys, and interviews, were analyzed for thematic content. Quantitative data on knowledge of hospice, advance directives, and personal preferences on use of hospice and end-of-life experience were summarized using univariate statistics tabulated at the state and regional levels, by survey respondent group. All data and information were aggregated for reporting in the de-identified format found in this report.

Preliminary findings were reviewed with the Vermont Hospice Study Advisory Committee to assist with interpretation.

Study Sample Description and Limitations

Professional focus group participants completed questionnaires to capture demographic characteristics and individual history and experience with end-of-life care. While the discussion in conference call focus groups was informative, and the large turn out in southeastern Vermont offered great insights, questionnaires were not consistently returned to capture demographic data on those groups to inform our sample description. From questionnaires collected at in-person focus groups, we have evidence that these groups included a balance of new- mid- and late-career professionals as shown in Figure 5: In-person Focus Group Participants' Years in Profession.

Figure 5: In-person Focus Group Participants' Years in Profession



Web based survey response rates could not be calculated as there were no quantifiable sampling frames articulated for the survey groups. Survey respondent characteristics are presented below in Table 5: Community Members and Provider Survey Respondents. Both community member and provider survey respondents were predominantly females, aged 45-64.

Table 5. Community Member Survey Respondent Demographics, by Region

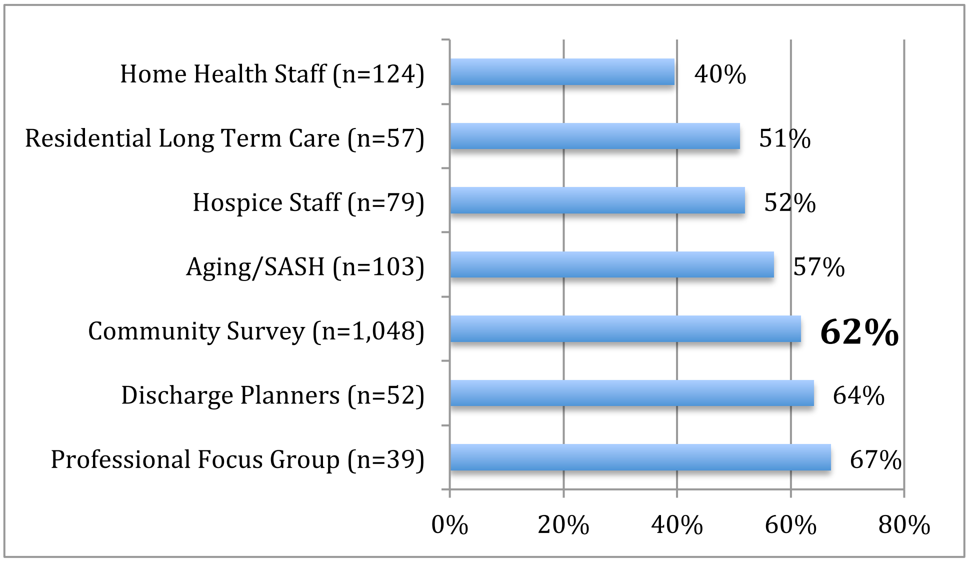
Community Member Demographics	**Northeast Kingdom** (n=112)	**Central Vermont** (n=232)	**Champlain Valley** (n=483)	**Southwest** (n=114)	**Southeast** (n=119)
Female	79%	82%	76%	69%	79%
Live Alone	19%	24%	21%	23%	25%
Age 25-44	15%	9%	13%	8%	8%
45-64	50%	52%	48%	52%	41%
65-74	25%	34%	28%	27%	34%
75+	8%	6%	11%	13%	15%

Table 6. Provider Survey Respondent Demographics, by Group

Provider Demographics	**Home Health/ Hospice** n=209	**Residential Long Term Care** n=57	**Aging/SASH** n=104	**Discharge Planners** n=52
Female	92%	82%	91%	94%
Age: 18-24	1%	2%	4%	0%
25-44	33%	26%	26%	33%
45-64	56%	60%	62%	60%
65-74	8%	9%	8%	8%
75+	1%	2%	0%	0%

It is important to note that study findings, while informative, are not generalizable. Survey participants were self-selected; therefore survey data were subject to selection bias. For example, community members surveyed appeared to be more attuned to the discussion of hospice and end-of-life care issues in Vermont than would be expected in the general population. The majority of survey respondents reported having talked with their families about their wishes for end-of-life care and 62 percent reported having an advance directive/health care agent. These rates were higher than averages reported in the literature[87] and were similar to those of professional groups, as depicted in Figure 6: Percentage of Survey Respondents Who Report Having an Advance Directive.

Figure 6: Percentage of Survey Respondents Who Report Having an Advance Directive



Analyses were largely qualitative due to time and fiscal constraints on the study that precluded quantitative hypothesis testing. To avoid possible interpretation errors based on small sample sizes, sub-state findings are reported for five regions[88] as shown in Figure 7: Regions for Vermont Hospice Study below.

Figure 7: Regions for Vermont Hospice Study

Prepared by Muskie School, University of Southern Maine

Findings

This section highlights findings relevant to three stakeholder groups: community members, healthcare providers, and hospice providers. It is important to note that all three of these groups are potential sources of referrals to hospice. Later sections of this report synthesize findings on the five research questions and highlight educational needs that became apparent during the research phase of this study.

Community Member Perspectives on Hospice

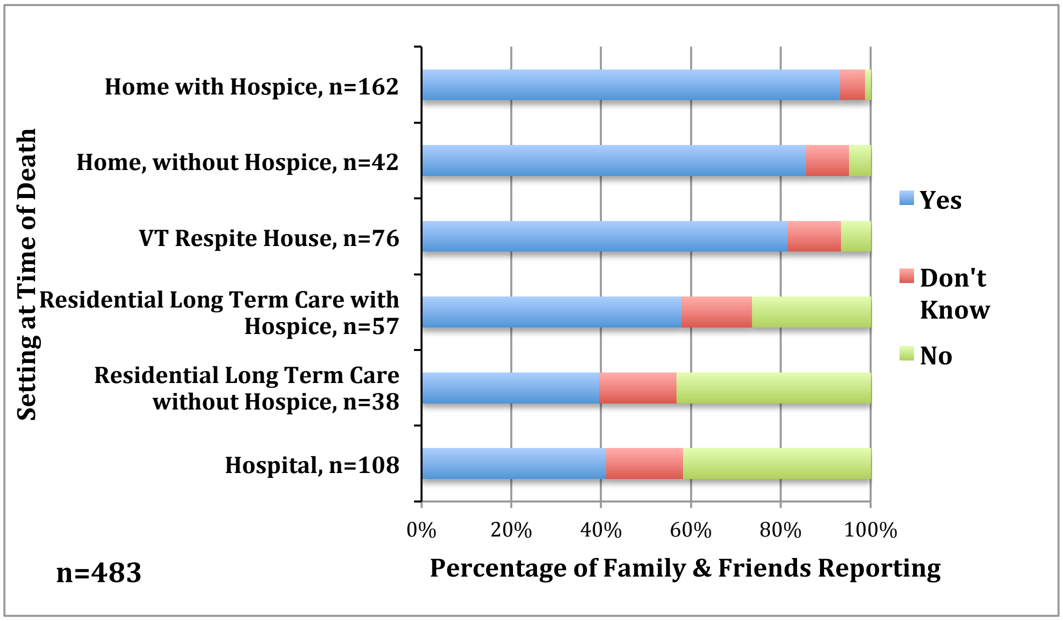
People learn about hospice from one another. Nearly 70 percent of community members surveyed reported learning about hospice from direct experience with a family member or friend who utilized hospice. Only 15 percent reported learning about hospice by attending a community workshop or speaker event. Only 8 percent learned about hospice by talking with a physician. Professional focus group participants speculated: *"Maybe current short stay utilization patterns come from perceptions."*

> *"People think (of hospice) in terms of days to weeks, not months"*
> *- Nurse*

Several study informants reported "quality" deaths at home without hospice involvement, and noted reluctance to enroll among Vermonters who already receive in home care from familiar providers including privately employed in home caregivers. Focus group participants reported that older Vermonters have access to a more generous set of long term services and supports available in home than older New Hampshire residents.

Community members surveyed who had lost a friend or family member in the last three years were most likely to report that their family member or friend was most comfortable if they died at home with hospice when asked to reflect on that experience: "Would you say your loved one was cared for where they felt most comfortable at the end of life?" In contrast, fewer than half felt their family member or friend was cared for where they felt most comfortable when they died in a hospital or in a residential long term care setting without hospice. As depicted in Figure 8: Family & Friends' Perceptions of Comfort with Setting and Care, community members were more uncertain about comfort levels when their friend or family member was cared for outside of the individual's home.

Figure 8: Family & Friends' Perceptions of Comfort with Setting and Care

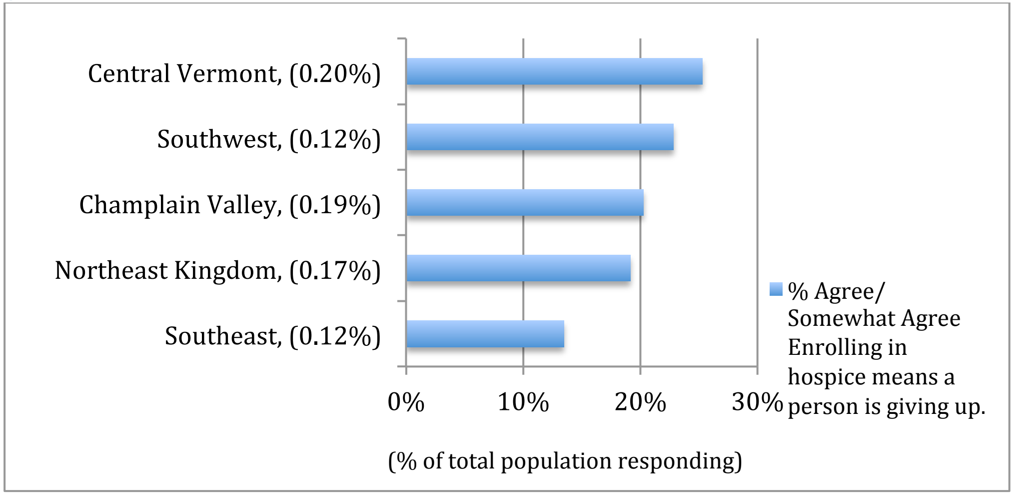


Nearly unanimously, study participants described the benefits of hospice in terms of improved quality of life. Community members frequently added that they wished their loved one had enrolled earlier so that they could have had more quality time. One professional focus group exchange summed up this positive commentary...

> *Hospice Medical Director: "Hospice doesn't mean death, it means quality."*
>
> *Primary Care Physician: "That was fabulous – hospice does not equal death, hospice equals quality."*

Views of hospice among community members varied by region. As noted in Figure 9: Percent of Community Members Who View Hospice Enrollment as Giving Up, by Region, thirteen to twenty five percent of community members agreed or at least somewhat agreed with the statement "Enrolling in hospice means a person is giving up," varying by region. In comparison, providers rarely (5 percent) shared this perception.

Figure 9: Percent of Community Members Who View Hospice Enrollment as Giving Up, by Region



Provider focus group participants reported a popular perception that hospice = morphine + death. However, fewer than 15 percent of community members reported concern about overuse of pain medication in hospice.

Fears of being alone, not having help when a loved one is in pain or distress and retelling of negative experiences were also raised as barriers by professional and community members. As one hospitalist summed it up "*If you are promising wrap-around service, and they don't get it, they tell people that. It's a bad experience they share. Managing expectations is important.*

Despite concerns and fears discussed, more than 90 percent of study participants[1] who were asked reported that they would choose hospice for their own end-of-life care. Fewer than 5 percent reported they would not choose hospice for their own end-of-life care.

Critical junction

The tenor and language of relationships between patients, families and healthcare providers is changing. Providers reported that patients don't know whom to turn to for help understanding end-of-life situations and choices. Community members reported experience with providers unprepared to convey necessary information for end-of-life care planning. Additionally, community members and providers reported that the vocabulary used can complicate these conversations. For example, in one focus group "advance directive" was described as jargon. At the critical junction between the community and providers, individuals in all groups reported unfamiliarity with key terminology and concepts. *"People don't want to feel stupid so they don't ask what it means."*

Healthcare Providers Perspectives on Hospice

Study participants shared that they did not understand the difference between palliative care and hospice. In addition, professional focus group participants in several regions were unaware of the palliative care referral trigger question… *"Would you be surprised if this patient died in the next year?"*

Professional focus group participants had mixed impressions of palliative care. Integration of palliative care varied regionally. Some physicians said they saw no need to refer patients for palliative care consults because they provide palliative care, themselves. Others reported that palliative care was only needed for "the special, special ones." In most focus groups, colleagues challenged palliative care resisters' experience and articulated the value of palliative care consults.

Physicians and hospice medical directors reported that families of hospice patients are confused about whom to call with their questions and concerns. *"We need to do a better job of defining the roles. The absence of clarity creates anxiety." (Physician)*

Hospitalists' changing roles were the subject of candid discussion during professional focus groups. Hospitalists and their colleagues reported challenges, particularly regarding their roles in conversations with patients about goals of care and the responsibility to refer to hospice. Individual practitioners and teams varied in their understanding of hospitalists' part in these conversations, resulting in confusion and even the loss of patient trust during transitions between curative care, palliative care, and hospice care. This need for clarification of roles was identified in most regions of the state.

There was general consensus that care teams need to allow for all team members to respond to moments of opportunity for end-of-life conversation with patients. Hospice medical directors stressed the important role nurses play in bringing changes in patient status to the attention of physicians.

"Role isn't the key, relationship is…"
- Hospice Director

Efforts to reduce inpatient deaths in tertiary care hospitals are having a mixed impact on patients and hospice. Smaller hospitals report being asked to not transfer patients to tertiary care centers near the end of life, increasing the likelihood of patients being nearer family and potentially being referred to hospice if they wish to return to their own homes to die. Conversely, pressure to discharge patients near the end of life may be fostering misunderstandings about hospice.

Pressure to reduce avoidable readmissions has shifted incentives for healthcare providers. Hospice agency directors reported that acute care and accountable care organization partners are now eager to learn about hospice and community-based service and support networks.

All professional focus groups discussed the importance of documentation. Participants noted that ease of entry and retrieval of notes on end-of-life conversations requires documentation systems for use within the hospital and after discharge. Additionally, the importance of written protocols to foster provider-to-provider communications and referrals to hospice and palliative care was stressed.

In addition to patient and provider relationships, professional focus group participants shared their insights on the importance of provider-to-provider relationships, and communication within the hospital and at and after discharge**.** Identified keys to this communication were documentation, and provider ease of entry and retrieval of information. "*Primary Care Physicians get buried by the notes….there is no system for flagging." (Oncologist)*

Critical Junction

The systems surrounding hospice care are in flux in response to the changing age structure of the population, the rising cost of healthcare, and greater patient participation in guiding their healthcare. The roles of physicians and other healthcare providers have been altered by interdisciplinary care teams, rapidly evolving expectations of palliative care, the development of new and seemingly endless treatment options, and new relationships between facility and community based providers. All parties are under pressure and largely without a forum for communication among groups, without a mechanism to bridge the systems of curative and palliative care.

Hospice Providers Perspectives on Hospice

Strong hospice medical directors were credited with (agency-defined) growth of hospice enrollments*.* Hospice directors, professional focus group participants, and hospice council interviewees reported that growing a hospice program requires relationship building through routine outreach by the hospice medical director.

In communities with strong hospice medical directors and palliative care champions, professional focus groups were collegial. In these regions, more participants shared a common understanding of how palliative care referrals assist patients, families and physicians with transitions. Palliative care programs were viewed as a valuable complement to hospice.

Strong hospice medical directors and palliative care champions described palliative care as the *"pregame"* for hospice.

In communities with less shared experience, professional focus group conversation gravitated to the logistics of hospice referrals. In these regions, focus group and provider survey comments included concerns about: the timeliness of hospice assessment and enrollment, the burden of hospice referral documentation, and misunderstandings about care plans for palliative care patients during hospital stays and for hospice patients on subsequent emergency room visits.

Outpatient palliative care was viewed as unavailable by many providers, and, when offered through the Medicare home health benefit, was seen as insufficient due to Medicare's "homebound" requirement. A third of home health and hospice agency directors report they offer in-home palliative care, an additional 50 percent said they provide palliative care services as a part of home health care. Surveyed providers comments included requests for information about outpatient palliative care and how to access such services in their area.

Critical Junction

The national literature suggested that hospice use increases with the addition of hospice providers; and Vermont has recently seen the addition of a second provider. Participants were reluctant to be explicit when more than one agency was being discussed. Northernmost county participants implied that services were almost exclusively provided by a single agency. Growth was attributed to the introduction of a second hospice provider by only two interviewees, both of whom had statewide responsibilities. The effect of the introduction of a second provider on hospice service to nursing home residents in the southeastern region was discussed. The impact of this change on the delivery of quality end-of-life care, including the rate of hospice use, settings of death, and where care is provided, is difficult to assess.

Research Questions

Question 1: Is hospice use lower in Vermont due to reluctance of health care professionals to refer patients to hospice?

Findings Summary: Healthcare provider reluctance to refer to hospice was found in all regions of Vermont. The sources of reluctance varied, and some were unexpected. Improving understandings of roles, and the relationship between hospice and palliative care providers (inpatient and out-) and across the care settings for all practitioners is an opportunity.

Physicians shared their personal experiences caring for patients at the end of life with great honesty and humility. Primary care physicians reported feeling loss when patients leave their practices to be cared for by oncologists and other specialists and hospice providers. Specialists reported feeling out of the communication loop. Physicians reported that they sometimes feel guilty when they can't do anything else for a patient. As one physician explained, "*I worry if I convince them into hospice, I may face having to not treat them when it could help."*

Physicians voiced concerns about some possible consequences of hospice referral. Some noted the limitation of treatment options. Others were concerned that patients may feel "given up on" when referred to hospice.

Physicians were discomfited by Medicare requirements for hospice enrollment. The complexity of prognostication and the Medicare "six month rule"[89] were raised in every professional focus group. Conversation included concern about sanctions, and about "looking like a fool." Hospice medical directors were less deterred, noting that the best prognosticians are only 70 percent correct. Some physicians "*wait and wait and wait to be certain*."

Nurses and other non-physician providers expressed reluctance to discuss end-of-life goals with patients and families. Many refer patients to doctors when they ask about end of life. Several indicated they know there are worse things than dying, "*but, you can't say that."*

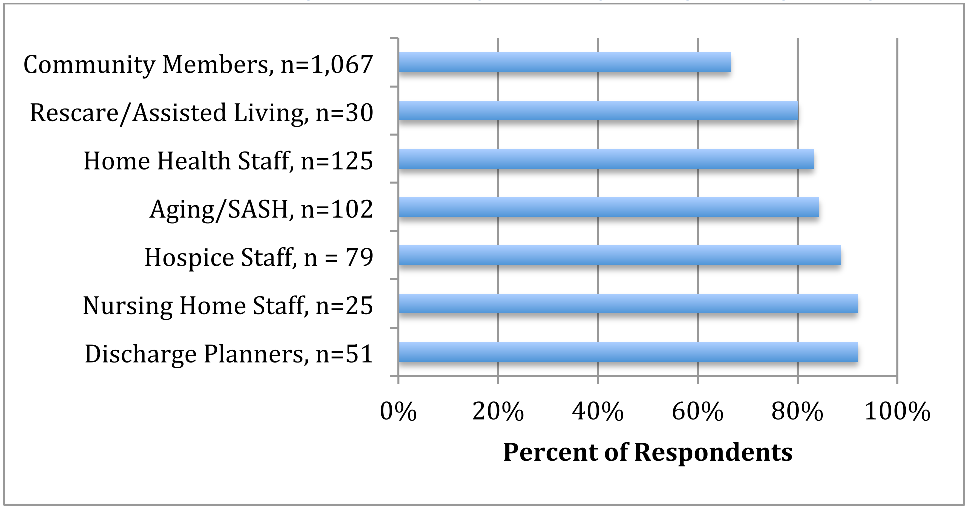
Likeliness to refer to hospice varied among provider groups surveyed. Respondents were asked a series of questions about the frequency with which they discuss hospice with patients, and their comfort in having advance care planning discussions with the people they serve. Survey responses indicated that residential long term care staff were most likely to report being comfortable having discussions about advance care planning with patients, and the percentage who discussed, suggested, or referred to hospice or palliative care was highest among discharge planners (94 percent), followed closely by residential long term care staff (93 percent). The group with the lowest number of respondents discussing or referring to palliative care and hospice are Aging/SASH, and other in-home care staff (75 percent). Details for each group are provided in Table 7: Comfort with Advance Care Planning Discussions and Hospice Conversations.

Table 7: Comfort with Advance Care Planning Discussions and Hospice Conversations

Survey Group	Comfortable with Advance Care Planning Discussions	Comfortable with Hospice Conversations
Discharge Planners	80% (n=41)	94% (n=48)
Home Health and Hospice	85% (n=179)	85% (n=179)
Aging/SASH Staff	87% (n=90)	75% (n=72)
Residential Long Term Care Staff	93% (n=52)	93% (n=52)

Healthcare providers knowledge of hospice and perceptions of hospice are known to influence referral patterns.[86] In addition to focus group discussion of perceptions of hospice, a 10-question series derived from the literature was included in all online surveys to measure community member and provider awareness and knowledge of hospice. Figure 10: Awareness That Anyone Can Request Hospice by Survey Group indicates that surveyed hospice and nursing home staff, and discharge planners, were aware that anyone can request a hospice evaluation. More than 35 percent of community members, and 15 to 20 percent of residential long term care, home health and SASH provider respondents, were unaware of this provision.

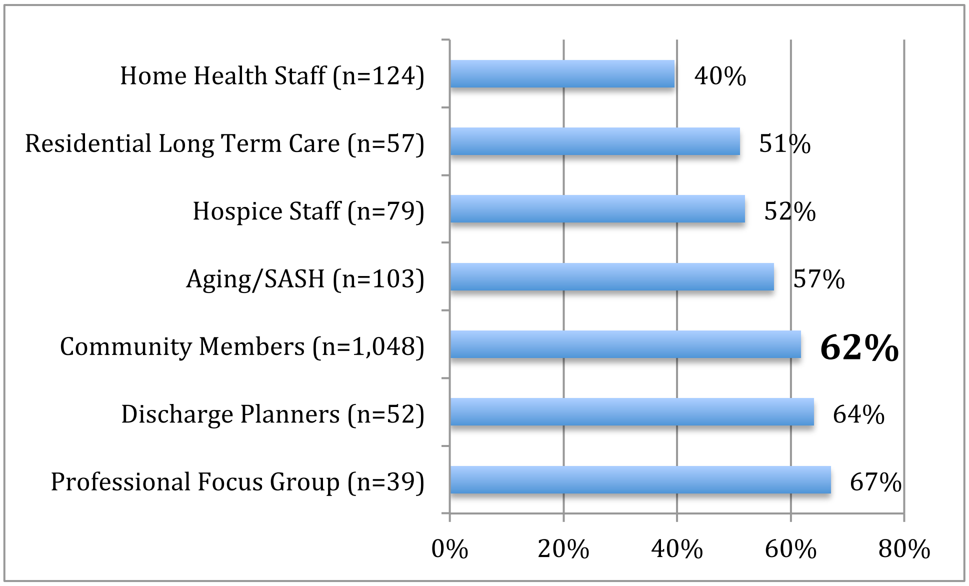
Figure 10: Awareness That Anyone Can Request Hospice, by Survey Group



Professional Focus Group discussion of conversations in acute care settings about advance directives and end-of-life care goals suggested that healthcare staff may be less experienced with these conversations than the community-based providers surveyed. Regarding health care staff with whom they work, one physician reported that staff "*... have an understanding of what death is, but maybe not how to talk about it. The more they talk about it, the better they are*."

Professional focus group participants reported having an advance directive more frequently than community members and provider survey respondents. As noted in Figure 11: Percentage of Survey Group Who Report Having an Advance Directive, statewide, professional focus group participants and discharge planners were more likely to have an advance directive than other surveyed providers. Details on regional variation by provider group are presented in Appendix C: Regional Provider Group Responses. Regional information on community members' responses to survey questions on advance directives and discussion of end-of-life wishes with family can be found in Appendix E: Community Survey Responses Regarding End-of-Life Wishes.

Figure 11: Percentage of Survey Group Who Report Having an Advance Directive



Experienced hospice and palliative care champions, reframed focus group discussions about "the conversation" as the series of conversations patients and families need, and emphasized the importance of patients' and families' readiness for these conversations. These professionals discussed their approaches and offered advice to others participating in discussions with patients about their goals for care: *"We don't have to have all of the answers. It's about bringing up the issues."*

Study participants new to Vermont shared experience from other states. These new Vermonters reported that in other states, discussions about death were more frequent, more direct and more comfortable for patients, and for clinicians within and beyond acute settings.

Indicators of Regional Variability: In the Northeast Kingdom and Champlain Valley regions, professional focus group members' discussion involved nuanced consideration of the interface between hospice and palliative care, opportunities for engaging specialists, and mechanisms for strengthening relationships and communication to enhance the quality of end-of-life care. In the Central Vermont and Southeastern Vermont regions, professional focus group discussions of the definition of palliative care revealed knowledge gaps. Focus group conversation in these two regions also revealed opportunities to enhance the responsiveness and timeliness of hospice referral.

Question 2: Is utilization of hospice in Vermont lower than in other states due to lower rates of hospice use by residents of nursing homes and assisted living facilities?

Findings Summary: The relationships between hospice and nursing facilities are constrained by fiscal disincentives in Medicare reimbursement policy in Vermont and nationally. Family members, nursing home staff, and other providers, reported challenges to obtaining hospice for nursing home residents. Some nursing facilities have embraced working partnerships with hospice providers and are inspiring models for development in other areas.

We know that nationally, nursing home residents' use of hospice services has been increasing steadily for several years.[78] Relationships between nursing home staff and hospice staff are complex, and sometimes strained. Care plans developed must support each organization's relationships with patients and their families, Medicare and Medicaid requirements, and staff needs. Hospice and nursing home staff in three regions reported successful investment of time and effort to develop positive relationships.

Study participants from all perspectives noted hospice access challenges in nursing homes. The frequency of comments and magnitude of the challenges reported varied markedly across regions. In one region, nursing home staff reported that multiple calls to physicians are required to get permission to set up hospice, discouraging some referrals. *"If we know a patient will need to go to a nursing facility I might not raise hospice because it becomes an unrealistic expectation."* Access in the easternmost regions was described as improving. Strategies to improve communication included: regular meetings between hospice and nursing home staff, and formalized referral and communication protocols developed in partnership

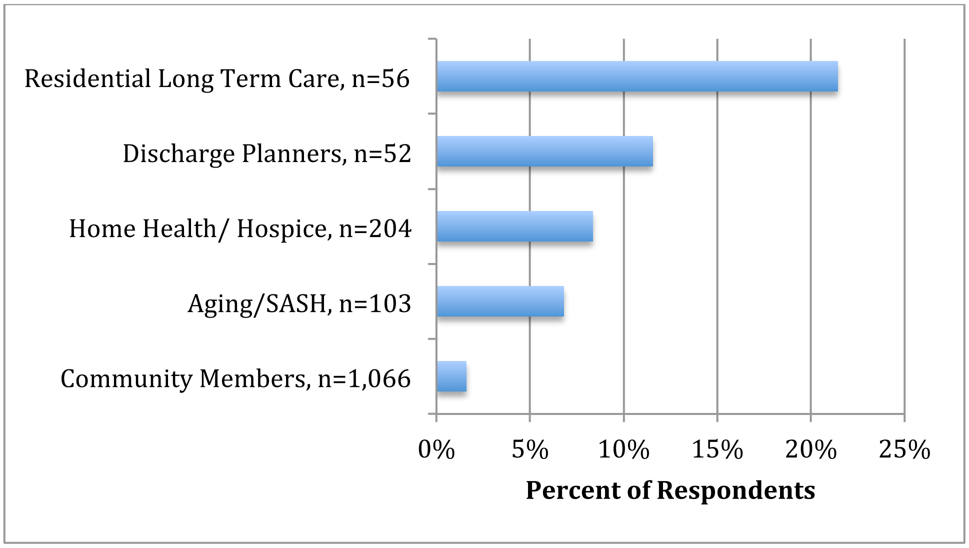
Cost restricted hospice use according to one-third of nursing home providers surveyed. Misaligned Medicare reimbursement policies pose significant challenges to hospice access for nursing home residents**.** These challenges are nationwide and have been under discussion in many states for years. Discussion continues about necessary federal policy changes. Hospice care in nursing homes is not available in some communities, for patients not yet covered by Medicaid and who have limited personal funds, due to nursing homes' unwillingness to risk financial loss.

In some regions of the state, hospice and nursing home providers have forged mutually supportive relationships*.* One professional focus group discussed exceptional cooperation at an area nursing home and voiced hopes for a "mini-wing" at the facility that would function like the inpatient Respite House facility in Williston. Some hospice providers scheduled regular outreach visits to area nursing homes. Staff at some nursing homes reported routine communication with hospice providers: *"Weekly, I alert the (agency name) hospice team to people who are hospice eligible. Then we let the client know that they are hospice eligible and that they can have a hospice informational."* Other nursing home staff explained that they approach the resident's primary care provider for referral to hospice.

The literature on nursing home and hospice points to the importance of nursing home staff knowledge and awareness of hospice as an important precursor to referral for hospice. Residential long term care staff respondents to the online survey were experienced caregivers, with over 70 percent having worked with people with life-limiting illnesses for more than 10 years. Statewide, nearly 60 percent had taken part in formal education about hospice within the previous three years. However, there was notable variation regionally. For additional details, see Appendix C: Regional Provider Group Responses. As noted by hospice leaders, education and training of nursing facility staff are a requirement of Medicare certified hospice agencies.

On average, these residential long term care providers matched discharge planners in the number of correctly answered questions on ten-question series about hospice knowledge and awareness*.* Like members of other groups, residential long term care providers answered a question about the role of hospice in treating the emotional needs of the dying individual and their family incorrectly more frequently than other questions in the knowledge of hospice series. And, in contrast to Community Members' perceptions (2 percent), 21 percent of care staff viewed nursing homes as providing the same services as hospice. Responses to this question by provider group are shown in Figure 12: Percent Who View Nursing Homes as Providing the Same Services as Hospice.

Figure 12: Percent Who View Nursing Homes as Providing the Same Services as Hospice



Perceptions of competition and complementarity between hospice and nursing home care varied among nursing home and hospice providers. More than 20 percent of residential long term care staff believed nursing homes provide the same services hospice offers. Residential long term care staff reported that some physicians see no need for hospice service for their residents and are reluctant to refer. *"Dr. ------ has been resistant to letting his hospice eligible patients receive hospice. Not just once - again, and again, and again."*

Providers' views varied about whether hospice services complement or compete with nursing home care. Some hospital discharge planners shared stories about patients seeking hospice who were unable to receive Medicare hospice services once they moved to a nursing home. And, not all physicians saw benefits in hospice for their patients who live in nursing homes. Some voiced the opinion that there is no need for hospice in nursing homes.

Many long term residential care providers valued hospice. They also noted misconceptions about hospice that discourage use. Not all comments were positive. Four of the 40 comments reported negative experiences with hospice agencies, or suggested that nursing homes ought to be able to become certified hospice providers. One nursing home staff person was more explicit: "*I have had good and bad experiences with our local hospice, mostly good experiences but the bad ones are the ones remembered most vividly."*

Community focus group members and providers of all types reported that there are nursing homes that do not support hospice for their residents. Nursing home provider refusal to engage with hospice is viewed as an important barrier by both family members and professionals. One physician shared a story that paralleled stories shared by patient families: "*I recently had a patient who went into a nursing home but did not enroll in hospice. Family thought the patient received very poor care.*

Staff at the nursing home thought they did a good job." However, some nursing home staff described hospice as a process for "*improving quality of life as opposed to helping people to die…. We use hospice all the time and it is amazing."*

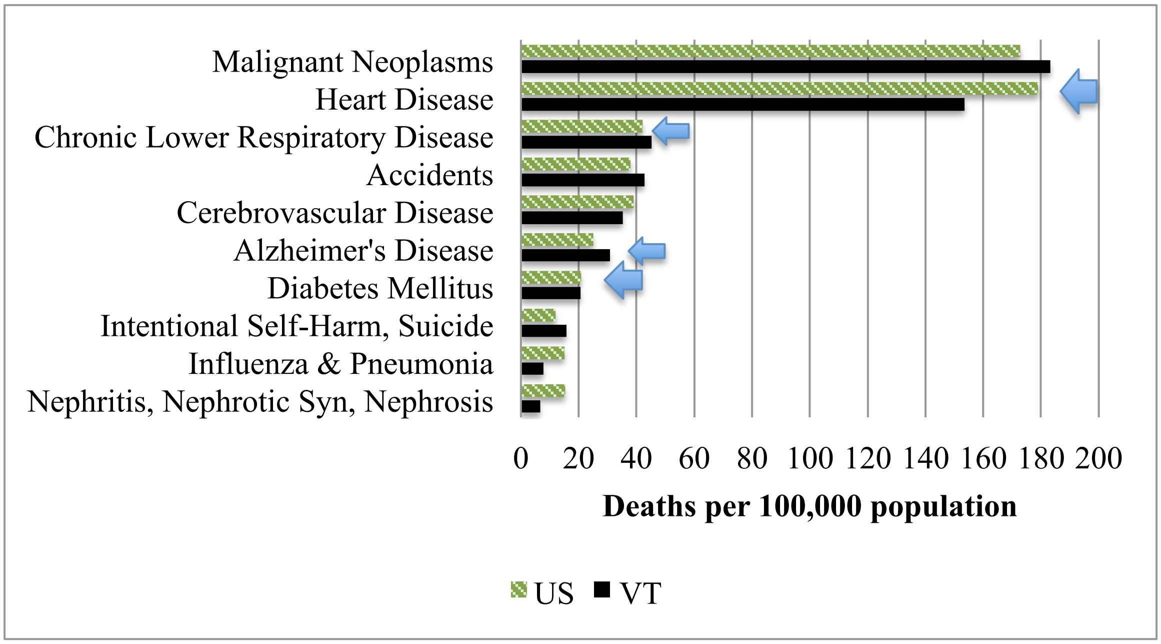
Indicators of Regional Variability: Relationships are strengthening between hospice and nursing facilities in the Northeast Kingdom where there is interest in building upon these relationships to create a local version of Vermont Respite House in the wing of a nursing home. In Central Vermont there were reports both of some nursing homes refusing patients requests for hospice in their facility, and of other nursing homes supporting patient enrollment in hospice. In the Champlain Valley and Southeastern Vermont there were reports of weekly meetings between hospice and nursing home staff.

Question 3: Is Vermont's relatively low utilization of hospice attributable to rates of death due to malignant neoplasms, chronic lower respiratory disease, and Alzheimer's disease that are higher than the national average?

> Findings Summary: Hospice use rates for people with chronic illness in Vermont are lower than would be expected based on national averages. Potential referral sources reported that they did not routinely consider hospice for patients with chronic illness or dementias. Data were not available to assess the magnitude of these effects statewide or regionally.

While the development of hospice is often associated with care for people with cancers, the literature is clear on the importance of considering hospice for people with chronic illness. Providers that work most closely with hospice through home health and hospice agencies were asked whether they routinely consider hospice for people with chronic illness. As can be found in Appendix C, Regional Provider Group Responses, consideration of hospice for people with chronic illness varies markedly by region. Specific challenges associated with hospice for persons with chronic illness are referenced in the literature. For Vermonters this may be of particular significance given the number of deaths attributed to chronic illness. See Figure 13: Top 10 Leading Causes of Death: Vermont & United States, 2010.

Figure 13: Top 10 Leading Causes of Death: Vermont & United States, 2010[90]



Source: Murphy SL, Xu, I and Kochanek KD. Deaths: Final Data for 2010 National Vital Statistics Reports, Vol. 61, No. 4, May 8, 2013

Malignant Neoplasms

Malignant neoplasms are the leading cause of death in Vermont. Medicare claims data from the Dartmouth Atlas of Healthcare,[35,36] indicated that Vermont Medicare decedents with cancer diagnoses used hospice at half the rate of the national average in 2012. Extrapolating from the Dartmouth Atlas data for 2012, if national enrollment rates were applied to the 569 Vermont Medicare beneficiary deaths attributed to cancer, nearly 100 additional persons would have been enrolled in hospice. In 2012, these Vermont Medicare cancer decedents were also more likely to die in hospital than their counterparts in more than 40 other states.

The challenges encountered in providing hospice care for patients with cancer were much discussed in professional focus groups. Participants wondered aloud about what moves colleagues' to begin discussions of palliative care and hospice with patients who have life limiting illness. Physicians in these groups raised concerns that financial incentives to treat can be a barrier to hospice use for patients with cancer. Nurses described communication gaps with patients.

Hospice poses nuanced challenges for oncologists. Participants in the cancer care/oncology focus group and those with an oncology focus who participated in other professional focus groups urged: "*Watch the denominators:*" cancer is not one diagnosis. Specialists also noted benefits of palliative radiation and chemotherapies, which were generally regarded as too expensive for small hospice providers.

Evolving oncology practice quality standards were discussed in the oncology focus group. These professional practice standards[91] currently measure and report hospice enrollment in the 3 days prior to death, and administration of chemotherapy within the last 2 weeks of life. Some speculated that these indicator parameters contribute to "late" referral to hospice.

Chronic Lower Respiratory Disease and Chronic Illness

Surveyed providers indicated they were least likely to consider hospice for patients with chronic lower respiratory disease, among chronic illnesses listed. As detailed in Table 8: Percentage of Surveyed Providers Routinely Considering Hospice for Patients with Specific Chronic Illnesses, home health and hospice staff and discharge planners were more likely than other provider groups to routinely consider hospice for patients with chronic illness. Aging/SASH providers were the least likely to consider hospice for people with chronic illnesses.

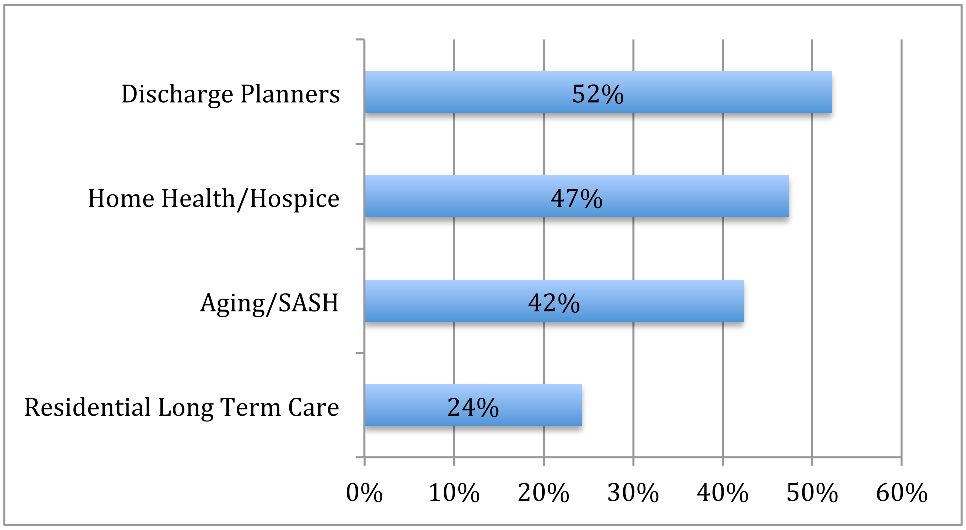
Table 8: Percentage of Surveyed Providers Routinely Considering Hospice for Patients with Specific Chronic Illnesses

Provider Group	**Chronic Lower Respiratory Disease**	**Congestive Heart Failure**	**Kidney/Liver Disease**
Home Health/Hospice	47 %	59 %	62 %
Discharge Planners	44 %	60 %	58 %
Residential Long Term Care	39 %	53 %	47 %
Aging/SASH	27 %	37 %	37 %

Dementia/Alzheimer's Disease

With the exception of discharge planners, fewer than half of surveyed providers routinely considered hospice for patients with dementias. As portrayed in Figure 14: Percent Who Routinely Consider Hospice for People with Dementia, the surveyed group least likely to consider hospice for people with dementia was residential long term care staff.

Figure 14: Percent Who Routinely Consider Hospice for People with Dementia



Additional detail on regional provider variability in consideration of hospice is available in Appendix C: Regional Provider Group Responses.

Hospice referrals for individuals with dementia may have been inhibited by challenges in determining eligibility. Medicare hospice rule changes created confusion about hospice eligibility for persons with dementias nationally. Professional survey respondents and focus group participants reported these challenges.

State-level interviewees in Maine described a partnership formed to provide hospice and dementia care information and tools to healthcare providers, family members and other stakeholders. Now nearly ten-years old, this initiative has been widely credited with increasing access to hospice for people with dementia in Maine. No similar partnership was identified in Vermont.

Indicators of Regional Variability: With the information available, it was not possible to consider sub-state variability in hospice use by patients with specific diagnoses, including dementia. Data available through secondary sources provide a pertinent picture of variability of the rate of malignant neoplasm diagnoses at the county level. See Appendix D: Vermont Malignant Neoplasm Cancer Death Rates.

Question 4: Is Vermonters' utilization of hospice low because informal caregivers (family, friends, neighbors, etc.) lack confidence and are not prepared to give end-of- life care?

Findings Summary: While confidence is an important factor, so too are the financial strains faced by families. Families need to work. They express concerns about the cost of care before asking about the care itself, and when no primary caregiver is available at home and they do not have Medicaid, there are n resources to assist with payment for round the clock care when physical needs exceed their capacity.

In the abstract, people prefer to die at home, but patients and families often make other choices when they learn 24/7 on-site professional care is not available. Identified challenges to dying at home included the need for caregiver respite and, most frequently, the absence of full-time primary caregivers. Home health and hospice staff noted that families have greater confidence in hospital care, and that families are often unprepared to handle physical care of patients referred to hospice a few days or weeks before death.

Community focus group participants with hospice experience wished they had been provided reading materials about the dying process. One participant wondered why she did not receive information about the dying process from hospice in her community when she needed it.

Professional focus group participants' perception of the suitability of hospice at home was variable for patients with working family caregivers. At the extremes, some discharge planners and physicians expressed the sentiment that *"there is absolutely no way"* working family members can take loved ones home to die. Others supported families making the choice.

- *"We make a judgment call about what people can pull off. (I've been surprised!)"*
- *"Hospice shifts the cost of care from the public to the private domain, for example, families miss work to provide care."*

Twenty percent of community members surveyed noted concern about the expense of hospice as a barrier to enrollment. Professionals also reported patient financial concerns and indicated surprise that money questions arose before care needs in conversation with some patients. Several physicians admitted having limited awareness of how hospice services are paid for; some wanted more information on insurance and cost.

> *"The second thing a Vermonter thinks about after absorbing their personal mortality is:* What kind of money is this going to cost?"
>
> \- *Discharge Planner*

Inexperience with death contributes to patients' and families' reluctance to enroll in hospice. Family members without healthcare experience may be hesitant to undertake the physical care of a loved one at the end-of-life according to professional focus group participants. *"It's the first time for all of these people."* Professional focus group participants agreed that a series of conversations with trusted providers is required to address patient and family fears.

Indicators of Regional Variability: There was discussion of volunteer hospice support in Champlain Valley and Southeast regions, and of the erosion of a volunteer base in the Northeast Kingdom due to increased participation of women in the workforce.

Question 5: Are lower hospice use rates a function of the practices of Vermont hospice providers?

Findings Summary: Vermont is served by a network of regional, non-profit hospice agencies, and by a statewide, for-profit hospice agency. Work force challenges were reported in all regions of the state. Hospice providers operating on a smaller scale face competing demands on limited resources that may have an impact on developing the relationships necessary for reaching underserved populations. Similarly, the Hospice and Palliative Care Council of Vermont operates with very limited resources compared to its counterparts in other states. In other parts of the country, statewide entities support development of education and initiatives to reach underserved populations in support of their local agencies.

The size and availability of financial resources for some Vermont hospice organizations may pose challenges for hospice growth. Some hospice medical directors acknowledged serious concern about Medicare reviews and the expense to an agency if a patient's eligibility is denied. Professional focus group members in two regions described hospice agencies that could not afford to provide expensive palliative treatments. In other regions, development of hospice received less priority due to competing demands on staff and limited resources.

The need for more residential hospice facility space "like Respite House in Williston" was articulated in most regions and by all types of respondents. This is consistent with the finding that a quarter of home health and hospice provider comments identified lack of primary caregivers, caregiver fears, and need for more assistance (24/7 and respite) as the greatest challenges. While some hospice agencies have explored their opening their own facilities, lack of funding was is a barrier. Study participants from eastern Vermont noted that a new facility affiliated with Dartmouth Hitchcock is in development.

In some regions, arrangements with nursing homes have been made to provide this type of residential care integrated with hospice care.

Half of home health and hospice staff survey comments described lack of experienced workforce as the most frequent challenge they face in meeting patients' and families' needs. The importance for consistent hospice leadership was also emphasized. In some regions, declining hospice enrollments were ascribed to gaps in leadership due to turnover.

Like many of its agency members, the Hospice and Palliative Care Council of Vermont operated on a limited budget. Support provided by hospice councils in comparison states varied with state population size. The Maine Hospice Council wrote grants and facilitated statewide hospice development, including expansion of access for people with dementias, veterans, and prisoners in Maine, and coordination of Physician Orders for Life Sustaining Treatment[92] (POLST) education efforts. The New Hampshire Hospice and Palliative Care Association provided training to long term care providers to help lift the burden on member agencies. Additionally, in New Hampshire, the Alzheimer's Association has helped to build relationships between hospice and nursing homes.

Some larger state hospice organizations offer easy access to resources. Organizations like the Minnesota Network of Hospice and Palliative Care and the Carolinas Center for Hospice and End of Life Care have websites that include calendars of events, webinars on new policies, educational materials and resources for provider and community education, data, and links to national resources.[93]

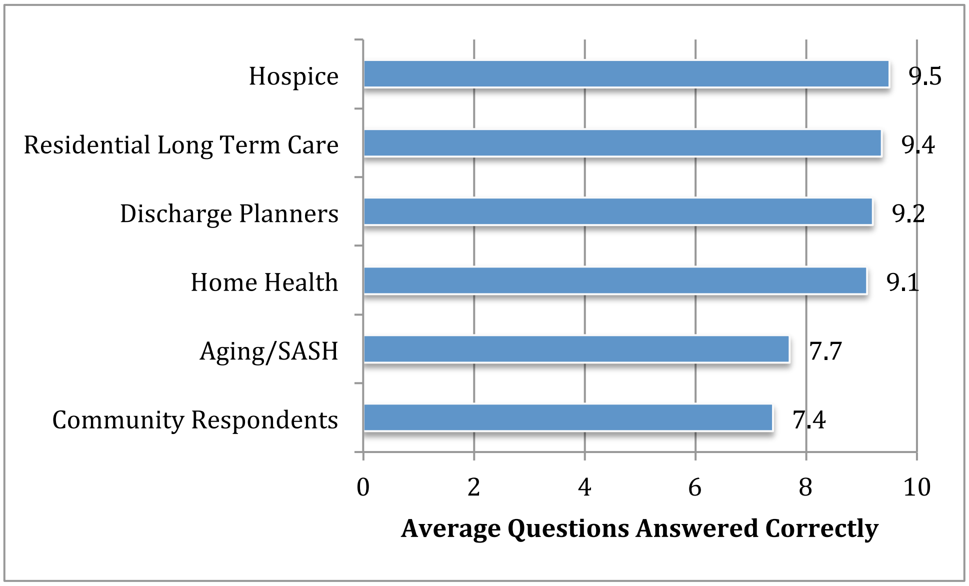
Indicators of Regional Variability: No regional variability was identified by this study; variability by agency was noted, largely attributable to the scale of operations.

Knowledge of Hospice

Awareness and understanding of hospice among study participants was assessed in addition to investigation guided by the five research questions.

According to the literature, knowledge and awareness of hospice are associated with referrals to and enrollment in hospice. All survey respondents were asked a 10-question series of questions on knowledge of hospice. For each group surveyed, correct answers were summed to assess familiarity with hospice across groups. Figure 15: Survey Respondents' Knowledge of Hospice provides survey group knowledge of hospice results. Hospice and residential long term care staff had the highest average number of correct answers; Aging/SASH providers and community members, on average, gave the fewest accurate responses.

Figure 15: Survey Respondents' Knowledge of Hospice



Knowledge of hospice varied. Based on the ten question series used to assess knowledge of hospice, hospice staff and residential long term care providers gave the highest statewide average number of correct answers. Aging/SASH providers and community members, on average, gave the fewest correct responses, 7.7 and 7.4 questions respectively. It is important to note that regional differences among discharge planners may reflect discharge planner specialization in larger health systems. See Appendix F: Regional Knowledge of Hospice, By Survey Group.

The question least frequently answered correctly asked whether: "a primary goal of hospice is to treat the emotional needs of the dying individual and their family." Aging/SASH providers were the most likely to answer this question correctly (83 percent). The groups with the lowest proportion of correct responses to this question were home health staff and discharge planners (78 percent each) and residential long term care staff (74 percent).

More than 35 percent of community members, and 15 to 20 percent of home health, Aging/SASH, and residential long term care staff were unaware that anyone can request hospice. Hospice and nursing home staff, and discharge planners were aware that anyone can request a hospice evaluation. The two additional knowledge of hospice questions that were more frequently answered incorrectly (true/false) were: Hospice must stop services if an individual lives longer than 6 months (f), and hospice services are typically paid for by health insurance(t). More detail on knowledge questions responses is presented in Appendix G: Information Gaps, by Provider Group.

Statewide, home health and hospice staff (90 percent) and discharge planners (85 percent) had the highest proportion of respondents who reported receiving formal education on hospice during the past three years. The proportion of providers who received recent formal training on hospice varied regionally. For additional detail, see Appendix C: Regional Provider Group Responses.

The vast majority of survey respondents saw a need for more education (80 percent of residential long term care staff, 85 percent of discharge planners, 92 percent of Aging/SASH staff, 94 percent of home health and hospice staff, and virtually 100 percent of professional focus group participants). In addition, lack of hospice awareness and need for community education were leading topics of comments submitted by community members. Other frequently noted topics were: building clinicians' skill in conversation about goals for care at the end-of-life, education about palliative care (requested by providers, for themselves), and the need for information on the services hospice provides.

Educational Opportunities Identified

Professional focus group participants in all regions reflected that bringing death into the public discourse may improve lives. Providers were asked if they thought more education about hospice and palliative care was needed. All professional focus group members believed there is a need for more education. With few exceptions, so did the majority of other providers surveyed. Additional information on this variability is provided in Appendix C: Regional Provider Group Responses.

All groups indicated need for provider education on the interplay between hospice and palliative care.

Home health and hospice staff indicated the need for hospice education for professional staff twice as many times as they called for community education on hospice. Home health and hospice providers reported that they themselves wanted more education on pain management, symptom control, and pediatric hospice. Home health and hospice staff also reported a need for education of other professionals on palliative care, and for training in end-of-life conversation skills.

Discharge planners emphasized the need for hospice education for healthcare professionals with the majority of regions reporting the need for education on the interplay between hospice and palliative care and end-of-life conversation skill building.

Surveyed providers perceptions of education needs for physicians most frequently included the need for education on prognostication and on the timing of referral to hospice. Providers reported need for education on the benefits and philosophy of hospice, and hospice services available both for themselves and of community members.

About Having the Conversation

Participants in all professional focus groups spoke about the time required to have end-of-life conversations well. They reflected: "*these discussions are, by their very nature time consuming.*" And, they noted that healthcare providers do not have the luxury of time to have these talks*.* Participants in four out of five provider groups surveyed saw a need for additional education on skills in having the conversation.

Study participants talked about "conversations" arising in various ways. Professional focus group participants described a subtle telegraphing of queues by patient/family to providers, including physicians and other team members; providers plant seeds for the "conversation"; physicians initiate "the conversation" directly; and sometimes patients or families initiate "the conversation" directly. From all survey participants, we learned that people also often hear about the hospice experiences of friends and family. Significant numbers of Aging/SASH, home health, and residential long term care staff reported routine engagement in end-of-life care planning discussions. Individual patients, their family and community supports, as well as healthcare team members, all participate in the series of conversations many patients need as they near the end-of-life. Study participants advocated for the fostering of sensitivity and skill in all of these “conversation” modes and in all healthcare team members to improve the quality of end-of-life care. Many providers still defer to physicians as the appropriate initiators of conversations about end-of-life goals, though study participants in all groups reported that one-to-one relationships and seizing the opportunity are pivotal.

Participant Suggestions and Recommendations

Participants in the professional focus groups exchanged useful information, identified opportunities to build relationships, and noted training and education needs. Periodic forums for information exchange, community priority setting, and opportunities for providers to share strategies and knowledge may foster hospice and palliative care.

An important priority is to strengthen collaborative statewide development of hospice.

An example of the shared resources developed in, and available from, other states are the Stratis Health’s Targeting Resource Use Effectively (TRUE) hospice utilization project working with community partners. See Appendix I: State Organizations, Websites.

Community members and home health and hospice providers observed that individuals with direct experience with hospice care of a loved one currently serve as de facto hospice ambassadors. Intentional development of this role, encouraging these ambassadors to build community understanding of the value of earlier hospice enrollment, was recommended.

In one region, community and professional focus participants suggested involving Aging/SASH providers in community and individual client conversations about end-of-life care planning.

The hospice liaison at the University of Vermont Medical Center was valued by VNA agency directors and by professional focus group participants. Focus group participants recommended development of a similar hospice liaison at Dartmouth-Hitchcock.

Areas for Further Study

Participants of one professional focus group suggested that open conversation on the roles and relationships of hospitalists may have been constrained by the structure of mixed focus groups employed for this study. A hospitalist-specific focus group might reveal important information about barriers to the use of hospice in Vermont that did not emerge in the inter-disciplinary professional focus groups.

Evidence of lower hospice use rates by Vermont decedents with diagnoses of cancer, and their higher than average in-hospital death rates, suggest the need for more in-depth study and discussion of end-of-life cancer care in Vermont.

Vermonters are understood to be independent, private, and even culturally averse to hospice. These generalizing observations about patients may inhibit appropriate referral to hospice and thus merit scrutiny.

Conclusions

Health system reforms have created opportunities for the development of new systems of communication and documentation within hospitals and across care settings.

Providers and communities are challenged to understand the evolving role of hospice in a healthcare system that has undergone so much change since 2010. As the boomer generation experience the deaths of their parents, expectations about the end-of-life are entering public discourse.

Study participants were clear that addressing the underlying causes of physician reluctance to refer patients to hospice is an important avenue for development.

In circumstances in which personal relationships make difficult conversations too hard, allowing more care team participation was identified as an opportunity to reduce the burdens physicians bear as increasing numbers of Vermonters approach the end-of-life. Working partnerships between hospice providers and nursing homes are at varying levels of development across the state. Opportunities exist to expand these relationships.

> *"You treat people for years and years and you get really attached. You want them to live. It's hard to have the discussion when you are really tight with a patient."*
>
> *- Physician*

Prognosis and disease specific issues related to malignant neoplasms, chronic illnesses and dementia may be contributing to Vermonter's lower than average hospice use rates. At a minimum, study participants' comments suggested that the care of patients with these diagnoses represents an opportunity to build inter-disciplinary relationships, knowledge, and communication to assure access to hospice and improve the quality of end-of-life experience in Vermont.

Limited family capacity appears to be less problematic than financial concerns, including payment for in-home caregiver support near the end-of-life. Hospice volunteer programs historically helped provide respite and other support to families. Creative solutions are now needed to assist the growing number of older patients who have no- or limited family support. As one provider suggested, payment for short-term caregiver support is needed so more people can choose to die in their own homes.

Finally, the provision of training and education continues to be an important opportunity, especially targeting clinicians; residential long term care, home health and hospice staff; Aging/SASH providers; and community members. Priority setting and coordination will maximize the benefit from resources devoted to these efforts.

From the change management literature, we know that change is internalized as loss by providers. With this in mind, in the words of an advance practice nurse, if hospice "*could swing some of that psychosocial care back to the providers they would get earlier referrals and have better relationships.*

References and Notes

1. Dartmouth Atlas of Health Care. Percent of Decedents Enrolled in Hospice During the Last Six Months of Life. 2015; http://www.dartmouthatlas.org/data/table.aspx?ind=16. Accessed April7, 2015.
2. Dartmouth Atlas of Health Care. Care of Chronically Ill Patients During the Last Two Years of Life. All Chronically Ill Patients. 2015; http://www.dartmouthatlas.org/downloads/tables/DAP_state_data_2012.xls. Accessed March 24, 2015.
3. Last Acts National Program Office K, K. O., & Peres, J. R. (2002). Means to a better end: A report on dying in America today. Washington, DC: Last Acts. *Means to a Better End: A Report on Dying in America.* 2002.
4. Madigan EA, Wiencek CA, Vander Schrier AL. Patterns of Community-Based End-of-Life Care in Rural Areas of the United States. *Policy Polit Nurs Pract.* Feb 2009;10(1):71-81.
5. Dartmouth Atlas of Health Care. Hospice Days Per Decedent During the Last Six Months of Life. 2015; http://www.dartmouthatlas.org/data/table.aspx?ind=4. Accessed April 7, 2015.
6. Fralich J, Lenardson J, Skillings H. *A Review of the Literature on End-of-Life Care: Setting a Research Agenda for Maine.* Portland, ME: University of Southern Maine, Muskie School of Public Service; October 2007.
7. Temkin-Greener H, Zheng NT, Mukamel DB. Rural-Urban Differences in End-of-Life Nursing Home Care: Facility and Environmental Factors. *The Gerontologist.* 2012;52(3):335-344.
8. Goodman DC EA, Fisher ES, Chang C. Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness. *A Report of the Dartmouth Atlas Project.* 2011. http://www.dartmouthatlas.org/search.aspx?query=eol trend report 2011. Accessed 3/1/2015.
9. Carlson MDA, Bradley EH, Qingling D, Morrison RS. Geographic Access to Hospice in the United States. *Journal of palliative medicine.* 2010;13(11):1331-1338.
10. Gozalo PL, Miller SC, Intrator O, Barber JP, Mor V. Hospice Effect on Government Expenditures among Nursing Home Residents. *Health Services Research.* 2008;43(1 Pt 1):134-153.
11. Obermeyer Z, Makar M, Abujaber S, Dominici F, Block S, Cutler DM. Association between the Medicare Hospice Benefit and Health Care Utilization and Costs for Patients with Poor-Prognosis Cancer. *JAMA.* Nov 12 2014;312(18):1888-1896.
12. Blecker S, Anderson GF, Herbert R, Wang N-Y, Brancati FL. Hospice Care and Resource Utilization in Medicare Beneficiaries with Heart Failure. *Medical Care.* 2011;49(11):985-991.

13. Chung KB, Sloane. Characteristics of Hospice Patients Utilizing Hospice Inpatient/Residential Facilities. *American Journal of Hospice & Palliative Medicine.* 2012;30(7):640-647.
14. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life. Key Findings and Recommendations. 2015: http://www.iom.edu/~/media/Files/Report Files/2014/EOL/Key Findings and Recommendations.pdf. Accessed 3/1/2015.
15. Commissioner of Health, Harry Chen, McCoy R. *In Accordance with Act 25 (2012), an Act Relating to Pailliative Care.* Burlington, VT: Vermont Agency of Human Services, Department of Health; October 1 2013. Report to the Vermont Legislature.
16. McCoy R. Annual Report on Deaths and Hospice Care: 2015 in Accordance with Act 25 (2009), Section 16, *an Act Relating to Palliative Care*. In: Agency of Human Services DoH, ed2015.
17. Brown AJ, Sun CC, Prescott LS, Taylor JS, Ramondetta LM, Bodurka DC. Missed Opportunities: Patterns of Medical Care and Hospice Utilization among Ovarian Cancer Patients. *Gynecologic oncology.* Nov 2014;135(2):244-248.
18. Mack JW, Cronin A, Keating NL, et al. Associations between End-of-Life Discussion Characteristics and Care Received near Death: A Prospective Cohort Study. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology.* 2012;30(35):4387-4395.
19. Aldridge Carlson MD, Barry CL, Cherlin EJ, McCorkle R, Bradley EH. Hospices' Enrollment Policies May Contribute to Underuse of Hospice Care in the United States. *Health Aff (Millwood).* Dec 2012;31(12):2690-2698.
20. Welch LC, Miller SC, Martin EW, Nanda A. Referral and Timing of Referral to Hospice Care in Nursing Homes: The Significant Role of Staff Members. *The Gerontologist.* 2008;48(4):477-484.
21. Zheng NT, Mukamel DB, Caprio TV, Temkin-Greener H. Hospice Utilization in Nursing Homes: Association with Facility End-of-Life Care Practices. *Gerontologist.* Oct 2013;53(5):817-827.
22. Tupper J. *Barriers to Medicare Hospice Utilization: A Qualitative Study of Maine Medicare Hospice Providers.* 2007.
23. Bischoff KE, Sudore R, Miao Y, Boscardin WJ, Smith AK. Advance Care Planning and the Quality of End-of-Life Care in Older Adults. *Journal Of The American Geriatrics Society.* 2013;61(2):209-214.
24. Freund K, Weckmann MT, Casarett DJ, Swanson K, Brooks MK, Broderick A. Hospice Eligibility in Patients Who Died in a Tertiary Care Center. *J Hosp Med.* Mar 2012;7(3):218-223.
25. Bernacki RE, Block SD. Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices. *JAMA Internal Medicine.* 2014;174(12):1994-2003.
26. Scheffey C, Kestenbaum MG, Wachterman MW, et al. Clinic-Based Outpatient Palliative Care before Hospice Is Associated with Longer Hospice Length of Service. *Journal Of Pain And Symptom Management.* 2014;48(4):532-539.

27. Munn JC. Telling the Story: Perceptions of Hospice in Long-Term Care. *The American journal of hospice & palliative care.* 2012;29(3):201-209.
28. Unroe KT, Cagle JG, Dennis ME, Lane KA, Callahan CM, Miller SC. Hospice in the Nursing Home: Perspectives of Front Line Nursing Home Staff. *Journal Of The American Medical Directors Association.* 2014;15(12):881-884.
29. Miller SC. A Model for Successful Nursing Home-Hospice Partnerships. *Journal of palliative medicine.* 2010;13(5):525-533.
30. Martz K GA. Perceptions of Coordination of Care between Hospice and Skilled Nursing Facility Care Providers. *J Hosp Palliat Nurs.* 4/2/2015 2011;13(4): 210-221.
31. Cagle JG, Van Dussen DJ, Culler KL, et al. Knowledge About Hospice: Exploring Misconceptions, Attitudes, and Preferences for Care. *The American journal of hospice & palliative care.* 2014.
32. Waldrop DP, Meeker MA. Hospice Decision Making: Diagnosis Makes a Difference. *Gerontologist.* Oct 2012;52(5):686-697.
33. Hirschman KB, Corcoran AM, Straton JB, Kapo JM. Advance Care Planning and Hospice Enrollment: Who Really Makes the Decision to Enroll? *J Palliat Med.* May 2010;13(5):519-523.
34. Dartmouth Atlas of Health Care. Care of Chronic Illness in Last Two Years of Life. 2015; http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=1. Accessed March 24, 2015.
35. Dartmouth Atlas of Health Care. Hospice Days Per Cancer Patient During the Last Month of Life, 2003-2007. 2015; http://www.dartmouthatlas.org/data/table.aspx?ind=171&tf=20&ch=&loc=2,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35,36,37,38,39,40,41,42,43,44,45,46,47,48,49,50,51,52&loct=2&fmt=196. Accessed April 6, 2015.
36. Dartmouth Atlas of Health Care. Hospice Days Per Cancer Patient During the Last Month of Life, 2010. 2015; http://www.dartmouthatlas.org/data/table.aspx?ind=171&tf=23&ch=&loc=2,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35,36,37,38,39,40,41,42,43,44,45,46,47,48,49,50,51,52&loct=2&fmt=196. Accessed April 6, 2015.
37. Miller SC, Lima J, Gozalo PL, Mor V. The Growth of Hospice Care in U.S. Nursing Homes. *J Am Geriatr Soc.* Aug 2010;58(8):1481-1488.
38. Sengupta M, Park-Lee E, Valverde R, Caffrey C, Jones A. Trends in Length of Hospice Care from 1996 to 2007 and the Factors Associated with Length of Hospice Care in 2007: Findings from the National Home and Hospice Care Surveys. *The American journal of hospice & palliative care.* 2014;31(4):356-364.
39. Aldridge MD, Schlesinger M, Barry CL, et al. National Hospice Survey Results: For-Profit Status, Community Engagement, and Service. *JAMA Intern Med.* Apr 2014;174(4):500-506.
40. Canavan ME, Aldridge Carlson MD, Sipsma HL, Bradley EH. Hospice for Nursing Home Residents: Does Ownership Type Matter? *J Palliat Med.* Oct 2013;16(10):1221-1226.

41. National Hospice and Palliative Care Organization. *N H P C O's Facts and Figures: Hospice Care in America.* Alexandria, VA: NHPCO;2014.
42. Hunt. Medicare Hospice Payment Reform: A Review of the Literature (2013 Update). 2014.
43. Dartmouth Atlas of Health Care. Care of Chronically Ill Patients During the Last Two Years of Life. 2015; http://www.dartmouthatlas.org/tools/downloads.aspx?tab=40. Accessed April 7, 2015.
44. Eager E. Waldo County Home Health and Hospice: A Case Study, November 2014. 2014.
45. Miller SC, Mor V, Teno J. Hospice Enrollment and Pain Assessment and Management in Nursing Homes. *Journal Of Pain And Symptom Management.* 2003;26(3):791-799.
46. Teno JM, Gozalo PL, Lee IC, et al. Does Hospice Improve Quality of Care for Persons Dying from Dementia? *Journal Of The American Geriatrics Society.* 2011;59(8):1531-1536.
47. O'Connor NR, Hu R, Harris PS, Ache K, Casarett DJ. Hospice Admissions for Cancer in the Final Days of Life: Independent Predictors and Implications for Quality Measures. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology.* 2014;32(28):3184-3189.
48. Bergman J, Saigal CS, Lorenz KA, et al. Hospice Use and High-Intensity Care in Men Dying of Prostate Cancer. *Archives of internal medicine.* 2011;171(3):204-210.
49. Berry JI. Hospice and Heart Disease: Missed Opportunities. *J Pain Palliat Care Pharmacother.* Mar 2010;24(1):23-26.
50. Aldridge MD, Canavan M, Cherlin E, Bradley EH. Has Hospice Use Changed? 2000-2010 Utilization Patterns. *Med Care.* Jan 2015;53(1):95-101.
51. Unroe KT, Sachs GA, Hickman SE, Stump TE, Tu W, Callahan CM. Hospice Use among Nursing Home Patients. *J Am Med Dir Assoc.* Apr 2013;14(4):254-259.
52. Miller SC, Lima JC, Mitchell SL. Hospice Care for Persons with Dementia: The Growth of Access in Us Nursing Homes. *Am J Alzheimers Dis Other Demen.* Dec 2010;25(8):666-673.
53. Miller SC, Lima JC, Looze J, Mitchell SL. Dying in U.S. Nursing Homes with Advanced Dementia: How Does Health Care Use Differ for Residents with, Versus without, End-of-Life Medicare Skilled Nursing Facility Care? *J Palliat Med.* Jan 2012;15(1):43-50.
54. Sammon JD, McKay RR, Kim SP, et al. Burden of Hospital Admissions and Utilization of Hospice Care in Metastatic Prostate Cancer Patients. *Urology.* Feb 2015;85(2):343-350.
55. Odejide OO, Coronado DYS, Watts CD, Wright AA, Abel GA. Focus on Quality. End-of-Life Care for Blood Cancers: A Series of Focus Groups with Hematologic Oncologists. *Journal of Oncology Practice.* 2014;10(6):e396-e403.
56. Cheung WY, Schaefer K, May CW, et al. Enrollment and Events of Hospice Patients with Heart Failure Vs. Cancer. *J Pain Symptom Manage.* Mar 2013;45(3):552-560.

57. Schellinger S, Sidebottom A, Briggs L. Disease Specific Advance Care Planning for Heart Failure Patients: Implementation in a Large Health System. *Journal of palliative medicine.* 2011;14(11):1224-1230.
58. Centers for Disease Control and Prevention. Stats of the State of Vermont. 2013; http://www.cdc.gov/nchs/pressroom/states/VT_2014.pdf. Accessed April 6, 2015.
59. Harris P, Wong E, Farrington S, et al. Patterns of Functional Decline in Hospice: What Can Individuals and Their Families Expect? *Journal Of The American Geriatrics Society.* 2013;61(3):413-417.
60. Mitchell SL, Miller SC, Teno JM, Kiely DK, Davis RB, Shaffer ML. Prediction of 6-Month Survival of Nursing Home Residents with Advanced Dementia Using Adept Vs Hospice Eligibility Guidelines. *JAMA.* 2010;304(17):1929-1935.
61. Brown MA, Sampson EL, Jones L, Barron AM. Prognostic Indicators of 6-Month Mortality in Elderly People with Advanced Dementia: A Systematic Review. *Palliative Medicine.* 2013;27(5):389-400.
62. Fulton AT, Rhodes-Kropf J, Corcoran AM, Chau D, Castillo EH. Palliative Care for Patients with Dementia in Long-Term Care. *Clinics In Geriatric Medicine.* 2011;27(2):153-170.
63. Han PKJ, Lee M, Reeve BB, et al. Development of a Prognostic Model for Six-Month Mortality in Older Adults with Declining Health. *Journal Of Pain And Symptom Management.* 2012;43(3):527-539.
64. Li Q, Zheng NT, Temkin-Greener H. Quality of End-of-Life Care of Long-Term Nursing Home Residents with and without Dementia. *Journal Of The American Geriatrics Society.* 2013;61(7):1066-1073.
65. Gozalo PL, Miller SC. Hospice Enrollment and Evaluation of Its Causal Effect on Hospitalization of Dying Nursing Home Patients. *Health Services Research.* 2007;42(2):587-610.
66. Temkin-Greener H, Zheng NT, Xing J, Mukamel DB. Site of Death among Nursing Home Residents in the United States: Changing Patterns, 2003-2007. *J Am Med Dir Assoc.* Oct 2013;14(10):741-748.
67. Casarett D, Karlawish J, Morales K, Crowley R, Mirsch T, Asch DA. Improving the Use of Hospice Services in Nursing Homes: A Randomized Controlled Trial. *JAMA.* 2005;294(2):211-217.
68. Hanson LC, Sengupta S, Slubicki M. Access to Nursing Home Hospice: Perspectives of Nursing Home and Hospice Administrators. *Journal of palliative medicine.* 2005;8(6):1207-1213.
69. Tyler DA, Leland N, Lepore M, Miller SC. Effect of Increased Nursing Home Hospice Use on Nursing Assistant Staffing. *Journal of palliative medicine.* 2011;14(11):1236-1239.
70. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice Use and Outcomes in Nursing Home Residents with Advanced Dementia. *Journal Of The American Geriatrics Society.* 2010;58(12):2284-2291.
71. Klapwijk MS, Caljouw MAA, van Soest-Poortvliet MC, van der Steen JT, Achterberg WP. Symptoms and Treatment When Death Is Expected in Dementia Patients in Long-Term Care Facilities. *BMC Geriatrics.* 2014;14:99-99.

72. Unroe KT, Sachs GA, Dennis ME, et al. Hospice Use among Nursing Home and Non-Nursing Home Patients. *J Gen Intern Med.* Nov 2014.
73. Huskamp HA, Kaufmann C, Stevenson DG. The Intersection of Long-Term Care and End-of-Life Care. *Medical Care Research & Review.* 2012;69(1):3-44.
74. Woolley DC, Old JL, Zackula RE, Davis N. Acute Hospital Admissions of Hospice Patients. *Journal of palliative medicine.* 2013;16(12):1515-1522.
75. Chung K, Richards N, Burke S. Hospice Agencies' Hospital Contract Status and Differing Levels of Hospice Care. *The American journal of hospice & palliative care.* 2014.
76. Teno JM, Gozalo PL, Bynum JP, et al. Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009. *JAMA.* Feb 2013;309(5):470-477.
77. Whoriskey PK, D. Terminal Neglect: How Some Agencies Fail the Dying. *The Washington Post.* May 3, 2014, 2014.
78. NHPCO. *Nhpco's Facts and Figures: Hospice Care in America 2014 Edition.* 2014.
79. Dartmouth Atlas of Health Care. Hospital Discharges and Post-Acute Care. 2015; http://www.dartmouthatlas.org/tools/downloads.aspx?tab=41. Accessed April 6, 2015.
80. Morrison RS, Augustin R, Souvanna P, Meier DE. America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals. *J Palliat Med.* Oct 2011;14(10):1094-1096.
81. Ciemins EL, Stuart B, Gerber R, Newman J, Bauman M. An Evaluation of the Advanced Illness Management (Aim) Program: Increasing Hospice Utilization in the San Francisco Bay Area. *Journal of palliative medicine.* 2006;9(6):1401-1411.
82. Dartmouth Atlas of Health Care. Home Health Agency Visits Per Decedent, by Interval before Death. 2015; http://www.dartmouthatlas.org/data/table.aspx?ind=3&loc=2,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21&loct=2&tf=23&fmt=5&ch=1. Accessed March 24, 2015.
83. Waldrop D, Kirkendall AM. Rural-Urban Differences in End-of-Life Care: Implications for Practice. *Soc Work Health Care.* 2010;49(3):263-289.
84. Vermont Vo. *Report from Hospice Focus Groups.* 2010.
85. Thomas KS, Rahman M, Mor V, Intrator O. Influence of Hospital and Nursing Home Quality on Hospital Readmissions. *The American Journal Of Managed Care.* 2014;20(11):e523-e531.
86. Snyder S, Hazelett S, Allen K, Radwany S. Physician Knowledge, Attitude, and Experience with Advance Care Planning, Palliative Care, and Hospice: Results of a Primary Care Survey. *Am J Hosp Palliat Care.* Aug 2013;30(5):419-424.
87. Rao JK, Anderson LA, Lin F-C, Laux JP. Completion of Advance Directives among U.S. Consumers. *American Journal Of Preventive Medicine.* 2014;46(1):65-70.
88. The five regions used for description in this study are: Northeast Kingdom (Caledonia, Essex, and Orleans Counties), Central Vermont (Lamoille, Orange, and Washington Counties), Champlain Valley (Addison, Chittenden, Frankliin,

and Grand Isle Counties), Southwestern Vermont (Bennington and Rutland Counties), and Southeastern Vermont (Windsor and Windham Counties).

89. The "six month rule" requires physicians to certify that they believe the patient has less than six months to live if the illness runs a normal course to qualify for Medicare hospice benefits.
90. Murphy SL XI, and Kochanek KD. Deaths: Final Data for 2010. *National Vital Statistics Reports* 2013; http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_04.pdf. Accessed 4, 61.
91. American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI). http://www.asco.org/institute-quality/summary-current-qopi-measures
92. "The National Physician Orders for Life Sustaining Treatment (POLST) Paradigm is an approach to end-of-life planning based on conversations between patients, loved ones, and health care professionals designed to ensure that seriously ill or frail patients can choose the treatments they want or do not want and that their wishes are documented and honored." The Vermont variant on POLST is called Clinician Orders for Life Sustaining Treatment (COLST). For more information, see: http://www.polst.org and http://www.vtethicsnetwork.org/colst.html
93. Minnesota Network for Hospice and Palliative Care: http://mnhc.com/
    Carolinas Center for Hospice and End of Life Care: http://cchospice.org/

Appendix A: Vermont Hospice Study Advisory Committee Members

- Meagan Buckley, Executive Director, Burlington Health & Rehab
- Jeff Carr, President, Economic & Policy Resources
- Jaina Clough, MD, Hospice Medical Director for VNA of Chittenden and Grand Isle Counties, and University of Vermont Medical Center
- Allan Eisemann, MD, Rutland Regional Medical Center
- Holly Miller, Madison-Dean Initiative, VNA Hospice Volunteer
- Priscilla Minkin, Chaplain, Palliative Care Program, Central Vermont Medical Center
- Kevin Mullin, State Senator (Rutland)
- Anson Tebbetts, News Director, WCAX-TV
- Susan Wehry, MD, (Former*) Commissioner, Vermont Department for Aging and Independent Living

Project Staff

- Christine Werneke, VP of Business Development & Marketing, VNA of Chittenden & Grand Isle Counties
- Coleen Wright, Madison-Deane Initiative Coordinator, VNA of Chittenden & Grand Isle Counties
- Kevin Veller, Project Manager Contracted to the VNA of Chittenden & Grand Isle

**Susan Wehry, MD remained on the committee after her tenure as Commissioner ended in July, 2015.*

Appendix B: Survey Respondents, by Region and County

	Survey Respondents	
Regions Counties	**Community Members**	**Providers**
Northeast Kingdom Region	**112**	**56**
Essex	5	4
Orleans	43	17
Caledonia	64	35
Central Vermont Region	**232**	**63**
Orange	35	7
Washington	146	43
Lamoille	51	13
Champlain Valley Region	**483**	**188**
Franklin	34	36
Grand Isle	25	6
Chittenden	338	117
Addison	86	29
Southwest Region	**114**	**67**
Rutland	68	44
Bennington	46	23
Southeast Region	**119**	**70**
Windham	67	27
Windsor	52	43

Appendix C: Regional Provider Group Responses

Respondents	Northeast Kingdom	Central Vermont	Champlain Valley	Southeast	Southwest
Home Health/ Hospice n=209	23 (11%)	37 (18%)	80 (38%)	34 (17%)	35 (16%)
Residential Long Term Care n=57	7 (13%)	11 (19%)	26 (46%)	14 (15%)	8 (7%)
Aging/SASH n=104	16 (15%)	6 (6%)	48 (47%)	17 (16%)	17 (16%)
Discharge Planners n=52	7 (13%)	8 (15%)	23 (44%)	8 (12%)	6 (15%)

	REGION				
PERCENT WITH ADVANCE DIRECTIVE, BY SURVEY PROVIDER GROUP	**Northeast Kingdom**	**Central Vermont**	**Champlain Valley**	**Southwest**	**Southeast**
Discharge Planners	43%	50%	30%	75%	60%
Aging/SASH	33%	67%	54%	63%	75%
Home Health	17%	31%	50%	44%	60%
Hospice	50%	63%	56%	29%	61%
Residential Long Term Care	43%	63%	52%	50%	50%

	REGION				
PERCENT THAT WOULD USE HOSPICE THEMSELVES, BY SURVEY PROVIDER GROUP	**Northeast Kingdom**	**Central Vermont**	**Champlain Valley**	**Southwest**	**Southeast**
Discharge Planners	43%	38%	83%	75%	80%
Aging/SASH	53%	83%	76%	58%	50%
Home Health	83%	79%	85%	83%	60%
Hospice	100%	88%	92%	100%	93%
Residential Long Term Care	43%	75%	76%	50%	50%

	REGION				
PERCENT WHO *DISAGREE* THAT HOSPICE & PALLIATIVE CARE ARE THE SAME, BY SURVEY PROVIDER GROUP	**Northeast Kingdom**	**Central Vermont**	**Champlain Valley**	**Southwest**	**Southeast**
Discharge Planners	83%	50%	96%	88%	60%
Aging/SASH	67%	83%	76%	84%	81%
Home Health	79%	90%	92%	81%	100%
Hospice	100%	75%	92%	79%	81%
Residential Long Term Care	43%	71%	88%	75%	67%

	REGION				
PERCENT WHO ARE FAMILIAR WITH POLST, BY SURVEY PROVIDER GROUP	**Northeast Kingdom**	**Central Vermont**	**Champlain Valley**	**Southwest**	**Southeast**
Discharge Planners	100%	100%	91%	88%	80%
Aging/SASH	73%	83%	87%	74%	69%
Home Health	79%	66%	74%	89%	40%
Hospice	100%	75%	96%	86%	78%
Residential Long Term Care	100%	88%	100%	100%	75%

	REGION				
PERCENT WHO ROUTINELY CONSIDER HOSPICE FOR DEMENTIA PATIENTS, BY SURVEY PROVIDER GROUP	**Northeast Kingdom**	**Central Vermont**	**Champlain Valley**	**Southwest**	**Southeast**
Discharge Planners	14%	50%	35%	75%	60%
Aging/SASH	7%	33%	13%	58%	31%
Home Health	47%	52%	29%	35%	40%
Hospice	100%	71%	75%	86%	81%
Residential Long Term Care	29%	50%	50%	75%	57%

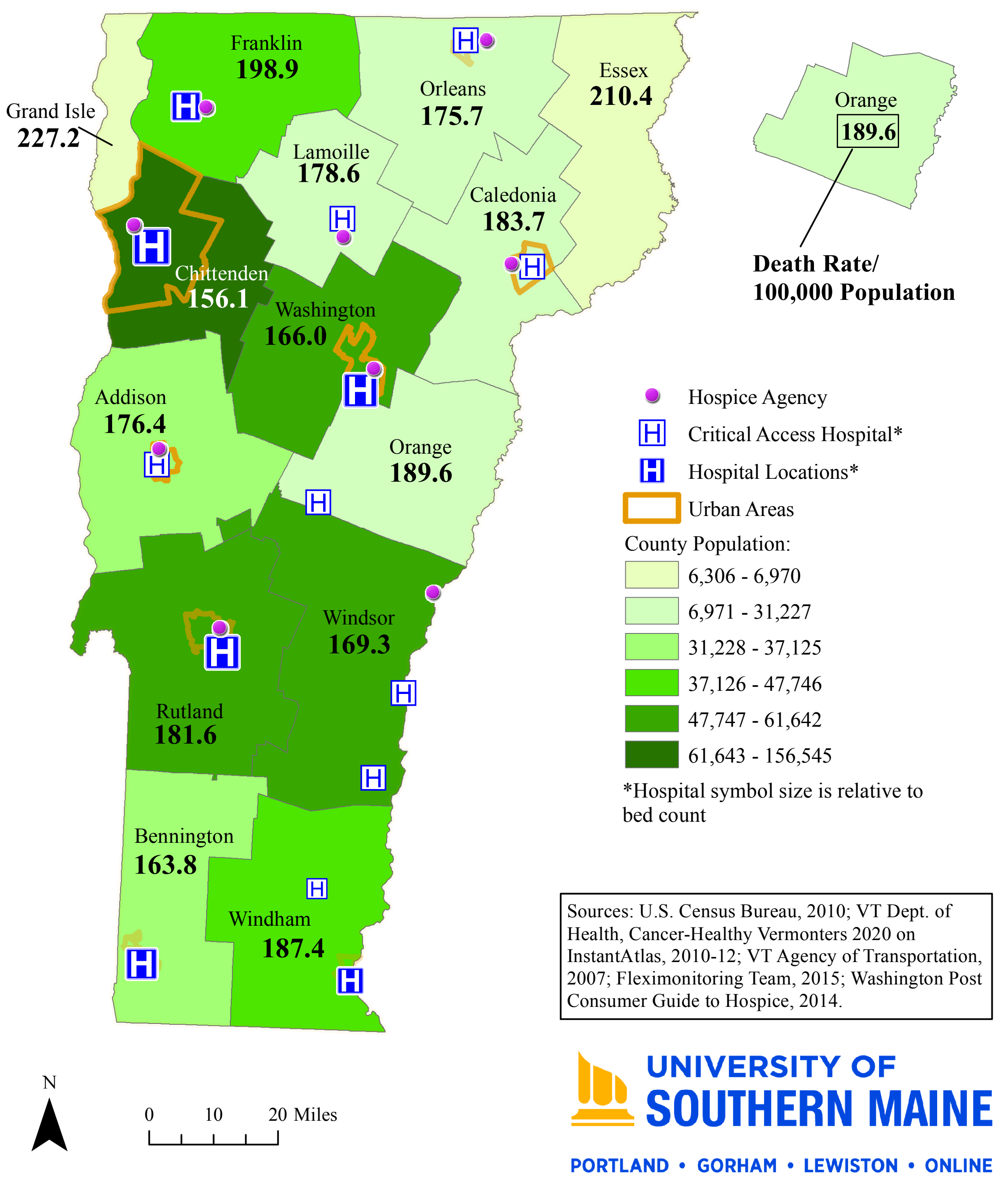
	REGION				
PERCENT WHO ROUTINELY CONSIDER HOSPICE FOR PATIENTS WITH CHRONIC ILLNESS, BY SURVEY PROVIDER GROUP	**Northeast Kingdom**	**Central Vermont**	**Champlain Valley**	**Southwest**	**Southeast**
Home Health	53%	52%	23%	59%	80%
Hospice	50%	57%	50%	79%	69%

	REGION				
PERCENT WHO HAVE HAD FORMAL HOSPICE TRAINING IN THE PAST THREE YEARS, BY SURVEY PROVIDER GROUP	**Northeast Kingdom**	**Central Vermont**	**Champlain Valley**	**Southwest**	**Southeast**
Discharge Planners	57%	38%	30%	88%	40%
Aging/SASH	27%	33%	37%	50%	31%
Home Health	53%	43%	31%	44%	60%
Hospice	50%	88%	83%	94%	80%
Residential Long Term Care	43%	38%	50%	75%	75%

	REGION				
PERCENT WHO SAW NO NEED FOR ADDITIONAL EDUCATION, BY SURVEY PROVIDER GROUP	**Northeast Kingdom**	**Central Vermont**	**Champlain Valley**	**Southwest**	**Southeast**
Discharge Planners	14%	33%	28%	0%	0%
Aging/SASH	0%	0%	9%	11%	13%
Home Health	0%	11%	9%	17%	0%
Hospice	0%	13%	4%	0%	0%
Residential Long Term Care	43%	25%	25%	25%	0%

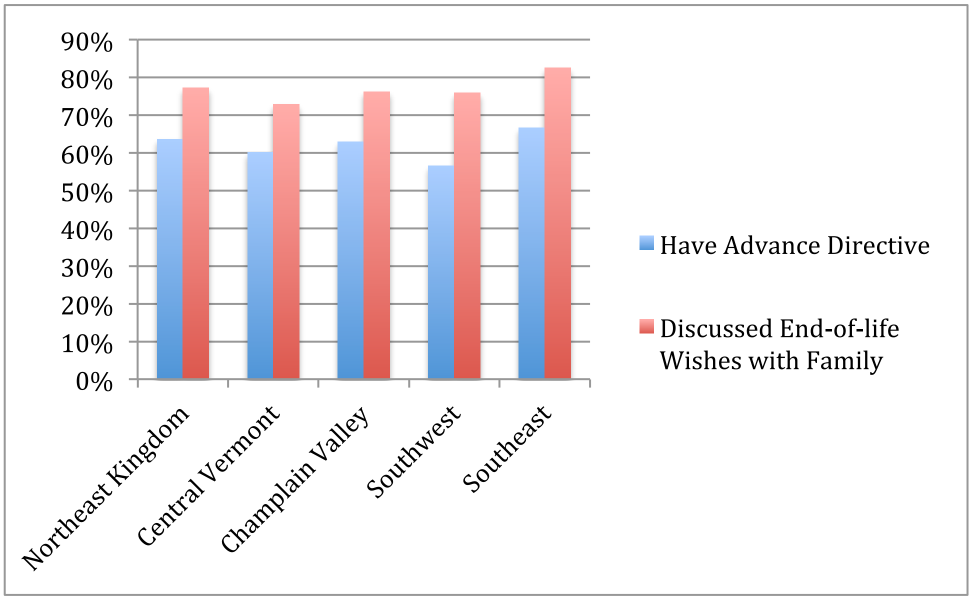
Appendix D: Vermont Malignant Neoplasm Death Rates Map

Vermont Malignant Neoplasm Cancer Death Rates



Sources: U.S. Census Bureau, 2010; VT Dept. of Health, Cancer-Healthy Vermonters 2020 on InstantAtlas, 2010-12; VT Agency of Transportation, 2007; Fleximonitoring Team, 2015; Washington Post Consumer Guide to Hospice, 2014.

Appendix E: Community Survey Responses Regarding End-of-Life Wishes



Appendix F: Regional Knowledge of Hospice, by Survey Group

KNOWLEDGE OF HOSPICE - SCORE OF"10" IS PERFECT

REGION	Community Members	Residential Long Term Care	Home Health Staff	Hospice Staff	Discharge Planners	Aging/SASH
Northeast Kingdom	7.3	9.8	9.2	10.0	9.6	7.6
Central Vermont	7.3	9.2	9.2	9.8	9.5	8.4
Champlain Valley	7.5	9.2	9.0	9.5	8.8*	7.6
Southwest	7.2	9.0	9.1	9.6	9.3	8.1
Southeast	7.5	9.3	9.0	9.4	9.6	7.4

* likely reflects specialization of discharge planners in larger health systems

Appendix G: Information Gaps, by Provider Group

Universal Information Gap:

Question most frequently answered incorrectly by Hospice Staff and ALL other Provider Groups:

A primary goal of hospice is to treat the emotional needs of the dying individual and their family.

Most Frequently Missed Questions:

Discharge Planners

Hospice must stop services if an individual lives longer than 6 months.

Hospice provides medications, treatments, medical equipment, and supplies that are related to a patient's primary illness.

Nursing Home, Residential Care & Assisted Living Staff

Anyone can request an evaluation for hospice enrollment.

Hospice services are typically paid for by health insurance.

Aging/SASH/Other In-home Service Providers

Anyone can request an evaluation for hospice enrollment.

Hospice services are typically paid for by health insurance.

Hospice must stop services if an individual lives longer than 6 months.

Hospice provides medications, treatments, medical equipment, and supplies that are related to a patient's primary illness.

Hospice staff is available by phone any time, day or night.

People who live in nursing homes are eligible for hospice.

Home Health Staff

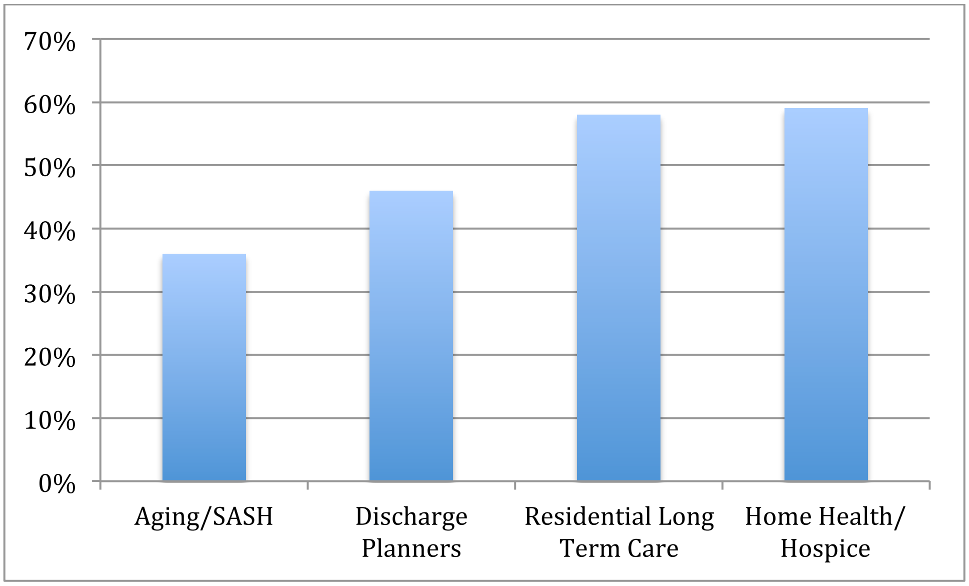
Anyone can request an evaluation for hospice enrollment.

Hospice services are typically paid for by health insurance.

Hospice must stop services if an individual lives longer than 6 months.

Hospice provides grief support to families.

Appendix H: Hospice Education in the Last Three Years, by Provider Group



Appendix I: State Organizations, Websites

Maine

Alzheimer's Association, Maine Chapter. http://www.alz.org/maine/

Maine Hospice Council and Center for End-of-Life Care. http://www.mainehospicecouncil.org/

Maine Office of Aging and Disability Services. www.maine.gov/dhhs/oads/

Minnesota

Community Partners Working Together to Improve Hospice Utilization.

http://c.ymcdn.com/sites/mnhomecare.site-ym.com/resource/resmgr/AM_Handouts_2015/502_MHCA_Annual_Meeting_2015.pdf and Stratis Health's (Quality Improvement Organization) TRUE: Targeting Resource Use Effectively (TRUE) hospice utilization project toolkit: http://www.stratishealth.org/providers/hospice.html

Minnesota Home Care Association. http://mnhomecare.site-ym.com

Minnesota Network of Hospice and Palliative Care. www.homeandhospicecare.org

New Hampshire

Alzheimer's Association, Massachusetts/New Hampshire Chapter. http://www.alz.org/MANH/

New Hampshire Hospice and Palliative Care Organization. http://www.nhhpco.org/

North Carolina

Association of Home and Hospice Care of North Carolina. www.homeandhospicecare.org

The Carolinas Center. http://cchospice.org/

NC Secretary of State Advance Health Care Directive Registry. http://www.secretary.state.nc.us/ahcdr/pdf/registrybrochure.pdf

Vermont

Alzheimer's Association, Vermont Chapter. http://www.alz.org/vermont/

Vermont Department of Disabilities, Aging and Independent Living. http://dail.vermont.gov/

Hospice and Palliative Care Council of Vermont. http://www.hpccv.org/

Vermont Department of Health, McCoy, R. Annual Report on Deaths and Hospice Care: 2015. Public Health Statistics, Division of Health Surveillance, Vermont Department of Health, Agency of Human Services, Burlington, VT. September 30, 2015. http://legislature.vermont.gov/assets/Legislative-Reports/Annual-Report-on-Deaths-and-Hospice-Care-2015-.pd

---