

**End-of-Life Care in New Hampshire:
A Report from Communities**

New Hampshire Partnership for End-of-Life Care

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- NH County Nursing Homes
- NH Association for Healthcare Quality
- University of New Hampshire

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WHAT IS THE FOUNDATION?

The Foundation for Healthy Communities is a non-profit corporation that exists to improve health and health care. It was formed in 1968 by the New Hampshire Hospital Association as an educational and research organization for hospitals. In 1996, it was re-organized with a new and broader mission--to be an incubator that has the potential to affect people's health beyond the hospital and beyond New Hampshire.

Today, the Foundation is a partnership involving northern New England acute care hospitals, health plans, clinicians and home care agencies. It is guided by a broad-based Council representing the organizations involved.

The Foundation's primary objectives are:

- a.) to collect and analyze data about health, and the delivery, financing, management and organization of health services,
- b.) to promote, sponsor and conduct research and scientific investigation relative to health delivery process improvement and health policy, and
- c.) to publish information, sponsor education and training, and facilitate innovation for the improvement of health and the creation of healthy communities.

WHAT IS THE N.H. PARTNERSHIP FOR END-OF-LIFE CARE?

The Partnership is a group of New Hampshire organizations that helps people to plan for their health care, talk about their choices and have them respected. It's goal is to create a statewide advance care planning initiative to increase understanding about end-of-life care and promote policy changes that support the delivery of quality, comprehensive end-of-life care.

End-of-Life Care in New Hampshire: A Report from Communities

EXECUTIVE SUMMARY

Hospitals, nursing homes, home care agencies and hospice programs serving communities throughout New Hampshire were invited to participate in a statewide, voluntary, medical chart review project to document end-of-life care issues. The information, based on 782 adult deaths (age 18 years or older) during February-March 2002, was compiled to provide information on end-of-life care concerns. This chart review data represents approximately half the adult deaths in a two-month period in New Hampshire (Vital Records, 1998, average of 783 adult deaths/month). Over half of all deaths in this study (54%) occurred in hospitals, 19% occurred in nursing homes, and 27% occurred in hospice. Compared to 1998 Vital Records report, there were significantly more deceased subjects who died in hospitals (54% versus 45%) and fewer in nursing homes (19% versus 25%) in the study group. Key findings are noted below.

Most decedents were over the age of 75, female and had Medicare as their primary source of insurance.

- The average age (mean) of decedents in the study was 76 years. For nursing home decedents, the average age was 86 years; 16% of hospice decedents were age 64 or younger.
- More than half (54%) of the decedents in the study were female.
- Forty-five percent of decedents in the study were married. Most nursing home decedents (62%) were widowed.
- Medicare was the primary insurance (74%), followed by managed care/private commercial insurance (11%), and Medicaid (9%) for all organizations.
- Significantly more of the deaths in nursing homes were covered primarily by Medicaid (34%) compared to either hospitals (4%) or hospice (1%).
- Compared to the chart study in 1998ⁱ, decedents in the 2002 study population tended to be slightly older (34% over the age of 85 in 2002 versus 30% in 1998) and more likely to have Medicare (77% in 2002 versus 64% in 1998) as their primary insurance.

The majority of deaths in 2002 were from “other internal causes” (e.g., respiratory failure, UTI, food/vomit pneumonitis, etc.) or cancer. The five most frequent primary diagnoses did not change, but their order of importance did change. The most likely reason for the differences in the two study groups is the fact that more charts were obtained from hospitals in 2002 compared to 1998.

- The most frequent primary diagnosis in 2002 was “other internal causes” (26%); followed by cancer (22%), heart disease (19%), pneumonia and influenza (9%) and strokes (5%).
- The top five diagnoses were the same for 2002 as 1998; however, significantly more decedents died of cancer (30% in 1998 compared to 2002; 17% died of other internal diseases compared to 26% in 2002; and 16% died of heart disease in 1998 compared to 19% in 2002.
- There were significantly more deaths from pneumonia in 2002 (9% versus 3% in 1998) and significantly fewer deaths from stroke (5% in 2002 versus 9% in 1998).

More people are using hospice care at the end of life in 2002 compared to 1998. Hospice care is highly regarded yet not fully understood.

- While 27% of cases in the study were known to be in hospice programs, more than one third (35%) of those cases entered hospice care in the week before they died. This is an increase from 28% of the decedents entering hospice in the week before death in 1998.
- Almost two-thirds of hospice decedents (64%) entered hospice within a month of death.

- Among hospice decedents, the median length of stay in hospice was 14 days; however, 12% of hospice decedents used hospice for over 3 months and 5% used hospice for over 6 months.
- More than half (53%) of hospice decedents died at home, while 20% died in a nursing home. There was an increase from 3% in 1998 to 9% in 2002 of hospice decedents who died in a hospital. It was unknown for 15% of hospital decedents whether they were in hospice care and hospice status unknown for 10% of nursing home decedents.
- The majority of focus group participants indicated that hospice services were seamless and outstanding. However, many participants were unaware of how hospice actually worked or that services could be accessed much sooner than the last week or month of life.

Major interventions at the end of life are limited.

- Fifteen percent of all decedents, or 40% of the hospital cases, were in a hospital intensive care unit (ICU) at the time of death or within that last 48 hours before death.
- 11% of the decedents were admitted to the ICU on the day of death, while 25% were admitted within 48 hours of death.
- Key treatments at the end of life were generally limited within the last 48 hours of death: 12% of the patients were on a ventilator, 9% were resuscitated, 7% were extubated, and 2% had surgery.
- The median length of stay among hospital decedents was 4 days and for nursing home decedents it was 708 days, almost 2 years.

While pain assessment, other symptom assessment and psychosocial support for the patient and family at the end of life did not change significantly between 1998 and 2002, notations in the charts for chaplaincy or a spiritual care consult for the family increased significantly (20%) in 2002.

- Pain/discomfort was assessed within 48 hours of death for 88% of the study population for both 1998 and 2002.
- Other physical symptoms besides pain/discomfort was the problem or symptom assessed most often by all health providers in the last 48 hours before death (93%).
- The family's emotional needs were noted in 73% of charts and 43% of the charts recorded a chaplaincy or spiritual care consult for the decedent in the last 48 hours before death. The offer of a spiritual care consult represents a 15% increase from 1998.

A “Do Not Resuscitate” (DNR) order was the most common Advance Directive. Compared to 1998, the number of decedents with a Durable Power of Attorney for Health Care (DPAHC) or Living Will decreased, most likely due to an increase in hospital charts and decline in nursing home charts in the study. However, the inclusion of a values history almost tripled between 1998 and 2002.

- Over 80% of decedents had a DNR order in both study populations. The majority of DNRs were prepared on (36%) or after (58%) admission to a facility.
- Forty-five percent of the decedents had a DPAHC, and 37% had a living will.
- Only 25% of persons under age 55 years had either a DPAHC or living will, while 73% of persons 55-84 years had either these two directives; 60% of persons in this age group had both a DPAHC and living will, compared to only 10% of those under age 55.
- Compared to 1998, there were significantly fewer individuals in the 2002 study population who had either a DPAHC (45% versus 57%), or a Living Will (50% versus 37%). The most likely reason for this finding is the greater proportion of charts coming from hospitals compared to nursing homes in 2002. Nursing home decedents were significantly more likely to have a DPAHC than hospital or hospice decedents.
- A values history was noted in significantly more charts of decedents in 2002 (59%) than in 1998 (21%).

About two-thirds (65%) of the charts documented the ability of the deceased to make their own decisions, and a DPAHC or a Living Will was activated in about one-third of the cases.

- About one-third (35%) also documented an alternative decision-making process.
- DPAHCs were activated in 28% of the cases, while living wills were activated in only 13% of the cases.

The chart audit identified variations among the individual organizations that submitted data. The findings are being used to inform health professionals and the public and initiate statewide efforts to improve the delivery of end-of-life care in New Hampshire.

According to focus group participants, end-of-life care planning is still more likely to be conducted during a crisis, Advance Directives are still a source of confusion, and more education and on-going communication between patients, families and providers is needed.

- Nine focus groups encompassing 83 patients, family members and providers were conducted in Laconia, Dover and Merrimack during the spring and summer of 2002.
- Focus group participants indicated that they generally waited to discuss or prepare advance directives until a crisis arose (death or imminent death), or they conducted advance care planning as part of their on-going estate planning. In either case, they did not generally talk to their physicians about it. This finding supports data from the 1998 New Hampshire baseline survey conducted at the beginning of this project in 1998 in which only 7% of respondents said they talked to their health care provider about end-of-life care decisions.
- Some participants did not know about advance directives. Others indicated that although they had been asked about them when they or a loved one entered the hospital and had indicated that they would like more information, there was little or no follow-through.
- The DNR order, particularly with respect to the use of 911 and EMS was particularly confusing to participants.
- Participants generally felt that there is too much emphasis on the documents and not enough on the actual wishes of the loved one.
- Most reported that having the advance directive documents was not sufficient to ensure dignity at the end of life, especially as disease or illness progressed and the needs and desires of patients and families evolved during the transition to death.
- Families, patients and providers all reported that conflict among family members remains a barrier to improve end-of-life care.
- All participants agreed that there is a need for better communication among the various healthcare providers, and between providers and patients and their families. The groups were unanimous that there needs to be more dignity at the end of life.

PROJECT OBJECTIVE:

Assess the level of interest in end-of-life care services among health providers and collect new information to better understand end-of-life care issues in a cross-section of health care provider organizations in New Hampshire.

METHODS:

A volunteer committee of health professionals, the N.H. Partnership for End-of-Life Care, was organized by the Foundation for Healthy Communities to create a chart review instrument for health care organizations statewide to conduct an end-of-life care chart review. The committee adapted a chart review instrument based on the toolkit instrument by the Center for Care of the Dying at George Washington University in Washington, DC. The instrument was pilot tested at a home care and hospice program and revised. It was estimated to take 20-24 minutes for a nurse to complete one chart review. The chart review had 20 questions and was designed to minimize interpretation by the reviewer. General demographic information, diagnoses, problem/symptoms and treatments administered in the last two days of life and directives were the major topics included in the chart audit. Appendix A. contains copies of the chart review instrument and instructions for the project.

A letter of invitation to participate in the project with chart review instructions and the instrument was sent in May 2002 to:

- the senior administrator responsible for quality management at the 26 acute care and 2 specialty hospitals in NH;
- executive directors of 43 hospice/home care agencies; and
- administrators at 84 nursing homes.

The health care organization lists were compiled with the cooperation of the NH Hospital Association, Home Care Association of New Hampshire, NH Health Care Association, NH Hospice and Palliative Care Organization and the ten county nursing homes. The 155 organizations surveyed represent all of the major licensed health care provider agencies in New Hampshire. A reminder notice to submit chart reviews was sent in June. The deadline for completed chart review instruments was July 31, 2002.

Data entry was conducted at the Foundation for Healthy Communities and data analysis was provided by Michele Solloway, Ph.D. at the University of New Hampshire.

RESULTS:

A total of 803 completed chart reviews were submitted from 48 health care organizations. The overall response rate was 42 percent. Twenty hospitals out of 26 (77%) responded; 11 home care/hospice programs out of 39 home care/hospice programs and one independent hospice responded (28%) and 17 nursing homes out of 88 nursing homes responded (19%).

A check for duplicate chart reviews among the different health care organizations was done once the data entry was completed. This occurred because some hospice or home care patients died in a hospital or nursing home. For purposes of this analysis, when duplicate chart reviews were submitted from both a hospital and a home care/hospice program the hospital's chart review was used for this analysis. If a duplicate chart review came from a nursing home and a home care/hospice program then the home care/hospice chart review was used. There were 21 duplicate records identified and omitted from the database providing a total of 782 cases for the study (424/54% cases from hospitals, 148/19% cases from nursing homes and 210/ 27% cases from home care/hospice programs). This chart review data represents approximately half the adult deaths in a two-month period in New Hampshire (Vital Records, 1998, average of 783 adult deaths/month).

FINDINGS:

General Characteristics:

A total of 782 charts or cases were used in the analysis. The average age (mean) of decedents in the study was 76 years. For nursing home decedents, the average age was 86 years. Analyzing age groups by the type of provider organization identified that almost two-thirds (65%) of nursing home deaths were in the age group 85+ years old while among home care/hospice decedents less than one-third (30%) were 85 years or older (Figure 1).

More than half (54%) of the decedents in the study were female. Among hospital cases, males accounted for 55% of the deaths. In nursing homes, females accounted for 75% of the deaths. Forty-five percent of decedents in the study were married: more than half of the home care/hospice decedents (59%) were married, slightly less than half of hospital (47%) decedents were married, and only 22% of the nursing home cases were married. The majority of nursing home decedents (66%) were widowed. The next of kin identified in the medical record was most often the spouse (39%) or a son or daughter (38%), followed by a sibling (5%); 18% were non-family members (16%) or unknown (2%). Among nursing home cases, more than half (55%) identified a son or daughter as next of kin (Figure 2).

Figure 1

AGE PROFILE BY PROVIDER ORGANIZATION

	All Decedents (n=779)	Hospitals (n=424)	Nursing Homes (n=148)	Hospice (n=210)
Average Age (mean)	76 years	73.5 years	86 years	76 years
Age Groups				
18 - 44	2%	4%	0%	1%
44 - 54	5%	6%	0%	6%
55 - 64	8%	10%	2%	9%
65 - 74	19%	22%	8%	22%
75 - 84	32%	34%	25%	32%
85+	34%	25%	65%	30%
Total	100%	100%	100%	100%

*Differences are statistically significant at $p < .0001$.

The predominant religion of decedents in the study was Roman Catholic (38%) followed by Protestant (22%) and None (19%). The religious affiliation of a decedent was known most often among nursing home cases with only 7% Unknown, while the religious affiliation of more than one third (37%) of home care/hospice cases was Unknown. Medicare was the primary insurer for most decedents (74%) in the study. Managed care/private commercial insurance represented the next largest source of insurance coverage (11%) followed by Medicaid (9%). There were no uninsured represented in this study. Primary insurance varied by the type of provider organization with Medicare covering nearly three-fourths (73%) of hospital decedents while among nursing home deaths the major split was Medicare (60%) and Medicaid (34%). Among home care/hospice decedents, Medicare covered 85% with managed care providing coverage for 9% (Figure 2).

Figure 2

GENERAL PROFILE BY PROVIDER ORGANIZATION

Gender*	All Decedents (n=782)	Hospitals (n=424)	Nursing Homes (n=148)	Hospice (n=210)
Male	46%	53%	30%	45%
Female	54%	47%	70%	55%
Total	100%	100%	100%	100%
Marital Status*				
Married	45%	47%	23%	59%
Widowed	39%	32%	66%	32%
Divorced/Separated	7%	9%	5%	6%
Never Married	9%	13%	7%	3%
Total	100%	100%	100%	100%
Next of Kin*				
Spouse	39%	42%	22%	43%
Son/Daughter	38%	31%	55%	41%
Other	16%	18%	20%	11%
Sibling	5%	7%	2%	3%
Unknown	2%	2%	1%	1%
Total	100%	100%	100%	99%
Religion*				
Roman Catholic	38%	41%	45%	28%
Protestant	22%	23%	24%	20%
Unknown	19%	14%	7%	37%
None	12%	15%	9%	9%
Other	8%	7%	14%	5%
Jewish	1%	1%	1%	1%
Total	100%	100%	100%	100%
Insurance*				
Medicare	77%	73%	60%	85%
Commercial/Managed Care	11%	15%	1%	9%
Medicaid	9%	4%	34%	1%
Unknown	3%	4%	3%	2%
Other	0%	3%	2%	2%
Self-Pay/Uninsured	0%	0%	0%	0%
Total	100%	100%	100%	100%

*Differences are statistically significant at $p < .0001$.

Diagnoses:

Cancer was the most frequently identified primary diagnosis (169 cases) representing 22% of decedents in the study. It was followed by heart disease (155 cases, 19%), pneumonia and influenza (69 cases, 9%) and cerebrovascular accident or strokes (43 cases, 5%; Figure 3). Using the same ICD-9 Codes for causes of death as the NH Department of Health and Human Service's Health Statistics Section, the ten leading diagnostic groups for decedents in the study are shown in Figure 3. Other Internal (respiratory failure, food/vomit pneumonitis, urinary tract infections nos (not otherwise specified), post-traumatic pulmonary insufficiency, etc.) was the largest group at 26% with Malignant Neoplasm (Cancer) representing 22% of cases in the study and Heart Disease at 20%.

Figure 3

TEN PRIMARY DIAGNOSTIC GROUPS

Diagnosis Group	ICD-9 Code¹	All Cases (n=782)
1. Other Internal ²	001 - 799	26%
2. Malignant Neoplasm (cancer)	140 - 208	22%
3. Heart Disease	390 - 398	20%
4. Pneumonia & Influenza	480 - 487	9%
5. Cerebrovascular	430 - 439	5%
6. Chronic Obst. Pulmonary Disease	490 - 496	4%
7. Mental Disorders	290 - 319	3%
8. Central Nervous System	329 - 349	3%
9. Unintentional Injuries	800 - 949	3%
10. Nephritis, Nephrotic Syndrome, Nephrosis	580 - 589	1%
All Other Diagnoses		4%
Total		100%

1. The Diagnostic groups and ICD-9 Codes were selected to match those used by the NH Department of Health and Human Services, Office of Community and Public Health, Health Statistic Section (Vital Records)
2. Other Internal includes respiratory failure, food/vomit pneumonitis, urinary tract infections, post traumatic pulmonary insufficiency, gastrointestinal hemorrhage nos, hypertension nos, post inflammatory pulmonary fibrosis, etc.

Analyzing the top five diagnostic groups by type of provider organization identified Malignant Neoplasm accounting for nearly two-thirds (64%) of the cases among home care/hospice cases. Only for nursing home cases does Mental Disorders (13%) appear among the top five diagnostic groups. Other Internal (25%) and Heart (24%) represent nearly half of all hospital cases (Figure 4).

Figure 4 **PRIMARY DIAGNOSIS GROUPS BY ORGANIZATION TYPE**

Organization Type	Diagnosis Group	% of Cases
Hospitals		
	Other Internal ¹	30%
	Heart Disease	26%
	Pneumonia & Influenza	13%
	Malignant Neoplasm	11%
	Cerebrovascular	5%
Nursing Homes		
	Other Internal	24%
	Heart Disease	16%
	Mental Disorders	11%
	Central Nervous Systems	9%
	Cerebrovascular	9%
Home Care/Hospices		
	Malignant Neoplasm (Cancer)	53%
	Other Internal	20%
	Heart Disease	9%
	Chronic Obst Pulmonary Dis	9%
	Cerebrovascular	3%

1. Other Internal includes respiratory failure, food/vomit pneumonitis, urinary tract infections, post traumatic pulmonary insufficiency, gastrointestinal hemorrhage nos, hypertension nos, post inflammatory pulmonary fibrosis, etc.

Hospice Care:

Almost one third (32%) of decedents in the study received hospice care. There is a wide range among the three types of provider organizations with home care/hospice organizations reporting 90% of their cases receiving hospice care, nursing homes reported 10% and hospitals reported 5%. Some provider organizations did not know if the decedent was receiving hospice care. Over one-fifth (21%) of hospital cases and 10% of nursing home cases indicated that they did not know from the medical chart if the decedent was receiving hospice care (Figure 5).

Figure 5	DECEDENTS IN HOSPICE CARE			
	All (n=782)	Hospitals (n=423)	Nursing Homes (n=146)	Home Care / Hospices (n=207)
Yes	27%	4%	19%	82%
No	60%	81%	70%	11%
Don't Know	12%	15%	11%	7%

Length of Stay:

The average length of stay (median) among the three types of provider organizations ranged from 4 days for hospital cases to 574 days, about 1.5 years, for nursing home cases. The home care/hospice organizations reported 14 days as the average length of stay. Examining length of stay for hospice cases (n=210) more closely reveals that 23% of decedents were admitted into hospice care within 3 days before death, more than one third (35%) within a week before death and almost two-thirds (64%) in the month before death.

Place of Death:

Most home care/hospice decedents died at home (53%) with 22% dying in a nursing home and 9% dying in a hospital. Most nursing home cases died in the nursing home (96%) although 3% died in a hospital. Similarly, 96% of the hospital decedents died in the hospital, while 3% died in a nursing home (Figure 6). For reference, the 1997 New Hampshire Department of Health and Human Services (Vital Records) identified 42% of all New Hampshire resident deaths in the state (n=8,785) occurred in a hospital and 28% in a nursing home, 22% at home and 8% in other places.

Figure 6

PLACE OF DEATH BY ORGANIZATION TYPE

	Place of Death	Cases	%
Hospitals (n=424)	Hospital	407	96%
	Nursing Home	13	3%
	Home	4	1%
Nursing Home (n=148)	Nursing Home	142	96%
	Hospital	4	3%
	Other/Unknown	1	1%
Hospice (n=210)	Home	111	53%
	Nursing Home	46	22%
	Hospice	32	15%
	Hospital	19	9%
	Other/Unknown	2	1%

Intensive Care:

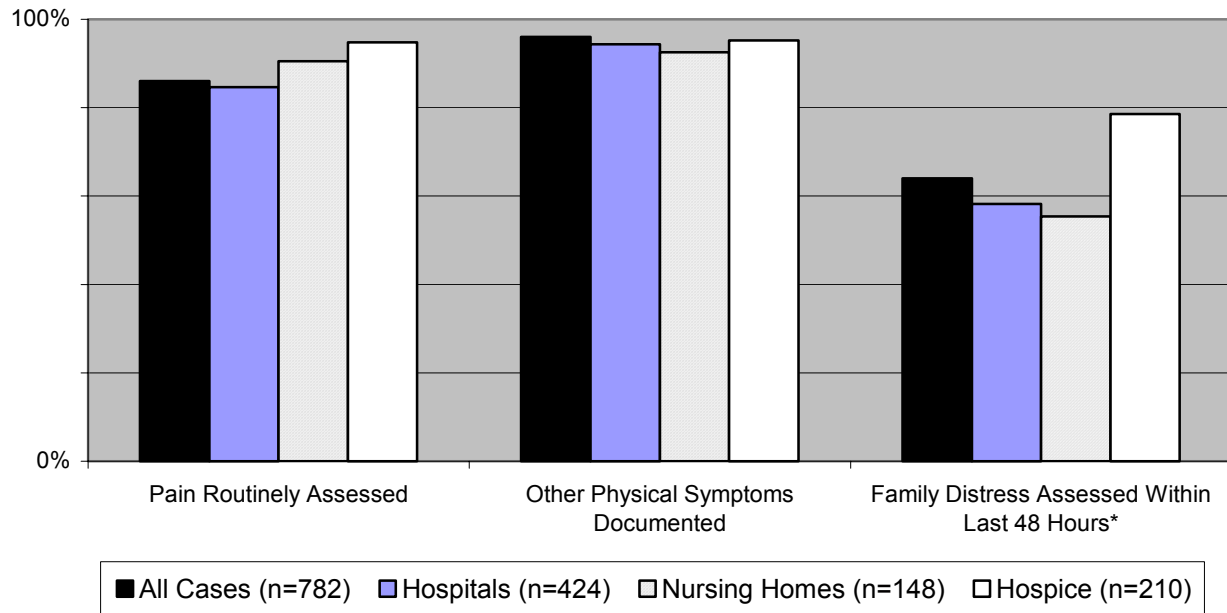
There were 114 decedents in a hospital intensive care unit (ICU) at the time of death or within the last 48 hours before death. This represents 15% of the total number of decedents in the study and 28% of the cases reported by hospitals. Of the 114 decedents, 11% were admitted to the ICU on the day of their death and an additional 25% were admitted within 48 hours of death. Among decedents known to be in hospice care (n=210), only 3% were admitted to an ICU.

Assessment:

Pain and other symptoms were consistently documented in the vast majority of the decedents' charts. In addition, psychosocial support for both patients and families was routinely noted in the decedents' charts. Hospitals and hospice were significantly more likely to note these services than nursing homes. Family distress was assessed within 48 hours of death for over half of the decedents' families. Hospice was significantly more likely to note this assessment in the chart than hospitals or nursing homes (Figure 7).

Figure 7

SYMPTOMS ASSESSED IN LAST 48 HOURS OF LIFE BY ORGANIZATION TYPE



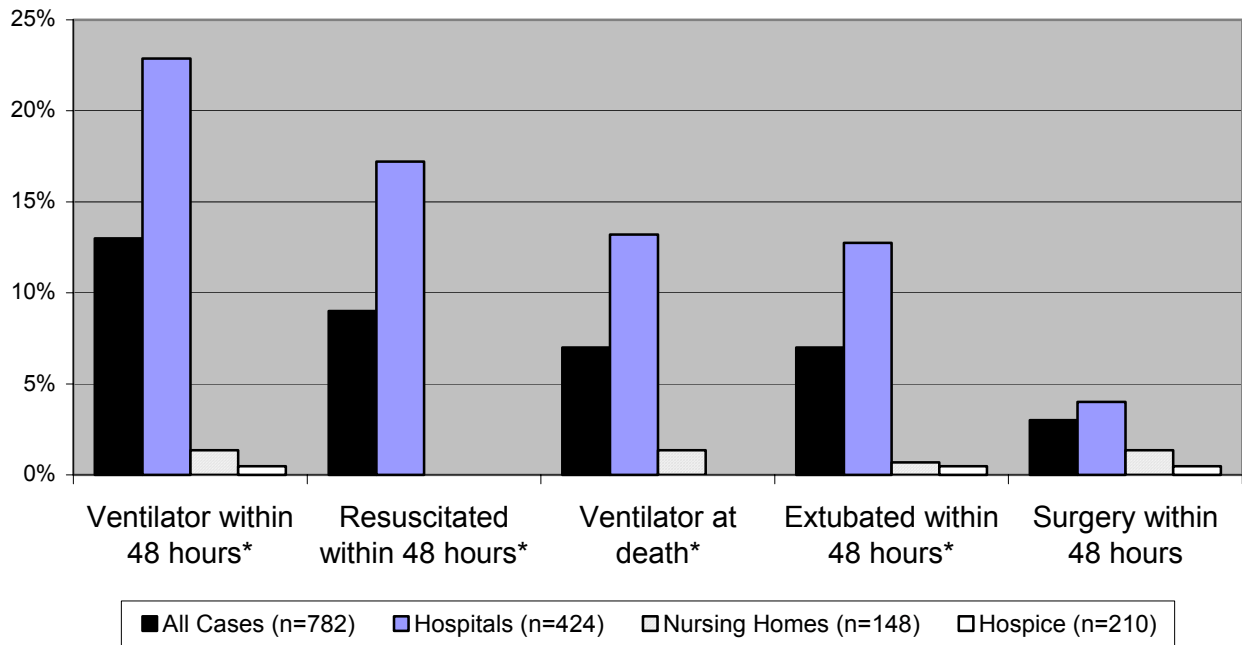
* $p < .0001$

Selected Treatments:

Nineteen percent (n=149) of all decedents received at least one treatment within the last 48 hours. 13% were on a ventilator within the last 48 hours of death; 9% were resuscitated before death; 7% were either on a ventilator or were extubated at death; and 2% received surgery within 48 hours of death. Hospital cases were significantly more likely than nursing home or home care/hospice cases to receive treatments within the last 48 hours of death (Figure 8).

Figure 8

**TREATMENTS IN LAST 48 HOURS OF LIFE
BY ORGANIZATION TYPE**



* $p = <.0001$

Emotional and Spiritual Care:

The emotional needs of the decedent’s family was noted in the medical chart in over three-quarters (76%) of all cases in the study. Among different types of provider organizations the range was 84% for home care/hospice cases and 55% for nursing home cases. A chaplaincy or spiritual care consult in the last 48 hours before death was noted in over half (53%) of all medical charts in the study.² Similarly, a chaplaincy or spiritual care consult was noted for families in 55-60% of the decedents’ charts and for patients in 43-58% of the charts, depending upon the organization type (Figure 9).

² Unduplicated counts.

Figure 9

**EMOTIONAL AND SPIRITUAL NEEDS FOR PATIENTS
AND FAMILIES BY ORGANIZATION TYPE**

	Psychosocial Support Noted in Chart		Chaplaincy or Spiritual Consult Noted in Chart	
	Patient	Family	Patient	Family
All Cases (n=782)*	72%	76%	44%	48%
Hospitals (n=424)*	70%	75%	43%	58%
Nursing Homes (n=148)*	60%	55%	49%	55%
Hospice (n=210)*	78%	84%	58%	60%

* $p = <.0001$

Advance Directives

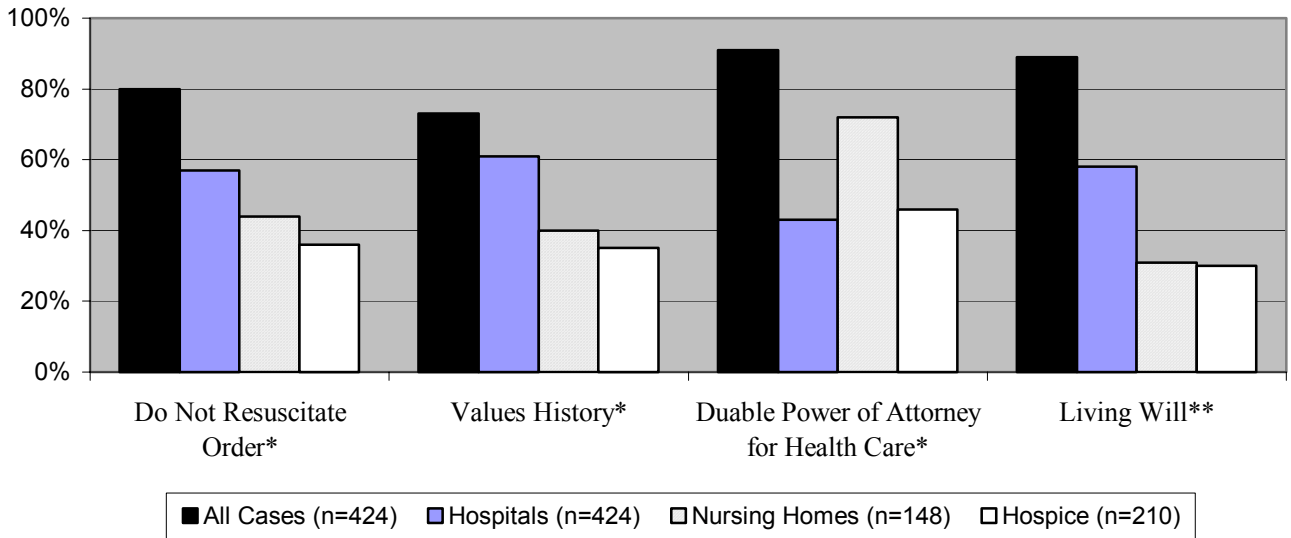
The most frequent directive among all decedents in the study was a Do Not Resuscitate (DNR) order (80% for all cases). This was followed in frequency by a Values History (57%), Durable Power of Attorney for Health Care (DPAHC, 46%) and Living Will (36%). There were significant differences among provider organizations. All advance directives were more likely to be found among nursing home cases than hospital or hospice cases (Figure 10)

Analyzing more closely the characteristics of the decedents with a DPAHC, living will or DNR identifies the greatest number as widowed (46%); more than two thirds were 75 years or older; most named a son or daughter as their next of kin (49-42% depending upon the type of directive); and Medicare was their primary insurer (Figure 11). Statistically significant differences were found in all variables for DPAHC and DNR and in age for living will.

More than half of DNR directives (58%) were done after the admission date into the facility; another 36% were done on the day of admission. In contrast, only 24% of the living wills and 27% of the durable power of attorney for health care were done after the admission date (Figure 12).

Figure 10

DIRECTIVES BY ORGANIZATION TYPE



* $p = <.0001$

** $p = .0072$

Figure 11

**DECEDENTS WITH KEY DIRECTIVES
BY GENERAL CHARACTERISTICS**

	Decedents with Key Directives		
	DPAHC* (n=344)	Living Will (n=282)	DNR** (n=628)
Age Group			
18 - 44	0%	0%	2%
44 - 54	3%	3%	4%
55 - 64	6%	7%	7%
65 - 74	20%	22%	21%
75 - 84	30%	29%	31%
85+	40%	39%	35%
Marital Status			
Married	33%	35%	39%
Widowed	46%	43%	39%
Divorced/Separated	8%	7%	7%
Never Married	7%	7%	8%
Next of Kin			
Spouse	29%	33%	36%
Son/Daughter	49%	41%	42%
Other	17%	18%	16%
Sibling	5%	4%	5%
Unknown	1%	1%	2%
Primary Insurance			
Medicare	74%	78%	75%
Medicaid	14%	10%	10%
Commercial/Managed Care	8%	10%	10%
Other	3%	1%	2%
Unknown	1%	1%	3%
Self-Pay/Uninsured	0%	0%	0%

* Durable Power of Attorney for Health Care

** Do Not Resuscitate Order

Figure 12

TIMING OF DIRECTIVES NOTED IN CHART

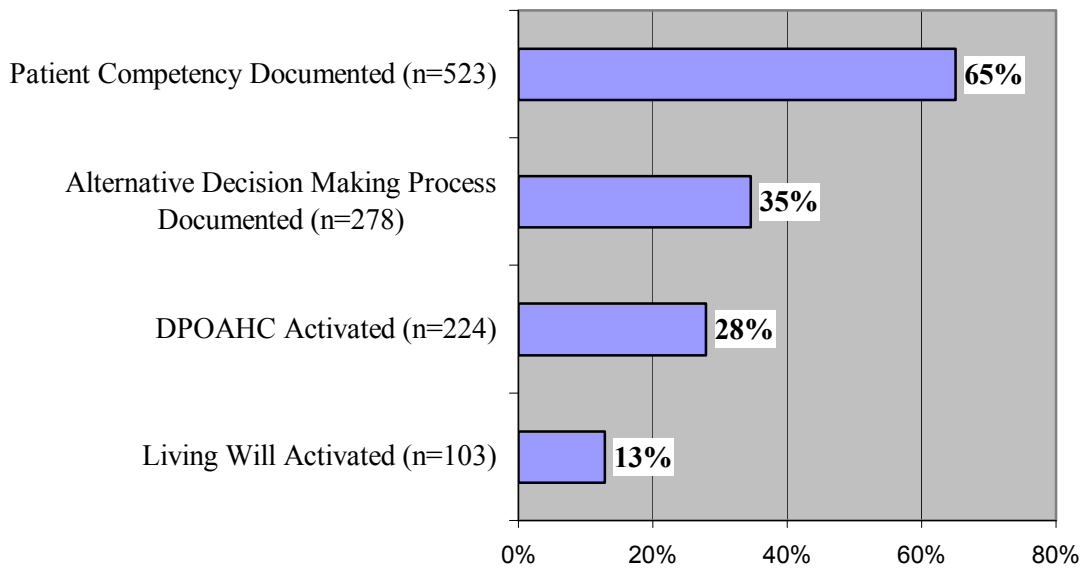
When Noted in Chart	DPAHC (n=259)	Living Will (n=206)	DNR (n=460)
After admittance	27%	24%	58%
On day of admittance	39%	40%	36%
One week prior to admittance	3%	2%	4%
One month prior to admittance	6%	5%	5%
One year prior to admittance	15%	13%	5%
Greater than 1 year	18%	23%	1%

Patient Decision-Making

Advance directives are most critical when a patient is unable to make decisions for him-or herself. The chart review examined the extent to which facilities documented whether: a) patients were able to make their own decisions; b) an alternative decision-making process was in place; c) a DPAHC was activated; or d) a living will was activated. Almost two-thirds (65%) of the charts documented whether patients were able to make their own decisions; 35% of the charts documented an alternative decision-making process; 28% of the cases had activated a DPAHC; and only 13% had activated a living will (Figure 13). It is important to note that not all cases require an activated DPAHC or living will. These data suggest that about one-third of the cases required an alternative decision-making process for the deceased.

Figure 13

**DOCUMENTATION OF PATIENT DECISION-MAKING
& ACTIVATION OF ADVANCE DIRECTIVES**



COMPARISONS WITH 1998 CHART REVIEW

Compared to 1998, this study population contained significantly more cases from hospitals and fewer nursing homes (Figure 14). While there were not significant differences in gender and religion, decedents in the 2002 study population tended to be slightly older, more likely to be widowed, and more likely to have Medicare as their primary insurance (Figure 15).

Figure 14

**COMPARISON OF RESPONDING ORGANIZATIONS
1998 AND 2002**

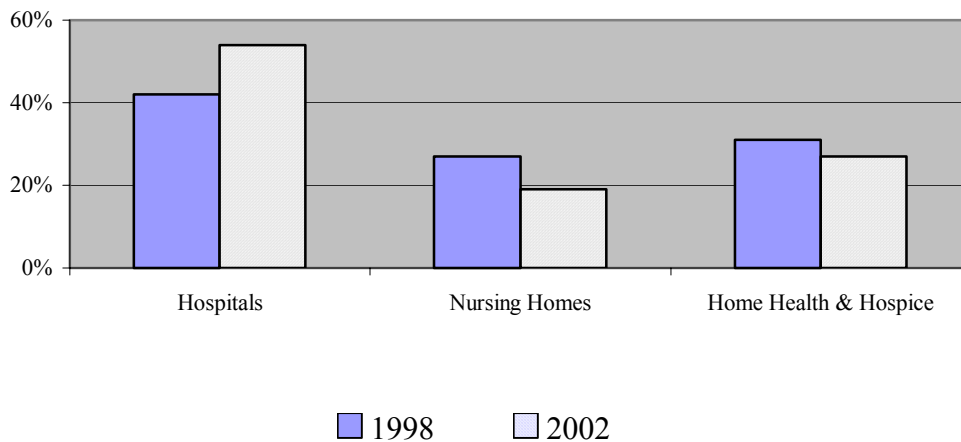


Figure 15

**COMPARISON OF DECEDENTS' DEMOGRAPHIC
CHARACTERISTICS: 1998 AND 2002**

	1998	2002
Age Group		
18 - 44	4%	3%
44 - 54	3%	5%
55 - 64	10%	8%
65 - 74	20%	20%
75 - 84	33%	32%
85+	30%	34%
Gender		
Male	45%	46%
Female	55%	54%
Marital status		
Married	45%	45%
Widowed	41%	39%
Divorced/Separated	14%	7%
Never Married	NA	9%
Religion		
Roman Catholic	35%	38%
Protestant	30%	22%
Jewish	1%	1%
Other	8%	8%
Unknown	26%	26%
Primary Insurance		
Medicare	64%	77%
Medicaid	12%	9%
Commercial/Managed Care	14%	11%
Other	4%	3%
Self-Pay/Uninsured	2%	0%

Place of Death and Diagnosis Group

Similarly, we found differences in place of death and primary diagnosis groups: 55% of the cases died in the hospital in 2002, compared to 45% in 1998. Compared to 1998, fewer people died of cancer in 2002 (22% vs 30%) or stroke (5% vs 9%); and more people died of other internal diseases (26% vs 17%), heart disease (20% vs 16%) and pneumonia and influenza (9% vs 3%, Figure 16).

Figure 16

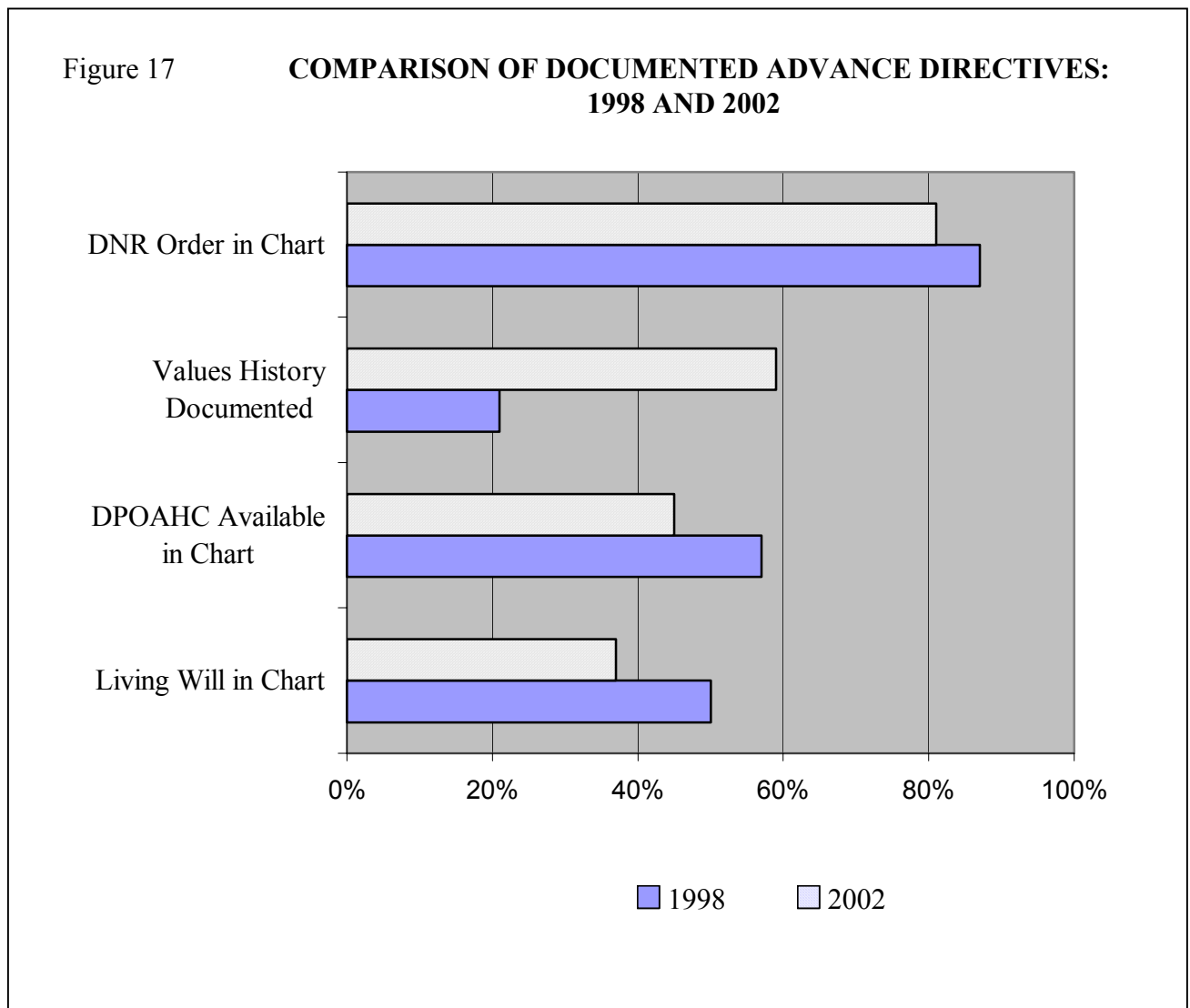
**COMPARISON OF PLACE OF DEATH AND
PRIMARY DIAGNOSIS GROUP: 1998 AND 2002**

	1998	2002
Place of Death		
Hospital	45%	55%
Nursing Home	31%	25%
Home	20%	15%
Home Health & Hospice	NA	4%
Other	4%	1%
Primary Diagnosis Group		
Other Internal*	17%	26%
Malignant Neoplasm (cancer)	30%	22%
Heart Disease	16%	20%
Pneumonia & Influenza	3%	9%
Cerebrovascular	9%	5%
Chronic Obstruction Pulmonary Disorder	3%	4%
Mental Disorders	4%	3%
Central Nervous System	4%	3%
Unintentional Injuries	3%	3%
Nephritis, Nephrotic Syndrome, Nephrosis	2%	1%
All Other Diagnoses	9%	4%

* Other Internal includes respiratory failure, food/vomit pneumonitis, urinary tract infections, post traumatic pulmonary insufficiency, gastrointestinal hemorrhage nos, hypertension nos, post inflammatory pulmonary fibrosis, etc.

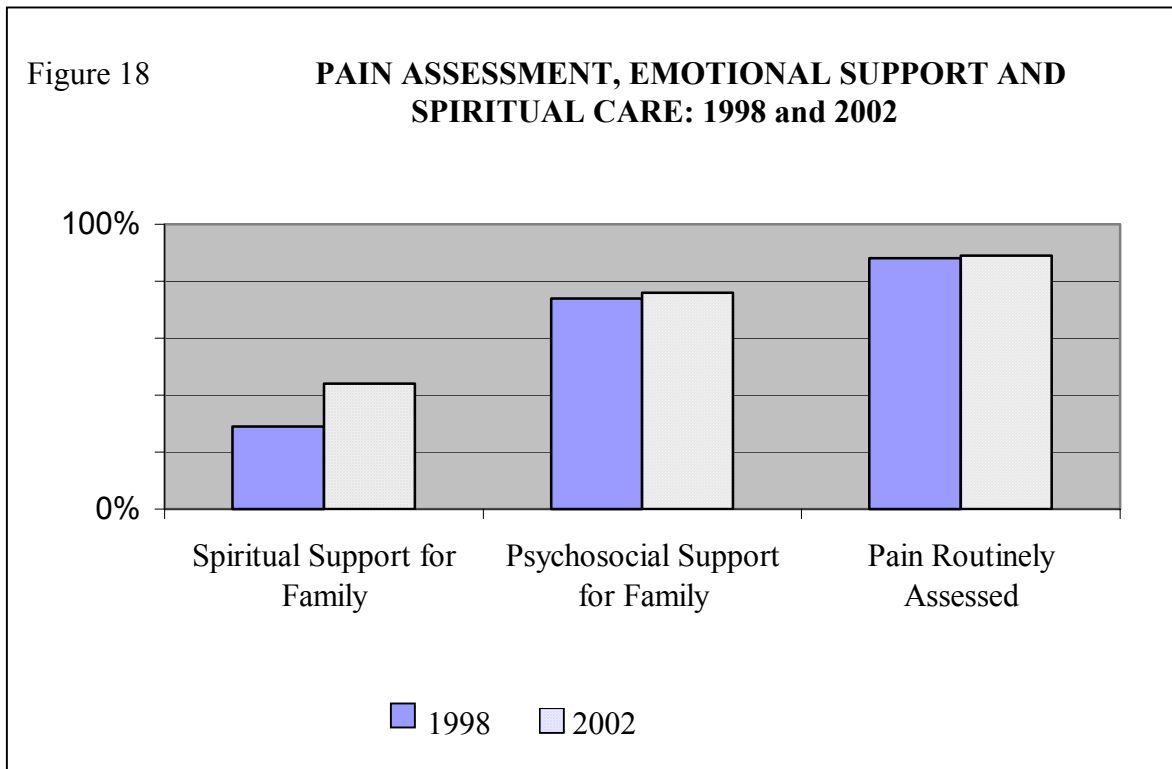
Advance Directives

As in 1998, the DNR order was the most prominent directive noted in the decedents' charts. More than 4 of 5 cases noted the DNR order in the chart. DPAHC and living wills were documented less frequently in 2002. This can be explained by the fewer number of cases from nursing homes and greater number from hospitals. The most striking difference was the significant increase in documentation of the values history. In 1998 only 21% of the cases had documented the values history in the chart. In sharp contrast, 59% of the cases in 2002 had values history documented in the chart (Figure 17).



Pain Assessment, Emotional Needs and Spiritual Care

Although the two chart reviews were not identical, several items relating to pain assessment, emotional needs and spiritual care could be compared. Pain assessment (88% and 89%) and psychosocial support for the family (74% and 76%) were essentially the same. However, the 2002 chart review showed a significant increase in chaplaincy or spiritual consult for the family, increasing from 29% in 1998 to 44% in 2002 (Figure 18).



LIMITATIONS:

There are limitations in the process employed in collecting this information that must be considered in reviewing this data. The health provider organizations that responded to the data request may represent those health care organizations in New Hampshire that are more active and concerned about end-of-life care. This could bias the overall study to show more favorable results. Similarly, the individual health care staff persons who completed the chart audits may have been inclined to complete the survey to show the most desirable findings. The 2002 chart review instrument was modified to minimize interpretative questions and the Foundation for Healthy Communities was available to answer questions by telephone from staff completing the chart reviews. There were no resources available for specific reliability checking of the data from each organization that submitted charts. This process is always limited by the available documentation in the medical chart and it may not identify events that occurred but were not recorded in the medical chart. The focus on the last 48 hours of life may also limit understanding the full range care during final stages of end-of-life.

CONCLUSION:

This represents a renewed effort to collect statewide information for health providers and the public to better understand end-of-life care in New Hampshire. The data suggest areas for further study such as why is there a decline since 1998 in durable power of attorney documents in the medical chart? What does a late referral to hospice care mean for quality end-of-life care? Do the relatively high rates of symptom assessment mean that corresponding care plans are in place and appropriate services provided? The project also identified much variation among the health care organizations that submitted data.

This project is intended to stimulate further study and work on improving different elements of care. The N.H. Partnership for End-of-Life Care has worked on advance care planning as one priority issue in which to organize community efforts to change policy and practices. A dedicated group of more than 500 trainers and community facilitators statewide are using the *Respecting Choices* program in creating local strategies to help people understand advance care planning. Also, there is an effort underway to reduce barriers to hospice care among different providers and some health plans in the state. The ability to make improvements in the delivery of care depends upon understanding the issues and being able to measure change. The strong level of participation in this project indicates a strong desire to understand end-of-life care issues. The Foundation for Healthy Communities welcomes an opportunity to continue work to improve policies and practices related to end-of-life care.

SUMMARY OF FINDINGS FROM NINE FOCUS GROUPS IN NEW HAMPSHIRE

Goal

The purpose of the focus groups was to gather information on advance care planning and experience of end-of-life care from patients, families and providers around the state to supplement information from the Chart Review.

Methods

During the spring and summer of 2002, the Foundation conducted a total of 9 focus groups in 3 cities: Laconia, Dover, and Merrimack. In each location, we conducted focus groups with patients, families of deceased, and healthcare providers, including primary care and specialist physicians, nurses, social workers, and facility administrators. As illustrated in Figure 19, we talked with slightly more family members than other types of participants, and we had fewer participants in Merrimack.

	Laconia	Dover	Merrimack	Total
Patients	13	6	4	23
Families	9	14	9	32
Providers	10	13	5	28
Total	32	33	18	83

Each focus group lasted approximately 2 hours. During the first hour we asked participants about Advance Care Planning, including whether and which advance directives they had prepared, what type of conversations they were having about end-of-life care, what sort of difficulties they encountered and what recommendations they had for improving information about end-of-life care and preparing for end-of-life decision-making. During the second hour, we explored participants' experience of care at end of life, including notification of illness, care coordination, their choices and expectations, and strategies and recommendations for improving end-of-life care. Participants were paid a small honoraria and food was provided.

Demographic Characteristics

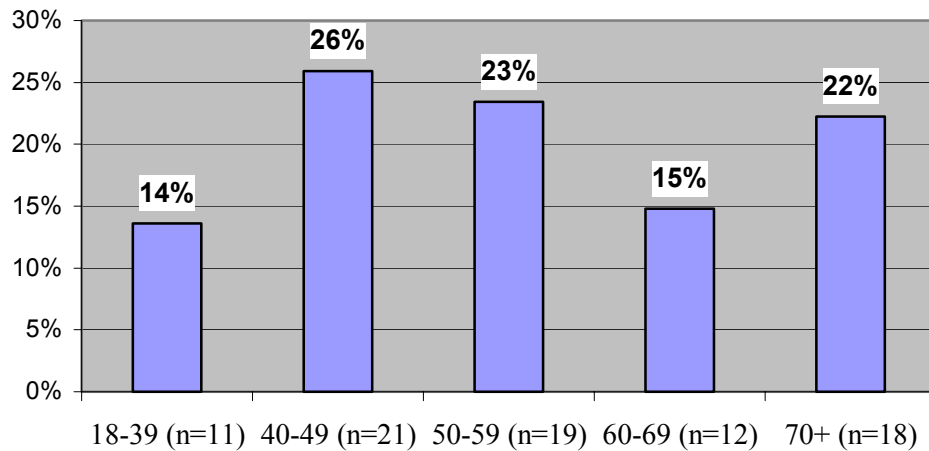
The vast majority of the participants (74%) were women and most were either married (52%) or widowed (32%). Over half (53%) of the participants had graduated from college (Figure 20). Participants were also fairly evenly distributed across the age groups (Figure 21).

Figure 20

**DEMOGRAPHIC CHARACTERISTICS
OF FOCUS GROUP PARTICIPANTS**

	N	%
Gender		
Female	59	74%
Male	21	26%
Total	80	100%
Marital Status		
Married/Life Partner	40	52%
Widowed	25	32%
Separated/Divorced	9	12%
Single, Never Married	3	4%
Total	77	100%
Education		
< High School	2	2%
High School/GED	18	22%
AA or Technical College	12	15%
Bachelors Degree	22	27%
Post Baccalaureate	27	33%
Total	81	100%

Figure 21 AGE DISTRIBUTION OF FOCUS GROUP PARTICIPANTS



General Themes

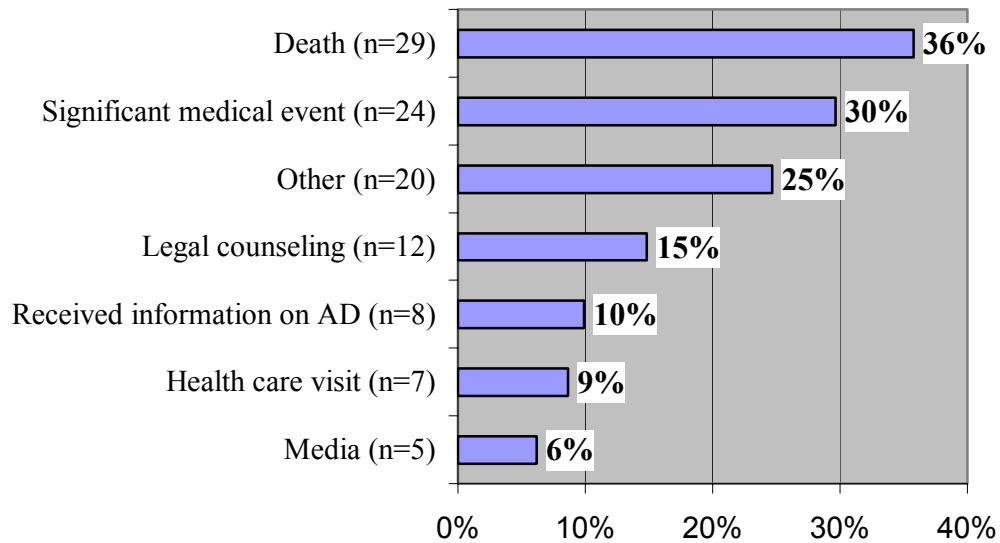
Several major themes emerged from the focus groups. First, participants indicated that they generally waited to discuss or prepare advance directives until a crisis arose (death or imminent death), or they conducted advance care planning as part of their on-going estate planning (Figure 22). In either case, they did not generally talk to their physicians about it. This finding supports data from the baseline community survey conducted at the beginning of this project in 1998 in which only 7% of respondents said they talked to their health care provider about end-of-life decisions³.

Second, there was substantial confusion about advance care planning documents. Some participants did not know about advance directives. Others indicated that although they had been asked about them when they or a loved one entered the hospital and had indicated that they would like more information, there was little or no follow-through. According to all participants, the *Do Not Resuscitate* (DNR) order was particularly difficult. A number of family and patients that believed the presence of a DNR order was sufficient to ensure that their wishes would be followed but were unfamiliar with how the order was actually used and what protocols had to be followed to activate the DNR. The use of 911 and the emergency medical system (EMS) was especially problematic because emergency medical technicians (EMT's) frequently do not have access to the DNR orders, and one of their primary responsibilities is to attempt resuscitation. So patients and families would find that the wishes of the loved one would not be honored, in part because of lack of knowledge about how the DNR operates within the EMS.

³ *End-of-Life Care Planning in New Hampshire: A Statewide Survey*, Foundation for Healthy Communities, May 2000.

Figure 22

WHAT PROMPTED CONVERSATIONS ABOUT END-OF-LIFE CARE PLANNING AND ADVANCE DIRECTIVES?



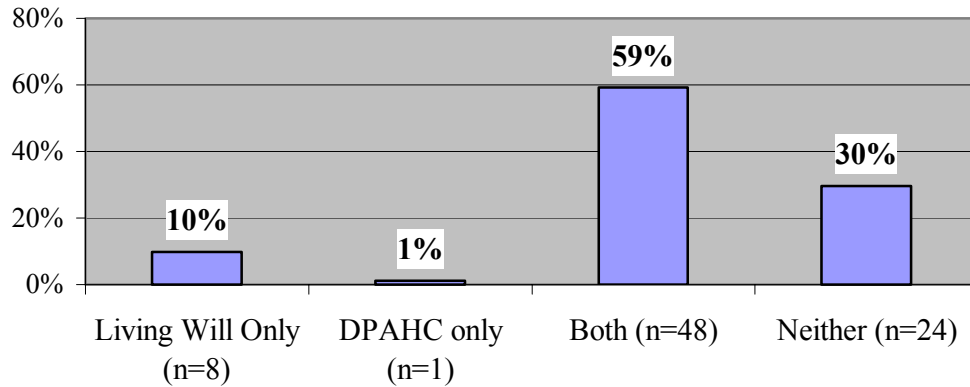
Third, participants generally felt that there is too much emphasis on the documents and not enough on the actual wishes of the loved one. Most reported that having the documents was not sufficient to ensure dignity at the end of life, especially as disease or illness progressed and the needs and desires of patients and families evolved during the transition through death. Finally, families, patients and providers alike reported that with or without advance directives or information about preferences for care at the end of life, there is often conflict among family members as to the correct course of action. All participants agreed that there is a need for better communication among the various healthcare providers, and between providers and patients and their families. The groups were unanimous that there needs to be more dignity at the end of life.

Advance Care Planning

A fair proportion of participants had prepared living wills, Durable Power of Attorney for Health Care (DPAHC), and trusts prior to onset of illness as part of general estate planning (Figure 23). Nonetheless, many patients and family members were caught off guard when a crisis took place. In addition, patients and families experienced substantial confusion about who to talk to about advance directives. Some reported not knowing what advance directives were.

Figure 23

**ADVANCE DIRECTIVES
AMONG FOCUS GROUP PARTICIPANTS**

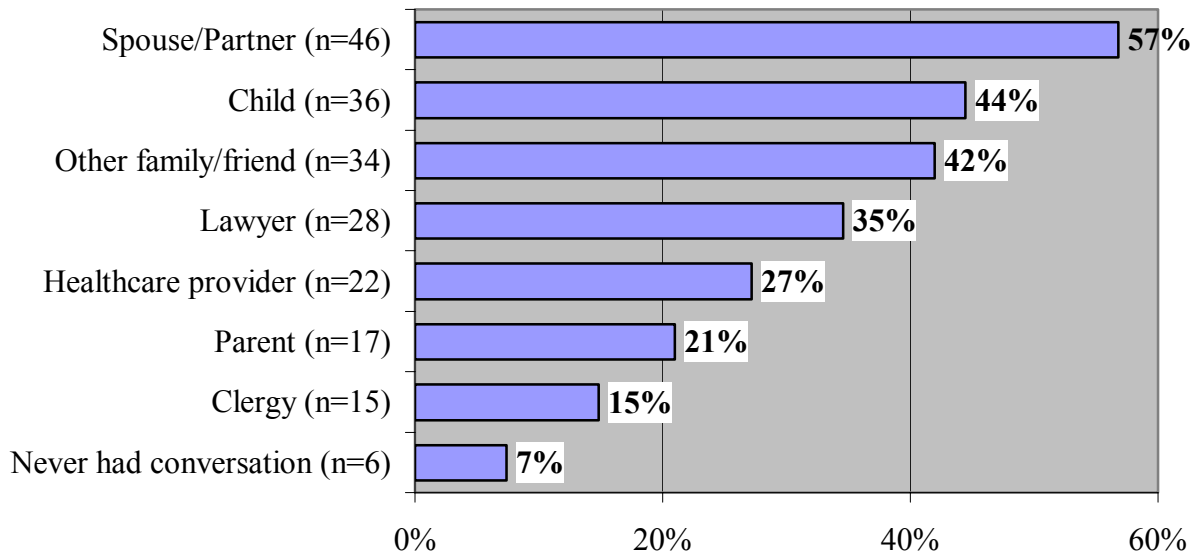


On the positive side, the majority of patients and family members who had advance directives reported knowing that their advance directives were in their medical charts and knew where other copies of these documents were located. Over half (53%) had copies of their advance directives; about one-third had given copies to lawyers (35%), their health care providers (33%) or their hospitals (30%).

Only 7% of the participants reported never having a conversation about end-of-life care planning. Most participants had talked with their spouse, children, other family members and friends and their lawyers. However, only slightly fewer than one in four participants (27%) talked with their health care providers (Figure 24). A number of participants indicated that providers did not or do not generally ask them about end-of-life care issues. In addition, many participants reported difficulty talking with spouses, children and friends, saying that their close family and friends did not want to hear about death or deal with mortality issues.

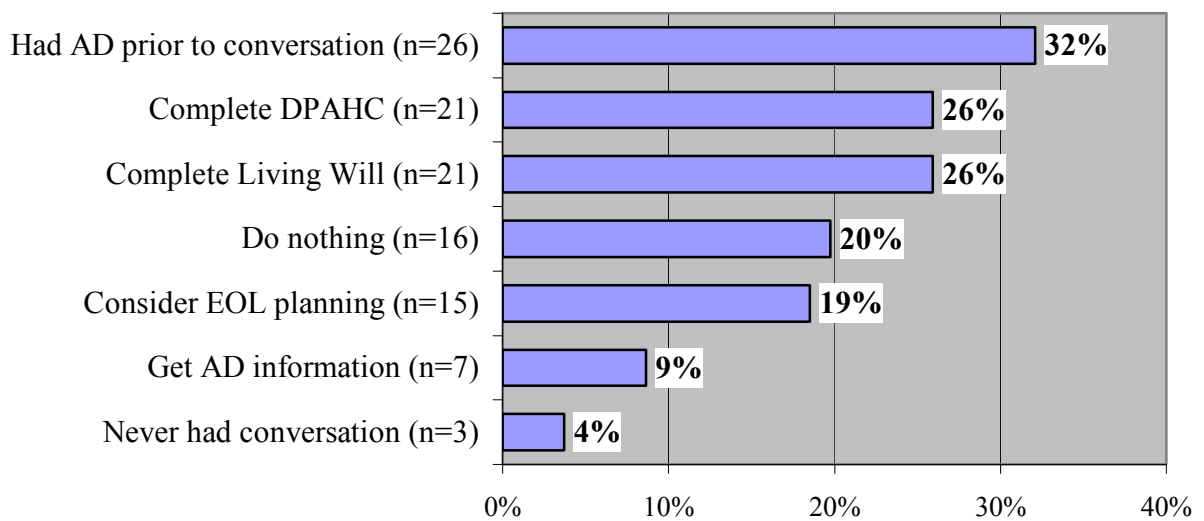
While about one third (32%) of the participants already had advance directives, having conversations about end-of-life care prompted about one in four participants (26%) to complete their advance directives or consider doing advance care planning (9%, Figure 25).

Figure 24 **CONVERSATIONS ABOUT END-OF-LIFE CARE PLANNING***



* Counts are duplicated as participants could have conversations with more than one person.

Figure 25 **WHAT CONVERSATIONS ABOUT END-OF-LIFE CARE PLANNING PROMPTED PARTICIPANTS TO DO**



Providers concurred with reports from the patients and families about the lack of end-of-life care planning conversations, saying that it is often difficult to talk with patients about advance care planning, particularly on the first visit. Insufficient time allotted to medical visits was cited as the primary reason. However, providers also indicated that when the topic of death is brought up, it raises fears in the patients and their families, and the patients then think that the providers know something they are not telling them. Also, many patients are reluctant to discuss it and don't bring it up themselves. Nonetheless, a number of the providers, particularly the specialists and social workers, conduct regular conversations about advance directives and end-of-life care planning with their patients. Participants agreed that there is much confusion about DNR orders and in particular about the use of *911* and the EMS system.

Providers discussed how communication style and content about the specific procedures at the end of life is key to patients' understanding and their decisions. What is communicated and how procedures are described will influence patients' choices. Thus, it is critical that communications be on-going, and that providers be not only well-informed but have effective communication skills. A number of providers suggested that in-service training for communicating difficult information would be helpful, as they do not receive such training in medical school or their residencies. Providers also indicated that advance care planning documents are not really valuable for guiding delivery of care. However, they are useful tools for opening dialogue with patients and family about their wishes for end-of-life care. They also reported that advance directives are generally well marked and in a specific location in the patients' medical charts.

Providers suggested that more pre-discharge planning is needed, particularly in instances where the patient is being discharged to a nursing home for the first time. They stressed the need to understand the culture of the patient and family when bringing up advance care planning and end-of-life care. They also stressed the need for greater public awareness, saying it would make their jobs easier. All participants concluded by saying the advance care planning documents need to be more explicit to be useful, that conversations need to be on-going, and that advance care planning needs to happen sooner.

Experience of Care at the End of Life

Substantial differences were found between patients/families and providers concerning participants' experiences of care at the end of life. According to patients and family members, patient care was quite variable. Some people had wonderful experiences and care was excellent: care coordination was smooth and effortless, the patient received high quality care and the patient's wishes at the end of life were honored. For these people, the experience was as good as it could have been. For others, however, the experience was a nightmare. Families and patients reported significant lack of coordination among providers within a hospital and between hospital and other levels of care. The most common complaint was that "doctors should talk to each other." Providers' perspective on the experience of end-of-life experience somewhat mirrored patients and families in terms of lack of time during the medical visit and the lack of care coordination. Primary care providers felt that once a life-threatening diagnosis is made and the patient is referred to a specialist, they are out of the loop and don't have much follow-up with the patient. This was a source of frustration for them.

Patients and family members also experienced difficulties getting consistent and good information about their loved one's illness, tests, procedures, and the amount of time the loved one had left to live. They complained that providers don't listen to the patient or spouse. Another common experience was that when the shift change occurred the new personnel did not seem to know about the patient's needs, wishes or conditions. Numerous reports of insensitive notification were discussed. For example, people were told of a life-threatening illness or disease over the phone or, in one particularly horrible instance, the person was not notified that her husband had died during surgery and found out only after she went in to see him.

Providers also concurred with some of the communication problems experienced by patients and families. However, they pointed out that patients and their families do not always hear well or integrate the information when being told bad news the first time. Providers indicated that sometimes it takes 3 or 4 conversations before they feel the patient or family member really understands the situation or choices they need to make. As discussed above, providers indicated that they are not trained in how to give bad news to patients and families and would appreciate more learning opportunities in this area. Providers also discussed how family conflicts arise when difficult decisions need to be made. Often, family members do not understand legal parameters of patient care or the provider's responsibility, and this could create difficulties and a poor experience for the patient, family and provider at the end of life.

Providers also said that decisions in emergency room situations are always difficult, especially if they have been brought in by EMT who acted contrary to patient wishes. This relates back to problems associated with DRN orders and how DNR is activated within the EMS system. These findings support both consumer and provider experiences that improved communication is paramount to having a positive end-of-life experience.

All participants reported redundancy in tests and procedures that seemed unnecessary – for example, the same tests were ordered when patients went to a different provider. There was some concern for the cost, but more so for the inconvenience and hardship that some of the tests demanded. Patients and families also reported that pain and other medication management was inadequate. Providers agreed that pain management could be problematic. In part, they said, this is true because a patient's perception of comfort tends to change over time and patients and families have evolving needs over the course of an illness and particularly during the last days of life. In addition, multiple medications and drug interactions can be complicated. Providers did acknowledge, however, that pain management was paramount and that no suffering should happen needlessly.

Providers suggested that the team approach is best, and that this would improve some of the problems associated with poor continuity and care coordination. They also indicated that expectations need to be clearly delineated and discussed continually with patients and families, as they will change over time. Finally, all agreed that more education of both providers and patients is critical.

The one glowing exception to complaints about end-of life care experience was hospice care. Participants consistently reported that hospice care was amazing. Specifically, patients and families said that regardless of who provided care, everyone seemed to know everything about the patient's needs and wishes. The hospice experience was very honoring of patient preferences

at end of life and contributed much to families having a good experience with death. However, most participants were not aware of hospice services until the very end of life – for example, the last week or few days. Most were unaware that hospice was available much sooner.

Conclusions

It is clear that people's hearts are in the right place. However, there are systemic problems within our healthcare system that continue to make end-of-life care planning difficult. These include issues related to health insurance and health care financing, care coordination within and between levels of care, and the ability of the healthcare system to truly honor patients' wishes at end of life. In addition, there is the larger problem that as a society, we are youth oriented and we do not like to discuss death. There is a clear and compelling need to demystify the death process and make it part of life. Finally, all participants stressed the need for frequent and on-going communication and increased public awareness. Some participants suggested that this topic be introduced into high schools and middle schools as a way to demystify the subject and increase awareness.

New Hampshire End-of-Life Care Chart Review

General Instructions

Introduction

Hospitals, nursing homes, home care agencies and hospice programs are being invited to participate in a voluntary chart review project. The information will be compiled on a statewide basis to provide a 'snapshot' of how end-of-life care is delivered. Your participation in the chart review project is important in helping to improve end-of-life care for patients and their families.

We estimate that it takes about 15 minutes for a nurse or medical records person to complete a chart review and we recommend that you keep a copy of the completed chart reviews. **Please return your completed chart review forms as soon as possible or by June 30, 2002.**

Summary data will be reported back to participants in the fall. If you have any questions about the project please contact Shawn LaFrance or Kathy Bizarro at 225-0900.

These data will be collected after death from a review of the medical charts. These instructions have been prepared for the chart abstractor. Typically, the chart abstractor is an experienced nurse clinician or other health care professional that is familiar with medical terminology, medical technology, and the clinical environment. Also, the chart abstractor is detail-oriented and well organized. The data instrument used by the chart abstractor should be completed while reviewing the patient's chart.

How to select records for chart review

Study participants will be identified as those NH residents age 18 years or older who died in your facility or organization in February and March 2002.

Confidentiality

The chart abstractor must not discuss the contents of a patient's chart or medical record other than for necessary discussions with other personnel involved in this project. It is important that all data collection instruments which have a patient's name, medical record number, or other identifiers never be left unattended or in such a manner that they would be seen or read by other people. All data will be handled with strict confidentiality and the reporting of aggregate data will not attribute specific data to any patient, facility or organization.

Completing the Chart Review

General Information

Every field must be completed

1. **Date** - Date of chart audit
 2. **Organization Name**
 3. **Chart Abstractor Name and Telephone**
 4. **Patient ID #** - Record the patient's medical record number or other ID number. *(This number is requested in the event that we need to contact you with a question about a specific chart.)*
 5. **Gender** - Check the appropriate box.
 6. **Religion** - Record the patient's religion as indicated in the medical record. Check the appropriate box.
 7. **Primary Insurance** - Check one box for the primary insurance carrier for the patient.
 8. **Marital Status** - Check the box for the marital status at time of death.
 9. **Relationship of next of kin** - Check the box of the relation to the patient of the next of kin listed in the record.
 10. **Date of Admission** - Record the date the patient was admitted to the hospital, nursing home, home care or hospice program. Record the month/day/year in this order
 11. **Date of Death** - Record the date the patient died. Record the month/day/year in this order
 12. **Date of Birth** - Record the patient's date of birth. Record the month/day/year in this order
 13. **Place of Death** - Check the box where the patient died. If the patient died in the hospital please answer 13a.
 - 13a. **Hospitals:** Indicate where in the hospital the patient died.
 14. **Medicare Certified Hospice Program** - Identify if the patient was in a Medicare Hospice Certified program.
- 15 & 16. Primary Diagnosis & Secondary Diagnoses** - Record the ICD-9 code listed for the primary diagnosis and secondary diagnoses for that patient's stay at the time of death.
- 17. Advance Directives (If documents are in the chart, then the last date noted in the chart must be recorded)**
- a. The chart abstractor should note the existence of a legal Durable Power of Attorney for Healthcare document in the chart.
 - b. The chart abstractor should note the existence of a legal Living Will document in the chart.
 - c. Is there documentation in the chart of a discussion with the patient or surrogate about the patient's preferences for end-of-life care in the last 48 hours before death? This may be a progress note, a form with the patient's values recorded or other non-legal form that records care preferences.
 - d. The chart abstractor should note the Do Not Resuscitate order by a physician in the chart at the time of death.

18. Patient Decision-Making Capacity - Within 7 Days of Death

- a.,b. Capacity is defined as the ability to understand and effectively communicate decisions to manage one's care. This is determined and documented by a physician.*
- c. Capacity is defined as the ability to understand and effectively communicate decisions to manage one's care. This is determined and documented by a physician. Examples of other decision-making processes include consensus among family members and health care team or legal guardianship.
- d. Was the living will activated because the patient was determined to be permanently unconscious or determined to be terminally ill by two physicians?

19. Symptom Assessment - 48 Hours Prior to Death

Examples:

- A 50-year-old motor vehicle accident patient arrives dead on arrival to the emergency room; therefore symptom assessment could not be conducted. (answers for this section would be N/A).
 - A 90-year-old nursing home patient in a persistent vegetative state. Symptom assessment would be answered yes or no.
 - A 68-year-old hospice patient with terminal cancer. Symptom assessment would be yes or no.
- a. Was pain routinely assessed, according to your organization's protocols, with treatment provided and documented?
- b. Were other physical symptoms such as anxiety, nausea, and shortness of breath assessed and documented?
- c,d. Was psycho/social assessment done and counseling, medications or other support offered?
- e,f. Was spiritual support offered by a chaplain, counselor or clergy person?
- g. Was assessment of emotional needs of the patient's family noted?

20. Treatments - 48 Hours Prior to Death

- a. The patient received any surgery performed in the operating room. This does not include surgery to harvest organs.

Examples of surgery are:

- A 22-year-old motorcyclist underwent surgery after massive trauma but died within 24hrs.
 - A 76 year old presented with ruptured aortic aneurysm and died during attempted surgical repair.
 - A 56-year-old undergoing elective surgery had a fatal myocardial infarction in the recovery room.
- b. Patient on ventilator at time of death.
- ### Example:
- A 70-year-old patient treated for pneumonia with respiratory failure one month ago has developed hypotension, congestive heart failure, and renal failure.

c. Patient placed on the ventilator within 48 hours prior to death.

Examples:

- A 64 year old with lung cancer is placed on a ventilator for sudden onset of respiratory distress, hypoxia and hypotension.
- A 38 year old with HIV develops massive pneumonia and respiratory failure

d. Extubation or ventilator support withdrawn within 48 hours prior to death.

Examples:

- An 84 year old with chronic pulmonary disease underwent surgery for colon cancer followed by multiple infections and cardiac complications. Attempts to wean have been unsuccessful. Patient has been comatose since a cardiac arrest with resuscitation 2 weeks ago.
- A 28 year old with massive head trauma and brain death is withdrawn from life support following organ donation.

e. Resuscitation attempted within 48 hours prior to death.

Examples:

- A 74 year old is found pulse less by family and is transported to hospital
- A 48 year old walks into ER complaining of severe chest pain and collapses.

An 82 year old with advanced vascular disease who has repeatedly stated that on religious grounds he wants all attempts made to prolong his life, is found unresponsive on rounds.

New Hampshire
End-of-Life Care Chart Review Form
(Please read the instructions before completing this form.)

1. Date: _____ 2. Organization Name: _____

3. Chart Abstractor Name: _____ Telephone: _____

4. Patient ID# _____

5. Gender: Male Female

6. Religion:

- Protestant
- Roman Catholic
- Jewish
- Other
- None
- Unknown

7. Primary Insurance:

- Medicare
- Medicaid
- Commercial/Managed Care
- No Insurance/Self Pay
- Other Insurance

8. Marital Status: Married Widowed Divorced/Separated Never Married Unknown

9. Next of Kin: Spouse Sibling Son/Daughter Other Unknown

10. _____ / _____ / _____
Mon Day Year
Date of Admission

11. _____ / _____ / _____
Mon Day Year
Date of Death

12. _____ / _____ / _____
Mon Day Year
Date of Birth

13. Place of Death: Hospital Nursing Home Home Hospice House Other

13a. If patient died in the hospital, please indicate which unit the patient was in:

- Emergency Department
- ICU
- Acute care bed
- Alternate level of care (skilled) bed
- Palliative care bed
- Other

14. Was the patient enrolled in a Medicare Certified Hospice program?

- At time of death
- At time of admission to this facility
- Not enrolled in hospice program
- Unknown

15. Primary **Diagnosis**, ICD-9 Code:

16. Secondary **Diagnoses**, ICD-9 Codes:

<u>17. ADVANCE DIRECTIVES</u>	Yes	No	Last Date Noted in Chart
a. Was a legally executed DPOAHC available in chart?			
b. Was a legally executed Living Will available in chart?			
c. Was a discussion of patient care preferences or a values history documented?			
d. Was a Do Not Resuscitate (DNR) order in the chart at time of death?			

<u>18. PATIENT DECISION-MAKING CAPACITY - WITHIN 7 DAYS OF DEATH</u>	Yes	No	Not Applicable
a. Was patient decision-making capacity documented <u>within 7 days</u> of death?			
b. If patient did <u>not</u> have capacity, was a DPOAH activated for care decisions?			
c. If patient did <u>not</u> have decision-making capacity, was another decision making process documented?			
d. Was the living will activated because the patient was determined to be permanently unconscious or determined to be terminally ill by two physicians?			

For Symptom Assessment and Treatments
please refer to any notes in the patient's chart for 48 hours prior to death.
Please check appropriate box.

<u>19. SYMPTOM ASSESSMENT</u>	Yes	No	Not Applicable
a. Was pain routinely assessed, treated and documented?			
b. Were other physical symptoms assessed and documented?			
c. Was psycho/social support offered to the patient?			
d. Was psycho/social support offered to the patient's family?			
e. Was spiritual support offered to the patient?			
f. Was spiritual support offered to the patient's family?			
g. Was the family's distress assessed during 48 hours prior to death?			

<u>20. TREATMENTS</u>	Yes	No
a. Did patient have surgery within 48 hours prior to death?		
b. Was patient on a ventilator at time of death?		
c. Was patient on a ventilator within 48 hours of death?		
d. Was patient extubated or ventilator support withdrawn in 48 hours prior to death?		
e. Were there efforts to resuscitate after cardiac or respiratory arrest within 48 hours of death?		

Thank you

ⁱ DEATH in NEW HAMPSHIRE: A Review of Medical Charts, June 1999, Concord, Foundation for Healthy Communities, www.healthynh.com.