



WEST VIRGINIANS ATTITUDES AND PRACTICES TOWARD END-OF-LIFE CARE

By The Manahan Group
March 2013

Executive Summary





Background:

The West Virginia Center for End-of-Life Care retained The Manahan Group in February of 2013 to conduct health consumer research relating to awareness and perceptions of end-of-life issues in six regions of West Virginia.

The assignment was to probe awareness of the end-of life issues and to compare 2013 results with results from previous years, in order to track trends in the Mountain State. This was the second time The Manahan Group (formerly The Phillips Group) conducted the survey. Two associates – Kelly Stadelman and Chris Stadelman – participated in the earlier surveys over the years for WVEOLC and had tracked the results and trends when the research was conducted by Ryan-McGinn-Samples, later RMS Strategies. Their participation brings an institutional history and consistency to this project.

In all, 1,007 West Virginians were interviewed by telephone in February 2013. The respondents were divided nearly equally among men and women. Residents were surveyed in six media markets – Charleston/Huntington, Parkersburg, Wheeling, Clarksburg/Fairmont, Martinsburg and Beckley/Bluefield.

The questionnaire for the survey was jointly developed by the staff at the Center and our research personnel. Trial interviews were conducted and monitored before the actual survey began in order to spot any difficulties. There were none. Since this is a shorter survey than previous ones – one to measure ten key benchmark issues – the average telephone interview required only three minutes to complete. Three of the ten questions were new.

The report on this survey and how the results compare to previous findings is attached.

We appreciate the opportunity to work with the West Virginia Center for End-of-Life Care.

Objectives

- Measure completion of advance directives
- Evaluate importance of end-of-life discussions
- Identify frequency of discussions with family and physicians of end-of-life issues
- Test awareness of the WV Center for End-of-Life Care
- Assess attitudes toward end-of-life care options



Methodology

- **Eight Tracking Telephone Surveys**
 - Conducted in December 1999, March 2000, August 2000, July/October 2003, January 2006, April 2007, June 2010 and March 2013.
 - 1,007 interviews in March 2013.
 - Conducted within six media markets: Charleston/Huntington; Parkersburg; Wheeling; Clarksburg/Fairmont; Martinsburg; Beckley/Bluefield W.Va.
- **Maximum Sampling Variation**
 - March 2013 (± 3.1) percentage points at the 95% confidence level.



This report is a follow-up survey conducted for the West Virginia Center for End-of-Life Care in March 2013 in six of West Virginia's media markets. A random digit dialing procedure was used. For aggregate reporting purposes, the data were combined and weighted to reflect the actual population distribution of each county within each media market as well as age distribution to reflect the 2007 and preceding years' survey results. The goal was to provide an even distribution of responses among men and women.

The computer-assisted telephone interviewing was conducted from February 20 to 26. Professionally trained interviewers conducted all interviews. On average, each telephone interview required three minutes to complete. This report provides an executive summary, detailed findings and a master questionnaire with aggregate results. Tracking data are provided where applicable.

Tracking Data History:

1,075 interviews in December 1999

1,005 interviews in March 2000

1,002 interviews in August 2000

(December 1999/March 2000/August 2000 interviews were conducted within the five media markets of Charleston/Huntington, Parkersburg, Wheeling, Clarksburg/Fairmont, and Martinsburg.)

1,201 interviews in July/October 2003

1,000 interviews in January 2006

508 interviews in May 2010

1,007 interviews in March 2013

(July/October 2003, January 2006 and May 2010 interviews conducted within the six media markets of Charleston/Huntington, Parkersburg, Wheeling, Clarksburg/Fairmont, Martinsburg, and Beckley/Bluefield.)

Maximum sampling variation: December 1999 (± 3.0), March 2000 (± 3.1), August 2000 (± 3.1), July/October 2003 (± 2.8), January 2006 (± 3.0), April 2007 (± 3.1), May 2010 (± 4.4) and March 2013 (± 3.1) percentage points at the 95% confidence level.

Summary

Experience with End-of-Life Situations

- Nearly one in three people in West Virginia, or a member of their household, has been involved in making decisions regarding medical care and treatment for a friend or family member in the last days of their life. This is the first year that question has been asked in the statewide survey, with 29% saying they had such experience in the past couple years. That compares with 71% who had not.
- The numbers were fairly stable across geographic areas of the state, with Wheeling (22%) being the only region with significantly fewer people having such experience.
- People who have been involved in making such decisions are far more likely to have heard of the West Virginia Center for End-of-Life Care. A total of 32% percent of people who have had such an experience have heard of the Center, compared to 19% overall.

Living Will / Power of Attorney

- More than half (62%) of respondents say they have a Living Will, Medical Power of Attorney or both, with nearly half (48%) having both. Those figures represent significant increases from the June 2010 survey, when 49% of people had at least one form and 35% had both. Of those with just one, Living Wills (8%) are slightly more common than a Medical Power of Attorney (6%). The overall figure has nearly doubled since the initial survey in March 2000, when 34% of respondents had at least one form.
- There are some variations within the different regions of the state. Clarksburg/Fairmont residents (52%) are more likely to have both a Living Will and a Medical Power of Attorney followed by Parkersburg with 50%. The figures approach half in most regions of the state, including Charleston (47%), Wheeling and Beckley/Bluefield (46%), and Martinsburg (44%).
- There are also variations within the regions for those who have just one advance directive. People in Parkersburg and Wheeling (18%) are the most likely to have either a Living Will or a Medical Power of Attorney, with just one directive least common in Clarksburg/Fairmont (12%).
- Older residents are more likely to have a Living Will or Medical Power of Attorney, with 73% of those older than 65 having at least one and 59% having both. Both of those figures represent an increase of 6 percentage points from the 2010 survey. The figures consistently decline among younger populations, with just 33% of those 18-34 having at least one. Half (48%) of those ages 35-54 have at least one directive compared to 58% of those ages 55-64. In both cases, this is the first time a survey has shown more than half of respondents in groups under 65 having at least one advance directive.
- Three-quarters (74%) of those who have heard of the WV Center for End-of-Life Care have at least one, with 61% having both advance directives. By comparison, 58% of those who have not heard of the Center have at least one directive, with fewer than half (45%) having both.

Summary

Quality of Care for Pain and Suffering

- More than half of people surveyed said their friends and relatives who had passed away in the past year or so received excellent (24%) or good (34%) care for their pain and suffering.
- A quarter (26%) of respondents did not know or chose not to rate the quality of care their loved ones had received.
- Very few (4%) rated the quality of care for pain and suffering poor, while another 11% said it was fair. This was the first time this question has been asked in the survey.
- Those who had heard of the West Virginia Center for End-of-Life Care were more likely to say their friends or relatives received excellent/good care (66% compared to 56% who have not heard of the center).
- There were some geographic differences in the way people rated pain and suffering care. Those in Clarksburg/Fairmont (65%) and Wheeling (61%) were most likely to say it was excellent or good. Charleston (54%) and Parkersburg (56%) had the lowest ratings.

Perceived Importance of End-of-Life Communication

- The vast majority of West Virginians surveyed (89%) agree it is important to talk with their families or doctors regarding how they want to be treated at the end of life, with 55% strongly agreeing that such conversations are important. The figures are consistent with the results of surveys conducted in 2010, 2007 and 2006.
- There is little variation among age groups, with all demographics at 86% or higher. The highest figure actually is among those ages 35-54 (94%).
- There is little geographic variance with regard to perceived importance, with all areas at 87% or higher. Parkersburg, Clarksburg/Fairmont and Beckley/Bluefield all tied for the highest figure at 90%.
- The numbers agreeing with the importance of such communication vary only slightly based on whether respondents had heard about the WV Center for End-of-Life Care, with 92% of those who had knowledge agreeing and 89% agreeing even if they had not heard about the Center. Those figures are identical to the 2010 survey.
- Just 2% of people disagreed such conversations are important, with 5% neutral.

Talking to Family/Friends about End-of-Life Treatment

- The number of people who have talked to a close friend or family member regarding end-of-life care has remained fairly stable since 2007. About three-quarters (72%) said that was the case in 2013. That compares to 75% and 74% in the two most recent surveys.
- Although there is little variation among geographic regions, older residents statewide are much more likely to have had conversations than younger people. While 73% of those 65 and older and 75% of those 55-64 had discussed their wishes with friends and/or family, that number is just 61% of people ages 18-34.
- Awareness of the WV Center for End-of-Life Care does increase the likelihood that people will talk about their wishes. Those who had heard of the Center (81%) were more likely to have had conversations than those who had not (70%).
- Those who have advance directives (83%) are far more likely to have talked to family and friends about end-of-life treatment than those who do not (55%).

Summary

Talking to Doctors about End-of-Life Treatment

- While about three-fourths of people have discussed end-of-life issues with family, the survey finds they are far less likely to have talked to their doctor about what kind of care they would want at the end of life. Just a quarter (26%) say they have done so. The overall figure is up slightly from the 2010 survey results (22%) and about the same as 2007 (27%).
- People who have talked to family and friends about their wishes are more likely to have also talked to a physician (34%).
- Age was not a significant factor in the decision, with 28% of those 65 and older having had such conversations compared to 26% between ages 55-64. The figure was 26% for people ages 18-34 and the lowest among people 35-54 (19%).
- People who have heard about the WV Center for End-of-Life Care are twice as likely to have talked to their doctors about advance directives (43% vs. 22%).
- Those who have a Medical Power of Attorney or Living Will are much more likely to have talked to their doctor (35% vs. 11%).

Choices Regarding End-of-Life Care

- Nearly three-quarters (73%) say they would rather live a shorter time to avoid suffering and machines than would prefer to be kept alive as long as possible even if it meant suffering (12%). Another 15% were not sure. The number of people who prefer to avoid pain and suffering is fairly consistent over the years (76% in 2000). Fewer people prefer machines than in 2010 (12% compared to 17%), while the number who aren't sure has risen from 10% three years ago.
- Figures are fairly consistent across age ranges, although those ages 18-34 are most likely to want to be kept alive by machines (23%).
- Just 8% of those who have heard of the WV Center for End-of-Life Care want to be kept alive by machines, while 84% say they would prefer living a shorter time to avoid suffering and machines.
- There is little variance by media market. People in Martinsburg (75%) and Beckley/Bluefield (74%) are the most likely to choose the shorter life to avoid suffering. People in the Parkersburg area (71%) are the least likely to make that choice.

Where People Would Prefer to Die

- If people were diagnosed with a terminal illness and could plan with family and friends where they would like to die, a large majority (67%) would choose to die at home.
- The next largest percentage (14%) were not sure. Hospitals (8%) and inpatient hospice (7%) were the next most popular choices.
- Men (71%) were more likely than women (63%) to prefer dying at home. Another 12% of women said they would prefer an inpatient hospice, compared to just 5% of men who would choose that setting.
- People in Martinsburg (73%) and Clarksburg/Fairmont (72%) were most likely to choose a home setting, while the figure was lowest in Wheeling (62%).

Summary

Awareness of WV Center for End-of-Life Care

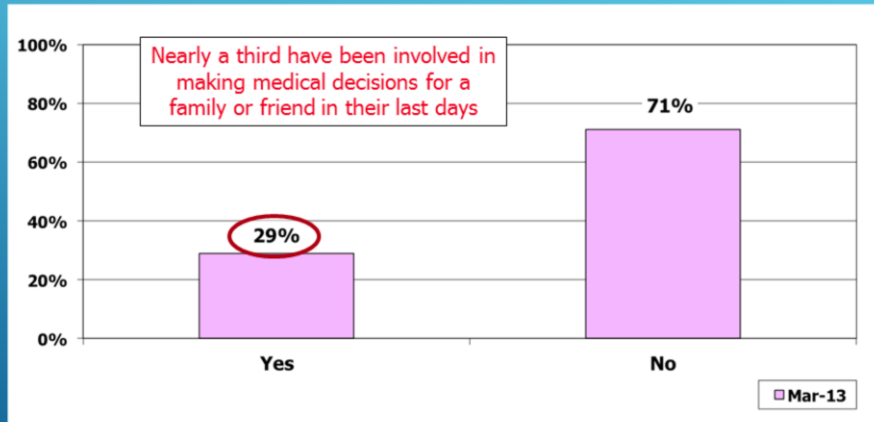
- The number of people aware of the WV Center for End-of-Life Care has gone up in the past three years and is at its highest level since its inception. A total of 19% have heard of the Center, compared to 13% in 2010 and 12% in 2007. The current figure is more than double the figure of the first survey in 2000, when it was 8%.
- Awareness is at 18% among those 65 and older, with similar figures for people ages 35-54 (20%) and 55-64 (21%). Not surprisingly, the lowest figure was among those 18-34 (7%).
- The Center has the highest name recognition in the Charleston market (23%) and Clarksburg/Fairmont market (22%). It is the lowest in Martinsburg (9%) and Parkersburg (12%). Martinsburg was the only region to decline slightly in awareness, from 11% in 2010, while the figures doubled for Parkersburg (12% compared to 6%) and Wheeling (17% compared to 8%).
- Awareness is about the same for women (19%) and men (18%).
- About a quarter (24%) heard about it through “word of mouth”, with television (16%) and newspapers (15%) the next most frequent sources. (Participants were able to list more than one source.) The figure for newspapers is the highest it has been since 2003, while television is up 3 percentage points since 2010. Radio remained consistent at 7%.
- Word of mouth was most likely in Wheeling (31%) and Martinsburg (30%), while television was most popular in Parkersburg (35%) and Beckley/Bluefield (21%) Radio was at 13% in Martinsburg but television was just 6% in that market.

Key Findings



Experience with end-of-life

Has your household been involved in making medical decisions for a family or friend in their last days?



Actual Question: *"In the past couple of years or so, have you or has anyone in your household been involved in making decisions regarding the medical care and treatment for a friend or family member who is in the last days of his or her life "*

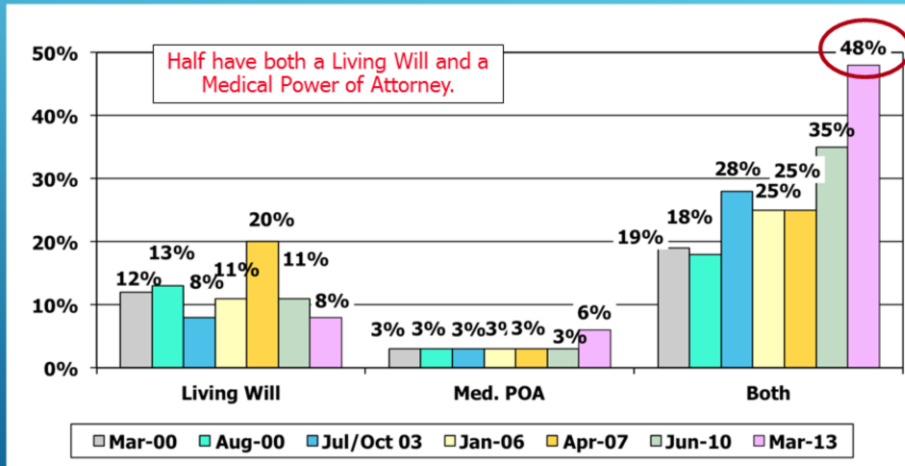
(29%) Yes

(71%) No

*Asked for the first time in March 2013

Living Will/Power of Attorney

Do you...have a Living Will or Medical Power of Attorney?



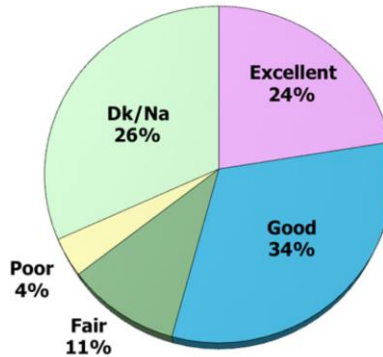
Actual Question: “Do you, yourself, have a Living Will or Medical Power of Attorney?”

- (8%) Yes, a Living Will
- (6%) Yes, Medical Power of Attorney
- (48%) Yes, Both
- (38%) No
- (1%) Dk/Na

Quality of Care for Pain & Suffering

How would you rate the quality of care your friends or relatives received from their pain and suffering?

One in four say their friends or relatives received "excellent" care for their pain & suffering before passing away.



Actual Question: *"When you think about friends or relatives who may have passed away in the last year or so that may have experienced pain or suffering, how would you rate the quality of care they received for their pain and suffering?"*

(24%) Excellent

(34%) Good

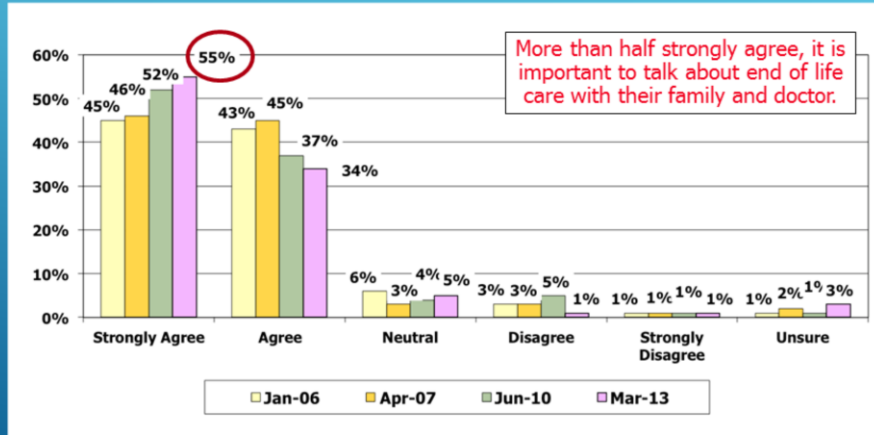
(11%) Fair

(4%) Poor

(26%) Dk/Na

End-of-Life Communication

Agree or disagree...It is important to talk with my family and doctor about how I want to be treated at the end of life?

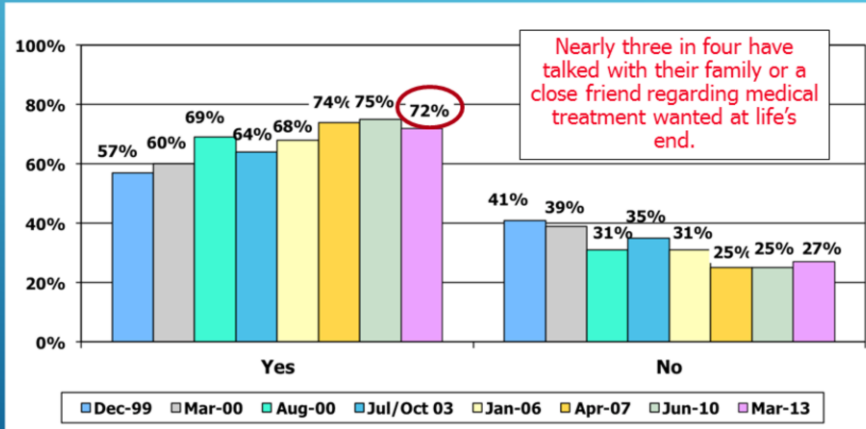


Actual Question: “How would you respond to the following statement? It is important to talk with my family and doctor about how I want to be treated at the end of life?”

- (55%) Strongly agree
- (34%) Agree
- (5%) Neutral
- (1%) Disagree
- (1%) Strongly disagree
- (3%) Dk/Na

Talked to Family

Have you talked to your family or a close friend regarding what medical treatment you would and would not want at life's end?

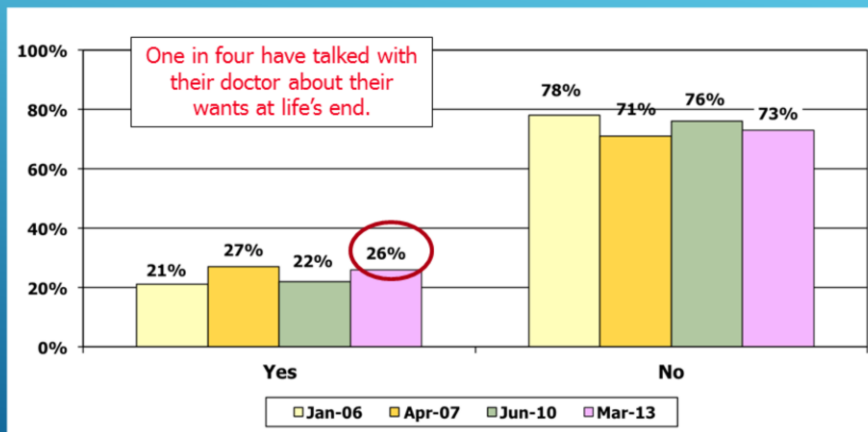


Actual Question: *"Have you, yourself, talked to your family or a close friend regarding what medical treatment you would and would not want at life's end?"*

(72%) Yes
(27%) No
(1%) Dk/Na

Talked to Doctor

Have you talked to your doctor regarding what medical treatment you would and would not want at life's end?

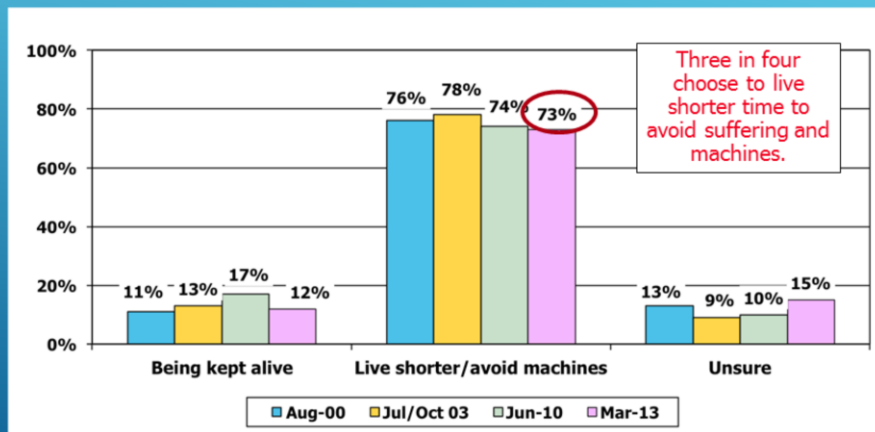


Actual Question: “Have you, yourself, talked to your doctor regarding what medical treatment you would and would not want at life’s end?”

(26%) Yes
(73%) No
(1%) Dk/Na

End-of-Life Choice

If you had to choose between being kept alive as long as possible or living a shorter time to avoid pain, which would you pick?



Actual Question: *"If you had to choose between being kept alive as long as possible even if you were experiencing pain and suffering or living a shorter time to avoid pain, suffering, and being put on machines, which would you pick?"*

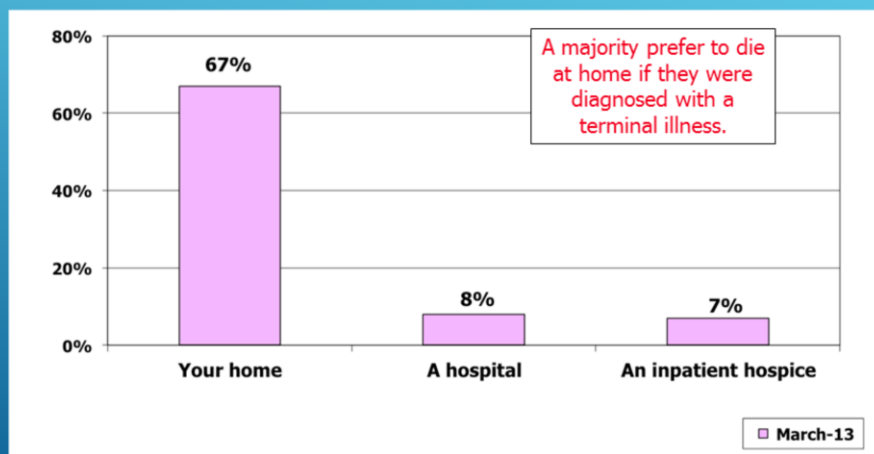
(12%) Being kept alive as long as possible even if I had to suffer

(73%) Living a shorter time to avoid suffering and machines

(15%) Dk/Na

Dying Preference

Where would you prefer to die?

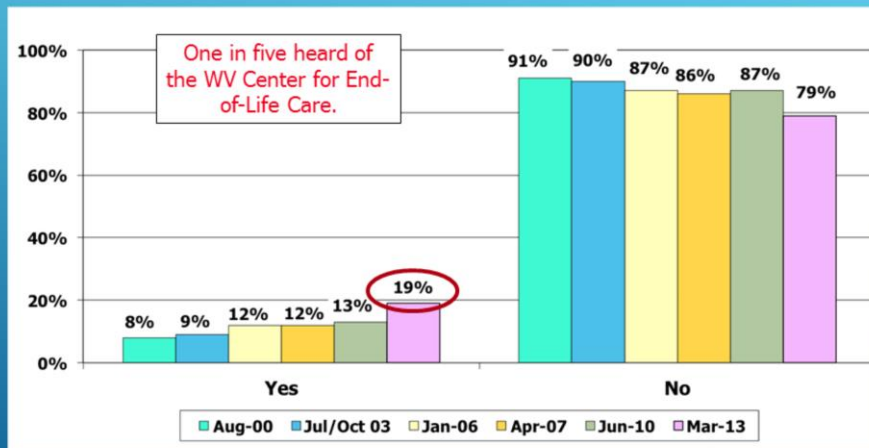


Actual Question: *"If your physician diagnosed you with a terminal illness and you could plan with your family and friends where you would like to die, where would you prefer to die?"*

- (67%) Your Home
- (8%) A hospital
- (7%) An inpatient hospice
- (1%) A nursing home
- (1%) A family member's home
- (2%) Other
- (14%) Dk/Na

Aware of WV Center for End-of-Life Care

Have you heard of the WV Center for End-of-Life Care?



Actual Question: *"Have you heard of the West Virginia Center for End-of-Life Care?"*

(19%) Yes

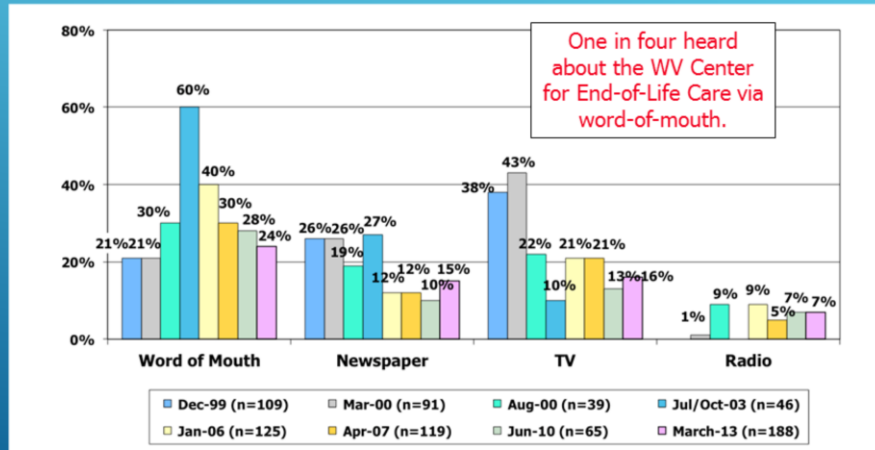
(79%) No

(2%) Dk/Na

*Question wording differs from August 2000, July/October 2003, January 2006: West Virginia Initiative to Improve End-of-Life Care.

Mode of Awareness

Where did you hear about it?



Actual Question: *“Where did you hear about it?” (Mark all that apply)*

- (24%) Word-of-mouth (friends/family/co-workers)
- (15%) Newspaper
- (16%) Television
- (7%) Radio
- (4%) Internet
- (11%) Other
- (16%) Dk/Na

Conclusions



Conclusions

- The percentage of people with *both* a Living Will and a Medical Power of Attorney is up 13 percentage points over three years ago (48%), which is a positive. The number of people with at least one advance directive also rose above 50% for the first time ever, with 62% having either a Living Will, a Medical Power of Attorney, or both. This shows efforts by the West Virginia End-of-Life Care Center is to reach more West Virginia residents are succeeding, but more work remains to be done.
- Nearly a third (29%) of respondents said in the past few years either they or a member of their household had been involved in making medical decisions for a friend or family member in the last day of their life. That is a relatively high figure, and one that will bear watching in the coming years as the Baby Boomer population ages.
- Awareness of the Center for End-of-Life Care is at its highest point in the Center's 10-year history and has increased by nearly 50% in the past three years. A total of 19% of respondents are familiar with the Center, compared to 13% in 2010 and 8% in the first survey in 2000. The only region in which awareness declined was Martinsburg (9%), which should be an increased focus going forward.
- "Word of Mouth" remains the most prevalent way for people to have heard of the Center for End-of-Life Care (24%), but newspaper and television both increased from the 2010 survey. It suggests that a mix of direct communication, earned media and paid advertising remains the best combination to reach the maximum number of people.
- Results show that people familiar with the WV Center for End-of-Life Care are much more likely to have a Living Will and/or a Medical Power of Attorney (74% vs. 62%). Logically, therefore, increasing the effort to get the word out about the Center should result in additional people getting advance directives and greater awareness on the part of communities and state leaders.
- A clear majority (58%) of those who said friends or relatives who had passed away in the past year or so received excellent or good care for their pain and suffering. A quarter were not sure, which may indicate the need for additional communication between end-of-life patients and their families and/or physicians.
- Building relationships with physicians and physician organizations continues to be a solid outreach opportunity. Although three-quarters of people have discussed these issues with the family, just a quarter of people have had discussions on the subject with their physicians. Those who have heard about the Center are twice as likely to talk to their doctors about end-of-life care.
- Two-thirds of people said if they were diagnosed with a terminal illness and could plan where they would like to die, they would choose their own home. This figure was far larger than any other option, with 14% unsure and hospitals (8%) and inpatient hospices (7%) well behind.

