



FOUNDATION FOR
HEALTHY COMMUNITIES

End-of-Life Care Planning
in New Hampshire:
A Statewide Survey

New Hampshire Partnership for End-of-Life Care

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What is the Foundation for Healthy Communities?

The Foundation 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 for Healthy Communities 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 NH Partnership for End-of-Life Care?

The NH Partnership for End-of-Life Care is a group of organizations that helps people to plan for their health care, talk about their choices and have them respected. It was formed by the Foundation for Healthy Communities in 1999. Partner organizations include: Home Care Association of NH, NH Hospice Organization, NH Hospital Association, NH Health Care Association, NH Medical Society, NH Cancer Pain Initiative, NH Nurses Association, AARP-NH, NH Council of Churches, NH Interfaith Volunteers Caregiver's Network, Franklin Pierce Law Center, Norris Cotton Cancer Center, NH Bar Association and NH Department of Health and Human Services.

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End-of-Life Care Planning in New Hampshire: A Statewide Survey

Executive Summary

The Foundation for Healthy Communities initiated the NH Partnership for End-of Life Care to improve end-of-life care planning for state residents. The Partnership is a group of organizations that helps people to plan for their health care, talk about their choices and have them respected. A primary goal of this effort is to promote and make more commonplace conversations about end-of-life care and to demystify end-of-life care issues.

To start, the Foundation undertook a statewide survey to collect baseline data on New Hampshire residents regarding end-of-life care planning activities and raise awareness about end-of-life care planning. The research focused on identifying the characteristics of residents who were having conversations about end-of-life care and who had Advance Directives (Durable Power of Attorney for Health Care & Living Will). A brief self-administered questionnaire was distributed statewide between November 1999-February 2000 to a convenience sample in four settings: primary care health clinics, the state legislature, selected senior centers, and selected faith community settings. There were **1,062 respondents to the survey** with a majority of responses (76%, n = 807) from primary care settings.

A little more than half the respondents (57%, n = 593) have had an end-of-life care planning conversation. People least likely to have **end-of-life care planning conversations** include those who are under age 50, have a high school education or less, are single, and to a lesser degree, living in rural areas of the state. Similarly, risk factors for not having **Advance Directives** or other end-of-life care documents are age ($p \leq .05$), education ($p \leq .01$), marital status, and to a lesser degree location. Women are more at risk for not having Advance Directives ($p \leq .005$), while men are more likely not to have end-of-life care planning conversations. ($p \leq .002$). Given the difference between the respondent population and NH residents, the findings tend to understate the magnitude of the problems being addressed by the NH Partnership for End-of-Life Care.

People tend to be **reactive rather than proactive** regarding end-of life care. They wait until being confronted with a significant medical event or death of the family member or friend. People are having conversations predominantly with their family members and their lawyers. Thus, conversations about end-of-life care are largely viewed as personal and legal matters. Health care providers appeared to play only a small role in facilitating end-of-life care planning conversations. Less than half of the survey respondents (43%) had been appointed as a Durable Power of Attorney for Health Care. Data on **concerns about end-of-life care** were not discriminatory. The vast majority of respondents (95%) indicated that all items listed (talking about end-of-life care, dying alone, pain, who will care for them, and wishes not being followed) were of concern. The survey findings suggest that the NH Partnership for End-of-Life Care has a significant opportunity to improve end-of-life care planning in New Hampshire by targeting residents most at risk and by reaching out to the health care profession.

End-of-Life Care Planning in New Hampshire: **A Statewide Survey**

Introduction

In November 1999, the Foundation for Healthy Communities in Concord, NH received a three-year grant from the Robert Wood Johnson Foundation to improve end-of-life care planning for residents statewide. A primary goal of the project is to promote and make more commonplace conversations about end-of-life care among residents of all ages and to demystify end-of-life care issues. As a starting point, the Foundation for Healthy Communities undertook a statewide community survey to determine who is discussing end-of-life care issues, with whom those conversations are occurring, what prompted the conversations, and what actions are residents taking as a result of those conversations. This report provides the findings from the survey.

Background

The NH Partnership for End-of-Life care is a group of organizations that helps people to plan for their health care, talk about their choices and have them respected. It was formed in 1999 by the Foundation for Healthy Communities to improve end-of-life care by increasing professional and public knowledge and promoting policy changes that support the delivery of quality end-of-life care.

In June 1999, the Partnership for End-of-Life Care issued a report Death in New Hampshire: A Review of Medical Charts based on over 800 chart reviews submitted from 64 health care organizations in New Hampshire. This represented nearly half the deaths in the state in the two-month period. Response rates from key sectors were: 73% of hospitals, 42% of home care/hospices; and 31% of nursing homes. This was the first statewide chart review on end-of-life care in New Hampshire. (see Appendix 1, Executive Summary). The study found:

- One half of the cases or deaths had a living will and 57% had a durable power of attorney for health care (DPAHC). There was variation among health organizations, with nursing homes reporting 74% of deaths with a DPAHC, home care/hospice reported 66% and hospitals reported 39%.
- Comfort measures only were noted for 45% of the deaths and 12% of cases had a values history recorded. There were do not resuscitate (DNR) orders for 87% of deaths. There were 37 decedents with a do not intubate (DNI) order who received intubation/ventilator.
- One third of DPAHCs and 35% of Living Wills were completed within the last week before death. Persons who were widowed were more likely to have completed a DPAHC (69%) than never married/separated/divorced (53%) or married (47%).

- Only about a third of persons under age 55 years had a DPAHC or Living Will while nearly half of persons 55-84 years had these two directives. More than 70% of cases age 85 years or older had a DPAHC.

In 1996, the NH Health Care Fund Community Grant Program provided support for a statewide project on end-of-life issues. Results from that project's eleven focus groups and four community forums identified many concerns:

- Difficulties using the Advance Directive forms and few resources to promote the process of advance care planning.
- No statewide group to address end-of-life policies or concerns and very little information on how well end-of-life care needs are currently being provided for in the state.
- A media focus on proposed state legislation for physician-assisted suicide.
- A need for honest information on prognosis for decision-making, more emotional support in caring for a loved one who is dying; more spiritual support and worry about financial matters were expressed.

This initiative builds on these earlier efforts and is focused specifically on advance care planning--a process that promotes dialogue among an individual, their loved ones and caregivers on life, death, personal goals and values, and the affirmative tasks of end-of-life care. Advanced care planning is the focus because it offers a practical means to raise awareness and promote a dialogue about end-of-life care concerns and there are specific actions that can be taken by the public and professionals.

Survey Objectives

The objectives of this survey are to:

- 1.) collect a baseline profile of New Hampshire residents regarding end-of-life care to identify strategic opportunities to improve planning for end-of-life care, and
- 2.) increase awareness about advance care planning and concerns about end-of-life care throughout the state.

Methodology

The survey investigated four research questions:

- What is the nature of end-of-life care planning conversations in New Hampshire, including what are the characteristics of residents who are having end-of-life care planning conversations; when and with whom are those conversations occurring; what is the quality of the discussions; what prompted the conversations and what actions resulted from the discussions?

- What end-of-life care documents do New Hampshire residents have, what are the characteristics of residents who have these documents and who is at risk for not having end-of-life care planning documents?
- Do New Hampshire residents play a role in planning for end-of-life care for their family members or friends? and
- What concerns do New Hampshire residents have about planning for end-of-life care?

A self-administered survey instrument was developed by the University of New Hampshire, Department of Health Policy and Management (See Appendix 2, Survey Instrument) and distributed by the Foundation for Healthy Communities between November 1999 - February 2000 using a convenience sample and multiple methods of distribution. Primary care centers in all regions of the state were recruited. Each primary care setting (n=25) was asked to submit 50 completed surveys over a two week period. In addition, the survey was mailed to all state legislators (n=424), of which 109 were returned. Finally, individuals associated with the project distributed the survey in selected senior centers and in faith community settings. Staff from the Foundation input the survey data into a database and the analysis was conducted at the University of New Hampshire using statistical analysis software (SAS).

Results

The Foundation for Healthy Communities received 1,062 completed surveys. The majority of the surveys (76%, n=807) came from primary care centers. There were more women (62%, n=604) in the sample than men (38%, n=366), possibly due to the fact that women are often users of the health care system more than men. Responses were collected fairly uniformly throughout the state and across all age groups (Figure 1). The majority of respondents were married or life partnerships (70%, n=684) and had at least a high school education (93%, n=922). Over one-third of the respondents (36%, n=359) had a college degree or post-graduate education. In comparison to all New Hampshire residents, survey respondents were older (Figure 2), more educated and more likely to be female, and more likely to be living in rural areas of the state (Figure 3).

Findings

Below are the detailed findings from the End-of-Life Care Planning in New Hampshire: A Statewide Survey. It is organized around four themes and follow the research questions: (1) end-of-life care planning conversations; (2) end-of-life care planning documents (Advance Directives); (3) respondent's role in end-of-life care planning for family members and friends; and (5) concerns about end-of-life care planning.

End-of-Life Care Planning Conversations

Over half of the survey respondents (57%, n=593) have had end-of-life conversations (Figure 4). This section provides data on (1) who is having end-of-life care planning conversations; (2) when and with whom those conversations are taking place; (3) what is the quality of those conversations; (4) what prompted end-of-life conversations and what happened as a result of the discussions; and (5) what can we conclude about the nature of end-of-life care planning conversations in New Hampshire?

Who is Having End-of-Life Care Planning Conversations?

The data show some clear trends regarding the characteristics of people who have had end-of-life conversations. Age (over age 50), education (beyond high school), marital status (ever married) and gender are all significant predictors having end-of-life conversations. As might be expected, the likelihood of having an end-of-life care planning conversation increases with age ($p \leq .005$, Figure 5). Only 43% of the respondents under the age 40 had conversations compared with 63% of respondents age 60 and older. Similarly, education is also a strong factor in determining who will have conversations about end-of-life care ($p \leq .01$, Figure 6). Only 46% respondents with a high school diploma or less have had conversations, compared to 74% of those with post-graduate education. Marital status (ever being married) is also a strong predictor of who is having conversations ($p \leq .02$). The proportion of currently married respondents who have had conversations is almost double that (60%) of single (never married) respondents (32%, Figure 7). Women are significantly more likely to have end-of-life conversations than men ($p \leq .002$).

When and With Whom did the End-of-Life Care Planning Conversations Occur?

Of respondents having end-of-life care planning conversations (n=589), slightly more than half had conversations within the last year (54%, n=317), compared to those whose conversations had occurred over one year ago (46%, n=272, Figure 8). As seen in Figure 9, respondents are having conversations primarily with family members, including their spouses (41%, n=435) and immediate family members (26%, n=276). Lawyers represent the next largest category of conversation partners (16%, n=170). It is notable that few respondents had conversations with their healthcare providers (7%, n=74).

What was the Quality of Conversations about End-of-Life Care Planning?

Of all respondents who had end-of-life conversations (n=522), almost half (48%, n=250) indicated that the conversations were of high quality.¹ Another 40% (n=211) said the conversations were of moderate quality. Only 12% (n=61) said the conversations were insufficient. This suggests that when people do have end-of-life care planning conversations, they are generally quite thorough.

What Prompted End-of-life Conversations and What Happened as a Result of Those Conversations?

The majority of conversations were prompted by a medical event, either death (20%, n=211) or a non-lethal significant medical event (12%, n=128, Figure 10).² Discussions with healthcare providers prompted only a small proportion of the conversations (4%). This would suggest that most respondents are reactive rather than proactive to end-of-life care planning. Nonetheless, a fair portion of respondents were actively engaged in end-of-life care planning, as indicated by those who said conversations were prompted by discussions with lawyer or estate planner (12%, n=128), receiving information about Advance Directives (5%, n=50), discussions with healthcare providers (4%, n=42), receiving information through the media (3.6%, n=38). Other things that prompted discussions (10%) included having family discussions about wishes of family members and concerns about children (n=24); general planning (n=15); taking some action related to end-of-life care planning issues (n=10), such as signing an organ donor card or taking an estate planning class; and working in the healthcare field (n=7).

Once the conversations had taken place, some respondents were prompted to take action, including complete a Living Will (18%, n=190); complete a Durable Power of Attorney for Health Care (DPAHC, 11%, n=122) or get Advance Directives (5%, n=51).² Another 15% (n=156) were prompted to consider end-of-life care planning. More than 1 in 4 respondents (27%, n=287) indicated that they were prompted to do more than one thing. Fourteen percent (n=145) of the survey respondents indicated that they did nothing; 8% (n=80) already had Advance Directives and 42% (n=450) had not yet had a conversation (Figure 11).

¹Quality of conversation was scored on a scale of 1 to 6, with 1=insufficient and 6=thorough. High quality was scored as either 5 or 6; moderate was scored as either a 3 or 4; and insufficient was scored as either a 1 or 2.

²Categories are not mutually exclusive. Respondents could have been prompted to have a conversation by more than one event. Therefore, numbers do not add to 100%.

What do the Data Tell Us about End-of-life Care Planning Conversations in New Hampshire?

There are several conclusions that can be drawn from these data. First, respondents least likely to have end-of-life care planning conversations include those who are under age 40, have at most a high school education, are single and, to a lesser degree, are male. Second, many respondents tended to be reactive rather than proactive regarding end-of-life care. They generally waited until they are confronted with a significant medical event or death of the family member or friend. It is even more curious that under these circumstances that healthcare providers appear to play only a small role in facilitating end-of-life care planning conversations. A fair proportion of respondents, however, did engage in some form of end-of-life care planning.

Third, discussions about end-of-life care prompted some respondents to take action, such as completing Advance Directives or obtaining documents or additional end-of-life care planning information. However, discussions in themselves do not guarantee action, as indicated by the low numbers. Moreover, conversations about end-of-life care are largely viewed as personal and legal matters. Finally, because the survey population is biased in favor of characteristics that would predict having conversations about end-of-life care, the findings understate the need for addressing the issues around end-of-life care planning among state residents as a whole.

End-of-Life Care Planning Documents

(Advance Directives - Living Will & Durable Power of Attorney for Health Care)

More than half of all respondents (59%, n=622) were without Advance Directives (Figure 12). Only 1 in 4 respondents (25%, n=265) had both a Living Will and a DPAHC. As with having conversations, factors associated with not having Advance Directives include age ($p \leq .05$), education ($p \leq .01$), and gender ($p \leq .005$) and to lesser extent, marital status. For example, only 19% (n=82) of respondents under the age of 50 had Advance Directives compared to 42% (n=97) of respondents ages 50-59 and 69% (n=230) of those over the age of 60 (Figure 13). Similarly, respondents who had been married in the past were four times as likely to have Advance Directives (53%, n=112) compared to single (never married) respondents (13%, n=11, Figure 14).

Education, residence (by region) and gender are also factors in distinguishing between respondents who have Advance Directives from those who do not, but they are not as significant as age and marital status. Among respondents with a high school diploma or less (n=429), approximately one-third (34%, n=147) had Advance Directives; however, among those with some college education or more (n=557), almost half (46%, n=258) of the respondents had Advance Directives (Figure 15). These differences are also found when comparing women and men, with women slightly less likely to have Advance Directives (39%) than men (45%). Almost two-thirds of respondents in the Central Lakes region (64%, n=144) and the North Country (62%, n=128) are without Advance Directives, compared to 51-56% of respondents in other regions of the state (Figure 16). Nonetheless, over 50% of respondents from every district were without Advance Directives.

Interestingly, state legislators were significantly more likely to have Advance Directives than other respondents (Figure 17). Fifty-nine percent of all responding legislators (n=64) had end-of-life care documents, compared to only 33% (n=367) of other respondents. Since we do not know who among the legislators did not respond, it is not possible to discern what type of biases or self-selection might be affecting this result. However, the results do show that as a group, state legislators exhibit many of the characteristics associated with having Advance Directives, including being older, male, having advanced education, and being currently married (Exhibit 1). It may also be that serving in the legislature has increased their awareness of the issues.

Exhibit 1

Comparison of Legislators and Other Survey Respondents by Selected Demographic Characteristics

| Demographic Characteristic | Legislators | Other Respondents |
|--|--------------------|--------------------------|
| Percent over age 60 | 60% | 31% |
| Percent male | 61% | 31% |
| Percent with some college education or above | 83% | 53% |
| Percent currently married | 76% | 69% |

Respondent's Role in End-of-Life Care Planning for Family Members and Friends

A Durable Power of Attorney for Health Care (DPAHC) is a document in which you name another person to act as your agent to make medical decisions should you become incapacitated. It is an important document that should be completed when conversations between the person completing it and the person designated to make their medical decisions have taken place. Less than half of survey respondents had been appointed as a DPAHC (Figure 18). Respondents were most likely to be appointed as a DPAHC for their spouses (21%, n=226) and/or parent (11%, n=114).³ Fewer respondents had been appointed as a proxy for medical decision making for a child (5%, n=55) or other family member or friend (6%, n=63).

³Counts are duplicated as respondents could answer yes to all categories, and therefore should not be added from this chart. Numbers will not add to 100%.

Among respondents who have been appointed a DPAHC (n=62), 70% have had a conversation about end-of-life care planning (Figure 19). The data thus illustrate that while most individuals identified as medical decision-makers for people facing death are indeed discussing end-of-life care planning issues, there are still a significant proportion of individuals (30%) who have not had end-of-life care conversations. In the absence of end-of-life care conversations between people and their proxies, the chances of the person's end-of-life care wishes being followed is likely to decrease. This suggests that the NH Partnership for End-of-Life Care Planning has an opportunity to improve end-of-life care planning in the state.

Concerns About End-of-Life Care

Survey respondents were given the following list of potential end-of-life concerns and asked to indicate whether those particular ones (or others) were of concern to them. These include:

- Talking about end-of-life care;
- Wishes not being followed;
- Pain;
- Who will take care of me (respondent); and
- Dying alone.

A small proportion of respondents (6%, n=65) indicated additional concerns. These largely centered on the impact of a significant medical event on family members (e.g, not being a burden to their families, what would happen to their children, and having a significant event). Of particular interest, respondents also indicated concerns about the reaction of the health care system. Some respondents were worried that end-of-life care documents would be used to withhold treatment. Other respondents were also concerned about not having access to sufficient medication by which they could choose to end their lives. Additional concerns about the medical profession were that providers would order additional and unnecessary medical tests to inflate the costs of care, and that they would not provide realistic information about medical conditions.

In addition to identifying concerns, respondents were also asked to rate each concern on a scale of 1 to 6, with 1 'Very Concerned' and 6 'Not at all a Concern/Not an Issue'. Ninety-five percent of respondents indicated being concerned about each of the identified issues. Perhaps of more interest, when asked to rate how concerned they were, most respondents indicated only a moderate to low level of concern (Figure 20). The average score for the listed concerns ranged from 3.74 (moderately concerned) about being in pain to 4.41 regarding talking about end-of-life care issues. This suggests that while conversations are not yet commonplace, the public may be generally responsive to having them. Respondents who identified specific issues were more likely to be somewhat concerned about them. The 'Other' category received an overall score of 2.96. The data on concerns was not discriminatory and additional research on New Hampshire residents' concerns about end-of-life care planning would be useful.

Conclusions

The survey findings confirm the need for the efforts of the NH Partnership for End-of-life Care and demonstrate foresight in developing new strategies to address end-of-life care issues in the state. For example, the data clearly show that healthcare providers play a small role in facilitating conversations about end-of-life care. The Partnership has designed an initiative to improve end-of-life care planning in communities statewide. Similarly, the data further indicate that most survey respondents tend to deal with end-of-life care issues when an immediate need arose, such as death of a family member or significant medical event. End-of-life care planning conversations and Advance Directives are not currently part of everyday dialogue in New Hampshire. A second component of the project is directed at training community members to facilitate end-of-life care planning discussions around the state (See Appendix 3, Project Summary).

The data collected in this study found that people most at risk of not having conversations were essentially the same as those not having Advance Directives: people who are under the age of 50, single, less educated, and living in more rural parts of the state. Men tend to be slightly more at risk of not having end-of-life care planning discussions, while women tend to be at more risk for not having Advance Directives.

The findings from this survey further suggest that the Foundation for Healthy Communities has a significant opportunity to improve end-of-life care planning in New Hampshire by targeting residents most at risk and by reaching out to the health care profession. These activities are planned and are in the initial stages of implementation.

Figure 1
Survey Respondents by Age
(n=1004)

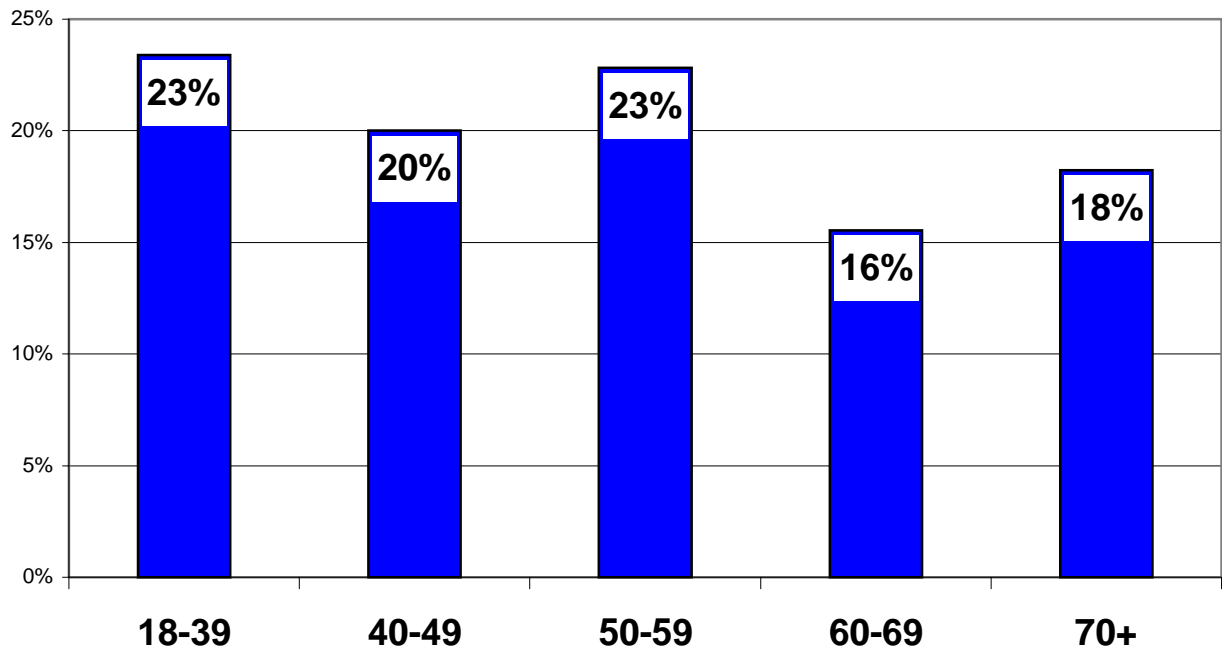


Figure 2
Comparison of Survey Respondents to New Hampshire Residents:
Distribution by Age
(n=1004)

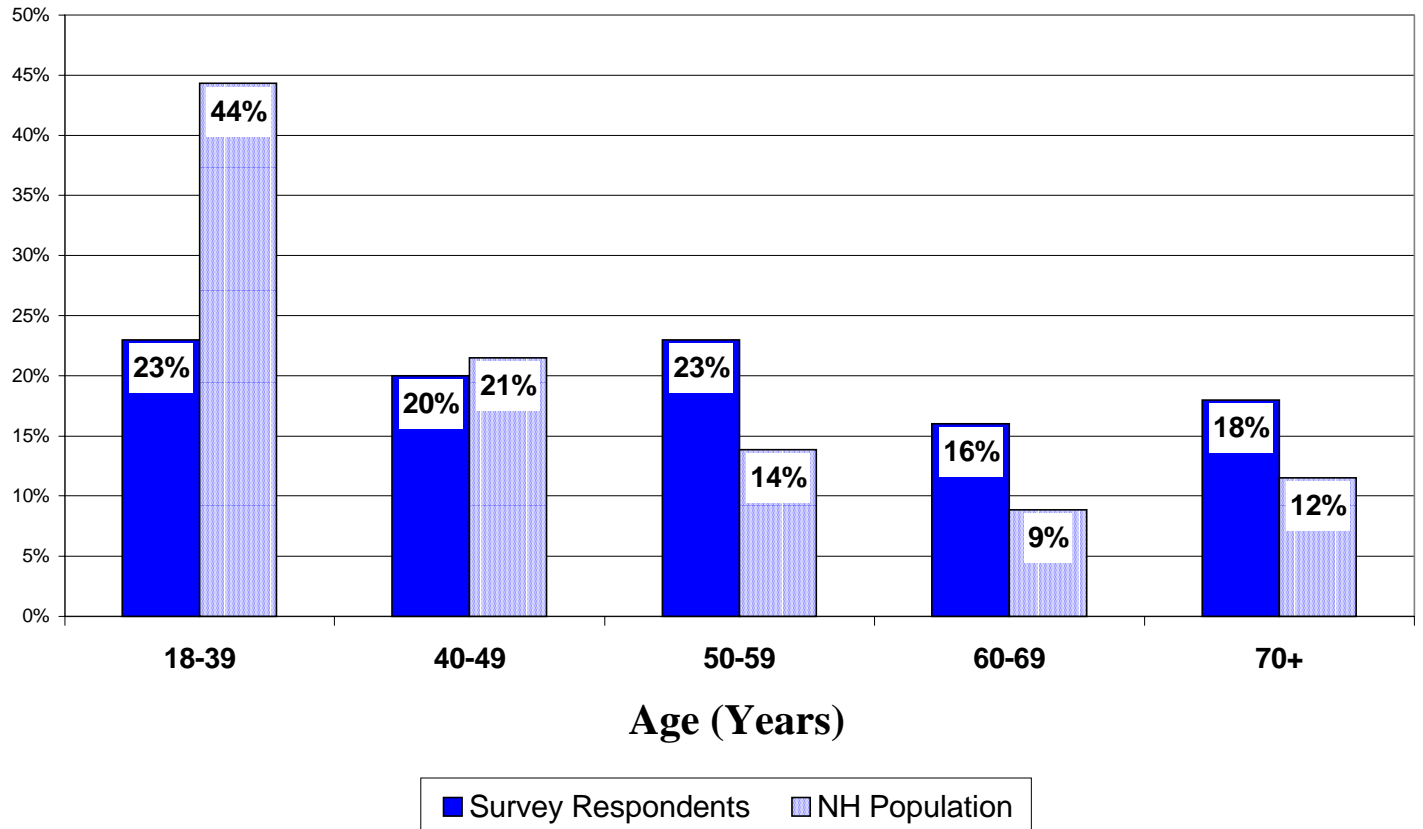


Figure 3
Comparison of Survey Respondents to New Hampshire Residents:
Distribution by Region
(n=1058)

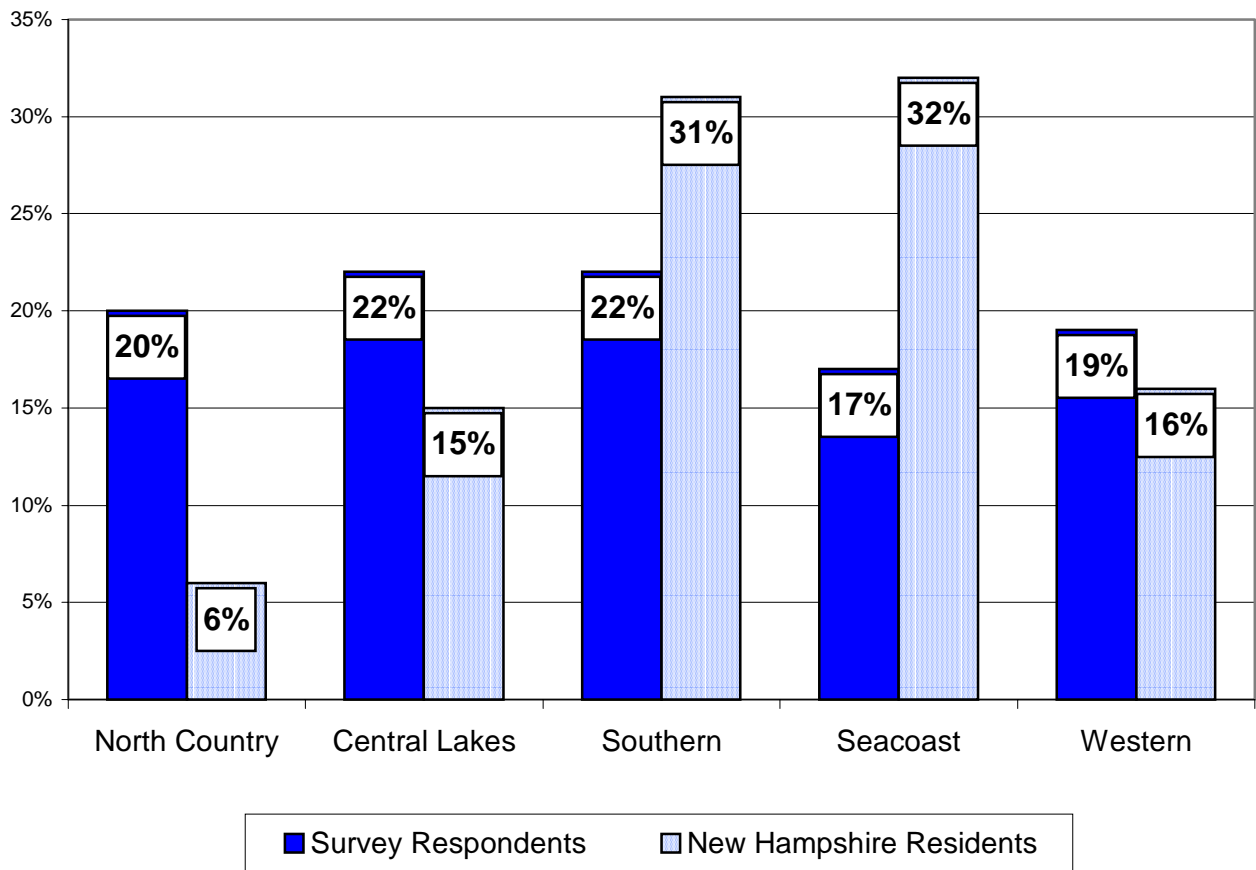


Figure 4
End-of-Life Care Planning Conversation
(n=1040)

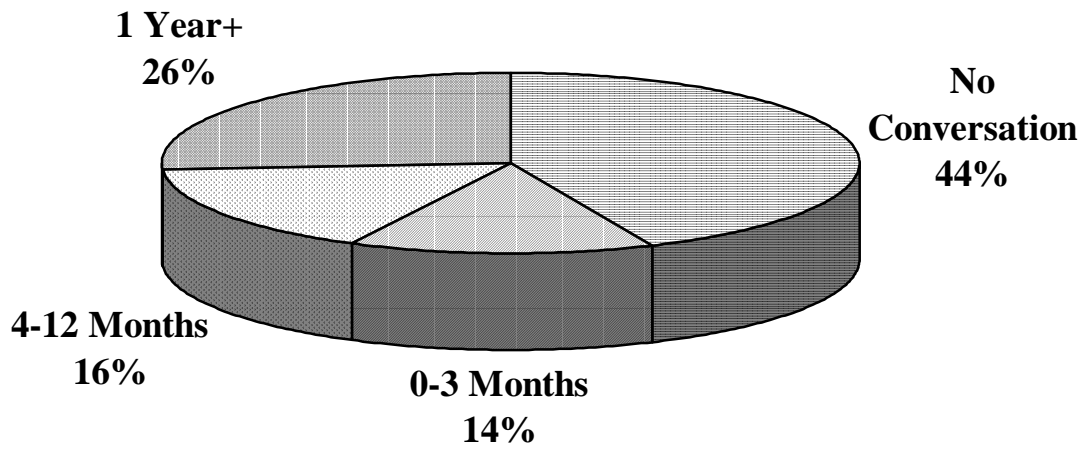


Figure 5
Had End-of-Life Care Planning Conversations by Age
(n=990)

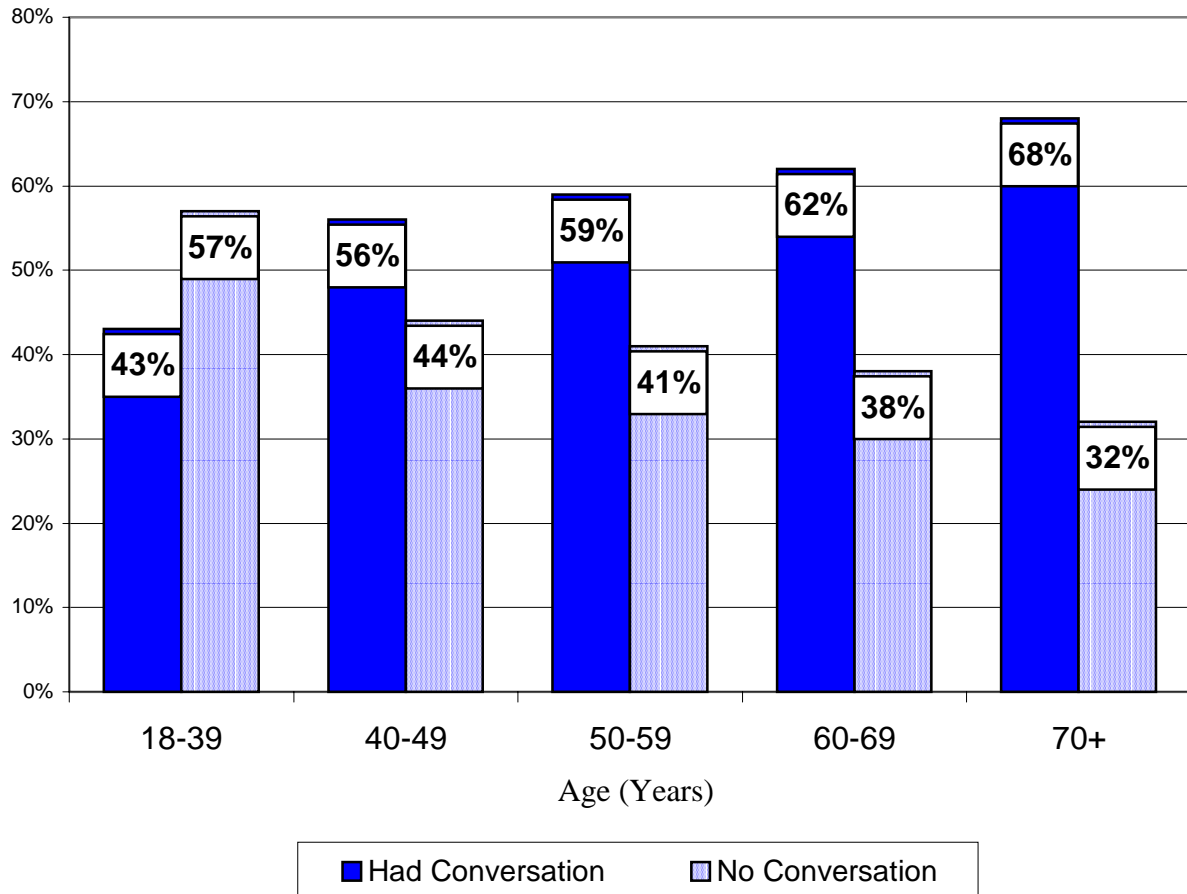


Figure 6
Had End-of-Life Care Planning Conversation by Education
(n=979)

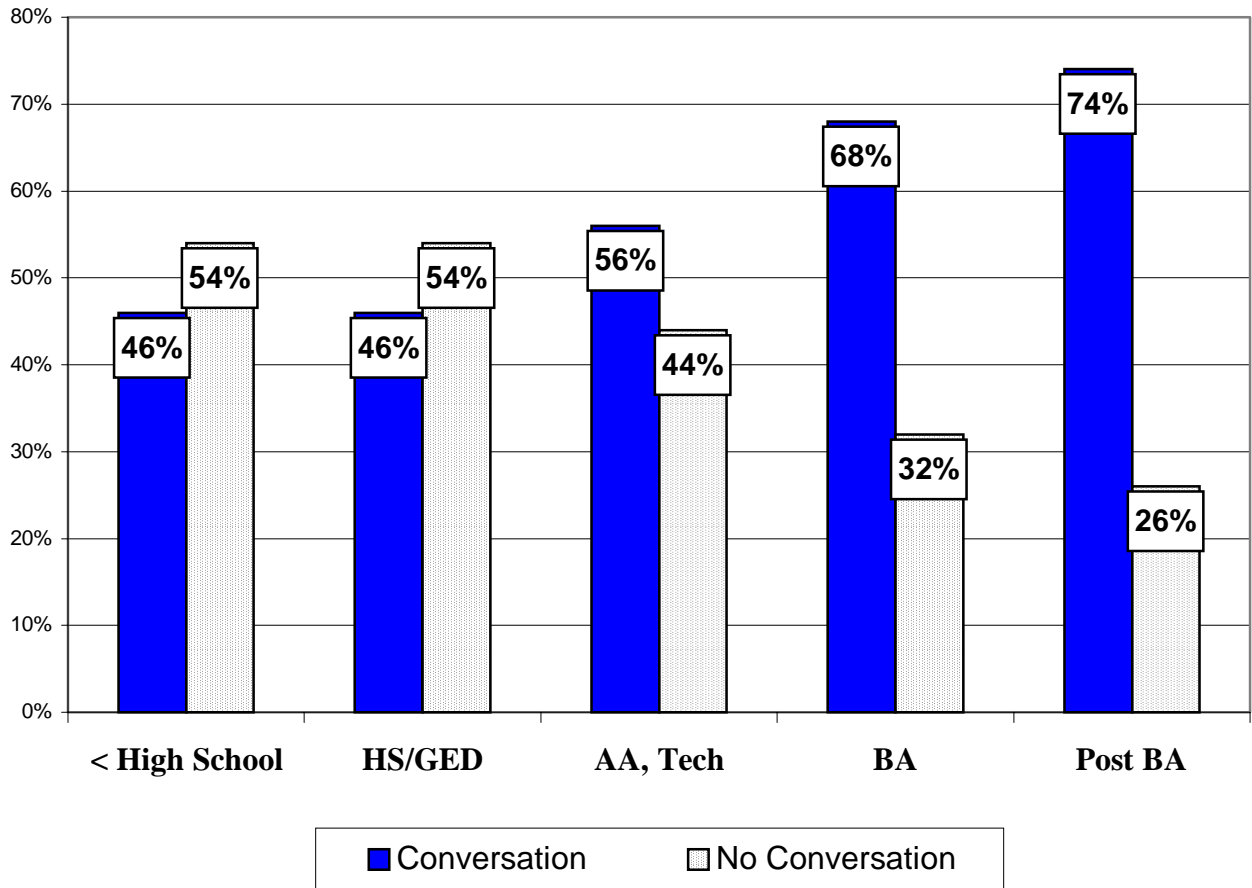


Figure 7
Had End-of-Life Care Planning Conversation
By Marital Status
(n=965)

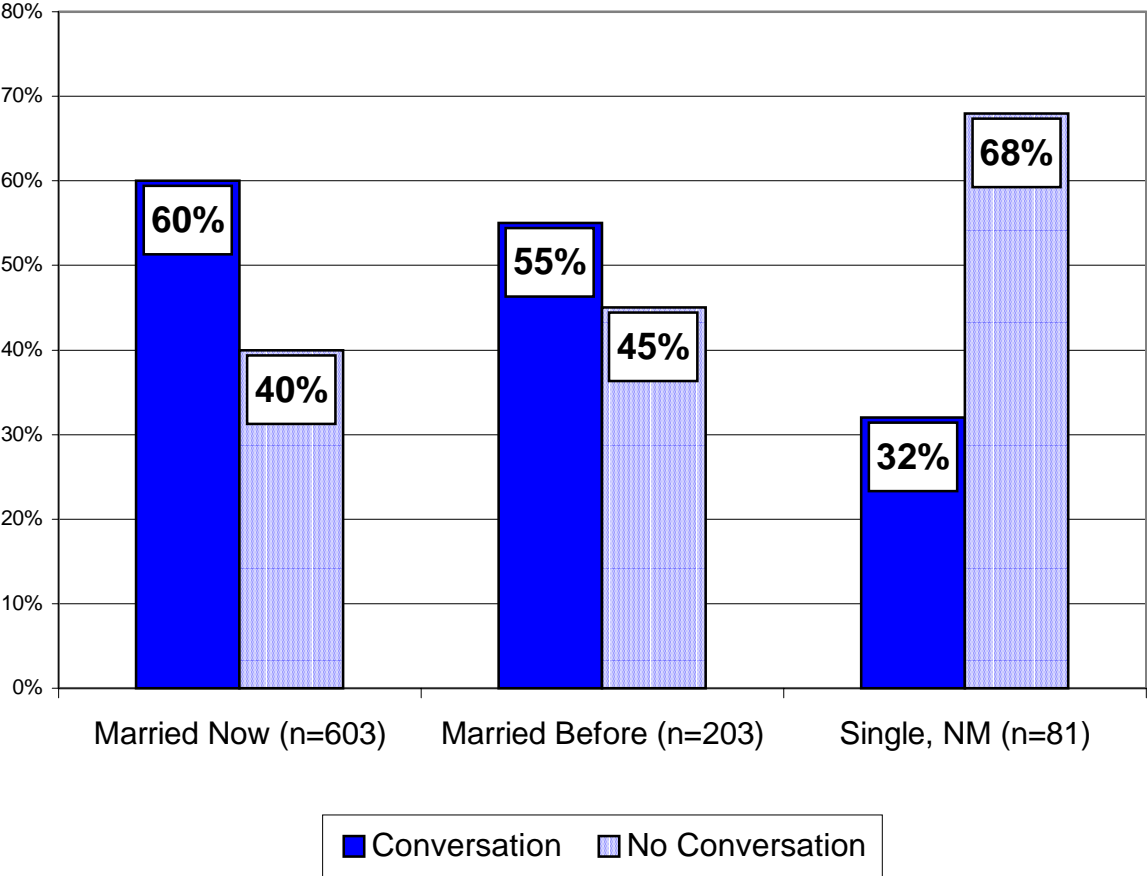


Figure 8

Timing of End-of-Life Care Planning Conversation (n=589)

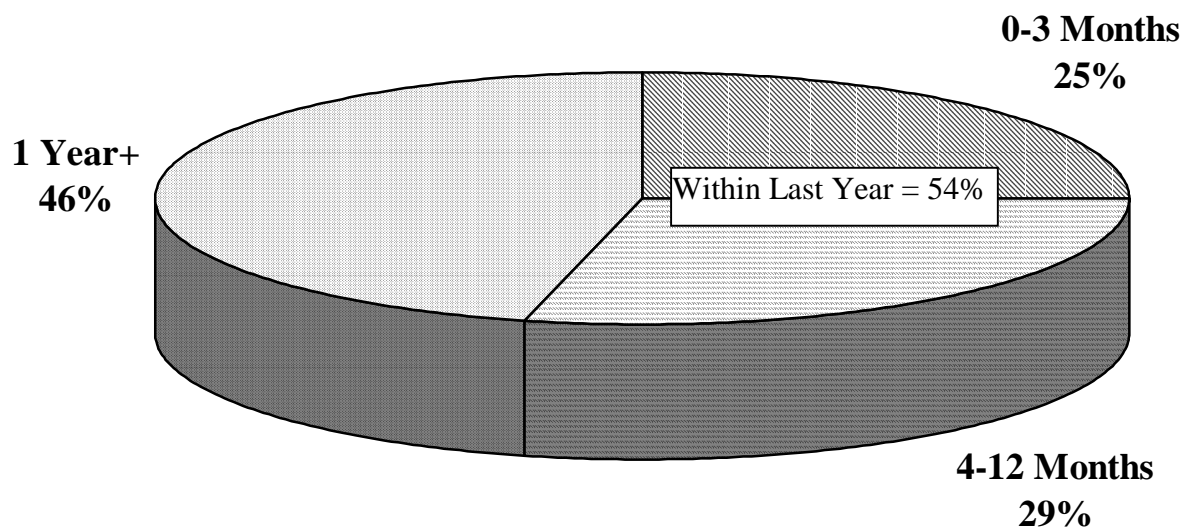
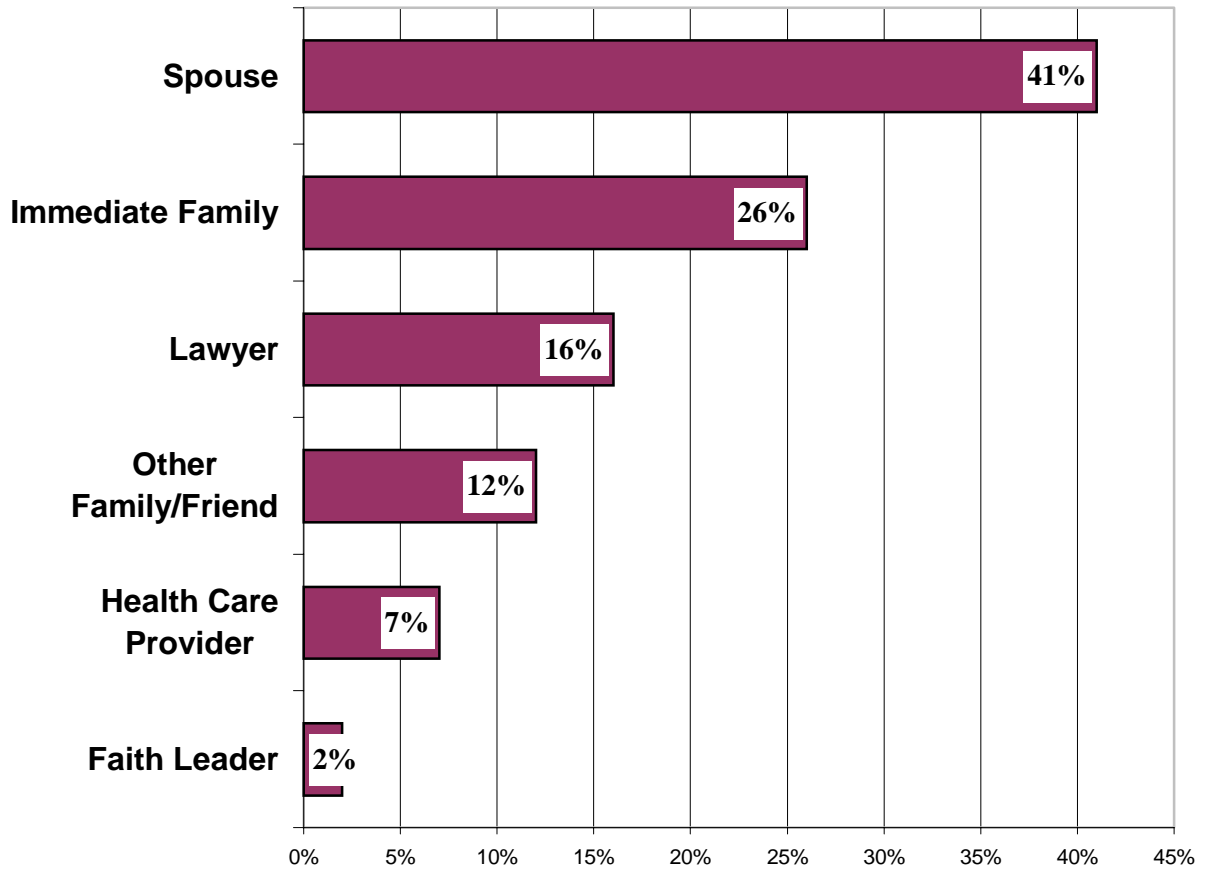
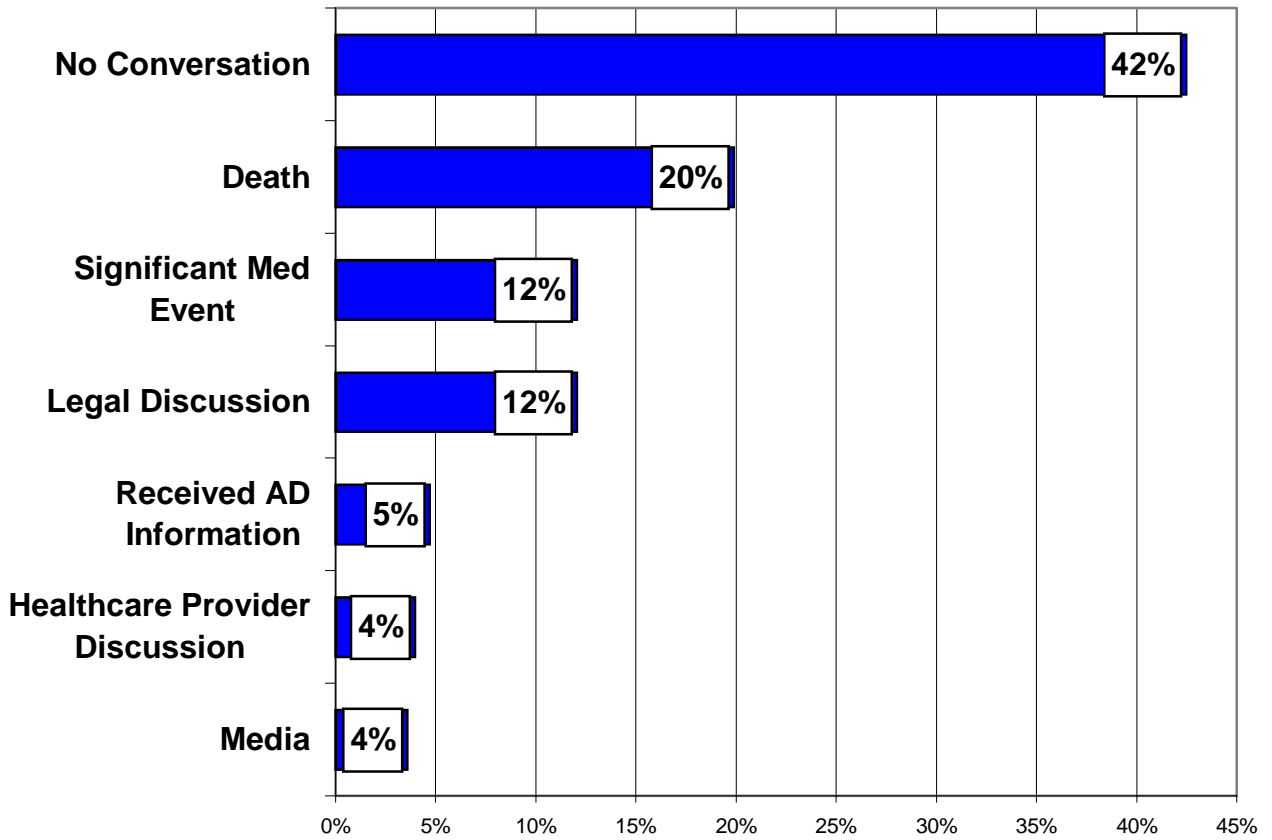


Figure 9
End-of-Life Care Planning Conversation Partners
(n=1062)*



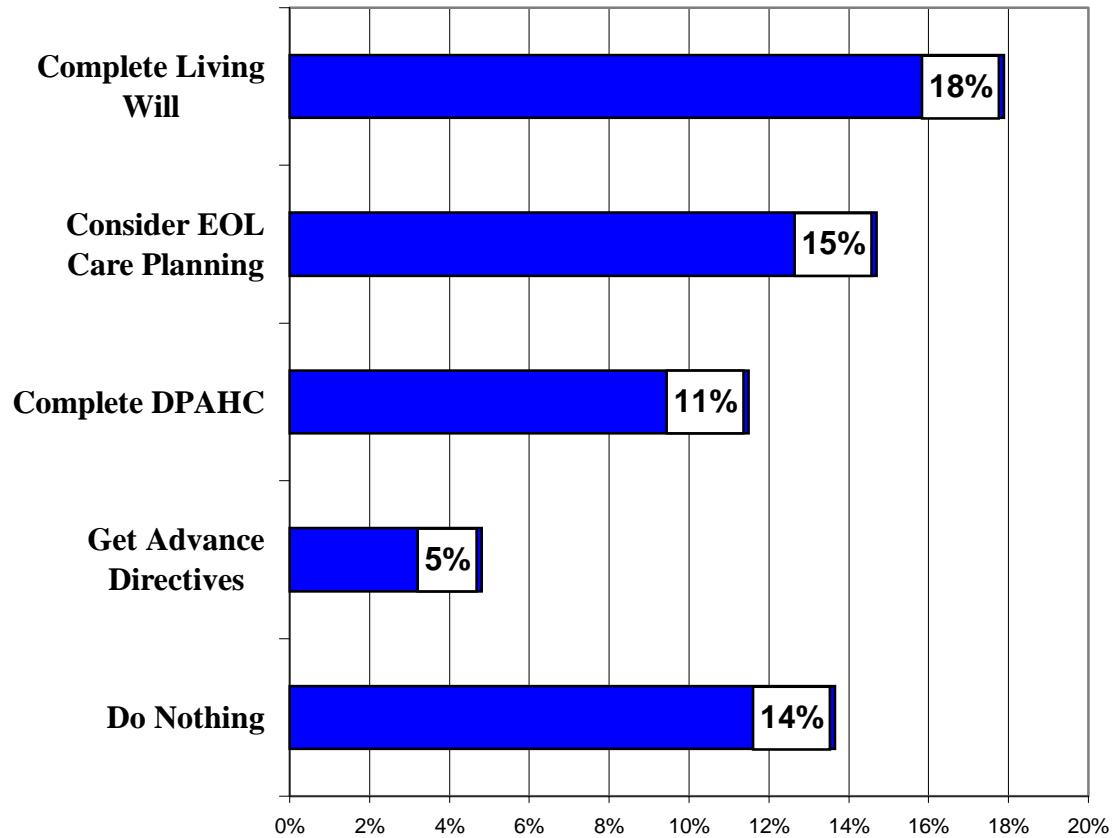
*(Counts are duplicated. Respondents could have conversations with more than one partner.)

Figure 10
What Prompted End-of-Life Care Planning Conversation?
(n=1062)*



*(Counts are duplicated. Respondents could have conversations with more than one partner. Therefore, numbers do not add to 100%.)

Figure 11
Actions Taken as a Result of Having End-of-Life Care Planning Conversation (n=1062)*



*Counts are duplicated. Respondents could have conversations with more than one partner. Therefore, numbers do not add to 100%.

Figure 12
Respondents with Advance Directives
(n=1054)

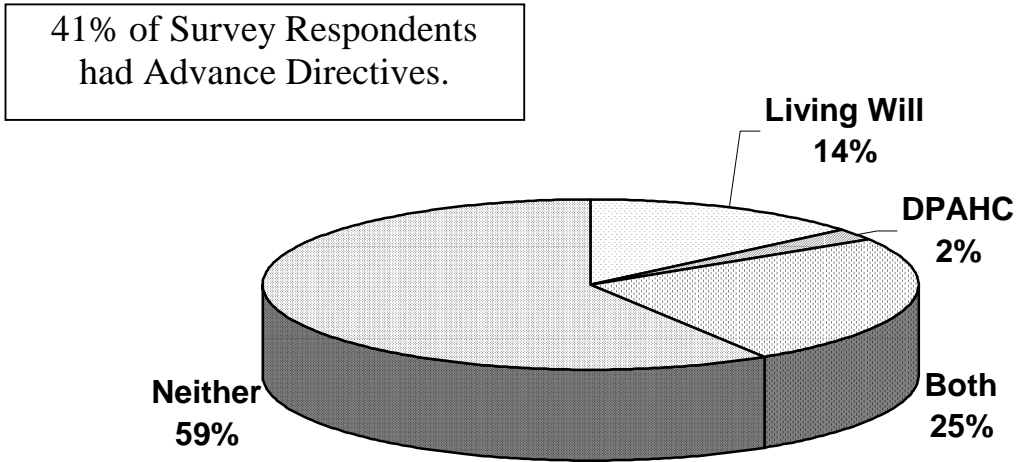
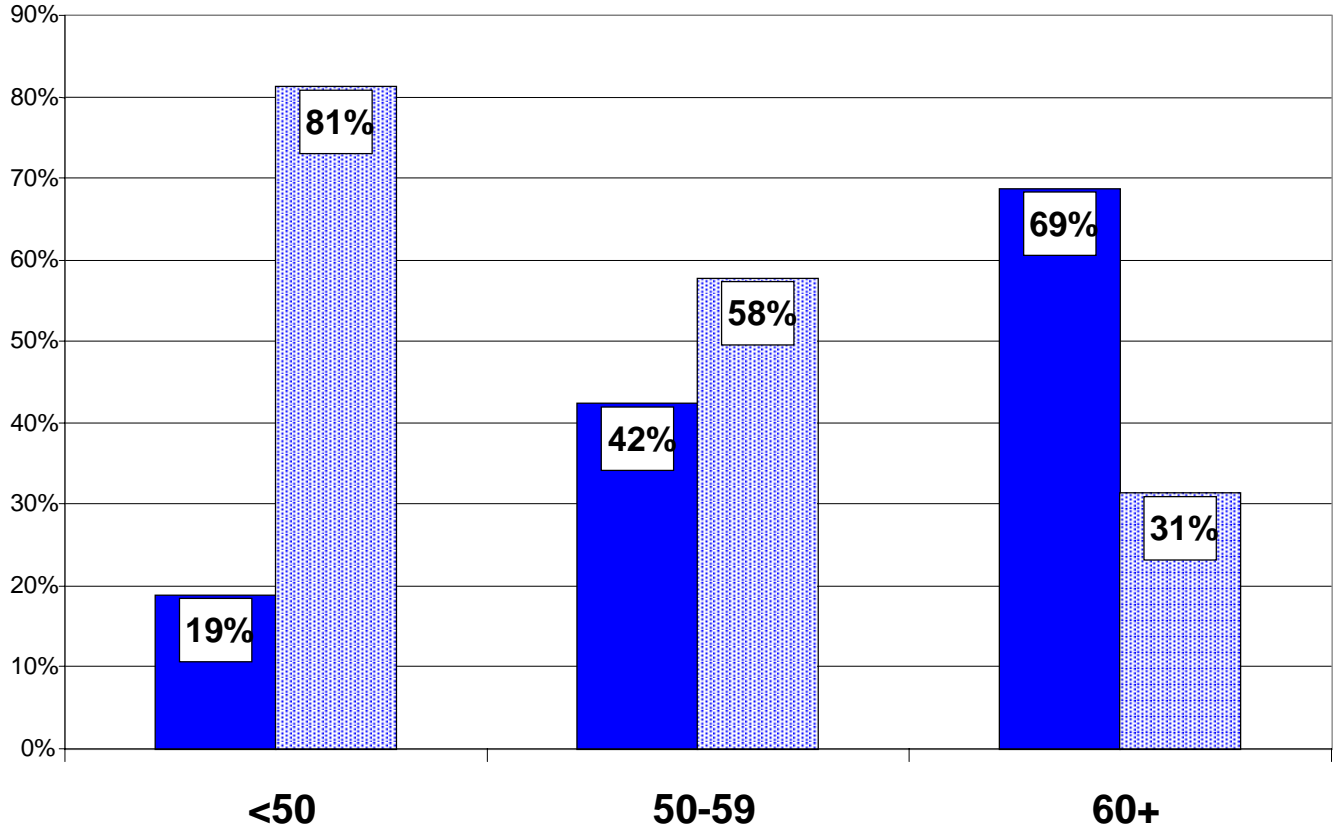


Figure 13
Advance Directives by Age
(n=999)



■ Yes ■ No

Respondent Age (Years)

Figure 14
Advance Directives by Marital Status
(n=974)

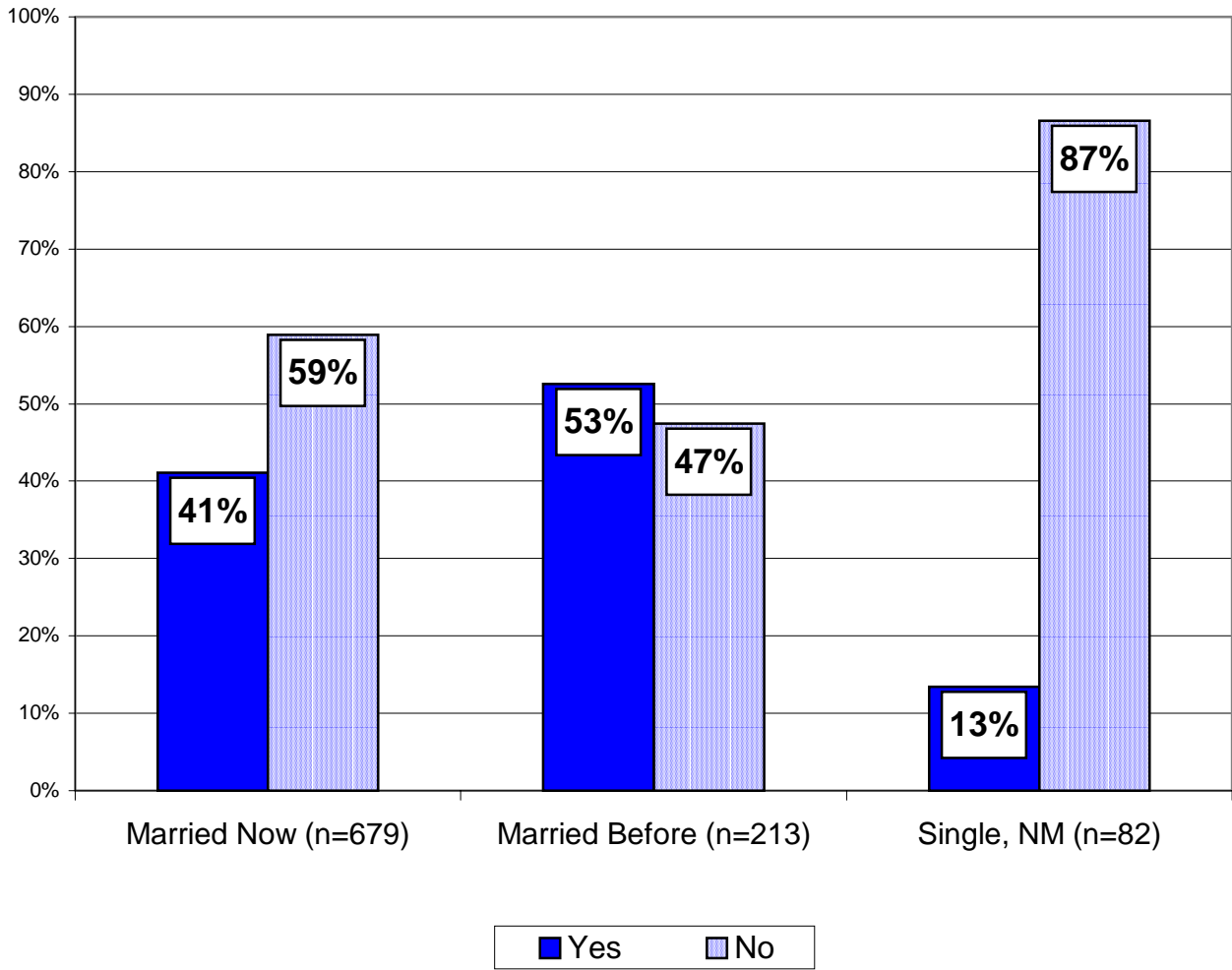


Figure 15
Advance Directives by Education
(n=986)

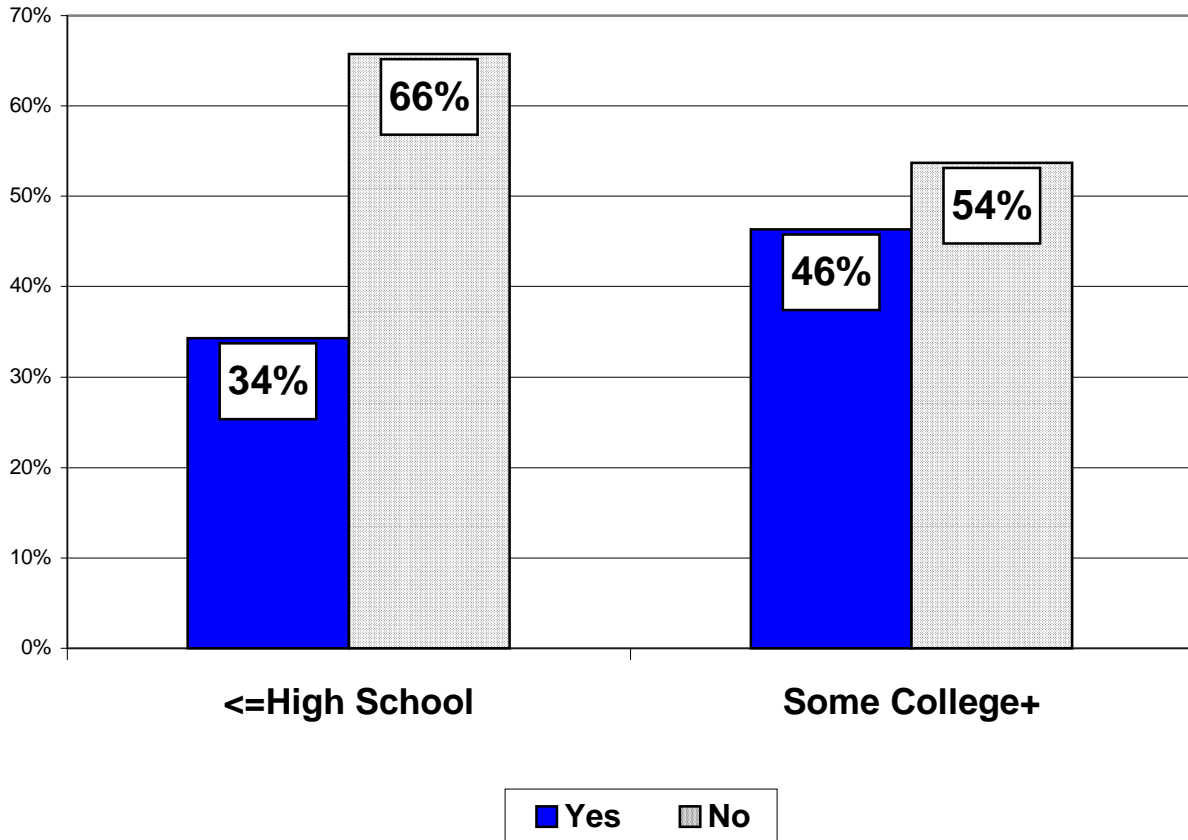
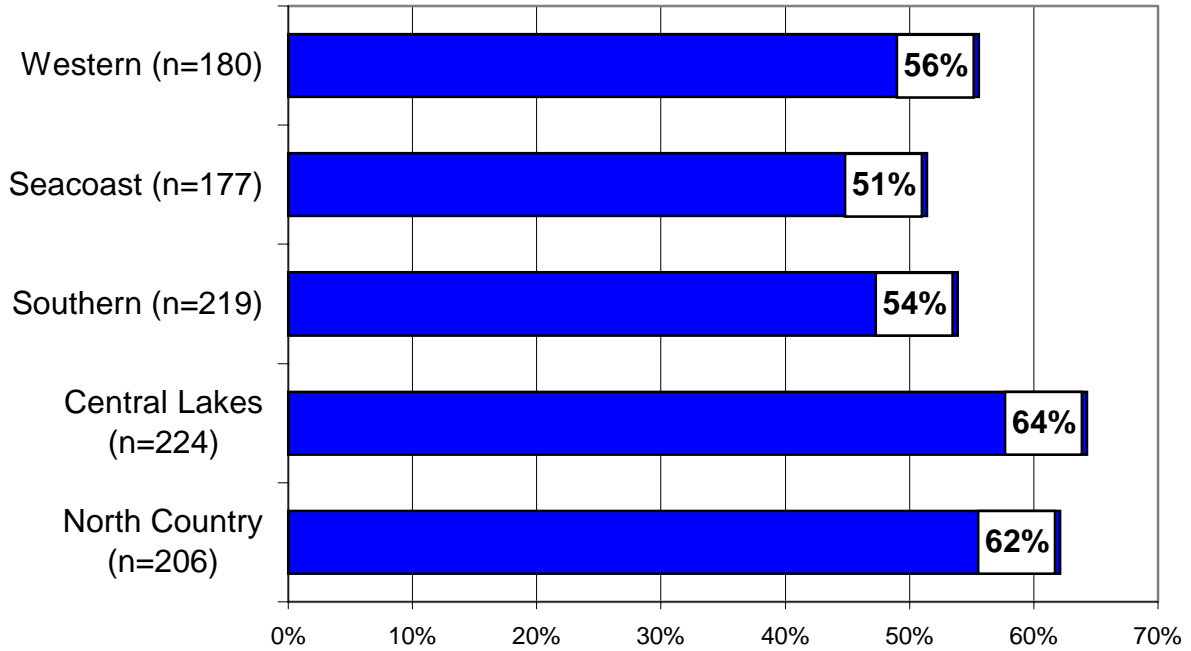


Figure 16
Advance Directives by Region
(n=1006)*



*Does not include out-of-state responses (n=33).

Figure 17
Advance Directives by Source of Survey Responses
(n=1053)

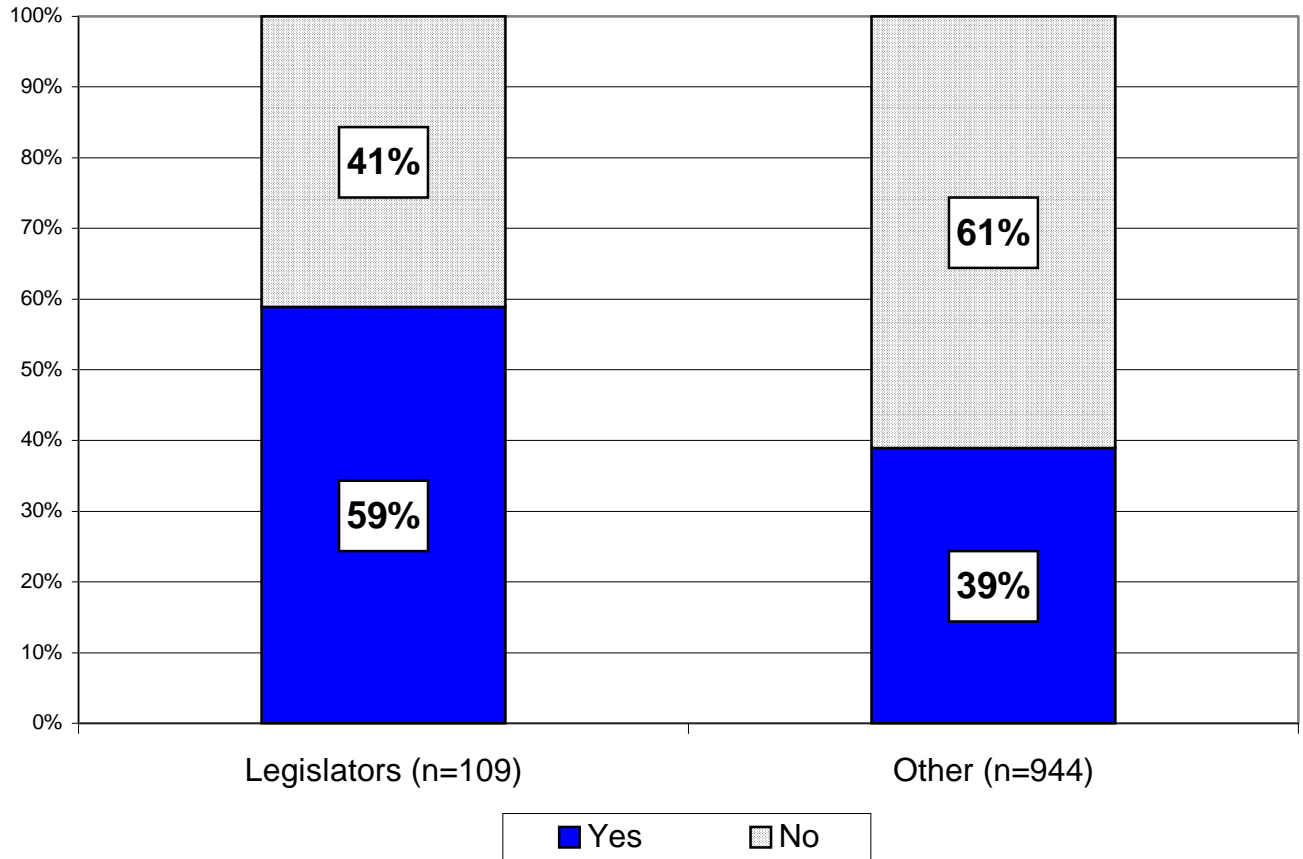
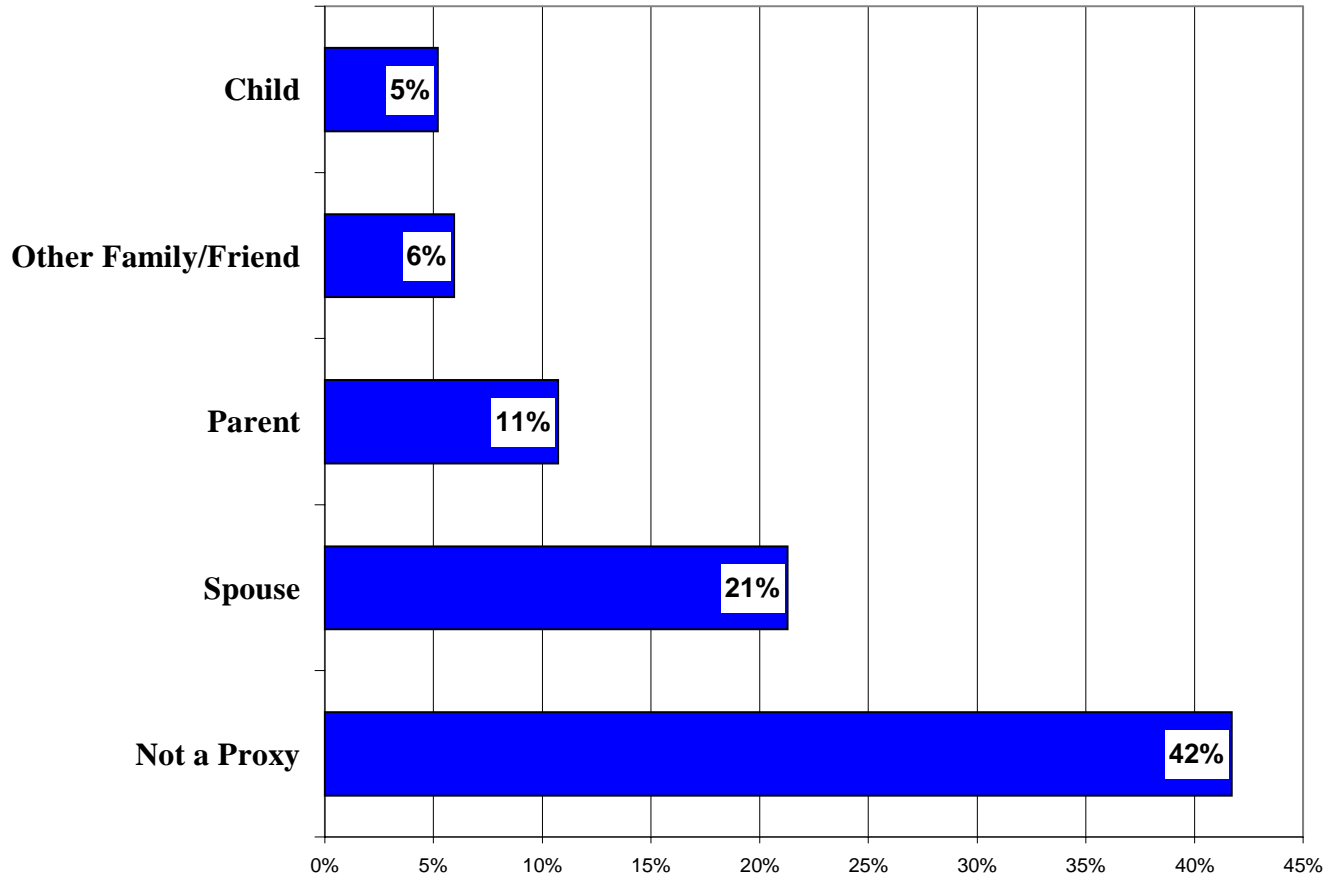


Figure 18
Respondents Appointment as Durable Power of Attorney
for Health Care (n=1062)*



*Counts are duplicated. Respondents can be appointed a DPAHC for more than one person. Therefore, numbers do not add to 100%.

Figure 19

**End-of-Life Care Planning Conversations Among Respondents Who
Have Been Appointed as a Durable Power of Attorney for Health Care
(n=620)**

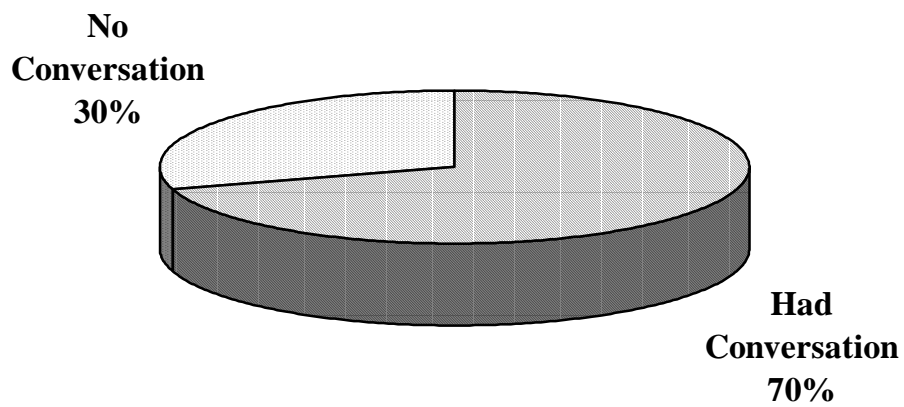
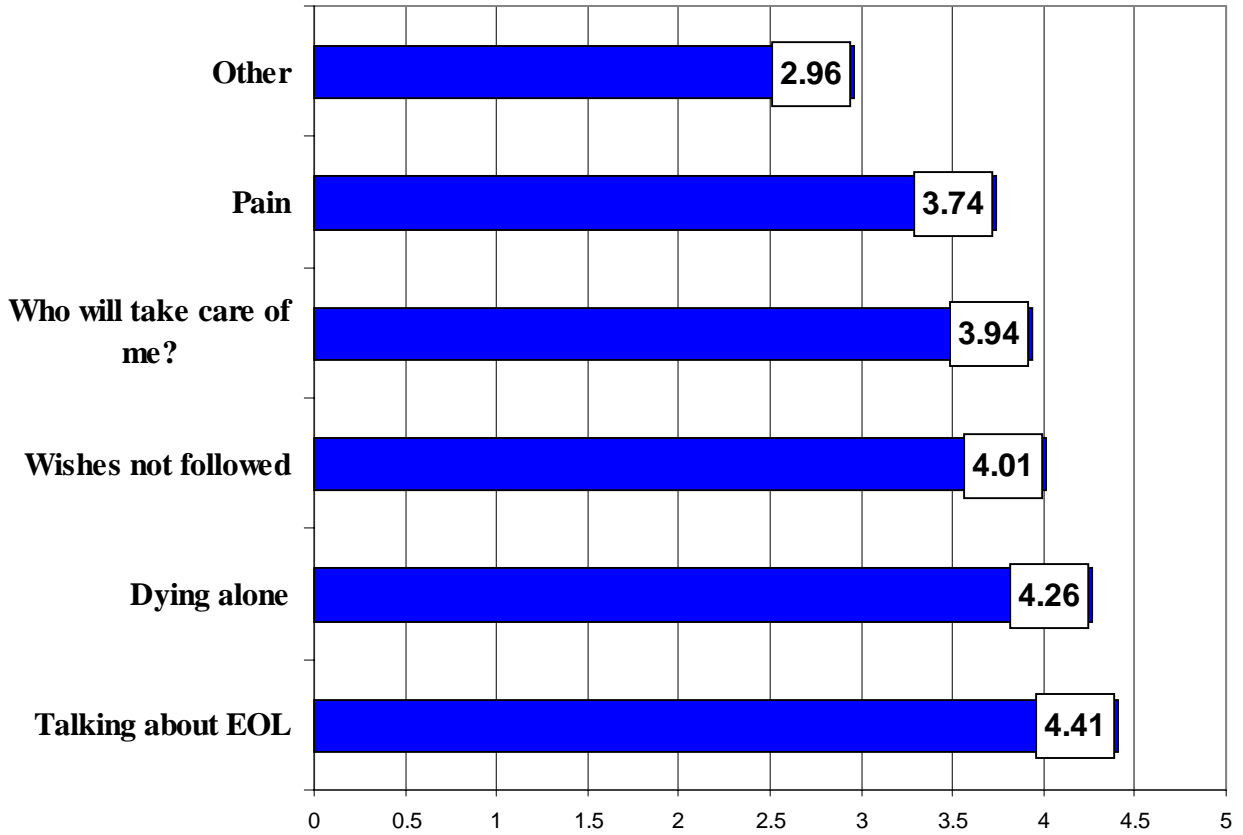


Figure 20
Level of Concern About End-of-Life Issues
(n=1062)*



Rating Scale: 1 = Very Concerned, 6 = Not at all Concerned

*Respondents can have more than one concern. Therefore, numbers do not add to 100%.

Counts are duplicated. Respondents could indicate more than one concern. Therefore, numbers do not add to 100%.

DEATH in NEW HAMPSHIRE: A Review of Medical Charts

EXECUTIVE SUMMARY

Hospitals, nursing homes, home care agencies and hospice programs in 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 786 adult deaths (age 18 years or older) in October and November 1998, was compiled to provide baseline data on end-of-life care issues and assess interest among health provider organizations in end-of-life care concerns. Some key findings include:

- The average age of decedents in the study was 76 years. For nursing home decedents, the average age was 84 years.
- More than half (55%) 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.
- Lung cancer was the most frequently identified primary diagnosis representing 10% of decedents in the study. It was followed by congestive heart failure (7%), Alzheimer's disease (2%) and strokes (2%).
- While one third of cases in the study were known to be in hospice programs, 28% of those cases entered hospice care in the week before they died.
- The average length of stay among hospital decedents was 8 days and for nursing home decedents it was 712 days, almost 2 years.
- Seventeen percent of the total number of 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.
- Pain/Discomfort was the problem or symptom assessed most often by all health providers in the last 48 hours before death (88%). This assessment of symptoms was followed in frequency by shortness of breath (75%), anxiety/confusion/agitation (74%), lack of appetite (60%), fever (58%) and difficulty swallowing (48%).
- The family's emotional needs were noted in 74% of charts and 20% of the charts recorded a chaplaincy or spiritual care consult in the last 48 hours before death.
- Treatments provided in the last 48 hours before death: narcotics (75%), foley catheter (43%), IV fluids (42%), antibiotics (23%), intubation/ventilator (12%) and enteral tube (10%).
- One half of the decedents had a living will and 57% had a durable power of attorney for health care (DPAHC). There were do not resuscitate (DNR) orders for 87% of all the deaths.
- Only about a third of persons under age 55 years had a DPAHC or living will while nearly half of persons 55-84 years had these two directives.
- Medicare was the primary insurance (64%), followed by Medicaid (12%), managed care (7%) and private commercial insurance (7%) for all organizations. Managed care was higher among home care/hospice cases (12%).

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-care in New Hampshire.

Foundation for Healthy Communities

End-of-Life Care Community Survey

The Foundation for Healthy Communities is currently seeking to improve knowledge and communication concerning End-of-Life Care. Your participation is **very important** and will help us in meeting your needs for improving the ease and quality of discussing plans for your medical wishes should you become seriously ill. Please answer the following questions to the best of your ability.

1. Do you currently have...

- Living Will
- Durable Power of Attorney for Health Care
- Both
- Neither

2. Who has copies of your Advance Directive(s)? *(Please check all that apply)*

- | | |
|---|--|
| <input type="checkbox"/> Do not have Advance Directives | <input type="checkbox"/> Other Family/Friend |
| <input type="checkbox"/> I have copy | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Spouse/Partner | <input type="checkbox"/> Hospital |
| <input type="checkbox"/> Child | <input type="checkbox"/> Lawyer/Estate Planner |
| <input type="checkbox"/> Parent | <input type="checkbox"/> Minister/Priest/or other clergy |

3. Have you had a conversation about End-of-Life Care planning with...

(Please check all that apply)

- Never had End-of-Life Care planning conversation
- Spouse/Partner
- Parent
- Child
- Other Family/Friend
- Healthcare Provider
- Lawyer/Estate Planner
- Minister/Priest/or other clergy

4. When was your most recent End-of-Life Care planning conversation?

- Never had End-of-Life Care planning conversation
- Within the last 3 months
- 4-12 months ago
- More than 1 year ago

5. What prompted your most recent conversation about End-of-Life Care planning?

(Please check all that apply)

- Never had End-of-Life Care planning conversation
- Death of family member/friend
- Significant medical event (not death)
- Media (movie, TV, radio, internet, magazines)
- Legal Counseling/Estate Planning
- Received Advance Directives information
- Discussed with healthcare provider
- Other (please specify)_____

6. *Please describe the quality of your most recent End-of-Life Care planning conversation.*
 (Please circle the most appropriate number)

Insufficient **Thorough** **Never Had Conversation**
 1.....2.....3.....4.....5.....6 7

7. **Did your most recent conversation about End-of-Life Care planning prompt you to...**
 (Please check all that apply)

- Never had End-of-Life Care planning conversation
- Had Advance Directives prior to conversation
- Consider End-of-Life Care planning
- Get Advance Directives information
- Complete Living Will
- Complete Durable Power of Attorney for Healthcare
- Do nothing

8. **Have you been appointed as a Durable Power of Attorney for Healthcare (Proxy) for**
 (Please check all that apply)

- Spouse/Partner
- Parent
- Child
- Other Family/Friend
- Not a Proxy

9. **What are your concerns about End-of-Life Care Planning?** (Please circle your level of concern)

| | <i>Very Concerned</i> | <i>No Concern</i> |
|---|---------------------------------|---------------------------------|
| <i>Talking about End-of-Life Care planning</i> | 1.....2.....3.....4.....5.....6 | 1.....2.....3.....4.....5.....6 |
| <i>Wishes not being followed at end of life</i> | 1.....2.....3.....4.....5.....6 | 1.....2.....3.....4.....5.....6 |
| <i>Pain/Discomfort</i> | 1.....2.....3.....4.....5.....6 | 1.....2.....3.....4.....5.....6 |
| <i>Who will take care of me</i> | 1.....2.....3.....4.....5.....6 | 1.....2.....3.....4.....5.....6 |
| <i>Dying alone</i> | 1.....2.....3.....4.....5.....6 | 1.....2.....3.....4.....5.....6 |
| <i>Other (please specify)_____</i> | 1.....2.....3.....4.....5.....6 | 1.....2.....3.....4.....5.....6 |

Please tell us about yourself

10. **Age**

- 18-39
- 40-49
- 50-59
- 60-69
- 70 +

12. **Current marital status**

- Married
- Life Partnership
- Separated/Divorced
- Widowed
- Single/Never Married

11. **Highest education level completed**

- Less than High School Diploma
- High School Diploma/GED
- Associate's Degree or Technical College
- Bachelor's Degree
- Post Graduate Degree

13. **Gender**

- Female
- Male

14. **County of Residence**_____

Thank you for your help!

New Hampshire Partnership for End-of-Life Care

... a group of organizations that helps people to plan for their health care, talk about their choices and have them respected.

Goal:

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.

Objectives:

- 1) Create the New Hampshire End-of-Life Care Leadership Task Force to provide an interdisciplinary coalition to act on policy development (Medicaid hospice benefit, pain assessment, managed care incentives, death certificate reporting) and communicate information to the public and professional audiences.
- 2) Modify the current advance directives pertaining to living wills and durable power of attorney to create more consumer-friendly documents.
- 3) Establish a train-the-trainer system for advance care planning and expand this effort by training a minimum of 450 people statewide to assist as facilitators in advance care planning.
- 4) Apply a quality improvement approach in at least 75 health care organizations to support better advance care planning.
- 5) Create a targeted public information program that will increase understanding of advance care planning and offer practical resources to support the process.

Partners include: Home Care Association of NH, NH Hospice Organization, NH Hospital Association, NH Health Care Association, NH Medical Society, NH Cancer Pain Initiative, NH Nurses Association, AARP-NH, NH Council of Churches, NH Interfaith Volunteers Caregiver's Network, Franklin Pierce Law Center, NH Bar Association & NH Department of Health and Human Services.