Idaho End-of-Life Survey

Medical Considerations

A Better Way Coalition: Life on Our Own Terms and the **Center for the Study of Aging** at Boise State University collaborated in this effort to gather Idaho-specific data about views on end-of-life issues. Sponsoring members of the Coalition provided resources for printing, postage, and other costs while the Center matched these and managed the project. The objective of this project was to capture information that can help Idaho service providers and policy makers better understand the preferences and needs of people as they near the end of life.

The 12-page survey was mailed to a random sample of 3,003 Idaho residents over the age of 35 in February 2006. Over thirty-nine percent, or 1,181 people returned their surveys. The survey was designed to collect information on attitudes, beliefs, experiences, and behaviors related to end-of-life preferences and planning as well as basic demographic and health-status information. Similar surveys have been administered in other states and numerous communities around the country. The Idaho version was based on a questionnaire developed by the Missoula Demonstration Project and most recently adapted for the Massachusetts Commission on End-of-Life Care. The Idaho version contained only minor wording changes to reflect state specific laws, programs, resources, and a small number of additional items.

Death and dying has changed—A century ago, most people died quickly after an illness or injury, living their last days at home, cared for by family members. Today people live longer and are more likely to die of chronic illnesses. Now medical care providers have more frequent interactions with dying people and their families and, as a result providers play a larger role in decisions and care at the end of life.

People in Idaho want information and want to make decisions about their care.

- 97% say it is important to be able to understand and to choose treatment options
- 93% want to know if they had a serious illness
- 93% want honest answers from their doctors
- 52% say spiritual practice/religion affect end-of-life decision making to a great extent and 28% said it is somewhat of a consideration
- 7% have talked about their wishes for end of life with their primary care physician but 35% wish their physician would initiate the conversation
- 3% have talked about their wishes for end of life with an MD specialist such as cardiologist or oncologist and 15% wish the MD would initiate the conversation

People want their pain to be managed, but have concerns about pain medication.

- 97% said freedom from pain is important and 63% believe living with great pain would be worse than death
- 98% want information about options for managing pain
- 37% are afraid they would be given too much pain medicine and 43%are afraid of becoming addicted
- 55% worry that pain medication would make them confused, "out of it" or lose consciousness
- 80% strongly or somewhat agree that they would take the lowest amount of medicine possible to save larger doses for later when the pain is worse [Experts generally agree that this approach is not the most effective use of pain medication and does not produce the greatest reduction of pain.]

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Profile of Survey Respondents
3,003 surveys mailed
1,181 returned (39.3%)

Age
50% aged 45 to 64
18% 44 and younger
18% 65 to 74
13% 75 and older

Sex
42% male
57% female

Marital Status
72% married
10% divorced
10% widowed

Education
46% some college or technical training
20% high school diploma
18% college graduates
12% professional degree or post-graduate coursework

Employment
44% full time
30% retired and not working
15% part time
9% other, like homemaker
1% unemployed

Income
30% $20,000 to $39,000
29% $60,000 or more
21% $40,000 to $59,000

Health
33% very good
31% good
18% excellent
14% fair
3% poor

Region
43% western part of the state
40% eastern
17% northern

Race/Ethnicity
94% White
4% Hispanic or Latino
2% American Indian or Alaskan Native

*percentages may not add to 100 as all survey respondents did not complete all items

Dying - Hopes and Fears

- 80% want to die in their own home and 56% are somewhat or very afraid of dying in an institution
- 95% are aware of hospice services and 78% would use hospice support if needed
- Just 18% have heard about hospice from a health care professional
- 72% want no artificial life-sustaining procedures at the end of life
- 80% believe being at peace spiritually is very important when they die

Next Steps

Medical policies and individual providers can either be of enormous help and comfort to dying people and those close to them or they can complicate the last days of life. The following ways to expand the range of care provided at the end of life may help ensure care meets the needs and reflects the preferences of each individual.

1. The interdisciplinary team and medical community recognize the importance of good end-of-life care and respond with compassion to dying people.
2. Palliative care is available and considered at the time of diagnosis.
3. Effective pain management policies are created, approved and implemented and pain at the end of life is significantly reduced.
4. Dying people are provided the information they desire and are included in decision providing for autonomy and self determination.
5. Hospice services are discussed and physicians make referrals earlier in the allowable 6-month time frame (expanding beyond the median of 22 days).
6. Professionals providing care recognize achieving spiritual peace can be as important as relief from pain and management of physical symptoms.
7. Advance directive documents are used by physicians, nurses, social workers and chaplains in treatment plans that respect people's preferences.
8. Documents, such as living wills and advance directives stating desires for care at the end-of-life travel with individuals to all facilities and are followed by medical and emergency personnel.

More Information…
Additional copies of this focus brief, as well as three focus briefs on other topics, an executive summary of the project, the full report of the survey results are available in electronic formats from the websites of A Better Way Coalition (www.abetterwaycoalition.org) and the Center for the Study of Aging (aging.boisestate.edu). For additional information, please contact the Center at 208-426-5802 or aging@boisestate.edu.