

Thoughts of Nebraskans
about living at the end
of life and implications for
those working to improve
care and conditions
for chronically and
terminally ill Nebraskans

NEBRASKA END-OF-LIFE SURVEY REPORT

November 2011

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—and implications for those working to improve care
and conditions for chronically and terminally ill Nebraskans*

Prepared:
November 2011

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About the Nebraska Hospice and Palliative Care Association

The Nebraska Hospice and Palliative Care Association (NHPCA) is a collaborative effort of more than 60 organizations with an interest in quality care for terminally and chronically ill Nebraskans. Established as a 501(c)3 community betterment non-profit in 1983, NHPCA includes Nebraska's hospices, community end-of-life coalitions, and more than a dozen other health and elder-care organizations.

NHPCA pursues initiatives in five broad areas: professional education, community engagement, advocacy, research, and quality improvement. For more information about NHPCA initiatives and how you can get involved, visit nehospice.org.

Vision: No Nebraskan lives in pain or dies badly. Nebraskans with chronic or end-of-life conditions, regardless of age, live their last months to the fullest, with their wishes expressed and respected, their pain and suffering alleviated, their fears and questions heard and addressed, their relational, spiritual, cultural, and financial needs met, and their loved ones around them and supported up to and following their death.

Acknowledgements

In 2003, three organizations – NHPCA, Nebraska Coalition for Compassionate Care, and Robert Wood Johnson Foundation (RWJF), through the end-of-life coalition Last Acts – collaborated to conduct in Nebraska a first-in-the-nation statewide survey of perceptions of end-of-life issues. Three years later, in 2006, the survey was repeated. Results of all surveys are at www.nehospice.org.

This survey draws on the work of the Life's End Institute: *Missoula Demonstration Project* and of AARP-North Carolina and the Carolinas Center for Hospice and End of Life Care, who generously provided their 2003 survey and report of North Carolina AARP members as a model.

The principal researcher for this survey was the University of Nebraska at Lincoln, Bureau of Sociological Research. Kaye Norris, PhD, was the principal researcher for the 2003 and 2006 surveys. Charles Asp, PhD, provided statistical analysis support for the 2003 and 2006 surveys. NHPCA Associate Director Jennifer Eurek has chaired the project since 2003. Input for the surveys also came from the NHPCA Research and Quality Improvement Committee, chaired by Greg Schieke of CIMRO of Nebraska.

Principal funding for the 2011 project came from Blue Cross Blue Shield of Nebraska. Additional funding was provided by AseraCare Hospice Foundation, The Nebraska Medical Center, Nebraska Medical Association, Odyssey Health Care, Hospice of Siouxland, York County Health Coalition - End of Life Partnership, Alzheimer's Association of the Great Plains, Hillcrest Nursing Home, and Seward County BRIDGES End of Life Coalition.

NHPCA thanks each of these individuals and organizations for their contributions to this pioneering research: a first-in-the-nation third follow-up survey of a state's perceptions of end-of-life issues.

Nebraska End of Life Survey Report November 2011

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Definitions

Hospice provides an interdisciplinary team of a doctor, nurse, social worker, chaplain (if desired), various therapists (as needed), home health aides and volunteers. Hospice is 100% paid by Medicare, Medicaid, the VA System, and many private insurance carriers for individuals diagnosed by a physician as having six months or less to live who choose to forego further curative treatment. Hospice helps families and the health care system know and respect the wishes of the terminally ill. Available wherever a dying person calls home—including assisted living and nursing facilities, hospitals, and prisons—hospice assesses and addresses physical, social, spiritual, and psychological issues to alleviate pain, symptoms, and suffering and improve the quality of life of those in their last months of life.

Hospice does not provide room and board services or serve as the on-site caregiver for a terminally ill person, but hospice provides regular visits, needed medications, medical supplies, and equipment and is available on call 24/7 to address and assist with needs and issues whenever they arise. Hospice supports both the dying person and his/her family or other caregivers with practical expertise and education on pain and symptom management, living arrangements, identifying and meeting end-of-life wishes, the dying process and issues to expect, end-of-life financial considerations, relationship and spiritual issues, and access to respite care and other resources. Hospice also provides bereavement support up to and beyond the first anniversary of a loved one's death, a service many hospice programs extend to any community member, not just those whose loved one received hospice care.

Hospice listens. Hospice addresses pain, symptoms, questions, and fears. Hospice educates. Hospice provides support and comfort. Hospice consistently earns the highest satisfaction ratings in health care.

Palliative Care is focused on improving the quality of life of people, of any age, facing serious illness. It is appropriate from the time of diagnosis and can be provided along with curative treatment. Like hospice, palliative care is holistic; it focuses not only on pain and symptom management but also on identifying and addressing social, psychological, and spiritual issues that can impact both an individual's physical condition and the effectiveness of medical interventions. Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. Most insurance plans, Medicare, and Medicaid cover all or part of the palliative care treatment you receive in the hospital, as with other hospital and medical services.

Advance Directives allow you "in advance" to "direct" the health care system and loved ones on what medical decisions you would want made if you are physically or mentally unable to communicate for yourself, either temporarily or permanently. This might occur, for instance, if you were in a coma or persistent vegetative state, if you had Alzheimer's disease or other dementia, if you were under sedation, or if you suffered a brain injury. There are several kinds of advance directives:

- **Health Care Power of Attorney (HCPA)** allows you to legally name another person to make health care decisions on your behalf if you are incompetent or unable to make them for yourself.
- **Living Will** allows you to identify treatments you would or would not want if you were dying: for instance, whether, under what conditions, or for how long you would want a feeding tube.
- **Organ Donor** provides your permission for your organs to be given to others when you die.
- **Do Not Resuscitate (DNR)** or **Allow Natural Death (AND)** gives your permission to health care workers to forego emergency interventions if you stop breathing or your heart stops.
- **POLST (Physician Order for Life-Sustaining Treatment)** is a one-page form that accompanies a patient's medical chart to make HCPA, DNR/AND, and Living Will information immediately useable in health care settings.

I. Analysis and Overview

In August of 2003, the Nebraska Coalition for Compassionate Care and the Nebraska Hospice and Palliative Care Association (NHPCA) conducted the first randomly-sampled statewide end-of-life survey in the United States. The purpose was to find out Nebraskans' views on end-of-life issues, to identify baseline measures for efforts to improve end-of-life care and conditions in Nebraska, and to help those involved in such efforts to focus their activities and set appropriate priorities. Three hundred (300) Nebraskans completed the survey in 2003, with the results released as the Nebraska End-of-Life Survey Report in January of 2004, available online at www.nehospice.org.

In August of 2006, the survey was repeated by NHPCA with another random sample of Nebraskans. From this random sample, 324 Nebraskans completed the survey. In August of 2010, the survey was repeated again with another random sample of Nebraskans. From this sample, 862 Nebraskans completed the survey. Unless otherwise identified, this report provides the views of these 862 Nebraskans, and at some points, compares them with views of the 300 respondents from 2003 and the 324 respondents from 2006 to highlight changes over time. In addition, in 2010 and 2006, surveys were mailed to the 300 respondents from 2003. From this sample, 167 responded again in 2010, giving a second window on changes over time and reported in the last section of *Changes Over Time*.

Demographics of the 2010 random sample are included in the methodology section of this report. Key Findings are reported in the next section in the following areas: wishes, planning in advance, pain issues, fear issues, resources and support, knowing about hospice, and knowing about palliative care.

In these same categories the 2003 and 2006 responses were then compared with those from 2010, first comparing the three random samples, then comparing the responses of those households that completed the survey in multiple years. Differences are reported for responses that were "statistically significant," which means that if two random samples of Nebraskans were drawn and asked this item, there would be less than one chance in 20 that there would be the same magnitude of difference as seen here. When "statistically significant" results are referenced, it means that the difference is unlikely to be the result of chance. Since there is less than one chance in 20 that the "statistically significant" results are due to chance, it is assumed that the difference is because of group membership and not random error.

HIGHLIGHTS OF THE CURRENT (2010) DATA

Role of the Physician in End-of-Life Care

According to those who completed this survey, the role of the physician in end-of-life care is very important. In particular:

- 99% of respondents expect honest answers from their doctor.
- 98% of respondents stated that it is important to understand their treatment options.
- 83% of respondents choose to know if they have six months or less to live.
- 71% of respondents trust their doctor to provide information about end-of-life care.
- 63% of respondents indicate that their doctor would believe them if they were in pain and would take action to remedy the pain. 37% believe their doctor would NOT believe them if they were in pain and would NOT take action to alleviate the pain.

The Role of Hospice and Palliative Care

A majority of participants (97%) have heard about hospice, but not palliative care. Interestingly:

- 36% of respondents are interested in receiving more information about hospice while 47% are not interested. 17% are unsure.
- 34% of respondents trust the local hospice to provide information about end-of-life care.
- 69% of respondents learned about hospice through knowing someone who used hospice. 21% learned about hospice from a professional.
- 58% indicate they would want hospice if they were dying. 38% are unsure if hospice is right for their needs.

- A majority (54%) of respondents who want hospice prefer service in their home. 25% would like service in a hospice facility.
- 27% of respondents have heard about palliative care. 72% have not heard about palliative care.
- Since palliative care is less familiar than hospice, 76% are unsure if they want this type of care.
- 43% of respondents would like to know more about palliative care, while 34% are not interested. 23% are unsure.

Medical Intervention

Medical intervention during a terminal illness is a source of concern for not only the patient, but also for the family. According to the survey:

- 70% of respondents DO NOT want any medical intervention if they know they are dying. 30% would want medical intervention to keep them alive as long as possible.
- 76% of respondents are fearful of dying painfully while 24% are not.
- 65% of respondents agree that “living with great pain” is a matter worse than death.

End-of-Life Decisions

Many decisions are to be made regarding end-of-life care. Although it is important to many survey participants that they play an active role in making end-of-life decisions and plans, less than half have actually taken the step to engage in the planning and decision making process. In particular:

- 95% of respondents indicate that it is important to be able to complete their own will. However, only 44% have heard about and completed their last will and testament, while 53% have heard about but not completed their last will and testament. Only 3% have not heard of a last will and testament.
- 57% of respondents have heard about and registered for organ donation, while 41% have heard about but not registered for organ donation. Only 2% have not heard about organ donation.
- 74% of respondents find it is very important to plan their own funeral or memorial service. However, only 13% of respondents have actually pre-planned their services.
- 32% of respondents have heard about and completed a health care power of attorney. 58% have heard about a health care power of attorney, but HAVE NOT completed the paperwork. 10% of respondents have not heard about a health care power of attorney.
- 33% of respondents have heard about and completed a living will while 63% have heard about completing a living will but have not completed the paperwork. Only 4% have not heard of a living will.
- 72% of respondents state that “not being able to communicate my wishes/needs” is a matter that is worse than death.
- 82% of respondents expressed that “total physical dependency on others” is a matter that is worse than death.

Financial Concerns

Financial concerns regarding end-of-life care can be overwhelming. Survey participants noted the following:

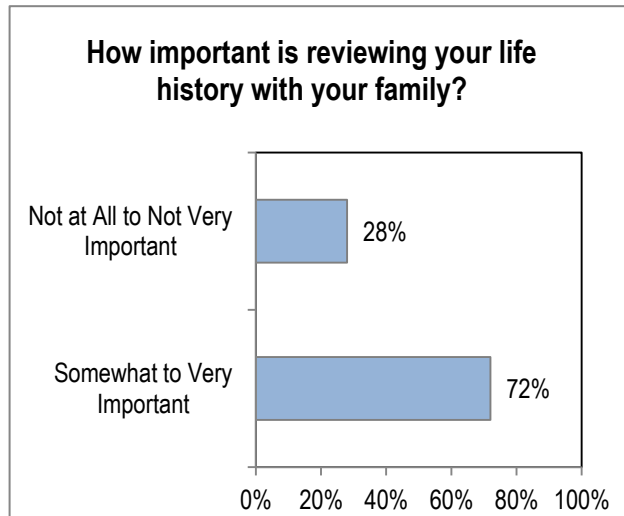
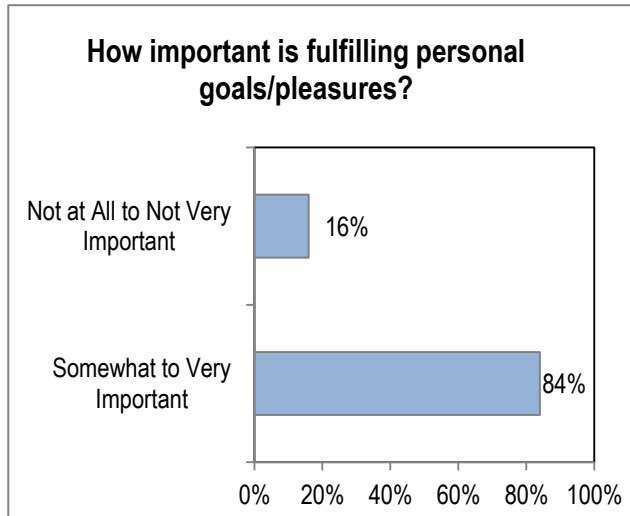
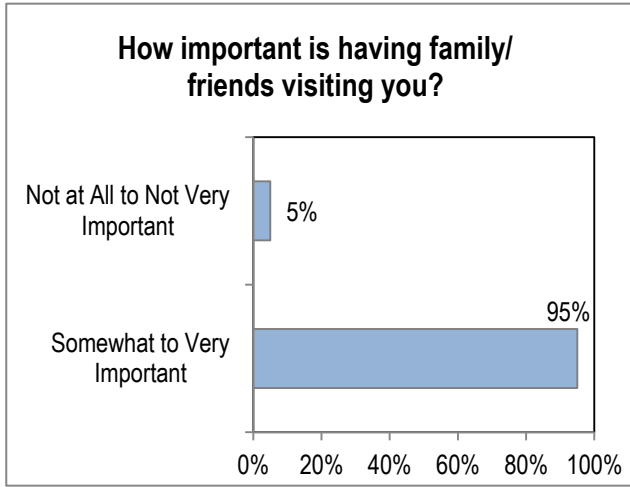
- 95% find getting their finances in order to be somewhat to very important
- 67% are unsure as to whether or not Medicare pays for hospice, while 28% understand that Medicare does cover hospice costs. 5% thought hospice was not covered by Medicare.
- 87% are unsure as to whether or not Medicare pays for palliative care, while 10% understand that Medicare does cover palliative care costs. 4% thought palliative care was not covered by Medicare.¹

The responses of Nebraskans through this survey will guide our efforts to reduce the impact of death on the dying and their caregivers, to improve the end-of-life experience for all Nebraskans, and to help Nebraskans avoid dying badly. We share these survey results with you so they may guide your efforts as well.

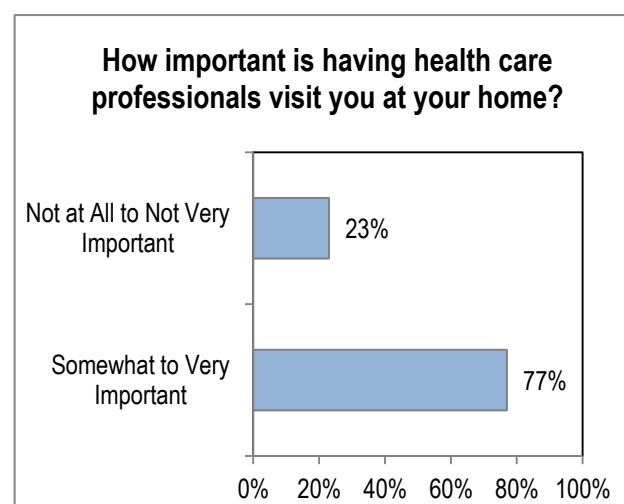
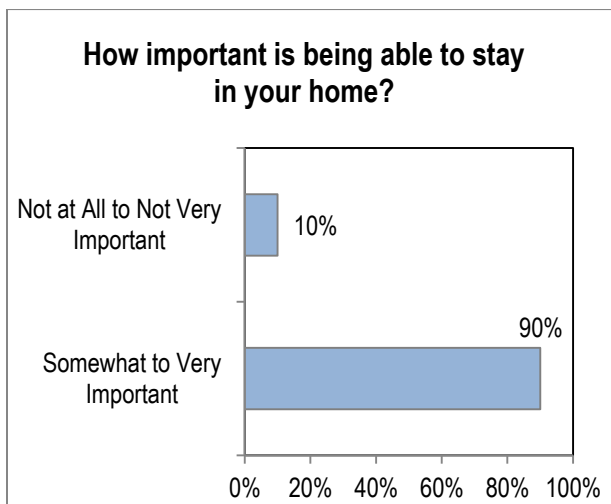
¹ The sum of these percentages equals 100% due to rounding.

II. Key Findings

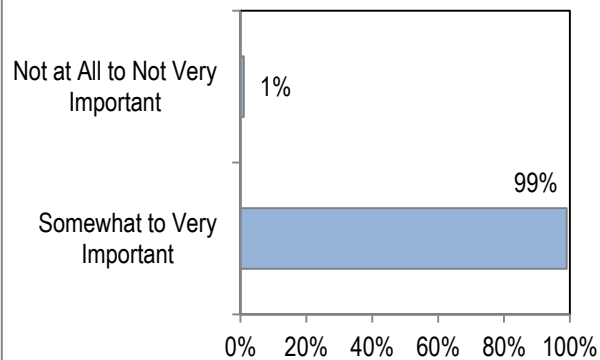
1. WISHES



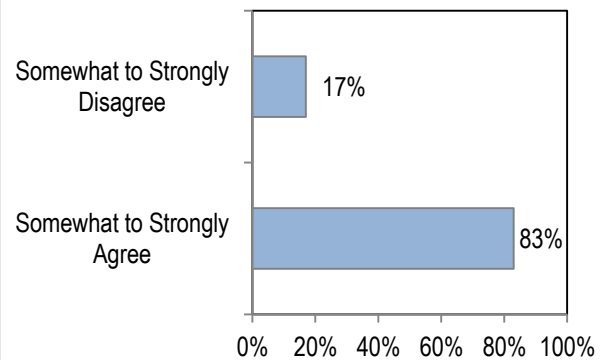
When asked what would be important during their dying experience, respondents indicated a strong desire to have family and friends visit, to give to others, to fulfill personal goals and to review their life history with family.



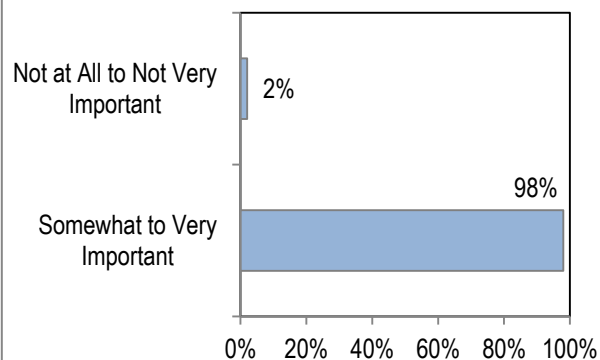
How important are honest answers from your doctor?



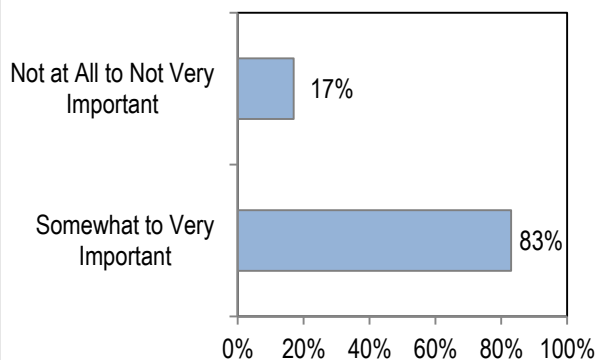
If someone could tell me that I likely have six months or less to live, I would want to know.



How important is understanding your treatment options?

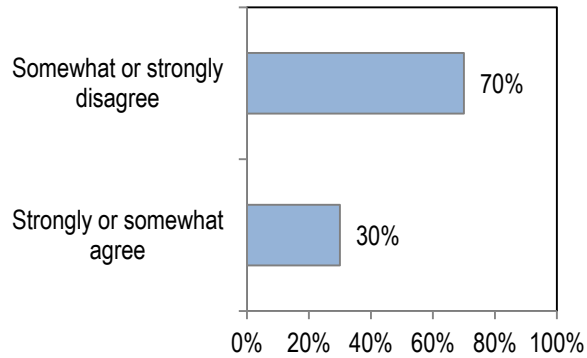


How important is comfort from religious/spiritual services or persons?

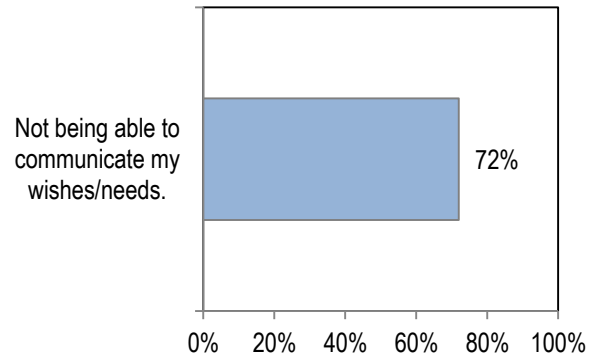


Our respondents feel an overwhelming desire for honest answers from their doctors, with 99% indicating this would be important. Eighty-three percent indicated that they also want to know if they only have six months to live. Yet, that type of prognosis is difficult to determine and there are still strong social mores and medical reluctance to acknowledge pending death. Understanding treatment options is also important for almost all of our participants as well as receiving comfort from religious/spiritual services or persons.

If I knew I was dying, I would want medical intervention to keep me alive as long as possible.



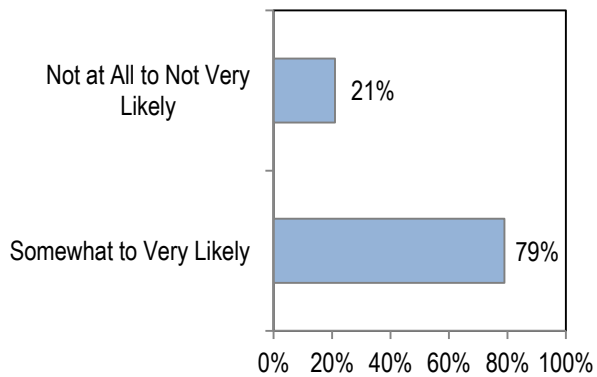
Which of the following problems would be worse than death?



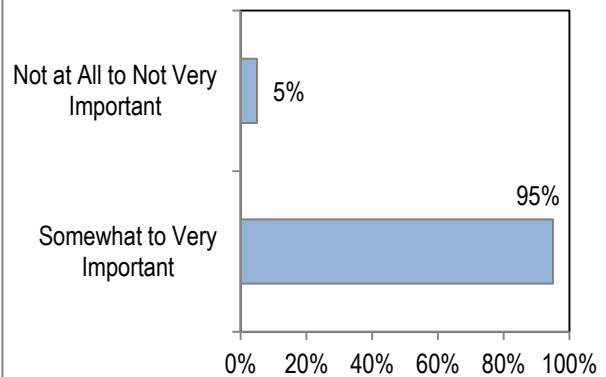
Even though our medical system has a natural bias toward continued treatment, only 30% of our participants indicated that they would want medical interventions to keep them alive as long as possible. In fact, 72% believe that not being able to communicate their wishes would be worse than death.

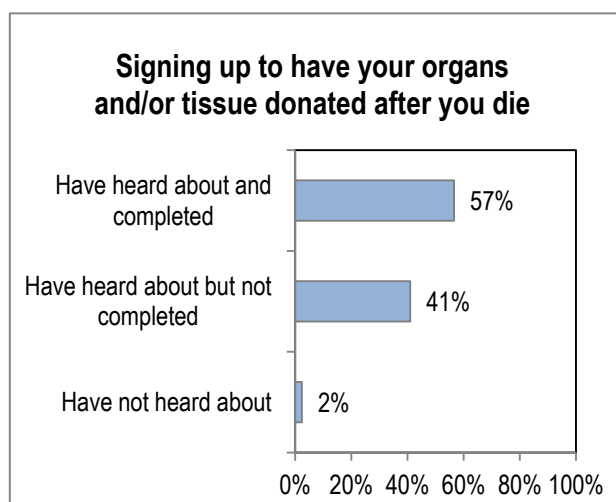
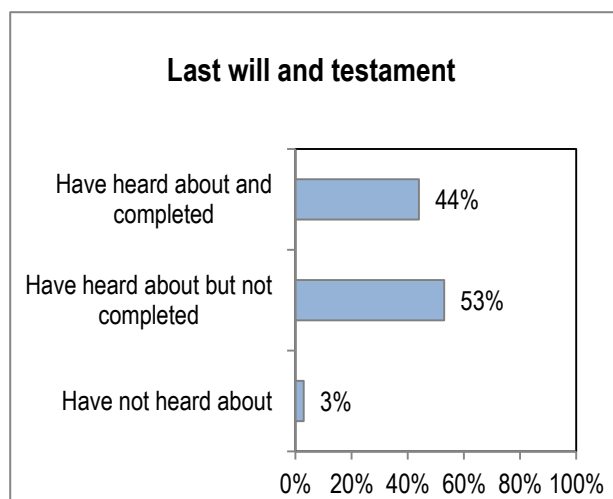
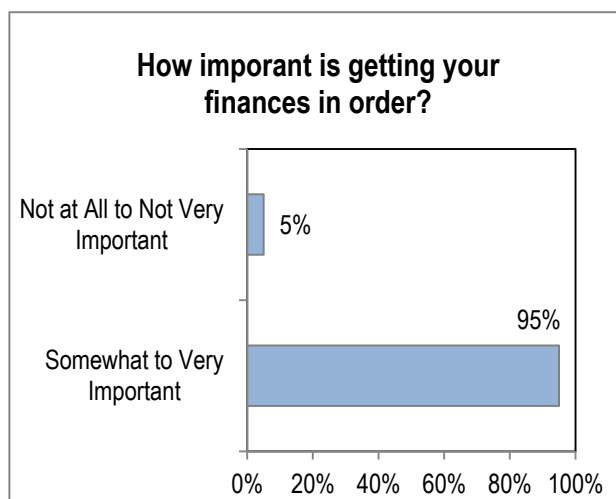
2. PLANNING IN ADVANCE

How likely are you to speak freely with loved ones about death and dying?

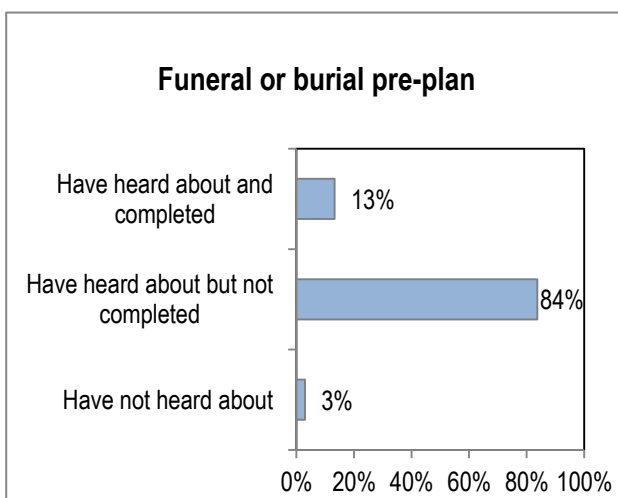
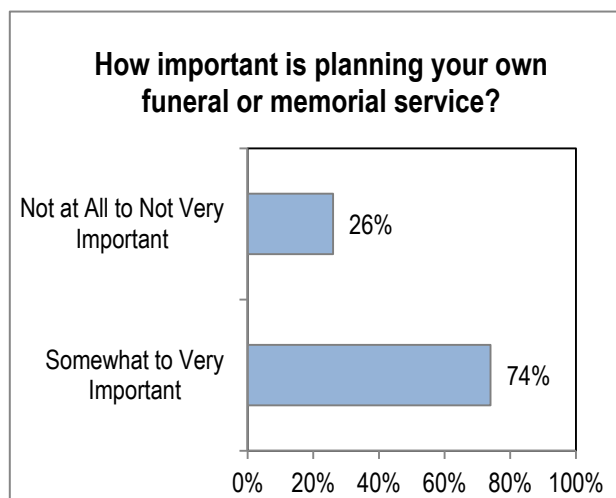


How important is being able to complete your own will?

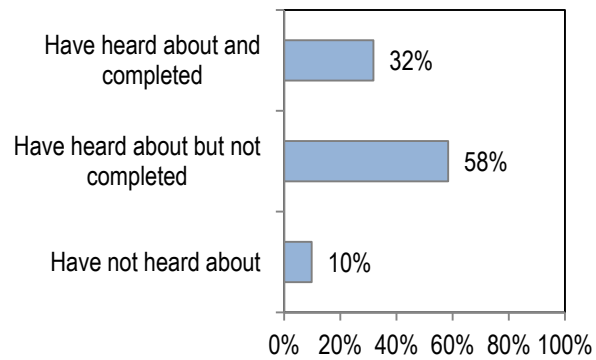




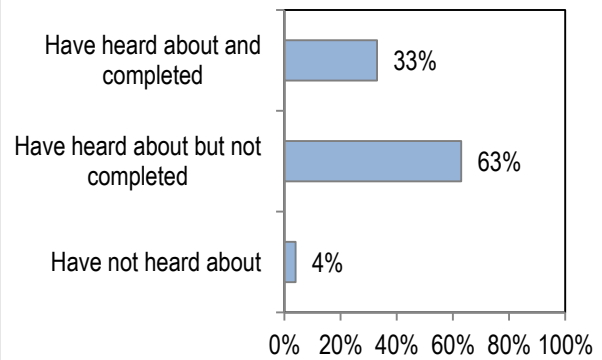
As previously indicated, a high percentage of our respondents know what they would wish to happen if they were dying. Above we see that 79% are likely to speak freely with loved ones about death and dying. Being able to complete their will and having their finances in order is important, however just 44% have actually completed their will. Regarding organ donation, 57% have signed up for organ donation, which is an increase from 39% in 2006.



Health Care Power of Attorney



Living Will

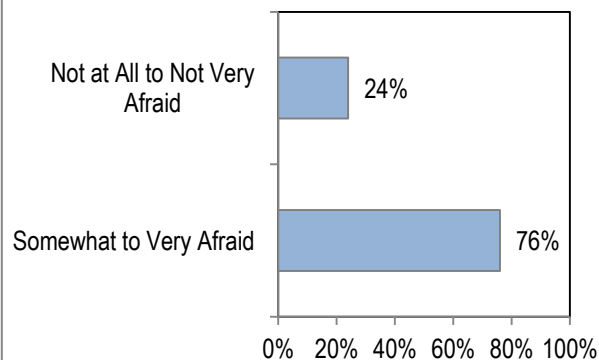


Additionally, even though three-fourths of respondents indicated that planning their own funeral or memorial would be important, only 13% have pre-planned funeral or burial services. Finally, only 32% of the respondents have completed a health care power of attorney (HCPA) and 33% a living will. This is a decrease from 2006, where 36% had an HCPA and 38% had a living will. These statistics explain that the rates of advance planning are still low.

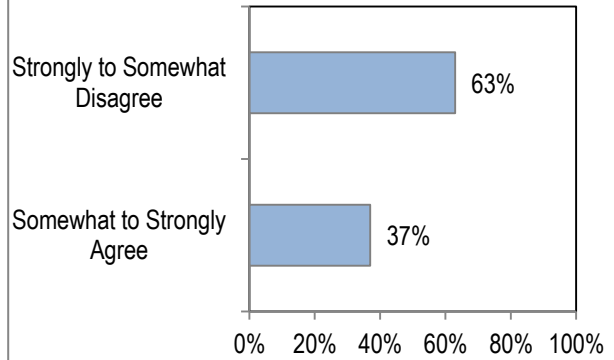
3. PAIN ISSUES

Because pain is commonly experienced during the dying process, we asked respondents about their concerns and their understanding of pain treatment.

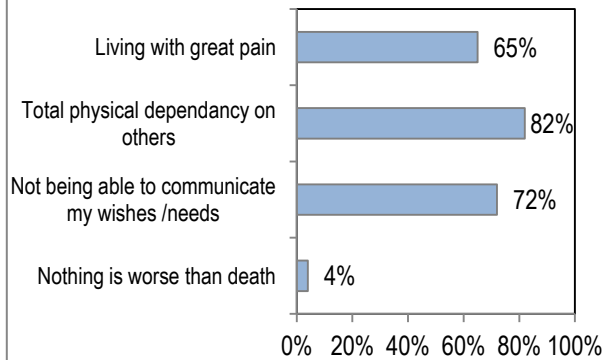
How afraid are you of dying painfully?



I am afraid my doctor may not believe I am in pain or may not treat my pain.

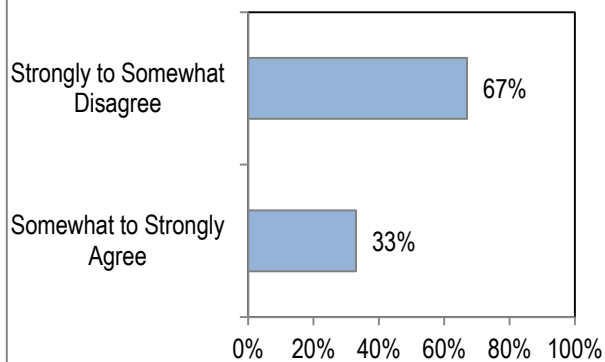


**Which of the following problems
would be worse than death?**

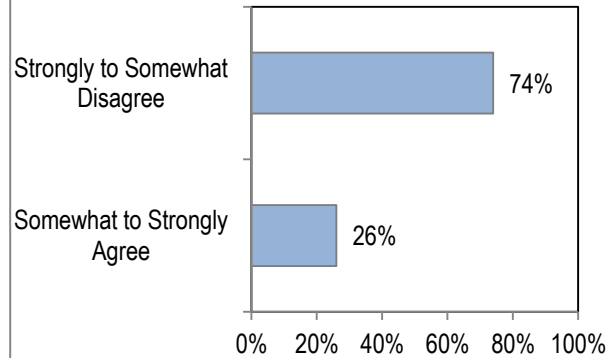


Over three-fourths of the respondents indicated a fear of dying painfully, and over half (63%) are concerned that their doctor may not believe they are in pain or treat it. A strong statement regarding fear of pain is that 65% indicated that living with great pain would be worse than death.

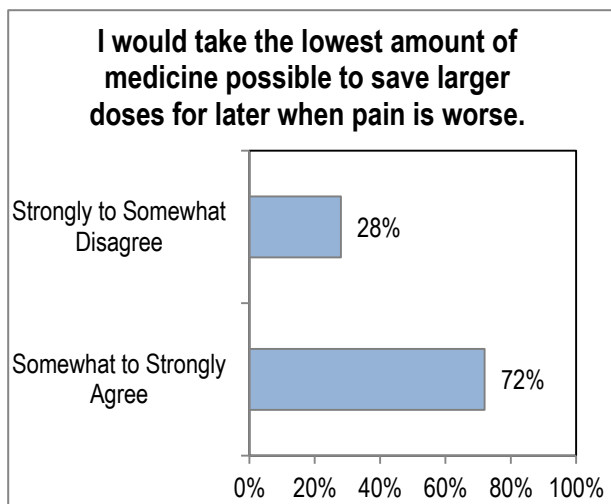
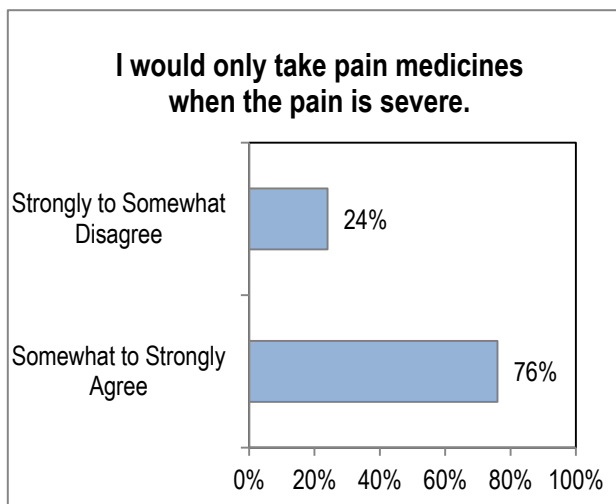
**I am afraid I will become addicted to
the pain medicine over time.**



**I am afraid I would be given too much
pain medicine.**



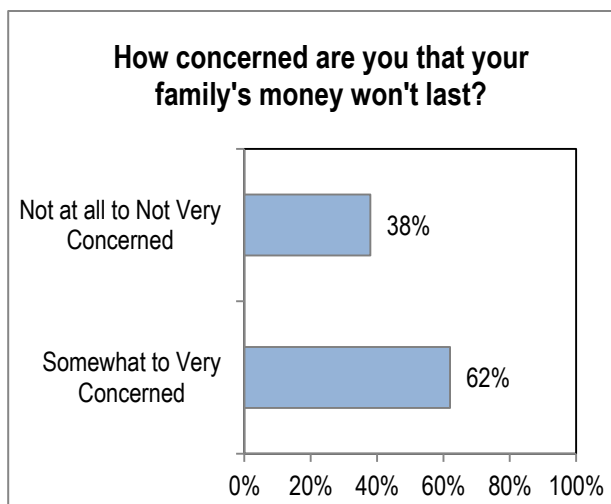
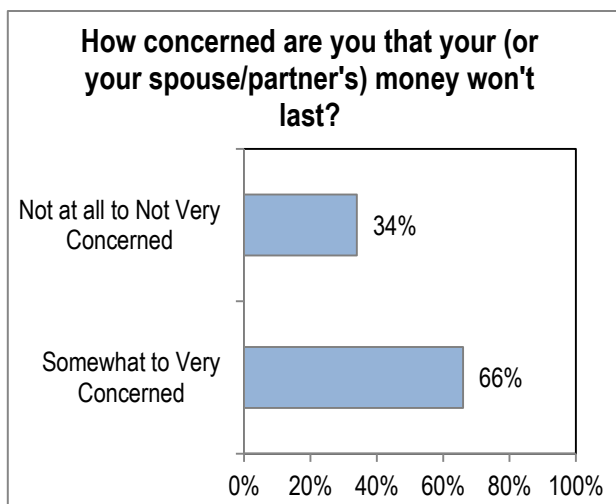
Although in recent years there has been much education and media coverage regarding appropriate treatment for pain, 33% of our participants have some worry that they would become addicted to pain medicine, and 26% are afraid that they would be given too much pain medication.



Even though current understanding of effective pain treatment indicates that medication should be taken in large enough doses and as soon as the pain begins to keep pain from escalating, respondents are reluctant to use medication until the pain is severe and would wait until the pain was worse before taking a larger dose.

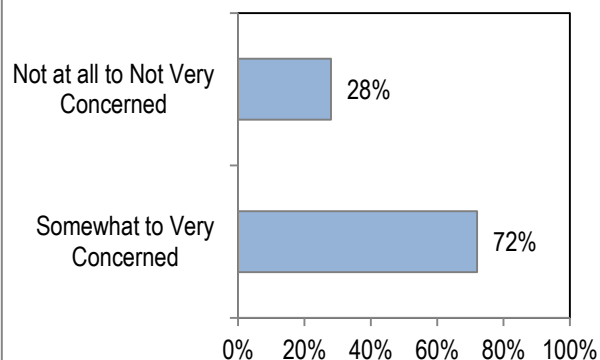
4. FEAR ISSUES

Many Nebraskans express fear regarding specific aspects of dying.

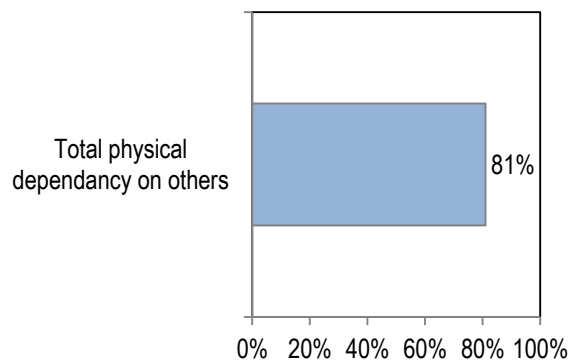


Financial concerns regarding both the respondent's money, as well as the family's money are shared by over 60%.

How concerned are you that you will be a burden to your family or friends?

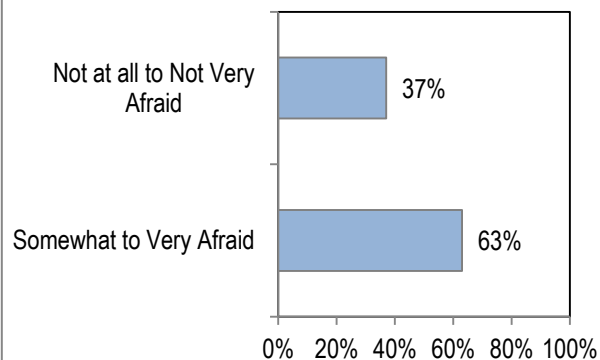


Which of the following problems would be worse than death?

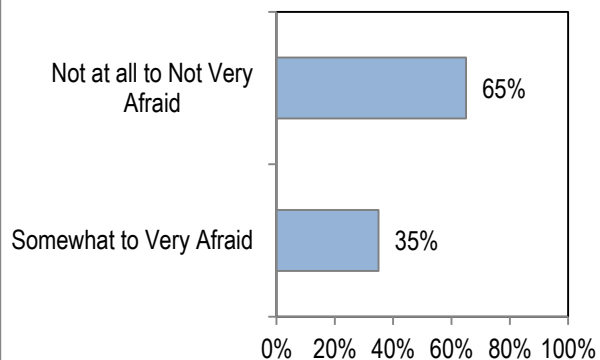


Not being a burden to loved ones is important with 72% of participants concerned that they will be a burden. Additionally, being totally physically dependent on others is seen as worse than death to 81% of participants.

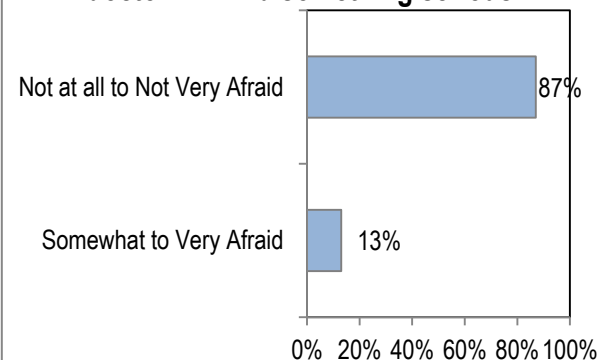
How afraid are you of dying from a long-term illness?



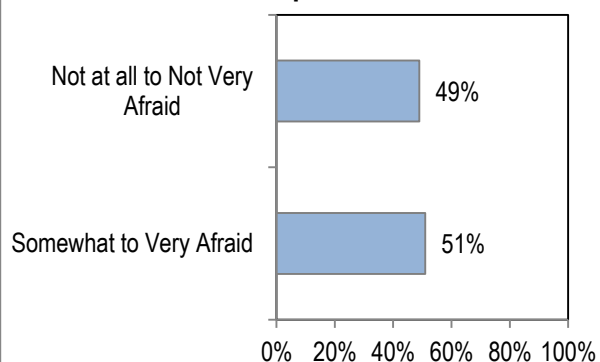
How afraid are you of dying suddenly?

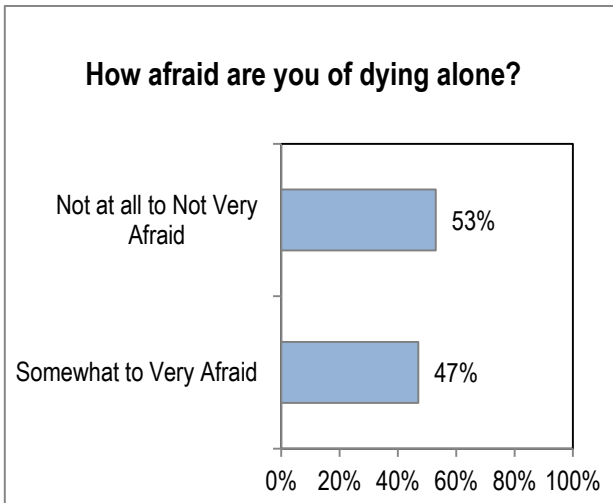


How likely are you to avoid medical checkups because you are afraid the doctor will find something serious.



How afraid are you at dying in an institution such as a nursing home or hospital?

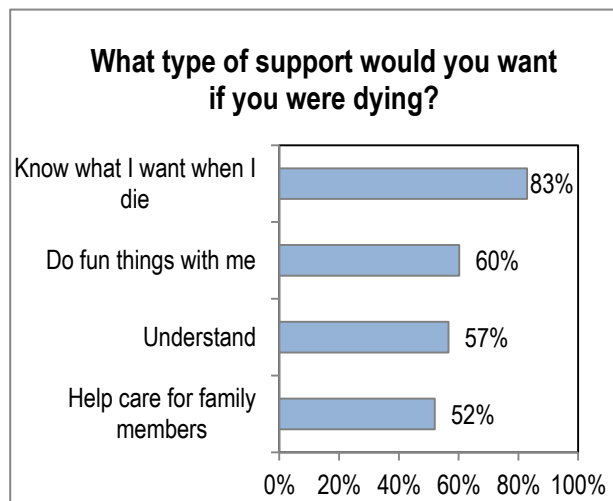
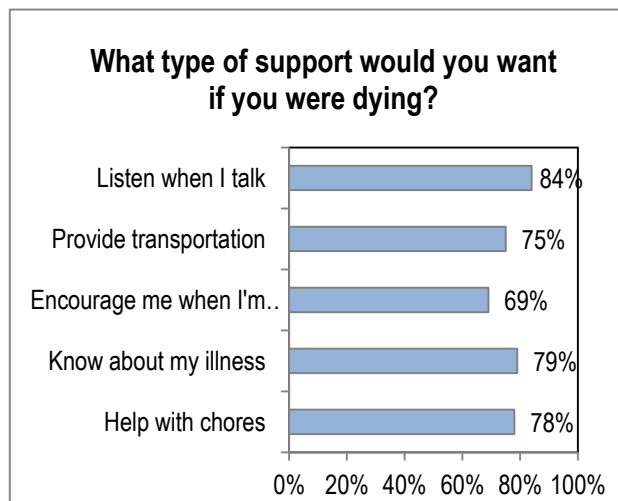




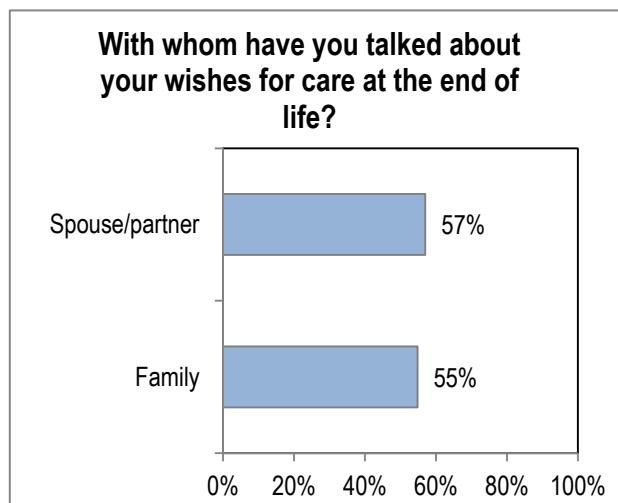
Respondents indicated that they have some fear of dying from a long-term illness (63%), while only 35% are afraid of dying suddenly.

Thirteen percent of respondents would be likely to avoid medical checkups for fear that they might have a serious medical condition. Over half of participants are afraid of dying in an institution, and 47% of participants are afraid of dying alone.

5. RESOURCES AND SUPPORT



We know from the survey that a high percentage of respondents indicated they know what they would want if they were dying, and share common fears. The results above indicate that most participants also want similar types of support during the dying process.

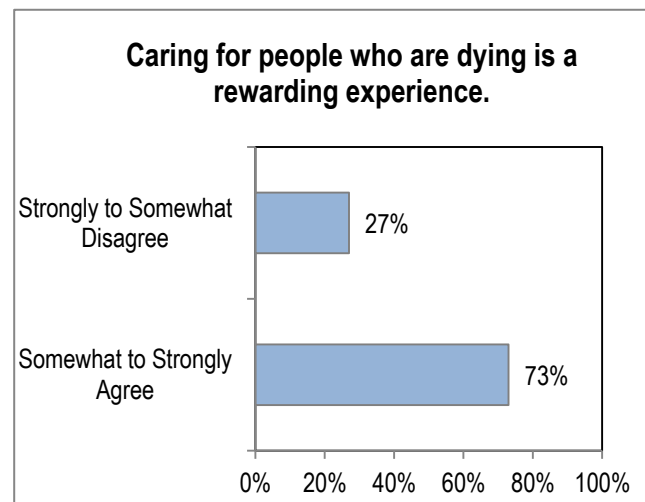
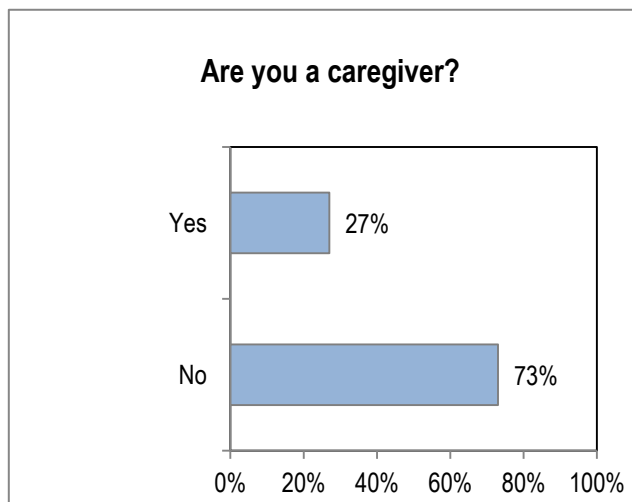


Although respondents have this awareness, only 57% have talked to their spouse or partner, and slightly less to their family, about their end-of-life wishes. When asked whom they would want to provide them with types of support, the highest percentages of respondents reported family as indicated by the total average for the rows in the table on the next page.

Table 1: Types of Support Expected and by Whom

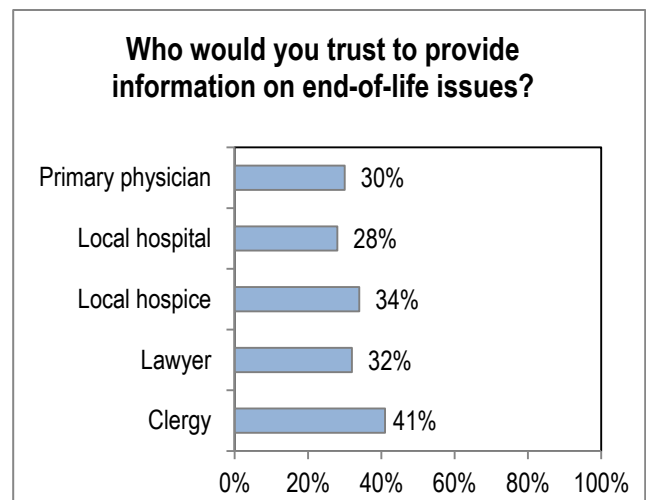
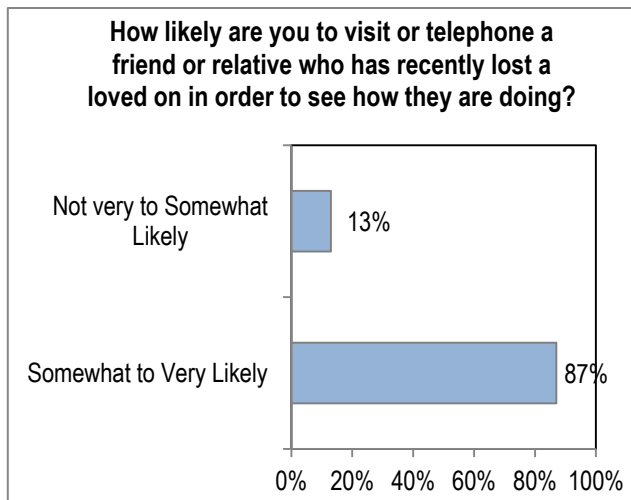
	Listen	Transport	Encourage	Know illness	Chores	Know desires	Fun things	Understand	Care for family	Total Average
Spouse/ Partner	65%	55%	53%	51%	56%	62%	47%	36%	35%	51%
Children	63%	53%	50%	49%	57%	62%	48%	34%	32%	50%
Other Family	52%	42%	44%	38%	42%	40%	38%	29%	35%	40%
Friends/ Neighbors	40%	35%	42%	24%	32%	18%	40%	24%	20%	31%
Health Providers	41%	13%	21%	47%	10%	13%	3%	30%	6%	20%
Community Organization	6%	16%	9%	8%	18%	2%	7%	10%	5%	9%
Work Associates	9%	3%	8%	6%	3%	1%	6%	6%	2%	5%

Taking the average across all the types of support shows us that the respondents have the highest expectation of their spouse/partner, then children, then other family members. This is different than the 2006 data, where 78% expected support from their children and 63% expected support from their spouse. However, almost one-third would turn to friends and neighbors to provide them with support.



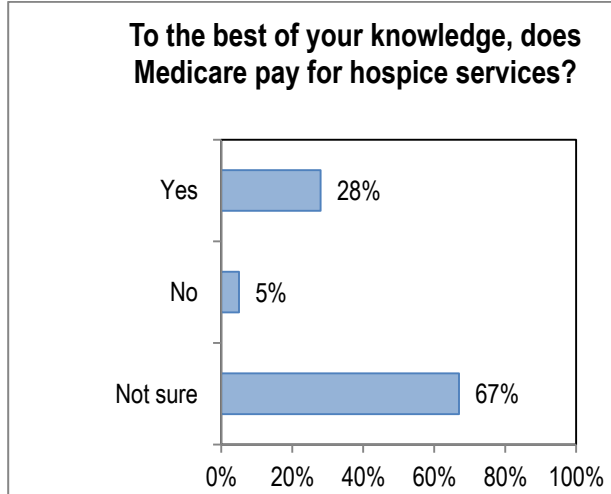
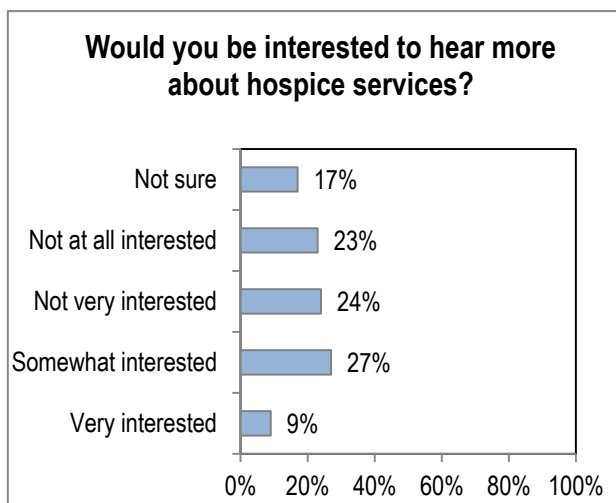
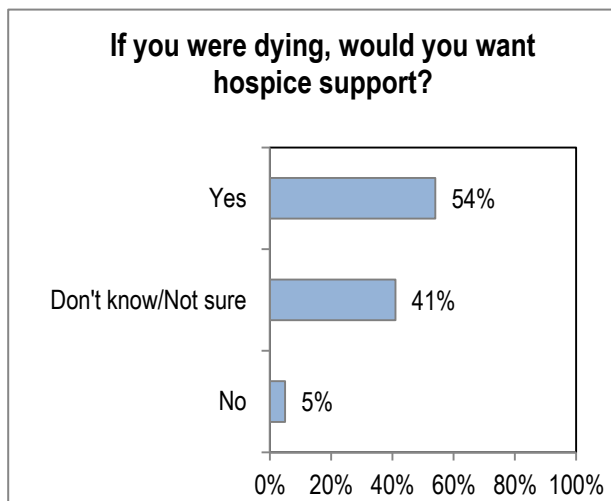
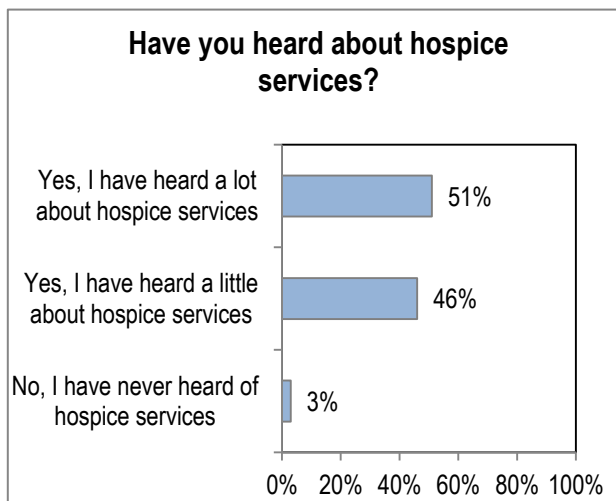
As indicated above, slightly more than one-fourth of respondents identified themselves as caregivers and almost three-fourths agree that caring for people who are dying is a rewarding experience. On the next page we see that 87% would visit or telephone a friend who had recently lost a loved one.

Finally, respondents indicated that they would particularly trust clergy (41%) and local hospice (34%) to provide end-of-life information. This finding encourages the growing efforts to include training on end-of-life issues in the educational programs of physicians and faith leaders, most of whom have had no formal training on death and dying.



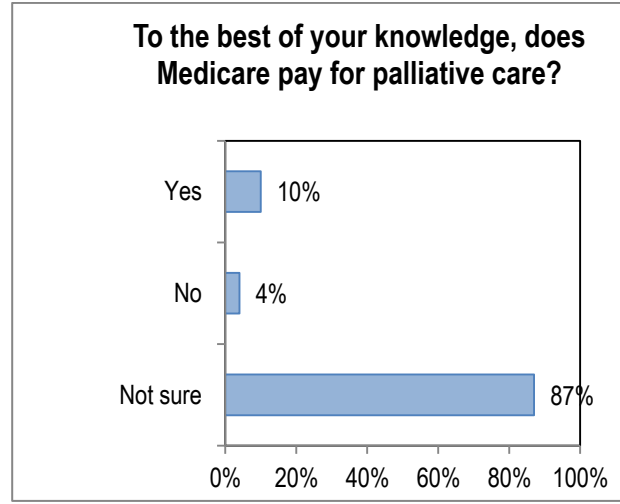
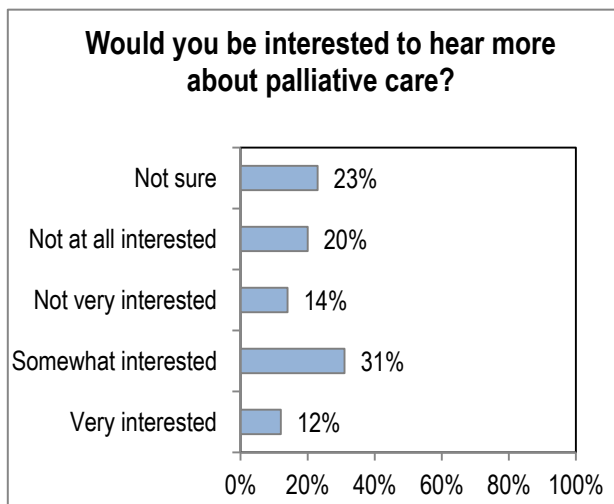
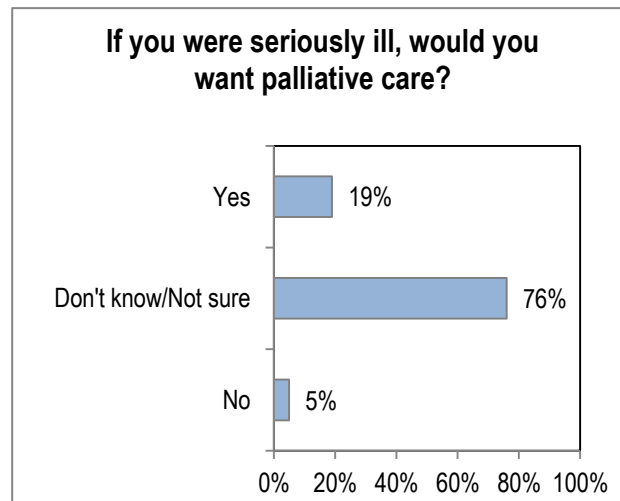
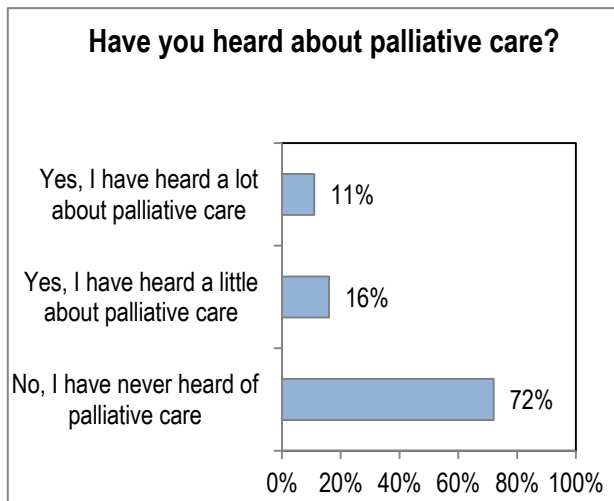
All of these results, taken together, suggest that people in Nebraska would tend to rely on their families for the help and support needed during their dying process. However, they are equally ready to provide support to others going through the dying process, either in an emotional way or by serving as a caregiver for their loved ones. This is an interesting finding because, as the results showed, most respondents were afraid of being a burden to their loved ones. Yet, they would not hesitate to provide support to a loved one during this difficult time. It is important to communicate the message that families do not consider assistance given at the end-of-life a burden. Instead, they were willing to provide the type of support that they would want if in the same situation.

6. KNOWING ABOUT HOSPICE



While 49% of participants have heard little or nothing about hospice services, 54% of participants would want hospice support if they were dying. Additionally 36% of participants were interested in hearing more about hospice services. Twenty-eight percent of participants said that Medicare does pay for hospice services while the majority, 67%, was unsure.

7. KNOWING ABOUT PALLIATIVE CARE



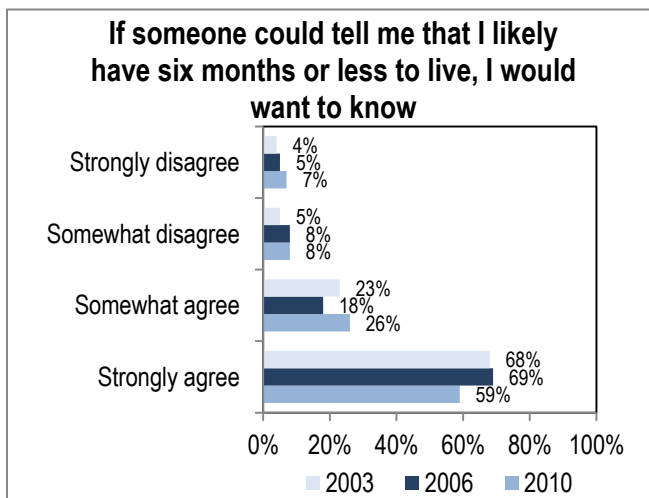
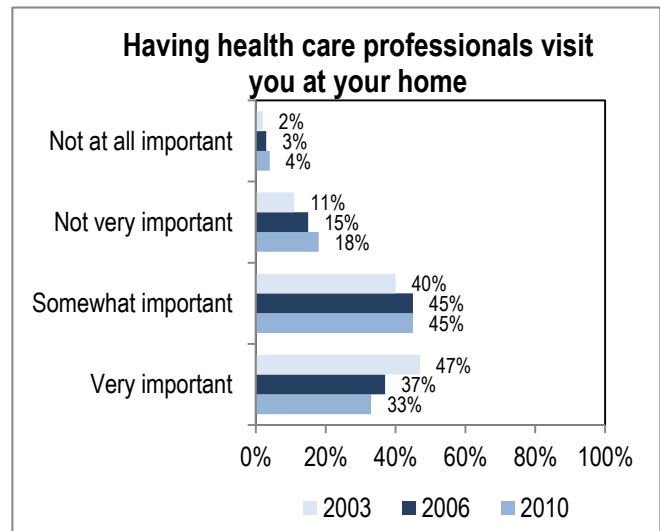
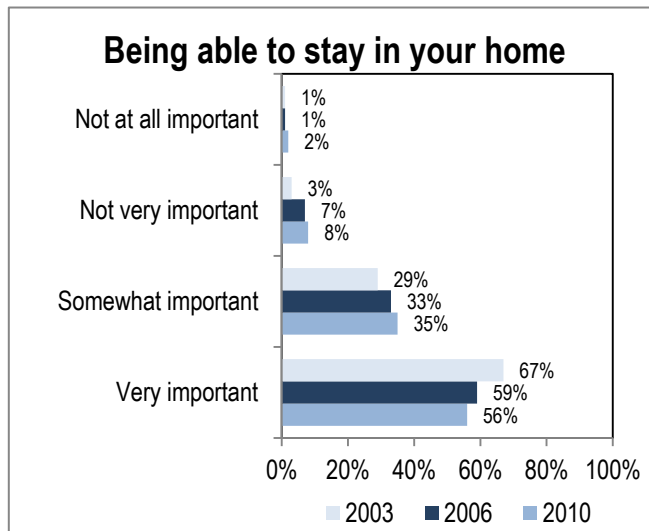
While the majority of participants had heard a lot about hospice services, only 11% of participants had heard about palliative care. Seventy-six percent of participants were not sure if they would want palliative care if they were seriously ill and 43% were interested to hear more about palliative care. The vast majority is unsure if Medicare pays for palliative care.

III. Changes over Time: 2003-2010

1. COMPARING THE RANDOM SAMPLES

WISHES

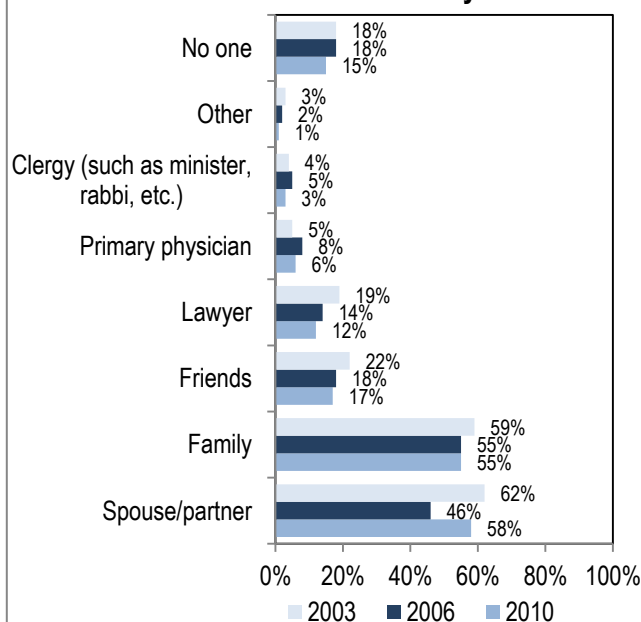
There were three items in the “Wishes” category where 2010 participants responded differently than 2006 and 2003.



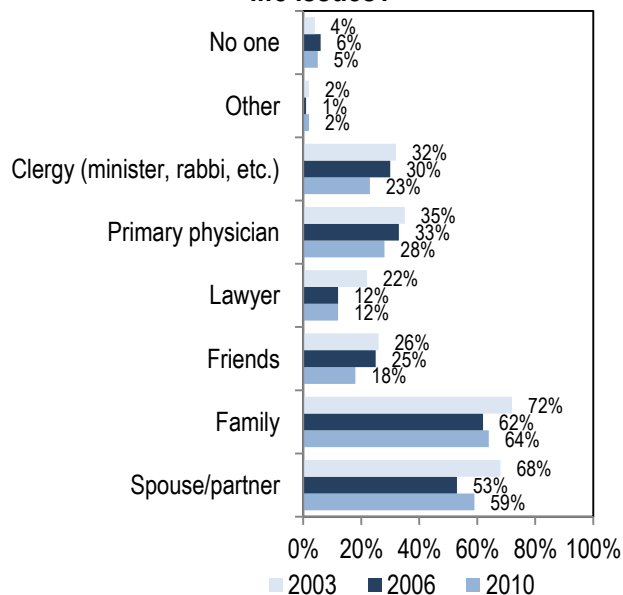
The 2010 participants were less likely to say that staying at home was “very important” (67%, 2003; 59%, 2006; 56%, 2010) and more likely to say it was “somewhat important” (29%, 2003; 33%, 2006; 35%, 2010); less likely to indicate that having health care professionals visit them at their home was “very important” (47%, 2003; 37%, 2006; 33%, 2010); and less likely to “strongly agree” that they would want someone to tell them if they have six months or less to live (68%, 2003; 69%, 2006; 59%, 2010).

PLANNING IN ADVANCE

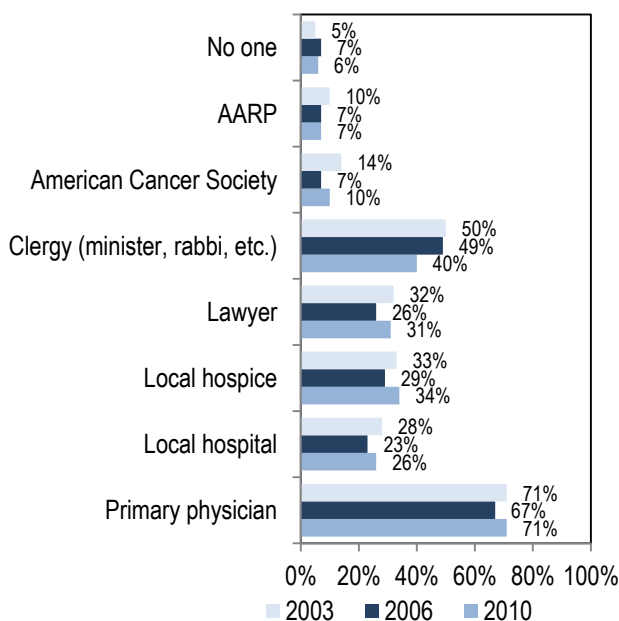
With whom have you talked about your wishes for care at the end of your life?



Who would you want to initiate a conversation with you regarding end-of-life issues?

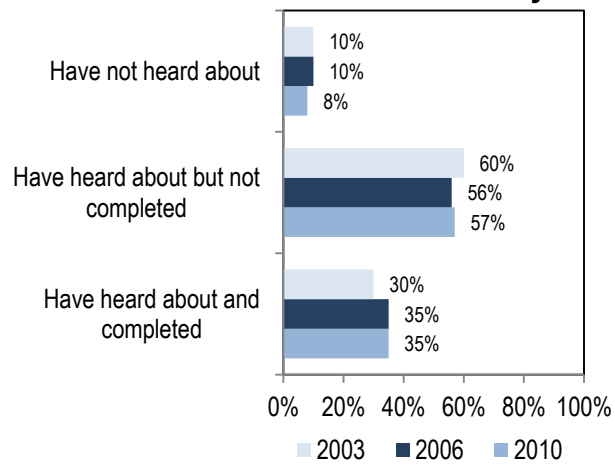


Who would you trust to provide information on end-of-life issues?

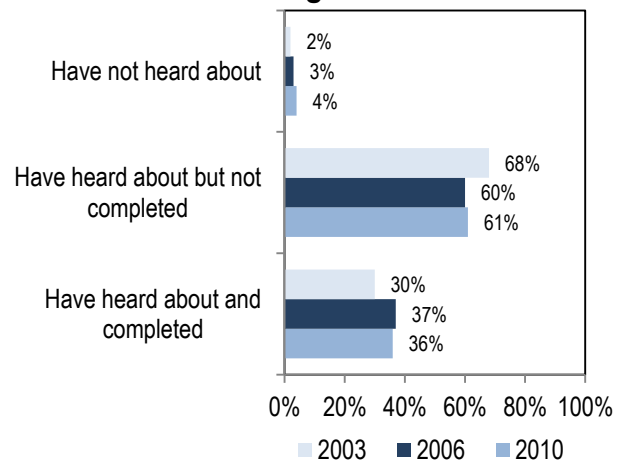


After dropping in 2006, the number of participants who have spoken to their spouse or partner about wishes for care at the end of life rose 12% in 2010, more similar to 2003, and they were less likely to have talked with a lawyer in 2010. More people responded that they would want their spouse or partner and family to initiate a conversation about end-of-life issues in 2010 than in 2006 but still lower than 2003; whereas, 2010 respondents were less likely to want their friends, lawyers, primary physicians, or clergy to initiate a conversation regarding end-of-life issues. In 2010, fewer people responded that they would trust clergy on end-of-life issues (down to 40% in 2010 from 49% in 2006 and 50% in 2003).

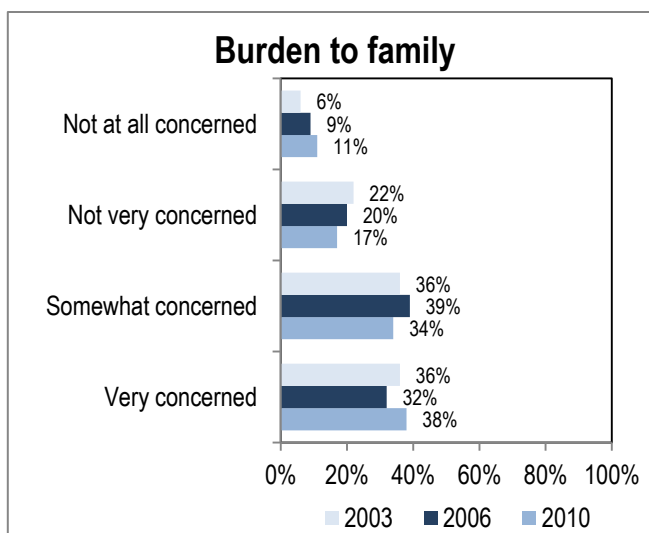
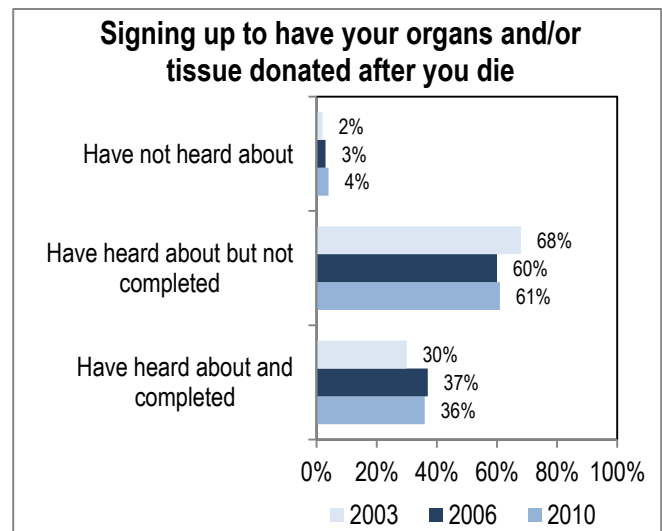
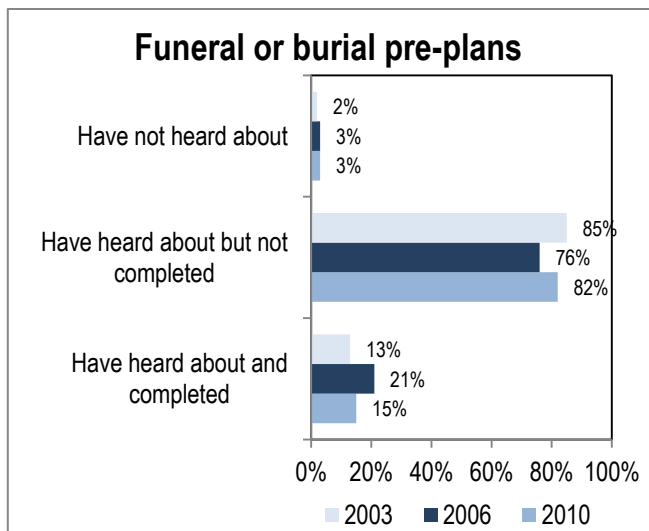
Health Care Power of Attorney*



Living Will*



* Responses to the Health Care Power of Attorney and Living Will questions did not show statistical significance (did not change significantly over time). They are included solely for informative purposes



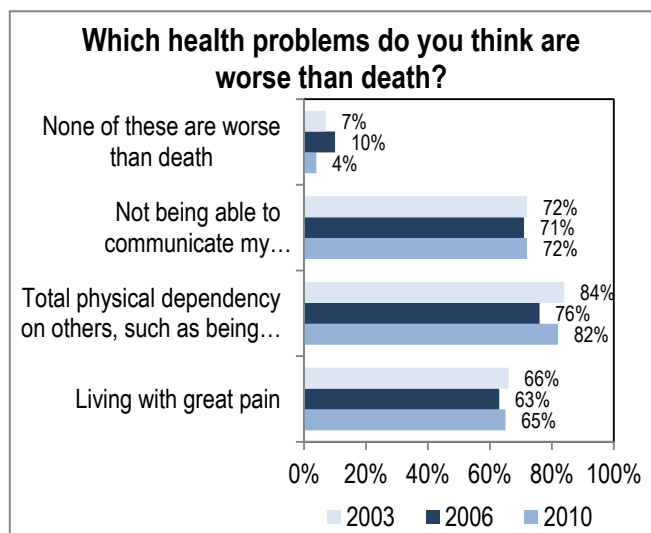
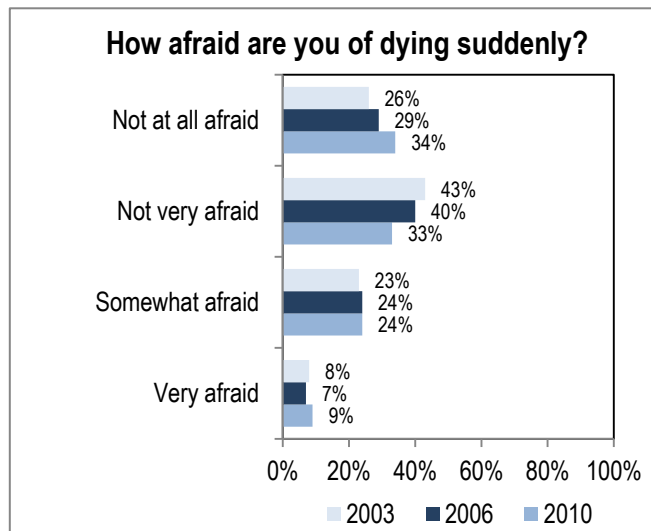
In 2010, the percentage of people who have completed funeral or burial pre-plans where goods or services have been purchased in advance has decreased from that of 2006 and is more similar to 2003 numbers. The number of people who have signed up to have organs or tissue donated for use by others in need of transplants in 2010 has stayed at the 2006 levels after increasing from 2003. In regards to being a burden to their family, 2010 participants who responded “not at all concerned” increased from previous years.

PAIN ISSUES

There were no statistically significant different responses between the three respondent groups on any items that related to the experience of dying painfully or related to the treatment of pain.

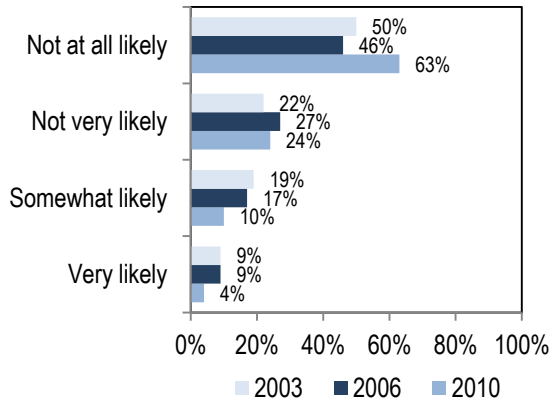
FEAR ISSUES

Overall, the amount of fear people have in regards to dying and end-of-life care is decreasing, as shown by the changes in the following six graphs.

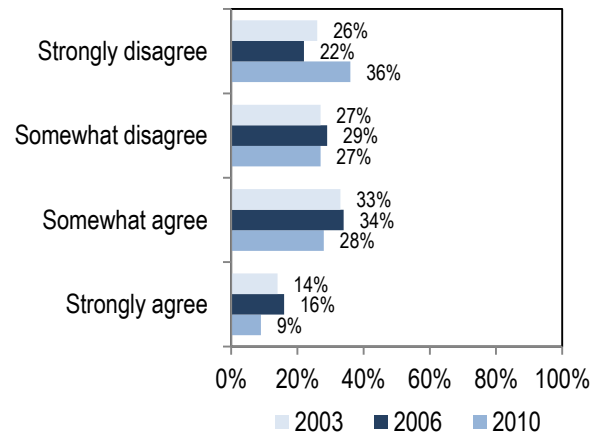


Compared to previous years, 2010 participants were more likely to respond “not at all afraid” (up 5% from 2006) and less likely to respond “not very afraid” (down 7% from 2006) when asked how afraid they are of dying suddenly. The trend of participants responding that they are “not at all afraid” of dying in a facility such as a nursing home or hospital continued to rise (up to 17% in 2010 from 14% in 2006 and 9% in 2003). When asked which health problems they think are worse than death, fewer 2010 respondents stated that they thought nothing is worse than death (down 6% from 2006).

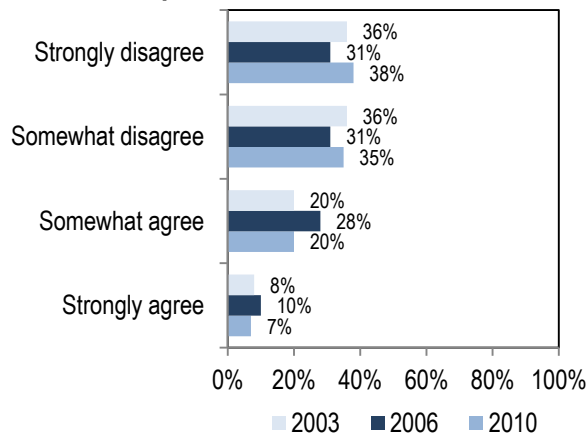
Likely to avoid medical checkups because I am afraid the doctor will find something serious



I am afraid my doctor may not believe I am in pain or may not treat my pain



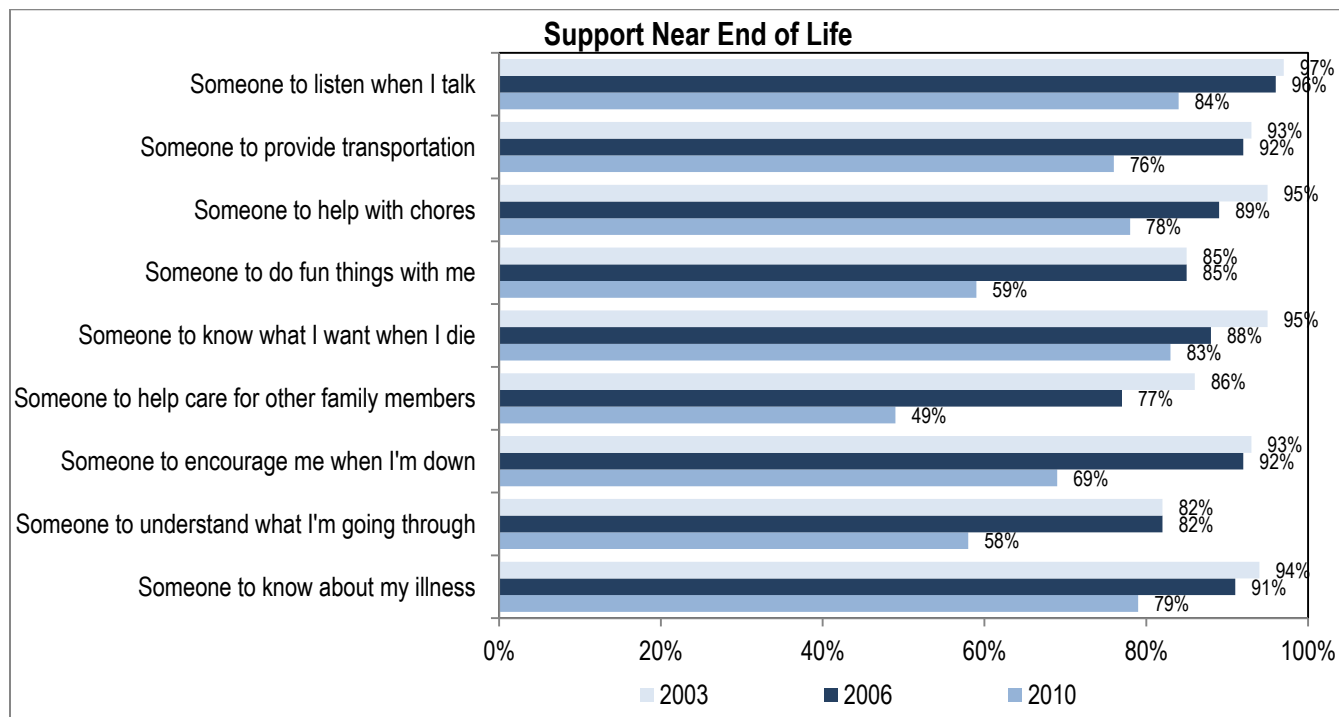
I am afraid I would be given too much pain medication



2010 respondents were less likely to avoid medical checkups out of fear that the doctor will find something serious. Sixty-three percent responded “not at all likely” to this question in 2010, up from 46% in 2006 and 50% in 2003. Participants were also less afraid that their doctor may not believe they are in pain or may not treat their pain with 36% responding “strongly disagree” (14% higher than in 2006). When asked if they were afraid they would be given too much pain medication responses to “strongly disagree” rose 7% from 2006 to 2010 and responses to “somewhat agree” dropped 8% from 2006 to 2010.

RESOURCES AND SUPPORT

Participants were asked about the types of support they expect near the end of their life and who they expect to provide each type of support. The 2010 participants showed significant differences in their responses compared to previous years.



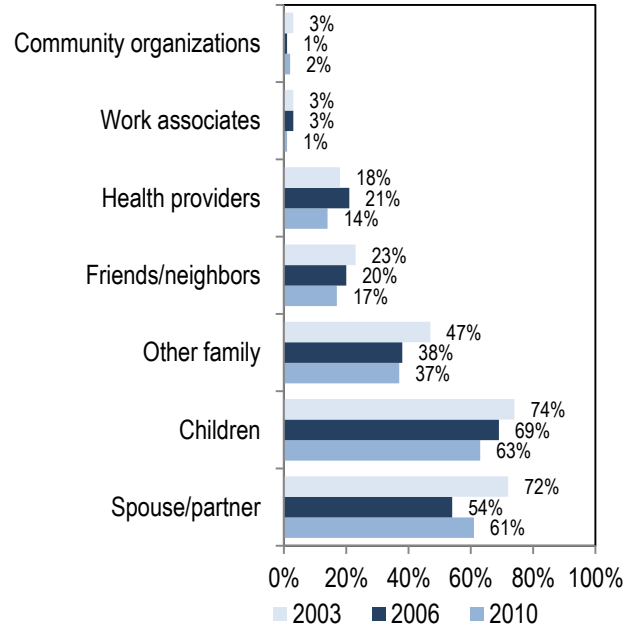
The rate of participants expecting to need near end of life support noticeably dropped in every category in 2010. Participants in 2010 responding “yes” when asked if they expect to need someone to do fun things, help care for other family members, encourage them when they are down, and understand what they are going through dropped more than 20% from 2006 in each of those categories of support. For the rest of the categories (expecting someone to listen when they talk, provide transportation, help with chores, know what they want when they die, know about their illness), the rate of decline was slightly less severe. The smallest decrease from 2006 to 2010 was 5% for expecting someone to know what they want when they die. The largest decrease from 2006 to 2010 was 28% for expecting someone to help care for other family members.

Participants also noted who they expect to provide each type of support.

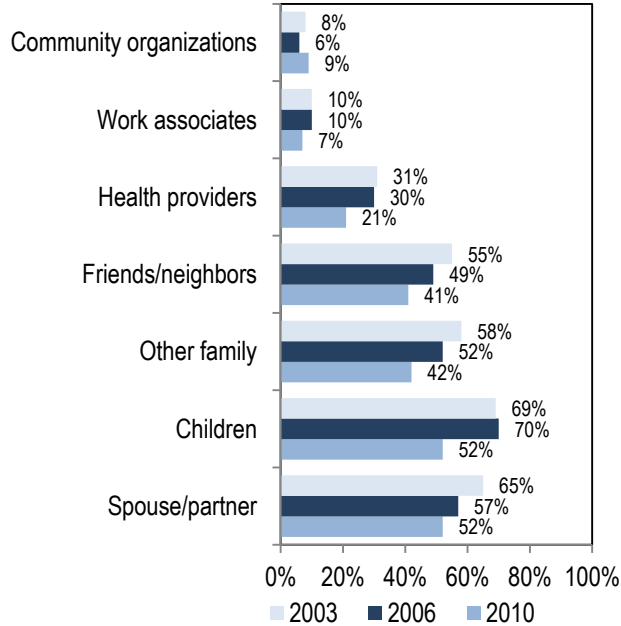
I expect to need someone to listen when I talk



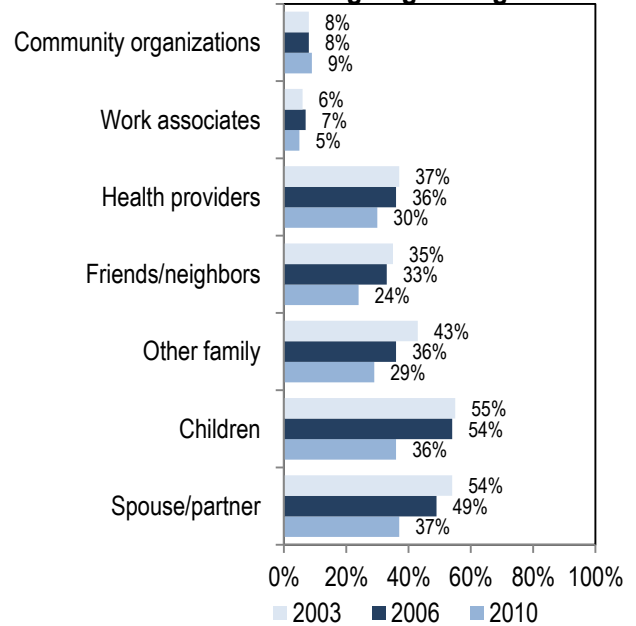
I expect to need someone to know what I want when I die

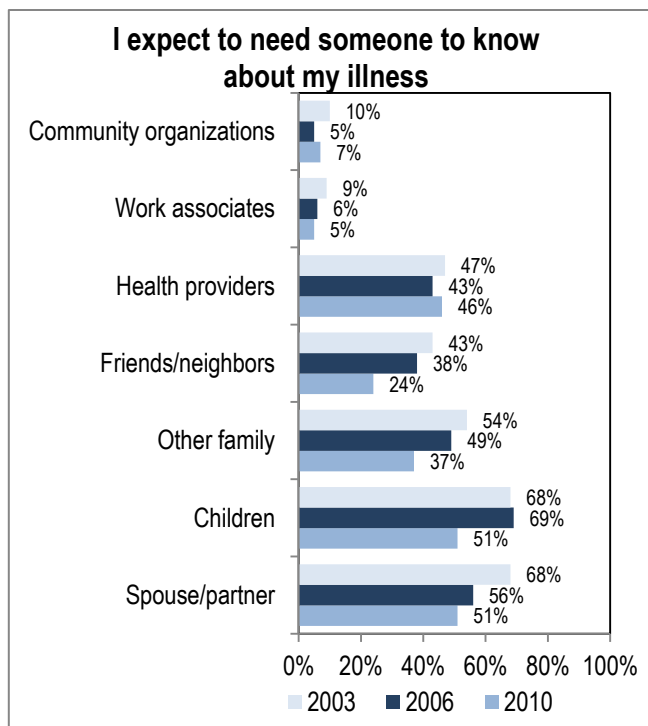


I expect to need someone to encourage me when I'm down



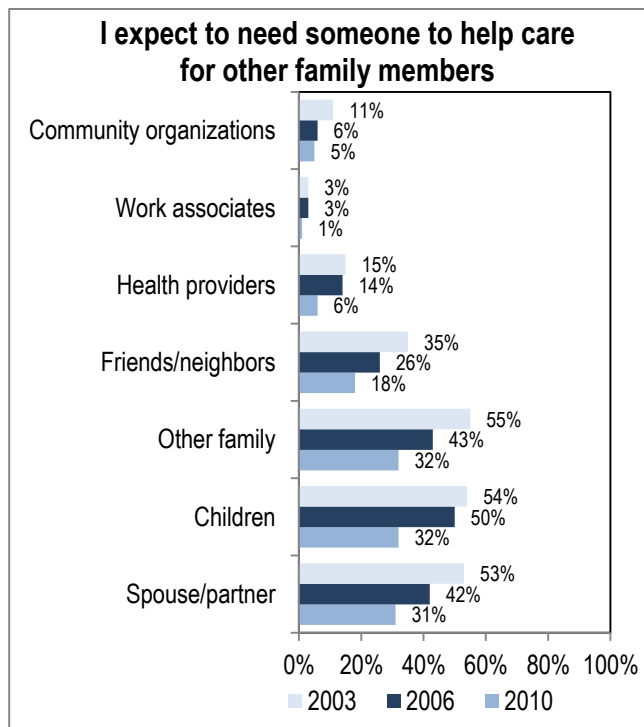
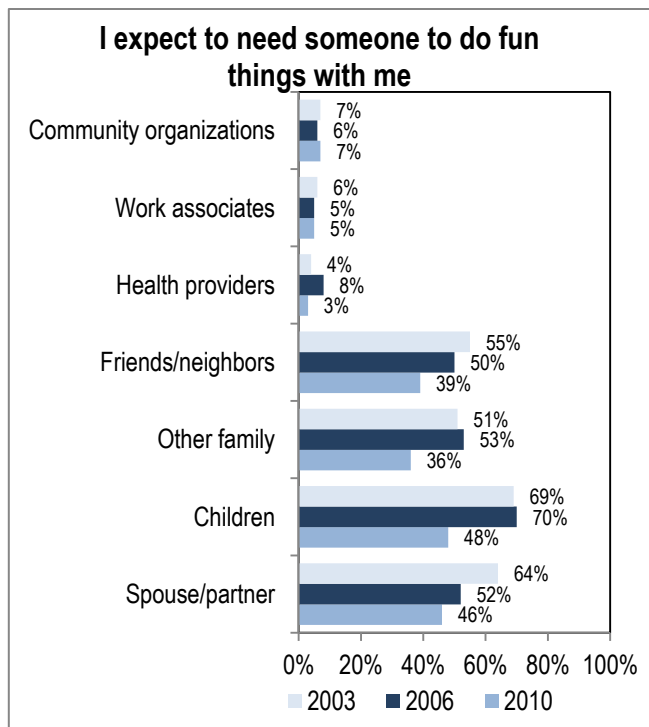
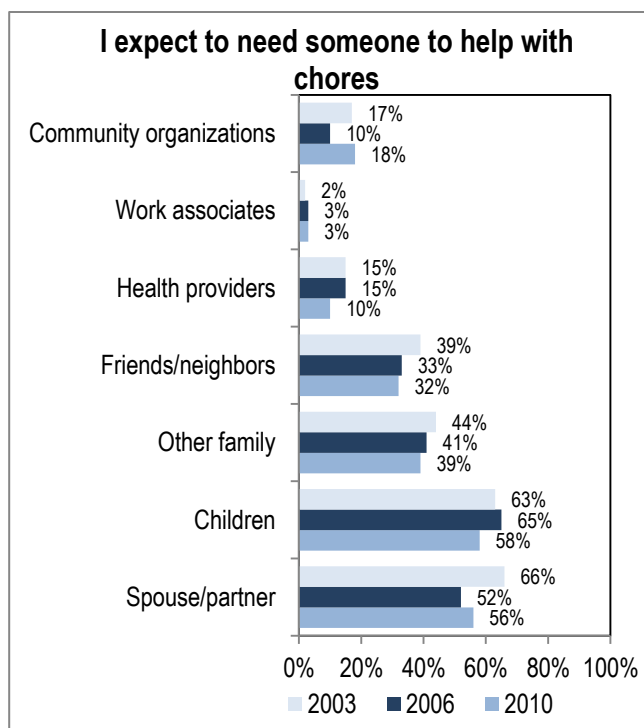
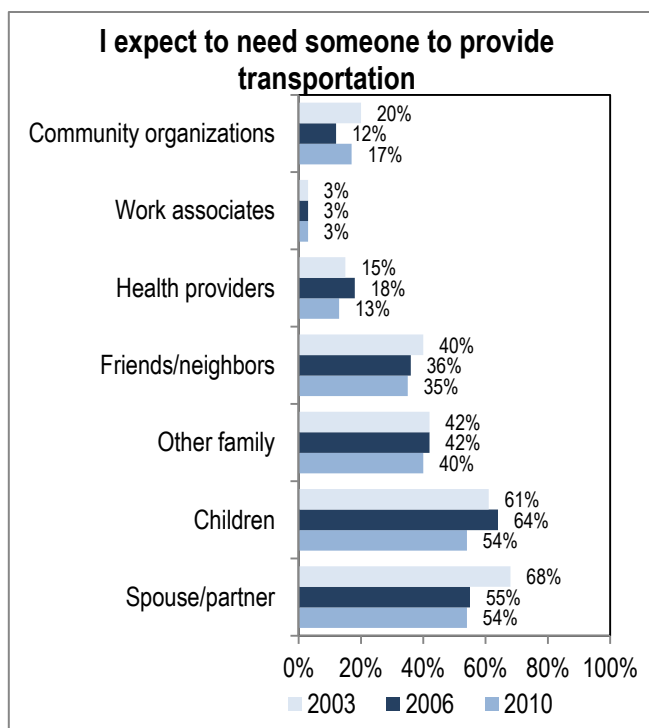
I expect to need someone to understand what I'm going through





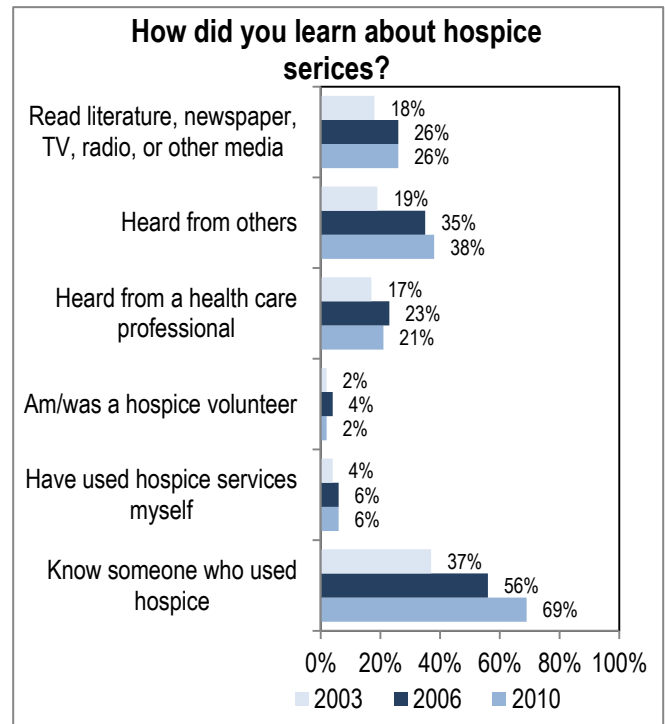
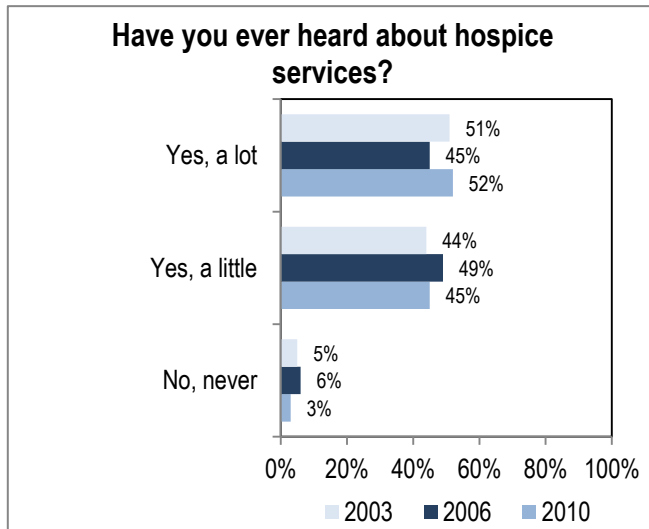
Generally, participants reported expecting less understanding and encouragement from their spouse or partner, children, and other family. The percentage of people expecting their spouse or partner to listen when they talk rose in 2010 (63%) since 2006 (60%) but is not as high as 2003 levels (74%) and fewer people expect their children to listen when they talk (down 16% from 2010 to 2006). Similarly, when asked who they expect to know what they want when they die, those who responded “spouse/partner” rose slightly from 2006 to 2010 but was not as high as 2003 levels. Those who responded “children” declined (63%, 2010; 69%, 2006), those who responded “other family” stayed near the lower 2006 levels in 2010 after dropping from 2003 to 2006. Participants were less likely to expect their spouse or partner to encourage them when they are down (down 5%), to understand what they are going through (down 12%), or to know about their illness (down 5%). Also, for those same categories, response rates decreased for “children,” “other family,” and “friends/neighbors.”

What people expect from their health providers has changed from 2006 to 2010. In 2010, participants were less likely to expect their health providers to listen when they talk (down 10%), encourage them when they are down (down 9%), understand what they are going through (down 6%), or to know what they want when they die (down 7%). Respondents were more likely to expect community organizations to know about their illness in 2010 than in 2006 but not as high as 2003.

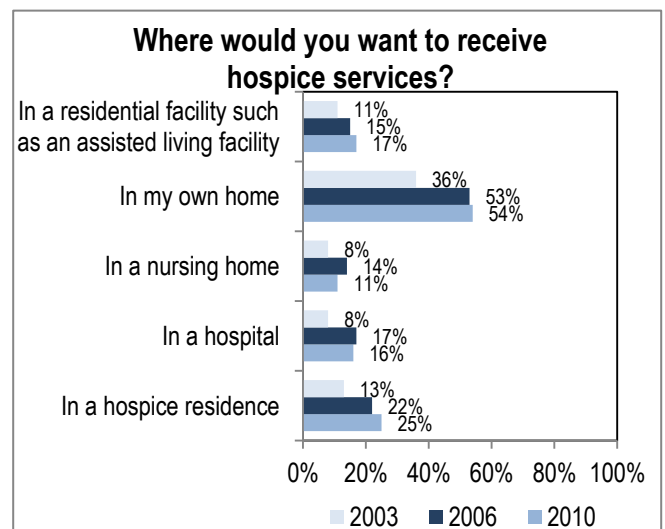
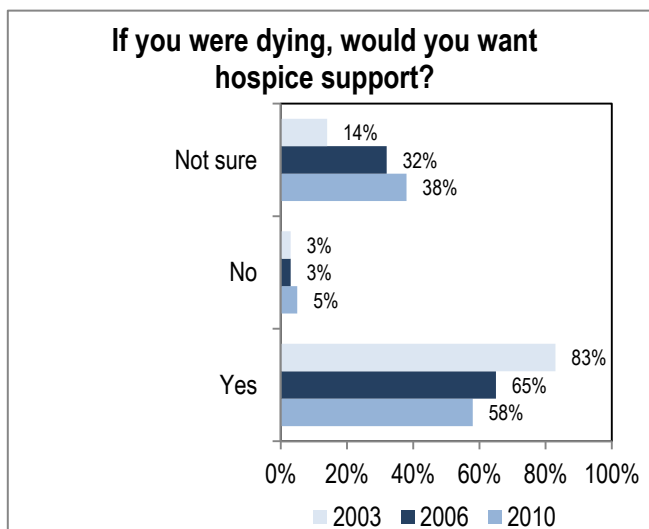


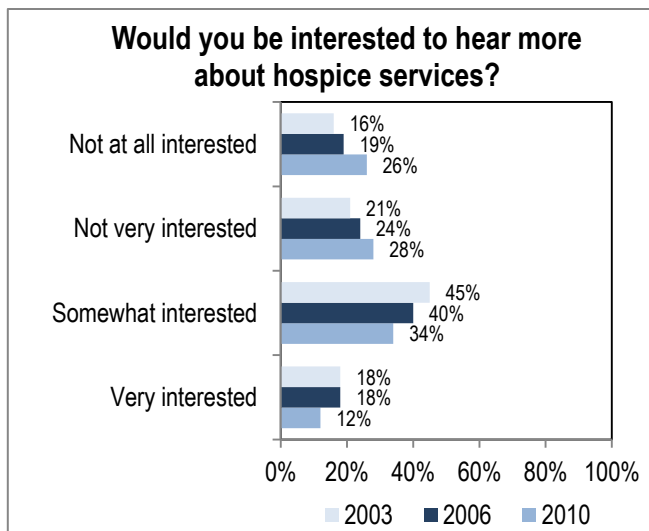
When asked who they expect to provide transportation, the rate responding with “spouse/partner” stayed near 2006 levels in 2010 (only a 1% difference) which was down 13% from 2003. Respondents expecting a spouse or partner to help with chores rose since 2006 but not as high as 2003. Participants were also less likely to expect their spouse or partner to do fun things with them or help care for other family members, continuing a trend from previous years. Participants who responded “children” decreased significantly in all the aforementioned categories. “Other family” expectation rates decreased since 2006 for someone to do fun things (down 17%) and someone to help care for other family members (down 11%). Expectations of “friends/neighbors” also fell. Help with chores stayed down after dropping in 2006, and someone to do fun things and help care for other family members continued to drop from 2006 level.

Fewer people expect health providers to help with chores (down 5%), to do fun things (down 5%), and to help care for other family members (down 8%). Participants' expectations of community organizations rose from 2006 to 2010. They were more likely in 2010 to expect community organizations to provide transportation than in 2006, but not as high as in 2003. Those expecting community organizations to help with chores increased 8% from 2006 to 2010. People were less likely to expect community organizations to care for other family members though, which stayed low after dropping in 2006.



Participants in 2010 were more likely to have heard about hospice services and the rate of those who responded “a lot” increased (52%, 2010; 45%, 2006) whereas those who responded “a little” decreased (45%, 2010; 49%, 2006). Those who have “never” heard about hospice services decreased from 6% in 2006 to 3% in 2010. Participants primarily learned about hospice services through knowing someone who used hospice (up 13% from 2006). They also learned about it by hearing from others and from literature, newspaper, TV, radio, or other media. Both methods remained high after significantly increasing in 2006.





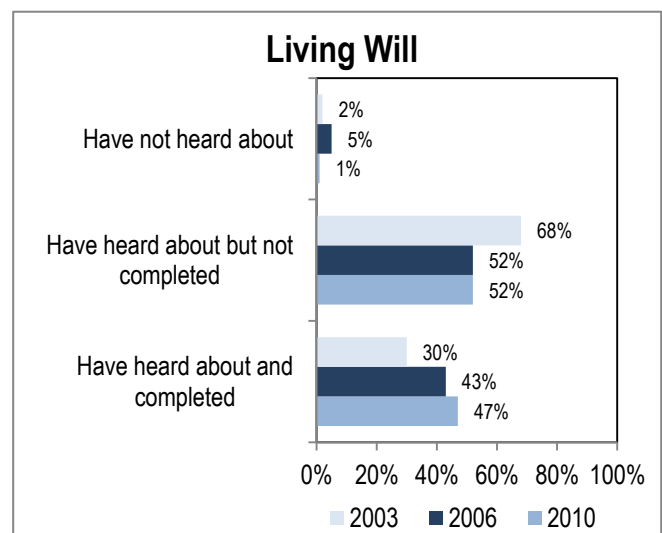
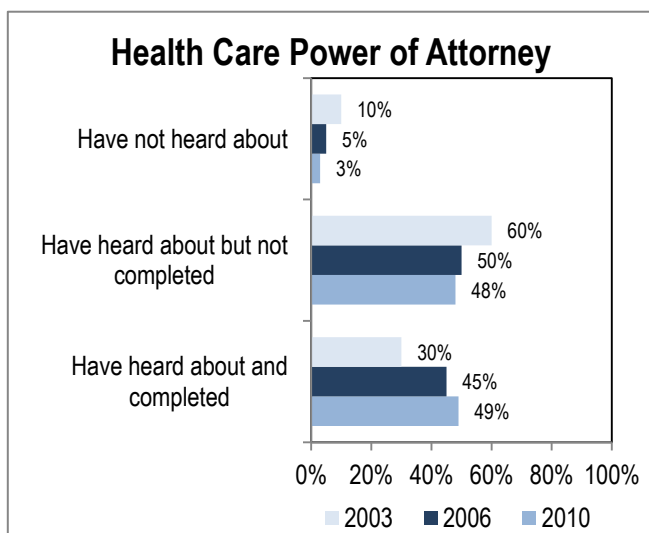
Respondents were more likely to be “not sure” (38%, 2010; 32%, 2006; 14%, 2003) whether they would want hospice support if they were dying, and less likely to say “yes” (58%, 2010; 65%, 2006; 83%, 2003). Of those who would want to receive hospice services, the percentage continues to increase of those who would want to be in a hospice residence or in their own home. Fewer respondents would want hospice services in a hospital. Participants in 2010 were more likely to respond “not at all interested” or “not very interested” when asked if they would be interested in hearing more about hospice services and less likely to be “somewhat interested” or “very interested.”

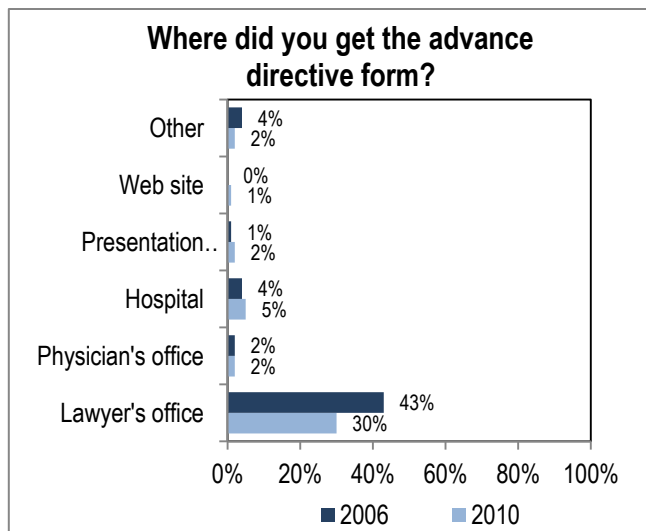
2. COMPARING THOSE WHO RESPONDED IN MULTIPLE YEARS

WISHES

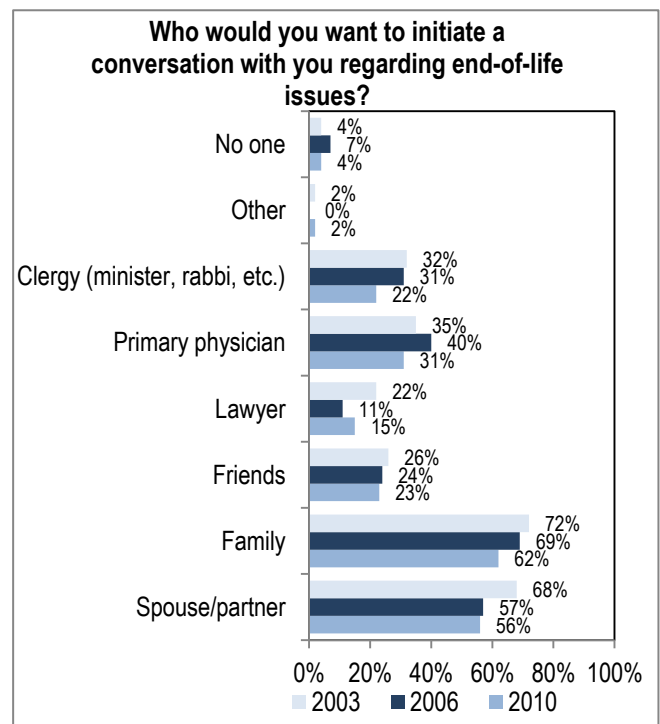
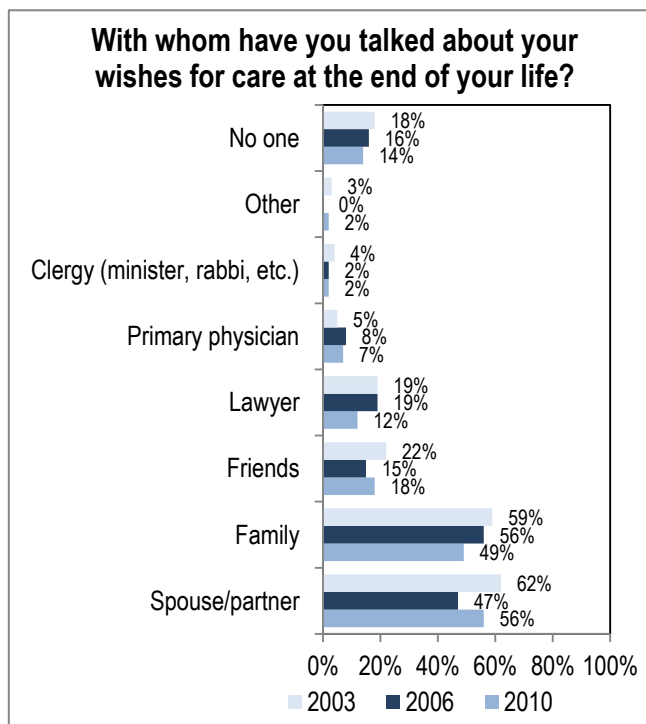
There were no statistically significant differences in any of the items pertaining to people’s wishes when comparing participants who responded in multiple years.

PLANNING IN ADVANCE





Those who responded in previous years are more informed on advance directives. The percentage of people who have not heard about a Health Care Power of Attorney has decreased consistently since 2003 (3%, 2010; 5%, 2006; 10%, 2003), and the percentage of people who have not heard about a living will decreased 4% since 2006. Of those who have heard about a Health Care Power of Attorney, the rate that participants have completed one continues to rise. Similarly, those who have heard about a living will are more likely to have completed one. People are less likely to get an advance directive from a lawyer's office in 2010, dropping 13% since 2006.

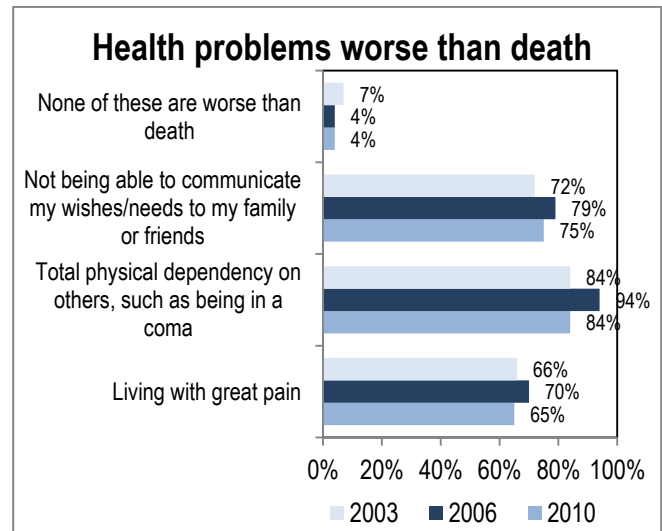
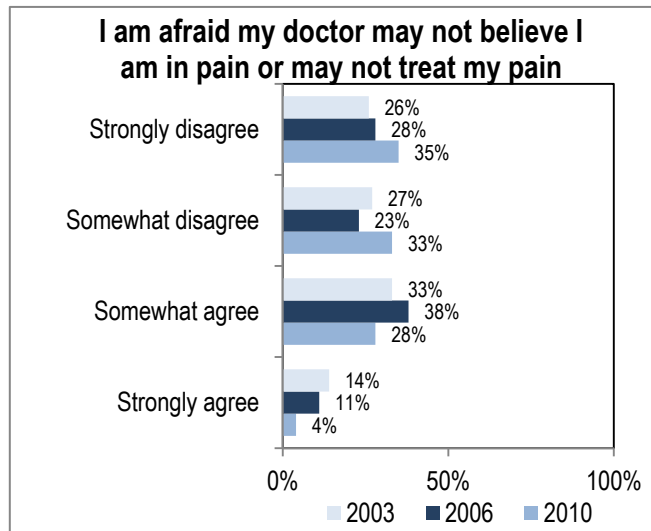


More participants in 2010 (56%) have talked about their wishes for care at the end of their life with their spouse or partner than in 2006 (47%), but fewer overall than in 2003 (62%). There continues to be a downward trend for participants who have talked to "no one." After decreasing from 2003 to 2006, participants are still less likely to want their spouse or partner to initiate a conversation regarding end-of-life issue. Participants are also less likely to want clergy to initiate a conversation regarding end-of-life issues (down 9%). Participants were more likely to want a lawyer to initiate that conversation in 2010 than 2006 (up 4%) but still less likely than 2003.

PAIN ISSUES

There were no statistically significant different responses when comparing participants who responded in multiple years on any items that related to the experience of dying painfully or related to the treatment of pain.

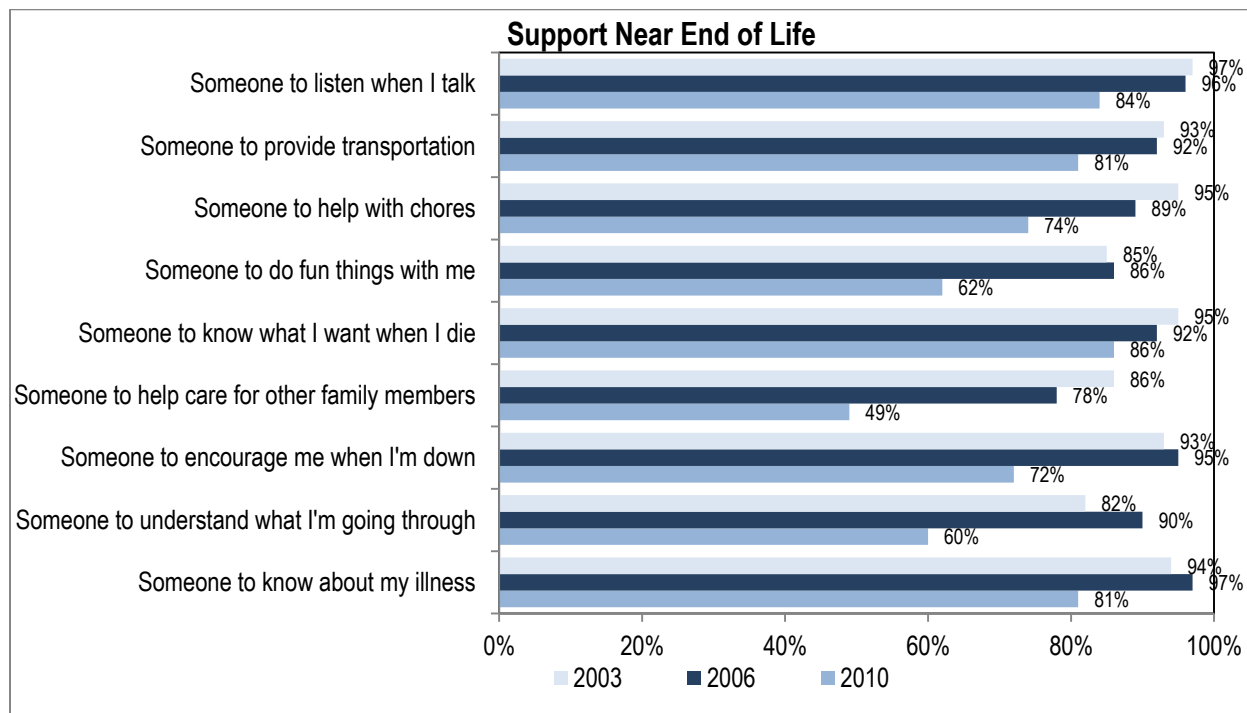
FEAR ISSUES



Participants were more likely to respond “strongly disagree” (35%, 2010; 28%, 2006; 26%, 2003) or “somewhat disagree” (33%, 2010; 23%, 2006; 27%, 2003) when asked if they are afraid their doctor may not believe they are in pain or may not treat their pain, and they are much less likely to “somewhat agree” (down 10%) or “strongly agree” (down 7%). When asked which health problems are worse than death, fewer participants responded “total physical dependency on others, such as being in a coma” (down 10% from 2006).

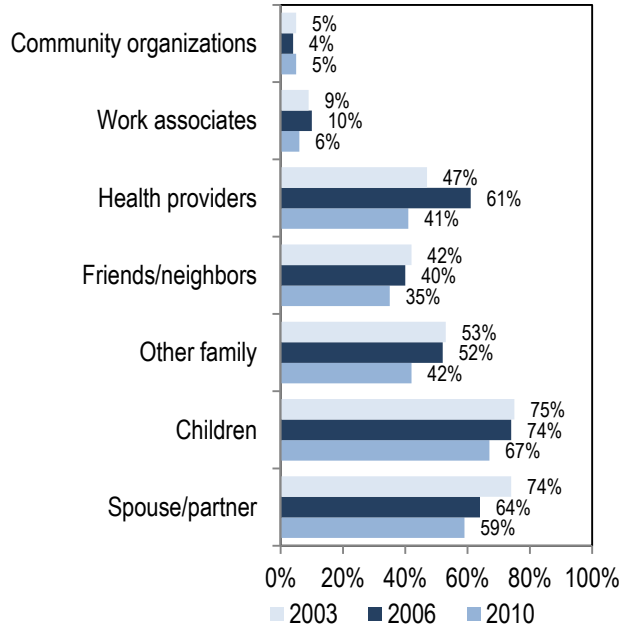
RESOURCES AND SUPPORT

When asked about the types of support expected near the end of life and who they expect that support from, those who responded multiple years showed significant difference in 2010.

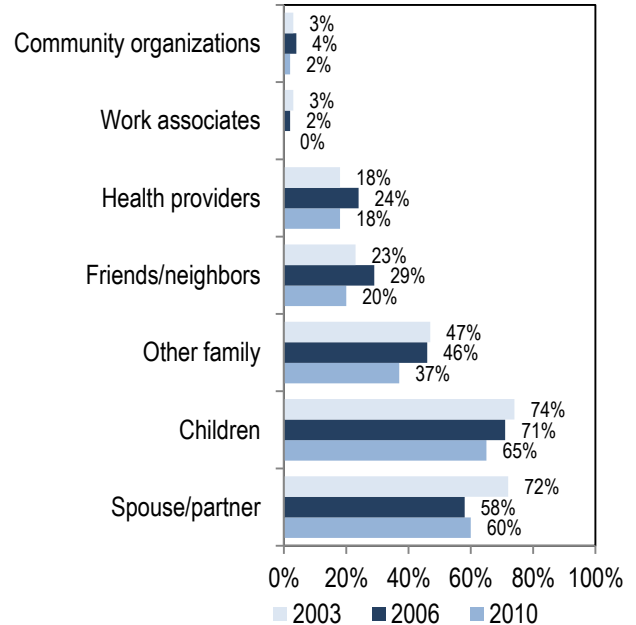


Like the general sample, participants were much less likely to respond “yes” to expecting each of these types of support near the end of their life. Some categories had substantial decreases (over 20% from 2006 to 2010) like someone to do fun things, help care for other family members, encourage them when down, and understand what they are going through (which was the highest with a 30% drop from 2006 to 2010). Almost all other categories had a 10% to 20% decrease including someone to listen when they talk, provide transportation, know about their illness. The lowest decrease was 6% from 2006 to 2010 for someone to know what they want when they die.

I expect to need someone to listen when I talk



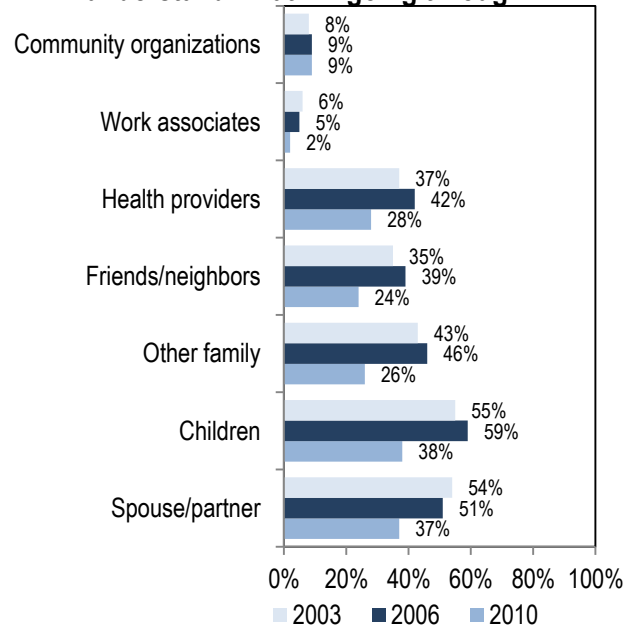
I expect to need someone to know what I want when I die

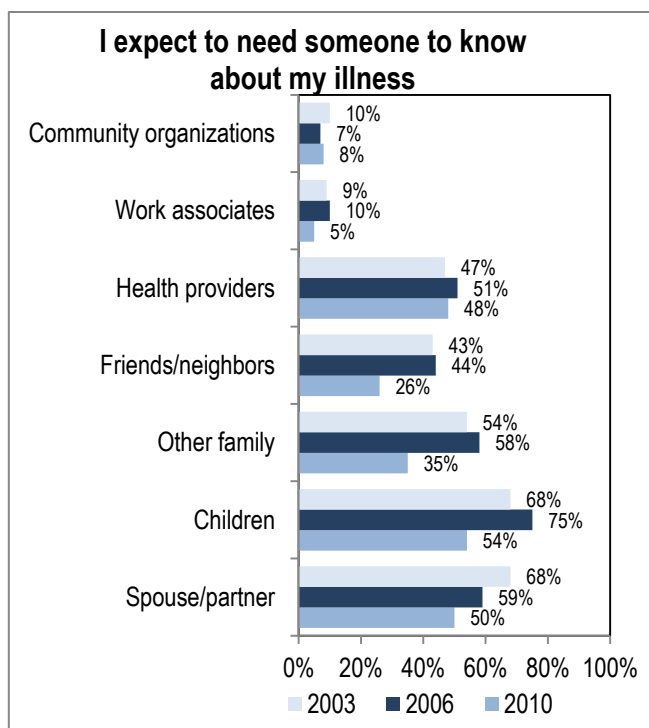


I expect to need someone to encourage me when I'm down

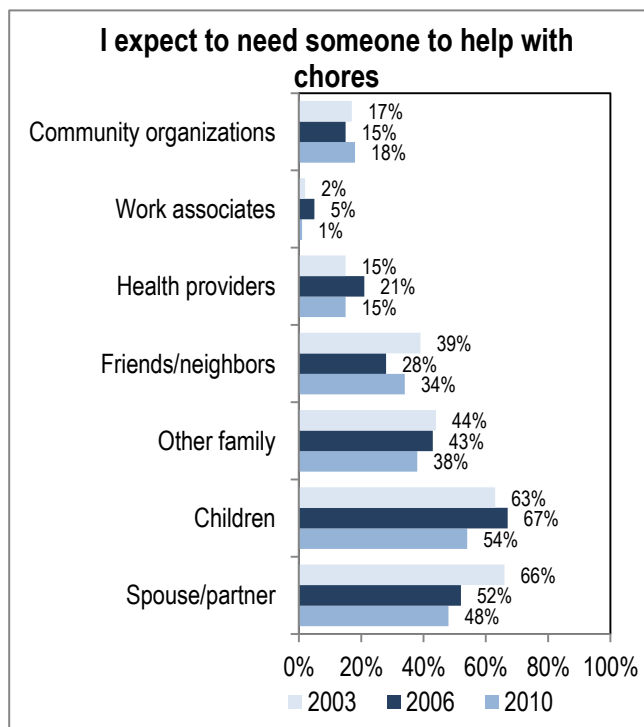
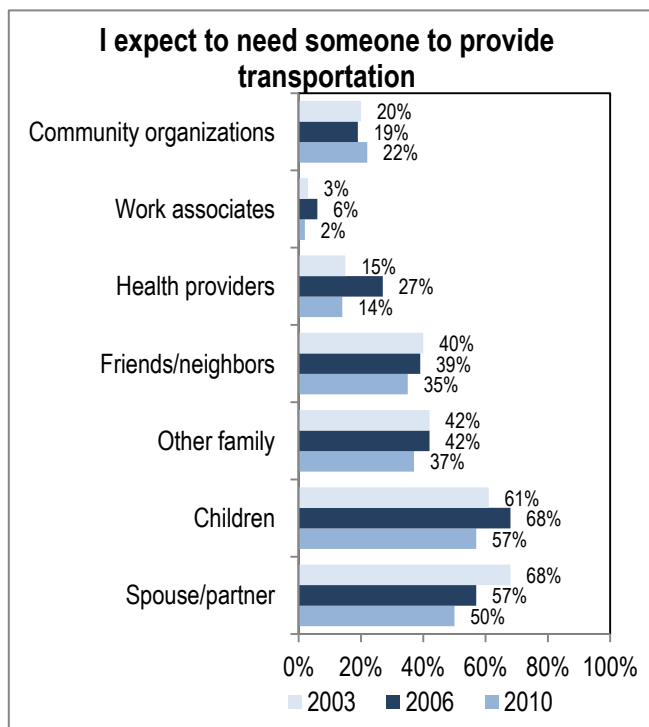


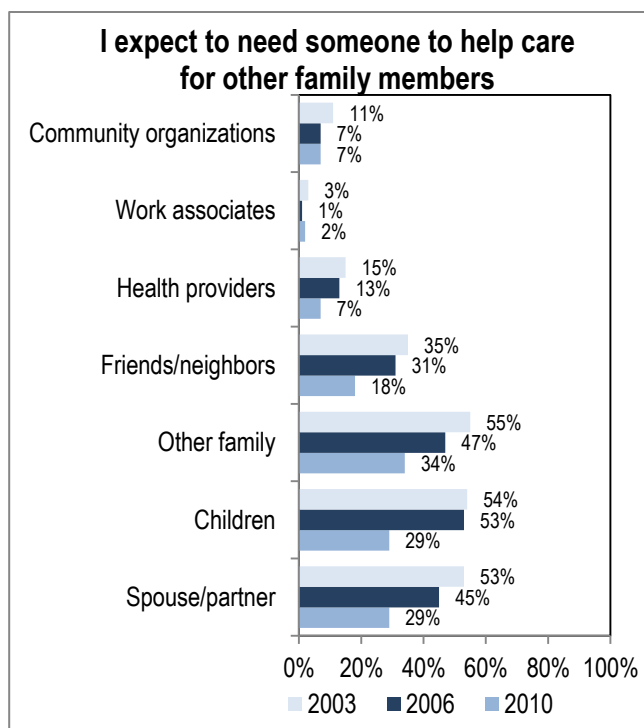
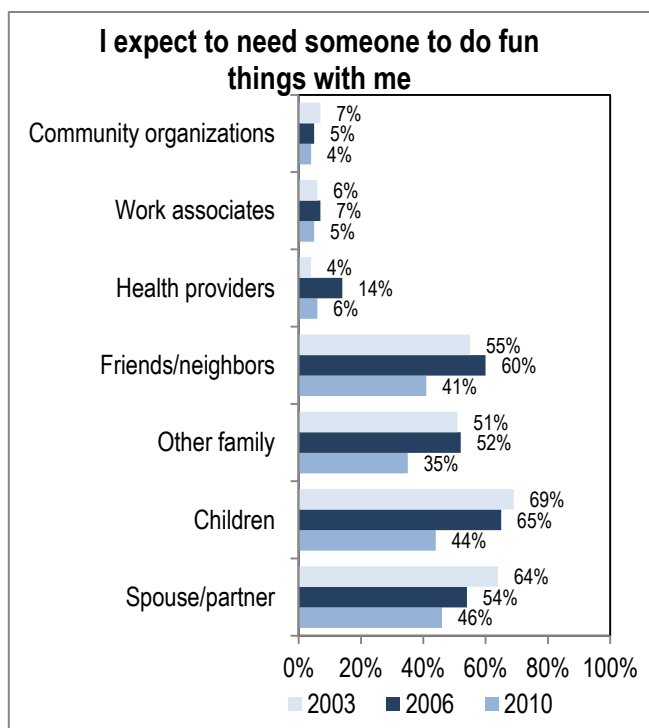
I expect to need someone to understand what I'm going through



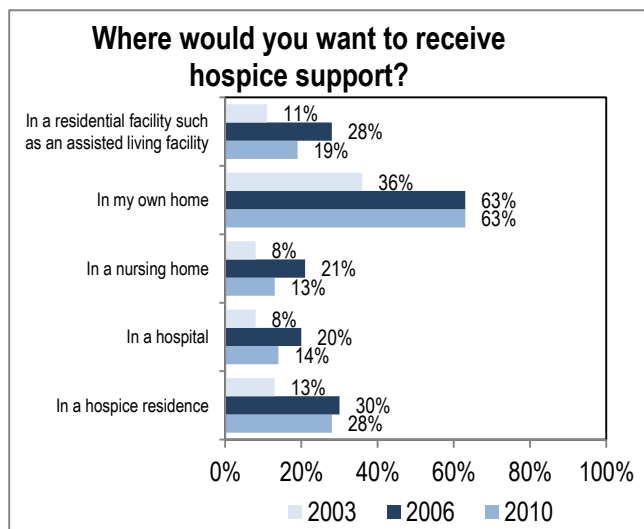
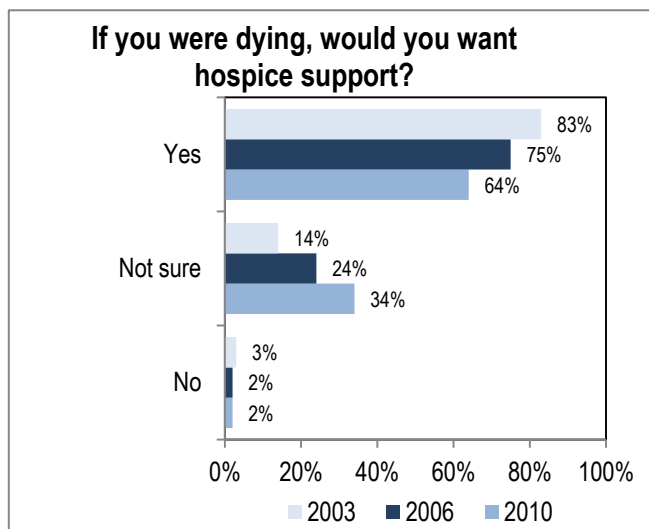


There is a continuing downward trend when considering the categories of support that deal with emotional needs near the end of life, especially from family. Participants were less likely to respond with “spouse/partner,” “children,” or “other family” regarding the expectation to need someone to listen when they talk, know what they want when they die, encourage them when they’re down, understand what they’re going through, and know about their illness. Participants were also less likely to expect their “friends/neighbors” or “health providers” to provide support in any of those categories.





There was a similar trend regarding the categories on expectations of physical support as well. Again, expectations of support from “spouse/partner,” children,” or “other family” decreased in the categories of provide transportation, help with chores, someone to do fun things with, and help care for other family members. In terms of support expected from friends or neighbors, fewer expect them to help care for other family members (down 13% since 2006) but more people expect to need them to help with chores (this was the only area in all of these categories where there was a statistically significant increase). Additionally, fewer people expect their health providers to provide transportation or do fun things with them.



When asked if they would want hospice services if they were dying, participants were less likely to respond “yes” (11% less in 2010 than in 2006) and more likely to respond “not sure” (10% more in 2010 than in 2006). Of those who would want hospice services, participants are less likely to want hospice support in a hospital (down 6%), in a nursing home (down 8%), or in a residential facility such as an assisted living facility (down 9%). In one’s own home and in a hospice residence remain the more popular responses in 2010 as was the case in 2006.

Appendix A: Methodology

METHODOLOGY

This appendix presents a detailed account of the fielding of the 2010 Nebraska End-of-Life Survey commissioned by the Nebraska Hospice and Palliative Care Association, conducted by the Bureau of Sociological Research (BOSR). Users of the 2010 Nebraska End-of-Life Survey data will find it an important reference source for answers to questions about methodology.

A random selection of 2,550 listed household addresses was purchased from Survey Sampling, Inc. The specifications were for the sample to be drawn to contain half rural addresses and half urban addresses. Although more Nebraskans live in urban than rural locations, rural addresses were over-sampled to ensure there would be a large enough sample to compare urban and rural responses. In addition to the random sample of 2,550 households, individuals who completed the survey in 2003 (N=300), were also asked to complete the 2010 survey (as they were in 2006).

All 2,850 addresses were mailed an initial survey on October 25, 2010. This mailing included information about the purpose of the survey in a cover letter, a small post-it notepad gift, the survey, and a postage-paid addressed envelope to return the survey to BOSR. In order to increase the response rate, non-responders were mailed a reminder postcard on November 8, 2010. In addition to the reminder postcard, a second paper survey and cover letter were mailed to non-responders on November 19, 2010. Data collection concluded January 24, 2011.

For the new 2010 sample, the envelope and cover letter were addressed to “the residents at” and the cover letter included instructions to have the household member age 25 or older who most recently celebrated a birthday complete and return the survey in order to ensure a sample of individuals (rather than households).

A total of 1,029 completed surveys were received by the BOSR. This total includes 862 completed surveys from the new 2010 random sample and 167 from the panel (individuals who completed the survey in past). The overall response rate for this survey is 36.1% of the entire sample. The response rate for the 2010 random sample is 33.8%. The response rate for the panel is 55.7%. This is a response rate that is above average for surveys of similar methodology. It should be noted that due to the primary mode of data collection (mail), it is uncertain if surveys reached the entire sample. In fact, a total of 199 surveys (29 from the panel and 170 from 2010 sample) were returned as undeliverable with no forwarding address available. In addition, the BOSR received a survey which indicated that it was filled out by a child, making the response ineligible for inclusion and 13 panel responses indicating that the original respondent was deceased. After adjusting to reflect these returns the overall response rate is 39.0% (36.2% for the 2010 sample and 64.7% for the panel). In addition to receiving completed surveys, the BOSR also received a total of 154 refusals to complete the survey (many of which were indicated by the return of a blank questionnaire).

The 2010 Nebraska End-of-Life Survey data has been weighted to account for differences between the overall population and the individuals that responded as part of this research (completed interviews). For example, a higher proportion of surveys were completed by male Nebraskans age 75 and older (14.4%) than the population of the state according to 2008 U.S. Census estimates (8.4%).

Weighting is a statistical procedure that compensates for these differences to make results of the survey more generalized to the overall group being examined. It may be helpful to keep in mind that when using weighted data it is best to look at proportions (percentages) rather than the number of cases reported because the weights adjust the raw numbers. Weighting adjusts the number of responses doing “X” in order to create the representative proportion based on the population. In other words, the actual number of responses is adjusted in order to make the percentage more closely resemble the population.

A variable that allows the dataset to be weighted to more closely reflect the overall population is included in the dataset. The variable “Weight” contains an adjustment for the age and gender differences found between the population (using 2008 U.S. Census estimates) and the final compilation of individuals who are represented in the completed survey data.

Throughout this report 2010 data is presented in weighted form, so it is more representative of the population. For consistency with previous years' data, unweighted responses are used when comparing changes over time or panel responses.

The 2010 random sample data has a margin of error of plus or minus 3.34%. This means out of 100 samples of this size, the results obtained in the sample would fall in a range of plus or minus 3.34 percentage points of what would have been obtained if every Nebraska resident age 25 or older had been surveyed.

The percentages presented for each question in this report are the "valid percentages," meaning they were computed using the valid sample size for each question. To compute valid sample size for each question, respondents with missing or non-responsive answers were subtracted from the total number of respondents. The valid percentages for a given questions should add to approximately 100% (slightly more or less than 100% because of rounding error). The percentages for the missing/non-responsive answers are separate from the valid percentages and are not included in this sum.

SURVEY HISTORY

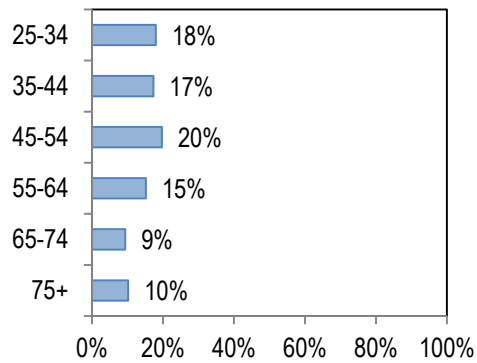
The survey is adapted from the original Life's End Institute: *Missoula Demonstration Project's* Community Survey. In 1997, Life's End Institute completed a seventy-three item comprehensive survey in Missoula County, Montana to determine prevailing attitudes, expectations and experiences with the dying process. Two comparison communities were also surveyed: Bannock County, Idaho and Albany County, Wyoming.

Using modified questions and a modified response scale from the Corriveau-Kelly Death Anxiety Scale (which itself was built upon Templer's Death Anxiety Scale), the survey tool gathers basic demographic information as well as data related to advance care planning, knowledge of hospice services, spiritual beliefs and customs related to death and dying, preferred medical practices, financial concerns, pain management, and social support systems.

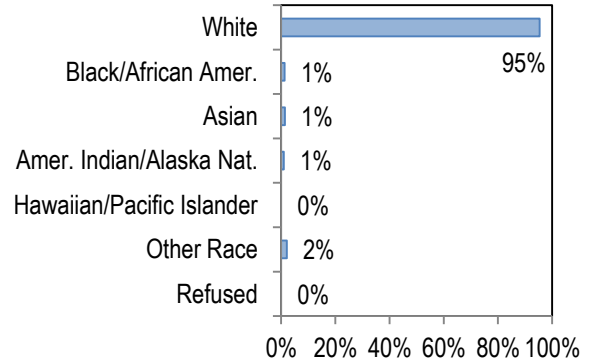
The data from the survey has proven to be useful, serving as the basis for several community engagement initiatives in Missoula County. Since its inception, the Missoula Community Survey has been adapted for statewide use and has been successfully used in several communities and states nationwide. In 2001, North Carolina was the first state to implement the survey to a random sample of AARP members. Because the original Missoula survey was developed in 1997, an advisory group was created to review and revise the survey so it would be more current. The core of the survey is the same. New items were added regarding advance planning and hospice. Nebraska was the next state to use the survey. We refined the advance planning questions. This survey was then used as the core survey in Massachusetts, Idaho, and South Dakota. Each state has included some unique items relevant to initiatives in their state, but the core survey remains the same.

DEMOGRAPHICS

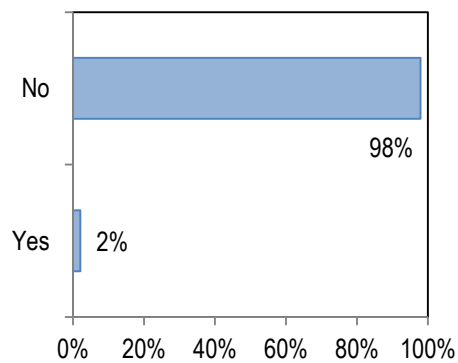
Age of Respondents



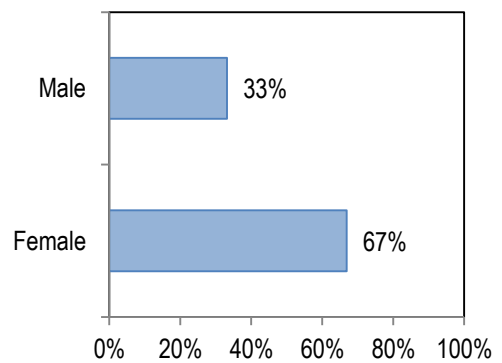
Race/Ethnicity



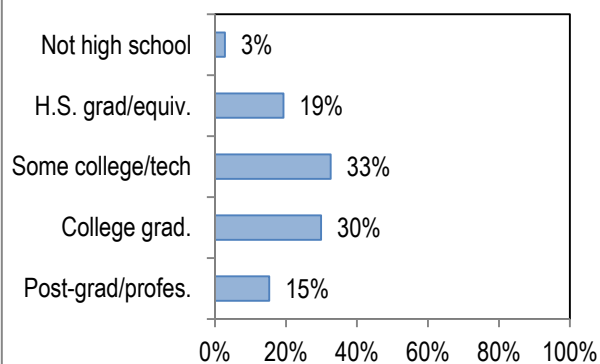
Are you Hispanic or Latino?



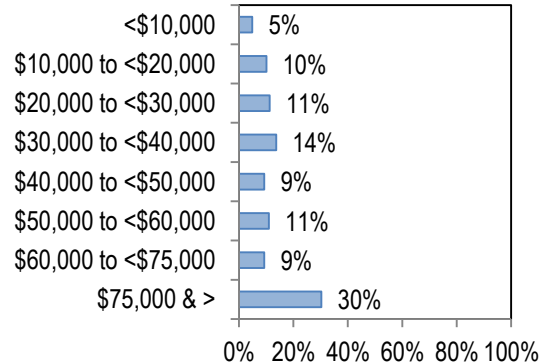
Gender



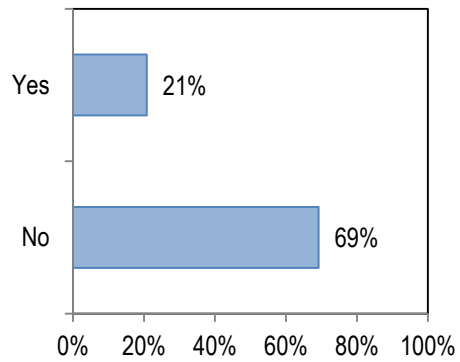
Highest level of education completed



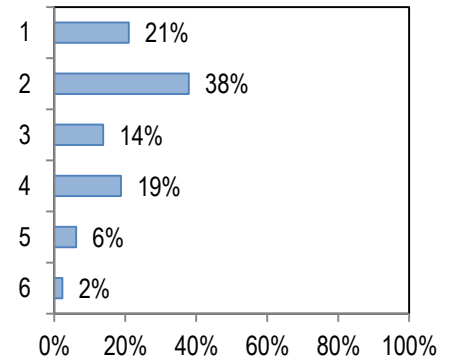
Household income



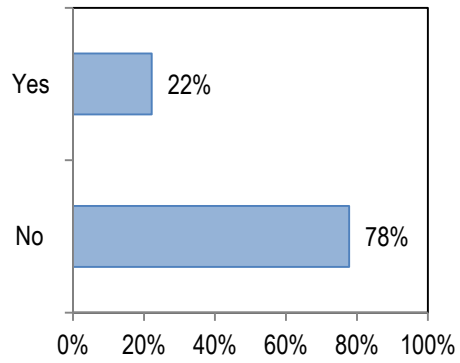
Do you live alone?



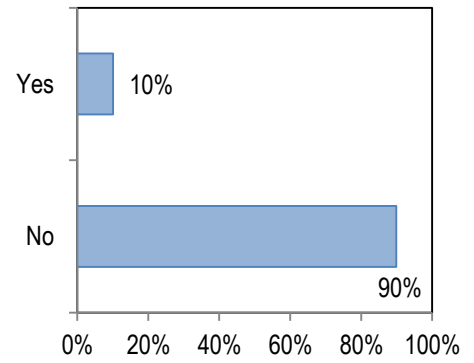
Number of persons living in household



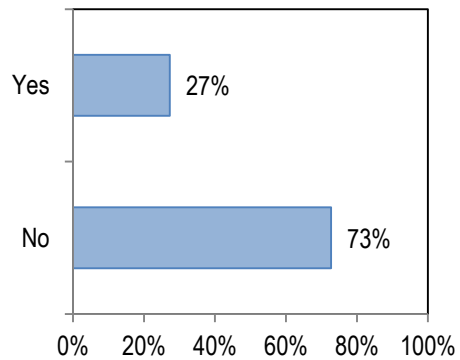
Are you a member of AARP?



Are you a United States Veteran?



Are you a caregiver?





nebraska hospice &
palliative care association

advocate. educate. support.

402/477-0204

info@nehospice.org

nehospice.org