Idaho Survey: Personal Preferences at End-of-Life

2018

BOISE STATE UNIVERSITY

CENTER FOR THE STUDY OF AGING

SURVEY PARTNERS

The Idaho Survey: Personal Preferences at End-of-Life is the result of a collaboration between Patient Centered Outcomes Research Institute (PCORI), Pipeline to Proposal award and the Center for the Study of Aging at Boise State University. Sponsoring members of the project included **Honoring Choices® Idaho (HCI), Boise State University School of Nursing, the Saint Alphonsus Health System** and the **St. Luke's Health System**. The Personal Preferences at End-of-Life survey was adapted from the Idaho Statewide End-of-life Survey conducted in 2006.

Patient-Centered Outcomes Research Institute (PCORI) was established to fund research that can help patients and those who care for them make better-informed decisions about healthcare choices, guided by those who will use that information (www.pcori.org).

The **Center for the Study of Aging** established in 2004, is a multidisciplinary research and service center located in the College of Health Sciences at Boise State University. The Center's mission is to advance the well-being of older people. The Center for the Study of Aging applies an interdisciplinary, lifespan approach to the study of aging and serves as a resource for Idaho and the rest of the nation.

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ACKNOWLEDGEMENTS

The Idaho Survey: Personal Preferences at End-of-Life is based on the Idaho Statewide End-of-Life Survey conducted in 2006. The 2006 study was led by Cheryl Simpson-Whitaker, MSW, Idaho Better Way Coalition and Annette Totten, PhD, Center for the Study of Aging, Boise State University. It used an instrument patterned after a tool that was developed by Life's End Institute: The Missoula Demonstration Project's Community Survey. The organization, content, and format of the work completed in 2006 guided the development of the 2018 report. A special thanks to Simpson-Whitaker, Totten, and their research team for the foundation of excellence provided by their effort.

The 2018 survey was conducted under the direction of Kim Martz, RN, PhD, School of Nursing, Boise State University, Sarah Toevs, PhD, Center for the Study, Boise State University, and Lynsey Winters Juel, MPA, Honoring Choices® Idaho, Jannus, Inc. Thanks go to Kirk Ketelsen, PhD, Department of Community and Environmental Health, College of Health Sciences for statistical support, graduate student McKenzie Hanson for project management and research assistance and undergraduate students Jennifer Stibrany, Julie Rekiere, and Annalise Goyette for data entry and other technical assistance.

Much gratitude and appreciation is also extended to project sponsors, Honoring Choices® Idaho, Saint Alphonsus Health System, St. Luke's Health System, and Boise State's School of Nursing and Center for the Study of Aging. These partners contributed financial and in-kind support to make this work possible.

Finally, a special thanks to the 827 people living in Idaho who took the time to share their preferences about communication and care at end of life. This information will be used to support conversations and guide system change in Idaho and across the country.

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PREFACE

Assuring that a person's health care choices are expressed and honored is a catalyst for conversation and change by families, communities, health care organizations, and state and federal agencies. Conversations and change are underway in Idaho, as evidenced by recent initiatives lead by Honoring Choices® Idaho (HCI), two major Idaho-based health systems, the Idaho Health Quality Planning Commission, the Idaho Department of Health and Welfare, and others. This survey project will inform those initiatives, the general public and policy makers about the personal preferences of Idahoans age 35 and older for end-of-life conversations and care. The survey tool used in this effort was based on the Idaho Statewide End-of-Life Survey conducted in 2006.

The 2018 Personal Preferences at End-of-Life survey is the result of a collaboration between Patient Centered Outcomes Research Institute (PCORI) Pipeline to Proposal award, Honoring Choices® Idaho, and the Center for the Study of Aging at Boise State University. In 2016, HCI in partnership with Boise State University Center for the Study of Aging, received a Tier I PCORI Pipeline to Proposal award. This award was used to develop relationships between older adults, healthcare providers and other community partners to build a shared understanding about how clinician–patient communication and planning about end-of-life can be improved. The Advance Care Planning Community Advisory Board was established which engaged community partners in developing research ideas and processes. A Tier II PCORI Pipeline to Proposal award was secured in 2017 and guided by the Advisory Board and others, to replicate the 2006 Idaho Statewide End-of-Life survey. The goal is to create a current picture of attitudes, beliefs, experiences, and behaviors related to end-of-life preferences and planning and examine change over time. It is the goal of the Advisory Board, HCI, and others that these findings will be used to guide system change in Idaho.

Results from the 2018 survey are consistent with many of the findings from 2006. Foremost, many people in Idaho are willing to thoughtfully consider a wide range of issues related to the end-of-life. They are talking to family and friends and some are speaking to their health care providers, however many would like their providers to initiate conversations with them about dying and death. While more people in 2018 indicated they knew about health care agents/proxies and living wills, approximately the same proportion of individuals (less than 50% in 2006 and 2018) had taken steps to complete this advance planning or documents. A notable difference occurred in that 75% of respondents in 2018 were comfortable identifying a health care agent as compared to 56% in 2006. While this may indicate a greater level of awareness, only 40% of respondents in 2018 had identified a health care agent suggesting that barriers to taking action exist.

The respondents were also very clear about their wants and desires regarding end-of-life. Over 90% want to die at home, the majority do not want to be a financial or physical burden to loved ones at the end of life, and most would consider using hospice support.

The authors used the 2006 survey report as a guide, modifying this 2018 survey report to reflect Idaho-specific programs and resources. Early sections of the report include demographics followed by key findings. Further details from the survey are presented in Communicating Wishes, Compassionate Care, and Meaning & Spirituality. A call to action is presented in the section 'Where do we go from here?' The technical details on survey administration processes, the survey form distributed to participants, and the complete survey response frequencies follows as Appendices.

This survey report reflects the perceptions of people living in Idaho and attempts to convey survey results and provide a context for their interpretation. All assertions, conclusions, and any errors are responsibility of the authors and do not necessarily reflect the opinions of individuals or supporters.

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DEMOGRAPHICS

Who responded to the Idaho Survey: Personal Preferences at End-of-Life? This section describes the people who completed the 12-page survey and compares them to those completing the survey in 2006.

The 2018 survey was distributed to a random sample of 4000 adults 35 years and older who lived in private residences in Idaho. The sample was comprised of equal numbers of men and women and represented the geographic distribution of the population across the state of Idaho.

Of the 4000 surveys mailed, 827 or 21% were returned with the survey form completed totally or in part. The majority (91%, n = 750) of the surveys were returned via postal mail with the remainder completed using a web-based survey tool.

HOW CLOSELY DO THE PEOPLE WHO FILLED OUT THE SURVEY REPRESENT THE POPULATION OF IDAHO?

The survey respondent population is similar to Idaho's population in race and ethnicity, income, education levels, employment, and marital status. The age and gender distribution of the survey respondents did not reflect the population. A post-stratification weighting of these variables was conducted during analysis of the results to more accurately reflect the population. Details on weighting are included in Appendix A.

IS THERE STATEWIDE REPRESENTATION IN THE SURVEY?

Yes. People across the state received the survey and respondents live in all corners of the state. Forty-eight percent of the survey respondents were from the western part of the state, 35% from the east and 17% from the north.

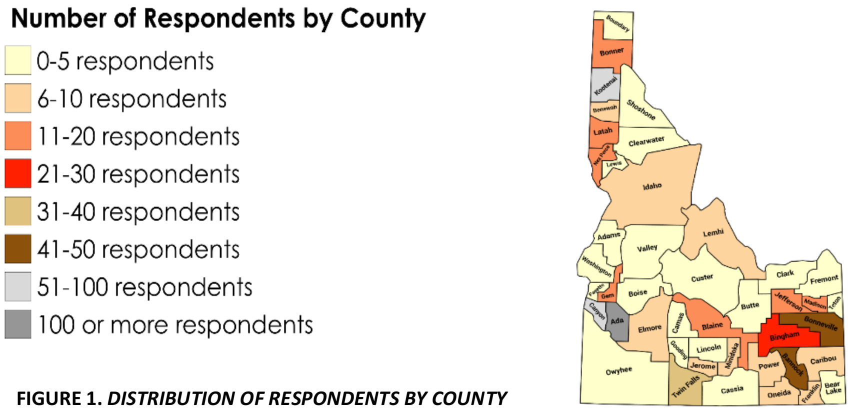

FIGURE 1. ***DISTRIBUTION OF RESPONDENTS BY COUNTY***

SOME SPECIFICS ABOUT RESPONDENTS

MARITAL STATUS

The vast majority of respondents were married (71%) while 9% were divorced and 10% were widowed. Only 5% were single or never married and another 3% were living with a partner.

EDUCATION LEVEL

Just over half (55%) of the respondents reported they did not have a college degree. Thirteen percent had obtained a high school diploma or the equivalent, 40% had some college or technical training, 24% were college graduates, and 19% had a professional degree or have completed post-graduate coursework. Only 2% reported having less than a high school diploma.

EMPLOYMENT

Half (52%) of the survey respondents were employed in some capacity. Thirty-four percent of respondents were employed full time, 45% were retired and not working, 12% were employed part time and 6% noted the other category such as a homemaker. Only 1% of the respondents were unemployed and looking for work.

AGE

Approximately half (49%) of respondents were over the age of 65. Twenty-nine percent were age 65 to 74 and 26% were in the 55 through 64 age group. The 54 and younger age group comprised 22% of the total sample and those 75 to 84 in age were 16% of the sample. People age 85 and older were 4% of the respondents.

The respondents under-represent younger populations and over-represent the older adult population in Idaho. Based on the 2010 census[i], the distribution of adults between the ages of 35 to 44, 45 to 54, and 55 to 64 is approximately 24% per category. These were not reflected by the survey respondents. In addition, a smaller proportion of respondents were age 65 to 74 (18%) and age 75 and older (11%). The variable of age was weighted in the analysis to produce representative estimates of the population parameters of Idaho.

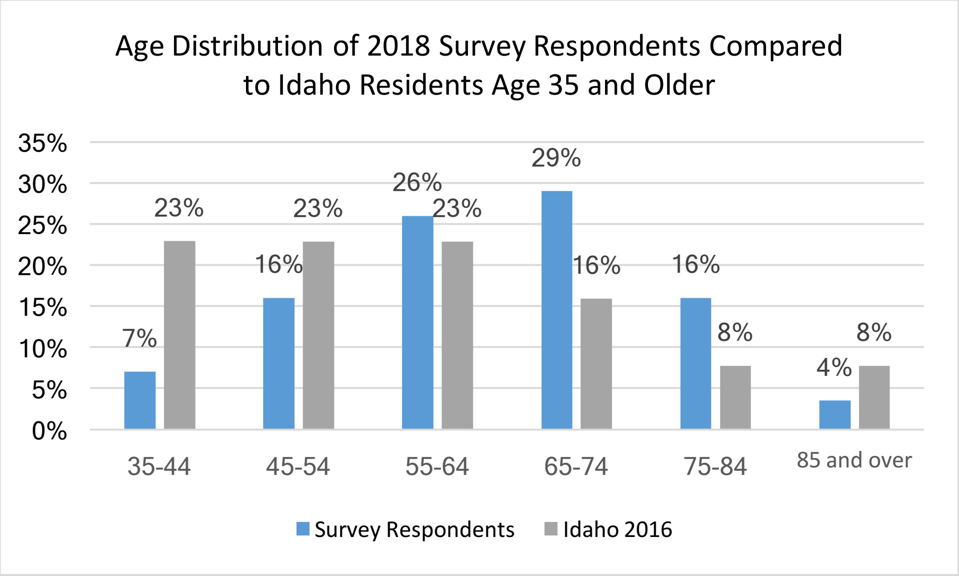

FIGURE 2. ***AGE DISTRIBUTION OF 2018 SURVEY RESPONDENTS COMPARED TO IDAHO RESIDENTS AGE 35 AND OLDER***

DID MEN RESPOND? IT SEEMS LIKE THIS WOULD BE SOMETHING ONLY WOMEN WOULD FILL OUT.

Yes. In fact, 41%, of survey respondents were male and 57% female. In 2010 the Idaho population distribution for people age 35 and older 49% was male and 51% was female.[ii] The variable of gender was weighted in the analysis to produce representative estimates of the population parameters of Idaho.

RACE AND ETHNICITY

Ninety-four percent of the people who filled out the survey are White and 2% are American Indian or Alaskan Native. One percent of the survey respondents are of Hispanic or Latino ethnicity compared to 6.5% of the Idaho population age 35 and older of Hispanic or Latino ethnicity. [iii]

INCOME

The median income for a family of four ("standard family") in Idaho was $49,179 in 2016.[iv] Overall, survey respondents had higher household income compositions than the "standard family". Forty-seven percent had an income level of $60,000 or more; 21% of respondents reported an income of $40,000 and $59,000 and 18% had an income between $20,000 and $39,000.

HEALTH STATUS

The majority (83%) of respondents considered themselves to be in good to excellent health. Thirty-six percent rated their health as "very good," 28% rated it as "good" and 19% rated their health as "excellent." Thirteen percent reported being in "fair health" and 3% were in "poor health."

Chronic illness was on the minds of some survey respondents. Twenty-two percent of respondents reported having a serious chronic illness themselves and 18% said someone else in their household had a chronic illness.

HOW CLOSELY DO THE PEOPLE WHO FILLED OUT THE 2018 SURVEY MIRROR THOSE FROM 2006?

The characteristics of the respondent populations completing the survey in the 2006 and 2018 survey were similar in level of education, health status, and race/ethnicity and by region of the state. More individuals over the age of 65 and more females responded to the 2018 as compared to the 2006 survey. The respondents in 2018 also reported higher levels of income.

KEY FINDINGS

The Idaho Survey: Personal Preferences at End-of-Life was a joint project between Patient Centered Outcomes Research Institute (PCORI), Pipeline to Proposal award, the Center for the Study of Aging at Boise State University and Honoring Choices® Idaho (HCI). The decision to replicate the 2006 Idaho Statewide End-of-Life Survey was guided by input from the Advance Care Planning Community Advisory Board established as a component of the PCORI award. The Advisory Board and other community partners identified the need for a current snapshot of the attitudes, beliefs, experiences, and behaviors related to end-of-life preferences and planning and examine change over time. It is the hope of the Advisory Board, HCI, and others that the findings will be used to support conversations and guide system changes in Idaho.

The survey was conducted February 2018 through April 2018 and 827 people responded for a response rate of 21%. A selection of the findings are outlined here and presented in more detail in the next sections of this report.

COMMUNICATING WISHES

PEOPLE IN IDAHO ARE COMFORTABLE TALKING ABOUT DEATH…

- 50% remember death and dying being talked about either occasionally or often in their families when they were children
- 88% are very comfortable or somewhat comfortable talking about death with family
- 84% are comfortable with writing their own living will concerning healthcare decisions
- 50% are very comfortable with appointing a health care agent who would act on their behalf if they were unable to communicate
- 73% have spoken with their spouse or partner about advance directives for care at the end-of-life
- 69% say not being able to communicate wishes and/or needs would be worse than death

PEOPLE IN IDAHO HAVE STRONG PREFERENCES ABOUT THEIR OWN END-OF-LIFE CARE

- 93% say it is important or very important that they are able to stay in their own home when dealing with their own dying
- 86% say it is somewhat or very important that they are not on artificial life-sustaining support when dying
- 60% are somewhat or very afraid of dying in an institution
- 72% are concerned or very concerned they will experience a financial burden paying for medicine or medical care
- 79% say it is very important to not be a physical burden to loved one
- 60% are concerned they will be a financial burden to family or friends
- 94% would want to know if they had a serious illness
- 95% say it is important to be able to understand treatment options

- 97% say it is important to be able to choose treatment options
- 59% want their primary care physician and/or specialist to initiate the conversation

BUT, OFTEN THEY HAVE NOT HAD KEY END-OF-LIFE CONVERSATIONS…

- 55% have NOT completed a living will or written instructions concerning healthcare decisions
- 60% have NOT identified a health care agent who would act on their behalf if they were unable to communicate
- 86% have NOT talked about wishes for care at end-of-life with their primary care physician and/or specialist
- Only 16% of those over 65, had their health care provider discuss Advance Care Planning with them in the past year

THEY REALIZE THE IMPORTANCE OF PAIN MANAGEMENT AND PALLIATIVE CARE…

- 95% believe it is important or somewhat important to be free from pain
- 98% want information about options for managing pain
- 68% believe living with great pain would be worse than death

…BUT THEY HAVE CONCERNS.

- 42% are afraid of becoming addicted
- 80% say they would take the lowest amount of medicine possible to save the larger does for later when their pain is worse
- 38% are afraid they would be given too much pain medicine

THEY KNOW ABOUT HOSPICE AND WOULD CONSIDER USING THIS TYPE OF SERVICE AT THE END-OF-LIFE…

- 98% are aware of hospice services
- 84% would use hospice support if needed

…BUT THEY MAY NEED MORE DETAILED INFORMATION.

- 57% are aware that Medicare and Medicaid pay for hospice services
- Most of the information about hospice comes from talking with others (34%), the media (20%) or knowing someone who used hospice (72%)
- Only 19% heard about hospice from a health professional

MEANING AND SPIRITUALITY

IDAHOANS REPORTED THEIR VALUES AND MEANING AT THE END-OF-LIFE…

- 94% strongly agree or somewhat agree that death is important part of life
- 67% believe caring for people who are dying is a rewarding experience

…AND THE IMPORTANT TASKS OF COMPLETING LIFE.

- 69% rate reviewing their life history with family an important or somewhat important end-of-life activity
- 84% hope to share time, gifts and wisdom with others
- 89% want to have relationship issues settled with family
- 92% want to know how to say goodbye

THEY BELIEVE MEANING AND SPIRITUALITY ARE IMPORTANT…

- 81% consider themselves very or somewhat religious/spiritual
- 53% are affiliated with an organized faith community
- 86% want to have a sense of their own worth at the end of their life

…AND PLAY A SIGNIFICANT ROLE AT THE END-OF-LIFE…

- 89% said being at peace spiritually was very important or somewhat important when they think about dying
- 40% report that their spiritual practice or religion affect end-of-life choices to a great extent

…TO THE EXTENT THAT PEOPLE WANT SPIRITUAL LEADERS AND FAMILY COMMUNITIES TO BE INVOLVED IN THEIR END-OF-LIFE CARE.

- Between 17% and 35% indicated their faith community should provide support ranging from encouraging them when they are down to providing transportation.
- 18% want a spiritual leader/clergy to initiate a conversation with them about end-of-life
- The presence of a spiritual leader is very important to 35% and somewhat important to 29% of people when they think about their own death

COMMUNICATING WISHES: PREFERENCES, AWARENESS, ACTIONS, AND CONVERSATIONS

Significant efforts to promote advance care planning conversations have been made since the 2006 Idaho Statewide End-of-Life Survey was conducted. Two national examples of public engagement and system-changing initiatives include The Conversation Project and the Honoring Choices® National Network. Idaho, has more recently (over the past 2 years) seen an increase in public awareness activities such as Death Cafes, National Health Care Decisions Day events and system-change initiatives similar to Honoring Choices® Idaho (HCI).

> While 92% of Americans say it's important to discuss their wishes for end-of-life care, only 32% have had such a conversation. The majority of Americans (95%) say they would be willing to talk about their wishes, and 53% even say they'd be relieved to discuss it.[v]

The question at hand is: Will these initiatives make a difference? This 2018 Idaho Survey: Personal Preferences at End-of-Life provides a baseline for measuring the impact of these Idaho-specific initiatives over the coming years. This survey also provides a snapshot of the experiences, attitudes, knowledge, and actions of adults related to end of life conversations and care. A comparison of findings from the 2006 and 2018 surveys affords an opportunity to explore changes over time. While it is too early to assess changes from the Idaho-specific initiatives, the 2018 survey provides a baseline for looking forward as the initiatives expand throughout the state.

PREFERENCES

People in Idaho have strong preferences about their own end-of-life care. Results from the 2006 and 2018 surveys are similar: over 90% of respondents expressed the desire to die in their own homes, 80% do not want to be a physical burden to loved ones, and 72% say not being able to communicate their wishes and/or needs would be worse than death.

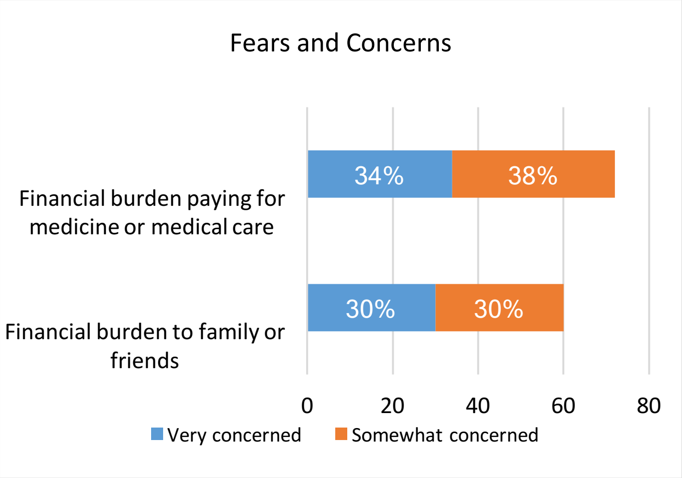

FIGURE 3. ***FEARS AND CONCERNS***

While there are fears and concerns associated with death and dying, only 34% of respondents were afraid of dying. The more pressing fears or concerns were related to being a financial burden to family and experiencing a financial burden paying for medicine or medical care.

AWARENESS

Respondents to the surveys conducted in 2006 and 2008 indicated high levels of awareness of communication and planning tools such as a living will, health care proxy, last will and testament, funeral plans, and organ and tissue donation.

	Have Heard About 2018	Have Heard About 2006
Living Will	94%	98%
Health Care Proxy/Durable Power of Attorney for Health Care/Health care agent	100%	91%
POST document	75%	Not available in Idaho in 2006
Last Will and Testament	99%	97%
Funeral Pre-Plans	97%	96%
Organ and Tissue Donation	97%	95%

FIGURE 4. ***HAVE YOU HEARD ABOUT…?***

The results from the 2018 survey suggest a lack of awareness and use of the new Medicare benefit for advance care planning with a health care provider. Only 16% of respondents over the age of 65 reported having had their health care provider discuss advanced care planning with them.

As of January 1, 2016, the Centers for Medicare and Medicaid Services began paying providers for guiding voluntary Advance Care Planning conversations under the Medicare Physician Fee Schedule and the Hospital Outpatient Prospective Payment System.[vi]

TAKING ACTION

While 97% of respondents to the Idaho 2018 survey indicated that it was somewhat or very important that they get to choose their treatment options when dealing with their own death, only 45% had completed a living will or other written instructions. Findings from the 2006 and 2008 revealed similar patterns for the use of communication and planning tools.

	Have Heard and Completed (65 and older)	Have Heard and Completed (Younger than 65)
Living Will	59%	33%
Health Care Proxy/Durable Power of Attorney for Health Care	63%	39%
POST document	44%	19%
Last Will and Testament	66%	38%

FIGURE 5. ***2018 HAVE YOU HEARD ABOUT AND COMPLETED…?***

Results from the 2018 survey identifies an area of possible confusion about the use of the Idaho POST document (Physician's Order for Scope of Treatment). Twenty-seven percent of respondents indicated they had heard about and completed a POST document. An analysis of the respondents indicating they had a POST In Idaho, revealed that 85% reported their health to be in good to excellent condition and only 26% had a serious or chronic illness. This is inconsistent with the language and intent of Idaho Statutes (39-4512A) and guidelines published by the Idaho Department of Health and Welfare (see box). This inconsistency suggests a need for public awareness campaigns and alignment of policy and processes with the stated intent of the POST.

In Idaho, an individual or the person's surrogate decision maker is provided with access to the POST form by an attending physician, Physician Assistant, or Advanced Practice Registered Nurse.[viii]

A physician's order for scope of treatment (POST) form is generally recommended in cases where a patient has an incurable or irreversible injury, a chronic, progressive or end-stage disease, illness or condition, or where a patient is in a persistent vegetative state. A post form is also appropriate if such conditions are anticipated. [vii]

CONVERSATIONS WITH FAMILY

Increasing the number of people who discuss and communicate wishes and complete advance care planning documents is important to improving care at the end of life in Idaho.

The majority of respondents (87%) reported being somewhat or very comfortable talking about death with family and 73% indicated they had talked to their spouse or partner about their wishes for care near the end of life. These findings are similar to those from the 2006 Idaho survey and consistent with findings from other state and national surveys (Figure 6).

One indicator of a change in readiness to have conversations about end-of-life wishes in Idaho from the surveys was that more than 75% of respondents in 2018 were comfortable with identifying a health care agent as compared to 56% in 2006. While this may indicate a greater level of awareness, only 40% of respondents in 2018 had identified a health care agent suggesting that barriers to taking action exist.

Percent of respondents who say…

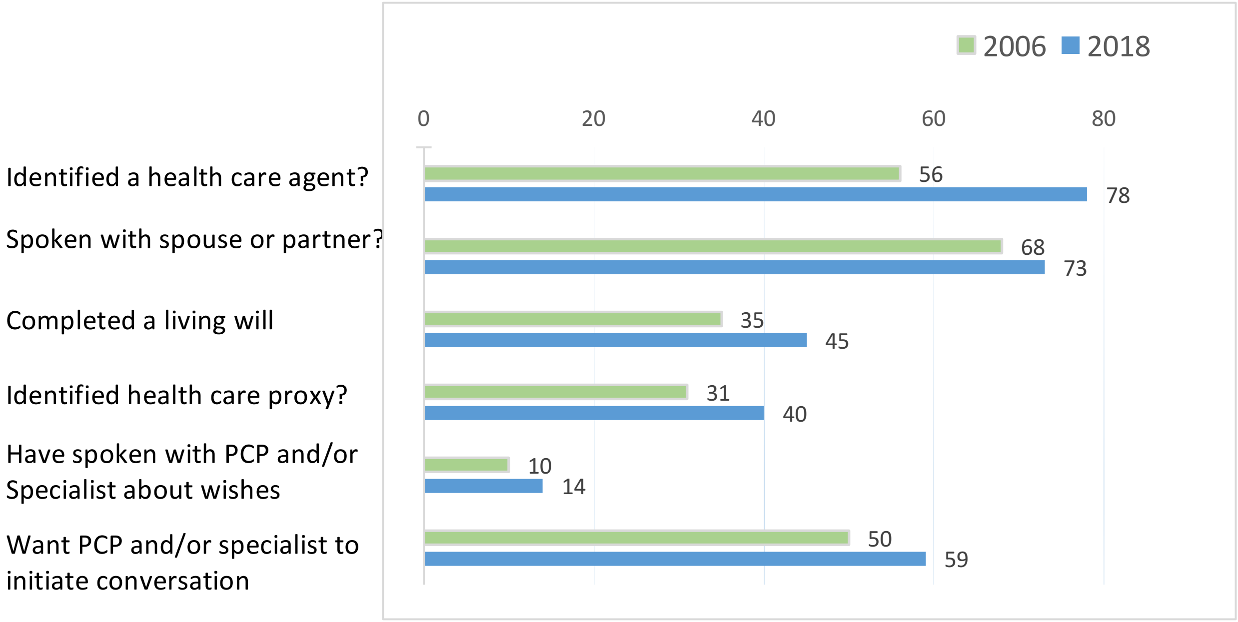

FIGURE 6. PERCENT OF RESPONDENTS WHO SAY…

CONVERSATIONS WITH HEALTHCARE PROVIDERS

The percentage of individuals who had spoken with their primary care provider and/or specialist about end of life wishes remains low with only 14% and 10% having done so in 2018 and 2006, respectively. This is in stark contrast to who respondents report wanting to initiate a conversation and who they would trust to provide information about end of life issues. Almost 60% want their primary care physician and/or specialist to start the conversation and these professionals are viewed as the most trusted source of information by 79% of respondents (multiple responses were allowed to each question.)

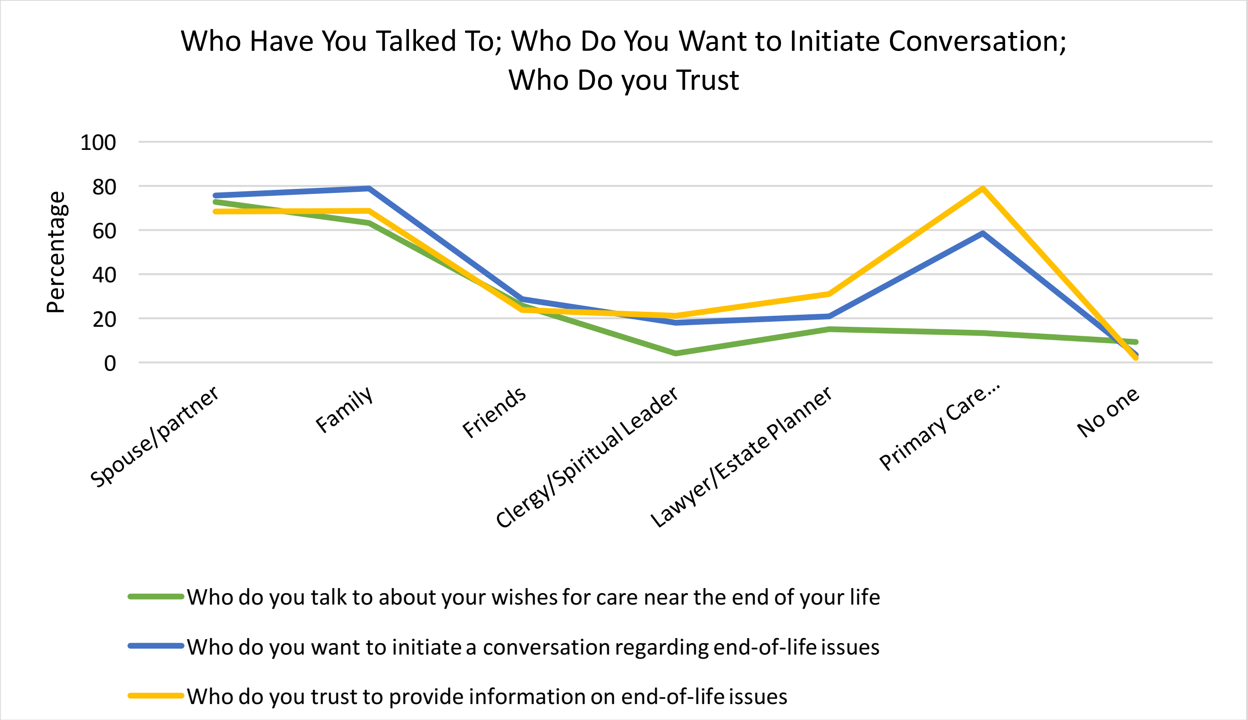

FIGURE 7. WHO HAVE YOU TALKED TO, WHO DO YOU WANT TO INITIATE THE CONVERSATION, WHO DO YOU TRUST

The differences between people who initiated conversations about end-of-life issues and their desire to have others initiate the discussion is similar to the gap between knowledge about advanced care planning tools and their use. As noted earlier, respondents are familiar with the available tools, but most have not taken action.

	Have Heard and Completed (65 and older)	Have Heard and Completed (Younger than 65)
Living Will	59%	33%
Health Care Proxy/Durable Power of Attorney for Health Care	63%	39%
POST document	44%	19%
Last Will and Testament	66%	38%

FIGURE 8. HAVE HEAR AND COMPLETED (OVER 65 AND YOUNGER THAN 65)

A national report published in 2017 indicated that individuals over the age of 65 were more likely to complete any type of advanced directives.[ix] Results of the Idaho survey reflect similar findings with individuals 65 years of age and older much more likely to have taken steps to document and communicate their wishes.

COMPASSIONATE CARE

[1]

Compassionate care is the combination of medical, emotional, psychological and spiritual care for people with serious or terminal illness to make their lives more comfortable. It can occur at the onset of a chronic illness and is known as Palliative Care, or when the illness is terminal and is known as Hospice Care. Hospice care is generally provided in a person's home.

MEDICAL TREATMENT

Since 2006, many local and national efforts to support end-of-life decision making and advance care planning conversations have been instituted. Although efforts to raise awareness have increased, findings from the 2006 and 2018 Idaho survey highlight the need for integration of conversations into health care systems. While over two-thirds of respondents in the 2006 and 2018 survey indicated they had talked about their wishes for care near the end-of-life with their spouse or partner, less than 15% had spoken with their primary care provider or a specialist. This lack of communication with a health care provider contrasts with the importance of having honest answers and information about treatment options when dealing with their own death, Figure 9.

From the Institute of Medicine's *Dying in America:*

Ideally, health care should harmonize with social, psychological, and spiritual support to achieve the highest possible quality of life for people at all ages with serious illnesses or injuries. Toward this end, the IOM committee recommends that integrated, person-centered, family-oriented, and consistently accessible care near the end of life be provided by health care delivery organizations and covered by government and private insurers. [x]

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[1] Atul Gawande, MD, MPH, is a surgeon, writer, and public health leader. Dr. Gawande has been a staff writer for *The New Yorker* magazine since 1998 and has written four *New York Times* bestsellers: *Complications*, *Better*, *The Checklist Manifesto,* and *Being Mortal*: *Medicine and What Matters in the End.* [1] He serves as an advisor to the *Conversation Project.*

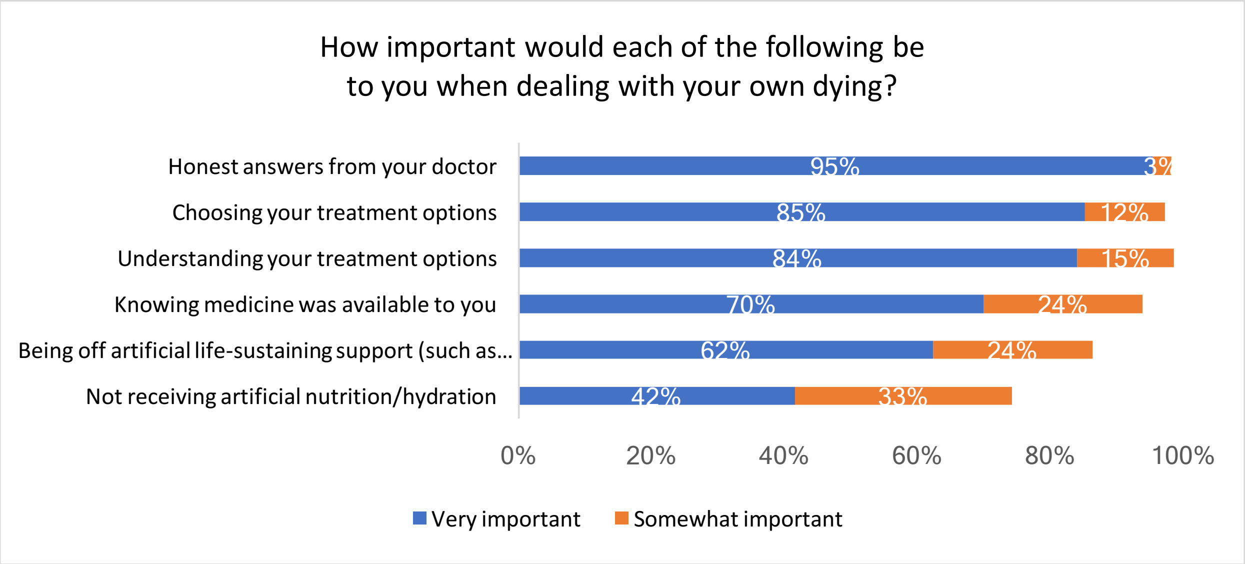


FIGURE 9. ***HOW IMPORTANT WHEN DEALING WITH YOU DYING***

PAIN MANAGEMENT

The need to balance the management of pain with appropriate use of medication is a significant challenge for patients and providers and has garnered the attention of the public and policy makers. In 2013, the Idaho Board of Medicine adopted the Policy for the Use of Opioid Analgesics in the Treatment of Chronic Pain. This was followed by the Idaho Opioid Misuse and Overdose Strategic Plan 2017-2022 developed by the Idaho Office of Drug Policy.

Pain management is a complex issue, especially in light of the opioid crisis in the United States. Respondents in 2016 and 2018 reported similar levels of concern about becoming addicted to pain medications (13%) and being given too much medication (9%).

Pain management continues to be a significant issue in end-of-life care with the majority of respondents 68% (2018) and 63% (2006) reporting that living with great pain would be worse than death. Almost all (95%) also identified being free from pain as “very or somewhat important.”

The importance of information and having resources available to manage pain were high priorities and consistent across time. Almost all respondents “strongly or somewhat agreed” with wanting information about pain management available (96%) and access to medications to manage pain (95%), Figure 10.

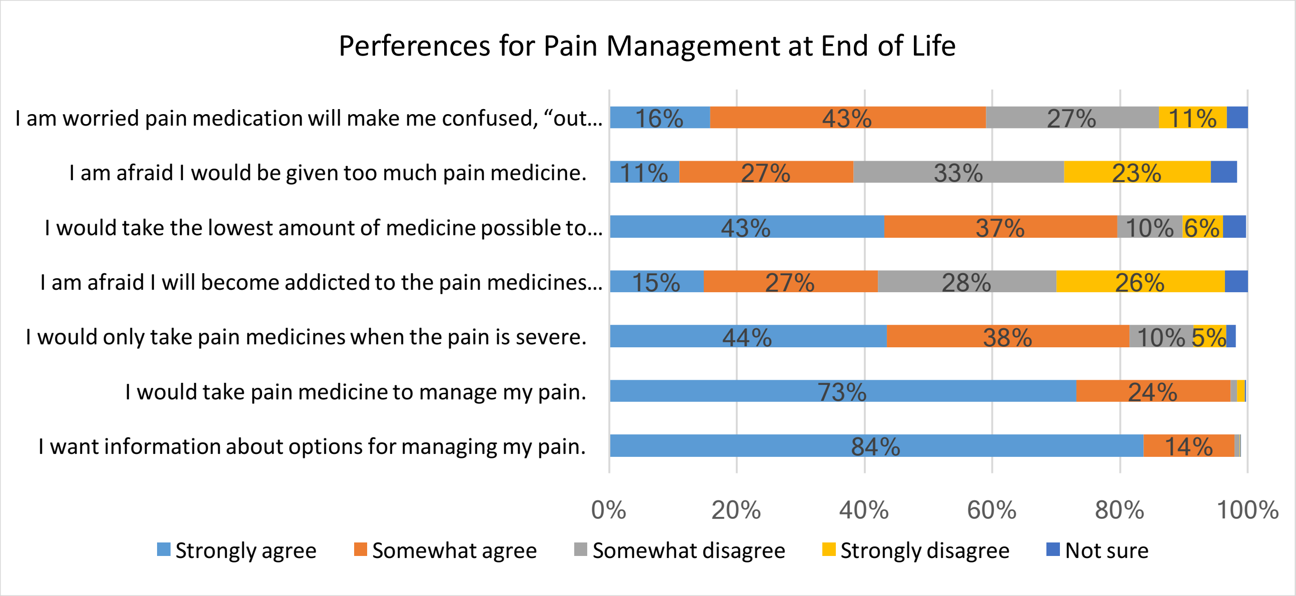


FIGURE 10. ***PREFERENCES FOR PAIN MANAGEMENT***

HOSPICE SUPPORT

The findings from this survey indicate high levels of awareness about hospice with 84% of participants expressing an interest in using hospice support; this represents an increase from the 2006 survey findings of 78%. More people, 75% (2018) and 66% (2016) know someone who has received hospice and more people (12% vs 6%) have received hospice services themselves.

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so. [xi]

Although the majority (86%) would want to receive hospice support in their own home, 21% would want to receive hospice in a hospice residence. The number of people who learned about hospice services from someone who used hospice increased by 11% from the 2006 survey. The number who have used hospice services themselves increased from 6% in 2006 to 10% in 2018. Also 57% said they were aware that Medicare and Medicaid paid for hospice services compared to only 43% in 2006. The Medicare hospice benefit covers support for two 90 day benefit periods followed by an unlimited number of 60 day benefit periods.[xii]

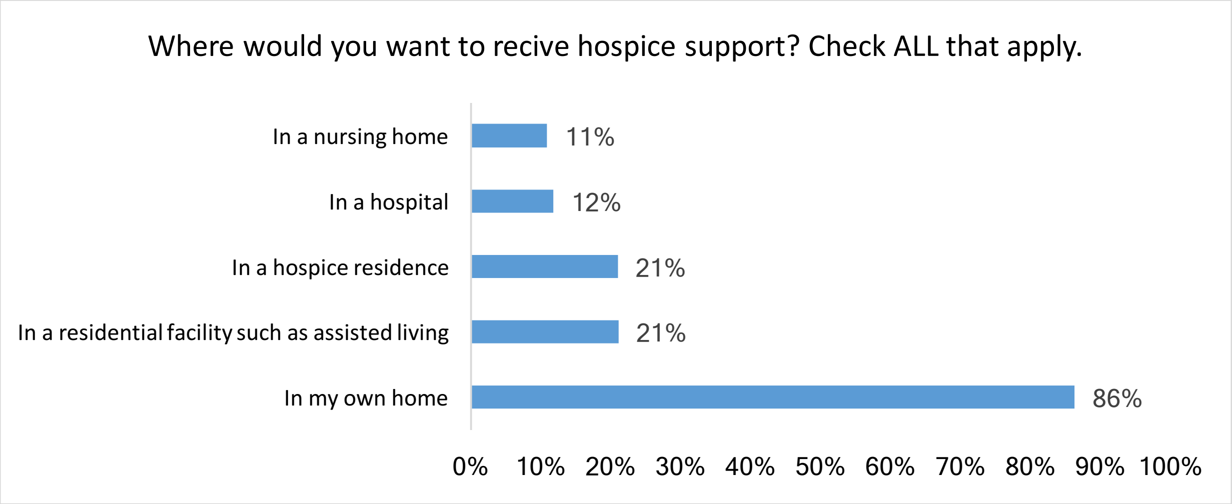


FIGURE 11. ***WHERE YOU WOULD WANT HOSPICE SUPPORT***

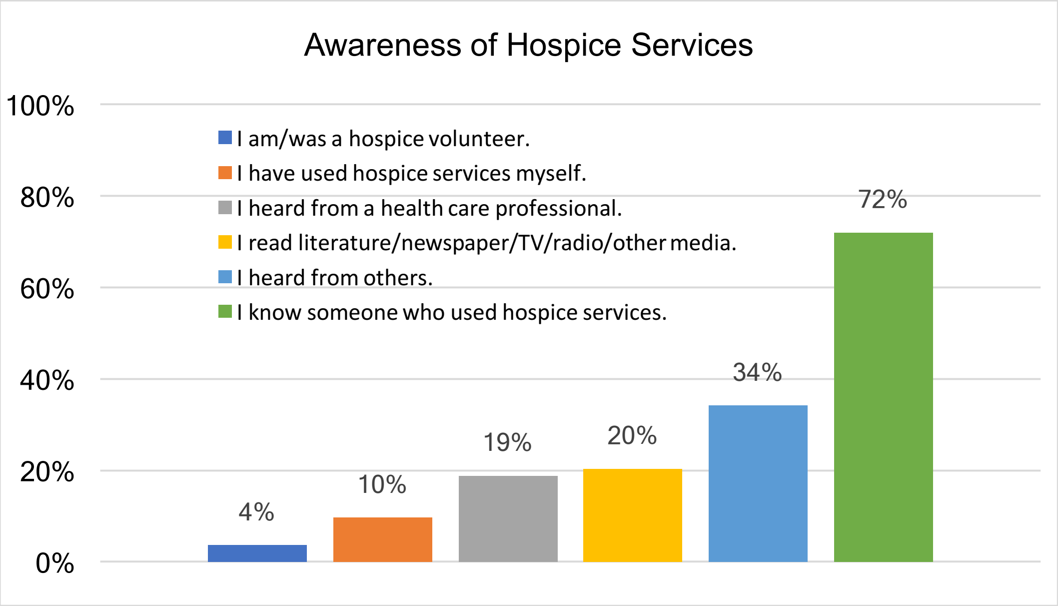


FIGURE 12. ***AWARENESS OF HOSPICE SERVICES***

CARING COMMUNITIES

Most people who provide care for a family member, friend or neighbor near the end-of-life don't think of themselves as a "caregiver." Caregivers play an important and potentially stressful role.

In 2015, the National Alliance for Caregiving and AARP reported 44 million caregivers have provided unpaid care to an adult or child in the last 12 months.[xiii]

Caregivers across Idaho must manage multi-faceted and complex care on behalf of their loved one, and many do this without the information, training, and support they need. The result of this is caregiver burnout, costly hospitalization, or institutional care for the care recipient.[xiv] With the passage of House Concurrent Resolution 24, the 2015 Idaho Legislature formally recognized family caregivers as an essential part of Idaho's health care system, providing uncompensated support and care to a family member or loved one who is elderly or has a physical or intellectual disability or mental illness.

FAMILY SUPPORT

The importance of family caregivers was evidenced in the results of the 2018 survey. Over 75% of respondents identified children or other family, as their primary source of support at end of life. The desire to have family members involved and informed was clear; the majority want their children and/or other family to "know what they want when they die" (88%), "know about my illness" (87%), and "listen when I talk" (88%). Respondents also recognized family members as a primary source of caregiver support, i.e., providing transportation, helping with chores, and offering encouragement (Figure 13). These results were similar to the 2006 survey.

FRIENDS AND NEIGHBORS

Support from "friends and neighbors" was identified as less of a source of support than spouses and children in both the 2018 and 2006 survey. Fifty percent report they would like encouragement from friends and neighbors "when they are down."

HEALTH PROVIDERS/ FAITH COMMUNITY/PAID CAREGIVERS

Members of the health and faith communities and paid caregivers were consistently recognized as secondary sources of support in comparison to family members, see Figure 13. A notable change from 2006 was a decline in the level of support anticipated or expected from their faith community. This could be a reflection of a smaller number of respondents reporting an affiliation with an organized faith community; 53% in 2018 and 62% in 2006.

	Spouse/ partner	Children and other family	Paid caregivers	Friends/ neighbors	Community organizations	Health providers	Faith community
Listen when I talk	81%	88%	44%	42%	7%	50%	27%
Provide Transportation	78%	84%	43%	37%	16%	17%	17%
Help with chores	72%	78%	52%	32%	10%	8%	20%
Know what I want when I die	81%	88%	25%	24%	3%	32%	18%
Encourage me when I am down	77%	84%	28%	50%	8%	30%	35%
Know about my illness	79%	87%	43%	41%	6%	56%	27%

FIGURE 13. ***WHO SHOULD PROVIDE VARIOUS TYPES OF SUPPORT***

MEANING AND SPIRITUALITY

"Meaning of life" may mean different things to different people, and when contemplating the end of our lives we explore and possibly reframe what gives ultimate meaning to our lives. The capacity to search for life's meaning is common to all people. It is one of the things that connect us to each other.[xv]

In the 2018 end-of-life survey, the majority of respondents identified the following activities and situations as "important or very important:" being at peace spiritually, having relationship issues settled, having family and friends visit, being able to complete a Last Will and Testament, having a sense of your own worth, sharing time and gifts of wisdom, fulfilling personal goals/pleasures, and reviewing life history with family.

> **"A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives."**
>
> **Atul Gawande**
> Advisor To The Conversation Project
>
> the conversation project

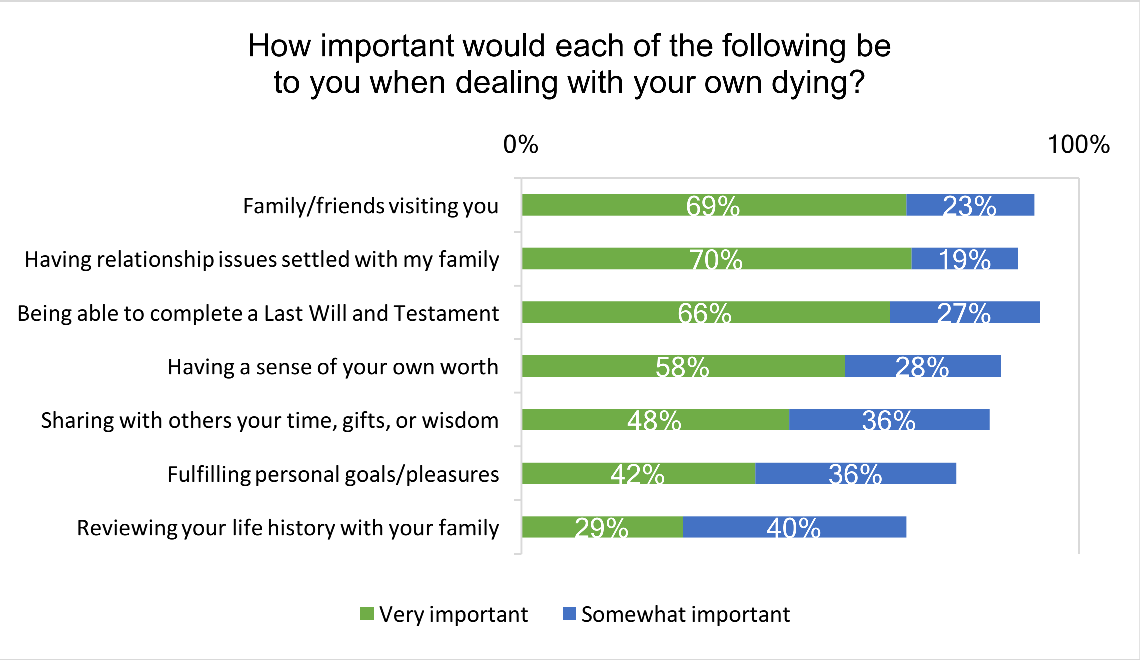


FIGURE 14. *DEALING WITH YOUR OWN DYING*

Respondents considered understanding treatment options as well as choosing treatment options very important (84%). Not being a physical burden to loved ones was also considered very important as well as knowing how to say goodbye. When asked to share their fears about dying more Idahoans were afraid of dying painfully (77%), than dying from a long-term illness (71%). Twenty-five percent are very afraid of dying in an institution and 11% were very afraid of dying alone.

The spiritual dimensions of dying are important to Idahoans. Forty percent of respondents said they are very religious/spiritual. A greater number (41%) identified themselves as somewhat religious/spiritual. Nine percent identified themselves as not at all religious/spiritual compared to 3% in 2006.

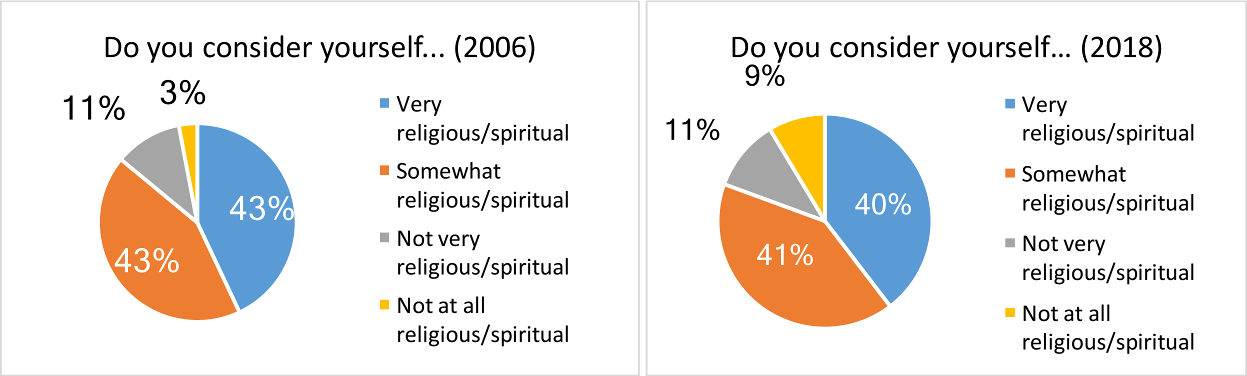


FIGURE 15. ***CONSIDER YOURSELF RELIGIOUS/SPIRITUAL (2006 & 2018)***

Fifty-three percent are affiliated with an organized faith community/spiritual practice which is 9% less than in 2006.

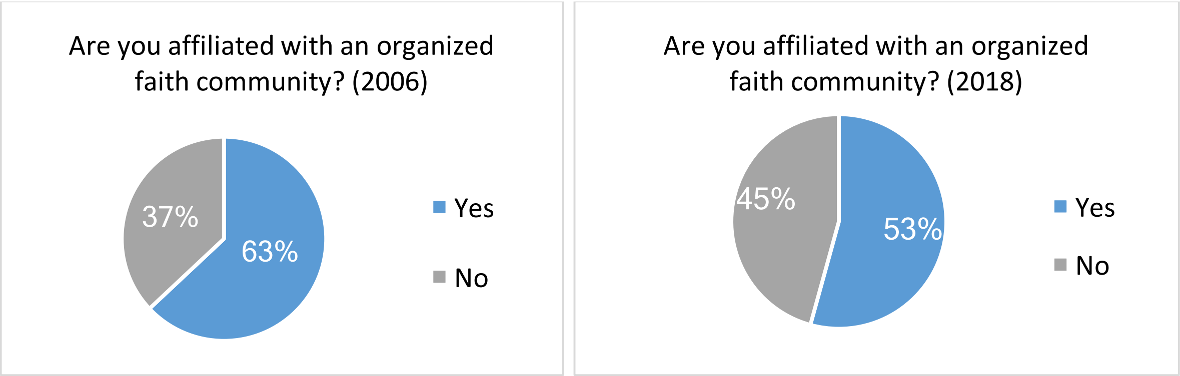


FIGURE 16. ***AFFLIATED WITH AN ORGANIZED FAITH COMMUNITY (2006 & 2018)***

The trend towards a decreasing need for clergy/spiritual leaders to have a role in end of life care, conversations and decisions was also evident in the respondents in 2018 indicating that their spiritual practice/religion affects their end-of-life decision making “to a great extent” (40%

compared to 52% in 2006). Additionally, 14% reported that their spiritual practice/religion did not affect end of life decision making compared to 6% in 2006.

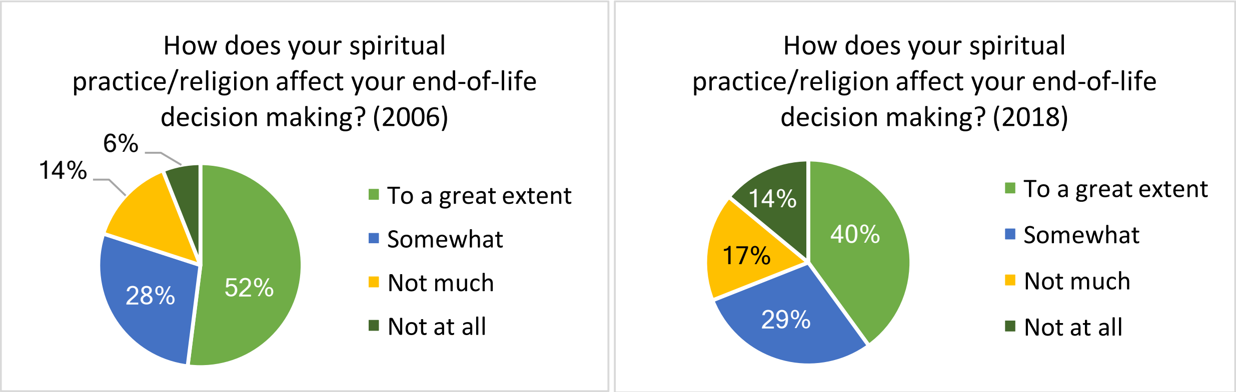


FIGURE 17. ***HOW DOES YOUR SPIRITUALITY EFFECT YOUR EOL DECIONSION MAKING? (2006 & 2018)***

The value of being at peace spiritually was recognized as "very or somewhat important" for 89% of respondents with 63% indicating the presence of a spiritual leader would be very or somewhat important. Again, these numbers are lower than those from the 2006 survey.

Fewer individuals in the 2018 survey (18%) indicated a desire to have clergy/spiritual leaders initiate conversations regarding end-of-life issues compared to 2006 (24%). Fewer respondents also indicated they would trust clergy/spiritual leaders to provide information on end-of-life issues (21%). Although respondents are indicating their desire to have clergy/spiritual leaders initiate these conversations, only 4% (in 2006 and 2018) reported having a conversation with clergy or spiritual leaders.

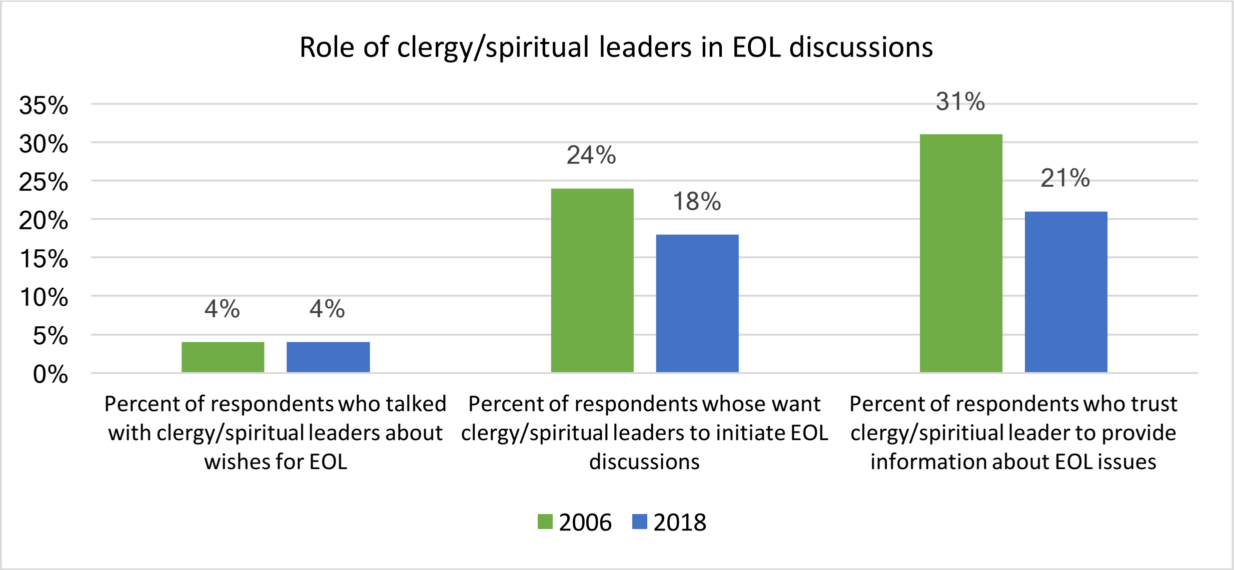


FIGURE 18. ***ROLE OF CLERGY/SPIRITUAL LEADERSIN EOL DISCUSSIONS (2006 & 2018)***

WHERE DO WE GO FROM HERE?

The results of this survey reveal “a glass half full, half empty” perspective on individual preferences for conversations and care at the end of life. Although Idahoans are comfortable talking about death and wish to engage in advance care planning, few have done so—few have completed a living will, and even fewer have identified a health care agent or spoken with their health care provider about wishes for care.

GLASS HALF FULL:

People in Idaho are comfortable talking about death . . .

84% are comfortable with writing their own living will concerning healthcare decisions

50% are very comfortable with appointing a health care agent who would act on their behalf if they were unable to communicate

73% have spoken with their spouse or partner about advanced directives for care at the end of life

69% say not being able to communicate wishes and/or needs would be worse than death

95% believe it is important or somewhat important to be free from pain

GLASS HALF EMPTY:

BUT often they have not had key end-of-life conversations . . .

45% have completed a living will or written instructions concerning healthcare decisions

40% have identified a health care agent who would act on their behalf if they were unable to communicate

14% have talked about wishes for care at end of life with their primary care physician and/or specialist

59% want their primary care physician and/or specialist to initiate the conversation

98% want information about options for managing pain

42% are afraid of becoming addicted to pain medicines over time

38% are afraid they would be given too much pain medicine

Positive outcomes for Idahoans are at stake if the gaps between what they say they want, what actions they take, and the care they ultimately receive are not addressed. Idaho currently lacks a systemic and systematic approach to advance care planning (ACP), palliative care and caregiver support, however there is current work in Idaho that can be leveraged to address these gaps. We propose the following recommendations.

In 2015 the Institute of Medicine identified the need for culturally appropriate public education and engagement about end-of-life care planning at the societal, community and individual levels.

1. The societal level, to build support for public and institutional policies that ensure high-quality, sustainable care;
2. The community and family levels, to raise awareness and elevate expectations about care options, the needs of caregivers, and the hallmarks of high-quality care; and
3. The individual level, to motivate and facilitate advance care planning and meaningful conversations with family members and caregivers.[xvi]

RECOMMENDATIONS FOR ADVANCE CARE PLANNING IN IDAHO

Asking people what matters to them, and ensuring that what matters plays a decisive role in the medical care they receive is the essence of advance care planning. Since 2016 Honoring Choices® Idaho (HCI) has been addressing community, family and individual needs related to advance care planning (ACP). The mission of HCI is to promote opportunities for advance care planning conversations in the context of one's values, empower individuals to make and document decisions, and help ensure health care choices are honored.

HCI in partnership with Idaho's two largest health systems, St. Luke's and Saint Alphonsus, and other healthcare and non-healthcare organizations in southwest Idaho are achieving a standardized approach to ACP. HCI provides a centralized infrastructure to coordinate training and technical assistance to help organizations and community partners (including faith-based organizations and employers) weave evidence based advanced care planning into routine care and service; develop and distribute standardized ACP tools and materials; advocate for system changes; and develop and distribute public education. The ultimate goal is that this standard approach to advance care planning is implemented in healthcare and non-healthcare settings statewide, normalizing planning conversations and honoring the plans that result.

Updating Idaho's system of centralizing all ACP related information is a need recognized by HCI, health care providers, the Idaho Health Quality Planning Commission and policy makers. Clinicians in Idaho still largely rely on paper forms, which are not easily accessible when needed most, as in a medical emergency. While ACP documents and conversations have evolved, the method for storing and accessing this important information has not kept pace. It can't be understated how important it is for Idahoans' advance care planning documents to be available when and where they are needed.

RECOMMENDATION 1: ESTABLISH SUSTAINABLE FUNDING FOR HCI.

Achievement of this recommendation will assure ongoing outreach, public and professional education about advance care planning, and access to advance care planning assistance for individuals statewide. Sustainable financial support for HCI is needed.

RECOMMENDATION 2: ESTABLISH THE INFRASTRUCTURE AND TECHNOLOGY TO SUPPORT A WEB-BASED DOCUMENT REGISTRY.

Achievement of this recommendation will establish a secure, accessible, sustainable platform to ensure documented advance care planning documents (advanced directives and POST documents) are available wherever and whenever individuals and health care providers need them.

RECOMMENDATION 3: INTEGRATE EVIDENCE-BASED ADVANCED CARE PLANNING PRACTICES STATEWIDE THROUGH THE SUPPORT OF HCI.

Achievement of this recommendation will weave standardized, evidence-based ACP practices within health care and community organizations statewide, promote widespread use of consistent and easy-to understand language about advance care planning, and increase access to high quality planning assistance. Integrating ACP into routine healthcare, normalizing the conversations among all adults regardless of age or health will result in easier and more frequent ACP conversations for people with serious illness and at the end of life.

RECOMMENDATIONS FOR PALLIATIVE CARE IN IDAHO

The survey results suggest a need to improve end-of-life care in Idaho to assure that outcomes reflect the wishes and preferences of individuals. Survey respondents make clear that pain management is very important to them, as is dying at home. These preferences can be accomplished by integrating palliative care, hospice services, and ACP into a variety of health delivery and community-based settings.

Palliative care is an approach to care that can improve the quality of life for patients and their families facing serious and life-threatening illnesses. Palliative care, unlike hospice, can and should go hand-in-hand with curative treatment and is primarily delivered in hospital settings. Optimally, palliative care is provided in a patient/family-centered environment -where the patient wants to be - by a team of physicians, nurses, social workers and others, working to assure the effective management of symptoms, pain, and stress associated with a chronic or serious illness. Family meetings and communication about the patients' goals of care, treatment, and management of pain are the specific competencies of palliative care.

RECOMMENDATION 1: ENCOURAGE IMPLEMENTATION OF PALLIATIVE CARE EDUCATION AND LICENSURE/RE-LICENSURE STANDARDS THAT ASSURE THE DELIVERY OF HIGH QUALITY, PATIENT-CENTERED SERVICES.

> Achievement of this recommendation will assure a skilled workforce prepared to provide support for patients and families in a variety of settings.

RECOMMENDATION 2: IMPLEMENT QUALITY MEASURES AND FISCAL SUPPORT NEEDED TO ASSURE DELIVERY OF PALLIATIVE CARE IN A VARIETY OF SETTINGS.

> Achievement of this recommendation will provide system-level support and oversight to develop community palliative care models that include primary, secondary, and tertiary delivery of care.[xvii]

RECOMMENDATION 3: INTEGRATE EVIDENCED-BASED PRACTICES FOR COORDINATION OF CARE ACROSS SYSTEMS AND COMMUNITY THROUGH SUPPORT OF IDAHO HEALTH CONTINUUM OF CARE ALLIANCE (IHCCA) AND SIMILAR ORGANIZATIONS.

> Achievement of this recommendation will enable individuals to live and age in their residence of choice; provide safer transitions of care and education across the continuum of care; and represent the interests of the acutely ill, chronically ill, disabled and dying Idahoans.[xviii]

RECOMMENDATIONS FOR RECOGNIZING FAMILY CAREGIVERS AND COMMUNITY-BASED NETWORKS IN IDAHO

Family bonds and support are hallmarks of Idaho and cornerstones of independence for older adults and individuals with physical or emotional disabilities, or chronic illnesses. The results of this survey highlight the importance of family caregivers at end of life. Family caregivers are identified as essential providers of physical, social, and psychological support and an important component of the communication network.

We support the work of the Idaho Lifespan Family Caregiver Alliance (ICA) and encourage expanding opportunities to engage caregivers and the individuals they care for in advance care planning conversations. The Alliance, established in 2013, is a broad coalition of public and private organizations and individuals. The goal of the Alliance is to advance the well-being of caregivers by promoting collaboration that improves access to quality support and resources for family caregivers across the lifespan.

We also recognize national efforts like the passage of Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act in January 2018. RAISE supports person- and family-centered care in all health settings and service planning including care transitions, coordination and advance care planning.

RECOMMENDATION 1: INTEGRATE EVIDENCE-BASED ACP PRACTICES IN COMMUNITY-BASED ORGANIZATIONS

> Achievement of this recommendation will increase participation in ACP and promote positive social norms around ACP conversations. Community-based organizations (e.g. Area Agencies on Aging, Centers for Independent Living, Patient-centered Medical Homes, faith community, etc.) are natural pathways for support for individuals and family caregivers. Integration of the education and support offered by HCI into these organizations is critical to assuring that conversations are conducted in the context of one's values and accessible when needed.

RECOMMENDATION 2: RECOGNIZE AND SUPPORT FAMILY CAREGIVERS IN THE CONTINUUM OF CARE

> Achievement of this recommendation will assure patient-centered, family-informed care. It is premised on the integration of caregivers into the patient-centered medical home and the availability of evidenced-based programs that promote caregiver self-care (Powerful Tools for Caregivers, community-based respite).

The results of this statewide survey provides rich information from a wide cross section of adults 35 years and older. People responding to the 12-page questionnaire shared deeply personal feelings and concerns, asked for information and expressed preferences for care at the end of life.

The significance of communication was recognized as important by almost all respondents, especially the sentiment **"not being able to communicate my wishes and/or needs to family and friends is worse than death."** Idaho must continue to work to build systems of care that promotes planning and communication within families and with health care providers and ensures accessibility to advance care planning documents wherever and whenever individuals and health care providers need them.

APPENDIX A - TECHNICAL DESCRIPTION

INTRODUCTION

The Idaho Survey: Personal Preferences at End-of-life was a joint project between Patient Centered Outcomes Research Initiate (PCORI), Pipeline to Proposal award and the Center for the Study of Aging at Boise State University. Sponsoring members of the project included Honoring Choices Idaho, Boise State University School of Nursing, the St Alphonsus Regional Medical Center and the St Luke's Health System. Resources from these partners were used for printing, mailing, staff time, and other associated costs. The Center managed the project and this Appendix describes the technical aspects of the project.

SURVEY INSTRUMENT

The survey items and format were adapted from the Idaho Statewide End-of-life Survey conducted in 2006. The 2006 instrument was patterned after the Community Survey, developed by Life's End Institute.

Adaptations of the survey were kept to a minimum to assure the integrity of the instrument was maintained and to allow for comparisons between the 2006 and 2018 surveys conducted in Idaho. Wording in a few items was changed to reflect Idaho-specific programs and resources.

The survey was designed to collect basic demographic, socio-economic, and health status information as well as information on attitudes, beliefs, experiences, and behaviors related to end-of-life preferences and planning, see Appendix B. Items included perceptions of:

- advance care planning,
- death,
- hospice services,
- preferences for medical practices and pain management,
- knowledge and/or use of planning tools such as wills and health care proxies,
- financial concerns, and
- current and desired sources of information and social support.

SAMPLING

The survey was distributed to a random sample of 4000 adults 35 years and older who lived in private residences in Idaho. The list of names, phone numbers, and mailing and email addresses was purchased from the Marketing Systems Group, a consulting and marketing research firm. Marketing Systems Groups data lists are compiled from many sources including telephone directories, U. S. Census Bureau data, U. S. Postal Service information, electronic email records, and other public records. For this project a sample was requested that included equal numbers of men and women and that represented the geographic distribution of the population across the state of Idaho.

DATA COLLECTION

Prior to contacting any persons in the sample, approval for the study was received from the Institutional Review Board (IRB) of Boise State University, which is the federally mandated mechanism used to protect human subjects in research. The cover letter for the survey stated that this research was approved by the IRB and provided phone and address information for the primary researchers and the IRB staff person who could be contacted with any questions.

The 4000 people living in Idaho who were included in the sample received two postal mailings. First, an announcement postcard was mailed on March 2, 2018. One week later, a packet was mailed including a cover letter, a survey booklet, a business return envelope, and an entry form for a drawing of five $100 prizes. For those individuals with an email address (n = 2077) an electronic version of the cover letter, survey, and entry form for the drawing was sent one week after the postal mailing of the postcard. The announcement postcard, email message, cover letter, and prize drawing entry form are also reproduced in Appendix B. A sample of recipients from under-represented areas of the state were called and offered another copy of the survey if the survey was not returned within three weeks. No surveys were completed as phone interviews. No names or addresses were included on the surveys and the database with this information was maintained on a secure computer and was not merged with the survey response data. A study identification number was used to track completion during the time the survey was being fielded.

Surveys were returned to the Center for the Study of Aging at Boise State University by US post or electronically. Envelopes were opened by Center staff and the survey booklet was immediately separated from the drawing entry form. Upon completion of the drawing, the entry forms were shredded.

ANALYSIS AND WEIGHTING

The Statistical Package for Social Science (SPSS, v24.0) and Statistical Analysis Software (SAS, 9.4) computer programs were used in the analysis of findings from 2018 and the comparison of results to the 2006 survey. Descriptive analysis of the demographic, socio-economic, and health status information as well as information on attitudes, beliefs, experiences, and behaviors related to end-of-life preferences and planning were performed.

The demographic characteristics of the respondent population were compared to the Idaho population. Post-stratification weighting was used to correct for differences in age and gender of the sample population.

RESPONSE RATE AND SAMPLE & RESPONDENT CHARACTERISTICS

Of the 4000 surveys mailed, 827 (21%) were returned with the survey form completed totally or in part. The majority (91%, n = 750) of the surveys were returned via postal mail with the remainder completed using a web-based survey tool. With 827 respondents, the survey has a sampling error estimated to be +/- 3% at the 95% confidence level.*

For respondents, self-reported demographic and additional socio-economic information is available from the survey. The responses to these items are provided on the following page.

RESPONDENT CHARACTERISTICS

Gender		%	Marital Status		%
	Female	57. 0%		Single, never married	4. 5
	Male	40. 6%		Married	70. 6
				Living with a partner	3. 0
Age				Separated	0. 2
	44 and under	6. 8		Divorced	9. 2
	45-54	15. 6		Widowed	10. 2
	55-64	26. 4	Live alone		
	65-74	29. 4		Yes	18. 9
	75-84	15. 7		No	76. 8
	85 and older	3. 5			
			Self-Rating of Health		
Hispanic	Yes	1. 5		Excellent	19. 0
	No	94. 6		Very Good	35. 7
Race				Good	28. 1
	White	94. 1		Fair	12. 6
	Asian	1. 0		Poor	2. 7
	Black	0. 1			
	Native American	2. 1	Have a serious chronic illness		
Income				Yes	21. 6
	Less than 10K	2. 5		No	74. 6
	10K to under 20K	7. 0	Another member of household with a serious chronic illness		
	20K to under 30K	8. 3		Yes	18. 4
	30K to under 40K	9. 4		No	78. 7
	40K to under 50K	11. 7	Covered by any Health Care Insurance		
	50K to under 60K	9. 6		Yes	92. 6
	60 to under 75K	12. 7		No	4. 2
	75K or more	33. 9			
	Missing	4. 8			
Education			Employment status		
	Less than high school	1. 5		Full time	34. 0
	HS or equivalent	13. 1		Part time	11. 9
	Some College	40. 1		Retired and not working	45. 1
	College Graduate	23. 9		Other such as homemaker	5. 7
	Post-grad or professional degree	18. 9		Unemployed and looking for work	1. 1

* Note: In theory, with a sample of this size, one can say with 95 percent certainty that the results have a statistical precision of plus or minus 3 percentage points of what they would be if the entire adult population over 35 had been surveyed with complete accuracy. However there are several other possible sources of error in all surveys that may be more important than theoretical calculations of sampling error that are difficult or impossible to quantify.

APPENDIX B - SURVEY AND COLLATERAL

1. Postcard mailed to potential respondent

2. Email recruitment message and link to survey

3. Cover letter

4. Prize drawing entry

5. Survey form with frequencies of responses.

   Note: the frequencies reported in this appendix are rounded to the nearest whole number and represent the actual percentages. This means that the percentage is calculated by dividing the number of people who endorsed a response by the total number of respondents. Using this method, respondents who did not answer the particular item (the response was missing) are included in the calculation. Including the missing means that the total of the reported percentages for each item may be less than 100.

Postcard Announcement

Idaho Survey: Personal Preferences at End of Life

Within the next few days, you will receive an important survey from Boise State University's Center for the Study of Aging. This survey is part of our effort to identify ways to improve the quality of the end of life. You are one of a randomly sampled group of people over the age of 35 in Idaho we are asking about their opinions and preferences.

- The survey will take only a short time to complete
- All survey responses will be kept completely confidential
- **Respondents will be entered in a drawing for $100**

We would appreciate your response and we thank you in advance for your help!

Kim Martz, PhD, RN
Associate Professor
School of Nursing
Boise State University

Sarah Toevs, PhD
Professor
Director, Center for
the Study of Aging
Boise State University

BOISE STATE UNIVERSITY
CENTER FOR THE STUDY OF AGING
1910 UNIVERSITY DRIVE, BOISE ID 83725-1835
3010.18700.2911045

NONPROFIT ORG
US POSTAGE
PAID
BOISE, ID
PERMIT NO. 1

Firstname Lastname
123 North College Street
Suite 123
City, State 12345-6789

EMAIL RECRUITMENT MESSAGE AND LINK TO SURVEY:

BOISE STATE UNIVERSITY
CENTER FOR THE STUDY OF AGING

Dear ___, ,

You have been selected to receive this survey from Boise State University Center for the Study of Aging. The survey is part of our effort to identify ways to improve quality of life at the end of life for people in Idaho. The survey should take about 20 minutes to complete. Answering this survey gives you a chance to tell us about your values, priorities and concerns. To complete the survey please see link below.

A similar survey was conducted in Idaho in 2006 and it has also administered in several other states and numerous communities around the country. The purpose of this effort is to update the information. The results will be used to develop community and statewide programs addressing issues such as pain management, access to services and family support at the end of life. Information from the Idaho survey will make it possible to tailor programs to specific needs in Idaho and more effectively promote advanced care planning conversations that will honor your choices.

Please complete this survey by April 30, 2018. By completing the survey, you consent to participate in this research project. If you chose to participant in the online survey, you will be provided with a link to enter the drawing for a $100.00 gift card.

All survey responses will be kept completely confidential and no individual responses will be reported. If you experience any discomfort or concerns while completing the survey we encourage you to contact your health care provider. If you have any comments or questions about this survey, please contact Dr. Kim Martz at (208) 426-3591, or Dr. Sarah Toevs at (208) 426-2452, or the Institutional Review Board at Boise State University, Office of Research Administration, 1910 University Drive, Boise, ID 83725-1135 or (208) 426-1574.

We thank you for your time and appreciate your assistance with this important project.

Kim Martz, PhD, RN	Sarah Toevs, PhD
Associate Professor	Professor
School of Nursing	Director, Center for the Study of Aging
Boise State University	Boise State University

Follow this link to the Survey: ${l://SurveyLink?d=Take the Survey}

Or copy and paste the URL below into your internet browser:
${l://SurveyURL}

Follow the link to opt out of future emails:
${l://OptOutLink?d=Click here to unsubscribe}

COVER LETTER

BOISE STATE UNIVERSITY
CENTER FOR THE STUDY OF AGING

January 11, 2018

You have been selected to receive this survey from Boise State University Center for the Study of Aging. The survey is part of our effort to identify ways to improve quality of life at the end-of-life for people in Idaho. The survey should take about 20 minutes to complete and is also available online at https://boisestate. az1. qualtrics. com/jfe/form/SV_e57g5YgmzBHJYlT for your convenience.

You are part of a small group of people 35 years and older in Idaho that are being asked for their opinion on living life on your own terms until the end-of-life. Answering this survey gives you a chance to tell us about your values, priorities and concerns.

A similar survey was conducted in Idaho in 2006 and it has also administered in several other states and numerous communities around the country. The purpose of this effort is to update the information. The results will be used to develop community and statewide programs addressing issues such as pain management, access to services and family support at the end-of-life. Information from the Idaho survey will make it possible to tailor programs to specific needs in Idaho and more effectively promote advanced care planning conversations that will honor your choices.

Please complete this survey and return it in the pre-paid envelope by March 15, 2018. By completing the survey, you consent to participate in this research project. If you choose to return the enclosed green paper attached along with your completed survey, your name will be entered in a drawing for 1 of 5 $100. 00 gift cards. This green paper card will be separated from the survey upon receipt and will be destroyed after the drawing on March 22, 2018. If you chose to participant in the online survey, you will be provided with a link to enter the drawing.

All survey responses will be kept completely confidential and no individual responses will be reported. If you have any comments or questions about this survey, please contact Dr. Kim Martz at (208) 426-3591, or Dr. Sarah Toevs at (208) 426-2452, or the Institutional Review Board at Boise State University, Office of Research Administration, 1910 University Drive, Boise, ID 83725-1135 or (208) 426-1574.

We thank you for your time and appreciate your assistance with this important project.

Kim Martz, PhD, RN
Associate Professor
School of Nursing
Boise State University

Sarah Toevs, PhD
Professor
Director, Center for the Study of Aging
Boise State University

Please enter me in the drawing for $100.00 gift card!

Thank you for taking time to complete the Idaho Survey:
Personal Preferences at End of Life.
Please provide the following information to enter the drawing.

*Your personal information will be kept confidential and will be used only to select the winners. This card will be destroyed after the winners are identified.

Please print in the following information:

Name: ____

Mailing Address:
____
____
____

Phone Number: _________________________________

Email address (if preferred for contact):____

Link to email version of entry card: Link to drawing

BOISE STATE UNIVERSITY
CENTER FOR THE STUDY OF AGING

Idaho Survey:
Personal Preferences at End-of-life

This survey is about life on your own terms. It includes questions about your attitudes, beliefs and experiences concerning topics that may be sensitive. Your responses will help us gain a better understanding of what is important to people in Idaho when they think about how they want to live until the end of their life. The survey should take only 20 minutes. We would really appreciate your participation.

For each survey item below, ☑ check the box that best represents your opinion or experience.

Thoughts about Death and Dying

1. Thinking back on your childhood, how often were death and dying talked about in your family?

☐ Often 8. 4%
☐ Occasionally 41. 2 %
☐ Rarely 38. 4%
☐ Never 10. 5%
☐ Can't remember 1. 3%

2. How comfortable are you with…

		Very comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable	Not sure
a.	Talking about death with family	☐ 51.3%	☐ 36.3%	☐ 9.7%	☐ 2.5%	☐0. 1%
b.	Taking about death with friends	☐ 44.8%	☐ 38.3%	☐ 11.3%	☐ 3.3%	☐ 2.2%
c.	Writing your own will concerning health care decisions	☐ 54.5%	☐ 29.8%	☐ 11.8%	☐ 2.7%	☐ 1.1%
d.	Appointing a health care agent to act for you if you were unable to speak or write	☐ 49.6%	☐ 28.0%	☐ 14.3%	☐ 5.4%	☐ 2.3%

2. How likely are you to…

		Very likely	Somewhat likely	Not very likely	Not at all likely	Not sure
a.	Attend funerals or memorial services	☐47. 4%	☐37. 7%	☐12. 4%	☐2. 3%	☐0. 3%
b.	Read books, newspaper articles or other information that deal with the subject of death and dying	☐27. 8%	☐42. 8%	☐19. 9%	☐9. 3%	☐0. 3%
c.	Watch television programs or movies that deal with the subject of death and dying	☐25.6%	☐43.6%	☐23.7%	☐6.6%	☐0.6%
d.	Avoid medical checkups because you are afraid the doctor will find "something serious"	☐3.0%	☐9.4%	☐26.5%	☐60.8%	☐0.3%
e.	Use alternative medicine such as massage, acupuncture, music, exercise, relaxation, etc.	☐34.9%	☐33.0%	☐17.2%	☐14.0%	☐0.9%
f.	Speak freely to loved ones about death and dying	☐45.5%	☐38.6%	☐13.7%	☐1.6%	☐0.5%
g.	Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing	☐47.5%	☐38.0%	☐10.7%	☐2.5%	☐1.3%
h.	Preplan your own funeral	☐37.3%	☐33.6%	☐17.7%	☐9.0%	☐2.4%

3. How afraid, if at all, are you of…

		Very afraid	Somewhat afraid	Not very afraid	Not at all afraid	Not sure
a.	Dying	☐3.8%	☐30.2%	☐35.6%	☐28.4%	☐2.0%
b.	Dying from a long-term illness	☐21.4%	☐49.5%	☐19.0%	☐8.1%	☐1.9%
c.	Dying suddenly	☐5.4%	☐19.6%	☐34.8%	☐39.3%	☐1.0%
d.	Dying alone	☐10.7%	☐31.6%	☐31.0%	☐23.3%	☐3.4.%
e.	Dying in an institution such as a nursing home or hospital	☐24.8%	☐35.5%	☐22.6%	☐14.8%	☐2.3%
f.	Dying painfully	☐37.9%	☐38.7%	☐17.4%	☐3.3%	☐2.7%

4. How strongly do you agree or disagree that…

		Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Not sure
a.	Death is an important part of life	☐67.2%	☐27.1%	☐1.8%	☐1.2%	☐2.7%
b.	You would want to know if you had a serious illness	☐68.7%	☐24.9%	☐2.5%	☐1.3%	☐2.6%
c.	You would want to know if you only had a few months to live	☐74. %	☐17.9%	☐4.3%	☐1.0%	☐2.7%
d.	Caring for people who are dying is a rewarding experience	☐30.6%	☐36.8%	☐15.0%	☐4.9%	☐10.4%

5. When you think about death and dying, how concerned are you that…

		Very concerned	Somewhat concerned	Not very concerned	Not at all concerned	Not sure
a.	Your (or your spouse/partner's) money won't last	☐27.2%	☐38.8%	☐22.6%	☐10.4%	☐1.0%
b.	Your family's money won't last	☐25.4%	☐34.6%	☐24.6%	☐11.1%	☐1.9%
c.	You will be a financial burden to your family or friends	☐29.8%	☐29.8%	☐25.5%	☐14.3%	☐1.0%
d.	You will experience a financial burden paying for medicine or medical care	☐34.2%	☐37.6%	☐15.9%	☐11.6%	☐0.7%

7. Which of the following health conditions, if any, do you think are worse than death?
Check ALL that apply.

☐ Living with great pain 68.4%

☐ Total physical dependency on others, such as being in a coma 83.3%

☐ Not being able to communicate my wishes and/or needs to family and friends 68.8%

☐ Severe mental deterioration or severe memory loss 81.2%

☐ Nothing is worse than death 2.1%

Advance Planning and Preparation

Advance Directives allow people to make their health care choices known in advance of an incapacitating illness, life-threatening condition or death.

8. Which of the following advance directives and other pre-plans have you heard about and completed?

		Have heard about and completed	**Have heard about but not completed**	**Have not heard about**
a.	A **health care agent or durable power of attorney** for health care in which you name someone to make decisions about your health care in the event you are unable to speak	☐ 39.5%	☐54.8%	☐4.3%
b.	A **living will or other written instructions** in which you state the kind of health care you want or don't want under certain circumstances	☐45.0%	☐54.7%	☐0.3%
c.	A **POST document** (physician orders specifying life-sustaining measures you do or do not want for future health care treatments)	☐26.8%	☐48.6%	☐22.7%
d.	A **last will and testament** that controls how your money and other property are to be distributed	☐45.0%	☐54.3%	☐0.6%
e.	**Funeral or burial pre-plans** in which you plan or purchase in advance any goods or services for yourself	☐13.6%	☐83.3%	☐3.1%
f.	Authorization to have your **organs and/or tissue donated** after you die for use by others in need of transplants	☐68.2%	☐28.5%	☐1.1%

9. **Whether you have completed any advance directives/pre-plans or not, with whom have you talked about your wishes for care near the end of your life?** ***Check ALL that apply.***

☐ Spouse / partner 72.8%

☐ Family 63. %

☐ Friends 25.7%

☐ Clergy/spiritual leader 4. %

☐ Lawyer/Estate Planner 15.1%

☐ Primary care physician 9.4%

☐ Nurse 0.2%

☐ MD specialists, such as: cardiologist, oncologist, palliative medicine 4.1%

☐ Mental health professional, such as: social worker, psychologist, or psychiatrist 1.1%

☐ No one 9.4%

☐ Other (Please specify): 2.3%

10. **Who would you want to initiate a conversation regarding end-of-life issues?** ***Check ALL that apply.***

☐ Spouse / partner 75.6%

☐ Family 78.7%

☐ Friends 28.7%

☐ Clergy/spiritual leader 17.9%

☐ Lawyer/Estate Planner 21%

☐ Primary care physician 33.9%

☐ Nurse 6.9%

☐ MD specialists, such as: cardiologist, oncologist, palliative medicine 24.7%

☐ Mental health professional, such as: social worker, psychologist, or psychiatrist 11.4%

☐ No one 3.6%

☐ Other (Please specify): 2.1%

11. Who would you trust to provide information on end-of-life issues? ***Check ALL that apply.***

- ☐ Spouse / partner 68.4%
- ☐ Family 68.6%
- ☐ Friends 23.9%
- ☐ Clergy/spiritual leader 21.1%
- ☐ Lawyer/Estate Planner 31.1%
- ☐ Primary care physician 43.4%
- ☐ Nurse 10.1%
- ☐ MD specialists, such as: cardiologist, oncologist, palliative medicine 35.4%
- ☐ Mental health professional, such as: social worker, psychologist, or psychiatrist 19.5%
- ☐ No one 2.0%
- ☐ Other (Please specify): 2.0%

Dealing with Dying

12. How important would each of the following be to you when dealing with your own dying?

		Very important	Somewhat important	Not very important	Not at all important	Not sure
a.	Family/friends visiting you	☐68.6%	☐23. 3%	☐4.6%	☐1.7%	☐0.7%
b.	Being able to stay in your home	☐61.8%	☐30.2%	☐6.1%	☐1.0%	☐0.9%
c.	Honest answers from your doctor	☐95.4%	☐2.8%	☐0.5%	☐1.1%	☐0 2%
d.	Presence of spiritual leader	☐34.8%	☐28.5%	☐20.2%	☐12.3%	☐2.0%
e.	Knowing medicine was available to you	☐70.0%	☐23.9%	☐4.7%	☐0.3%	☐1.2%
f.	Planning your own funeral	☐26 2%	☐39.2%	☐24.1%	☐9.3%	☐1.3%
g.	Being able to complete a Last Will and Testament	☐66.2%	☐26 6%	☐5.5%	☐0.7%	☐0.9%
h.	Fulfilling personal goals/pleasures	☐43.1%	☐36.2%	☐16. 3%	☐3.3%	☐1.0%

i.	Reviewing your life history with your family	☐28.7%	☐40.4%	☐23.0%	☐6.9%	☐1.0%
j.	Having good relationships with your health care providers	☐58.0%	☐33.7%	☐5.6%	☐2.3%	☐0.4%
k.	Getting your finances in order	☐67.0%	☐26.3%	☐4.2%	☐0.9%	☐0.1%
l.	Understanding your treatment options	☐84.0%	☐14.6%	☐1.3%	☐0.1%	☐0.1%
m.	Choosing your treatment options	☐85.2%	☐12.0%	☐2.6%	☐0.1%	☐0.1%
n.	Sharing with others your time, gifts, or wisdom	☐47.9%	☐35.7%	☐11.2%	☐2.8%	☐0.9%
o.	Having good pain management available	☐72.7%	☐23.2%	☐3.7%	☐0.1%	☐0.3%

13. How important is each of the following to you when you think about dying?

		Very important	**Somewhat important**	**Not very important**	**Not at all important**	**Not sure**
a.	Being physically comfortable	☐68.3%	☐29.5%	☐1.7%	☐0.4%	☐0.1%
b.	Being free from pain	☐60.1%	☐35.2%	☐4.4%	☐0.1%	☐0.2%
c.	Being off artificial life-sustaining support (such as ventilator or CPR)	☐62.4%	☐23.9%	☐7.1%	☐2.5%	☐4.0%
d.	Not receiving artificial nutrition/hydration	☐41.6%	☐32.6%	☐14.4%	☐4.6%	☐7.0%
e.	Being able to balance alertness and pain management	☐63.2%	☐33.7%	☐2.1%	☐0.3%	☐0.6%
f.	Having relationship issues settled with my family	☐70.1%	☐18.5%	☐7.7%	☐2.7%	☐1.1%

g.	Being at peace spiritually	☐72.0%	☐16.6%	☐5.9%	☐4.1%	☐1.4%
h.	Not being a physical burden to loved ones	☐79.1%	☐17.9%	☐2.3%	☐0.2%	☐0.6%
i.	Knowing how to say goodbye	☐64.1%	☐27.7%	☐4.8%	☐2.3%	☐1.1%
j.	Having a sense of your own worth	☐58. 0%	☐28. 2%	☐7. 9%	☐3. 7%	☐2. 2%

14. Do you consider yourself…

- ☐ Very religious/spiritual 39.6%
- ☐ Somewhat religious/spiritual 41.0 %
- ☐ Not very religious/spiritual 10.8%
- ☐ Not at all religious/spiritual 8.6%

15. How does your spiritual practice/religion affect your end-of-life decision making?

- ☐ To a great extent 40.3%
- ☐ Somewhat 28.5%
- ☐ Not much 16.9%
- ☐ Not at all 14.4%

Hospice is a program that provides care for people during the last 6 months of life. Hospice services can be provided in a person's home, their hospital room, long-term care or in a separate hospice facility.

16. If you were terminally ill and could choose where to die, where would you MOST want to be? ***Check ONE answer only.***

☐ In your own home 85.1%	☐ In a nursing home 0.4%
☐ In an assisted living facility 3.6%	☐ In a residential hospice (hospice services provided by a hospice owned facility) 5.0%
☐ In a hospital 2.7%	☐ Other : 3.2%

17. Have you heard of hospice services?

☐ I have never heard of hospice service. 2.2% **IF NEVER, SKIP TO QUESTION 21**

☐ I have heard a little about hospice services. 33.5%

☐ I have heard a lot about hospice services. 64.3%

18. How did you learn about hospice services? ***Check ALL that apply.***

☐ I know someone who used hospice services. 72.0%	☐ I heard from a health care professional. 18.8%
☐ I have used hospice services myself. 9.6%	☐ I read literature/newspaper/TV/radio/other media. 20.3%
☐ I am/was a hospice volunteer. 3.6%	☐ I heard from others. 34.1%

19. Would you consider using hospice support?

- ☐ Yes 83.6%
- ☐ No 2.9% → **IF NO, SKIP TO QUESTION 21**
- ☐ Don’t know/not sure 10.0%

**20. Where would you want to receive hospice support? *Check ALL that apply.* **

- ☐ In a hospice residence 21.0%
- ☐ In a hospital 11.8%
- ☐ In a nursing home 10.9%
- ☐ In a residential facility such as assisted living 21 1%
- ☐ In my own home 86.3%

21. Are you aware that Medicare and Medicaid pay for hospice services?

- ☐ Yes 56.7%
- ☐ No 26.8%
- ☐ Not sure 16.5%

22. Below are some statements related to pain near the end-of-life. How strongly do you agree or disagree with each statement?

		Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Not sure
a.	I want information about options for managing my pain.	☐83.7%	☐14.2%	☐0.8%	☐0.1%	☐1.2%
b.	I would take pain medicine to manage my pain.	☐73.2%	☐24.1%	☐1.0%	☐0.1%	☐1.6%
c.	I would only take pain medicines when the pain is severe.	☐43.5%	☐38.0%	☐10.0%	☐5.1%	☐1.5%
d.	I am afraid I will become addicted to the pain medicines over time.	☐14.8%	☐27.3%	☐28.0%	☐26.3%	☐3.6%
e.	I would take the lowest amount of medicine possible to save larger doses for later when the pain is worse.	☐43.1%	☐36.5%	☐10.2%	☐6.3%	☐3.6%
f.	I am afraid I would be given too much pain medicine.	☐11.0%	☐27.3%	☐33.0%	☐22.9%	☐4.1%
g.	I am worried pain medication will make me confused, “out of it” or lose consciousness.	☐15.8%	☐43.2%	☐27.1%	☐10.6%	☐3.3%

Support from Others

23. When people are near the end-of-life, they may need support from others. Which of the following types of support do you expect to need when near the end of your life, and who should provide it to you?

a. **Listen when I talk**

☐ Yes 97.9% → If YES, who should provide this type of support?

☐ No 2.1% *Check ALL that apply.*

☐ Spouse/partner 81.1%
☐ Children and other family 87.6%
☐ Paid caregivers 43.6%
☐ Friends/neighbors 41.5%
☐ Community organizations 7.0%
☐ Health providers 50.1%
☐ Faith community 27.2%

b. **Provide transportation**

☐ Yes 97.8% → If YES, who should provide this type of support?

☐ No 2.2% *Check ALL that apply.*

☐ Spouse/partner 77.7%
☐ Children and other family 83.8%
☐ Paid caregivers 43.2%
☐ Friends/neighbors 36.7%
☐ Community organizations 15.6%
☐ Health providers 16 8%
☐ Faith community 17.1%

c. **Help with chores**

☐ Yes 96.0% ⟶ If YES, who should provide this type of support? *Check ALL that apply.*

☐ No 4.0%

☐ Spouse/partner 71.8%

☐ Children and other family 78.4%

☐ Paid caregivers 52.3%

☐ Friends/neighbors 32.4%

☐ Community organizations 10.4%

☐ Health providers 8.1%

☐ Faith community 19.9%

d. **Know what I want when I die**

☐ Yes 97.5% ⟶ If YES, who should provide this type of support? *Check ALL that apply.*

☐ No 2.5%

☐ Spouse/partner 81.4%

☐ Children and other family 88.3%

☐ Paid caregivers 25.2%

☐ Friends/neighbors 23.6%

☐ Community organizations 2.9%

☐ Health providers 32.3%

☐ Faith community 18.1%

e. **Encourage me when I am down**

☐ Yes 92.8% ⟶ If YES, who should provide this type of support? *Check ALL that apply.*

☐ No 7.2%

☐ Spouse/partner 76.9%

☐ Children and other family 83 8%

☐ Paid caregivers 28.2%

☐ Friends/neighbors 50.0%

☐ Community organizations 7.8%

☐ Health providers 29.7%

☐ Faith community 34.6%

f. **Know about my illness**

☐ Yes 96.8% → If YES, who should provide this type of support? *Check ALL that apply.*

☐ No 3.2%

☐ Spouse/partner 79.2%

☐ Children and other family 87.0%

☐ Paid caregivers 43.0%

☐ Friends/neighbors 40.8%

☐ Community organizations 5.5%

☐ Health providers 55 7%

☐ Faith community 27.3%

About You

The following questions are for classification purposes only and will be kept entirely confidential.

24. In general, how would you rate your own health right now?

☐ Excellent health 18.0%

☐ Very good health 34.4%

☐ Good health 32.5%

☐ Fair health 12.5%

☐ Poor health 2.4%

25. Do you have a serious chronic illness? ☐ Yes 20.0% ☐ No 80.0%

26. Are you currently covered by any health care insurance or program including insurance through work/retirement, the military, Medicare, Medicaid or some other government program?

☐ Yes 93.1%

☐ No 6.5%

☐ Not sure 0.5%

27. In the last 12 months, about how much did you spend *each month* out of your own pocket for insurance and doctor visits?

☐ Less than $50 per month 29.9%
☐ $50 to less than $200 per month 30.2%
☐ $200 to less than $500 per month 23.4%
☐ $500 more per month 13.3%
☐ Not sure 2.1%

28. In the last 12 months, about how much did you spend *each month* out of your own pocket for prescription drugs?

☐ Less than $50 per month 70.3%
☐ $50 to less than $200 per month 22.5%
☐ $200 to less than $500 per month 5.2%
☐ $500 more per month 0.9%
☐ Not sure 1.1%

29. Does any *other* member of your household have a serious chronic illness?

☐ Yes 16.7% → If ***yes***, are you incurring costs for: *Check ALL that apply.*
  ☐ Caregivers or home health aides 1.1%
  ☐ Medicines 12.4%
  ☐ Insurance 10.6%
  ☐ Transportation and/or parking for appointments 5.4%
  ☐ Lost wages for missing time at your work 3.1%
☐ No 83.3%

30. Who would you ask to find out whether end-of-life care services are covered by insurance, Medicare, Medicaid? *Check ALL that apply.* I would contact

- ☐ SHIBA- Senior Health Insurance Advisors Program 11.5%
- ☐ Area Agency on Aging 11.3%
- ☐ Local home care agency 7.8%
- ☐ Local senior center/ council on aging 8.6%
- ☐ My doctor 52.5%
- ☐ My health plan 72.8%
- ☐ Other (please specify): 5.1%
- ☐ Medicaid 20.6%
- ☐ Medicare 39.5%
- ☐ My friends/ neighbors 17.2%
- ☐ My relatives 25.3%
- ☐ My employer 17.7%
- ☐ Social worker 12.4%

31. Medicare now pays for Advance Care Planning conversations. If you are over the age of 65, in the past year, has your health care provider discussed Advance Care Planning with you?

- ☐ Yes 16%* (n=400)
- ☐ No 83%*

* n= 400 (number of respondents over the age of 65)

32. What is your sex?

☐ Male 40. 6% ☐ Female 57%

33. What was your age at your last birthday? _______________ (in years)

34. Do you live alone? ☐ Yes 18.9% ☐ No 76.8%

35. What is your current marital status?

- ☐ Single, never married 4.5%
- ☐ Married 70.6%
- ☐ Living with a partner 3.0%
- ☐ Separated 0.2%
- ☐ Divorced 9.2%
- ☐ Widowed 10.2%

36. What is the highest level of education that you completed?

- ☐ Less than high school 1.5%
- ☐ High school graduate or equivalent 13.1%
- ☐ Some college or technical training beyond high school 40.1%
- ☐ College graduate (4 years) 23.9%
- ☐ Post-graduate or professional degree 18.9%

37. Which of the following best describes your current employment status?

- ☐ Employed or self-employed full-time 34.0%
- ☐ Employed or self-employed part-time 11.9%
- ☐ Retired and not working 45.1%
- ☐ Other, such as homemaker 5.7%
- ☐ Unemployed and looking for work 1.1%

38. Are you Hispanic or Latino? ☐ Yes 1.5% ☐ No 94.6%

39. Which one or more of the following would you say is your race? Check ALL that apply

☐ White 94.1%

☐ Black or African American 0.1%

☐ Asian 1.0%

☐ American Indian or Alaskan Native 2.1%

☐ Don't know/not sure 0.8%

☐ Other 1.6%

☐ Refused 1.8%

40. In what language do you prefer to read or discuss information related to death and dying?

☐ English 97.2%

☐ Spanish 0.2%

☐ Other (please specify): 0. 4%

41. What was your annual household income before taxes in 2017?

☐ Less than $10,000 2.5%

☐ $10,000 to under $20,000 7.0%

☐ $20,000 to under $30,000 8.3%

☐ $30,000 to under $40,000 9.4%

☐ $40,000 to under $50,000 11.7%

☐ $50,000 to under $60,000 9.6%

☐ $60,000 to under $75,000 12.7%

☐ $75,000 or more 33.9%

42. Are you a United States Veteran? ☐ Yes 17.2% ☐ No 81%

43. Are you affiliated with an organized faith community?

☐ Yes 53.3% If so, which denomination? ☐ No 44.9%

44. What is your 5-digit zip code? (WRITE IN YOUR ZIP CODE) ____ ____ ____ ____ ____

The Mission of the Center for the Study of Aging at Boise State University is to promote the wellbeing of Idaho's growing population of older citizens. For more information visit:

https://hs. boisestate. edu/csa/

Thank you for completing the survey!

APPENDIX C – EOL PREFERENCES INFOGRAPHIC

Idaho Personal Preferences at End of Life, 2018
Survey Highlights

People in Idaho have strong preferences about their own end-of-life care

92% want to die in their own home

60% are concerned they will be a financial burden to family or friends

72% are concerned they will experience a financial burden paying for medicine or medical care

80% say it is very important to not be a physical burden to loved ones.

GLASS HALF FULL:

People in Idaho are comfortable talking about death . . .

84% are comfortable with writing their own living will concerning healthcare decisions

50% are very comfortable with appointing a health care agent who would act on their behalf if they were unable to communicate

73% have spoken with their spouse or partner about advanced directives for care at the end of life

69% say not being able to communicate wishes and/or needs would be worse than death

GLASS HALF EMPTY:

BUT often they have not had key end-of-life conversations . . .

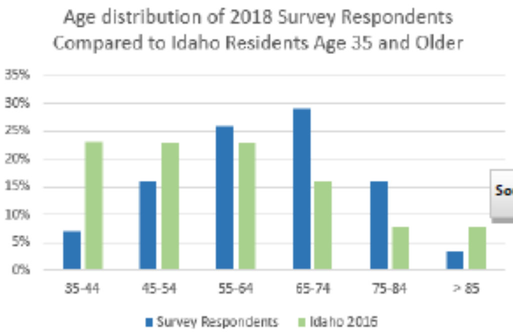
45% have completed a living will or written instructions concerning healthcare decisions

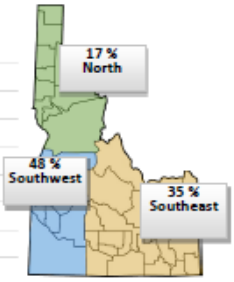
40% have identified a health care agent who would act on their behalf if they were unable to communicate

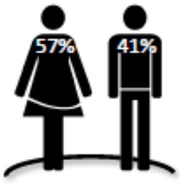
14% have talked about wishes for care at end of life with their primary care physician and/or specialist

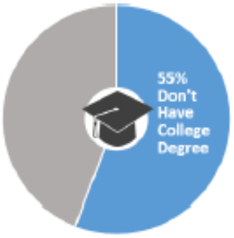
59% want their primary care physician and/or specialist to initiate the conversation

Who responded to the Idaho Personal Preferences at End of Life Survey in 2018?









SOURCE: Idaho Survey: Personal Preferences at End of Life, 2018 (7/2018)
For more information contact Kim Martz, kimmartz@boisestate.edu or Sarah Toevs, stoevs@boisestate.edu

BOISE STATE UNIVERSITY
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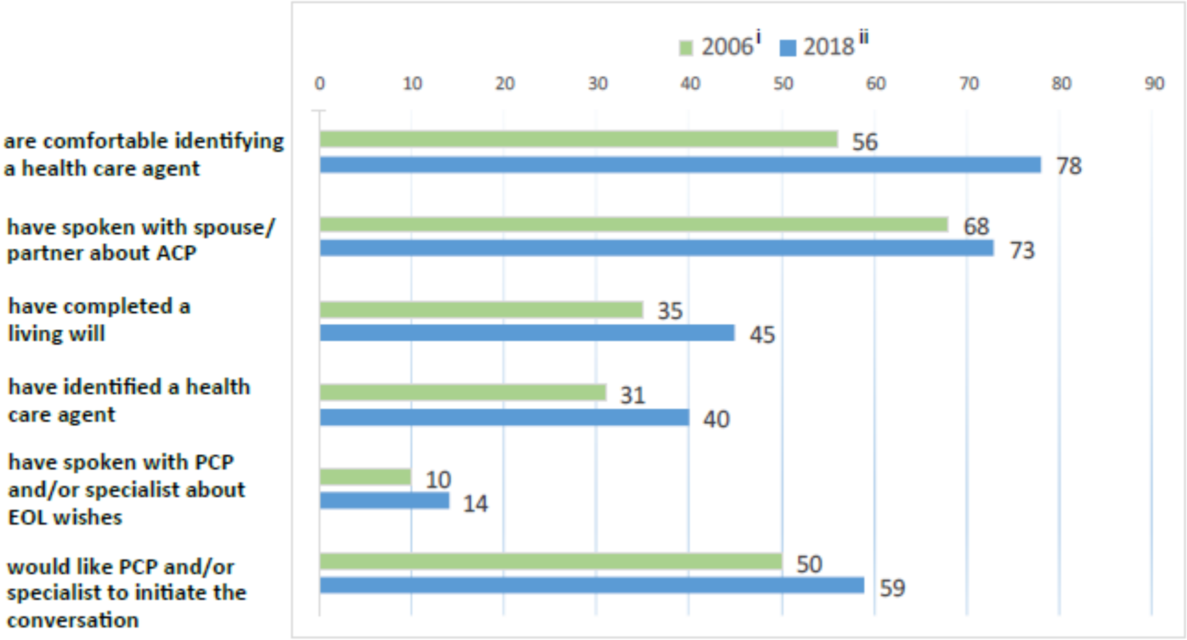
Idaho Personal Preferences at End of Life
Comparison of Results: 2006 to 2018

Has the needle moved?

Percent of respondents who say they…



i. 2006 Response Rate: 39% (n=1181)
ii. 2018 Response Rate: 21% (n=827); 2018 findings weighted to reflect Idaho population distribution by age and gender

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SOURCE: Idaho Survey: Personal Preferences at End of Life, 2018 (7/2018)

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