

MONROE COUNTY
HOSPICE NEEDS ASSESSMENT
TASK FORCE
REPORT

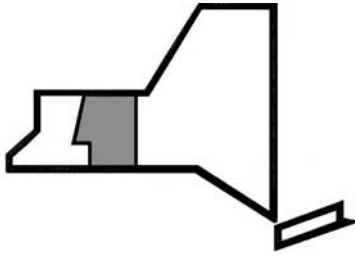
Finger Lakes Health Systems Agency
July 2004

Acknowledgment:

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FINGER LAKES HEALTH SYSTEMS AGENCY

1150 UNIVERSITY AVENUE, ROCHESTER, NEW YORK 14607-1647
(585) 461-3520, FAX 461-0997, TTY 461-4075
Email: FLHSA@FLHSA.org Website: FLHSA.org

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On behalf of the Monroe County Hospice Needs Assessment Task Force, we are pleased to present this report to the community.

We would like to thank each of the Task Force members for their contributions of time, thoughtful deliberation and demonstrated commitment to ensuring that the needs of the dying in our community are understood and met in accordance with the wishes of the patient and the family.

We would also like to acknowledge and thank the staff and leadership of Genesee Region Home Care and Visiting Nurse Service for sharing their data with us so that a comprehensive local analysis of hospice utilization could be conducted.

The recommendations in this report and the hospice services that are developed as a result of the recommendations belong to the community.

To that end, on behalf of the Task Force, we encourage all hospice providers to work collaboratively in developing additional hospice services.

John J. Mahoney
Chair,
Monroe County Hospice Needs Assessment Task Force

Bonnie C. DeVinney
Executive Director
FLHSA

TABLE OF CONTENTS

Hospice Needs Assessment Task Force Members	ii
List of Figures	iii
Executive Summary	iv
I. Background to Study	1
Specific Study Objectives	3
II. Study Process	3
III. Review of Relevant Professional Literature on Hospice Care	4
Brief History of Hospice Development in U.S.	4
Sociodemographic Characteristics of Hospice Patients	5
Diagnostic Characteristics of Hospice Patients	6
Length of Stay in Hospice Care	7
Barriers to Hospice Use	8
Cost Effectiveness of Hospice Care	10
Variation in Hospice Use By County	10
IV. Local Hospice Statistics	11
Hospice Enrollment	11
Site of Care	12
Inpatient Hospice Facility Utilization	14
Hospice Deaths by Gender	14
Hospice Deaths by Age	15
Hospice Deaths by Marital Status	16
Hospice Deaths by Primary Diagnosis	16
Local Statistics: Summary and Observations	18
V. Task Force Discussion and Individual Member Comments	20
Current Limitations to Providing Hospice Care	20
Service Sites	20
Unrealized Demand	23
Major Barriers	23
Criteria For Choosing an Inpatient Hospice Model	23
VI. Recommendations	24
General	24
Residential Options	25
Inpatient Hospice Facility Options	26
Proposal Development	26
End Notes	27
Bibliography	30
Appendix 1 - Projected Hospice Inpatient Bend Need	34

**MONROE COUNTY
HOSPICE NEEDS ASSESSMENT TASK FORCE**

Nancy Adams
Executive Director
Monroe County Medical Society

Howard Beckman, MD
Medical Director
Rochester Independent Physicians Association

Patricia Bomba, MD
Excellus BlueCross BlueShield, Rochester Region

Mary Brady, MD

Mark Broussard
Director
Webster Comfort Care Home

Thomas Dennison, Ph.D.
Syracuse University
The Maxwell School

Judy Deter, CSW
Director
Care Management Services, Unity Health System

Bonnie C. DeVinney
Executive Director
Finger Lakes Health Systems Agency

Renee Jean DeVore, CSW
Social Worker/Medical Case Manager
Strong Memorial Hospital

Beth Dorscheid
Director of Hospice
Visiting Nurse Service of
Rochester and Monroe County

Richard Gangemi, MD
Senior VP for Academic Affairs for ViaHealth
Rochester General Hospital

Barb Quinlan Giehl
Director of Palliative Care Services
Genesee Region Home Care

Robert W. Harrison, III, MD

Pat Heffernan
Executive Vice President
Genesee Region Home Care Assn.

Victoria G. Hines
President and CEO
Visiting Nurse Service of Rochester and Monroe County

Mordecai Kolko

Susan LeDoux, RN
Monroe Co. Dept. Of Health & Human Services

John J. Mahoney, CHAIR
Principal
Summit Business Group, LLC

Kathleen McGrail, MD
Bay Creek Medical Center

William Northwood
Public Relations Director
Genesee Region Home Care & Hospice

Linda Pawlik-Sullivan, RN
Manager, Advanced Practice Nursing- Geriatrics

Drusilla Peyton-Taylor

Timothy E. Quill, MD
Professor of Medicine, Psychiatry,
and Medical Humanities
University of Rochester School of Medicine & Dentistry

Dan Ross
Controller
Visiting Nurse Service of Rochester and Monroe County

Julia Smith, MD
Lipson Cancer Center

Joseph Stankaitis, MD
Chief Medical Officer
Monroe Plan for Medical Care

Father Laurence Tracy
Our Lady of Perpetual Help

Fran Weisberg
President/CEO, Lifespan

Staff
Sara Hartman
Hartman and Associates

List of Figures
all data represent the Monroe County population

Figure	Page
Fig. 1: % of U.S. hospice patients with malignant neoplasms (1992-2000)	7
Fig. 2: Hospice deaths (1998-2003)	11
Fig. 3: Hospice deaths as % of all deaths (1998-2001)	11
Fig. 4: Hospice deaths as % of natural deaths (1998-2001)	11
Fig. 5: Hospice deaths as % of all deaths, age 65 and over (1998-2001)	11
Fig. 6, 7: Hospice deaths, by site of care (1998-2003)	12
Fig. 8: Non-SNF deaths, the average number of hospice days of care (1998-2003)	13
Fig. 9: Average daily hospice inpatients, by month (1998-2003)	14
Fig. 10: Inpatient facility occupancy (2002-03)	14
Fig. 11: Hospice deaths, by gender (1998-2003)	14
Fig. 12: Distribution of hospice deaths, by gender (1998-2003)	14
Fig. 13: Hospice deaths as % of all deaths, by age and sex (2000-01)	15
Fig. 14: Hospice deaths, by age (1998-2003)	15
Fig. 15: Hospice deaths as % of deaths, by age (2000-01)	15
Fig. 16: Hospice deaths as % of deaths, by age/sex/marital status (2000-01)	16
Fig. 17: Hospice deaths, by primary diagnosis (1998-2003)	17
Fig. 18: Distribution of hospice deaths by primary diagnosis (1998-2003)	17
Fig. 19: Hospice deaths as % of deaths, by primary diagnosis (1998-2001)	17
Fig. 20: Hospice deaths, by primary diagnosis and gender (2000-01)	18
Fig. 21: Hospice deaths, by primary diagnosis and age (2000-01)	18
Fig. 22: % of non-nursing home hospice deaths, by zip code (2000-01)	19

Hospice Needs Assessment Task Force

Executive Summary

It is often said that ‘an important measure of our civilization is the care we give to those who are dying.’ While the Hospice movement originated in England in the 1960s, it was not until 1973 that a Hospice was established in the United States. Steady growth in hospice services did not begin to occur in this country until hospice became a Medicare benefit in 1986.

The Finger Lakes Health Systems Agency issued its first report on hospice services in 1975, and following three subsequent analyses of need, recommended in 1988 that the Finger Lakes Region needed 19 inpatient hospice beds.

Today, Monroe County has one dedicated 15 bed inpatient hospice facility at the Genesee Street Campus of Unity Health System (formerly St. Mary’s Hospital), operated by Genesee Region Home Care (GRHCA), several hospice beds scattered throughout hospitals in the community, two certified Hospice agencies – GRHCA and Visiting Nurse Service (VNS); and seven Homes for the Dying/Comfort Care homes operated by voluntary organizations throughout Monroe County.

In February 2004, the FLHSA convened the Monroe County Hospice Needs Assessment Task Force to answer the following questions:

1. Are there gaps in meeting the Rochester-area community’s present and future needs for excellent end-of-life care?
2. Are there barriers to present and future use of hospice as a means of providing excellent end-of-life care?
3. To meet the community’s present and future needs for inpatient hospice care, what kind of facility(s) is required and where should that facility(s) be located?

While the focus of the study was on the need for inpatient beds, the Task Force consistently reinforced the value that the ideal site for hospice care was in the home setting.

In conducting this study, the Task Force reviewed national and local data. Among the most significant local findings are:

1. Enrollment in hospice care has grown steadily from 1,343 persons in 1998 to 2,197 persons in 2003, a growth of 64%.
2. In 2001, 34% of all natural deaths among persons 65 years or older from Monroe County occurred in hospice care.
3. In 2003, for 60% of all Monroe County hospice deaths, all care occurred at home (including nursing homes).
4. Depending on the setting in which the patient receives hospice services, the length of stay ranges from 5 days (inpatient hospice) to 50 days.
5. More than 40% of the patients in hospice care have non-cancer diagnoses.

Based upon analysis of the data and deliberations regarding hospice care in Monroe County, the Task Force concluded:

1. There are gaps in meeting the needs for excellent end-of-life care with the largest gap being the timeliness of referral to hospice. Gaps in meeting the needs of select populations including males, non-cancer patients, inner city and rural residents, persons dying from AIDS, as well as African Americans and Hispanics, were also identified.
2. There are barriers to present and future use of hospice services which are not unique to Rochester and exist at the patient/family level, the physician level, and at the hospice level.
3. There is need for additional inpatient hospice in Monroe County.

The recommendations of the Task Force to address these gaps and eliminate the barriers are on the following page.

RECOMMENDATIONS

GENERAL

1. Hospice care in the home setting, whenever possible, should be promoted and facilitated.
2. Enrollment in hospice care should continue to be promoted. In Monroe County, currently, approximately 30% of all deaths receive hospice care. In some counties across the United States, approximately 40% of all deaths receive hospice care, providing evidence of greater opportunity to serve persons in need. The Task Force identified numerous target areas for expanding hospice enrollment including persons with non cancer diagnosis, males and persons living in inner-city and rural areas of the county.
3. Continue to promote earlier referrals to hospice care, enabling a longer length of stay and greater support to patients and their families in managing the physical, emotional, and spiritual dimensions of the dying process should be promoted.
4. Physicians, particularly specialists treating non-cancer conditions, should be encouraged or required to obtain a consultation at the earliest possible time from an end-of-life specialist for seriously ill patients. Area hospitals should designate appropriately experienced physicians to fill that role within the medical staff.
5. Promote the development of palliative care services, preferably in a designated area, within each hospital. Palliative care units have the potential to generate increased demand for hospice care as we begin to recognize and accept, well in advance, selected clinical conditions as being terminal. The options for palliative care should be discussed with the patient and a palliative care plan should be developed as early in the disease process as is feasible.

RESIDENTIAL OPTIONS

As the population continues to age, resulting in an expanding number of older hospice enrollees, additional residential options will be needed. To meet this growing need and to address the unmet needs of the populations currently underutilizing Hospice services, the Task Force recommends the following:

1. An 8-bed Hospice Residence (enabled in 2003 by New York State Department of Health regulations) should be established and should be equipped to care for persons that cannot be cared for in the Homes for the Dying (e.g. obese, behavioral, immune suppressed etc.).

Placement of this Residence in the central city, where hospice enrollment is lower than other areas in the County, may encourage greater hospice enrollment of ethnic and racial minorities.

2. To improve the efficiency of referring terminally ill persons to Homes for the Dying and the proposed Hospice Residence, a central referral office that is current on bed availability, specific limitations, and unique features of each Home should be established.

INPATIENT HOSPICE FACILITY OPTIONS

1. The Task Force believes that if the community is able to successfully overcome some of the barriers to hospice use, given the aging of the population, Monroe County will need an additional 10 hospice beds for a total community capacity of 25 hospice beds.
2. Recognizing that scattered hospital beds do not optimize hospice care and that hospital Medical/Surgical occupancies will continue to be high, the community should seek to consolidate inpatient hospice services in an appropriate hospice inpatient setting.
3. To recognize the value of geographic distribution and different models offering choice, the potential for two units should be explored. To achieve operational efficiencies, one unit might be co-located with an 8-bed Hospice Residence. A second unit might be co-located on a hospital campus with a palliative care unit. Staff could be shared among these co-located services to accommodate swings in daily census.

4. The lessons learned from the Hildebrandt Palliative Care Center, when located at the former Genesee Hospital, should be carried forward in the development of inpatient hospice services; close proximity, if not co-location with the acute care setting, promotes use of hospice services, allows for the continued involvement of the patient's physician and facilitates ease of transfer from acute care to hospice.

PROPOSAL DEVELOPMENT

The Task Force strongly encourages the development of collaborative community proposals to address the goals cited above. With examination of the possibilities of different sites, perhaps using existing facilities refurbished to meet new uses, creative solutions that were not contemplated by the Task Force may emerge.

MONROE COUNTY

HOSPICE NEEDS ASSESSMENT TASK FORCE

I. Background to Study

In February, 2004, recognizing the increasing utilization of hospice services in the Rochester region, Genesee Region Home Care (GRHC) approached the Finger Lakes Health Systems Agency (FLHSA) to request the Agency's technical assistance in projecting future need for hospice services in Monroe County. Of particular concern were growing capacity constraints in various components of the hospice continuum of services and inadequacies of current inpatient facility arrangements.

The FLHSA had produced its first plan for hospice services in the nine-county Finger Lakes Region in 1981. At that time, interest in hospice services for terminally ill patients as an alternative to "mainstream" acute, terminal care services in community hospitals was beginning to gain momentum nationally. Local health care providers sought direction in developing hospice services, starting with a projection of need and the development of guidelines for establishing the various components of a hospice system in the region. Projections of overall need were based on two major assumptions about the target population:

1. that persons with cancer would be the primary users of hospice services (25% of patients who died from cancer in a given year would be hospice admissions); and
2. that patients with other diagnoses would use hospice services, to a lesser extent (in terms of numbers, representing 10% of cancer patients using hospice services).

By applying this formula, in 1981, the FLHSA estimated that Monroe County would have 362 admissions.

In 1984, subsequent to the enactment of hospice care as a Medicare benefit in 1982, the FLHSA updated its estimates of new hospice admissions. Applying the same formula to estimate need, 370 admissions in Monroe County were projected. A second update was provided in 1988, when the number of hospice cases in 1990 was projected to be 697.

The FLHSA's need methodology also addressed need for inpatient hospice bed capacity to meet short-term needs of hospice patients for management of difficult disease-related symptoms, and also for respite care. Seventy percent (70%) of inpatient bed days were projected to be used by 40% of hospice patients, each primarily dependent on inpatient services for their total hospice care, spending an average of 17 days per admission. The remaining 30% of bed days were projected to be used by the remaining 60% of hospice patients, each primarily relying on hospice care at home but benefitting from brief (i.e. average stay of five days) inpatient hospice care followed by returning home. Applying this bed need formula consistently in the hospice planning activities in 1981, 1984, and 1988, the FLHSA projected an initial need for thirteen (13) hospice inpatient beds in 1981, increasing to seventeen (17) beds to meet need in 1990 for Monroe County Hospice patients. A chart summarizing these need estimates follows: (See Appendix # 1 for the assumptions made to reach these need estimates.)

FLHSA Hospice Needs Estimates		
Monroe County		
Year	Estimated New Hospice Admissions	Estimated Number of Beds
1981	362	13
1984	370	13
1990	697	17

Despite the general expectation of widespread acceptance of hospice care, as more and more people expressed the desire to spend their dying days at home in the 1980s, actual hospice utilization fell short of the FLHSA's estimates of the number of persons who would benefit from hospice care. In 1987, Monroe County had only 173 hospice admissions. These patients were served by the Genesee Region Home Care Hospice of Rochester, which had commenced providing organized services to the terminally ill in 1978 and received hospice Medicare certification in 1985.

During the 1990s, greater awareness of hospice services, both among physicians and patients and their families, contributed significantly to hospice utilization. The Visiting Nurse Service of Rochester and Monroe County, Inc. established the second Medicare certified hospice program in 1991. Between the two hospice programs, enrollment steadily increased. By 2003, approximately

2,500 hospice patients were being served annually in Monroe County. Growth trends suggest a further increase in hospice utilization over the next decade. Between now and 2020 resident Monroe County deaths are projected to increase by 15 percent from an estimated 6,100 deaths in 2003 to 7,000 deaths in 2020. This study aims to anticipate the service requirements associated with growing demand, leading to recommendations specifically regarding acute inpatient hospice facility beds.

Specific Study Objectives

Convened in February 2004, the Monroe County Hospice Needs Assessment Task Force (hereafter referred to as the “Task Force”) identified the following questions to be answered through their study:

1. Are there gaps in meeting the Rochester-area community’s present and future needs for excellent end-of-life care?
2. Are there barriers to present and future use of hospice as a means of providing excellent end-of-life care?
3. To meet the community’s present and future needs for inpatient hospice care, what kind of facility(s) is required, and where should that facility(s) be located? Both geographical and categorical considerations will be evaluated regarding location.

II. Study Process

The Finger Lakes Health Systems Agency created a task force comprising twenty-nine members representative of the major stakeholders of the hospice care delivery system in Monroe County. Categorically, they included representatives of: 1) the medical and administrative staffs of the two Medicare-certified hospice programs, Genesee Region Home Care and Visiting Nurse Service; 2) the Monroe County Medical Society; 3) homes for the dying; 4) advocates and consumers; 5) the three health systems (Strong Health, Unity Health, and Via Health); 6) the Monroe County Department of Health, 7) physician Independent Practice Associations (IPAs); and 8) insurers. The Task Force was chaired by John J. Mahoney, Principal of the Summit Business Group, LLC and former president of the National Hospice Organization (now named the National Hospice and Palliative Care Organization).

The task force held five meetings during the months of February through June 2004. Meeting agendas included presentations on, and discussion of:

1. the professional literature regarding hospice issues relevant to this study,
2. historical hospice utilization trends at both the national and local levels,
3. barriers to hospice utilization and opportunities to expand access to hospice care,
4. basic models of inpatient, acute hospice care, including a presentation of the Hospice Buffalo program, and
5. study findings and recommendations.

Following is a summary of the above five topics.

III. Review of Relevant Professional Literature on Hospice Care

Brief History of Hospice Development in U.S.

It is often said that “an important measure of our civilization is the care we give to those who are dying”. In the United States, interest in hospice care as an exemplary model for addressing physical, emotional, spiritual, and practical needs of dying patients and their families was largely influenced in the 1960s by the hospice movement in England. The first hospice in the U.S. was established in the New Haven, Connecticut area in 1973, funded by a grant from the National Cancer Institute (NCI). Additional hospices received NCI funding through 1980. Based on the experience and outcomes of these demonstrations, the U.S. Department of Health, Education, and Welfare concluded that hospice care was appropriate for federal support ¹.

Following considerable study by the Health Care Financing Administration (HCFA), the Medicare hospice benefit was enacted on a trial basis in 1982², and made a permanent benefit in 1986³. Medicaid and many other insurers subsequently followed suit. With insurance coverage, hospice care for terminally ill patients grew substantially during the ensuing decades⁴ at the rate of 10%-20% per year⁵. As a result of this growth, hospice care has increasingly become recognized as a best practice model of end-of-life care, with its hallmarks including pain management, death at home surrounded by loved ones, and avoidance of needless medical interventions⁶.

Sociodemographic Characteristics of Hospice Patients

Age: Dramatic advances in health care technology in the U.S. over the last several decades have resulted in the majority of persons dying from natural causes. “The phenomenon of chronic illness with an associated prolonged period of decline is now a prevalent trajectory of dying. Indeed, a large majority of people living today can anticipate dying at an advanced age, from consequences of a disease with which they have lived for months to a number of years”⁷. Thus, as expected, the largest users of hospice services are adults, largely age 65 and over, with Medicare being the predominant payer. Of U.S. Medicare decedents age 65 and over, slightly less than 20% receive some hospice care⁸. The greatest growth in the past decade has been among the oldest Medicare beneficiaries who are residents of nursing homes⁹.

Despite their relatively small numbers, pediatric hospice care “has become an important service for children and their families in the past decade”¹⁰, extending to them the hospice program’s special expertise in pain management, symptom control, supporting children in dying at home rather than in a hospital, and providing extended bereavement counseling for parents and siblings. Admission criteria and care protocols may be more flexible than those commonly applied in adult programs and required by Medicare policies. Diagnoses most frequently represented include oncologic, cardiac, and genetic diseases¹¹.

Sex: Based on sampling techniques, the National Home and Hospice Care Association (NHHCA) in 1998 estimated hospice patients nationally as being 57% female and 43% male¹². This percentage distribution is consistent with the female-male percentage distribution in the overall U.S. resident population. Among persons 65 and over, females are 59% of the U.S. resident population; males are 41% (NHCS Population estimates).

Race: Nationally, according to the NHHCA study, 83% of hospice patients are white, 10% are non-white, and 7% are unknown¹³. In the U.S. resident population, 82% are white and 18% are non-white. Among persons age 65 and over in the U.S., 89% are white and 11% are non-white (NCHS Population estimates). Selected studies of hospice utilization using mortality data rather than census data indicate that the discrepancy between minority and white populations is not so large because many minority populations are younger and less in need of hospice services¹⁴.

In communities where there is documented under-utilization of hospice care by minorities, reasons contributing to lower minority use of hospice services include “language difficulties, beliefs about healthcare, lower referral rates, lack of insurance, economic disadvantage, caregiver requirements, and cultural and religious differences”¹⁵.

With increased emphasis on eliminating racial disparities in health outcomes, promoted by the President’s Race Initiative (1997), greater effort is being made to understand the influence of cultural differences on decisions affecting health care. “Although each individual has a perspective that is influenced by many factors such as personal psychology, gender, and life experiences, culture fundamentally shapes the way people make meaning out of illness, suffering, and dying; and therefore also influences how they make use of medical services at the end of life”¹⁶. While there is wide variation of beliefs and practices within any ethnic/racial group, culture gives meaning to life and guidelines for living¹⁷.

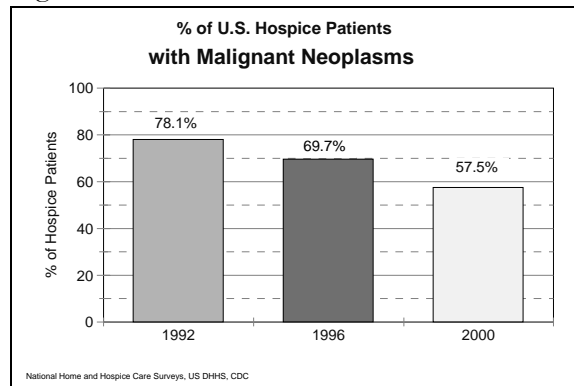
Analysis of lower utilization of hospice care by any racial/ethnic group must take culturally driven value systems into account. Advocates for improving access to hospice care for ethnic/racial minorities must seek to understand the reasons for the differing opinions and beliefs about death and dying to ensure that personal and family choices are appropriately influenced by culture and not driven by mistrust of the medical system, inadequate communication regarding the diagnosis, prognosis, and the treatment options for a terminal illness and racism¹⁸. Hospice providers are proactively seeking ways to promote culturally competent care.

Diagnostic Characteristics of Hospice Patients

Although hospice programs initially focused primarily on terminally ill patients with cancer, the current clinical profile of hospice enrollees nationally is compromised of approximately 60% dying from cancer and 40% dying of other causes, notably: congestive heart failure, chronic obstructive pulmonary disease, AIDS, amyotrophic lateral sclerosis, and other chronic, debilitating illnesses¹⁹. Recently, advocacy has mounted for extending hospice care to greater numbers of persons with end-stage Alzheimer Disease^{20 21}. While hospice care is largely home-based, nursing homes and other long-term care facilities are also included in the definition of “home”. The majority of end-stage Alzheimer Disease patients are in these settings²². Nursing home residents, now 17% of hospice

enrollees, are currently the fastest growing segment of hospice users²³. Figure 1 shows the decline in the percentage of cancer patients among hospice enrollees.

Figure 1



Length of Stay in Hospice Care

Hospice care is offered as a model of palliative care which seeks “to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure”. It “attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them”²⁴. As such, hospice providers emphasize that a reasonable length of stay in hospice care is essential to the patient’s and family’s realizing full benefits. When introduced as a Medicare benefit in 1982, eligibility for hospice care was established for persons with a life expectancy of six months or less, if the illness runs its normal course.

Despite the fact that hospice care provides what most persons²⁵ in the U.S. prefer in end-of-life care²⁵, and that more persons are being served by hospice programs²⁶, studies show that patients typically receive hospice care “for only about two to four weeks”²⁷. “The mean and median lengths of stay have decreased by 25 percent and 40 percent, respectively, over the last decade, and 28 percent of hospice patients die within seven days of admission. In other words, hospice is increasingly being used as a last resort – as a crisis management resource when patients are in or near the dying process. Better than nothing, certainly, but not at all the purpose for which it was designed”²⁸. In sum, the trend is for admission to hospice programs to occur increasingly later in the final phase of terminal illness.

Undesirable consequences of short hospice stays are documented to include:

1. deprivation to patients and their families of more humane and clinically appropriate care;
2. compromised ability of hospice programs to develop and implement a comprehensive care plan meeting patients' and families' goals;
3. abrupt change in care-giver-patient relationships, with too little time to form satisfying successor relationships; and
4. waste of resources associated with pursuing ineffective, aggressive care longer than necessary²⁹.

While premature referrals to hospice care also present problems, these represent a small percentage of cases.

Barriers to Hospice Use

Factors contributing to a dying person's late admission to hospice care, or to lack of admission altogether, are multiple and complex. Comprehensive analyses have been conducted by Dr. Nicholas Christakis, an expert in the field whose research on end-of-life care has been funded by the National Institute on Aging. His work indicates that barriers can occur at many levels: "1) the patient/family level, 2) the physician level, 3) the hospice level, and 4) the market level"³⁰. Excerpted from Dr. Christakis' testimony before the U.S. Senate Special Committee on Aging (2000), these are briefly summarized as follows:

1. Patient/family level
 - Fear of death, managing death, stopping curative care, and being abandoned by the medical providers;
 - Misconception about the purpose of hospice and its policies;
 - Aversion to home death and lack of understanding that alternatives to death at home are available within hospice;
 - Age, race, gender, marital status, income;
 - Attributes of the illness (e.g. its duration and type);
 - Home structure (e.g. whether the patient is living alone or not, how sick the patient's spouse is).

2. The Physician Level

- The need for a prognosis (6 months or less, given the normal course of the disease) and the presence of inaccuracy in any prognosis (the pattern is optimistic prognoses with consequent late referrals to hospice);
- Fear of facing death;
- Poor skills in communicating with patients regarding death, prognosis, and hospice referral;
- Stigmatized views of hospice (e.g. hospice seen as failure by physician);
- Misunderstanding about hospice care (e.g. only for cancer patients);
- Concern about loss of control of the patient;
- Concern about loss of income;
- More favorable attitudes of generalist physicians than of specialists towards hospice;
- Attitudes toward patient traits (e.g. preferential referral by physicians of patients with certain socioeconomic traits or diagnoses).

3. The Hospice Level

- Referral constraints (e.g. inefficient intake mechanisms, poor relations with physician referral base);
- Organizational features of hospices (e.g. in general, for-profit, free-standing, smaller, and newer hospices) tend to get patients early relative to hospices with other organizational models (e.g. hospital-based, larger and older non-profit models).

4. Market-Level (role of market factors is smaller than the role of patient factors)

- Medical infrastructure: earlier hospice enrollment is associated with communities with more hospital beds per capita age 65 and over, greater hospice enrollment per capita age 65 and over, larger percentage of generalist versus specialist physicians, and greater HMO penetration;
- For-profit market penetration;
- Local customs (e.g. there is substantial geographic variation in hospice use – studies of hospice use across the 3,000 counties in the U.S. show that the percentage of decedents who use hospice varies from 0% to 39%³¹).

In addition to the above barriers, Medicare hospice payment policies have also been cited as deterrents to hospice admission under certain circumstances. For example, Medicare reimbursement for specific categories of hospice reimbursement have been found inadequate to cover: 1) high cost palliative care (e.g. palliative radiation and chemotherapy, blood transfusions and products), and 2) the amount of home health aide and nursing care that some patients require to remain at home. These types of payment limitations may discourage referrals to, and acceptance or continuance in, hospice care³².

Cost Effectiveness of Hospice Care

Studies aimed at documenting costs of end-of-life care for hospice enrollees versus non-hospice enrollees have reached differing conclusions, primarily depending upon methodological considerations, e.g. the time period selected for study: last 30 days, last 90 days, last 6 months, or last year of life. There seems to be agreement that hospice care is 25% to 40% less costly than traditional hospital care provided to persons in the last 30 days of life, an advantage that may extend to the last 90 days of life. Studies examining costs of care during the last 6 months and the last year of life indicate that cost savings of hospice diminish, decreasing to 10% to 17% in the last six months of life and to 0-10% over the last year of life^{33 34}.

In summary, it is fair to say that hospice, at best, may produce cost savings over traditional medical care, and, at worst, is no more costly than traditional care. Advocacy of hospice care should therefore be primarily based upon non-economic considerations: a more humane care controlled by patients and their families³⁵.

Variation in Hospice Use By County

While little more than 15% of U.S. decedents use hospice care, analyses of hospice enrollment by county across the approximately 3,000 counties in the U.S. demonstrate considerable variation in hospice use. In terms of percentage of decedents, a range from 0% to 39% was documented, with counties in Florida representing high use and some counties in Indiana showing very low use. Less variation in length of stay in hospice across counties was noted³⁶.

IV. Local Hospice Statistics

Hospice Enrollment

Enrollment in hospice care has been increasing in Monroe County. The number of persons dying with the support of hospice care has increased from 1,343 persons in 1998 to 2,197 persons in 2003 (Figure 2).

Figure 2

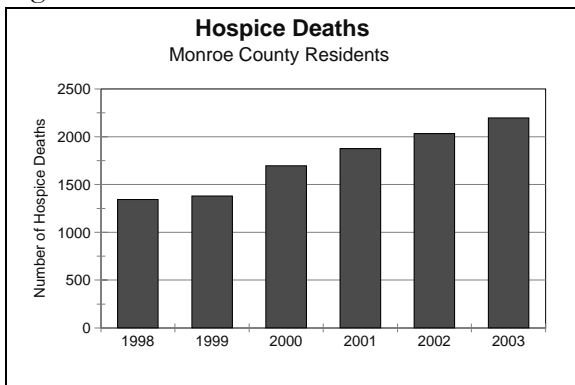
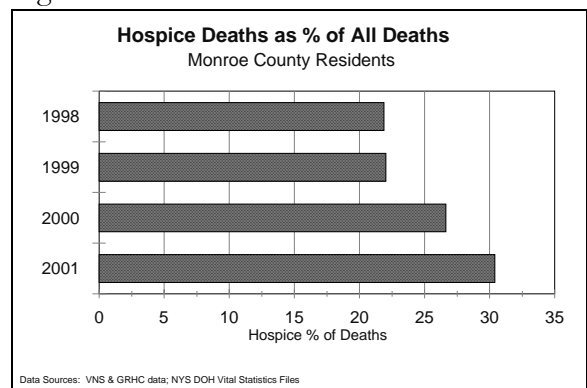


Figure 3



From 1998 to 2001, this represents an increase from approximately 22% to 30% of all deaths (Figure 3).

Hospice deaths as a percent of all deaths due to natural causes (excluding accidents, suicides, and homicides) are slightly higher (Figure 4).

Figure 4

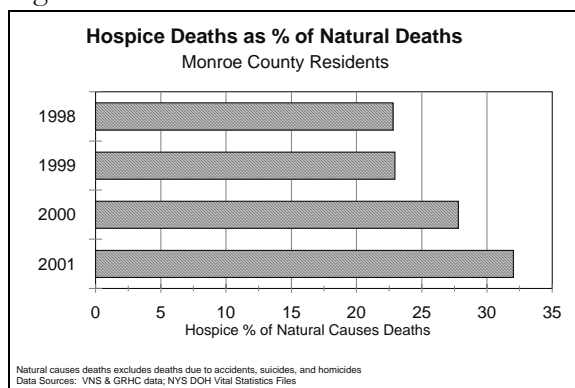
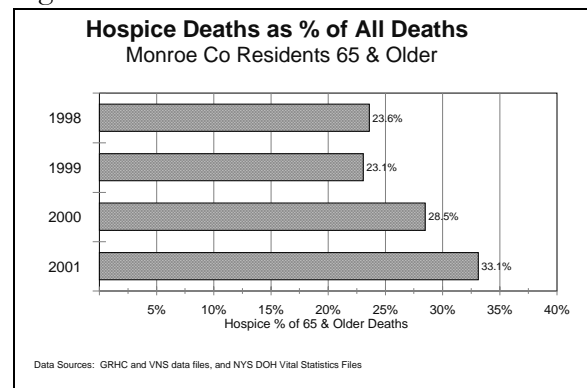


Figure 5



In terms of hospice deaths as a percent of all deaths, Monroe County's experience reflects higher hospice utilization than the nation. In 1998, the most recent year for U.S. data, hospice deaths in Monroe County as a percent of all deaths in the 65 years and older age group, was 23.6% (Figure 5); in the same year, slightly less than 20% of all U.S. Medicare decedents used hospice care³⁷.

Site of Care

In terms of site of care used, hospice patients fall into three categories: 1) those who use only home care (including care in a nursing home and a Home for the Dying/Comfort Care Home)* during their enrollment in hospice, 2) those who only use inpatient care, and 3) those who use a combination of home care and inpatient care.

Hospice care, in its program philosophy, supports dying at home. Approximately 60% of Monroe County hospice decedents die at home (including nursing home) (Figure 6). In 2003, for the first time in Monroe County, the number of hospice enrollees dying in a nursing home exceeded the number dying in their own home (Figure 7).

Figure 6

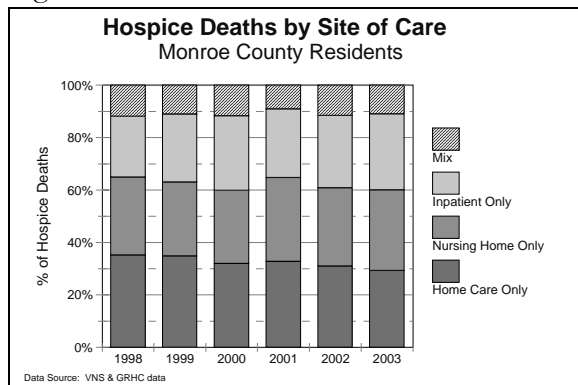
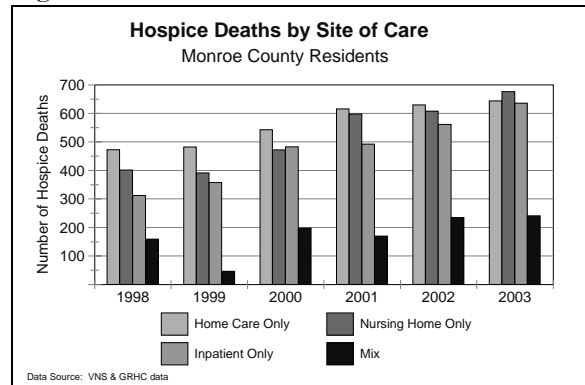


Figure 7

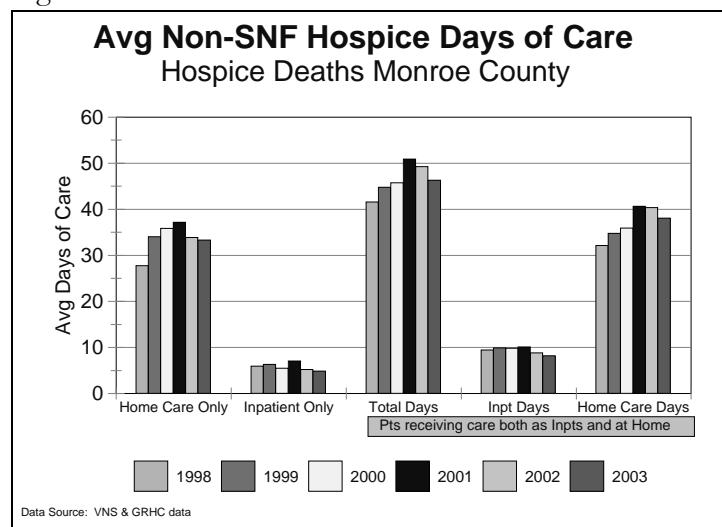


*Homes for the Dying/Comfort Care Homes are unique in New York State. They are residences, offering two beds each, for serving persons during the final stage of life. Admission policies indicate a prognosis of up to three months. These Homes, geographically dispersed throughout the County, are well suited to persons who can no longer remain in their own homes but do not require the acute level of care that is offered in the inpatient hospice settings. All are not-for-profit, independent organizations, operating largely with a volunteer staff. They do not require licensure by the New York State Department of Health. Persons served, however, are enrolled in one of the community's certified home hospice programs.

As shown previously in Figure 6, approximately 25% of hospice decedents in Monroe County receive hospice services only in an inpatient hospice facility. In Monroe County, the category “inpatient” site includes the 15-bed, freestanding inpatient facility operated by the Genesee Region Home Care’s Hospice program at the former St. Mary’s Hospital, as well as a variable number of scattered beds on the Medical/Surgical units of the local community hospitals. The remaining 15% of hospice patients use a mix of home care and inpatient care.

The preponderance of hospice services, measured by “days of care”, are provided in the home (including nursing home) setting. On average in the last five years, persons who use only home hospice care have a length of stay in hospice of approximately 30 to 35 days. Persons using only inpatient care use approximately 5 days of hospice care. Those who use a mix of home care and inpatient care have a length of stay in hospice care of approximately 50 days, of which approximately 10 days are spent in inpatient care. Patients using a mix of inpatient and home services are generally persons whose needs at the very end of life exceed the primary caregivers’ capacity to manage at home or who prefer not to have the actual death take place at home (Figure 8).

Figure 8



Inpatient Hospice Facility Utilization

During 2003, the average daily inpatient census by month in scatter beds and in the hospice inpatient facility ranged from 14 to 21 persons. The average daily census has been steadily climbing since 1998 (Figure 9).

Figure 9

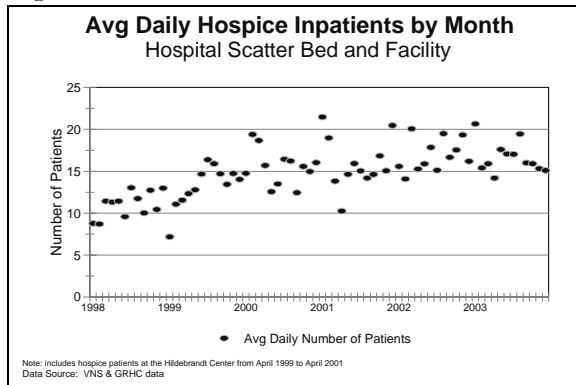
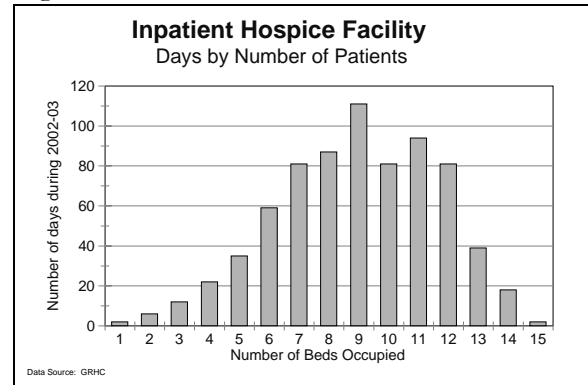


Figure 10



In 2003, the hospice facility was the site of care for 40% to 60% of all hospice inpatients. While inpatient facility occupancy has ranged from one patient to fifteen patients, the facility's usual occupancy fluctuates between seven and twelve patients (Figure 10).

Hospice Deaths by Gender

While hospice decedents in Monroe County who used hospice services have steadily increased over the past six years. The proportion who were females has remained consistently at 60%, and males at 40%, of decedents (Figures 11 and 12).

Figure 11

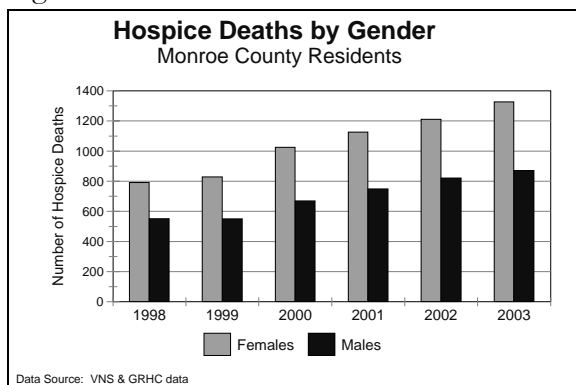
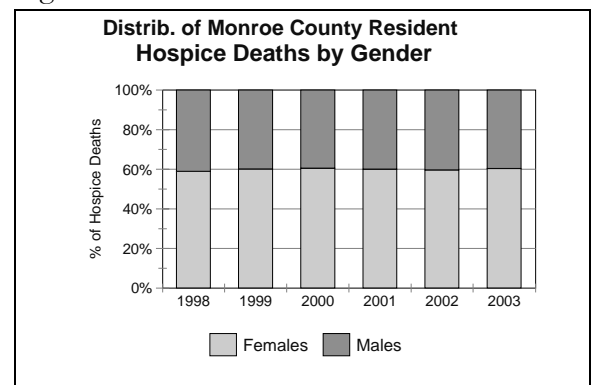
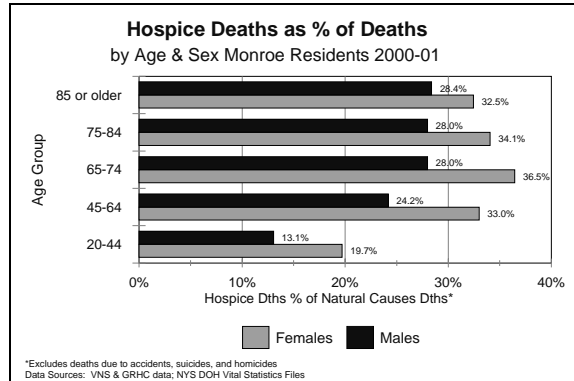


Figure 12



Consistently, across all age groups, females use hospice at a higher rate than males (Figure 13).

Figure 13



Hospice Deaths by Age

Since 1998, the fastest growing age-group represented among hospice patients is the 85 and older age group, followed by the 75-84 age group. This reflects the increasing acceptance of hospice care among nursing home patients and the overall aging of the population. The number of persons under age 75 who have enrolled in hospice has increased at a much slower rate (Figure 14).

Across the three age subgroups of the 65 and older population (65-74, 75-84, and 85 and older), hospice deaths as a percent of total deaths is fairly consistent, indicating that hospice has equally penetrated those markets. The percent of hospice deaths in the 45-64 age subgroup is somewhat lower, but the inclination to pursue aggressive treatment with the goal of prolonging life of younger persons may limit further expansion of hospice care in the under-age 65 population (Figure 15).

Figure 14

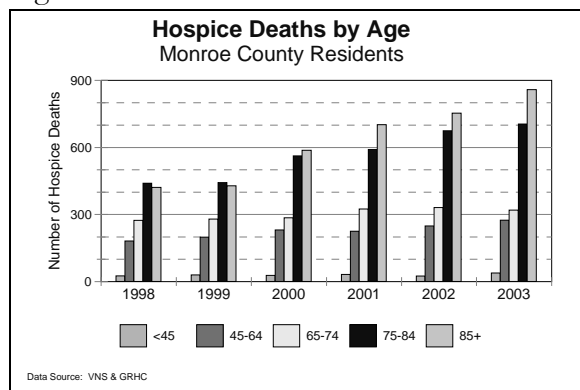
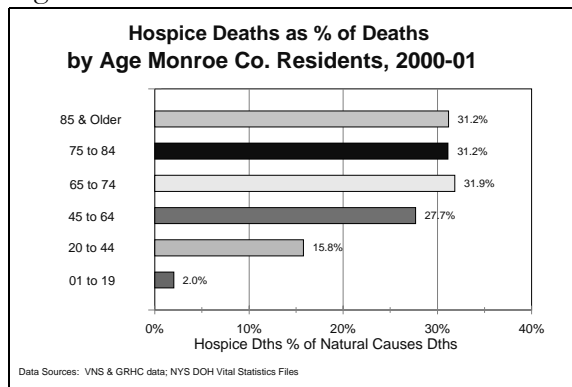


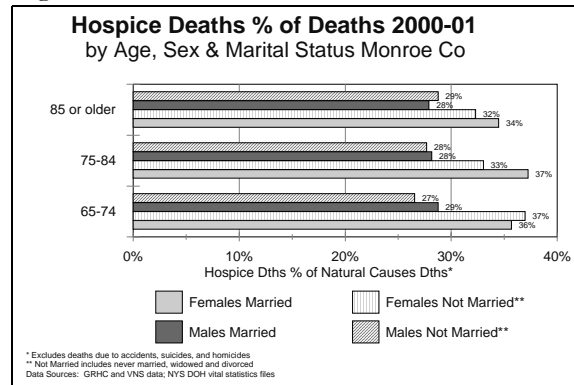
Figure 15



Hospice Deaths by Marital Status

Marital status is not a primary indicator of hospice enrollment for either men or women, with the exception that married women in the 75-84 age group are somewhat more likely to be in hospice than unmarried women. This may reflect a probability that their primary care giver is a frail husband (Figure 16).

Figure 16



Hospice Deaths by Primary Diagnosis

In Monroe County, the number of hospice deaths due to each of the most frequent diagnostic causes associated with hospice deaths is increasing (Figure 17).

Monroe County hospice deaths by primary diagnosis reflect the national trend of an increasing percentage of non-cancer patients (Figure 18). For the two most recent years for which both local and national data are available (year 2000), Monroe County hospice deaths due to non-cancer diagnoses represented approximately 50% versus the national percentage of 42% of all hospice deaths. Monroe County hospices have moved more aggressively to identify and serve non-traditional hospice patients.

Figure 17

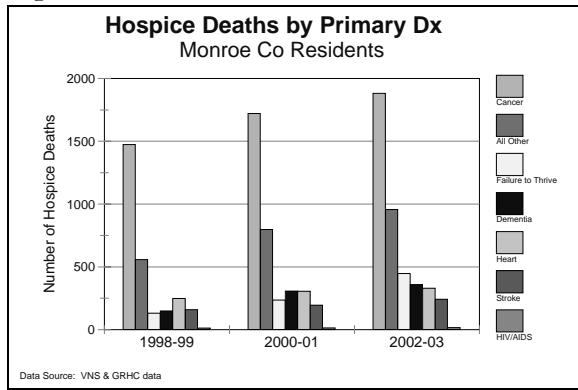
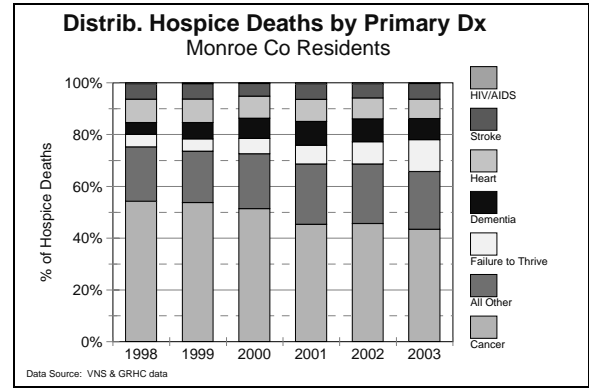
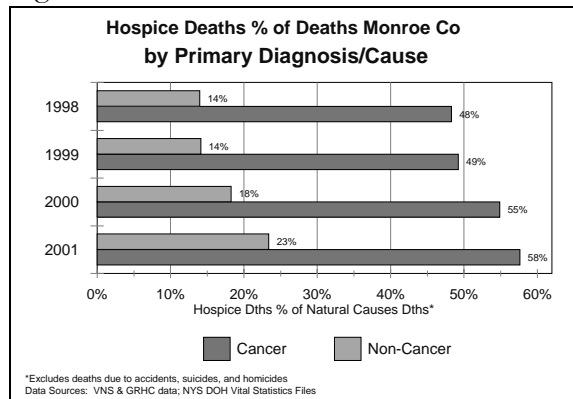


Figure 18



However, when analyzing hospice deaths as a percent of all deaths for that cause of death, persons in Monroe County with cancer are still much more likely to be enrolled in hospice than persons without cancer. In 2001, over 55% of persons who died from cancer in Monroe County were served by hospice; less than 25% of persons who died from other natural causes were served by hospice (Figure 19).

Figure 19



There remains significant opportunity in the local community to further promote hospice enrollment among terminally ill persons with non-cancer diagnoses. This opportunity presents across all age groups and both genders (Figures 20 and 21).

Figure 20

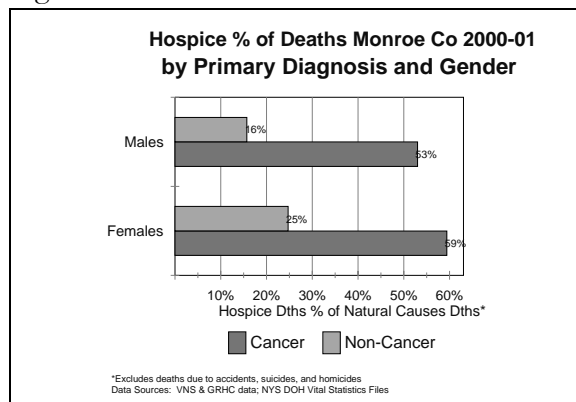
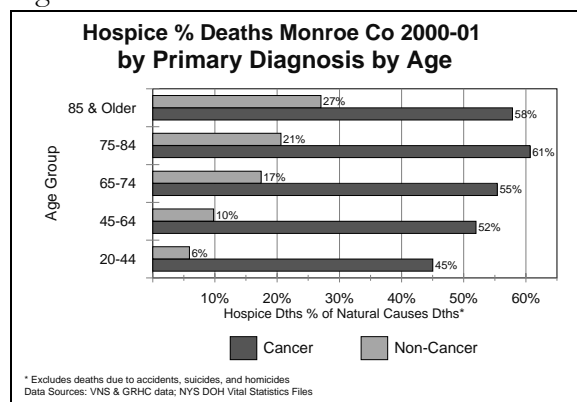


Figure 21



Local Statistics: Summary and Observations

Hospice care continues to reach an expanding number of terminally ill persons and their families in Monroe County. Hospice enrollment increased by 64% from 1998 to 2003, and currently represents approximately 30% of all resident deaths in the County. This experience reflects a higher hospice utilization than the national experience, but there are counties across the nation that achieve comparable or higher utilization (up to 39%). This suggests a potential for achieving higher hospice enrollment locally.

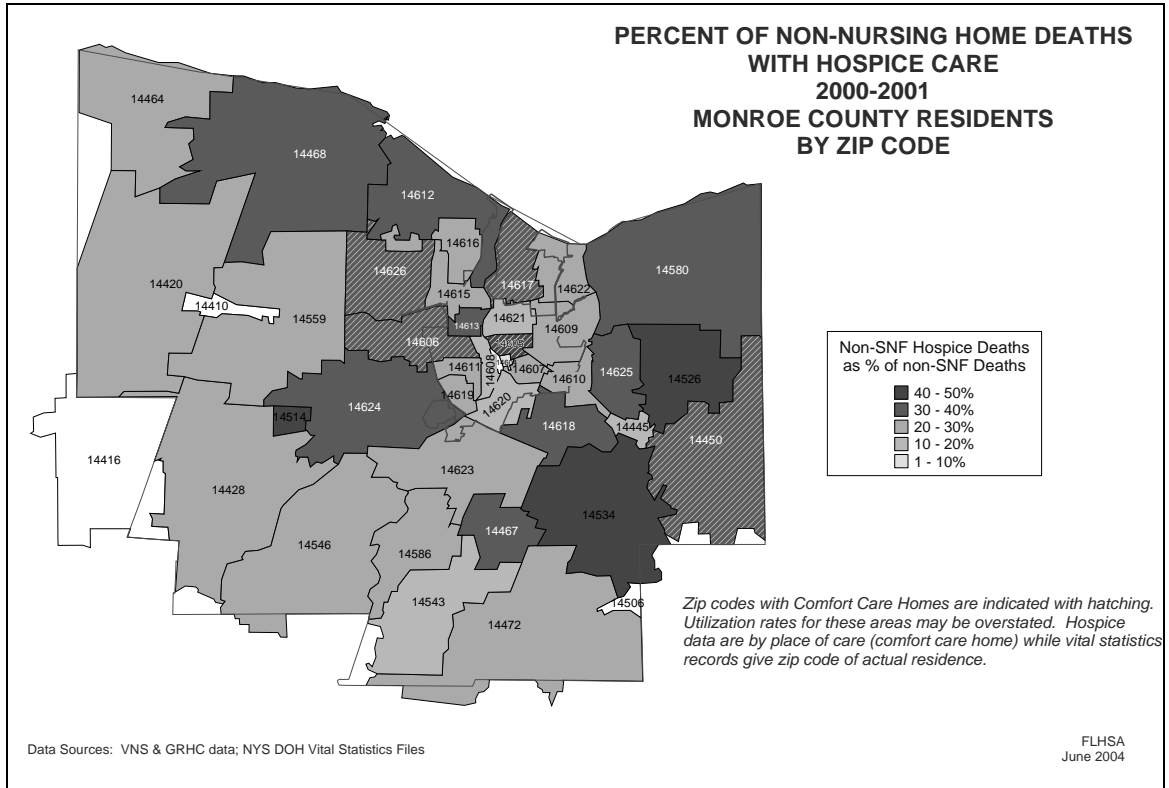
The data suggest significant opportunities for greater enrollment among the following categories of patients:

1. Males: Across all age groups, males represent only 40% of hospice enrollees. Although the lower percentage of male enrollees in the oldest age groups, where females dominate in numbers, would be expected, their lower percentage in the younger age groups, where the male-female ratio is more balanced, suggests barriers to referral.
2. Non-cancer patients: While 55% of terminally ill cancer patients are enrolled in hospice, only 25% of decedents with other diagnoses are enrolled. Greater awareness among physicians and families of the benefits of hospice care for these persons, across all age groups and both genders, needs to be created. Oncologists have become very familiar with hospice; it has been recognized as an integral part of cancer care. Other specialists have less knowledge of

hospice benefits and, thus, less incorporation of hospice in the continuum of care of non-cancer diagnoses.

3. Inner-city and rural residents: Substantial variation of hospice use by zip code, ranging from a low of less than 10%, to a high of 50% of decedents enrolled in hospice care, indicates opportunities for community education that may lead to increasing hospice utilization. (Figure 22)

Figure 22



Opportunities to expand length of stays in hospice care, enabling patients and their families to benefit from comfort care and psychosocial support, are also suggested by the data. The major opportunity includes identification and earlier referral of terminally ill patients who have no potential to benefit from ongoing curative-oriented care. Of special note is the very low average length of stay (5 or fewer days) for patients who receive only inpatient hospice care. This begs the question of whether more accurate prognostication and more effective communications between health care providers, patients and families might lead to more satisfying end-of-life care.

V. Task Force Discussion and Individual Member Comments

Task Force members presented an extraordinary depth and breadth of knowledge about end-of-life care from a wide variety of perspectives, including those of consumers, providers, and insurers. Complementing the analysis of statistical information on hospice utilization and trends and related end-of-life issues, their thoughts and opinions add other relevant information to, and interpretation of, the statistical information. Following are their topics of concern.

Current Limitations to Providing Hospice Care

The two major limitations in delivering hospice care in Monroe County appear to relate to physical capacity and caregiver/staffing availability. Following is a summary presentation of these issues:

1. Service Sites:
 - a. Own home: For a significant number of patients, many factors contribute to one's own home being unsuitable:
 - Patient is not independent in activities of daily living and does not have adequate availability of a primary caregiver to provide coverage 24 hours per day, seven days per week;
 - Primary caregiver is physically or economically unable to provide care at home;
 - Home is not handicapped accessible and/or is unsafe.

Hospice enrollees in Monroe County in these circumstances essentially have two alternative residential options: homes for the dying/comfort care homes (no charges but family donations are significant) and nursing home placement (covered by Medicaid or private pay).

- b. Homes for the Dying/Comfort Care Homes: There are 8 Homes for the Dying/Comfort Care Homes geographically dispersed around Monroe County. Seven operate two beds each; the eighth does not currently have bed capacity but provides volunteers in patients' own residences. These Homes accept hospice enrollees referred by GRHC and VNS with a prognosis of 3 months or less, who are in the active dying process, and who can be safely managed by their staff, primarily comprised of volunteers. The Homes are generally well utilized and frequently do not have a bed available on the day that a referral is made. There are, however, times during the year when some Homes do not accept patients because of volunteer unavailability (e.g. Christmas and New Year's weeks, July/August).

The major reasons for admission to a comfort care home are caregiver burnout, unsafe home, and financial limitations. Not every patient is suitable for these Homes. Depending on the Home, patient status restrictions include, but are not limited to: persons with IVs, obesity, AIDS and other suppressed immune system conditions, behavioral problems, insulin dependent diabetics, infectious diseases, and tracheotomies.

While all the Homes have non-discriminatory admission policies, a scarcity of staff and volunteers in the community representing racial and ethnic minorities presents challenges in meeting culturally driven needs of diverse patients.

- c. Inpatient Hospice Facility: Genesee Region Home Care Hospice has a 15-bed facility at the former St. Mary's Hospital. The facility provides acute care and respite care and is intended for short-stays only (i.e. 2 weeks for acute care, 5 days for respite care). Operating cost issues related to efficient staffing patterns dictate using 12, occasionally 13, beds. Census fluctuates drastically day-to-day. If a consistently high census could be achieved, or if there were an adjacent unit providing another level of service to which staff could "float" as census fluctuates, staffing for the total 15-bed complement would be financially feasible.

While, theoretically, there is more capacity at the inpatient hospice facility than is being used, the geographic location of the facility is perceived by some patients, families, and providers as being a major deterrent to greater use.

Although the inpatient facility accepts referrals from both the GRHC and VNS hospice programs, the vast majority of referrals come from GRHC (93% of the 276 admissions to the facility during the period 11/03-5/04 were GRHC hospice patients). During this same period, the largest number of patients came from their own homes (45%). Of patients referred from area hospitals (127), 54% came from Park Ridge Hospital, 24% from Rochester General Hospital, and 23% from Strong Hospital and Highland Hospital.

- d. Scatter Beds in Area Hospitals: Historically, the inpatient hospice facility has had a higher utilization rate than scatter beds; however, in the past year, scatter beds and the inpatient facility beds have been used in fairly equal numbers. The census between both sites in the past year has ranged from 14 to 21 patients.

Increasing Medical/Surgical occupancy rates have created considerable stress on the hospitals to be able to accommodate hospice patients. While attending physicians have been encouraged by hospital administrative staff to discharge hospice patients to the inpatient hospice facility, a number of factors intervene, reducing the number of transfers:

- The late referrals to hospice result in patients' being close to death. For those already in the hospital, a move to another location is not always welcomed by patient and family.
- Transfer from a hospital inpatient bed to a hospice facility bed leads to a change of physician coverage of the patient. Physicians with long relationships with their patients are reluctant to "abandon" the patient and family at the time of death. Patients and their families, also, are resistant to losing established care providers.
- The complexion of hospice patients and the definition of comfort care are changing. Increasingly, technology is enabling prolongation of life for persons with terminal illnesses, and sophisticated palliative care (e.g. radiation) is available. These interventions are frequently hospital-based.

- More subtle in nature, and more difficult to quantify in terms of impact, is the growing competition that influences behavior and business/operational plans of the three major health systems and local insurers. As the parent organizations of the two certified hospice programs make their strategic alignments, opportunities for collaboration at the community level may be threatened.

Despite the above considerations, there is consensus among Task Force members that scattered beds in hospital settings are not: 1) suited to supporting a hospice philosophy of care, and 2) tenable in the long-run in this community given the growing stress on hospital Medical/Surgical bed occupancies.

2. Staffing: Specific staff shortages were noted in the following sites: own home (home health aides, LPNs), Homes for the Dying (home health aides, volunteers).

Unrealized Demand: The most compelling evidence of unrealized demand for hospice care locally is the very short hospice stay, with referrals to hospice coming very late in the dying process. Task Force members identified unrealized demand among persons in their own homes and, to a lesser extent, in nursing homes (given the already high hospice penetration in area nursing homes), who have progressing, terminal illnesses but are not yet in the imminent dying stage.

Major Barriers: Task Force members described the community's culture as being a major barrier. This culture emphasizes an orientation of both medical providers and their patients toward curative care. It dissuades acceptance of patient conditions as being terminal well in advance of death and precludes planning for end-of-life.

Criteria For Choosing an Inpatient Hospice Model: The community's current arrangements for inpatient hospice care in the unit at the former St. Mary's Hospital, complemented by use of scattered beds, are considered unacceptable by the Task Force to meet future needs.

Given the increasing Medical/Surgical occupancies at area hospitals, Task Force members anticipate that, as time goes by, hospitals will be less likely to devote scattered Medical/Surgical beds to hospice patients. This will drive demand for increased inpatient hospice facility bed capacity.

These considerations led the Task Force to consider new inpatient options. Desirable features of a new option were cited to include:

1. geographic distribution, in the southeast and northwest quadrants of the County, or a central location in the County;
2. utilization of an existing facility, if such could be converted to hospice use at less cost than new construction;
3. co-location or close proximity to a hospice residence and or palliative care unit in order to promote use of hospice, continued involvement of the patient's physician and to facilitate ease of transfer for the patient and the patient's family; and
4. governance that reflects community, versus proprietary, interests, or governance that equitably takes into account the issues presented by two competing hospice programs and three competing hospital systems.

VI. Recommendations

A. General

1. Hospice care in the home setting, whenever possible, should be promoted and facilitated.
2. Enrollment in hospice care should continue to be promoted. In Monroe County, currently, approximately 30% of all deaths receive hospice care. In some counties across the United States, approximately 40% of all deaths receive hospice care, providing evidence of greater opportunity to serve persons in need. The Task Force identified numerous target areas for expanding hospice enrollment including persons with non cancer diagnosis, males and persons living in inner-city and rural areas of the county.

3. Continue to promote earlier referrals to hospice care, enabling a longer length of stay and greater support to patients and their families in managing the physical, emotional, and spiritual dimensions of the dying process should be promoted.
4. Physicians, particularly specialists treating non-cancer conditions, should be encouraged or required to obtain a consultation at the earliest possible time from an end-of-life specialist for seriously ill patients. Area hospitals should designate appropriately experienced physicians to fill that role within the medical staff.
5. Promote the development of palliative care services, preferably in a designated area, within each hospital. Palliative care units have the potential to generate increased demand for hospice care as we begin to recognize and accept, well in advance, selected clinical conditions as being terminal. The options for palliative care should be discussed with the patient, and a palliative care plan should be developed as early in the disease process as is feasible.

B. Residential Options

As the population continues to age, resulting in an expanding number of older hospice enrollees, additional residential options will be needed. To meet this growing need and to address the unmet needs of the populations currently underutilizing Hospice services the Task Force recommends:

1. An 8-bed Hospice Residence (enabled in 2003 by New York State Department of Health regulations), should be established and should be equipped to care for persons that cannot be cared for in the Homes for the Dying (e.g. obese, behavioral, immune suppressed etc.).

Placement of this Residence in the central city, where hospice enrollment is lower than other areas in the County, may encourage greater hospice enrollment of ethnic and racial minorities.

2. To improve the efficiency of referring terminally ill persons to Homes for the Dying and the proposed Hospice Residence, a central referral office that is current on bed availability, specific limitations, and unique features of each Home should be established. (Currently, agencies frequently refer persons to all seven Homes for the Dying to find a bed available.)

C. Inpatient Hospice Facility Options

1. The Task Force believes that if the community is able to successfully overcome some of the barriers to hospice use, given the aging of the population, Monroe County will need an additional 10 hospice beds for a total community capacity of 25 hospice beds.
2. Recognizing that scattered hospital beds do not optimize hospice care and that hospital Medical/Surgical occupancies will continue to be high, the community should seek to consolidate inpatient hospice services in an appropriate hospice inpatient setting.
3. To recognize the value of geographic distribution and different models offering choice, the potential for two units should be explored. To achieve operational efficiencies, one unit might be co-located with an 8-bed Hospice Residence. A second unit might be co-located on a hospital campus with a palliative care unit. Staff could be shared among these co-located services to accommodate swings in daily census.
4. The lessons learned from the Hildebrandt Palliative Care Center, when located at the former Genesee Hospital, should be carried forward in the development of inpatient hospice services; close proximity, if not co-location with the acute care setting, promotes use of hospice services, allows for the continued involvement of the patient's physician and facilitates ease of transfer from acute care to hospice.

D. Proposal Development

The Task Force strongly encourages the development of collaborative community proposals to address the general goals cited above. With examination of the possibilities of different sites, perhaps using existing facilities refurbished to meet new uses, creative solutions that were not contemplated by the Task Force may emerge.

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**FINGER LAKES HEALTH SYSTEMS AGENCY
HOSPICE PLANNING STUDY**

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Monroe County Hospice Needs Assessment Task Force

	<u>PROJECTED HOSPICE INPATIENT NEED</u>			
	<u>2005</u>	<u>2010</u>	<u>2015</u>	<u>2020</u>
<u>Scenario 1: 2003 Utilization Rates Continue</u> → <ul style="list-style-type: none"> • Cancer Hospice Utilization is 61% and 45% and Inpt. Beds • Non-Cancer Hospice Utilization is 27% and 36% use Inpt. Beds • Avg. LOS in Inpt bed is 5.8 days • Increase Inpt. Days by 11% for non-terminal/respice stays and non-county residents • 80% occupancy 	20.0	20.7	21.3	22.3
<u>Scenario 2: 2010 Utilization Increase</u> → <ul style="list-style-type: none"> • Cancer Hospice Utilization increases to 70% and 45% and Inpt. Beds • Non-Cancer Hospice Utilization increases to 30% and 36% use Inpt. Beds • Avg. LOS in Inpt bed is 5.8 days • Increase Inpt. Days by 11% for non-terminal/respice stays and non-county residents • 80% occupancy 		23.4	24.2	25.3
<u>Scenario 3:2010: Scenario 2 + ALOS Increase</u> → <ul style="list-style-type: none"> • Cancer Hospice Utilization is 70% and 45% and Inpt. Beds • Non-Cancer Hospice Utilization is 30% and 36% use Inpt. Beds • Avg. LOS in Inpt bed increases to 7 days • Increase Inpt. Days by 11% for non-terminal/respice stays and non-county residents • 80% occupancy 		27.9	28.9	30.1
<u>Scenario 4:2010: Scenario 3 - Respice and Out of County Increase</u> → <ul style="list-style-type: none"> • Cancer Hospice Utilization is 70% and 45% and Inpt. Beds • Non-Cancer Hospice Utilization is 30% and 36% use Inpt. Beds • Avg. LOS in Inpt bed is 7 days • No additional days for Respice and non-county residents • 80% occupancy 		25.1	25.9	27.0