Nebraska Veterans’ Preferences for End-of-Life Care

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More than 1,800 veterans die in a variety of healthcare settings each day, illustrating a need to improve their end-of-life (EOL) care. In 2006, the Nebraska End-of-Life Survey was mailed to 2,713 urban and rural Nebraskan adults’ homes; 44 of 324 first-time respondents (14%) were veterans. This article compares survey responses from veterans and nonveterans and discusses four issues: personal desires during the dying process, fear of dying, completion of advance directives, and communication preferences. Compared to nonveterans, veterans were significantly less likely to want friends or family visiting at EOL, less likely to place importance on being at peace spiritually, less afraid of dying alone, more likely to turn to a spouse to initiate EOL conversations, and less trusting of primary physicians on EOL issues. In addition, veterans had higher rates of completion of advance directives. Examining the survey responses can help guide clinical oncology nurses in delivering EOL care to veterans.

Background

As the largest healthcare provider in the United States, the Veterans Affairs Medical System (VAMS) cares for an increasing population of older adults. To date, VAMS serves 9.2 million veterans older than 65 (more than 39% of the total veteran population) (National Center for Veterans Analysis and Statistics, 2009). By 2010, the number of veterans aged 75 years and older will increase by an estimated 12% from four million to 4.5 million, and the number of veterans aged 85 years and older is expected to triple from 422,000 to 1.3 million (National Hospice and Palliative Care Organization [NHPCO], 2008b). More than 1,800 veterans die in a variety of healthcare settings each day; therefore, improving end-of-life (EOL) care is particularly important for veterans (Department of Veterans Affairs, 2008). Sharing and discussing veterans’ views on EOL may help improve healthcare services; as a result, this article explores the views of Nebraskan veterans regarding EOL issues based on findings from a mailed statewide survey. The authors sought to raise awareness among clinical oncology nurses about veterans’ views on EOL issues, such as personal desires during the dying process, fear of dying, completion rates for advance directives, and communication preferences. Although the results may not be generalizable to veterans in other states, an awareness of these issues may help educate clinical oncology nurses who deliver EOL care to veterans.

At a Glance

- The 2006 Nebraska End-of-Life Survey identified that veterans’ preferences for end-of-life care differ from nonveterans, particularly regarding visitation, fear of dying alone, and trust in healthcare professionals.
- Efforts are needed to increase completion rates for advance directives, with rates of 44% for veterans and 36% for non-veterans reported in Nebraska.
- Nurses are in a unique position to advocate for patients and families and ensure that end-of-life preferences are honored.

American, Cape Coral, FL) and received a letter inviting participation in the survey. Specifications included a sample with half rural and half urban individuals. Demographic information collected included gender, area code, length of time at residence, county of residence, education, ethnicity, income, and marital status. Each survey was coded with no identifiers to maintain confidentiality.

In collaboration with the Nebraska Coalition for Compassionate Care and the Robert Wood Johnson Foundation, the Nebraska Hospice and Palliative Care Partnership ([NHPCP], 2007) used the Life’s End Institute’s Missoula Demonstration Project as a model...
when constructing the survey. The survey was modified from the Corriveau-Kelly Death Anxiety Scale (Kelly & Corriveau, 1985) and included 13 components that explored views, knowledge, and concerns regarding EOL issues as well as information on current health status and demographics (see Table 1). SPSS® statistical software was used for data analysis, including frequencies, chi squares, and t tests of significance to compare differences (α = 0.05) between veterans’ and nonveterans’ responses. Surveys with missing answers were subtracted from the total number of respondents.

A total of 424 surveys were returned for a response rate of 15.6%. The survey had a sampling error of 5.6%, meaning that these results would fall in the range of plus or minus 5.6 percentage points in 100 samples of equal size from the same population. Four surveys contained unusable data, decreasing the total to 420. Partially completed surveys were included. Of the 2006 survey first-time participants (N = 324), 44 (14%) were veterans. Most veteran respondents were men (95%), married (80%), retired (51%), and older than 65 years (58%). Most nonveteran respondents were women (69%), married (51%), employed full-time (45%) or part-time (12%), and older than 55 years (57%). Most veterans (98%) and nonveterans (95%) were Caucasian. In addition, most veterans (70%) and nonveterans (68%) graduated from high school or had some college or technical training beyond high school.

### Personal Desires During the Dying Process

Several statistically significant differences were found with t tests between veterans’ and nonveterans’ responses to questions about managing one’s own dying process (see Table 2). Responses indicated that veterans were significantly less likely than nonveterans to want friends and family visiting during EOL. Veterans also were less likely to find comfort from religious people or spiritual services and placed less significance on being at peace spiritually during the dying process. About 26% of veterans placed value in having healthcare professionals visit their homes compared to 39% of nonveterans. In addition, 55% of veterans reported that knowing medication was available at EOL was very important versus 75% of nonveterans. Of interest was that 64% of veterans and 73% of nonveterans were somewhat to very concerned about being a burden to family, and 77% of veterans and nonveterans considered being physically dependent on others worse than death. In addition, 95% of veterans and 96% of nonveterans had a strong desire to be off life-support machines.

Literature on veterans’ personal desires during the dying process showed similar findings. Multicultural focus groups reported that veterans (n = 15) were more likely to oppose the use of heroic measures that prolong life, felt that doctors should be frank and open, and supported do-not-resuscitate orders but were less likely to have a proxy or durable power of attorney (Duffy, Ronis, Fowler, Schim, & Jackson, 2006). Veterans also felt less strongly than nonveterans about remembering personal accomplishments, being with friends, and being listened to at EOL (Duffy et al.). Rodriguez and Young (2006) also found that veterans expressed concerns about being a burden to family, opposing heroic measures, and valuing quality of life.

### Fear of Dying

Veterans expressed significantly less fear than nonveterans when asked, “How afraid are you of dying alone?” Forty-three percent of veterans expressed no fear at all of dying alone compared to 19% of nonveterans (see Figure 1). Veterans also reported feeling less afraid of death than nonveterans did.

The 2006 Nebraska End-of-Life Survey was the first known by the authors to examine veterans’ fear of dying. Military training often is engraved into a soldier’s life and, therefore, likely affects his or her views on death. The survey responses may be explained by veterans’ previous confrontations with fear of death during war or service (Hallarman & Kearns, 2008). Most research on fear of death has been conducted in the general population. In a qualitative study of perceptions of death among people older than 80 in the community setting, death itself was accepted as an inevitable part of life; however, many people in the study expressed fears of the mode of death, suffering a long and debilitating death, and being a burden to family (Lloyd-Williams, Kennedy, Sixsmith, & Sixsmith, 2007). Therefore, older adults who deny fearing death and accept death as an inevitable part of life still have concerns about quality of life and the effect on family.

### Completion of Advance Directives

Advance directives allow individuals to direct healthcare professionals in advance to ensure that their wishes are followed if they become unable to communicate (NHPCO, 2007). Fifty-three percent of veterans responded that they had heard about but not completed advance directives. The completion rate was higher among veterans (44%) than nonveterans (36%) but not statistically different. Although the 44% completion rate for veterans is higher than the 30% national average reported in 2005, it clearly is not sufficient (NHPCO, 2008a). Studies within VAMS have demonstrated that advance directive–completion improvement projects have increased the rate of participants who complete a power of

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**Table 1. Questions in Nebraska End-of-Life Survey**

<table>
<thead>
<tr>
<th>SURVEY COMPONENTS</th>
<th>n</th>
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<tbody>
<tr>
<td>Personal desires during the dying process</td>
<td>23</td>
</tr>
<tr>
<td>Demographics</td>
<td>18</td>
</tr>
<tr>
<td>Types of support desired at end of life</td>
<td>9</td>
</tr>
<tr>
<td>Likelihood of exploring death and dying issues</td>
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<tr>
<td>Advance directives</td>
<td>7</td>
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<td>Knowledge of hospice</td>
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<tr>
<td>Fear of dying</td>
<td>5</td>
</tr>
<tr>
<td>Misconceptions about appropriate pain management</td>
<td>5</td>
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<tr>
<td>Values</td>
<td>5</td>
</tr>
<tr>
<td>Comfort questions</td>
<td>3</td>
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<tr>
<td>Level of financial concern</td>
<td>3</td>
</tr>
<tr>
<td>Spirituality</td>
<td>3</td>
</tr>
<tr>
<td>Communication preferences</td>
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</tr>
<tr>
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</tr>
<tr>
<td>Fears about the dying process</td>
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</tbody>
</table>

N = 100

*Components discussed in this article*
attorney to 56% and living will to 31%, with documentation rates as high as 80.9% for preferences regarding cardiopulmonary resuscitation or designation of a healthcare proxy (Chong et al., 2004; Rosenfeld & Rasmussen, 2003). No significant ethnic disparities were found in the documentation of advance-directive discussions, pain and symptom management, or do-not-resuscitate orders within VAMS (Fischer, Kutner, Sauaia, & Kramer, 2007).

The Nebraska survey’s findings conflict with Duffy et al.’s 2006 report that veterans were less likely than nonveterans to have a proxy or durable power of attorney. Results are similar to a 2008 report in which 34% of older veterans (N = 149) had documented care preferences and 46% had documentation of surrogate decision makers (Wu, Lorenz, & Chodosh). Low advance-directive completion rates among veterans may be caused by a miscommunication between patients and physicians on EOL issues. Qualitative interviews were conducted with 18 older adult veterans who were asked how they conceptualized the language contained within the U.S. Department of Veterans Affairs’ advance-directive form; respondents often identified specific mental images (e.g., being a burden) when trying to interpret advance-care terminology (Young, Ofori-Boateng, Rodriguez, & Plowman, 2003). Young et al. concluded that using compact definitions and incoherent terminology are ineffective for helping people make life-altering decisions. Another study interviewed 30 veterans and their healthcare providers to learn about their understanding of terms used in advance-directive forms. The interviews generated similar recurring themes, including expected quality of life, emotional and financial costs of treatment, likelihood of treatment success, and effect on longevity (Rodriguez & Young, 2005).

In the general population, advance-directive completion rates have been reported to be as low as 10% in the intensive care unit; living will completion rates were as low as 20% among nursing home residents (Degenholtz, Arnold, Meisel, & Lave, 2002; Gruenberg et al., 2006). In contrast to VAMS, racial disparities have been reported in advance-directive completion; Hispanics and African Americans are less likely than Caucasians to have completed advance-directive documents (Degenholtz et al.).

### Communication Preferences for End-of-Life Care

Veterans reported statistically different preferences than nonveterans when asked, “Who would you want to initiate a conversation with you regarding EOL issues?” Veterans selected their spouses or partners as the preferred person, followed by family and friends. Only 18% of veterans preferred that their primary physicians initiate conversations on EOL issues. Veterans also were less trusting of healthcare professionals than nonveterans, with 55% of veterans reporting that they would trust their primary physicians versus 70% of nonveterans. In addition, veterans preferred that their spouses and families initiate EOL discussions. The results strongly support previous findings that veterans feel more strongly than nonveterans that doctors should be frank and open (Duffy et al., 2006). Clinicians must identify and address individual patient-physician barriers when they ask patients and families about communication preferences regarding EOL (Knauff, Nielsen, Engelberg, Patrick, & Curtis, 2005; Rodriguez & Young, 2005). A review of the literature on communication among families and providers concluded that patients’ desires for information are highly individualized, but providers do not adequately discuss treatment options and quality of life or respond to emotional cues from patients (Tulsky, 2005). In an analysis of veterans and nonveterans (N = 115), 75% of participants reported

<table>
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<th>SURVEY COMPONENTS</th>
<th>NOT AT ALL IMPORTANT VETERAN</th>
<th>NOT AT ALL IMPORTANT NONVETERAN</th>
<th>NOT VERY IMPORTANT VETERAN</th>
<th>NOT VERY IMPORTANT NONVETERAN</th>
<th>SOMEWHAT IMPORTANT VETERAN</th>
<th>SOMEWHAT IMPORTANT NONVETERAN</th>
<th>VERY IMPORTANT VETERAN</th>
<th>VERY IMPORTANT NONVETERAN</th>
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<td>10</td>
<td>2</td>
<td>26</td>
<td>15</td>
<td>62</td>
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<td>Comfort from religious and spiritual services or people*</td>
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<td>2</td>
<td>12</td>
<td>6</td>
<td>24</td>
<td>22</td>
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<td>70</td>
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<td>Knowing medicine is available**</td>
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<td>2</td>
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<td>22</td>
<td>55</td>
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<td>–</td>
<td>2</td>
<td>1</td>
<td>30</td>
<td>16</td>
<td>67</td>
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<tr>
<td>Being at peace spiritually*</td>
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<td>–</td>
<td>7</td>
<td>2</td>
<td>21</td>
<td>11</td>
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<tr>
<td>Having healthcare professionals visit at home**</td>
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<td>23</td>
<td>12</td>
<td>44</td>
<td>46</td>
<td>26</td>
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<td>Reviewing life history with family*</td>
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<td>4</td>
<td>24</td>
<td>19</td>
<td>33</td>
<td>41</td>
<td>29</td>
<td>36</td>
</tr>
<tr>
<td>Giving time, gifts, or wisdom to others***</td>
<td>2</td>
<td>–</td>
<td>21</td>
<td>6</td>
<td>48</td>
<td>31</td>
<td>29</td>
<td>63</td>
</tr>
</tbody>
</table>

* p < 0.05  
** p < 0.01  
*** p < 0.001  

Note. Based on information from Nebraska Hospice and Palliative Care Partnership, 2007.
that their doctors probably or definitely knew their treatment preferences, but only 32% had discussed preferences with their doctors (Knauft et al.). When veterans were asked what advice they would give medical providers regarding communication, the highest priority responses were to ensure patient understanding and communicate honestly and truthfully (Rodriguez & Young, 2005).

Nurses who communicate openly and honestly with their patients serve as the liaison between physicians and families and as patient advocates at EOL. In a random sample of American Association of Critical Care RNs (n = 210), 178 (84.8%) reported counseling patients and their families about advance directives; 174 (82.9%) had initiated discussions about advance directives (Scherer, Jezewski, Graves, Wu, & Bu, 2006).

The most frequent barriers to effective communication reported by patients in a 2005 study were the desire to focus on life rather than death and uncertainties as well as being unsure of which physician will be caring for them at EOL (Knauft et al., 2005). Barriers reported by physicians included time restraints, fear of taking away hope, or feeling that the patient is not ready to discuss EOL treatment options (Knauft et al.). When nurses were asked to identify primary barriers to delivery of supportive EOL care by physicians, they identified differences in opinions and direction of care, avoiding communication with family members, being dishonest or unrealistic about a patient’s prognosis, and making decisions based on personal view of death as a medical failure (Beckstrand, Callister, & Kirchoff, 2006; Beckstrand & Kirchoff, 2005).

Summary

The first steps to improving healthcare services for dying veterans are sharing and discussing veterans’ views on the topic. This article informs oncology nurses about the views of Nebraskan veterans on EOL issues based on responses to a mailed statewide survey. The authors have compared the survey findings with literature regarding personal desires during the dying process, fear of dying, completion rates for advance directives, and communication preferences regarding EOL care. The 2006 Nebraska End-of-Life Survey results may generate discussions among clinical oncology nurses delivering EOL care to veterans, as recommended by the Oncology End-of-Life Nursing Education Consortium Training Program (Coyne et al., 2007).

The survey had many strengths, including a statewide focus, random sampling design, and use of a reliable instrument and valid percentages to compare the responses of veterans versus nonveterans. Limitations included a small sample of veterans from one state, with an oversampling of rural residents. Ninety-five percent of veterans were men, whereas 69% of nonveteran survey respondents were women; therefore, results may have been influenced more by gender and rural residency than by veteran status. Therefore, the generalizability of the study is limited to Nebraskan men who are veterans.

Practice implications include four nursing interventions.
• Oncology nurses should assess veterans and coordinate care with veterans and families to meet personal desires during the dying process.
• Nurses should assess each veteran’s fear of dying alone and listen to his or her fears.
• Oncology nurses and palliative care teams should empower veterans to complete advance directives and honor their wishes.
• Clinical nurses should identify and assist in resolving barriers to effective communication among veterans, families, and healthcare providers regarding veterans’ EOL care. Communication should be open and honest to identify and meet veterans’ preferences for EOL care in physical, mental, emotional, and spiritual dimensions.

Nurses are in a unique position to gain patients’ trust, bridge communication gaps, initiate family conferences, and serve as patient advocates to ensure their preferences are honored. The final acts of gratitude that healthcare providers can give veterans at EOL are to ensure honest and truthful communication and provide a dignified and honorable death.

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References


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