Advance Directives: Attitudes of Primary Care Providers

by

Patricia L. Strom

A clinical research project submitted in partial fulfillment of the requirements for the degree of

Master of Nursing

Whitworth College
Intercollegiate Center for Nursing Education
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We, the undersigned members of the committee,

have read and approved this clinical research project

Advance Directives: Attitudes of Primary Care Providers

by

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Abstract

Advance directives are the expression of a patient's preferences regarding the use of life-sustaining treatments made while they still possess decision making capacity. Primary care providers in family or general practice settings were surveyed to assess their attitudes towards advance directives. The majority of the respondents expressed a positive attitude toward advance directives. Fifty three percent of the respondents estimated that between 0-10% of their patients had a written advance directive in their office medical record. The most commonly identified barriers to addressing advance directives in a primary care setting were: insufficient time during patient visits, lack of reimbursement for patient advance directive discussions, reluctance of the patient and/or family members to discuss advance directives, lack of education and materials for the provider and patient, and inadequate and complicated documentation forms.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forepages</td>
<td></td>
</tr>
<tr>
<td>Signature Page</td>
<td>ii</td>
</tr>
<tr>
<td>Acknowledgments</td>
<td>iii</td>
</tr>
<tr>
<td>Abstract</td>
<td>iv</td>
</tr>
<tr>
<td>List of Tables</td>
<td>vii</td>
</tr>
<tr>
<td>List of Figures</td>
<td>viii</td>
</tr>
<tr>
<td>Introduction</td>
<td></td>
</tr>
<tr>
<td>Background</td>
<td>1</td>
</tr>
<tr>
<td>Literature Review</td>
<td>4</td>
</tr>
<tr>
<td>Purpose</td>
<td>9</td>
</tr>
<tr>
<td>Methods</td>
<td></td>
</tr>
<tr>
<td>Design</td>
<td>9</td>
</tr>
<tr>
<td>Sample and Setting</td>
<td>10</td>
</tr>
<tr>
<td>Instrumentation</td>
<td>10</td>
</tr>
<tr>
<td>Human Subject Protection</td>
<td>11</td>
</tr>
</tbody>
</table>
## Table of Contents (continued)

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Findings</td>
<td></td>
</tr>
<tr>
<td>Data Analysis</td>
<td>12</td>
</tr>
<tr>
<td>Discussion</td>
<td>23</td>
</tr>
<tr>
<td>Limitations</td>
<td>25</td>
</tr>
<tr>
<td>Implications for Practice</td>
<td>25</td>
</tr>
<tr>
<td>Conclusions</td>
<td>26</td>
</tr>
<tr>
<td>References</td>
<td>28</td>
</tr>
<tr>
<td>Appendix</td>
<td>31</td>
</tr>
<tr>
<td>A. Letter of Introduction</td>
<td>31</td>
</tr>
<tr>
<td>B. Advance Directives Survey</td>
<td>32</td>
</tr>
<tr>
<td>C. Institutional Review Board Approval</td>
<td>35</td>
</tr>
</tbody>
</table>
# List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Patient and Provider Responsibility</td>
</tr>
<tr>
<td>2</td>
<td>Percentage with Advance Directive</td>
</tr>
<tr>
<td>3</td>
<td>Characteristics of Respondents</td>
</tr>
<tr>
<td>4</td>
<td>Contingency Table</td>
</tr>
</tbody>
</table>
List of Diagrams

<table>
<thead>
<tr>
<th>Diagram</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Setting to Address Advance Directives</td>
<td>16</td>
</tr>
</tbody>
</table>
Introduction

Beginning with the case of Karen Ann Quinlan in 1976, society and the legal system have grappled with the issue of how to make decisions for individuals who have lost decision-making capacity. In the 1980’s, the issue came to a head with the case of Nancy Cruzan, a 33 year old woman who was in a persistive vegetative state following a 1983 motor vehicle crash. In 1986, after realizing that her condition would not improve, her parents requested that the tubes feedings be withheld. The hospital requested a court ruling, and in July of 1988 a Missouri trial court ruled that the tube feedings could be withheld. This ruling was based on statements that Nancy Cruzan had made to her parents before the accident, relating that she “didn’t want to live as a vegetable.” In November of 1988, the Missouri Supreme Court reversed the trial court’s decision. Stating that in the absence of a living will or other clear and convincing evidence of the patient’s wish to refuse life-sustaining treatments, the state’s responsibility to preserve life outweighed the right of an incompetent patient to forego treatment. In June of 1990, the decision was upheld in the United States Supreme Court, thus making this the Supreme Court’s first “right-to-die” case.

The Supreme Court’s ruling maintains that people would choose life-sustaining treatments if terminally ill or permanently unconscious. However, numerous
surveys indicate that Americans do not want to continue life-sustaining efforts if their disease or condition is considered terminal or irreversible (Emanuel & Emanuel, 1994).

Today's patient and family are becoming more actively involved in medical decision-making. Primary care providers are responding with a desire to conform to the ethical principles of nonmalfeasance (to do no harm) and autonomy (the right of self-determination) as evidenced by the increased use of do-not-resuscitate orders and advance health care directives (Ebell, 1994).

An advance health care directive is the expression of a patient's preferences regarding the use of life-sustaining treatments, made in advance, while he or she possesses decision-making capacity (Wachter & Lo, 1993). Currently there are several forms of advance directives available. One of the earliest forms is the Living Will. A Living Will allows a patient to give general directions to withhold or withdraw aggressive, death-delaying treatment should he or she become terminally ill and death is imminent (Sachs, 1992).

A Durable Power of Attorney for Health Care (DPAHC) allows a patient to appoint a health care agent or proxy. The proxy, usually a family member or close friend, is selected to make health care decisions in the event that the patient is unable to make those decisions personally. The DPAHC applies whenever the
patient is unable to make decisions and is not limited to terminal illness (Sachs, 1992).

The conversational disclosure of wishes is referred to as a “values history,” which is a written record, compiled by a physician or a nurse, of a patient’s attitudes toward treatment and survival in various hypothetical situations (Doukas & McCollough, 1991). Yet another form is a “statement of patient preferences” or a “medical directive.” The medical directive lists various treatments from antibiotics to resuscitation and lets the patient indicate whether or not they want treatment in scenarios that range from irreversible coma to life-threatening crisis (Conard, 1993).

The Patient Self Determination Act (PSDA) of 1990 was implemented to identify those persons who have an advance directive and to promote and encourage the completion of such documents. The requirements of the PSDA apply to all health care facilities that receive federal funding (Medicare and Medicaid) which includes, hospitals, nursing homes, hospices, and home care agencies (Sachs, 1992). The PSDA requires that: (1) participating institutions provide written information to patients admitted regarding their right to make medical care decisions, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives. (2) written information
be provided at the time of admission about the institution’s policies regarding advance directives. (3) Health care providers must document whether or not the patient had executed an advance directive (Cox & Sachs, 1994).

**Literature Review**

Despite the progress made in assisting patients to identify their wishes regarding end-of-life decisions, attitudes regarding advance directives vary greatly among primary care providers. Davidson, Hackler, Caradine & McCord (1989) identified arguments for and against advance directives. Arguments supporting the use of advance directives included an increase in patient autonomy and a decrease in patient anxiety over unwanted treatment. There is also a reduction in family strife over treatment decisions, as well as physician’s anxiety concerning legal liability. It was also proposed that advance directives may contribute to the lowering of health care costs by decreasing the financial expenditures at the end-of-life.

Those opposed to the use of advance directives believe such directives violate the sanctity of life, may lead to active euthanasia, or a lowering of the standard of care. Others view advance directives as a legal attempt to regulate medical
practice and reduce physician authority over treatment decisions (Conard, 1993; Cox & Sachs, 1994).

There also exists among primary care providers a concern advance directives may produce an adversarial patient-provider relationship. Additionally, some providers are concerned that an advance directive may fail to express the patient’s current wishes. A patient may change their mind and an instability of preferences could lead to inaccurate treatment decisions (Cox and Sachs, 1994).

Advance directives, Living Wills in particular, have also been criticized for being vague and lacking sufficient guidance when actual treatment decisions need to be made. Terms such as “extraordinary” or “artificial means” are difficult to interpret and fail to specify the types of treatment the patient wishes to forgo (Conard, 1993; Emanuel, 1993; Silverman, Vinicky & Gasner, 1992).

Even with a DPAHC, the patient’s wishes may not be followed. Several studies have documented that proxies and physicians can and do make inaccurate treatment decisions when compared to the treatments the patient would choose for themselves (Cox & Sachs, 1994; Emanuel & Emanuel, 1994; Wachter & Lo, 1993).

There is also concern among some physicians that the requirements of the PSDA are an attempt by the federal government to control health care costs. This
concern appears valid in that treatment interventions at the end-of-life may be reduced when following an advance directive. In 1993, Lubitz and Riley reported that 28% to 30% of Medicare payments each year are for the 5% to 6% of Medicare beneficiaries who die in that year. Payments during the last month of life constitute 40% of payments during the last year of life (Lubitz and Riley, 1993). However, in a study evaluating the effects of advance directives on health care costs, patients were randomly assigned to either a physician-initiated discussion encouraging the use of advance directives, or no physician intervention. There was no statistically significant difference in the medical costs between those patients with an advance directive and those without (Schneiderman, Kronick, Kaplan, Anderson, & Langer, 1992).

Yet another concern regarding the requirements of the PSDA is, where should initial discussions on advance directives occur? Although the PSDA requires that it occur on admission to a hospital, caregivers generally agree that the time of admission is a less than ideal time to initiate discussions regarding advance directives (Cox and Sachs, 1994; LaPuma, Orentlicher, & Moss, 1991; Sachs, 1992).

In an attempt to determine the best way to inquire about advance directives, a study conducted at the Massachusetts General Hospital compared
various settings including the admitting area, the pre-admissions area, and several hospital wards. Inquiry regarding advance directives was made by admitting clerks, nurses, social workers and physicians. The study determined patients were least disturbed when the person initiating the discussion was closely involved in their clinical care (Emanuel, 1993).

Who then should address and discuss the issue of advance directives with the patient and their family? Primary care providers are often seen as the most appropriate to initiate these discussions for numerous reasons (Arras, 1993; Kohut & Singer, 1993; LaPuma et al, 1991). Primary care providers are often most familiar with the patients and their families and have an understanding of their psychosocial environment. Routine office visits and examinations provide opportunities to communicate with the patient in a non-emergent setting allowing time for careful consideration and calm deliberation. Primary care providers often care for patients during a state of wellness or in the early stages of illness. Thus allowing for an introduction to the subject of advance directives with patients while they are still well and competent and before complications occur.

Studies have shown that patients have often discussed issues such as resuscitation with their families, and would like to discuss these issues and
concerns with their physician. However, patients are waiting for their primary care provider to initiate the discussion (Cox & Sachs, 1994; LaPuma et al., 1991; Sachs, 1992).

One of the most frequently identified obstacles is the time required to adequately address the issue of advance directives (Cox & Sachs, 1994; Ebell, 1994). In a busy practice, time and lack of reimbursement prove to be significant deterrents to discussing advance health care directives (Cox & Sachs, 1994).

Another barrier to discussing advance directives in the primary care setting is the level of discomfort on the part of the provider. Some providers see death as a failure and advance directives as a conflict of interest (Sachs, 1992). Others are uncomfortable discussing the issue because they believe it will be upsetting to the patients and their family. They believe that discussing advance directives with a patient who is ill, will cause them to become discouraged and lose hope (Ebell, 1994).

Some primary care providers feel that they were not adequately prepared to discuss advance directives with their patients, and cite a lack of education as the problem (Cox & Sachs, 1994; Sachs, 1992). Some simply state a lack of initiative on their part (Kohut & Singer, 1993), while others feel that the tools and documentation forms are vague and difficult to complete (Sachs, 1992).
Purpose

The purpose of this study was to assess primary care provider’s attitudes towards advance directives and to identify barriers and incentives to initiating discussions regarding advance directives in the office setting. The specific research questions addressed were: (1) What percentage of patients currently have a written advance directive in their primary care provider’s office record? (2) Is there a relationship between the percentage of patients with an advance directive and the demographic variables of the respondents? (3) Are nurse practitioners more likely to address the issue of advance directive with their patients than physicians?

Methods

Design

A descriptive exploratory design was used for this study. This design was selected as the research questions involved the description and identification of the attitudes of primary care providers towards advance directives, and the barriers and incentives to initiating discussions in the primary care setting.
Setting and Sample

Using a convenience sample, questionnaires were mailed or distributed to physicians and nurse practitioners within an eastern Washington county who were identified as family or general practitioners ($N = 187$). The primary care providers included generalists as well as subspecialists practicing in obstetric and gynecological medicine, women’s health, pediatrics and geriatrics. The physicians surveyed were identified from a roster of all county physicians maintained by a local physician’s directory. The nurse practitioners were identified from the current membership list of the local nurse practitioner group. Nurse practitioner students who were members of the organization were excluded from the survey. Seven physician surveys were returned undeliverable.

Instrumentation

A written survey along with a cover letter (Appendix A) explaining the Patient Self Determination Act and the purpose of the survey were mailed or distributed. Content validity of the survey instrument was ensured by including the pro and con arguments most frequently discussed in the current literature regarding advance directives. A panel of expert practitioners evaluated the tool and their suggestions were included in the final survey that was utilized.
The survey contained three sections (Appendix B). The first section assessed the attitudes of primary care providers. Using a 5-point Likert-type scale (strongly agree, agree, neutral, disagree, and strongly agree), providers were asked to rate their agreement or disagreement with 18 statements that dealt with the current controversial attitudes surrounding advance directives.

In the second section, participants were asked (1) if they addressed the issue of advance directives with their patients during an office visit (2) to estimate the percentage of patients who currently had a written advance directive on their office medical record and (3) to identify barriers and incentives to discussing advance directives in the office setting. The third section of the questionnaire requested the following demographic data: age, gender, type of practitioner, area of specialty, number of years in practice and the typical length of an office visit.

Human Subject Protection

Use of a self-administered questionnaire allowed for anonymity of the respondents. All data from the surveys were coded and the researcher maintained strict confidentiality of the data. Consent to participate in the study was implied by the return of the completed questionnaire. Approval of the study and use of the
data collection tool was granted by the Washington State University Institutional Review Board (Appendix C).

Findings

Data Analysis

Data were tabulated from 64 returned questionnaires. Forty seven of the respondents were physicians and 17 were nurse practitioners. The return rate from the physician group was 29.7% and 77.3% from the nurse practitioner group. The overall response rate was 35.6%.

Statements assessing attitudes towards advance directives revealed that the general attitude of the providers was positive. Fifty nine (92.2%) of the responders felt that time spent discussing end-of-life decisions with patients was worthwhile. The majority (78.1%) believed that such discussions enriched the patient-provider relationship. Sixty (93.8%) of the respondents did not believe that the PSDA was unethical or designed to contain health care costs. Ninety two percent disagreed that a patient would become discouraged and lose hope if advance directives were discussed during their illness. However, half of the providers disagreed with the statement, “end-of-life treatment discussions are
upsetting to patients and their family”. Twenty five percent were undecided, 23.4% agreed, and 1.6% did not respond to the statement.

When asked if they were concerned about legal liability when following an advance directive, 70.3% responded they were not. Twenty nine (45.3%) disagreed with the statement, “Living wills are vague, ineffective, and provide little guidance when actual end-of-life decisions arise.” Twenty two (34.4%) respondents agreed with the previous statement and 13 (20.3%) were neutral. Only 29.7% felt that their role in decision making was limited by an advance directive, and an even smaller percentage (10.9%) saw the PSDA as an attempt to legislate medical decision making.

Attitude statements that focused on the responsibility of the primary care provider and the patient, revealed that 55 (85.9%) of the respondents agreed with the statement, “Primary care providers are the appropriate persons to initiate discussions regarding end-of-life decisions.” Yet 29.7% (N=19) believed that advance directives are the patient’s responsibility rather than a professional or institutional responsibility (Table 1). Only 5 (7.8%) of the respondents related that they felt uncomfortable discussing advance directives with their patients.
The statement, “the hospital is the optimal setting for the initial discussion and preparation of an advance directive” was agreed with by only 6.2 % of the providers, leaving 84.4% in disagreement and 9.4% neutral. Most (59.4%) agreed that initial discussions should occur in primary care settings with the patient’s family or proxy present, however, 17.2% disagreed and 21.9% were neutral (see Diagram 1).
<table>
<thead>
<tr>
<th>Attitude Statements</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
</tr>
</thead>
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<tr>
<td><em>Primary care providers are the appropriate persons to initiate discussions regarding end-of-life decisions.</em></td>
<td>55</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td><em>Advance directives are the patient’s responsibility</em> rather than a professional or institutional responsibility.*</td>
<td>19</td>
<td>16</td>
<td>29</td>
</tr>
<tr>
<td><em>Patients should initiate discussion about life-sustaining treatments.</em></td>
<td>10</td>
<td>20</td>
<td>34</td>
</tr>
<tr>
<td><em>Primary care providers are obligated to provide their patients and families information regarding advance directives.</em></td>
<td>41</td>
<td>9</td>
<td>14</td>
</tr>
</tbody>
</table>

Note: N= 64

Percentage ≠ 100% as not all respondents answered every statement.
Diagram 1. Setting to Address Advance Directives
Of the providers surveyed, 84.4% (N = 54) stated that they address the issues of advance directives with their patients during an office visit. Several of the providers commented that they discuss and update the patients wishes regarding advance directives as a routine part of their annual visit or examination.

When asked to estimate the percentage of their patients who had a written advance directive on their office medical records, 21 providers (32.8%) estimated between 0% to 5%. Thirteen (20.3%) estimated between 6% and 10% of their patients had a written advance directive (see Table 2).

The distribution of the respondents by gender, age, physician or nurse practitioner, practice specialty, number of years as a primary care provider and length of office visit is provided in Table 3. Using nonparametric statistics, Chi Square analysis revealed no significant relationships between the variables age, gender, type of specialty, years in practice, length of office visit and the estimated percentage of patients with a written advance directive on their chart. When physician and nurse practitioner responses were compared, 45 (95.7%) of the 47 physician responders stated that they discuss advance directives with their patients. Where as only nine (52.9%) of the 17 nurse practitioners stated that they had discussions regarding advance directives with their patients. Chi Square analysis revealed a significant difference between the variables (see Table 4).
Table 2. Estimate of Percentage of Patients with a Written Advance Directive

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Total</th>
<th>Physician</th>
<th>Nurse Practitioner</th>
</tr>
</thead>
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<tr>
<td></td>
<td>With AD</td>
<td>N= 42</td>
<td>N= 13</td>
</tr>
<tr>
<td>0-5%</td>
<td>21</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>6-10%</td>
<td>13</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>11-15%</td>
<td>6</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>16-20%</td>
<td>6</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>21-25%</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>26-30%</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>31-35%</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>36-40%</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>&gt;40%</td>
<td>4</td>
<td>3</td>
<td>1</td>
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AD = Advance Directive
Table 3. Characteristics of Respondents

<table>
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<tr>
<th>AGE</th>
<th>N</th>
<th>% of Total</th>
</tr>
</thead>
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<tr>
<td>≤ 40 years</td>
<td>18</td>
<td>29.5</td>
</tr>
<tr>
<td>41-45 years</td>
<td>17</td>
<td>27.9</td>
</tr>
<tr>
<td>46-50 years</td>
<td>17</td>
<td>27.9</td>
</tr>
<tr>
<td>&gt; 50 years</td>
<td>9</td>
<td>14.7</td>
</tr>
<tr>
<td>GENDER</td>
<td>N = 61</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>40</td>
<td>65.6</td>
</tr>
<tr>
<td>Female</td>
<td>21</td>
<td>34.4</td>
</tr>
<tr>
<td>PRACTITIONER</td>
<td>N = 60</td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>45</td>
<td>75.0</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>15</td>
<td>25.0</td>
</tr>
<tr>
<td>SPECIALTY</td>
<td>N = 62</td>
<td></td>
</tr>
<tr>
<td>Family Practice</td>
<td>51</td>
<td>82.3</td>
</tr>
<tr>
<td>General Practice</td>
<td>2</td>
<td>3.2</td>
</tr>
<tr>
<td>OB/GYN/ Women’s Health</td>
<td>5</td>
<td>8.1</td>
</tr>
<tr>
<td>Pediatrics</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>Adult / Geriatrics</td>
<td>3</td>
<td>4.8</td>
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(table continues)
Table 3. Characteristics of Respondents (continued)

<table>
<thead>
<tr>
<th>Years in Private Practice</th>
<th>N = 62</th>
<th>% of Total</th>
</tr>
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<tbody>
<tr>
<td>≤ 5 years</td>
<td>18</td>
<td>29.0</td>
</tr>
<tr>
<td>6-10 years</td>
<td>12</td>
<td>19.4</td>
</tr>
<tr>
<td>11-15 years</td>
<td>7</td>
<td>11.3</td>
</tr>
<tr>
<td>16-20 years</td>
<td>18</td>
<td>29.0</td>
</tr>
<tr>
<td>&gt; 20 years</td>
<td>7</td>
<td>11.3</td>
</tr>
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<table>
<thead>
<tr>
<th>Length of Office Visit</th>
<th>N = 60</th>
<th></th>
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<tbody>
<tr>
<td>&lt; 20 minutes</td>
<td>29</td>
<td>48.3</td>
</tr>
<tr>
<td>20 minutes</td>
<td>19</td>
<td>31.7</td>
</tr>
<tr>
<td>&gt; 20 minutes</td>
<td>12</td>
<td>20.0</td>
</tr>
</tbody>
</table>

Note: N varies as not all of the respondents answered every question.
Table 4. Contingency Table

ADDRESS ADVANCE DIRECTIVES IN OFFICE

<table>
<thead>
<tr>
<th>PRACTITIONER</th>
<th>YES</th>
<th>NO</th>
<th>TOTALS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>O =45</td>
<td>O =2</td>
<td>47</td>
</tr>
<tr>
<td></td>
<td>E = 39.66</td>
<td>E = 7.34</td>
<td></td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>O = 9</td>
<td>O = 8</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>E = 14.34</td>
<td>E = 2.66</td>
<td></td>
</tr>
<tr>
<td>TOTALS</td>
<td>54</td>
<td>10</td>
<td>64</td>
</tr>
</tbody>
</table>

df = 1  \( p = 99.5 \)  \( \chi^2 = 17.313 \)
Several barriers to addressing end-of-life decisions and advance directives in the office or primary care setting were identified by the respondents. Overwhelmingly, 41 of the 64 respondents identified time constraints as being a barrier to discussion of advance directives (64.1%). Lack of reimbursement for time spent discussing advance directives with patients or families was also identified (N= 5). Several (23.4%) providers identified resistance or reluctance on the part of the patient or their family to discussing end-of-life decisions. Three of the respondents stated that discomfort on the part of the provider was a deterrent to the discussion. Twelve respondents felt that lack of educational preparation of the provider was a source of their discomfort. Lack of availability of educational materials such as brochures, videotapes and patient forums were mentioned by nine of the providers as a barrier to educating and preparing the patients and their families for a discussion.

Several mentioned problems with the advance directive documents themselves. Some described the forms as being vague and not specific or complete enough to give adequate guidance to the provider. While another commented that the “paperwork ends up being buried in the wrong place when needed so all is for nothing.”
When asked to identify incentives to discussing advance directives, some saw it from the patient perspective and related that a “close call”, recent hospitalization, death of a friend or family member, or taking a C.P.R. class were incentives for patients to initiate a discussion regarding advance directives with their primary care provider. They also stated that having an advance directive avoided unnecessary interventions, and resulted in “less family turmoil and decision-making in an emergency.”

From their perspective, providers saw advance directives as a way to “assist people in determining and expressing their desires for health care.” Many felt that it “enhanced the relationship and communication” and allowed them to “better direct patient care.”

Discussion

The main barrier identified in addressing advance directives in the primary care setting was the lack of time. However, seven of the eight providers who had typical office visits greater than 20 minutes, estimated the percentage of their patients with a written advance directive to be between zero and ten percent. This percentage was no higher than the providers with office visits of twenty minutes or
less. Some providers mentioned lack of reimbursement as a barrier to addressing advance directives. Perhaps it is not the lack of time, but the lack of reimbursement for the time spent that is the real barrier. At some point, productivity also becomes an issue. How focused and goal-directed are office visits after a certain length of time? Again one questions, is lack of time the real issue, or is it the productive use of time?

Providers who work in areas such as Women’s Health, may see themselves as specialists, not primary care providers. One nurse practitioner wrote, “in my current position I do not consider myself a primary care provider. I am an OB/GYN nurse practitioner and our group currently limits our practice to OB/GYN issues.” She then goes on to say, “women often see their GYN doctor as their ‘doctor’ and see them annually.” This raises the question, who is the patient’s primary care provider? Providers in a specialty settings such as cardiology, pulmonology or nephrology, may see themselves as a specialist, however, the patient may see the specialist as their primary care provider. It may prove beneficial for the provider to ask the patient who they consider to be their primary health care provider. If no primary provider is identified, it may be appropriate to perform a more extensive physical examination and address psychosocial issues such as advance directives during the annual visit.
Nurse practitioners market themselves as being more holistic in the care that they can provide to patients. However, when it comes to addressing the issue of advance directives, they appear to fall short when compared to physicians. Perhaps the psychosocial assessment of the patient at their routine office visit needs to include a discussion of end-of-life issues.

Limitations

The limitations of this study include the small sample size and the single setting in which the study was performed. The disparity in the numbers of respondents in each group poses yet another limitation as there were 47 physician respondents as compared to 17 nurse practitioner respondents.

Implications for Practice

This study revealed a need for further education of health care providers in the area of advance directives. Advance directives should be addressed during the initial training as well as in continuing education for physicians and nurse practitioners. Training materials such as videotapes, brochures, or booklets could also be developed to assist in educating the patient and their family in the use of...
advance directives. Increased public awareness and knowledge could be achieved by providing information regarding advance directives through public health care forums, health fairs, and the media.

A mechanism for reimbursement of the time spent counseling patients and their families in the use of advance health care directives needs to be developed. Health care providers in primary care settings are in the ideal position to discuss advance directives with their patients. A mechanism for reimbursement would remove a major barrier and provide physicians and nurse practitioners with an incentive.

Forms and tools used for documentation of advance health care directives need to be clear, concise, and legally binding, yet easy to complete and interpret. The completed directive needs to be accessible to health care providers when needed. Improved communication between the patient, their family or proxy, and the primary care provider will help to assure that the patient’s wishes are being followed when end-of-life decisions need to be made.

Conclusion

Primary care providers play a vital role in assisting patients and their families discuss and document advance directives for health care. However, this study
found that the majority of the providers estimated that between zero and ten percent of their patients had a written advance directive in their medical record.

Several barriers to addressing advance directives in the primary care setting were identified. These barriers included: insufficient time during patient visits, lack of reimbursement for advance directive discussions, reluctance of the patient and/or family members to discuss advance directives, lack of education and materials for the provider and the patient, and inadequate or complicated documentation forms.

Primary care providers are in an ideal position to initiate and discuss end-of-life issues and promote the autonomy and desires of their patients. Incentives, such as reimbursement for their time and services, educational materials, and improved documents may encourage primary care providers to address advance directives as part of providing holistic patient care.
REFERENCES


*Cruzan v. Director, Missouri Department of Health*, 110 S. Ct., 2841 (1990)

*Cruzan v. Harmon, Missouri Supreme Court* 760 S.W. 2d 408 (MO 1988)

*Cruzan v. Missouri Department of Health*, No. 89-1503


REFERENCES (continued)


In re Quinlan, 355 A. 2d 647, (NJ 1976)


REFERENCES (continued)


November 6, 1995

Dear Primary Care Provider,

I am a registered nurse and graduate student at the Intercollegiate Center for Nursing Education (ICNE) in Spokane, Washington. I am conducting a clinical research project examining primary care provider's attitudes towards advance directives. As you may know, the Patient Self Determination Act (PSDA) went into effect in December of 1991 and applies to all health care facilities that receive federal funding. This includes, nearly all hospitals, nursing homes, health maintenance organizations and home health care agencies, including hospice agencies. The PSDA requires that:

1. Participating institutions must provide written information to patients admitted regarding their right to make medical decisions, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives according to state law.
2. Written information must be provided at the time of admission about the institution’s policies regarding advance directives.
3. Health care providers must document in the patient’s medical record, whether or not the patient has executed an advance directive.

I would very much appreciate your thoughtful consideration in responding to this survey. I estimate the time to complete the survey to be between five and ten minutes. All responses will remain confidential, and your responses to this survey will never be associated with your name. In order to ensure this, please do not write your name or any other specifically identifying information anywhere on the questionnaire.

As an incentive to complete the survey, you may choose to enter a drawing for a $50.00 gift certificate to Patsy Clark’s Restaurant in Spokane. To enter the drawing, write your name, mailing address and phone number on the 3x5 card and place it in the small envelope. Seal the envelope and return it along with your completed survey in the large, return envelope. Upon receipt in our office, the envelope containing the 3x5 card will be immediately separated from the survey to maintain confidentiality. The drawing for the gift certificate will take place on November 20, 1995. To be included in the drawing, please return your completed survey by November 17, 1995.

Thank you for your willingness to complete this survey. Your responses and comments are very valuable in determining primary care provider’s attitudes towards advance directives. If you have any questions or concerns about the survey, you may call me or my graduate studies advisor, Margaret Bruya at the ICNE. The telephone number is (509) 324-7273.

Sincerely,

Patricia L. Strom, RN
Graduate Student
Intercollegiate Center for Nursing Education
Appendix B

Advance Directives Survey

Using the scale below, indicate your degree of agreement or disagreement with the following statements:

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

1. Advance directives are the patient’s responsibility rather than a professional or institutional responsibility. 5 4 3 2 1
2. Patients should initiate discussions about life-sustaining treatments. 5 4 3 2 1
3. The primary care provider’s role in making decisions about life sustaining treatments is limited by an advance directive. 5 4 3 2 1
4. I feel uncomfortable discussing advance directives with patients. 5 4 3 2 1
5. Advance directives are only appropriate for the elderly or the chronically ill. 5 4 3 2 1
6. Patients will become discouraged and lose hope if advance directives are discussed during their illness. 5 4 3 2 1
7. Patients do not want decision making authority when it comes to end of life decisions. 5 4 3 2 1
8. When following a written advanced directive, I am concerned about legal liability. 5 4 3 2 1
9. The hospital is the optimal setting for the initial discussion and preparation of a written advance directive. 5 4 3 2 1
10. Advance directives, as required by the Omnibus Reconciliation Act of 1990, are unethical and designed to contain health care costs. 5 4 3 2 1
11. Primary care providers are obligated to provide their patients and families information regarding advance directives. 5 4 3 2 1
12. Discussions with patients and their family members regarding end of life decisions enrich the patient-provider relationship. 5 4 3 2 1
13. Discussions about advance directives should first occur in primary care settings with the patient’s family or proxy present. 5 4 3 2 1
14. Discussions regarding end-of-life treatment and decisions are upsetting to patients and their family. 5 4 3 2 1
15. Primary care providers are the appropriate persons to initiate discussions regarding end-of-life decisions. 5 4 3 2 1
16. The Patient Self Determination Act is an attempt to legislate medical decision making. 5 4 3 2 1
17. Time spent discussing end-of-life decisions with patients is worthwhile. 5 4 3 2 1
18. Living Wills are vague, ineffective and provide little guidance when actual end-of-life decisions arise. 5 4 3 2 1
As a primary care provider, what do you see as barriers to addressing end-of-life decisions and advance directives in the office or primary care setting?

Do you address the issue of advance directives with your patients during an office visit?

Yes  No

If yes, with which groups of patients/family members do you generally address these issues?

- Patients with a terminal illness
- Patients who have an illness or disabling condition that is severe and irreversible
- Patients who may be considered to have a poor quality of life
- Patients who are at increased risk for cardiac or respiratory arrest
- Patients who have suffered an irreversible loss of consciousness
- Patients who are unlikely to benefit from resuscitation measures
- Patients who are of an advanced age
- Patients who have lost decisional capacity
- Other: ________________
  ________________
  ________________

What percentage of the patient medical records in your office would you estimate contain some form of a written advanced directive. (i.e. Living Will, a Durable Power of Attorney for Health Care, or a written document containing patient’s wishes regarding end-of-life medical decisions) ____%
What would you identify as incentives to discussing advance directives with your patients and their families in the office setting?

Demographic Data

1. Gender: _____ Male _____ Female

2. Age to closest year: _____

3. _____ MD _____ DO _____ ARNP

4. Type of Practice: _____ Family _____ General Practice
   _____ Specialty: (please specify) ____________________________

5. Numbers of years in practice as a primary care provider: _____

6. Length of typical office visit: _____ minutes

Comments:

Thank you for your time and consideration in completing this survey.
Appendix C

Washington State University Human Subject Review Summary Form

University procedures require Institutional Review Board (IRB) review and approval of funded projects. Under certain conditions, a departmental review and approval process can be conducted for non-funded or exempt categories and exceptions are described on the back of the Decision Aid. If a project is exempt, a completed copy of the first page of the Human Subject Review Summary Form is to be submitted to the OGRD for filing and an acknowledgment returned to the investigator prior to the initiation of the research. If the project is not exempt, 18 copies of this entire form must be filed with the OGRD (Phone 333-9661; Zip 3140). All IRB meetings are open to the public. IRB members do not vote on their own projects and will withdraw from the review/ vote of protocols when a conflict of interest exists with other applications.

Principal Investigator: Patricia L. Strom  
Academic Title: Graduate Student  
Department/Division: Nursing  
Zip Code: 99202  
Telephone: (509) 534-9091

Project Title: Advance Directives: Attitudes of Primary Care Providers  
Anticipated Starting Date: November 1, 1995  
Anticipated Termination Date: December 21, 1995

Faculty Sponsor (if principle investigator is a student): Margaret Auld-Bruyn

Is the project seeking Funds?  Yes  No

If yes:
  Granting agency: N/A
  Grant Title: N/A
  Principle investigator on grant: N/A
  If continuation, date of previous approval: N/A

I. Check type of exemption applicable to the project:
   1. 2. 3. X. 4. 5. 6. None

II. Abstract:
   A. Briefly describe the purpose of the research:
      1) To assess physician and nurse practitioner attitudes towards advance directives.
      2) To estimate the number of patients who currently have a written advance directive in their primary care provider’s office records.
      3) Compare and contrast physician and nurse practitioner responses.
      4) Identify barriers to primary care providers initiating discussions regarding advance directives.
      5) Identify incentives that would encourage primary care providers to address the issue of advance directives in the office setting.

   B. Describe the procedures: What will the subjects do?
      Complete and return a written survey

   C. Check the data collection method to be used:
      1. Survey  X  If survey, check how administered: Self X Telephone Personal Interview Other
      2. Observational  Public Record Taste Evaluation Pathological or Diagnostic Specimens
      3. Experimental
      4. Other  X  Describe

   D. Is data anonymous X or confidential X? If confidential, describe how confidentiality is to be maintained.
      Data/findings will be reported, but the subjects will not be identified

   E. Are any of the following types of data being collected? Yes No
      Personal records (medical, education, etc.)?
      Directly identifiable data?
      Data damaging to subjects’ financial standing, employability?
      Obtained from autopsy?
      Resulting from alcohol or drug use?
      Sexual behavior or criminality?

Principal Investigator: The information provided above is accurate and the project will be conducted in accordance with applicable Federal, State, and University regulations.

Signature: [Signature]  Date: October 10, 1995

Chair, Director, or Dean: The research is in accordance with applicable Federal, State, and University regulations.

Signature: [Signature]  Date: October 10, 1995

Institutional Review Board: This project has been properly filed as required by Federal, State, and University procedures.

Signature: [Signature]  Date: 10-12-95

WASHINGTON APPROVED

UNIVERSITY OF WASHINGTON

DATE: 10-20-95

INITIALS: MND