

Editor's Corner: Are Consumers Ready for the Virtual Living Will? Apparently Not.

Carol A. Schwab

For the past year or so, the North Carolina General Assembly has been studying whether to establish an on-line central registry for advance directives. To find out whether consumers would be interested in having their [living will](#) and [health care power of attorney](#) posted on-line, I wrote an editorial last summer for *The Forum* and posted a survey asking readers whether they were interested in an on-line central registry for their advance directives. (See, Schwab, Carol. 2000. Editor's Corner: [Posting advance directives on-line -- are consumers ready for the virtual living will?](#) *The Forum for Family and Consumer Issues* 5(2).)

As of April 27, 2001, 164 people had submitted a response, although not every participant answered each question. Some of the participants responded on a hard copy and their responses were entered into the database by my secretary. The survey responses were definitive. Respondents have little interest in posting their advance directives on-line, and they have only a slight interest in registering them with a state agency.

The survey questions and results follow.

1. I have the following advance directives (mark all that apply).
 - Living will: 42 percent
 - Health Care Power of Attorney: 35 percent
 - Advance Instruction for Mental Health Treatment: 8 percent
 - Organ donation: 36 percent
 - None: 33 percent

2. Are you interested in registering your advance directives with your state government?
 - Very interested: 10 percent
 - Somewhat interested: 30 percent
 - Not interested at all: 60 percent

3. Are you interested in having your advance directives posted on the Internet?
 - Very interested: 4 percent
 - Somewhat interested: 22 percent
 - Not interested at all: 74 percent

4. What is the maximum amount that you would be willing to pay to register your advance directives and to have them posted on the Internet?
 - \$0.00: 73 percent
 - \$10.00 or less: 14 percent
 - \$10.00 - \$25.00: 6 percent
 - \$25.00 - \$50.00: 3 percent
 - \$50.00 - \$100.00: 2 percent

5. If your advance directives were posted on the Internet, who would you want to have access to them? (Check all that apply.)
 - Myself: 77 percent
 - My health care agent and alternates: 36 percent
 - My attorney-in-fact (durable power of attorney): 40 percent
 - My lawyer: 40 percent
 - Selected family members: 64 percent
 - My minister/priest/rabbi or other member of clergy: 17 percent
 - My health care providers (including those in emergency situations): 40 percent
 - Other people of my choice: 23 percent
 - All of the health care providers in my State: 5 percent
 - All of the health care providers in the United States: 6 percent
 - Anybody in the world: 1 percent

6. Is it important for you to be able to control who has access to your advance directives on the Internet?
 - Very important: 78 percent
 - Somewhat important: 7 percent
 - Not very important: 14 percent

7. Is it important for your advance directives to remain confidential?
 - Very important: 72 percent
 - Somewhat important: 19 percent
 - Not very important: 9 percent

8. Are you a resident of North Carolina:
 - Yes: 81 percent

- No: 19 percent
9. What is your age?
- Under 20: 0 percent
 - 20-25: 3 percent
 - 26-35: 4 percent
 - 36-45: 11 percent
 - 46-55: 23 percent
 - 56-65: 19 percent
 - 66-75: 27 percent
 - 76-85: 12 percent
 - 86 and older: 2 percent
10. What is your gender:
- Female: 90 percent
 - Male: 10 percent
11. What is your current marital status?
- Single: 14 percent
 - Married (first): 40 percent
 - Divorced: 9 percent
 - Re-married: 10 percent
 - Widow/Widower: 27 percent
12. Please indicate the highest level of education you have attained:
- Elementary School (up through grade 4): 0 percent
 - Grade School graduate (up through grade 8): 4 percent
 - Some High School: 6 percent
 - High School Graduate: 20 percent
 - Some College: 24 percent
 - College Graduate: 14 percent
 - Some Graduate School: 6 percent
 - Post Graduate Degree: 26 percent
 - No formal education or schooling: 1 percent

The results of the survey raise a number of questions. Why do only 40 percent of the respondents want to give their health care providers access to their advance directives? Advance directives are generally made part of the medical record, so what is different about giving health care providers access over the Internet? Why do only 36 percent of respondents want to give their health care agent access to their advance directives? I would have predicted that both of these

figures would have been close to 100 percent. Are the responses a result of resistance to new technology? Or, are the responses based upon the same concerns expressed by elder law lawyers, i.e., potential problems with access, lag time, revocation, confidentiality, and security?

I sent a copy of the survey results to the staff attorney for the Committee. I made no claim that this survey is a scientific study that should decide the fate of the proposed on-line central registry. It is simply an opinion poll, with no scientific controls or random sampling. (One of the respondents stated that he or she wanted Elvis Presley to have access to his or her advance directives, so at least one of the responses is suspect.)

I would hope, however, that the survey results give the Committee pause to reflect, not just on the need for an on-line central registry, but also on how it should be structured if the project goes forth. Clearly, the respondents to this survey want to control who has access to their advance directives, and they don't want to pay a great deal to register them. Structuring the system to address those needs may ensure the long-term success of the proposed on-line central registry, if it comes to pass.

In January 2001, the Committee held another hearing. In response to my survey results, they had conducted an informal survey of their own, using two consumer groups. For one group, the questions were asked after the group was assured that the registry would be private and secure. Eighty-eight percent of this group stated that they would be interested in registering their advance directives on-line. The second group was simply given the questions, without assurances of security. Only 28 percent said that they would be interested in registering their advance directives on-line. The Committee's survey results are consistent with the results of my survey, and supports my conclusion that if the on-line central registry is structured to meet the needs of the consumer, consumers are more likely to use it. It also suggests that appropriate education will be needed to encourage consumers to take advantage of this service.

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